Stoma Care Specialist Nursing: A Guide for Clinical Practice

Maddie White
Angie Perrin
Editors

ASCN
Association of Stoma Care Nurses UK

Springer

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This book is dedicated to all Specialist Stoma Care Nurses, both past and present who have contributed to our specialism; leading the way, enhancing practice and raising the profile of specialist nurses in order to better serve individuals living with a stoma.

Foreword

Nurses who choose to work in the field of stoma care do so because they understand the value and satisfaction of the role that this specialism offers. Specialist Stoma Care Nurses teach, support and advise stoma patients with a level of knowledge and commitment to help them adapt to life with a new stoma and manage their ongoing concerns and worries for their life ahead. This book hopes to offer aspiring and current Specialist Stoma Care Nurses the evidence they require to fully develop in their roles and offer the patients the highest standards of care.

Rachel Henbrey
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Preface

Stoma care was the first area of clinical practice to identify the need for specialist nurses in the UK in order to deliver high quality, evidence-based care. This mantra has not changed and even now the stoma care speciality strives to evolve by continually evaluating relevant clinical and scientific evidence and updating practice with guidelines and recommendations to ensure that an optimum level of care is provided at all times.

Birmingham, UK Maddie White
Birmingham, UK Angie Perrin

About the Editor/Contributors (for edited books)

The editors, contributors and content reviewers are all healthcare workers experienced in stoma care; many have been involved in writing or assisting with national guidelines, competencies and standards for both paediatric and adult stoma care nursing in the UK.

The Association of Stoma Care Nurses UK (ASCN UK) continually strives to educate Specialist Stoma Care Nurses and evolve the speciality by providing evidence-based resources to help nurses achieve their ambitions and goals and to ensure the patients receive the best standard of care in order to both adapt to life with a stoma and achieve their full potential.

Acknowledgments

A huge thank you goes to all of our nurse/work colleagues who have supported us in the writing, editing and proofreading of this book. The vast knowledge and experience of the Association of Stoma Care Nurses UK Area representatives, some of whom have been instrumental in the writing of individual chapters of this book, has enabled us to capture the art and essence of stoma care nursing. We are extremely grateful to the authors of each chapter for their dedication and timely responses to our numerous requests—we recognise and value your commitment alongside your other clinical responsibilities to produce the first ASCN UK dedicated stoma care textbook. It is hoped that this information will be shared and utilised by nurses wishing to specialise in stoma care, as well as a resource for those already in stoma care practice.

Contents

Editors and Contributors

About the Editors

Maddie White, RN, MSc, BSc, ENB 216, ENB 980 is currently the lead Colorectal and Stoma Care Nurse at the University Hospitals Birmingham and has over 30 years stoma care experience. She has been Chair of ASCN UK (2017–2022) and WCET International delegate and has published widely on a variety of stoma-related topics as well as presenting both nationally and internationally. She recently won the BJN Stoma Care Nurse of the Year 2022.

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Rachel Henbrey, RN, BSc is currently Colorectal CNS at the University Hospital Birmingham and has over 20 years' experience in colorectal nursing. She has a keen interest in colorectal oncology and palliative care.

Libby Herbert leads Colostomy UK to ensure that charity represents the interests of ostomates in everything that they do. She is working closely with healthcare professionals to support, empower and advocate for people who have any type of stoma. 0800 328 4257 www.colostomyuk.org

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An Introduction to Stoma Care Nursing

1

Maddie White and Angie Perrin

Introduction

There are currently over 200,000 stoma patients in the United Kingdom (UK) [1]. Since the 1970s, Nurse Specialists have gradually gained more recognition for their ability to fully support the patient with their disease and treatment trajectories by understanding patients' holistic needs as well as having an in depth knowledge base and excellent communication skills. The 'art' of the specialist nurse develops over time and correlates with Benner's specialist nursing model of 'Novice to Expert' [2]. The role is now well integrated into health care environments with specialist nurses acting as the patient's advocate within multidisciplinary team settings and supporting patients with ever increasing complex needs [3]. Variations in roles are widespread and titles are sometimes confused (the title nurse practitioner for example). Some nurses have adopted the cancer nurse role for patients with colon, rectal and anal cancer as well as other benign conditions. Core competencies identified in a seminal body of work by Hamric and Spross in 1983 [4], stated that the Clinical Nurse Specialist (CNS) role should practice within distinct domains which include Education, Research, Clinical practice and Leadership. These domains now appear to underpin the four pillars of competence identified by the Royal College of Nursing (RCN) as a foundation for advanced nursing practice in the UK [5]. The value that specialist nurses bring to their area of expertise is well documented and authors have highlighted the added value and worth of investing in specialist posts to support patients fully [6]. Specialist nurses perform at a highly sophisticated level

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of practice [6], are both clinically and cost effective and it has been shown that they prevent hospital admissions, free up consultants time, and provide a service within the community to name but a few initiatives [7]. Above all they are recognised as an invaluable source of support and knowledge by the patient cohort, families and carers along with many other allied health care professionals [8]. Unfortunately, they may also be seen as a luxury and are often first in line for the reduction of services when the National Health Service (NHS) is under threat financially. Being able to demonstrate worth is a skill all nurse specialists must therefore understand [8].

Current Considerations for Stoma Care

In England and Wales, many Stoma Care Nurses (SCNs) are employed by the NHS with financial sponsorship provided by a manufacturing company. The practice of sponsorship was discontinued in Scotland in 2006 [9] but SCNs were still employed by health boards with financial support being given monies from industry for a specific time period so that posts could continue until review was completed. Sponsorships continue elsewhere in UK with an estimated 84% of hospitals in England and 77% in Wales and 2 hospitals in Northern Ireland having formal sponsorship agreements in place [10]. Whilst controversy has surrounded the widespread practice of sponsorship for many years, it can be argued that patients undoubtedly benefit from a service which may have been reduced or not offered without the support of industry. This is increasingly apparent in the primary care setting thereby reducing the burden on the ever increasing workload within the secondary care sector. The impact of any future changes to the health care processes in the UK remains to be seen.

The majority of ostomy appliance manufacturers as well as Dispensing Appliance Contractors (DACs) are governed by the British Health Trades Association (BHTA). This is one of the oldest healthcare associations in the UK representing the healthcare and assistive technology industry, who ensure that practice is ethical. Guidelines for Practice [11] stipulate the code that member companies should follow, but membership of BHTA is not mandated and entirely up to the individual company. At the time of writing, a national review of stoma expenditure is being undertaken as the financial burden has an ever increasing impact on the NHS. The reduction of waste and stockpiling of equipment is required within continence and wound care as well as stoma care necessitating an overhaul of the way in which appliances are dispensed. In 2001 the development and function of a collaborative forum known as Patient, Industry and Professionals forum was an initiative by BHTA [12], to allow significant parties to liaise, consult and offer an informed opinion on specific aspects of care which could impact stoma and continence care.

Stoma appliances are free to patients with prescriptions provided in a number of different ways throughout the UK but the emphasis must be on the provision of an appropriate appliance for the individual patient's needs (see Chap. 3). Changes within the primary care setting, including the introduction of Integrated Care Systems (ICSs) should see a more integrated and coordinated service designed to meet health and care across a geographical area, thereby reducing inequalities between different groups. It is also an opportunity to drive efficiencies and cost savings.

The Role of the Stoma Care Nurse (SCN)

The role of the SCN is often complex and multi faceted. The skills required for any nurse to develop into a' Specialist' with responsibilities for managing a clinical service are also well documented and supported at national level by the Royal College of Nursing [6, 7] as well as individual specialists nurses' professional forums such as the Association of Stoma Care Nurses UK (ASCN UK) [13]. Many specialisms are supported by a relevant medical forum and ASCN UK is no exception. Affiliation with the Association of Coloproctology for Great Britain and Ireland provides us with affirmation that we are addressing all the clinical needs of the patients as well as a professional understanding that care is collaborative. A multidisciplinary structure allows for sharing of ideas and concepts, contribution to national changes in the management of colorectal and urology patients as well as opportunities for research and improving clinical pathways of care.

The Role of ASCN UK

ASCN UK evolved from the UK section of World Council for Enterostomal Therapy in 2013 after a fruitful collaboration with this global association for many years. The desire to branch out and have a completely independent UK national body for stoma care nurses was widely felt and a new membership was established. It is a non-profit making charity managed by an independent company with all the restrictions and guidelines stipulated by the Charity Commission [14]; the ASCN UK committee is currently made up of five SCNs. The philosophy of the ASCN UK is to provide SCNs in the UK with a framework for specialist practice and high standard resources to enable nurses to practice from an evidenced base standpoint. The key objectives are to ensure that clinical care is equitable across the country, patients receive a gold standard of care and nurses are supported by each other. The rich membership also supports new specialist nurses with their own development and education as they can access clinical guidelines, templates for standards of care and collaborate via a website as well as social media. These recent developments ensure that members have access to the expertise available and any SCN is able to contribute with fresh ideas and innovation. Funding is also made available for nurses to support their educational needs with grants applied for directly through the charity.

Standards of Care

The provision of templates within the ASCN UK Standards of Care [15] were developed in collaboration with the Paediatric Stoma Care Nurses Group (PSNG) so that nurse specialists have a robust framework for clinical practice. For many nurses, writing a business plan for service development or future proofing, gathering data for an annual report or knowing where to start with auditing their service can be daunting. Providing templates allows nurses to consider the type of information and data required to support the development of their service. The standards are reviewed every 3 years to ensure that they are up to date and relevant and they have also been accredited by RCN. This endorsement assures nurses that the Standards have been thoroughly reviewed and are underpinned by the appropriate relevant evidence.

Clinical Guidelines

At present there are 26 ASCN UK clinical guidelines which have been written by SCNs; they are peer reviewed and updated 3 yearly [16].

The provision of clinical guidelines allows new specialist nurses to seek understanding and reassurance about their clinical practice as well as supporting their learning of new skills.

Competencies

It is extremely important for SCNs to practice in accordance with the Nursing and Midwifery Council (NMC) Code of Conduct [17] and within the confines of the specialism. To facilitate nurses' understanding and guidance around levels of competence, ASCN UK have written clear concise competencies based upon the pillars of competence suggested by the RCN. These have been written to reflect the roles of Band 6 and Band 7 SCNs but also more recently to reflect the role of a Band 2/3 and 4 support worker in stoma care. The distinction between levels of competence will help employers to define the needs and skill mix of a service.

As well as having a clinical remit, it is widely acknowledged that any specialist nurse practicing within Band 6 and 7 competencies must also demonstrate that their role incorporates other aspects of competence. This includes Education, Audit/Research and leadership qualities with a strategic vision for the development of future services that will advance practice and enhance patient care by addressing local and national policies. Annual appraisals should therefore take into account all domains and objectives set for each individual nurse accordingly.

Annual Conference

ASCN UK offer the provision of a conference for stoma care nurses run by stoma care nurses providing a platform for the sharing of knowledge, practice and research on a particular theme which reflect topical issues within health care and the speciality. Prior to 2020 this had always been as a face to face event, but more recently due to circumstances brought about by the Covid 19 pandemic the conference has evolved as a virtual event. Moving forward however, the conference will return to a more conventional face to face format if circumstances allow following member feedback. At the conference nurses are invited to present their work either as an oral presentation or a poster presentation. Key speakers enrich the conference further by addressing key issues around specialist practice and relevant NHS issues. The conference is also supported by Industry and National Stoma Charities with many manufacturing companies exhibiting to delegates, sharing product developments and patient resources. This is an ideal opportunity for all SCNs to update their knowledge of products and the resources available, which can assist them in offering best quality care to patients. It also provides an ideal forum for nurses and industry to come together and share experiences thereby collaboratively raising the profile of the stoma care speciality.

Conclusion

As we alluded to earlier it is fundamental that as expert, highly skilled nurses we are able to offer best evidence-based care to all of our patients. To support this expert practice, we have collaborated with key opinion leaders within the specialist sphere of stoma care and related subjects to provide relevant chapters that can be used as a guide to expert practice or as a reference manual to steer novice SCNs.

Each chapter will provide the reader with some key words and learning objectives, which can be used by any SCN to shape and guide good practice. Some chapters are very clinical and offer an in-depth exploration of anatomy and associated physiology, or offers information on how to care for patients with a specific disease condition or symptom if you are unfamiliar with it, however this should not be used independently. Effective collaboration with peers, colleagues and other disciplines within health care is always central to the art of good practice. Other chapters address professional issues such as health economics and the value of the SCN role.

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Raising the Profile of Stoma Care Nursing

2

Wendy Osborne and Amanda Gunning

Learning Outcomes

- Differentiate between the Specialist Nurse and Advanced Nurse practitioner roles and identify aspects of the role that correlate with either or both.
- Identify the components of the pillars of Advanced Nursing Practice and how they should be encompassed within the role of the Specialist Stoma Care Nurse (SSCN)
- Comprehend the scope of practice, competency and responsibility of a SSCN and how this will improve the perception of the service provided
- Highlight how application of advanced assessment skills, adherence to standards and application of evidenced based practice will enhance quality patient care
- Identify how tools and models of advanced communication enables improved outcomes to benefit both patients and stakeholders
- Identify specific outcome measures that demonstrate the value of any SSCN service
- Understand the importance of data collection, audit, report analysis and evaluation of a service that meets patient needs in line with local and national agenda's
- How to raise the profile of the SCNS role and integrate the service with key stakeholders

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Introduction

The role of the Specialist Stoma Care Nurse (SSCN) is complex, often extending into different specialties, and as such, is often very difficult to quantify or prove its value. The ability to demonstrate the outcomes of the specialist nurse intervention and the benefits of a preventative approach to care from cost, value and patient perspectives, helps nurses to showcase the significant advantages of their service to key stakeholders, and build the profile of their speciality.

Differentiating Between Roles - What is the Specialist Role

In order to highlight the significant value the role of specialists in stoma care bring, it is necessary to be succinct and consistent in the communication regarding who are the specialists in stoma care and what is incorporated into their role? Once this is established, it is important to then validate the impact of the quality of care delivered which is not only patient centred but cost effective. However, this information needs to be quantifiable within the outcomes of our interventions and tailored to demonstrate how this benefits each and every unique stakeholder (including but not limited to: patients and their families/carers, third party sector (e.g. voluntary charities), colleagues, management, commissioners in both the national health service (NHS) and commercial settings as well as influencers of health care provision and policy makers within the NHS and Government). This can be perceived as a huge undertaking, but as registered nurses (RN) within the speciality of stoma care many SSCN's in practice are already doing this and others just need the confidence and access to the tools required to raise the profile of the stoma care speciality, the patients and the nurses that work within this specialist sphere.

Within stoma care there is an abundance of titles used which include; stoma care nurse (SCN); specialist stoma care nurse (SSCN), stoma care nurse specialist (SCNS); clinical nurse specialist (CNS) in stoma care; advanced nurse practitioner (ANP) and advanced practitioner (AP) to name but a few. This myriad of titles requires consideration as a professional body of nurses within the speciality of stoma care as it questions inconsistencies in scope of practice, education and training. It is inferred from the range of titles that there is controversy in the definition of a Specialist Nurse. When the title of Stoma Care Nurse (SCN) is considered, it clearly identifies the area of speciality but questions the profile of the level of expertise, quantifiable qualification and potentially the respect and accolade of the nurse to a stakeholder who may not directly work with the nurse.

The word 'Specialist' within the title infers an individual holds a professional authority of expertise. The Royal College of Nursing (RCN) [1] has produced a factsheet on specialist nursing in the UK, stating "specialist nurses provide tailored care depending on the patient's level of need. They also provide education and support for patients to manage their symptoms, particularly patients with long term conditions and multiple morbidities." The RCN [1] go on to specify the educational requirements for a specialist nurse is an entry level Registered nurse (RN) qualification and a first level initial registration with the Nursing & Midwifery Council (NMC) [2]. They highlight the 'period of experience' should be of 'sufficient length' and may vary across specialities and roles, but there is general consensus in the UK, nurses practicing at specialist level should complete a 1 year full-time degree level programme concentrating on; clinical nursing practice, care and programme management, clinical practice development and clinical practice leadership. The course should cover 50% theory and 50% practice RCN [1]. In reality, a full-time degree level programme whilst working in the current NHS climate is not practical; however, accessing degree level education for a SCN on a part-time basis is more achievable and widely accepted as the norm. Most nurses who embark on a specialist career pathway will gain a vast amount of experiential learning daily, which complements this academic requirement. This is accompanied by working towards the defined specialist clinical competencies and objectives set by individual employers.

It is common practice within UK, (although unsubstantiated) for the term specialist to be included within a nursing title when an academic qualification or module within the remit of the anatomical speciality (stoma/colorectal/urology) has been undertaken. The qualification should reflect an assessed level of accredited competency by an academic institution. The academic level of qualification most recognisable would be at a minimum of Degree/Level 6, accredited by a university, although some specialist nurses choose to study modules at Masters/Level 7 in order to further advance their level of knowledge, critical thinking and research capabilities [3].

Prior to 2002 the English National Board (ENB) [4] under the auspices of United Kingdom Central Council for Nursing, Midwifery and Health Visitors, (latterly replaced by Nursing, Midwifery Council) had the legal responsibility as the approving institution for professional nursing courses in England. In stoma care this was the ENB 980 (Basic level of Stoma Care course) and ENB 216, a longer, more advanced course in stoma care nursing requiring the passing of assignments and observed specified skills to demonstrate achievement of competencies and knowledge to practice as a specialist in stoma care. These Nationally approved ENB stoma care courses had a specified curriculum which provided a standard of education and achievement to be a specialist in Stoma Care Nursing. Since the demise of the ENB, various modules in stoma care have been successfully developed with the educational content accredited by several universities. Nurses then choose to study at either Level 6 (Degree) or Level 7(Masters) depending on their own professional development requirements [3]. For example: the Association of Stoma Care Nurses (ASCNUK) [5] have developed their own accredited course in stoma care at Level 7 (Masters) Advanced Stoma Care at the university of East Anglia (UEA). There are also several other Level 6 (Degree) and Level 7 (Masters) accredited modules in the UK, which have been developed by either hospitals or stoma related companies, all affiliated with a university offering a recognised level academic knowledge and understanding [6].

Advanced Nurse Practitioner

Let us consider the advanced nurse practitioner role (ANP); the RCN [7] defines advanced practice as, “a level of practice, rather than a type of practice” educated at Masters/Level 7 in clinical practice and also possessing a prescribing qualification. This clearly indicates advanced practice is informed by a higher level of academic knowledge and skills that are applied in clinical practice. The RCN [8] go on to identify the competencies of an advanced practitioner within four domains: clinical expertise, leadership, improving quality and developing practice, as well as developing self and others. These domains form the foundations for the assessment of competency within practice highlighting how expert clinical knowledge and skills are applied. The RCN clinical competency states it is mandatory to be able to prescribe and actively monitor the therapeutic effectiveness of medications. This benchmark against which nurses working at this level are assessed to demonstrate competence, differentiates from assuming a title is based on years in a particular role or specialism. The debate continues regarding the use of the title ANP; many nurses will be practicing at this ANP level, but unable to register as such with the NMC as they do not hold an independent prescribing qualification [2].

It is important for all stoma care nurses to reflect on their roles and the competencies encompassed within their job title. Adhering to the NMC professional code [2] is mandatory for all nurses, as well as participating in regular appraisals and revalidation, all of which should equip every specialist nurse in their ability to demonstrate a higher level of expert knowledge and skill. It is equally important to consider how specialist nurses, interpret and evaluate advanced assessments with patients in accordance with the competencies and domains of the role. Integral to this, is the ability of the specialist nurse to apply and deliver best practice [1]. It is vital for any specialist nurse to keep themselves up to date with current literature and research, as well as being mindful to continually critique their practice and service provision as this is an essential element to evidence how to demonstrate the delivery of best practice. The undertaking of courses, attendance on study days and professional meetings all provide an opportunity to reflect on practice and learn from others, essential for all nurses’ revalidation. When attending any of these settings it is beneficial to maximise and initiate discussions with peers and colleagues to challenge and debate clinical practices and outcome measures.

There is a paucity of evidenced based practice within stoma care in comparison to other areas of specialism such as tissue viability or breast care. Specialist nurses and advanced nurse practitioners have a responsibility to contribute to the body of research-based evidence within stoma care. Research is often a daunting prospect to many nurses who have either not undertaken a research study or lack confidence in research methodology. There are many ways we can contribute to the body of evidence through clinical studies for example; the current national study on the prevention of parastomal hernia (CIPHER) [9], or, studies being undertaken by allied health professionals, product evaluations, local or regional audits. This also allows nurses to gain confidence and experience to critique, present and share best practice. Many SSCNs have published widely in professional journals such as British Journal of Nursing and Gastrointestinal Nursing, such activity supports the goal of sharing good practice within the stoma care speciality.

Many stoma care departments are now employing health care staff without the RN qualification as health care assistants (HCA), clinical assistants or maybe nurse associates. Such positions are hugely valued within the team. Competencies for such roles assigned within an NHS banding, of band 2–4 should be observed, templates of which are available from the ASCN UK website (ascnuk.com) [10]. It is up to the individual employer how they utilise these roles and what competencies the HCA should undertake. However, these roles should not be seen as a replacement for a role undertaken by a RN in order to increase cost savings; rather, they are complementary to the service and support the role of the SSCN with duties designed to free up the SSCN's time for service and staff development for example.

Evidencing Practice

It is recognised by Cooper et al. [11] that there are many similarities between the Clinical Nurse Specialist/Nurse Specialist (CNS/NS) and ANP. Both roles have significant professional autonomy [12] having "the freedom and authority to make autonomous decisions in the assessment, diagnosis and treatment of patients" [7]. Both act as a resource, facilitator for the multidisciplinary team and are involved in leadership, education, research, guidelines development and audits to varying degrees [11]. Cooper et al. [11] highlights within their systematic analysis of the research literature that the competencies originally identified as unique to the ANP are also fulfilled by CNSs and both are seen as having an equally positive impact. However, Cooper et al. [11] concludes the CNS role is often a disease/speciality specialist, and the ANP more of a generalist.

It is pertinent to note, that the RCN [1] identifies nurses working in advanced and specialist roles spend about 60% of their time in clinical activity, 17% of time in education, 14% in management activity and 4% in research. This highlights the importance to the term 'Clinical' in the stoma nurse title and a rationale for promoting consistency in the terminology. Leadership has been identified as a core competency within both CNS and AP roles, so it should be acknowledged that all specialists in stoma care are leaders in their own right. The significant differentiator as identified earlier is an ANP will be educated to Level 7 (Masters) and hold a prescribing qualification.

In view of the considerable overlap in both CNS and ANP roles, for the purpose of this chapter, the role of the RN specialising in stoma care will be referred to as a Specialist in stoma care nursing (SSCN). It could be suggested that those working as a SSCN could strive towards the RCN [8] competencies of the advanced nurse practitioners in order to raise the profile and academic credibility of the role. Many nurses within the speciality of stoma care are clearly seen to be working at an advanced clinical level, and it is hoped with an increased degree of definition and transparency in the roles, competencies and outcomes the value of stoma care nursing can be fully appreciated. However, nurses must be able to demonstrate the value of their advanced level of knowledge, expertise and critical thinking in order to raise the profile of the specialism further.

Table 2.1 highlights the RCN's [8] four pillars of competency which is self-explanatory in relation to the specific competencies encompassed within each pillar, but are all pertinent for the advanced practitioner in stoma care.

- Clinical/direct care
- Leadership and collaborative practice

Table 2.1 RCN (2018b) Advanced Level Nursing Practice. Section 2: Advanced level nursing practice competencies. Clinical professional resource. RCN Clinical professional resource

Clinical/Direct care	Leadership and collaborative practice	Improving quality and developing practice	Developing self and others
1.1 Practise autonomously, accountable and responsible for decisions, actions and omissions and are self-directed 1.2 Assess individuals, families and populations holistically using a range of different person centred approaches, assessment methods, some of which may not be usually exercised by nurses such as physical examination, ordering and interpreting diagnostic tests or advanced health needs assessment 1.3 Have a health promotion and prevention orientation, and comprehensively assess patients for risk factors and early signs of illness 1.4 Draw on a diverse range of knowledge in their clinical reasoning and decision making to determine evidence-based therapeutic interventions (which will include prescribing medication and actively monitoring the effectiveness of therapeutic interventions) 1.5 Plan and manage complete episodes of care, working in partnership with others, and delegating and referring as appropriate to optimise health outcomes and resource use, as well as providing direct support to patients and clients 1.6 Use their professional judgement in managing complex and unpredictable care events and capture the learning from these experiences to improve patient care and service delivery 1.7 Use existing and emerging technology and draw upon an appropriate range of multi-agency and inter-professional resources in their practice 1.8 Utilising the professional code of conduct appropriately define the boundaries of their practice.	2.1 Identify and implement systems to promote their contribution and demonstrate the impact of advanced level nursing to the health care team and the wider health and social care sector 2.2 Provide leadership and consultancy services in their own and other professions on therapeutic interventions, practice and service development 2.3 Acting as a role model, are resilient and determined and demonstrate leadership in contexts that are unfamiliar, unpredictable, complex and unpredictable 2.4 Engage stakeholders and use high-level negotiating and influencing skills to develop and improve practice advocating for developments that enhance and improve care 2.5 Work across professional, organisational and system boundaries and proactively develop and sustain new partnerships and networks to influence and improve health, outcomes and health care delivery systems 2.6 Develop practices and roles that are appropriate to patient and service need through understanding the implications of and applying epidemiological, demographic, social, legal, ethical, political and professional trends and developments 2.7 Identify the need for change, assessing risk and mitigating for it, proactively generate practice innovations and lead new practice and service redesign solutions to better meet the needs of patients and the service.	3.1 Are proactively involved in developing strategies and undertaking activities that monitor and improve the quality of health care and the effectiveness of their own and others' practice utilising clear governance strategies 3.2 Strive constantly to improve practice and health outcomes so that they are consistent with or better than national and international standards through initiating, facilitating, disseminating and leading change at individual, team, organisational and system levels 3.3 Continually evaluate and audit the practice of self and others at individual and systems levels, selecting and applying valid and reliable approaches and methods which are appropriate to needs and context, and acting on the findings 3.4 Continually assess and monitor risk in their own and others' practice and challenge others about wider risk factors 3.5 Critically appraise and synthesise the outcomes of relevant research, evaluations and audits, disseminating and applying the information when seeking to improve practice 3.6 Plan and seize opportunities to generate and apply new knowledge to their own and others' practice in structured ways which are capable of evaluation 3.7 Alert appropriate individuals and organisations to gaps in evidence and/or practice knowledge and, as either a principal investigator or in collaboration with others, support and conduct research that is likely to enhance practice 3.8 Use financial acumen in patient/client, team, organisational and system level decision making and demonstrate appropriate strategies to enhance quality, productivity and value.	4.1 actively seek and participate in peer review of their own practice 4.2 Enable patients/clients to learn by designing and co-ordinating the implementation of plans appropriate to their preferred approach to learning, motivation and developmental stage 4.3 Develop robust governance systems by contributing to the development and implementation of evidence-based protocols, documentation processes, standards, policies and clinical guidelines through interpreting and synthesising information from a variety of sources and promoting their use in practice 4.4 Work in collaboration with others who may mentor, supervise, coach or assess, plan and deliver interventions to meet the learning and development needs of their own and other professions 4.5 Advocate and contribute to the development of an organisational culture that supports continuous learning and development, evidence-based practice and succession planning 4.6 Have high-level communication skills and contribute to the wider development of those working in their area of practice by publicising and disseminating their work through presentations at conferences and articles in the professional press.

- Improving quality and developing practice
- Developing self and others

A reflection of the components within the leadership and collaborative practice resonates with the attributes identified by McGee [13]; that of integrity, interpersonal skills, knowledge and credibility. If such attributes are harnessed with confidence and belief, it is perceived that any specialist nurse may be able to achieve the same outcomes of the small, but impactful Irish study from Begley et al. [12] who concluded healthcare policy-makers believed specialists and advanced practitioners contributed to higher quality patient/client care, particularly at a strategic level. Begley et al. [12] recognised how the CNS/ANP leads in guideline development, new initiatives in care, education of staff, audit and policy development which is central to enhancing the quality and continuity of care. A key differential borne out within Begley et al's study [12] was that the CNS was said to demonstrate professional leadership at local level, while the ANP contributed nationally and internationally.

Scope of Practice

Having identified the competencies within the SSCN role, reflecting on the extensive scope of the role and the impact on collaborative working with other healthcare professionals should not only be recognised, but meticulously captured to demonstrate the extent of brokering and multidisciplinary relationships. (See Table 2.2). Astoundingly, every department and job role in the hospital all have the potential to come into contact with the nurse caring for a patient with a stoma. Many individuals living with a stoma are often admitted for a variety of differing conditions and illnesses which leads the SSCN accessing many different teams and departments within an acute hospital setting. In addition to this, many SSCNs often have additional roles and responsibilities that may extend into other departments such as colorectal and urological cancer, inflammatory bowel disease, endoscopy, continence, bowel management and wound care. Therefore, a SSCN caring for the person living with a stoma understands the entire integrated patient pathway, contributing throughout the patient journey efficiently providing expert clinical care and a better experience for the patients [14]. Leary [15] identifies how the cohort of patients cared for by specialist nurses are complex, indicating 20% may be seen as 'high risk complex' individuals taking up over 60% of our time. It is this complexity and multifaceted aspect of the SSCN role which often leads to the lack of understanding and perception that the contribution made by SSCN is intangible and difficult to describe.

On reflection, within the parameters of the pillars of competence it is important to gain confidence and a commitment to raise the profile and value of the SSCN role while addressing the NHS strategic priorities for our specialist service. It is recognised that SSCN's are busy juggling clinical/direct patient caseload/co-ordinating nurse led clinics, triaging referrals and phone calls with the needs and ongoing expansion of the service, as well as staff development. However, at a senior/strategic level this clinical practice may often go unseen and undervalued (Leary) [15]. It is necessary to take confidence in knowing the literature highlights the nurse specialist

Table 2.2 Extent of CNS/AP multidisciplinary working (but not limited to)

Nursing colleagues	Medical colleagues	Allied health care professionals	Non medical staff
Colorectal specialists Inflammatory Bowel Disease specialists Tissue viability/Wound care specialists Parenteral nutrition Oncology specialist nurses inc: Chemotherapy/Radiotherapy/Palliative care ITU/HDU Ward/general registered nurses Clinic/Out patient nurses Nurse practitioners Divisional/senior nurses Student nurses Other nurse specialists (diabetic/MS/enhanced recovery/renal) (community/hospital) Non qualified nurses (Hospital/community) District/practice nurses School nurse Mental health	Colorectal surgeons Gastro-enterologist (surgical/medical) Oncologist/palliative care Dermatologists Physicians General surgeons (benign/vascular) Speciality medics Senior/junior Doctors Medical students General practitioners	Dietician/intestinal failure Physiotherapists Occupational therapist Radiographer Pharmacists/medicine management Paediatric play therapists	Partners/family Carers Hospital managers/directors Medical secretaries PALS Social workers Care agency’s Academic institutions Schools/teachers Commissioners Procurement Practice managers Voluntary associations Safeguarding leads Policy makers CCG/ICS representatives Dispensing Appliance Contractor (DAC) Company representatives

as providing an optimal return on investment for income generation, cost savings, improvements in patient care and experience [17], as well as ensuring patient advocacy and safety. Leary [15] has written extensively on the value and worth of the nurse specialists and explores how this can be communicated effectively to others. The utilisation of available resources (Box 2.1) can help to structure and articulate the impact of the SSCN role to the decision makers.

Reducing patient readmission, improving patient satisfaction and experience in psychological and physiological well-being in both the primary and secondary care setting are all recognised benefits and outcome measures that the SSCN are integrally involved with. However, it is critical as a SSCN we justify and provide quantitative data in conjunction with the descriptions of the role.

Box 2.1 Resources to Assist in Demonstrating Worth

Audit—Patient reported Experience (PREMS).

Patient reported outcome Measures (PROMS).

patient satisfaction (ASCN UK) & outcomes in care (ASCN UK) Association of Stoma Care Nurses UK (ascnuk.com)

Evaluation of clinical guidelines Association of Stoma Care Nurses UK (ascnuk.com)

Evaluation of clinical measures e.g. number of complications (Cottam & Richards 2011).

Stoma related assessment tools (Russell-Roberts & Kay 2021)

Quality of Life (Prieto et al. 2005).

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- Annual report/service summary
- Template access job plans
- Key performance indicators
- Integrated service pathways
- Cassandra Matrix
- Business planning
- Future focused finance

Workforce planning (LSBU 2022) LSBU_Policy_Update_-_Healthcare_and_workforce_modelling_(2).pdf

Time and motion study.

Specialist data base/clinic coding to report activity.

Clinical coding/HES data (Hospital Episode Statistics) (admissions, outpatients, A&E, critical care data sets).

Inc.: readmission high output stoma/sepsis

Prescription costs within local area.

Having established your role it is important to focus on demonstrating ‘what the role encompasses’ to the wider health and social care services in order to raise the awareness of the service. Attendance at organisational meetings provides the opportunity for the SSCN to be an advocate of the stoma care patients’ needs and specialist service provided. Leary [16] suggests the following as a way to build on successfully achieving a high profile, through confident communication to highlight your patient needs, caseload and service:

- Identify and connect with the decision makers within your organisation/Trust
- Attend relevant departmental and organisational meetings
- Reach out to finance and operational managers, practice managers, or medicine management lead to discuss your service.
- Use affirmative language to tell stories of your expertise (example of case studies, audit or research)
- Promote you and your colleagues in a positive way.
- Attend and present your work at educational forums/conferences both nationally and internationally

Nurses need to try not to be too modest with regards to communicating any accolades and successes achieved by any member of the team; it is important to showcase such awards and achievements within the trust, as well as via local and National platforms. These ‘quick wins’ [16] also promote positivity as well as directing recognition and value to individuals of the holistic, patient centered, quality care provided.

What Is Your Worth?

Having considered some examples of raising the SSCN profile, there is the need to prove your worth. There are a number of ways this can be demonstrated. For example; the lack of a SSCN role poses a significant risk on quality of life for patients living with a stoma. The Association of Coloproctology of Great Britain and Ireland [18] identifies within their evidence based guidelines that the SSCN role is an essential member of the multidisciplinary team, and recommends the surgeon should not operate if a specialist nurse in stoma care is not a recognised member of the team. Effective and respectful professional relationships can be enhanced through proactive, confident, collaborative working with the surgeons/consultants. Surgical consultant colleagues can be significant advocates of the stoma care service provided. As an example when re-deployment to the wards is dictated by senior management (who may not recognise/understand the role in the patients’ pathway of care undertaken by SSCN), the consultant is able to champion the necessity and benefits of the SSCN role and therefore contributes to articulating the worth of the role.

When considering the worth of a SSCN, there are a number of questions posed by Leary [15] which are valuable in evidencing the benefits and outcomes of any interventions carried out by the SSCN. For example: quantifying the contribution in relation to safety, quality and efficiency. Leary [16] describes the work specialist nurses do as a ‘safety critical service’; *Consider what would happen if specialist nursing was unavailable?* It is important to highlight to managers the risks to patients on activities that would not be undertaken if a SSCN was not available, consequently certain activities will be omitted from pathway of care. For example: stoma siting for a patient before surgery has demonstrated significant benefits in reducing stoma complications, enabling patient self care and improved quality of life [19]. Other examples which may hinder the patient if a SSCN is unavailable may include the potential risks of readmission, including patient distress, bed occupancy which has an economic impact and an increase in patient comorbidity as well as failure to triage, manage and co-ordinate effective discharge planning. The SSCN managing a patient’s discharge will constantly be evaluating concordance with an appropriate stoma care routine. Through advanced assessment and tailoring of information, effective stoma care will help towards prevention of peristomal complications and readmission [23].

The ‘rescue work’ undertaken by SSCN includes examples such as ‘early detection of impending deterioration and taking pre-emptive actions to prevent adverse events’ (Leary [15, p. 62]). The holistic approach to patients is based upon knowledge and expertise gained through education and experiential learning which enables the SSCN to identify and respond to patient changes and deterioration [20]. In the stoma care speciality we need to evidence how we detect and manage a high output stoma, preventing/identify dehydration, urinary tract and chest infections and even thrombosis; all of these actions, we know as SSCNs we undertake daily, but our interventions may prevent readmission to hospital, and need to be demonstrated. Mental health and wellbeing is also a significant focus as changes in mental health status are often identified as a result of our involvement throughout the person’s healthcare journey. The proactive role of SSCN in collaborating and signposting to relevant health care specialists can mitigate deterioration or admission to hospital.

Audit

Justification of the SSCN roles and the services provided can be gathered from audit data, evaluation surveys and even clinical coding/HES data (Hospital Episode Statistics). For example: HES data will highlight trends and patterns of caseload activity which can be monitored year on year. This may provide a foundation for reviewing the impact on clinical activity. Various tools such as the Cassandra Matrix (Leary [15, p. 66]) provide an easy-to-use tool to capture nursing context intervention within a healthcare setting. It is like a detailed time and motion study which can help identify all the ‘multi-tasking’ activities undertaken. In addition, there are Workforce Modelling links which consider staffing levels, workload and patient outcomes [21]. There are a number of templates [22] which can be used as a starting point in building the evidence (see Box 2.1).

Specific clinical activity data can be gathered through several avenues depending on the systems available (e.g. trust (SystemOne; EPIC, EMIS) departmental/

specialist data bases, coding, paper records). However, this is reliant on the accuracy of the data input into the system and suggests managerial direction for consistency and processes for recording. Both in-patient and outpatient activity can be captured and recorded, including volume, purpose of intervention, length of time spent with each individual, brokering and outcomes. This can be assessed against the activity planned within patient pathways—highlighting any incongruities of planned versus actual care provided [23].

Often telephone support is not always captured in this data, but it is recognised as being an integral part of the SSCN service to both patients and colleagues. Hospital approved telephone clinics can be coded to enable recording of the calls as well as a charge for the service back to the Acute trust. However, it is of benefit to capture the length of call, purpose and activity incurred by the call as often multiple nursing actions are required as a consequence of one call. Recording the brokering, mitigating readmission or GP/hospital appointment and advice provided enables auditable data and further quantifiable evidence to demonstrate outcome measures. There are a number of stoma care specific audits that could be replicated including those by Bowles [24] who evaluated the quality of a nurse led clinic and Cottam & Richards [25] who audited stoma complications within 3 weeks of surgery.

Patient satisfaction and experience is often the most frequently considered metric of quality care and auditable data SSCNs are familiar with. Using patient-reported outcome measures (PROMs) to measure patients' view of their health status and patient reported experience measures (PREMs) to capture patients' perceptions of their entire experience whilst receiving care are important focuses for healthcare providers which aim to be used as tools to improve quality of care. When considering the specific measures/data points within such a tool to measure a service, these should reflect NHS agenda benchmarks e.g. compassion, dignity and respect [26, 27], encompass the key lines of enquiry within the Care Quality Commission [28] as well as national stoma care standards [27]. The ASCN UK National standards and audit tool [29] will provide evidence of standards being achieved but also experience from a patients perspective. Consider other local/Trust/National based evaluation surveys that may reflect the SSCN service; for example: The National Cancer Experience survey [30] or Inflammatory Bowel Disease [31].

Quality of Life (QOL) measures are another tool used to demonstrate the impact of SSCN interventions especially when used at specific points in the patient's journey and then compared following the SSCN interventions. Consider reliable and validated tools which may be undertaken by colleagues; for example the colorectal nurses or oncology staff that may capture SSCN involvement with the patient. Within stoma care, the stoma QOL tool [32] is a well-known valid and reliable tool, referenced within the ASCN UK guidelines [19] as a measure to evaluate the impact of peristomal complications. Any data collated must be evaluated and analysed with areas of practice clearly identified in terms of achievement, and those requiring improvement with specific actions required to address the issues/concerns. Collectively, this patient feedback will assist in future proofing and tailoring the service to the needs of the patient/service user, as well as evidence to support and prioritise service development.

Improving Outcomes

Professional development can be assessed using the trajectory of Benner's [33] Novice to Expert model, who indicates where there are more degree level educated/trained RN's you will have better outcomes for patients. As an expert, it is the intuitive grasp [34] of complex situations as well as the analytical ability to solve new situations 'beyond rules, guidelines and maxims' which shape the quality of patient outcomes [33]. Although Benners' work is over thirty years old, the framework has proven outcomes of building confidence and leadership capabilities, which have contributed to quality, safe patient care [35].

When considering how outcomes for patients can be improved within clinical practice, many SSCNs will relate to assessment of complex patients post operatively, where an intuitive grasp of the situation can result in a medical review/investigation being initiated by the SSCN. An example may involve safeguarding concerns, issues related to capacity to consent and/or mental health, where confidence in both advanced skills and knowledge of processes and management of such situations is required. The heightened advantage of the SSCN being involved in these situations is that the SSCN is a 'constant' health care professional within the individual's healthcare journey. The SSCN experience and ability to signpost or implement interventions for the safety of the patient are as a result of the expertise, competence and the credibility accrued with the healthcare professionals to respond swiftly to our assessments. This is another example of the benefits the SSCN brings to improving outcomes in care.

The application of research-based evidence and best practice is fundamental to safeguarding quality and delivering minimal standards. Practice, which is based on evidence, enables care which is clinically and cost effective, where high standards can be maintained and ensures best outcomes are achieved [36]. National standards and guidelines in stoma care [19, 29], IBD [31], colorectal cancer [18] Diverticular disease [37] and improving outcomes in urological cancer [38], provide the minimal standards that should be adhered to. The importance of audit has been highlighted; audits should be the benchmark which capture and demonstrate compliance to national frameworks, guidelines and standards. By implementing such a framework, improvements in the quality of care can be achieved in a collaborative and systematic manner. Clinical audits identify services which are performing well and achieving good practice; this will ensure quality of care and high standards are being met. Conversely, audit will identify where services require improvement, highlight either emerging trends or risks that require actions to be implemented so that changes can be made to support best practice and improve outcomes.

Effective Communication

Effective communication is the essential underlying aptitude which is instrumental in meeting the SSCN competencies and is common to the four competence pillars for an advanced practitioner [5]. The essence of the SSCN role is the skillful confident communication with both patients and stakeholders. This core skill can often be taken for granted. When exploring some of the key considerations for advanced communication from a SSCN perspective the focus on a person-centred consultation is pivotal, so referring to tools and frameworks that can provide structure and evidence will subsequently assist in improving effective patient outcomes. In addition to the advanced communication skills training undertaken with NHS multidisciplinary teams, it is important to highlight the Calgary/Cambridge model [39]. This excellent framework segments a patient consultation into six steps; initiating the consultation, gathering information, physical examination, explanation, planning and closing the session. Each step provides structure and a guide to improve the consultation which encourages the patient to be at the centre of the discussion. Skills within motivational interviewing cannot be underestimated and have demonstrated a supportive counselling style that encourages and strengthens a person's motivation for change [40], seen to improve patients' health and adoption of healthier behaviours. Both models justify further exploration, and the authors would very much promote further reading around these frameworks.

Fundamentally, the purpose of any clinical communication will significantly vary depending on the who and the why. This will be multifactorial, influenced by personalities, knowledge, opinions and culture to name but a few. It is important to initially identify how important the nurse-patient relationship is and the dialogue between the two to ensure patients feel heard, as well as their anxieties and fears being allayed. The ability to listen actively in a caring and genuine manner contributes to establishing a good rapport, this will enable patients to open up and disclose relevant information and this should ultimately improve patient satisfaction [41]. This effective, clear and honest communication will help to contribute towards accurate diagnosis, understanding care and treatment decisions, as well as having an impact on positive outcomes in care. The mode in delivering information in a way that is tailored to the individual's agenda and understanding, in a compassionate and professional manner is imperative to the delivery of quality care and achieving positive outcomes for the patient.

Experiences of delayed, insufficient, inconsistent, and complete failures in communication between both patients and team members are detrimental in increasing dissatisfaction, harm, length of stay and reducing staff morale [41]. The importance of communication has been highlighted within the NHS with advanced communication skills training to address the challenging communication scenarios within professional practice. The benefits of such courses have been shown to increase confidence and competence [41] which benefits outcomes in patient care, compliance to treatment, quality of life and patient experience and satisfaction; but could also reduce stress, complaints/medico-legal risk, costs to NHS and consultation length [26].

SSCNs should be able to demonstrate the application of credible communication models. Such tools provide the evidence to support clinical practice and prompt reflection, critique, and to continually enhance and develop our skills. Patient empowerment is a core principle of the NHS and especially in stoma care when one of the key goals is to promote the self-care of a patients stoma. This should extend into understanding the management of a patient's general health [42]. The changing expectations of 'expert' patients is a situation seen by many SSCNs working within stoma care, often influenced by increased access to information from the internet, news bulletins and social media. It is important that the communication provided should consistently encourage informed decision making based on the choices in treatment options available to patients as well as promote engagement and empowerment. There are a range of communication modes to consider that can maximise how the patient can understand and reflect on the information provided: from written booklets, online information, digital platforms, recordings, social media, patient stories. The use of translated literature, and translators where the patient's "mother tongue" is not the one which is providing the information should be considered.

Having focused on communication with patients, it is equally imperative that effective communication skills are undertaken with colleagues, other professionals and allied healthcare professionals. The ability of the SSCN to adapt and flex their skills, interpret the needs of the individual being communicated with, whether a patient, carer or any stakeholder as highlighted earlier, is imperative to the quality, safety and effectiveness of the role of a SSCN.

Identifying Specific Outcome Measures

The quality of care and support the SSCN offers has been reported by the RCN [1] as being instrumental in reducing unnecessary hospital admissions and readmissions, reducing waiting times, freeing up the consultant's time to treat other patients, improving access to care, educating health and social care professionals and supporting patients in the community

When looking at this in relation to work undertaken by two groups of experienced stoma care nurses [20, 43], they identify evidence to demonstrate that specialist nurses deliver cost efficiency savings, greater service efficiencies and better patient recorded outcomes. This bridges gaps in the system leading to a more seamless patient journey, resulting in improved patient experience and the prevention of readmission to hospital. Traditionally stoma care services have been a 9 am–5 pm; Monday to Friday service, but now, in response to Enhanced Recovery Programs (ERP), reduced inpatient length of stays and maximising efficiencies in bed management, this has led to many stoma care services now being more flexible in their working hours to support safe and effective discharge of the patient. The work from Virgin Elliston [20] clearly documents an integrated stoma care nursing patient pathway which incorporates the stoma care nurse intervention within the patient pathway. The five NHS high impact actions are assigned throughout the interventions at specific touch points in the patient's pathway including that of: your skin matters, keeping nourished, important choices, ready to go—no delays and protection from infection.

Raising your Profile with Stakeholders

Annual Service Summary Report

An effective and structured way to capture and present any specialist stoma care service is to undertake an annual service report. Templates for such a report may be available from your local organisation or can be found on the Apollo specialist nursing resource [22]. The investment in putting together an annual report cannot be under-estimated. Such a report should highlight individual needs, preferences and values of the people using your service. Collation of current service resources, activity in evaluation/audit of the service provided and key performance indicators and outcomes will be paramount. Undertaking this activity will demonstrate how the service's financial budget is managed, the skill mix required to deliver the service and impact of any changes in resources to meet the service needs. By undertaking this activity yearly, it is able to capture the changes in service provision year on year. Not only may these be as a response to audits, research based evidence, national or local agenda priorities but also specific service developments or changes in practice; such as response to the Covid-19 pandemic and need to revise the patient pathway—e.g. introduction of virtual/telephone clinics and report on the outcomes of these [44].

It is helpful to write a cover statement for the annual report to entice and attract all interested parties to read the document, take time to summarise the critical information showcasing the service and the value and worth provided as a SSCN or a team of SSCNs. Cascade the report widely within the organisation/trust including the chief executive, board of directors, chief nurse and consultants for maximum exposure to your service. Consider the wider MDT; this report will help inform colleagues and highlight the care provided for their patient/client groups. If the remit of the SSCN role extends out to primary care and secondary care – capture the 'joined up service' and continuity of care within both settings within the annual report, identifying the key stakeholders within the community. Tailoring the service summary should reflect both local and national agendas. For example General Practitioners (GPs), prescribing clerks, Integrated Care Systems (ICSs) and medicines managers will be wishing to understand the cost implication of prescribing in stoma care [45, 46] as well as evidence of interprofessional activity such as GP training days, prescription review clinics and multi-disciplinary teaching.

Financial Considerations

When it comes to the financial impact of a service and the patient to the NHS, costs of prescriptions are another significant factor stakeholders will be interested in and the impact your role can contribute to prescribing cost efficiencies. Annual patient reviews should be conducted to assess a patient's current product need and usage in accordance with prescribing guidance (PrescQIPP [47]) this then requires robust and accurate reporting, monitoring and analysis.

It can be helpful to gather data from a local pharmacy lead or Dispensing Appliance Contractors (DAC) that engage frequently with the service with regards to prescription costs; they may be able to provide detailed information to enable analysis of how the local ostomy spend compares with the national average. Contact with the local medicine management, pharmacy lead and procurement stakeholders is essential to achieve collaborative working relationships which will ultimately promote understanding of the needs of patients and engagement with any local formularies or centralised prescribing within the area.

The majority of stoma care departments across the UK receive some financial funding in the form of sponsorship or company employed nurses as a result of contractual arrangements between a NHS Trust and a commercial company. This established arrangement has saved the 'strapped for cash NHS' a significant amount of money, while ensuring an adequate resource to provide ongoing care and support to individuals with a stoma. An annual report provides an opportunity to articulate the contribution of the cost savings and cost efficiencies to the NHS [48–50]. These may be accrued through samples provided by the manufacturing stoma care companies and costs integral to resources such as staffing/equipment/expenses covered by the agreed funding so that an accurate reflection of the service is captured.

Analysis and summary of all the above information should be integrated into an annual/service report and will be of particular interest to local commissioners and providers of healthcare. NHS resources are constantly the subject of ongoing review that any individual working within health care in the UK are well aware of; unfortunately commissioners are constantly required to make decisions over funding and service development priorities. SSCNs have the advanced knowledge and skills to play a major role within any commissioning process. All SSCNs are responsible for representing and being an advocate for the needs of patients, and as leaders must be visible and proactive in ensuring stakeholders are not just aware of the service provided but the outcomes it delivers. Within many Integrated Care Systems (ICSs) there will be funding for packages of care agreed between the Acute and Primary health care commissioners, for example: a patient admitted for an Anterior Resection will have a funded package of care including inpatient and post-operative follow up with stoma care included. It is this aspect of stoma care that may be limited to the inpatient management only, leaving the question of whether additional funding has been allocated to support follow up care or how stoma care is funded/supported within primary care locally. This is where the impact of a specialist stoma care service to provide ongoing care to a person with a stoma incurs income generating revenue for the employing organisation/trust. Depending on the employer, the positioning and ability to have a financial value attributed to the intervention undertaken through a cost code for any follow up clinics, nurse led OPA clinic, home visits and or telephone calls will provide income for the Trust.

Educational/PR Activities

Stoma care educational activities are often central to providing essential information to a vast range of healthcare professionals to support consistency in care and management of individuals living with a stoma. They are also key to promoting and raising the profile of the SSCN and meeting the needs of the individuals with a stoma. Box 2.2 highlights some examples of the regular educational/training events that can be undertaken over the course of the year.

Box 2.2 Educational Opportunities to Pursue

- University setting/programmed module training for nurses and doctors
- Work placements (medical students/nurses/associate nurse)
- Training sessions F1 F2 local and national (part of foundation course)
- Training updates to allied health care professions—Dieticians/physiotherapists
- Part of Induction for the Trust for new starters to the specialist wards (Colorectal/urology)
- Health Care Assistant competency training
- Ward training sessions—bite size scheduled educational sessions/one to one spontaneous bed side teaching
- Planned hospital based stoma care course
- GP update/refresher training (invite yourself with your consultant)
- D/N’s/pharmacy/medicine management/procurement
- Community/nursing/care homes/residential/care agencies
- Ostomy awareness day
- Condition specific awareness sessions for public

Other considerations to ‘advertise’ the service are seeking out opportunities to promote what the service provides. This may be within the Trust/organisation via newsletters/media/website as well as extending into the local services such as GP/ICS/support groups. Promote any open days; educational events, patient meetings with the local/social media and charity associations, as well as communicating via email/posters/online to local healthcare settings to publicise any events.

Another reflection is to consider, how well is the stoma care service publicised or signposted to assist hospital visitors, patients and other members of the MDT to locate the department? Is the department easy to find on the trust/organisation website, social media, telephone directory and is it known to the main switchboard?

Conclusion

This chapter has highlighted competencies and leadership skills required as specialists working within stoma care nursing (SSCN) being affiliated to the CNS and ANP roles. Acknowledgement that the ANP requires a Master’s degree and a prescribing qualification has already been highlighted; but it has been demonstrated that the SSCN also possesses and works at an advanced level of academic knowledge, skills and expertise. These skills can rightly be attributed to both the CNS and ANP in order to promote the value and worth of their specialist service.

A significant number of resources have been identified to evaluate and audit the outcomes of the SSCN service. It is important that stakeholders are provided with the relevant information, so that they are aware of the value you bring to individuals with a stoma and recognise the worth of the role. Be confident, and craft stories with regards to the activities that cascade from the stoma care department and help raise the profile of people living with a stoma. The patient centric role is pivotal to the rescue work, brokering and effective collaboration with a significant number of health care and allied health professionals. Without such a role the high risk and complex patients are in jeopardy.

Understanding the essence and each competency of the SSCN role within the patient's pathway will support the high impact actions attributed within the touch points of the integrated stoma care nursing pathway. As an advocate it is important to recognise the on-going responsibility that the SSCN has for the people living with a stoma by representing their complex needs and requirements from a specialist service, as well as future proofing the service for its' ongoing provision of care. Confidence and transparency in the domains of competencies will help demonstrate the impact on patient safety, quality of life, mental health and wellbeing. Identify, measure and communicate the cost efficiencies and impact of the service with the evidence and quantifiable outcomes at local and national levels.

By applying the tools and strategies outlined within this chapter, it is hoped you will be able to make a commitment to publicise and promote the specialist stoma care service to senior managers and stakeholders both internally and externally. Utilising your extensive communication skills, articulating and substantiating the importance of the SSCN within stoma care will then positively impact your ability to contribute to the positive change in the perception of the stoma care speciality.

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3

Health Economics in Stoma Care

Andrew Bird and Anne Haston

Learning Outcomes
- Be able to demonstrate an understanding of health care costs
- Understand the implications of a prescribing role for the GP, Stoma Care Nurse, patient and industry
- Better understand the future developments in primary care settings

Introduction

The creation of a stoma not only affects the ostomate and their family but has an economic impact upon society as a whole. The cost of stoma care is an important issue for the UK and National Health Service (NHS) of which specialist stoma care nurses (SSCNs), prescribers and ostomates should be aware [1]. NHS England [2] predicted a shortfall of £30 billion by 2020/21 as expenditure exceeds resources so all should be done to ensure services are run as cost effectively as possible. The cost of stoma-based prescriptions is on the rise with in excess of £277 million being spent in 2015, up to almost £322 million in 2018 despite an overall reduction in the total prescription spend of over £436 million during the same time frame [3]. Savings can be made with reductions in over ordering, stock piling, inappropriate or excessive product use by ensuring that the correct appliances are being used [1] but this can only be done with regular reviews and patient education and with prescriptions being monitored and issued by someone with a knowledge of the specialty.

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Using comprehensive holistic care strategies, the SSCN is central to facilitating the successful recovery and rehabilitation of new ostomates following major surgery. The specialist knowledge and skills of the SSCN are used to provide support, education, and empowerment and to enhance quality of life. As well as improving quality of life the knowledge and skills of the SSCN can, through clinical effectiveness and appropriate product selection, improve cost effectiveness and demonstrate financial savings.

Significant health economic burdens associated with reducing or stopping work or time from work due to illness or complications are possible [4]. The Office for National Statistics reported a loss of around 141.4 million working days in 2018 due to illness or injury. People with long-term health conditions were more likely to be absent from work through sickness and problems that could be attributed to having a stoma such as gastrointestinal problems, genitourinary problems and mental health conditions accounted for 8.6 million (6.1%), 4.1 million (2.9%) and 17.5 million (12.4%) lost working days respectively. Timely intervention from the SCN can increase wellbeing, minimise the impact of any problems and reduce the likelihood of losing working days.

Acute and Community Aspects of Care

Although there are many similarities, the role of the SSCN varies dependent upon where they provide input within the care pathway. Some will provide acute, hospital-based care whilst others support ostomates in the community and some will manage both the acute and long-term care pathways. Regardless of the location or time of input, the economic impact of the decisions made will be felt across the NHS.

Acute Setting

The preoperative period and time spent in hospital after having a stoma formed is the start of the journey of life with a stoma. This should include the establishment of a manageable routine for the patient and an appropriate choice regarding products following a holistic clinical assessment by a specialist SSCN. Helping the new ostomate to choose the most appropriate appliance is in accordance with the ASCN UK Stoma Care Nursing Standards [5] and is an important first step in providing a clinically and cost-effective stoma care routine. PrescQIPP, an independent body with a mission to support quality prescribing within the NHS, recommends that complete freedom of choice is offered, without pressure from a sponsoring company [6]. It may be necessary for the patient to use additional items to address stomal complications, increase confidence or extend wear time whilst they adjust to their new body image and stoma changes during the initial postoperative period. The prolonged use of these additional items however, may not be necessary and it is therefore important that the ostomate is aware of the possible short term nature of their use and understands that regular short and longer term reviews are advisable as their needs may change over time [7]. Upon discharge from hospital 10–14 days' supply of products should be given to the patient to ensure there is adequate time for a prescription to be dispensed along with sufficient information being given to the GP or prescriber to ensure continuity of care.

Stoma appliances and accessory products can be prescribed if they are listed on Part IX of the Drug Tariff which is produced and updated monthly by NHS Business Services Authority on behalf of the Department of Health and Social Care. In addition to listing prescription items, the Drug Tariff also outlines reimbursement and remuneration rates for pharmacy contractors, rules for dispensing, fees and allowances and the price of appliances and products that will be paid by the NHS. The cost to the ostomate for a prescription for a stoma appliance is the same as for a medicine and is chargeable per prescription item. In certain circumstances, however, the ostomate may be exempt from prescription charges (see Table 3.1).

Within the UK, many products are freely donated to hospitals by manufacturing companies. This ensures that the SSCN has a wide variety of products available which is essential as all stomas are not equal. Having access to a comprehensive range of appropriate products allows choice and flexibility for both the patient and the clinician as well as huge cost savings for each acute care provider and therefore has an impact upon the economic health of the NHS.

England, Wales and Northern Ireland manage this in a broadly similar way however, in Scotland, NHS National Services Scotland (NSS) Procurement led on the provision of a Scottish national contract framework for a wide range of stoma appliance products for new stoma patients in acute hospital settings. SSCNs from across NHS Scotland are nominated to sit on the Commodity Advisory Panel to work with NHS National Procurement by providing clinical expertise to guide product choice for the stoma contract. A discounted pricing structure is in place within the acute sector which can lead to manufacturers' losses but these are recouped in the community due to the higher cost of products. On first September 2010 all stoma appliances and accessories were removed from the Scottish Drug Tariff [8]. When the

Table 3.1 Free prescription entitlements

Free prescriptions for people:	*Possible free prescription for people*:
Under 16 (or under 18 if in full time education)	Receiving tax credits
Aged 60 or over	Receiving Universal Credit
Receiving Income Support, Income-based Jobseeker's Allowance or Income-related Employment and Support Allowance	On low income—With a HC2 certificate (available through the NHS Low Income Scheme)
With a valid maternity exemption certificate—Pregnant or new mothers (up to 12 months)	With a war pension exemption certificate
With a valid medical exemption certificate for a permanent stoma/fistula, cancer (and its treatment) and some long term conditions	Receiving contribution-based benefits

patient is discharged from hospital a triplicate Ostomy Appliance Record Form is generated detailing the items supplied, their code number, size and quantity. The copies go to:

1. The patient
2. The GP
3. The supplier/pharmacy (via the patient) practitioner) [8].

NHS Scotland contract dispensers to provide their services for the Scottish population. Fees are paid as remuneration for service provision and reimbursement for dispensed products.

Community Setting

Prescriptions for stoma care products are largely issued and authorised by a patient's GP although in some areas of the UK centralised prescription services have been set up or commissioned to tackle the rising spend within the stoma care specialty. The Rotherham NHS Foundation Trust and NHS Rotherham Clinical Commissioning Group (CCG) developed the first such service in 2013. Managed by NHS SSCNs, this service ensures that prescriptions for stoma care products are issued by a Health Care Professional with a working knowledge of the specialty; the benefits of which can be seen in Table 3.2. Other CCGs have taken a different approach to prescription services by commissioning from a non-NHS provider. In 2016, six Nottingham and Nottinghamshire CCGs jointly commissioned the Nottinghamshire Appliance Management Service (NAMS) to provide immediate, easy to access clinical support and a reduction in stoma spend for their ostomate community. The development was led by the Nottinghamshire Shared Medicines

Table 3.2 Potential benefits of a Stoma Care Prescription Service

• A knowledgeable Health Care Professional issuing prescriptions
• Prescribing based on clinical assessment rather than historical trial and error
• Easy access to specialist advice and support
• Early identification of stoma-related problems
• Reduced spend on stoma care
• Reduction in stockpiling
• Reduction in wasted products
• Reduction in 'lost' ostomates
• Reduction in GP appointments
• Reduced presentations to Emergency Departments
• Reduced hospital admissions
• Increased patient satisfaction
• Increased patient education
• Improved patient outcomes

Table 3.3 Stoma prescribing guidelines (with permission from PIPs Forum, 2014)

Stoma type	Appliance	Wear time	Monthly quantity
Ileostomy	Pouch	1–3 days	10–30
	Baseplate (if using 2 piece)	2–4 days	8–12
Colostomy	Pouch	8–24 hours	30–90
	Baseplate (if using 2 piece)	2–4 days	8–12
Urostomy	Pouch	1–3 days	10–30
	Baseplate (if using 2 piece)	2–4 days	8–12

Management Team who continue to support and monitor the service provision through regular meetings with the service providers. Bird [9] reports on an unpublished service evaluation, as well as the authors perceived anecdotal and experiential learning which identifies some of the potential benefits of such a service that can be seen in Table 3.2.

Whether the GP or a prescription services oversees the prescribing, prescriptions are sent to a nominated dispenser; either a dispensing appliance contractor, community pharmacy or dispensing GP practice. The choice of dispenser should lie with the patient although often, the stoma care nurse will offer guidance based on their clinical judgement and aligned with the patient wishes.

Systems should be in place to support the ostomate to aid the early recognition, assessment and treatment of stomal issues that may result in a change of products. As these changes can occur at any juncture, it is important to consider the quantities of products ordered and stored at any one time. To minimise the cost associated with wastage due to over-prescribing and over-ordering, it is advisable to issue prescriptions on a monthly basis. The quantity of products used per month is likely to vary from person to person however, Patient Industry Professionals forum (PIPs), a forum incorporating patients, professionals and industry groups concerned with stoma and continence care offer prescribing guidance on average wear time and monthly quantities that can be seen in Table 3.3. These guidelines, adopted by ASCN UK [10], provide a useful standard on which to base product ordering and prescribing practice. Overuse is often an indicator of a stomal problem and therefore usage above these quantities should be investigated by the SSCN. Parrett et al. [11] described the benefits of working closely with the patients suggesting the collaboration between nurses and patients is a fundamental factor in achieving the continued delivery of a successful service. Williams [12] identified almost £30,000 savings in two GP practices through clinical review and recommendations of suitable products by collaborating with the lead community pharmacist and medicines management team. It is recognised that GP's lack of knowledge within the stoma care specialty is a contributory factor to the lost revenue as a result of product wastage [12–14]. Hart and Benn [15] discuss a collaboration between a CCG and product manufacturing company and report an initial wariness from the patients who felt the collaboration was simply a cost-cutting exercise. Importantly, in all cases, significant cost-savings were reported whilst improving the care received by the ostomates.

As the NHS Long Term Plan [16] unfolds, the healthcare landscape will undoubtedly change. Integrated Care Systems (ICSs) will plan and deliver services that meet the needs of local communities [17]. Partnerships between health and care providers will aim to reduce healthcare inequalities and improve health through better planning and coordination of services. An increased emphasis will be placed on people taking more control of their own health and care, with this care being easily accessible and conveniently located. ICSs will oversee the functions of the NHS across the whole system and as the appetite for the right care to be delivered at the right time and in the right place increases, and the drive to maximise value and patient outcomes increases, it is expected that stoma care services will be amongst those targeted to be delivered within the community with less input expected from acute care providers. It is imperative that SSCNs in their respective localities position themselves to be a part of such a change and help shape the future of stoma care.

Approved Stoma Product List/Formularies

When bringing a new product to market, an ostomy product manufacturer must satisfy NHS Prescription Services that the product is safe, of good quality, cost effective and appropriate for prescribing before it is included in Part IX of the Drug Tariff [18]. An ‘entry price’, based on similar products provides a guide for cost however, representations can be made for an increased price if innovation can be demonstrated. Therefore, all products currently available on prescription have met these criteria but there are variations in pricing and effectiveness within the different product categories.

In an attempt to control the spend on stoma products, particularly those products used in addition to the appliances, various clinical commissioning groups (CCGs) in England and Health Boards (HB) in Wales have devised formularies from which prescribers should choose products to prescribe. The intention of the formulary is to restrict prescribing practice to those products that are considered to be the most clinically and cost effective. They are often devised with input from various stakeholders including patient representatives, stoma care nurses, prescribers and members of the CCG/HB, usually from within the medicines management department. Whilst the use of a formulary is helpful in restricting an escalated spend it is important to acknowledge that the items available on such a formulary will not be suitable for everyone so flexibility is required which allows up to 20% variance. In cases where all formulary products are unsuitable collaboration and communication between the SSCN, prescriber and patient are key to successful stoma care management.

In Scotland, the National Services Scotland Information Services Division (NSS ISD) holds an approved list of products from which authorised prescribers can choose. This list is larger than the one used within Scotland’s hospitals as product manufacturers can apply for new products to be added and thus offers a wider range of products from which to choose in the hope of providing a person-centred and cost-effective approach. However, the list does not include all products listed on Drug Tariff and therefore may limit choice in some cases.

Sponsorship

Since its beginning in the 1970s commercial sponsorship of stoma care nurse roles within the NHS has grown. In 2005, the Scottish Executive took the decision to ban commercial sponsorships following a series of consultations on the matter with all stoma nursing roles transferred into NHS employment. Over a two-year transition period from 2006, the British Healthcare Trades Association administered funds from the sponsoring companies to allow NHS boards to disengage from the links between industry and patient care. The future use of sponsored, or company nurses was also forbidden at this time [19]. Elsewhere in the UK however, sponsorships continued with an estimated 84% of hospitals in England and 77% in Wales and 2 hospitals in Northern Ireland having formal sponsorship agreements in place [20].

Sponsored posts can improve the delivery of care through providing expertise, capacity and capability that cannot be funded from the NHS budget. NHS England warns of the potential conflict of interest that may arise between the aims of the sponsor and the organisation [21]. In line with the guidance, sponsored post holders should not favour or promote the sponsor's specific products and alternative products should be available and offered. Breaching policies relating to conflicts of interest could result in investigation and disciplinary action. In 2017, Medtech Europe implemented a new code of ethical business practice to which member companies must abide. This changed how industry and healthcare professionals interacted and provides a more transparent, ethical relationship between the two. Key changes include:

- Direct sponsorship of specific individuals replaced by sponsorship of post or department
- The use of transparent educational grants
- Guidance on company-led events and third party events such as ASCN UK annual conference [22]

Although currently, there is no legislation specifically governing the practice of company employed nurses, they are bound by The Code [23] as are all nurses, to ensure all advice and information relating to product use is evidence-based and without bias with consequences of inappropriate actions possibly resulting in fitness to practice proceedings or being struck from the NMC register. Furthermore, the General Data Protection Regulation [24] introduced in 2018 requires all involved with data handling, including nurses to comply with seven principles of protection and accountability to ensure that data is:

1. Processed lawfully, fairly and with transparency
2. Used only for the purpose explicitly specified on collection
3. Collected and processed only if necessary for the purpose specified
4. Accurate and up to date
5. Stored only for as long as necessary
6. Processed with integrity and confidentiality
7. Used with accountability to the above principles

The Role of the Ostomate

As the end user of the products, the ostomate has a key role to play in the economic impact of stoma care. Helping them to understand this is an important aspect of the role of the healthcare professional. Education about stoma care products and possible problems that can occur may lead to an increase in quality of life and autonomy. Inappropriate habits may be difficult to break and there may be a reluctance to trial a new stoma care routine but a comprehensive clinical review along with an explanation of the alternative solutions available may help. Understanding the cost implications of using unsuitable products may help but care should be taken to ensure that any changes are not seen as cost-cutting exercises. Gaining buy-in from the ostomate is essential and this can be achieved through information sharing, joint decision making and fully understanding what is important to them.

Variances in products use and ordering should be explained to, and understood by, the ostomate. For example, ordering every product available each time an order is placed, regardless of need can lead to unnecessary waste or stockpiling. However, on occasions, it may be prudent to request extra supplies such as when planning a long trip away from home.

It is also important that the ostomate has an awareness of the potential influences from manufacturing companies. This may appear in the form of free samples, advertisements in charity magazines or on social media. Whilst these products may be useful in some cases, targeted advertising like this can lead to the request and use of expensive products unnecessarily. The ostomate should be encouraged to seek clinical advice from their SCN before requesting such products to ensure the most clinically beneficial and cost effective products are being used.

It is also recommended that each ostomate has lifelong access to specialist support and advice with a clinical appliance use review recommended annually [5]. The provision of long term stoma care varies from location to location but the ostomate should be made aware of how such support can be obtained in their locality both for acute clinical issues and the ongoing reviews as recommended above.

Conclusion

The increasing cost of stoma care is a concern that impacts on prescription costs and the NHS as a whole. Whilst England, Wales and Northern Ireland continue to use Drug Tariff as a means of providing stoma care appliances, Scotland has embarked upon a different strategy of removing these items from Drug Tariff and procuring them separately. Regardless of the process of access, shared responsibility for reducing the cost of stoma care lies with the stoma care nurse, prescriber and the ostomate. Together, through the use of holistic clinical assessments, education and shared decision-making the most clinically and cost-effective stoma care solutions can be found.

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Anatomy and Physiology of the Gastrointestinal Tract and Associated Disease Processes

4

Angie Perrin

Learning Outcomes

- Reflect upon the structure of the bowel layers itself and describe the role each of these layers has in relation to peristalsis
- Consider how understanding the function of the Gastro-intestinal (GI) tract is useful in the care of patients with surgical changes for example the formation of an ileostomy.
- Reflect on the function of the small intestine and how having a high faecal output stoma might impact the patient.

The gastrointestinaI (GI) tract runs from mouth to anus, consisting of mouth, pharynx, oesophagus, stomach, small bowel (duodenum, jejunum, and ileum) and large bowel (colon) rectum and anus. In total it is thought to be approximately 9 m in length [1]. The primary function of the GI tract is digestion. Digestion is a mechanical and chemical process, that is made up of six key stages;

1. Ingestion
2. Secretion
3. Propulsion
4. Digestion
5. Absorption
6. Defaecation

Each stage will be further discussed as the chapter progresses.

Ingestion is the first stage to occur when food enters the mouth, the food is then chewed or masticated by the teeth, moistened by saliva and broken down by

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enzymes. This process forms a food bolus, which consequently goes down the pharynx and triggers a swallowing reflex. The food bolus then travels through the oesophagus, where two sphincters situated at the base of the oesophagus prevent its regurgitation into the pharynx and mouth, and also prevents acidic gastric juices from being regurgitated into the oesophagus.

The Bowel Wall

It is important when reviewing the GI tract to consider the structure of the bowel itself. The bowel wall consists of four layers; serosa (Adventitia), muscularis, submucosa and mucosa [1] (See Fig. 4.1).

The serosa is the outer layer and consists of a serous membrane made up of connective tissue and epithelial cells that allows the bowel to receive its blood supply, lymph vessels and nerves. The serosa (adventitia) is only present where there is a mesentery surrounding or suspending the bowel [1].

The muscularis essentially consists of two layers of smooth muscle, that contract in wavelike movements. The movement of smooth muscle is under involuntary control, unlike straited muscle which is voluntary. The two muscle layers are made up of longitudinal fibres and circular fibres, the contraction of these two layers of

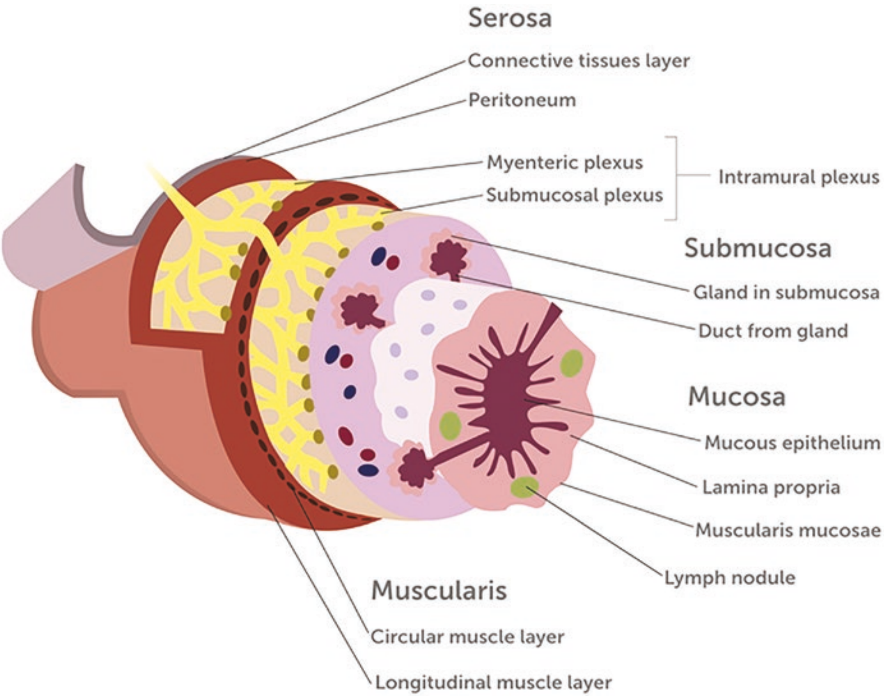

Fig. 4.1 Layers of the bowel (courtesy of A Perrin)

muscles is known as peristalsis and is present from mid-oesophagus to anus. Peristaltic (or propulsive) movement looks like a wave being propelled through the muscle, as the muscle constricts it then forces anything in front of the narrowed portion forward.

The submucosal layer consists of numerous plexuses of blood vessels, tissue, nerves and lymph vessels including the submucosal or Meissner's plexus, consequently it is extremely vascular.

The mucosa is the layer closest to the bowel lumen. It secretes mucus, hormones and digestive enzymes, it offers protection and facilitates absorption into the blood. It consists of a mucous membrane creating the inner lining of the GI tract.

The mucosa has three layers: the epithelium, lamina propria and muscularis mucosa.

The epithelium acts as a protective layer in the mouth and oesophagus, and has a secretory and absorptive function throughout the remaining GI tract. Epithelial cells are continuously renewed every 4–5 days eventually being shed off and passed into the faeces [2].

The lamina propria supports the epithelium by binding it to the muscularis mucosa and consists of loose connective tissue containing blood and lymph vessels [1]. The muscularis mucosa consists of very thin, smooth muscle fibres which accommodates movement and expansion of the bowel surface.

The Blood Supply

Blood supply to the abdominal organs is provided by three major vessels originating from the abdominal aorta, the coeliac trunk and the superior and inferior mesenteric arteries (SMA and IMA). This is known as the splanchnic circulation. The SMA and IMA supply oxygenated blood to the complete GI tract. The SMA supplies the jejunum and ileum via a series of intercommunicating paths which travel through the mesentery [3]. The splenic vein joins with the superior mesenteric vein to form the hepatic portal vein which takes blood from these organs to the liver.

Stomach

The stomach is located in the upper left quadrant of the abdomen, is a J-shaped organ composed predominantly of involuntary smooth muscle [4].

Anatomically, the stomach is divided into four main regions:

1. Cardia – which joins the oesophagus to the stomach
2. Fundic region or fundus – top left, dome-shaped region;
3. Stomach body – the expansive main stomach chamber;
4. Pyloric region or pylorus – funnel-shaped lower region connecting the stomach and duodenum

A typical adult human stomach is around 30 cm long and 15 cm wide with an average capacity of around 1.5 L [4, 5].

The stomach has three main functions; storage of food (about 1500 mls in adults), breakdown of ingested food into chyme and the controlled release of chyme into the small intestine [6]. Depending on the nature of the food consumed, food typically remains in the stomach for 3–6 h. Meals rich in protein and fat, such as a fried breakfast, tend to stay in the stomach for longer periods, [7]. Meals that contain a lot of fluid will leave the stomach faster than dry foods, therefore it is advisable for individuals experiencing a high faecal output to avoid drinking at meal times to help with retaining foodstuff within the stomach [8].

The digestion of protein and absorption of alcohol occur in the stomach [9].

When food is present within the stomach the muscular layer of the stomach wall; known as the muscularis, undergoes regular rhythmic contractions that help mix the food with the gastric secretions to speed up the process of chemical digestion. The muscularis consists of the same circular and longitudinal layers of smooth muscle found in other parts of the bowel within the GI tract. However, it also consists of an additional inner layer of oblique smooth muscle fibres. These layers of muscle allow the stomach to perform the strong churning motions that are vital for efficient mechanical digestion. Slowly solid pieces of food are mechanically and chemically digested, resulting in a semi-solid material called chyme [10].

The gastric secretions are hydrochloric acid, pepsin and intrinsic factor. Hydrochloric acid and intrinsic factor are secreted by Parietal cells. Hydrochloric acid supports chemical digestion, as well as activating the enzyme pepsin. Pepsin is produced at high concentrations, giving the stomach a pH of around 2.5–3.5 [10]; this high acidity helps the stomach sterilise ingested food. Intrinsic factor is a small protein that binds to vitamin B12 and transports it across the wall of the intestine into the blood.

About 3 Litres of gastric juice is produced daily [11] and secreted before and during the ingestion of food [12]. Gastric secretion occurs in three phases: cephalic, gastric, intestinal [8].

In the cephalic phase, gastric juice secretion is stimulated by sight, smell and taste or even the thought of food. This triggers the vagus nerve; facilitated by the parasympathetic nervous system to stimulate the stomach wall to produce gastrin. When a person is hungry, the mere anticipation of food is enough to stimulate gastric juice secretion [13]. The cephalic phase accounts for approximately 30% of gastric juice secretion and primes the stomach for the arrival of food. Chief cells secrete the inactive enzyme precursor pepsinogen, which is converted into the active enzyme pepsin in the presence of hydrochloric acid. Pepsin plays a role in protein digestion and enhances the bacterial killing activity of Hydrochloric acid [14].

The gastric phase is the longest phase of gastric secretion, typically lasting about 2–3 hours it begins when protein foods enter the pyloric area of the stomach. This stimulates the release of gastrin from the bowel mucosa into the blood stream, resulting in a surge of secretions of gastric juice [8]. Additionally, the stomach distends as a consequence of food being present which in turn stimulates the release of gastrin, leading to the activation of local and parasympathetic reflexes in the pylorus [8].

The intestinal phase is a stage in which food continues to pass slowly from stomach to the duodenum. The duodenum responds to arriving chyme and moderates gastric activity through nervous reflexes and the release hormones such as cholecystokinin, secretin and gastric-inhibiting peptide, which gradually reduce the secretion of gastric juice [5].

The Small Bowel/Intestine

The small bowel/intestine comprises of the duodenum, jejunum and ileum. Although the small bowel/intestine is narrower than the large intestine, it is actually the longest section of your digestive tract. The actual length varies considerably from person to person, but it's thought to range from 3 to 9 metres [15].

Duodenum

Chyme passes from the stomach to the duodenum via the pyloric sphincter to prevent regurgitation [8, 12]. The duodenum is the primary region for chemical digestion. Intermittently, the pyloric sphincter opens to release small amounts of acidic chyme, which stimulates the release of several hormones including Secretin, Cholecystokinin, Gastric inhibitory polypeptide and Vasoactive intestinal peptide.

The duodenum is C shaped and approximately 25–38 cm long [16]. It essentially consists of four regions; an upper, superior region called the duodenal bulb, that continues up to pyloric sphincter and the descending region that extends downwards into the abdominal cavity. About half way down the descending region is the entry point of the common bile duct and pancreatic duct which fuse before entering the duodenum. The bile and pancreatic juices are controlled entering the duodenum by a ring of muscle called the sphincter of Oddi. The horizontal section is the largest and is the main site for mineral absorption. The ascending region connects to the jejunum at the duodenojejunal flexure.

The duodenum has a mucosal lining that hosts tall columnar epithelial cells that extend into circular folds and finger-like projections, called villi. The villi increase the surface area allowing increased absorption of nutrients to occur although nutrient absorption predominantly occurs further down the small intestine.

The Jejunum

The jejunum is about 90 cm in length. It starts at the duodenojejunal flexure and ends at the ileum. There is no clear border between the jejunum and the ileum.

The jejunum has an immense surface area allowing for optimum absorption of nutrients. The wall of the jejunum consists of circular folds, villi and micro-villi that all assist with increasing surface area of the jejunum and the ileum where the villi are longer, more numerous and found at greater density. The numerous circular folds are microscopic and run parallel to each other in the mucosa of the jejunum. These deep ridges in the mucosal lining increase the absorption capacity by tripling the surface area of the absorptive mucosa in the intestinal wall. The villi, finger-like projections which can be found within the circular folds, measure 0.5–1 mm in length and multiply the surface area by 10 therefore enhancing the surface area available for nutrient absorption. The mucosal epithelial cells have thin, hair-like extensions about 0.01 mm in length; these tiny projections are known as micro-villi or brush border. There are approximately 200 million per 1 mm squared [17]. Villi have a very high rate of mitosis, so consequently are quickly replaced.

The Ileum

The ileum is the longest part of the small intestine making up to about three fifths of its total length. It is thicker and more vascular than the jejunum, and the circular folds are less dense and more separated [18]. The ileo-caecal valve can be found at the distal ileum and separates the ileum from colon. The valve is a sphincter formed of circular muscle that prevents reflux of the bacteria-rich fluid entering the colon and regulates the passage from small to large bowel.

Function of Small Bowel

As previously discussed the duodenum undertakes a large quantity of chemical digestion, as well as a small amount of nutrient absorption; however the key function for both the jejunum and the ileum is to finish chemical digestion and absorb nutrients along with water and vitamins. The mucosa of the small intestine secretes about 2 L each day of a slightly alkaline substance (pH 7.5–8) [8]. Consequently, if a patient has a high ileostomy output, they would be losing nutrients as well as bowel secretions.

To aid digestion there is a process called segmentation; where rings of circular smooth muscle hosting the villi and brush border found within the wall of both jejunum and ileum repeatedly contract and relax. Unlike peristalsis that involves rhythmic contractions of the longitudinal muscles, segmentation moves intestinal contents back and forth, distending the ileum, but this does not assist chyme through the tract; instead, it mixes it with digestive juices and then pushes it against the mucosa to allow nutrient absorption. For any patient who has undergone numerous ileal resections, and has a limited length of ileum remaining it may not be possible for them to reabsorb adequate nutrients. If a patient has less than 1 m of small bowel then it is unlikely that they will be able to reabsorb enough nutrients to maintain life without artificial feeding. It is important during surgery that following any resection of the duodenum, jejunum or ileum that the surgeon notes the length of small bowel remaining, rather than the length resected, so that an accurate future assessment can be formulated and appropriate care implemented.

Absorption

Within a 24 hour period it is estimated that about 8 litres of water from dietary ingestion as well as GI secretions and juices, (see table 4.1) along with several hundred grams of carbohydrates, ≥100 g of fat, 50–100 g of amino acids and 50–100 g of salt ions pass through the wall of the small intestine and into the blood [17, 20]. An individual living with an ileostomy may experience a high output which is classified as an output exceeding 1500 in 24 h period [21]; however opinions regarding the volume of the definition of high output do vary. Baker [22] suggests that patients with an output of between 1200–2000 mls/24 hours should have normal diet, fluids and salt, but may also require additional treatment. Please see ASCN UK guidelines of management of high output stoma in both hospital and community setting for further guidance on the complex issue [23].

Nutrients are transported across membranes of the intestinal epithelial cells into the villi, and then into blood capillaries and lacteals, which can occur either passively or actively. A lacteal is a lymphatic capillary that absorbs dietary fats in the villi of the small intestine. Passive transport requires no energy and involves the diffusion of simple molecules along a concentration gradient—moving from an area of high concentration to a lower concentration—in this case, the blood [17].

In the small intestine the villi present absorb a large percentage of all proteins, carbohydrates and fats. Carbohydrates are absorbed as monosaccharides (simple sugars) 80% of which is glucose [17]. Protein (amino acid) is absorbed via the capillaries into the portal vein and liver. Fats as fatty acids and glycerol pass into the lymph within the villi and drain into the lymphatic capillaries [8, 12].

Water and some vitamins can cross the gut wall passively. Some molecules—such as glucose, amino acids and vitamin B12—have their own carriers or transporters, which they use to ‘piggyback’ across the gut wall into the bloodstream [17]. This is an important consideration if caring for a patient suffering short bowel or experiencing severe diarrhoea/high faecal output requiring rehydration therapy. Rehydration therapy is only effective if it comprises of glucose and sodium within the water, as glucose is needed for sodium uptake.

In starvation, the intestinal epithelial cells shrink, resulting in the villi reducing in size (sometimes by half) which consequently reduces the absorption capacity of the small intestine. This is an important consideration following post-operative ileus or in the presence of a small bowel fistula. This effect can be reversed when enteric

Table 4.1 Volumes of fluid secretions from GI tract [19]

Segment	Fluid secretion	Fluid absorption
Saliva	200–1000 mls	
Stomach	500–2000 mls	
Bilary	1000 mls	
Pancreas	1000–2000 mls	
Jejunum	1000–2000 mls	
Ileum		Predominate so that only 1000–2000 mls pass through ICV
Colon		Stool contains less than 150 mls daily

feeding is commenced. Damage to such cells can be seen in Coeliac disease, Crohn's Disease or due to radiation damage [8, 24].

Gall Bladder

The gall bladder is a hollow pear-shaped organ approximately 8–10 cm in length, that is situated underneath the liver to the right of the stomach. The primary function is to store and concentrate bile secreted by the liver. The gall bladder acts as a reservoir for the unused bile whilst it is not being used for digestion. When food stuff enters the small bowel, a hormone called cholecystokinin is secreted. This causes the gall bladder to contract consequently pushing the bile into the duodenum to emulsify the fatty food [1, 25].

Pancreas

The pancreas is an important organ. It plays key roles in both the regulation of blood glucose levels and digestion [26]. It comprises of an endocrine and an exocrine portion. The endocrine function is responsible for the production of key hormones that control blood sugar levels and regulation of appetite and the exocrine which is the digestive portion of the pancreas [26]. The exocrine acinar cells secrete up to 1.5 L of pancreatic secretions daily. The secretions are released following a stimulation by hormones such as secretin that is released by intestinal mucosa [1]. This pancreatic secretion contains enzymes such as Trypsinogen, lipase and amylase. Trypsinogen is used to breakdown protein, amylase hydrolyses polysaccahirides to disaccaharides and lipases digest fat [8].

Large Intestine

The large intestine comprises of the caecum, colon (made of ascending, transverse, descending and sigmoid colon), rectum, anal canal and anus. It is approximately 1.5 metres in length and 7 cm in diameter at caecum reducing down to 2.5 cm at sigmoid colon [1]. Its structure is relatively similar to that of the small intestine except that its mucosa is entirely void of villi.

The caecum is a 6 cm long tubular sac made up of lymphoid tissue extending towards the appendix, now thought to be an obsolete organ.

Within the colon, haustra or pouches are formed as a result of 3 separate longitudinal ribbons of smooth muscle on the outside of the ascending, transverse, descending and sigmoid colons. They are visible and can be seen just below the serosa or fibrosa. They run the length of the colon but slightly shorter, causing a gathering effect and pouching (haustra) appearance of the colon.

The primary function of the colon is to absorb excess water and electrolytes converting semi-solid/liquid faeces into firmer faeces in readiness for evacuation. The presence of food residue in the colon stimulates haustral contractions which occur approximately every 30 minutes. Each contraction, causes the haustrum to distend and contract, pushing the food residue along to the next haustrum. The contractions facilitate the mixing of the food residues, thereby facilitating the absorption of water.

About 1500 mls of waste/fluid residue enters the caecum every 24 hours, but only 150 mls of this becomes faeces—it contains mostly bacteria and decaying epithelial cells, along with inorganic waste, undigested food matter and fibre, as well as water to help it pass smoothly through the remaining large intestine.

Colonic Movement

Food in the stomach and a distended caecum triggers a gastric colic reflex and colonic mass movements begin. Hustral contractions in the colon assist to propel the predominantly dehydrated contents through the colon into the rectum towards the anus. Such actions are usually initiated 3 or 4 times a day after meals. The strongest movement is suggested to be in the first hour after breakfast [24] resulting in a common time for people to open their bowels.

Colonic mass movements fill the rectum, resulting in an urge to defecate. This urge should not be ignored as once the movement has passed, the urge also ceases. If the urge to defecate is ignored for an extended period of time, the rectum overfills, the large intestine absorbs more fluid resulting in the faeces becoming drier and harder resulting in constipation [27].

Normal bowel emptying patterns vary greatly between individuals, from three times per day to three times per week [28].

The rectum itself is about 15 cm long, although this can vary depending on the literature consulted. Faeces entering the rectum are usually solid. The rectum can hold approximately 400 mls faeces [11]. As faeces enter the rectum, it begins to stretch; this action stimulates an impulse which is sent to the nervous system within the spinal cord to initiate a defaecation reflex. This results in the relaxation of the internal anal sphincter (involuntary control), allowing a small amount of faeces to pass into the anus. The anus is able to identify if the material is gaseous or solid and reacts accordingly. If the stool is solid and if it is convenient to defecate the external anal sphincter will relax and open, which is a voluntary control in most adults. If it is inconvenient to open bowels at that time the individual can consciously delay defecation until a more convenient time.

Anal Canal

The anal canal is approximately 2.5–4 cm in length from the ano-rectal junction to anus. The anal sphincter is comprised of two sphincter complexes; the internal anal sphincter, which is controlled by involuntary muscles and the external anal sphincter, which is made of skeletal muscle and is under voluntary control. Except during defecation, both anal sphincters normally remain closed.

Gut Microbiota

Gut microbiota or microbiome are the community of microorganisms including bacteria, archaea and fungi that live in the GI tract. As previously highlighted, the GI tract has an extremely large surface area which enhances the processes of digestion and absorption, and functions as an appropriate environment for microbial attachment and colonisation.

Previous and contemporary discussion suggests that it has been recognised that the bacteria living in the gut such as Escherichia coli (E coli), perform essential functions, such as the biosynthesis of Vitamin K, however, it is more recently – within last 10 years that the complex relationship between the micro-organisms of the gut microbiota and human tissues is slowly being understood.

Gut bacteria can have a direct influence on the immune system and the body's ability to deal with disease and infection. Antibiotic therapies, poor diet and psychosocial stress, as well as exposure to pathogenic organisms can also have an impact on gut microbionta [26].

Although there is some evidence regarding the effectiveness of probiotics, it is often contradictory, but stool pills and faecal transplant appear to be effective in reducing clostridium difficile infection and colitis [29]. Probiotics are live microorganisms that are intended to have health benefits when consumed or applied to the body, although given the limited data currently available they are not recommended for use in the majority of clinical settings. Further research is required to understand more fully the role of gut microbiota and its role in GI tract health. This inevitably will assist the SSCN to understand the importance of this part of GI tract function to patient health and GI disease management.

Diseases and the GI Tract

Inflammatory bowel disease (IBD) is a collective term used to describe chronic inflammatory disorders of the gastrointestinal (GI) tract, most notably ulcerative colitis (UC) and Crohn's disease (CD) [30].

Ulcerative Colitis (UC) is an inflammatory disease that affects the mucous membrane of some or all of the large bowel (colon) and rectum. Inflammation and ulceration starts at the rectum and extends proximally in continuity [31].

UC is characterised by episodes of acute exacerbation and remission. The time period of the remissions can vary greatly from just weeks to sometimes years. The exact aetiology of UC is not known although it is believed to involve interactions between the environment, immune system, gut microbiome and a genetic predisposition to the disease [32].

It is estimated around 1 in every 420 people living in the UK has ulcerative colitis. This amounts to around 146,000 people. However, this figure is also beginning to rise in developing nations (https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/ulcerative-colitis) [33].

UC has a bimodal age distribution with an incidence peak in the second or third decades and a second peak between 50 and 80 years [34].

The signs and symptoms individuals with UC can experience range from bloody diarrhoea, frequency and urgency often relieved by defaecation, pyrexia, weight loss, abdominal pain and lethargy. The cure for ulcerative colitis is to have the colon surgically removed (total colectomy) with the rectum removed as well (panproctocolectomy) or possibly have reconstruction surgery such as ileo-anal pouch/ restorative proctocolectomy/J pouch/ileal pouch anal anastomosis/IPAA. Many patients are managed extremely effectively with a range of pharmacological therapies.

5-aminosalicylic acid compounds (5-ASA) drugs represent the main therapies for mild to moderately active UC, and optimising patients' adherence to any given drug regime is important. The introduction of the Inflammatory Bowel Disease Nurse Specialist role has been fundamental in this provision of care [35].

In UC patients with inadequate response to 5-ASA, immunosuppressive or biologic therapies are indicated, and choice is dependent on multiple factors, including patient choice [34]. However, all drugs have side effects which may impact on the health of the patients.

Crohn's Disease Crohn's disease was thought to be an autoimmune disorder in which the immune system attacked the body's own gut lining. Contemporary theories suggest that there is evidence indicating that the immune system overzealously attacks a microbial antigen on the gut lining [36]. Crohn's Disease can affect any part of the GI tract from lips to anus, but most commonly seen in the distal ileum and proximal colon. One very notable difference with Crohn's Disease when compared to UC is the presence of "skip lesions"; these are areas of ulceration interrupted by sections of healthy tissue.

It is estimated that Crohn's Disease affects about one in every 650 people in the UK.

Crohn's disease can start at any age, but usually appears for the first time between the ages of 10 and 40, although recent studies suggest there is a small peak in the number of people diagnosed over the age of 60.

Crohn's disease is more common in urban than rural areas, and in Northern hemisphere countries such as Northern Europe and North America, although the numbers are beginning to increase in developing nations.

A theme from contemporary surveys suggest that more new cases of Crohn's disease are being diagnosed in recent years, particularly among teenagers and children. The reason for this is not clear. Crohn's disease appears to be slightly more common in women than in men. It is also more common in smokers [33].

There is no cure for Crohn's Disease, however timely interventions, careful assessment and appropriate drug therapies can minimise complications, induce remission and reduce the need for surgery. First line drug therapy for IBD is

5-ASAs along with steroids to gain disease remission. The second line of therapy is immunosuppression and then third line is biologic drug therapy [37].

Signs and symptoms can initially be quite vague and intermittent depending on the site of the ulceration within GI tract, which can result in a delay in diagnosis. Signs and symptoms can include; diarrhoea, fatigue, anorexia and abdominal pain. In patients who are experiencing a partial obstruction their abdominal pain will be described as crampy or cramping and intermittent, but an acute flare up, an exacerbation (possibly abscess or fistula) of Crohn's Disease will result in an individual experiencing prolonged persistent pain, associated with abdominal tenderness. Diarrhoea will be a consistent sign, but unlike in UC it is unlikely to be bloody.

Surgery is indicated when medical therapies are not adequately maintaining good quality of life for patient or if the patient experiences severe symptoms that are unmanageable through medical intervention. Occasionally such symptoms can be life threatening such as bowel perforation. Surgery would necessitate the resection of any diseased bowel; this could be ileal or colonic depending on the site of the active disease. It is important for the surgeon to record the length of bowel the patient has left insitu, as this will allow for accurate assessment to take place should there be a requirement in the future if considering re-anastomosis or if additional supplementary nutrition is required.

Please see colorectal surgery Chap. 6 for the specifics of surgery performed for Crohns disease.

Extra- Manifestations of IBD

Aetiology for UC and Crohn's Disease is not fully understood, however it is suggested that in both conditions the equilibrium of the intestinal mucosa as a host to antigens is disturbed. This disturbance results in chronic over expression of the immune response and over production of cytokines within the gastrointestinal mucosa leading to chronic inflammation [30, 38].

This increased response of the immune system may affect other organs, including the liver, skin, and eyes, causing inflammation within these structures and resulting in the development of extraintestinal manifestations of IBD [39, 40]; Williams [41] estimate that up to 40% of patients with IBD will experience extra intestinal manifestations. Common extra intestinal manifestations include peripheral arthritis, aphthous stomatitis (mouth ulcers), uveitis, and erythema nodosum [30, 39].

Other extra-manifestations that are commonly seen by SSCNs are in relation to skin, both Crohn's Disease ulceration as well as peristomal pyoderma gangrenosum (PPG). PPG is a rare, ulcerative inflammatory skin disorder. Common presentation includes a pustule that originates centrally and has a blue tinge to the surrounding skin [42]. Further information on PPG see Chap. 8 Managing complicated stomas.

Familial Adenomatous Polyposis

Familial Adenomatous Polyposis (FAP) is an autosomal dominant inherited condition (50:50) that can result in numerous adenomatous polyps developing within the large intestine. An autosomal dominant inherited condition means that a person affected has a 50 percent chance of passing the altered gene to each child, as well as a 50 percent chance that a child will not inherit the altered gene.

The polyps are frequently benign, however if left untreated they will develop into a malignant colonic cancer. Treatment is usually in the form of surgery. All patients will need some form of surgical intervention to rid them of the polyps. The exact surgical procedure needs careful consideration and can very much depend on age, hobbies and indeed what stage they are at in life, as FAP is predominantly diagnosed in young adulthood. Some patients may opt to have panproctocolectomy with a permanent ileostomy, others may choose to have a total colectomy and ileostomy formation initially, before deciding whether to have completion proctectomy resulting in a permanent ileostomy or opt for an ileo-anal pouch reconstruction or possibly an ileorectal anastomosis. Regardless of which procedure the patient chooses, if they have decided to have a surgical procedure which retains rectum then careful and regular assessment should be made of any retained rectum for the occurrence of polyps.

The genetic determinant in FAP can also predispose patients to other associated malignancies such as duodenal and stomach cancers. Other extra-intestinal manifestations include congenital hypertrophy of retinal pigment epithelium (CHRPE), jaw cysts, osteomata and fibromas.

Polyposis registries throughout the world are now in existence to allow for the careful monitoring, tracking and surveillance of family members of affected individuals. St Mark's registry in London was the first, in existence since 1924.

Diverticular Disease

Diverticular disease is commonly seen within the sigmoid colon of older people living in the western world. Small pouches called diverticula can form on small weakened areas of the intestinal walls as a result of increased pressure perhaps as a result of straining during defecation. Diverticulitis is seen when any of the diverticula pouches become inflamed and possibly infected. This tends to occur when bacteria have built up in diverticula blocked by faeces/waste material. Diverticular bleeding may result. Treatment is usually given in the form of antibiotics. Surgery may be required as an emergency if the diverticulitis becomes severe resulting in bowel perforation. (See Chap. 6 on surgical procedures).

Colorectal Cancer Please See Chap. 5

Peptic Ulceration

Peptic Ulceration is an umbrella term used to describe ulcers occurring in the stomach and/or duodenum. It is believed that stress and poor diet, especially spicy and greasy foods are contributing factors for the development of such ulcers. It is now also recognised that infections relating to Helicobacter pylori (H. pylori) is the major contributing factor. The use of NSAID's also increases the risk of peptic ulcers [43].

Patients will often report signs and symptoms of burning, epigastric pain and can often pin point the exact location of their pain. However, the only definitive way to locate a peptic ulcer is to visualise it via endoscopic route. Peptic ulcers must be treated as the risk of perforation can lead to life-threatening complications such as peritonitis and/or sepsis. Treatment is commonly offered in form of proton pump inhibitor drugs to reduce acid secretion and two antibiotics to eradicate H. pylori infection (triple therapy) [44].

Conclusion

As a SSCN, having a detailed knowledge and understanding of the anatomy and physiology of the GI tract is fundamental to ensure that the care of stoma patients is underpinned with a sound theoretical framework, enabling the SSCN to critically evaluate disease processes and treatments within the specialist colorectal field. This advanced level of knowledge leads to proactive management of patients and an intuitive recognition of potential complications or any deviations from a normal treatment trajectory which may occur.

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The Management of Colorectal Cancer

5

Rachel Henbrey

Learning Outcomes
- Consider the implications that a diagnosis of colorectal cancer may have for a person with an existing stoma. What support might they require?
- Try to identify specific points on the colorectal cancer pathway where intervention from a clinical nurse specialist may be needed.
- For a patient with advanced or metastatic colorectal cancer, many different specialities may be involved in their care. Can you identify some of them?

Introduction

Colorectal cancer refers to a malignancy that occurs in the colon or rectum. It is the fourth most common cancer in the UK accounting for around 43,000 cases per year, with incidence highest in people over the age of 50 [1, 2]. When diagnosed at the earliest stage, colorectal cancer can be successfully treated, with 92% of people surviving longer than 5 years [2]. However, symptoms often do not occur until an advanced stage. As a result, approximately 20% of patients diagnosed present with metastatic disease [3, 4]. Surgical resection remains the definitive treatment, providing the best possibility of a cure [3]. Depending upon the site of disease, this may involve stoma formation (see Chap. 6). A combination of interventions is often required in the management of colorectal cancer over time [5]. Support from a Clinical Nurse Specialist (CNS) is crucial for patients navigating complex pathways involving multiple specialities over extended periods [6, 7].

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Therefore knowledge surrounding the decision-making process involved in planning care and regarding available therapies and side effects is necessary for the CNS to provide accurate information and effective counselling to patients and families [5].

Development of Colorectal Cancer

The majority of colorectal cancers are adenocarcinomas which develop from normal bowel epithelium to adenomas or polyps through a process known as the adenoma—carcinoma sequence. [8, 9]. This is driven by gene mutations prompting changes within the adenoma from low grade dysplasia to high grade dysplasia and finally adenocarcinoma. [9]. See Fig. 5.1.

Adenocarcinoma can be further graded as well differentiated, moderately differentiated, and poorly differentiated, with poorly differentiated having the worst prognosis [11, 12].

The development of colorectal cancer can be classified as sporadic (occurring due to incidental mutations in cells in the bowel wall over time) or occur because of a genetic predisposition to develop a malignancy [13, 14]. Mismatch Repair genes (MMR) are responsible for correcting errors that have occurred during the DNA replication process [15]. Mutations in these genes can result in Microsatellite Instability (MSI) or an increased propensity for mutations to arise [15, 16]. Cancers where MMR genes are unaffected are referred to as proficient mismatch repair (pMMR) and as deficient mismatch repair (dMMR) where MMR genes are affected [17].

MSI is found in 10 to 15% of sporadic cancers [18]. This is commonly due to epigenetic changes in the MLH1 MMR repair gene [13]. However, in 2 to 3% of MSI tumours, germline mutations in MMR genes—MLH1, MSH2, MSH6 or PMS2 are responsible. This is the case with inherited conditions such as Lynch Syndrome,

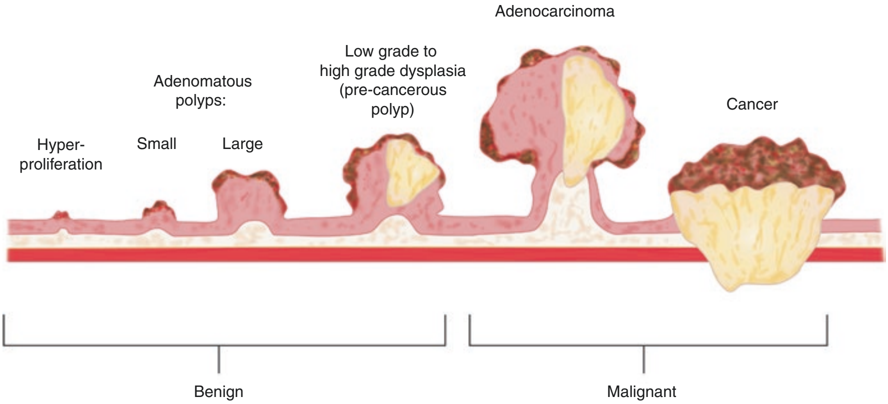


Fig. 5.1 Cancer progression from a polyp (copyright UHB NHS FT) [10]

increasing the likelihood of developing a colorectal cancer [13]. MSI high tumours are associated with a better prognosis than microsatellite stable tumours [19].

Mutations in the RAS and BRAF V600E genes in adenocarcinoma can also be predictive as to whether there will be a potential response to certain anti-cancer treatments. BRAF (V600E) mutation in metastatic disease is an overall poor prognostic factor [20]. NICE guidelines [21] recommend that all people with metastatic colorectal cancer be tested for RAS/BRAF mutations.

Testing on the molecular make-up of a tumour can now identify specific mutations which can provide prognostic information, guide treatment pathways, and suggest whether genetic screening of family members is advisable [21]. When looking at the histopathology of colorectal cancer multiple markers can be identified to individualise treatment [11].

Risk Factors

There is a strong association with colorectal cancer and age, with a steep rise in incidence over the age of 50 [1, 3]. Evidence that environmental factors such as smoking, high alcohol intake, a diet with limited fruit and vegetables and rich in processed foods, a sedentary lifestyle and obesity are all associated with colorectal cancer is well established [22, 23].

Pre-existing conditions can increase the probability of a cancer diagnosis. People who have a history of Crohn’s disease or Ulcerative Colitis are known to be at a higher risk of developing colorectal cancer at a younger age and more advanced stage than on average [24, 25].

Another risk factor is a strong family history of colorectal cancer. People with three first degree relatives (e.g. parent, sibling or child) with colorectal cancer over one generation are categorised as high risk, and as moderate risk if they have either one first degree relative under the age of 50 or two first degree relatives of any age [26]. Recommendations are that people in the high-risk category have a colonoscopy every 5 years from the age of 40, and those in the moderate category have a colonoscopy at age 55 [26].

Certain inherited conditions can also greatly increase the incidence of a colorectal cancer diagnosis:

Lynch Syndrome (previously known as Hereditary Non-Polyposis Colorectal Cancer—HNPCC) is an inherited condition resulting from a germline mutation to one of four MMR genes and is responsible for approximately 3% of colorectal cancers [27, 28]. People diagnosed with Lynch syndrome have a 50 to 70% lifetime risk of developing colorectal cancer and are more likely to develop this at a young age, with an associated increased risk of developing other cancers [27, 29]. Colorectal cancers should now be routinely tested using PCR (polymerase chain reaction) or immunohistochemistry to identify MSI status or dMMR [26, 29]. Subsequent testing to confirm Lynch Syndrome can then take place and allow for regular surveillance for the individual and screening of their relatives [29]. The development of a cancer can be rapidly progressing in Lynch Syndrome as it does not always follow the usual polypoidal pathway of colorectal cancer and can arise from seemingly normal bowel mucosa [27, 28]. Surveillance with colonoscopy is therefore recommended at two yearly intervals from the age of 25 or 35 depending on which MMR genes are affected [26]. Taking aspirin daily has also been found to reduce the risk of developing colorectal cancer in this group and is recommended by NICE [30]. When colorectal cancer does occur on a background of confirmed Lynch Syndrome, it should be considered that the chance of developing a further cancer is high, and therefore patients should be counselled regarding the risks and benefits of segmental resection vs sub-total colectomy [26, 27]. NHS England recommend that all Trusts nominate a surveillance lead for Lynch Syndrome to coordinate the pathway [31].

Familial Adenomatous Polyposis (FAP) is an inherited condition resulting in the development of numerous colorectal adenomas due to mutation in the APC (adenomatous polyposis coli tumour suppressor) gene [28]. If left untreated, development of colorectal cancer is inevitable [16, 27]. Testing of at-risk family members is recommended from age 12 with surveillance colonoscopy repeated every 1 to 3 years [26]. Prophylactic colonic resection is necessary to prevent the development of colorectal cancer. The timing of surgery will depend on colonoscopy findings. Surgical options include subtotal colectomy (STC) with ileo-rectal anastomosis or STC with an ileostomy. Further surgery with formation of an ileo-anal pouch may also be considered [26, 27]. Where the rectum is spared or an ileo-anal pouch formed, continued surveillance will be required [26, 27]. Preoperative counselling will be necessary to ensure that the patient is aware of the implications of the surgical procedures available to them (see Chaps. 6 and 11).

Referral Pathways

Early detection of colorectal cancer increases the potential for survival and cure [2, 21]. Routine screening programmes are well established in the UK and aim to identify disease in people who may not be exhibiting any symptoms. Currently, adults aged between 60 and 74 in England are offered a Faecal Immunochemical Test (FIT) every 2 years by the NHS Bowel Cancer Screening programme, with the aim to extend this to all adults over the age of 50 from 2021 [32]. Provision of screening varies across other countries in the UK. FIT can detect the presence of blood in the stool, and a positive test in people who are otherwise asymptomatic prompts a referral for endoscopy to exclude malignancy [5, 33].

There are some common symptoms associated with colorectal cancer—see Table 5.1 [5, 34]. Presentation in primary care with red flag symptoms should prompt an urgent “two week wait referral” for investigations [34]. A sigmoidoscopy or colonoscopy is then arranged, or a CT scan if there are concerns regarding fitness

Table 5.1 Red flag symptoms

Change in bowel habit
PR bleeding
Abdominal pain/bloating
Unintentional weight loss
Unexplained iron deficiency anaemia
Rectal/abdominal mass
Tenesmus

for endoscopy and bowel preparation (e.g., in cases of frailty or renal impairment) [5]. Should a likely malignancy be identified at endoscopy, biopsies will be obtained, and further investigations arranged in the form of a CT scan to look for distant metastases, and in the case of rectal cancer, an MRI to provide accurate radiological staging [9, 27]. A blood test for CEA levels, a tumour marker associated with colorectal cancer, may also be done at this stage [5]. All patients with a diagnosis of colorectal cancer will have their management plan discussed at a Multidisciplinary Team meeting (MDT) with core members including surgeons, radiologists, histopathologists, clinical and medical oncologists and Clinical Nurse Specialists, to formulate an individualised treatment plan based on the results of their biopsies, imaging, and overall health [9, 27]. In advanced disease, bowel obstruction may be the presenting complaint, potentially requiring emergency surgery [35]. However, post operatively, discussion will still take place at the MDT to decide on appropriate future management.

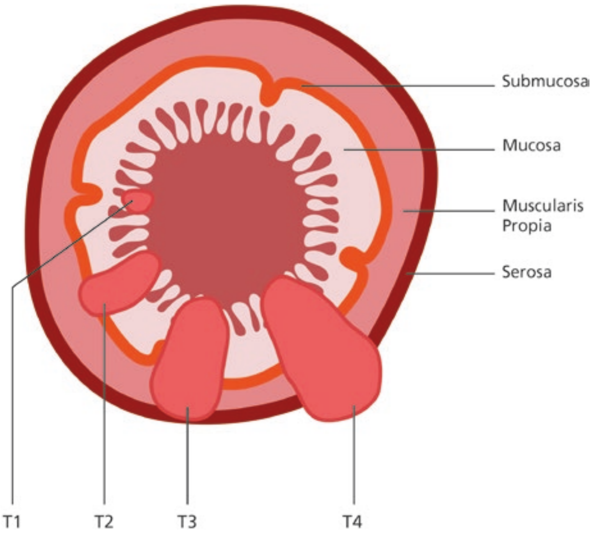
Further investigations may be recommended by the MDT before commencing treatment (e.g., MRI liver where liver metastases are identified on CT scan, or PET scan to further characterise features indeterminate on other imaging which are suspicious for metastasis) [36, 37].

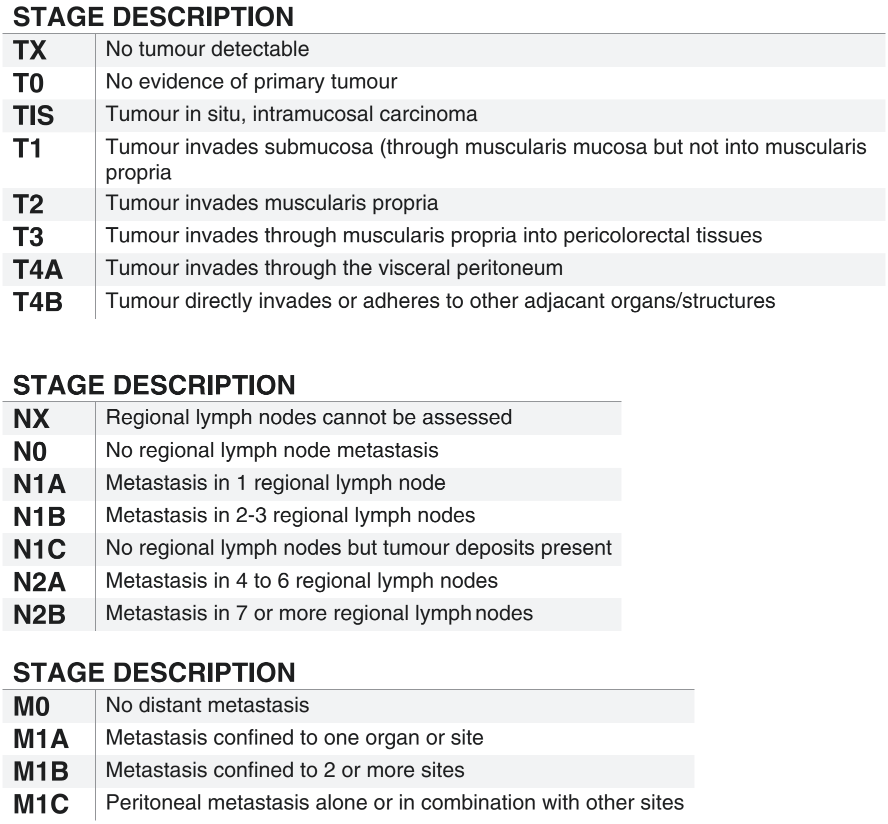
The UK government has targets in place for Trusts to achieve when investigating and treating colorectal cancer. These are currently 28 days from referral to diagnosis, 31 days from agreement to treatment plan to starting treatment and 62 days from referral to starting treatment [32, 38, 39].

Staging of Colorectal Cancer

Colorectal cancer is staged using the TNM classification system, with T referring to tumour invasion through the bowel wall, N to lymph node involvement and M to distant metastasis (see Figs. 5.2 and 5.3). Staging can be radiological or histopathological following surgical resection.

Fig. 5.2 Tumour invasion through the layers of the bowel (permission from UHB NHS Trust) see [40] for further information





STAGE	DESCRIPTION
TX	No tumour detectable
T0	No evidence of primary tumour
TIS	Tumour in situ, intramucosal carcinoma
T1	Tumour invades submucosa (through muscularis mucosa but not into muscularis propria
T2	Tumour invades muscularis propria
T3	Tumour invades through muscularis propria into pericolorectal tissues
T4A	Tumour invades through the visceral peritoneum
T4B	Tumour directly invades or adheres to other adjacent organs/structures

STAGE	DESCRIPTION
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1A	Metastasis in 1 regional lymph node
N1B	Metastasis in 2-3 regional lymph nodes
N1C	No regional lymph nodes but tumour deposits present
N2A	Metastasis in 4 to 6 regional lymph nodes
N2B	Metastasis in 7 or more regional lymph nodes

STAGE	DESCRIPTION
M0	No distant metastasis
M1A	Metastasis confined to one organ or site
M1B	Metastasis confined to 2 or more sites
M1C	Peritoneal metastasis alone or in combination with other sites

Fig. 5.3 T,N,M descriptors, unpublished table provided by author (see [40, 41] for further information)

In addition, evidence of blood vessel or extramural vascular invasion (EMVI), lymphovascular invasion and perineural invasion will be identified in the histology report. The surgical resection margin will be staged as R0 where there is a clear margin or R1/R2 where residual neoplastic tissue remains [9, 41, 42]. A prefix of p to TNM staging denotes pathological staging, and y identifies where preoperative chemotherapy or radiotherapy has been given [9, 41].

Treatments

Treatment for colorectal cancer depends on multiple factors including the site, stage, and molecular make-up of the cancer [4]. Pre-existing comorbidities and the overall health and fitness of the patient will be considered to assess the potential to tolerate interventions. This is commonly summarised using the WHO/ECOG Performance Status criteria (see Fig. 5.4).

Surgical procedures are discussed in Chap. 6. In this section, treatments that can be given in addition to surgery will be explored, either in a pre-operative (neoadjuvant), post-operative (adjuvant), or palliative setting. This is not an exhaustive list, and only options currently accessible through the NHS will be discussed.

Grade	Performance Status
0	Able to carry on all pre-disease performance without restriction, functions unlimited
1	Some limitations as restricted in physical strength but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work
2	Ambulatory and capable of all selfcare but limited ability to work; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of the time
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair; fully dependent
5	Dead

Fig. 5.4 Performance status descriptors—unpublished table provided by author based on WHO criteria (see [43] for further information)

Chemotherapy Agents

Fluorouracil forms the basis of systemic treatment for colorectal cancer and can be given as an infusion with folinic acid (5FU) or in tablet form as Capecitabine [44]. 5FU is given weekly via a cannula or via a PICC line in 2 weekly cycles. Capecitabine is given in 3 weekly cycles [45, 46]. The combination of other chemotherapy agents with Fluorouracil has been demonstrated to provide a potentially significant treatment benefit [14, 47].

Oxaliplatin is given as an infusion and can be combined with 5FU or Capecitabine (Folfox/Xelox) [14].

Irinotecan is also given as an infusion and can be combined with 5FU or Capecitabine to form Folfiri or Xeliri [48].

In some situations, all three chemotherapy agents will be given as a combination called Folfoxiri. This can provide a significant increase in response to treatment but also significantly increases the associated side effects, therefore a good performance status will be required. [14, 42, 49].

Lonsurf (trifluridine/tipiracil) is a tablet chemotherapy given in monthly cycles. It is only used in the palliative setting [50].

Chemotherapy affects both healthy and cancer cells, however healthy cells can regenerate after exposure while cancer cells cannot [51]. Cells with a high growth rate are more chemotherapy sensitive, therefore common side effects of chemotherapy involve the bone marrow with associated immunosuppression, damage to hair follicles causing hair loss and the GI tract resulting in mucositis, nausea, vomiting and bowel complications [51, 52]. Potential toxicity varies with each particular agent, e.g., hair loss is a common side effect of Irinotecan, but there may only be hair thinning or no hair loss at all with other chemotherapy agents given for colorectal cancer. In addition to general side effects there are side effects specific to chemotherapy drugs.

Dihydropyrimidine dehydrogenase (DPD) is an enzyme that breaks down Fluorouracil chemotherapy. A DPD deficiency can lead to severe toxicity, therefore a blood test will be taken prior to commencing 5FU/Capecitabine chemotherapy and if DPD deficiency is detected, doses will be adjusted accordingly [53].

Considerations for Ostomates

Common side effects of chemotherapy drugs given in colorectal cancer are diarrhoea or constipation. Capecitabine and Irinotecan, in particular, can cause severe diarrhoea. The combination of Capecitabine and Irinotecan, therefore, has the potential for severe toxicity [48]. People with an ileostomy are already at an increased risk of dehydration and Acute kidney Injury (AKI) [54]. Severe diarrhoea may result in hospitalisation, treatment delays, dose reductions or, in some cases, affect the ability to continue with treatment [55] (See Chap. 12 for management). Similarly, patients with a colostomy may experience diarrhoea necessitating change from their usual closed product to a drainable appliance to avoid multiple pouch changes [56, 57]. Constipation in colostomates may be exacerbated by medication used to manage side effects of treatment or opioid analgesia and require management with dietary modifications and laxatives [35, 56].

A side effect specific to oxaliplatin is neurotoxicity, resulting in peripheral neuropathy to the hands and feet. This builds over time and can resolve after chemotherapy finishes but may be permanent [47]. When severe, fine motor skills can be affected, impacting on the patient's ability to fasten buttons, or hold a pen, and potentially to manage stoma care independently [35, 57]. Oxaliplatin may be avoided in patients who already have some pre-existing neuropathy, or used and side effects closely monitored [14].

Palmar-plantar erythrodysaesthesia (PPE) or hand-foot syndrome is a common side effect of fluorouracil-based chemotherapy causing soreness to hands and feet. When severe this may also affect dexterity [35].

EGFR Inhibitors

Epidermal growth factor receptor (EGFR) inhibitors or monoclonal antibodies are targeted therapies utilised in conjunction with chemotherapy agents. Cetuximab and Panitumumab are EGFR inhibitors currently in use for colorectal cancer treatment [58]. EGFR is a cell protein which promotes cell growth. EGFR inhibitors work by targeting and blocking EGFR, inhibiting growth of cancer cells [59]. Evidence has shown that tumours in the right side of the colon or that have mutations in the RAS/BRAF gene exhibit a poor response to EGFR inhibitors [58]. Therefore, only patients with left sided tumours who are RAS/BRAF wild type have the potential to benefit from this treatment [12, 60]. EGFR inhibitors have not been found to add benefit in the adjuvant setting and as a result they are only recommended for use in metastatic disease, either as a neoadjuvant or palliative treatment [61].

Considerations for Ostomates

Side effects of EGFR inhibitors include diarrhoea, hypomagnesemia and skin rashes [62, 63]. The severity of diarrhoea as a side effect of EGFR inhibitors is exacerbated when given in combination with chemotherapy [63]. Close monitoring is therefore required when used for patients with an ileostomy, due to their inherent risk of dehydration and low magnesium levels with a high output from their stoma (see Chap. 12).

Common skin complications include dry and itchy skin and a papulopustular rash most commonly on the face, but which can extend to the torso and abdomen. Management is with antibiotics and regular moisturising of the skin, however there are additional implications for ostomates when skin integrity is affected with the potential to affect pouch adhesion [57].

Radiotherapy

Radiotherapy is given for the treatment of rectal cancer. Each dose of radiotherapy is described as a fraction and the amount administered is measured in units known as Grays (Gy) targeted at a specific area [3, 64]. A planning CT scan takes place before treatment to ensure that the radiotherapy damages as little surrounding healthy tissue as possible [64].

Short term side effects from radiotherapy for rectal cancer include erythema or desquamation of the skin in the local area, cystitis, diarrhoea or constipation, fatigue, and pain [65, 66]. Symptoms are cumulative and may worsen after treatment has finished before they improve [66, 67]. Advice regarding skin care and appropriate wound dressings are provided by the radiotherapy department [65]. Long term side effects may include a permanent change in bowel and bladder function, rectal or stomal bleeding and haematuria, cosmetic changes in the treatment area, delayed wound healing to exposed tissue, pelvic bone thinning, lymphoedema, erectile dysfunction and vaginal stenosis [27, 65]. Pelvic radiotherapy causes infertility in both men and women. In women early menopause can be initiated [68]. Pre-treatment counselling regarding sexual dysfunction and fertility including referral for sperm/egg storage for those who have not completed their families is essential [69, 70, 71].

Considerations for Ostomates

Radiotherapy has potential temporary and long-term side effects with specific implications for ostomates. Stoma formation can have a profound impact on body image and sexuality (see Chap. 16). Side effects from radiotherapy such as erectile dysfunction and vaginal stenosis can compound these issues [72]. Awareness of the possibility of bleeding from the stoma or changes to bowel function can help with symptom management and reduce anxiety. Delayed wound healing is of particular importance for patients who have undergone pre-operative radiotherapy followed by APR surgery, as dehiscence of the perineal wound may occur and therefore requires close monitoring [27].

Neoadjuvant Treatment

Neoadjuvant treatment refers to treatment given prior to surgery, and in colorectal cancer varies depending on the site of the cancer and the stage of the disease [73].

Patients with advanced cancers may present with intermittent obstructing symptoms that, combined with the side effects of chemotherapy or chemoradiotherapy, can cause acute illness, affecting the ability to tolerate treatment. It may be necessary to consider a defunctioning stoma as part of neoadjuvant therapy to prevent complications and subsequent disruption to treatment [27, 74].

Rectal Cancer

Neoadjuvant treatment for rectal cancer is given either to downstage the tumour to give the best chance of attaining clear surgical resection margins or to reduce the risk of local recurrence [27, 73]. Treatment varies according to the staging of the disease and follows evidence- based recommendations made by NICE and the Association of Coloproctology of Great Britain and Ireland (ACPGBI). It can comprise of radiotherapy alone, or a combination of radiotherapy and chemotherapy.

Short course radiotherapy—recommended for rectal cancers with radiological high-risk features for local recurrence (e.g., stage T3c, mesorectal lymph node involvement or EMVI). Short course radiotherapy is administered as 5 fractions over 5 days. This is usually followed by surgery the following week. It is also an alternative in people who need, but cannot tolerate, long course chemoradiotherapy. In this scenario, the surgery is usually delayed by 6–12 weeks post radiotherapy. [27, 73].

Long course chemoradiotherapy—this is recommended for rectal cancers threatening or involving the mesorectal fascia to downstage the tumour and optimise the chance of a clear surgical resection margin. It is administered as 25 fractions of radiotherapy given over a 5-week period [27]. Chemotherapy is given throughout the treatment to increase the effectiveness of the radiotherapy [5]. This is given as a low dose capecitabine, taken daily, or intravenous 5-FU given in week 1 and 5 of the radiotherapy. Restaging CT and MRI scans should take place prior to surgery to assess response [73]. Surgery should be scheduled 8 to 12 weeks after completion of chemoradiotherapy [27].

RAPIDO Trial—this trial has demonstrated that rather than pre-operative long course chemoradiotherapy with or without adjuvant chemotherapy post-operatively, patients may benefit more from short course radiotherapy followed by neo-adjuvant chemotherapy [75]. This would be either 6 cycles of CAPOX or 9 cycles of FOLFOX (in total 18 weeks of chemotherapy). Surgery takes place after completion of neoadjuvant chemotherapy with no adjuvant chemotherapy then required. This schedule has shown an increase in pathological complete response and decrease in development of distant metastases when compared to long course chemoradiotherapy with or without adjuvant chemotherapy post-operatively [75]. Suitability for this treatment depends on comorbidities and performance status.

Advanced Colorectal Cancer

Advanced colorectal cancers with lymphadenopathy or metastatic disease, downstaging chemotherapy is often given to control the cancer and reduce the disease volume, allowing the best chance of surgical resection [4, 6]. Treatment will usually involve combination chemotherapy with either Folfox/Capox or Folfoxiri depending on performance status [14, 42]. An EGFR inhibitor can be added if indicated by RAS testing [6]. Downstaging chemotherapy is usually given in 3-month treatment blocks followed by a restaging scan to assess response Should further downstaging be required then another treatment block may be recommended by MDT [4].

The FOxTROT randomised control trial concerned patients with resectable T3/T4 disease and compared the standard treatment of 24 weeks of adjuvant chemotherapy with 6 weeks of neo adjuvant Folfox chemotherapy followed by 18 weeks of adjuvant Folfox chemotherapy [76]. This was well tolerated, demonstrated histological regression, and resulted in a halving of incomplete resections [76]. The FOxTROT study is ongoing but based on initial findings NICE guidelines recommend that consideration is given to preoperative chemotherapy for patients with resectable T4 colonic cancer [21].

Adjuvant Treatment

The aim of adjuvant treatment is to reduce the risk of cancer recurrence, and in colorectal cancer is given after surgery as chemotherapy to treat microscopic disease [77]. The potential benefit from adjuvant treatment will depend on the histological staging post operatively. Poor prognostic features for cancer recurrence include pT4 tumour or tumour perforation, extramural vascular invasion, poor differentiation, involved resection margin, perineural invasion and poor lymph node harvest [9]. Evidence has shown that patients with dMMR and a low-grade cancer do not benefit from adjuvant treatment and therefore they would not be offered chemotherapy [28].

The recommendation about whether to refer for adjuvant treatment is made at the MDT, however that does not always guarantee that treatment will occur. Decisions about treatment are made on risk vs benefit ratio with potential benefits sometimes being statistically very low [78]. For patients with multiple comorbidities or the elderly, chemotherapy side effects can present a significant risk. Treatment is typically combination of 5FU/Capecitabine and oxaliplatin (Folfox or Capox) [21]. The potential long term neuropathic side effects and increased toxicity in those aged over 70 from oxaliplatin is well established [21, 78]. Except for patients with very high-risk features, reduction of the length of treatment from 6 to 3 months has been recommended by NICE [21] to help to mediate this risk. In those who are deemed too high risk for combination chemotherapy, single agent capecitabine may be offered. Decisions about adjuvant treatment are made following assessment of the individual and through detailed discussions regarding the risks and benefits of treatment [79].

Treatment for Metastatic Disease

Metastatic disease may be evident on presentation or develop over time as cancer recurrence [4, 80]. The most common sites of metastasis are the lymph nodes, liver and lung [6, 8]. Median survival without treatment is 6 months and traditionally patients diagnosed with metastatic colorectal cancer were deemed to have incurable disease [14]. However clinicians now have access to a combination of treatments that can prolong survival substantially with people remaining disease free for long periods [5, 6].

Surgery for Metastatic Disease

The potential for surgical resection in metastatic disease is multifactorial and the expertise of several MDTs will be required to plan care [42]. Surgical resection of metastases takes place at specialist centres, often requiring communication between Trusts [6]. Suitability for resection, site and number of metastatic deposits, the performance status of the patient and the speed of disease progression are all factors that will be considered, and neoadjuvant treatment may be required [4]. If resection is possible, combined surgical procedures may be offered (e.g., colonic and liver resection) however, where this is deemed too high risk, then separate major surgeries will be necessary [3, 6]. Radio frequency ablation (RFA) may be used to treat isolated deposits in the liver or lungs where surgery is not possible, or used in conjunction with surgical resection [3, 81].

Cytoreductive Surgery (CRS) and Hyperthermic Intraperitoneal Chemotherapy (HIPEC)

CRS and HIPEC can be used in some instances for the treatment of colorectal cancer which has spread to the peritoneum. There is a poor prognosis associated with colorectal peritoneal metastasis, with survival of less than 12 months without treatment, increasing to a median survival of 16 months with systemic treatment [82]. CRS and HIPEC offer 5-year survival rates of up to 52% [83]. Surgery involves stripping of the peritoneum, resection of affected organs and insertion of heated chemotherapy into the intraabdominal cavity, treating both macroscopic and microscopic disease simultaneously [84]. This intervention is a major undertaking and suitability will depend on performance status and the extent of the metastatic disease [84]. Patients will be referred to a specialist centre for MDT assessment for consideration. If surgical resection is not possible due to the volume of disease, then systemic treatment will be considered.

Immunotherapy

Immunotherapy treatments work by activating the body's immune system to attack cancer [85]. These have been shown to be very effective in other cancer sites such as melanoma and lung cancer [86]. However, in colorectal cancer, evidence has not demonstrated any significant benefit in pMMR/Microsatellite stable tumours, showing response only in dMMR/MSI high disease, which is in the minority [85]. Pembrolizumab is approved for first line treatment for metastatic colon cancer and has improved progression free survival and overall response compared with chemotherapy in this cohort of patients [4]. A combination of two immunotherapy drugs—Nivolumab and Ipilimumab is now also approved by NICE for second line treatment. [87]. Immunotherapy is better tolerated than long term chemotherapy [87]. However, when side effects do occur, they are in the form of an autoimmune response, resulting in symptoms such as colitis, arthritis and pneumonitis which can be severe [17].

Palliative Chemotherapy

Chemotherapy given in a palliative setting is usually discussed as first, second and third line treatment and has the aim of shrinking and controlling the disease [4]. Chemotherapy continues to be 5FU/Capecitabine based with options of either Oxaliplatin or Irinotecan, or both, being added [5]. For RAS/RAF wild type tumours, an EGFR inhibitor can also be added if appropriate [4]. Chemotherapy will typically be given in 3-month blocks, with CT scans to assess response to treatment [5]. The side effects of chemotherapy in a palliative setting will be closely monitored to ensure that quality of life is maintained. Adjustments to dosage and regime may be required when on treatment and treatment breaks can be added when the disease is well controlled to allow for recovery from symptoms [14, 42]. Cancer eventually develops resistance to chemotherapy resulting in disease progression [42, 88, 89]. When this occurs on first line treatment then Oxaliplatin can be switched to Irinotecan or vice versa for second line treatment [50]. When there is disease progression on second line treatment, then third line treatment would be considered with Lonsurf, however the benefit of this is small [50]. When chemotherapy options have been exhausted then the focus will shift to best supportive care and symptom control [89].

Colonic Stent

For left sided obstructing colonic tumours, endoscopic stent insertion can be considered as an alternative to surgery for patients with a poor performance status [21, 35]. Although this avoids the risks associated with emergency surgery, the cancer will continue to progress without further treatment and there remains a risk of colonic perforation or stent migration [42, 90].

Palliative Short Course Radiotherapy

For people with irresectable rectal cancers or for those who are not deemed fit for surgery, symptoms of pain, bleeding and discharge can be debilitating. Short course palliative radiotherapy can be given to slow disease progression and achieve improved symptom control [8, 91].

Anal Cancer

This is a rare cancer accounting for less than 1% of new cancer diagnosis in the UK [92]. Presentation is often with an anal mass with associated pain, itching and bleeding, which in many cases is initially mistaken for haemorrhoids [93]. When tumours are advanced, presentation may be with obstructive symptoms. Faecal incontinence can occur when the tumour involves the anal sphincter and there is also the potential for fistulation [93, 94]. Anal cancers are primarily squamous cell carcinomas (SCC). Anal Intraepithelial Neoplasia (AIN) is caused by the Human Papillomavirus (HPV) and anal lesions containing AIN are precursors to anal SCC. The incidence of anal cancer is 30 to 40 times higher in people living with HIV [27, 95]. All patients with a new diagnosis of anal cancer should be referred to a specialist Anal Cancer MDT for management [27]. Treatment is similar to long course chemotherapy for rectal cancer, with the same associated side effects from treatment. However, skin toxicity is more common and often more severe due to the superficial nature of these cancers. 28 fractions of radiotherapy will be given over a five and a half week period. Concurrent chemotherapy with Mitomycin C intravenously at the start of treatment and Capecitabine is administered. 5-FU during week 1 and 5 of radiotherapy can be given as an alternative to Capecitabine [27]. Anal cancer responds well to a combination of chemotherapy and radiotherapy, with frequent complete responses seen [96]. Cancer Research UK report 5 and 10 year survival rates from anal cancer as 58% and 52% respectively [97].

A defunctioning stoma may be necessary prior to commencing treatment particularly if the tumour is bulky or the patient is particularly symptomatic. This may also reduce the risk of treatment-related complications and reduce treatment gaps during radiotherapy [27, 93]. Anal stenosis and sphincter damage is a common long term side effect of treatment, and therefore, even though technically reversible, the stoma is likely to be permanent [94, 98]. Definitive resection is only considered if there is an incomplete response to chemoradiotherapy, or local recurrence of the cancer. In this case APR surgery with a resulting permanent colostomy would be performed [98, 99].

The diagnosis of colorectal cancer has far-reaching implications for the individual and their family [100]. The Clinical Nurse Specialist is a vital resource for patients, providing expert advice, continuity, and support throughout the pathway [27, 101]. The psychological impact of surgery involving stoma formation is well documented [102]. For patients with an existing stoma, the side effects from treatments can compound these issues and affect stoma management [72, 103]. The Clinical Nurse Specialist is ideally placed to provide ostomates with the practical management advice, and psychological support that is essential to reduce anxiety when undergoing treatment for colorectal cancer [35, 102]. They are also key to coordination of care when multiple specialities are involved [7].

Conclusion

Greater understanding about colorectal cancer and increasing individualised management options have significantly improved prognosis over recent years. Treatment may take place over extended periods when presentation occurs at an advanced stage, or recurrent disease develops, involving multiple specialities and health care professionals. The clinical nurse specialist not only provides expert knowledge and support, but also continuity for patients and relatives. Knowledge of established treatment pathways and new therapies as they are developed, including administration, side effects and implications for the individual receiving treatment, is essential for the clinical nurse specialist in order to practise effectively and to provide patient centred care.

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Gastrointestinal Surgery

6

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and Jackie McPhail

Learning Outcomes

- Understand the many different diseases which may lead to stoma formation
- Describe the impact of the surgery and stoma and the effect on an individual's lifestyle
- Be able to identify complications and the impact for the stoma patient

Introduction

There are many different aetiologies or disease processes which can result in the requirement for stoma forming surgery from the GI tract. Some of these are as follows:

- Cancer
- Inflammatory Bowel Disease—Ulcerative Colitis or Crohn's Disease
- Diverticular Disease
- Familial Adenomatous Polyposis (FAP)

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- Bowel Perforation/obstruction (can be spontaneous but usually secondary to a disease process)
- Trauma/obstetric injury
- Neurological damage (spinal cord injury)
- Congenital Abnormalities
- Or other reasons including fistulae, radiation damage, ischaemic bowel, intussusception, volvulus

Approaches to Surgery

Stoma forming surgery can be undertaken as an elective or emergency procedure.

Elective surgery is planned and scheduled in advance. It may be surgery that the patient chooses to have for a better quality of life or surgery that is required to maintain health. Ideally elective surgery enables the patient to prepare for their operation by meeting with a Specialist Stoma Care Nurse (SSCN), having a proposed site marked for their stoma as well as preparing their body by optimising their health as their condition allows. This may be through the use of pre-operative nutrition and carbohydrate drinks. Evidence has shown that the use of pre-operative carbohydrate drinks results in a shorter hospital stay, a quicker return to bowel function and a decrease in the loss of muscle mass [1]. Elective surgery is often planned for conditions including Ulcerative Colitis, Crohn's Disease and Cancer.

When a patient is informed that they will need to have a stoma created as part of their surgery they can often feel anxious and worried. Fear around the surgery and/or the stoma can manifest itself in a variety of psychological responses such as anger, depression, denial, repression, low self-esteem, socio-emotional problems and psychosexual problems [2]. When meeting with a stoma nurse prior to surgery a lot of anxieties can be addressed during the pre-op explanation, and it gives the patient time to ask questions in a safe environment and feel more psychologically prepared (See Chap. 11).

In contrast emergency surgery is performed for an urgent medical condition or a life-threatening condition. This may be for a bowel perforation, trauma or obstruction [3].

With emergency surgery the patient is unable to prepare adequately for stoma formation. Even if they meet with a SSCN prior to surgery it is often difficult to mark a proposed site for their stoma due to abdominal distention or extreme pain. In this situation the SSCN will meet with the patient following surgery to discuss the stoma formation in further detail. However, it is recognised that the patient may experience more psychological anxiety following emergency surgery as they may be aware of the stoma appliance on their abdomen prior to understanding why this was required. Perrin [4] found in a recent study that patients having had emergency surgery did not cope well psychologically, some even continued to struggle up to 3 years post stoma formation. This finding supports previous studies undertaken by Black [5], Borwell [6], reflecting an important aspect of the SSCN role. In addition to the psychological impact, emergency surgery can also have a physiological impact since the surgeon on call may not be a colorectal surgeon with the expertise to consider the impact on quality of life that a poorly fashioned stoma may cause. This can lead to higher stoma complications as well as an increase in patient morbidity/mortality [7].

Stoma surgery can be performed as an open procedure, laparoscopic procedure or robotic procedure. Some conditions may determine the type of surgery undertaken such as complex Crohn's disease where the patient has had several abdominal procedures previously. In this case, where a patient has previously had numerous open procedures the presence of adhesions is quite likely and will make laparoscopic surgery very difficult and as a result may cause damage to the bowel during a procedure. Elective surgery in this case would be the optimal approach but the decision regarding open v laparoscopic will be made by the surgeon following appropriate assessment. Increasingly, surgeons are starting the procedure as a laparoscopic one with a view to completing it laparoscopically and opening only if necessary.

An open procedure is where the abdomen is cut open usually with a vertical incision along the midline of the abdomen or a 'bikini' line opening. This allows the surgeon full view of the structures and organs involved. Following surgery, the bowel will be pulled through the abdominal wall to form the stoma prior to closing the abdominal wall using clips or sutures.

Laparoscopic and robotic surgery are considered less invasive than open surgery and there is increasing evidence that minimally invasive techniques associated with Enhanced Recovery Programmes reduce surgery related stress and promote faster recovery after major colorectal surgery [8].

Laparoscopic surgery involving stoma formation was introduced in the 1990s [9]. It allows the surgeon to access the abdomen and pelvis without having to make a large incision, and is commonly referred to as keyhole surgery. An instrument (laparoscope) with a light source and camera is used to relay images from inside the abdomen to a television monitor and gas is pumped into the abdomen to make it easier for the surgeon to observe the area and perform the required surgery. Between 1 and 4 small incisions are usually required for the instruments required in laparoscopic surgery.

Robotic surgery is similar to laparoscopic surgery in that they are both minimally invasive and use small incisions to allow access to the abdomen and pelvis. However, instead of holding and manipulating the surgical instruments (as with laparoscopic surgery), during robotic surgery the surgeon will sit at a computer console away from the patient's side and use controls to manipulate the robot. The console allows the surgeon to view in high definition, magnified 3D images with increased accuracy and vision, as well as allowing movement of the instruments in many different directions [10].

Despite this surgery being less invasive than open surgery, the operation is the same as the one performed as an open procedure. The morbidity and mortality risks associated with it are the same and the physiological 'hit' the patient takes is no less severe. The patient can still experience as much pain post operatively due to the inflation techniques used inside the abdomen during the procedure. The stoma is formed as part of the laparoscopic or robotic procedure. The pre-marked site for this can sometimes be used to remove the specimen thereby reducing the number of scars.

Stoma Formation

When a stoma is formed it may be temporary (potential to reverse) or permanent and it can be formed as an end or a loop stoma. A temporary stoma can be reversed from as early as 4 weeks if the anastomotic join is secure, but the average length of time is 12 weeks. However, in practice this length of time is often longer due to the length of waiting lists and priority of surgery. In a report from National Bowel Cancer Audit it suggests that individuals are waiting considerably longer than the 12 weeks for a variety of different reasons, some relating to physical health, others relating to geographical location within UK. Some people do opt to keep a temporary stoma, particularly if their quality of life has improved since having a stoma formed [11].

An end stoma is where a segment of the bowel is divided and the upper segment of the bowel is exteriorised onto the abdominal wall. The lower/distal segment of the bowel is either oversewn and secured inside the abdominal cavity or (rarely these days) exteriorised as a mucous fistula. In contrast, a loop stoma is where the bowel is only cut half way through and the two halves are turned back on themselves to create a loop, where there are two openings; a proximal loop (upper segment of bowel which expels faeces) and a distal loop (leading down to any distal bowel, rectum and anus).

If a loop stoma is created from the colon the surgeon may place a plastic stoma rod for up to 5 days underneath the intact loop of bowel to ensure the stoma does not retract back into the abdominal cavity (see Fig. 6.1). This may be indicated due to the size/weight of the colon or the ileum, as well as the abdominal habitus of the

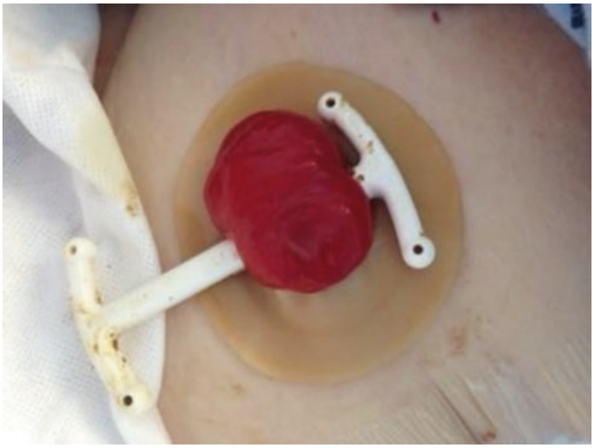


Fig. 6.1 Loop Colostomy with a rod insitu (photo courtesy of CRudoni)

patient. However, there is very limited evidence to support or refute the use of stoma rods and often complications such as pressure damage to the skin, stoma necrosis and skin dermatitis are evident following their usage [12]. Some surgeons will choose to use alternative options to a stoma rod such as a loop of catheter as this is less rigid.

Removal of the rod tends to be at around 5 days and is performed by the SSCN but this timeframe is not determined by research-based studies.

Occasionally a double-barrelled stoma is formed instead of a loop stoma; this is where the bowel is completely divided and both the afferent (proximal) and efferent (distal) end of the bowel are brought out on to the abdominal surface and sutured next to each other. A loop or double-barrelled stoma may be formed when the lower segment of bowel needs to 'rest' often due to inflammatory reasons or a defect in the bowel. In addition, a loop stoma is frequently formed to protect an anastomotic join lower down in the bowel.

The term defunctioning stoma is given to a loop stoma which diverts faeces away from a segment of bowel, in order to:

- relieve a distal obstruction,
- allow an anastomosis to heal,
- to enable radiotherapy treatment to occur
- for palliation

A stoma is very vascular with a lot of blood vessels near to the end of the stoma which can bleed easily. If the blood supply to the stoma is compromised the stoma will become a darker colour and turn dusky pink then purple and finally black (see Fig. 6.2). A referral to the stoma nurse and/or surgeon is important at this stage. See Chap. 12 for further discussion regarding this aspect of care.

Following stoma formation a newly formed stoma will be secured to the skin by sutures. These are often dissolvable such as pds or vicryl, but if not will be removed

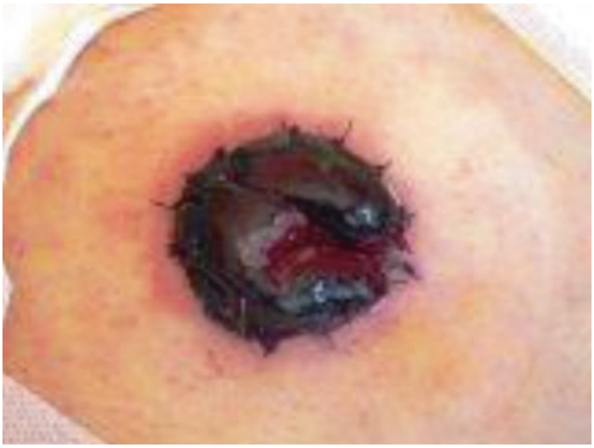


Fig. 6.2 Ischaemic colostomy (photo courtesy of CRudoni)

around day 10. Removable sutures are usually made from prolene. A newly formed stoma will be oedematous and as the oedema settles the stoma can shrink. This may cause pressure on the sutures and they can pull into the skin and become painful. This is often referred to as ‘cheese-wiring/cheese-grating’ and if this occurs the sutures will be removed earlier.

A colostomy is usually formed flat (flush) to the skin and this is because the output tends to be formed and will generally drop into the pouch easily. Cottam [13] suggests that a colostomy should be flush or stand just slightly proud of skin level to make management easier.

In some situations, a transverse colostomy will be formed. This is the largest and heaviest part of the bowel, so the stoma will tend to look much larger than a sigmoid colostomy or ileostomy.

An ileostomy ideally will be formed with a spout of around 2.5–4 cm in order to direct the more liquid faeces into the appliance and prevent seepage underneath the appliance wafer. This is commonly referred to as a Brooke Ileostomy [14].

The output from a transverse colostomy can vary from liquid faeces to a more formed stool depending on the exact point of the transverse colon used to form the stoma.

An ileostomy will usually start to function within 24 h of surgery, whereas a colostomy may take 4–5 days to function. See Chap. 10.

Types of Surgery

1. **Hartmann’s Procedure**

   A Hartmann’s procedure is often performed as an emergency following perforation of the sigmoid colon. This may be as a result of Diverticular disease, stercoral (aetiology unknown) perforation, trauma or a tumour (see Fig. 6.3).

   The sigmoid colon is removed and the descending colon is exteriorised on to the abdominal wall. An end colostomy is formed which may be temporary and the rectal stump is sutured closed and secured inside the abdominal cavity [15]. Sometimes the distal stump can be exteriorised and brought out at the lower end of the wound as a small stoma called a mucous fistula. A rectal stump whether left within pelvic cavity or exteriorised will produce mucus. This is a regular function of the bowel. The mucus can be passed rectally or passed through the mucous fistula into a small pouch. Mucus from a rectal stump can be quite unpleasant for the patient due to the odour and consistency. Initially the mucus is often a brown/red colour and is a mix of stool/blood following surgery and as time progresses it will become paler in colour, but can be quite thick and stringy in consistency.

   Ideally a Hartmann’s procedure is followed by reversal of the colostomy to restore intestinal continuity in the future. However, in reality the formation of a temporary end colostomy for a Hartmann’s procedure is often retained as a permanent stoma, since it is a difficult stoma to reverse successfully and is considered a major operation associated with high morbidity rates of up to 58% and

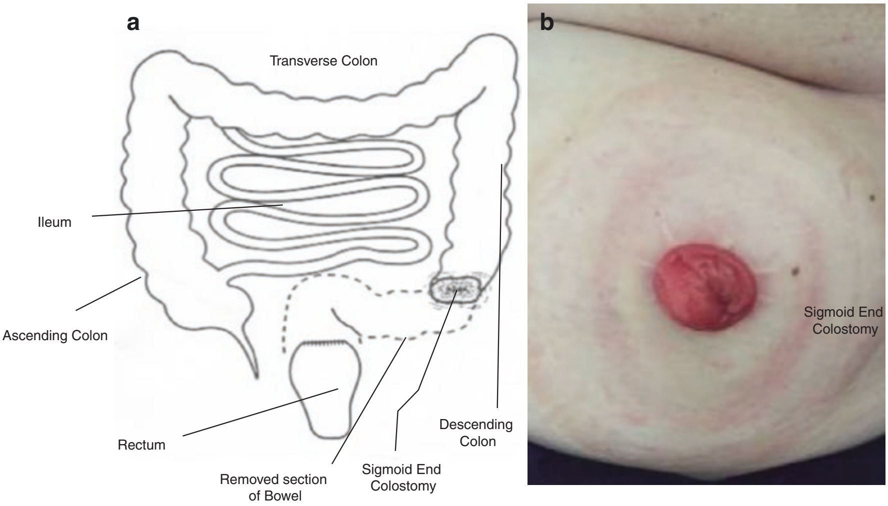


Fig. 6.3 Hartmann's procedure with end colostomy (courtesy of CRudoni). (**a**) Hartmann's procedure with end colostomy (**b**) sigmoid end colostomy

mortality of up to 3.6% [16]. This is due to several factors which includes age of the patient, other co-morbidities present and the complexity of anastomosing an end stoma to the distal end of the bowel, where the risk of anastomotic leakage is increased with full circumferential suturing [16].

According to the National Bowel Cancer Audit in 2015 it was suggested that 95% of patients undergoing a Hartmann's procedure still have a stoma at 18 months [16].

2. **Abdomino-Perineal Excision of the Rectum (APER)**

An APER is performed via an abdominal and a perineal approach. The rectum, anal canal and anal sphincter are removed and the perineum is sutured (see Fig. 6.4). The sigmoid colon is brought to the surface of the abdominal wall as a permanent end colostomy [17]. This means that the stoma can never be reversed since the rectum and anus have been removed.

This procedure is mainly performed for a low rectal or anal tumour where the sphincter muscle is either involved by disease or its function compromised resulting in faecal incontinence. An APER is occasionally performed for perineal Crohn's disease which has not responded to medical therapy.

More extensive surgery may require a wider surgical excision of the rectum and pelvic side walls or even sacrum, which often leads to large perineal wounds which can be a challenge for both colorectal surgeons and reconstructive surgeons. There are various surgical options available for reconstruction such as mesh placement, skin flap repair or negative wound pressure therapy, but currently there is no definitive recommendation regarding the most appropriate management strategy for perineal defect after APER [18]. The perineal wound/s must be observed and cleaned daily and any infection or opening of the wound

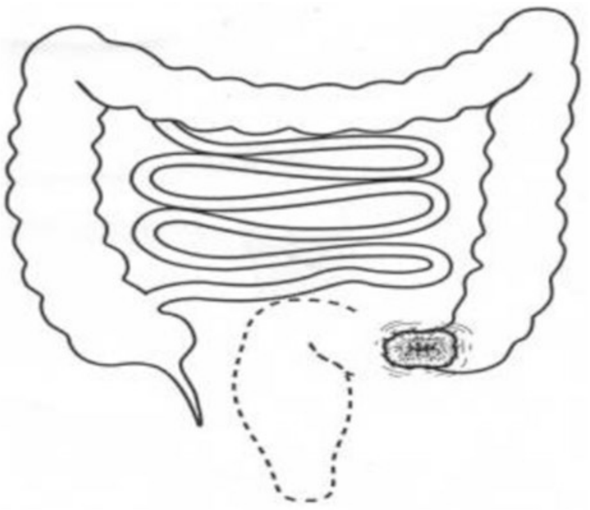


Fig. 6.4 APER (courtesy of CRudoni) with resulting end colostomy as in Fig. 6.3

treated accordingly. The patient should not sit directly on their perineum (bottom) during the post-operative recovery phase as this will put pressure on the wound and could compromise the blood supply and delay healing. A pressure relieving cushion should therefore be provided for these patients.

Prior to an APER for rectal cancer it is common for a patient to undergo treatment to downstage or shrink the tumour prior to surgery. The amount of treatment and type of treatment given varies. This is determined after pre-operative investigations such as pelvic MRI which accurately stages the tumour and highlights other features such as pelvic side wall node involvement or adherence to other organs. A locally advanced tumour may therefore require 5 weeks of combined radio and chemotherapy both of which have side effects during and after treatments. Alternatively 5 days of radiotherapy may be given with or without a delay before surgery. The aim of neo-adjuvant therapy is to optimise the surgical procedure with best possible outcomes for the patient. See Chap. 5 for further discussion on pre-operative radiotherapy. As a consequence, the wound can breakdown or dehisce resulting in delayed or prolonged healing.

3. **Anterior resection (High or Low)**

This procedure is usually undertaken as a result of rectal cancer [19]. An Anterior Resection involves resecting the area of the rectum affected by disease whilst preserving the anal sphincters to maintain faecal continence (see Fig. 6.5). Part or all of the rectum is removed, and the sigmoid colon is anastomosed to the upper/mid rectum (high anterior resection) or the lower rectum or anal canal (low anterior resection). A colonic pouch may be constructed if a significant section of the rectum needs to be removed, as the presence of a colonic pouch will ensure adequate storage capacity which may also improve bowel function. Potential problems with altered bowel function following surgery must be discussed with the patient during the pre-operative preparation stage as the resulting bowel function is likely to be compromised. It is well documented in the

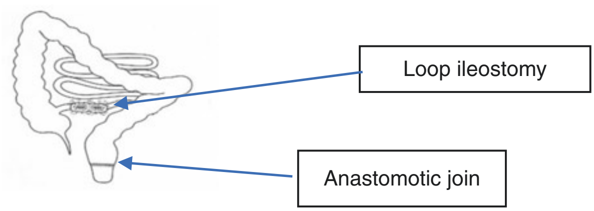


Fig. 6.5 Anterior resection showing anastamotic join (courtesy of CRudoni)

literature that a low anastomosis can lead to low anterior resection syndrome (LARS) [20]. LARS is an extremely distressing and debilitating condition for many patients. Patients experiencing symptoms of LARS need to be assessed, adequately supported and assisted with management of symptoms [21].

A defunctioning temporary loop ileostomy may be required to allow the anastomosis time to heal and prevent faecal leakage. Where the anastomotic join is low in the rectum or the patient has previously undergone radiotherapy, a temporary loop ileostomy is much more likely [19].

A two centimetre distal margin is clinically advisable with the removal of a low rectal cancer to minimize local recurrence rates, which increases the potential need for a very low anastomotic join [22].

Alternatively, the patient may not have an anastomosis if a decision has been made to bring the sigmoid out as an end colostomy, rather than anastamose the bowel at the time of surgery. Patients with poor sphincter control may have a better quality of life by having a permanent end colostomy and this option should be explored with the patient pre- operatively [23].

4. **Wet Colostomy**

A Double-Barrelled Wet Colostomy (DBWC) is an alternative surgical procedure for patients with cancer [24], which would have alternatively led to formation of a separate colostomy or faecal stoma as well as an ileal conduit (urostomy). Patients may be offered the option of DBWC or a separate colostomy and ileal conduit, but this will depend on the service available at their local Trust. It is sometimes referred to as a Wet Colostomy or Carter's procedure [25]. Research has shown that the findings for complications are similar for both types of surgery [26]. However, patients with Lynch syndrome, who are at greater risk than the normal population for developing a cancer, are not offered the option of DBWC due to the extremely high risk of cancer development in the reservoir.

Patients consented for surgery leading to stoma formation (either potential or definite) will have their stoma correctly sited by a registered nurse with a defined level of competency to perform this procedure. In this situation it may be prudent to site on both sides [27] in case the surgeon decides at point of surgery that it is not possible to do DBWC. The patient should be made aware of this prior to surgery.

Careful pre-operative preparation for patients undergoing this procedure is key to a successful outcome [27].

The Specialist Stoma Care Nurse (SSCN) will need to do the following;

- Provide a confidential and reassuring environment for a pre-operative discussion. Make the patient aware that this is a loop stoma and it will have the output of both faecal effluent and urine. The output will limit the types of

  pouches the patient will be able to use. To help the patient make their decision ensure that the patient is made aware that they may be able to perform rectal irrigation through the colostomy portion of the DBWC, as long as the surgeon gives permission for this. This will impact on the type of pouches that the patient may then be able to use with this type of stoma.
  - If suitable, ensure that the patient has an option to speak to a person with DBWC and two separate stomas to gain their insights to the surgery and managing the stoma.
  - Show the patient the types of appliance that can be used post op – two-piece urostomy system is often recommended as the stents present for the first 2 weeks may require flushing, therefore use of a two-piece system will make this easier to accommodate. The output will usually only be urine for the first few days.
  - Once the faecal limb of the DBWC starts to work, the system will need to change to a two piece high output system, because the faecal output will block the anti-reflux valves on the urostomy pouch, and the pouch has to accommodate both urine and faeces. This will enable the patient to change the pouch twice a day without changing the skin barrier with the flange. There are limited two-piece high output pouches available on prescription
  - Note that limitations on pouches may help the patient to decide between DWBC and separate ileal conduit and faecal stomas.
  - It is also worth noting that if a patient has two separate stomas that the patient may be able to irrigate the colostomy if their consultant agrees to this 3 months following surgery.
  - Initially after the surgery the patient is likely to have both a stoma rod (to support the loop stoma) and two stents (to aid the kidneys to drain post-operatively).
  - Make the patient aware that the size of the stoma will be enlarged straight after surgery and that this will reduce in size once the stoma rod and stents are removed.
- Assimilate referral information to ensure relevant information is tailored to the needs of the patient.
- Have access to patient health care records to ensure information pertinent to diagnosis and proposed correct stoma site(s) is/are marked in accordance with operation to be carried out.
- Include family/carers with consent/agreement of patient.
- Utilise specialist skills to assess the patient's ability to understand information regarding the importance of pre-operative information and optimum site for stoma formation.
- Provide a level of information appropriate to the individual patient's needs utilising written, verbal, social media options as applicable, especially where the patient has a choice of either DBWC or two separate stomas to aid informed consent.
- Follow guidelines for stoma siting (see Chap. 11).

- If the patient has a formation of a flap with closure of the anal area at the time of surgery, they should be advised that they will be nursed from side to side lying down for the first 4 days approximately, and then they will be allowed to gradually stand up for limited periods and have limited periods of sitting down. Initially this will be for 10–20 min a day to allow for good perfusion of the flap and prevent loss of the skin flap.
- The flap formation depends on the position of the cancer and the defect left after removal, this will be discussed in depth by a Plastic Surgeon.

Process

Day 1 to Day 3 (while output is urine it is advisable to use a large skin barrier, possibly as large as a 70 mm two-piece system with a urostomy pouch and suitable night drainage bag.

Day 3 onwards (when output is both urine and faecal) use of a two-piece system with a high output pouch and a fistula drainage night bag or night bag with wide bored tubing is recommended. Two-piece high output pouches may need to be changed twice a day as the faecal limb produces output.

Month 3; if the surgeon gives permission the patient may be able to irrigate the colostomy limb of the DBWC and then the pouch system may be a one piece or two-piece urostomy pouch depending on the patient's preference, as the output will be urine alone. This is only suitable if the patient regularly performs irrigation and has achieved a successful regime with no spillage between washouts.

5. **Subtotal colectomy**

   A subtotal colectomy is the removal of the colon resulting in an end ileostomy. It is often performed as an emergency for acute Ulcerative Colitis (see Fig. 6.6a, b).

   The surgeon will remove the colon but leave the rectum in situ, so the patient has future choices regarding reconstructive surgery or completion proctectomy.

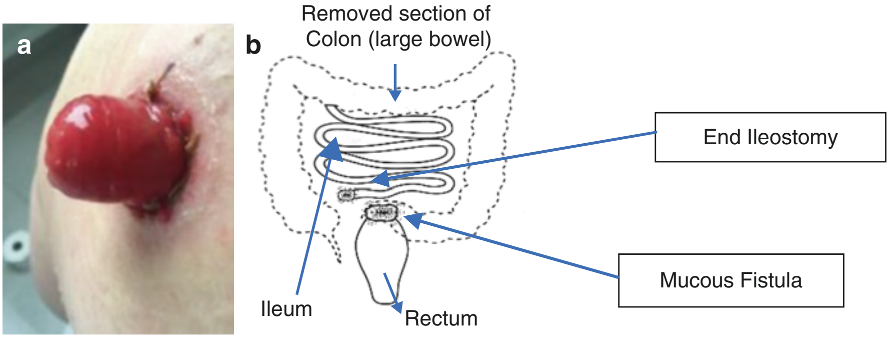


Fig. 6.6 Subtotal colectomy with end ileostomy and mucous fistula. (**a**) End Ileostomy (**b**) Sub total colectomy with end ileostomy and mucous fistula (courtesy of CRudoni)

A temporary end ileostomy is formed, and the rectal stump is usually oversewn and attached underneath the sub-cutaneous layer of skin at the lower end of the wound. If there is disease evident in the rectal stump it may be exteriorised as a mucous fistula and is often situated at the base of the wound. This allows an outlet for any mucus/blood associated with active Ulcerative Colitis to drain and prevents a collection forming internally.

Ulcerative Colitis predisposes the patient to an increased risk of colon cancer. Many studies imply a colorectal cancer risk of 5 to 12% after 20 years of colitis and 1% per year risk increases thereafter [28]. Therefore, surveillance of the rectum following a sub-total colectomy is extremely important to identify dysplasia, with a goal of preventing malignancy or at least detecting lesions in an earlier, pre-symptomatic stage.

Subsequent surgical options include Restorative Proctocolectomy (ileo-anal pouch), where an internal ileal pouch is created or a Proctectomy which involves removing the rectum and suturing the perineum, resulting in the existing temporary end ileostomy becoming a permanent ileostomy.

A sub-total colectomy can also be performed for Familial Adenomatous Polyposis (FAP) which is a rare hereditary disease where multiple pre-cancerous polyps develop in the colon (large intestine) increasing the risk of developing cancer if the bowel is not removed. A sub-total colectomy is performed as a preventative treatment for patients diagnosed with FAP. However, it is important for the retained rectum to be regularly (according to local policy) investigated to ensure no further polyps develop within the retained rectum. This is the case regardless of whether the patient had had a sub-total colectomy or an Ileo-rectal anastomosis (IRA), where the colon has been removed and the ileum anastomosed to the rectum [29].

6. **Restorative Proctocolectomy**

Restorative proctocolectomy or ileal pouch-anal anastomosis (IPAA) is the gold standard surgical treatment for ulcerative colitis ([30], see Fig. 6.7). However, despite the popularity of IPAA, many aspects of this treatment still remain controversial, such as the approach (open or laparoscopic), number of stages in the surgery, type of pouch, and construction type (hand-sewn or stapled ileal pouch-anal anastomosis) [31].

The IPAA is performed as a 2 or 3 stage procedure: the first stage being subtotal colectomy and temporary end ileostomy, stage 2 involves construction of the IPAA using terminal ileum which is then connected to the anal canal fol-

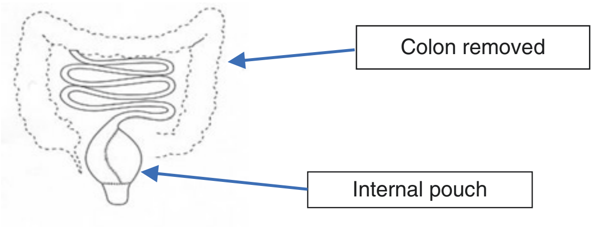


Fig. 6.7 Ileo anal pouch (courtesy of CRudoni)

lowing removal of the rectum. At this stage a temporary loop ileostomy is usually formed to protect the pouch anastomosis.

Stage 3 follows after 8 weeks when the loop ileostomy is closed, and continuity of the bowel restored.

Some surgeons will elect to perform stage 1 and 2 as one stage, thus the second stage will be closure of the ileostomy.

All patients considering this surgery must be adequately prepared about the subsequent lifestyle changes that are associated with reconstructive surgery. The provision of adequate information is paramount and the option to discuss with other patients is encouraged. Bowel function will never be 'normal 'again and quality of life for the patient may well be determined by how many times a day they have their bowels open and whether they need to get up at night. The surgery is complex and the patient may have a complication such as an anastamotic leak, fistula from the anastomosis to other structures (i.e. vagina) or an anastamotic stricture. Therefore the procedure should be carried out by a surgeon with expertise to both perform the surgery and to manage any complications [32].

Following subtotal colectomy if a diagnosis of Crohn's Disease is established, then IPAA would be discouraged due to the risk of Crohn's developing elsewhere within the small bowel. If the rectum is spared of disease an ileorectal anastomosis may be recommended.

7. **Pan proctocolectomy**

This procedure removes the colon, rectum, anal canal, and anal sphincter during one surgical procedure, with the formation of a permanent end ileostomy (see Fig. 6.6a). Patients whose rectum and/or anus are badly affected by Ulcerative Colitis or Crohn's Disease may require this procedure [33]. This stoma cannot be reversed following this surgery.

Despite the radical and final nature of this surgery, it does guarantee a cure from or Crohn's disease and removes the risk of developing colorectal cancer as well as avoiding the need for multiple surgery and hospital visits associated with having IPAA [33].

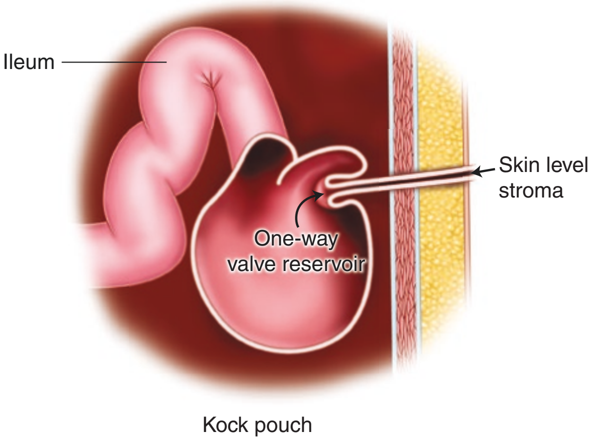
While many patients with Ulcerative Colitis will be offered the opportunity of undergoing restorative proctocolectomy, it is still important that pan-proctocolectomy is offered as a choice to ensure the patient is well informed of their options.

Following surgery, the patient will have a perineal wound. The perineal wound must be observed and cleaned daily and any infection or opening of the wound treated accordingly. The patient should not sit directly on their perineum (bottom) during the post-operative recovery phase as this will put pressure on the wound and could compromise the blood supply and delay healing. A pressure relieving cushion should be provided for these patients.

8. **Kock Pouch**

An alternative to stoma surgery or restorative proctocolectomy for patients with a weak anal sphincter is a Kock's continent pouch, also known as a continent ileostomy (see Fig. 6.8).

Fig. 6.8 Kock pouch (courtesy of A Perrin)



The creation of a Kock pouch is complex and intricate—following a total colectomy two loops of adjacent ileum are stapled together and folded into a U-shape; this is then folded horizontally, and the apex of the proximal limb sutured in place. To create the valve, 15 cm of distal ileum is intussuscepted (turned inwards) into the pouch. The nipple of the valve is then stapled securely using several rows of stapling [34].

Post-operatively a catheter remains in the pouch to allow it to drain. This is removed around 14 days when the patient learns how to self-catheterise the continent pouch at regular intervals, approx. 2–4 times during the day to evacuate faeces [35]. This procedure should only be undertaken in specialist centres where there is adequate expertise and support from a SSCN who is able to support the patient's education and offer ongoing follow up.

9. **ACE procedure**

An Antegrade Colonic Enema (ACE) is performed for patients with chronic constipation requiring a conduit to enable colonic irrigation. It can be defined as a proximal colonic stoma that allows antegrade wash out of the distal colon [36].

Patients quality of life can be improved as a result of this procedure as they may no longer require huge amounts of laxatives to evacuate their bowel.

The appendix or a small segment of the ileum is used to create a continent stoma (which is a non-refluxing valve) or conduit through which water is introduced via a catheter to "flush" the whole colon. The patient will then evacuate rectally. Once a regime has been established the patient will remain continent between washouts. The procedure is often performed in children, but can also be offered to adults as a method of bowel management.

A fluid regime is established according to the patients' individual needs. The volumes required for a successful result will vary, some patients may also require the addition of an enema within the fluid to ensure complete evacuation.

For further guidance please refer to ASCN guideline on ACE procedure [37]. See Appendix 1.

10. **Revision or Refashioning of a Stoma**

    Complications after stoma formation are common and most can be managed conservatively. However, some complications require further surgery to revise or refashion the stoma. Early complications may involve ischaemia where the blood supply is compromised to the stoma following surgery and reoperation may be required [38]. Later complications may involve stoma retraction, stoma fistula, stenosis, stoma prolapse or parastomal hernia. Refashioning of a stoma involves mobilisation of the bowel, removing the problematic area and creating a new stoma [38]. The refashioned stoma is often positioned in the same place as the previous stoma but in some situations, for example recurrent parastomal hernia or skin damage the stoma may be repositioned to another site (See Chap. 12).

11. **Parastomal Hernia Repair**

    A parastomal hernia (PSH) is where additional loops of bowel protrude through the abdominal wall around the stoma creating a bulge (see Fig. 6.9). Incidence of PSH varies widely and is reported as anything from 7% to 57% [39]. In many cases PSHs are asymptomatic and can be managed conservatively through abdominal core exercises or the use of support garments. However, it is approximated that 1 in 3 patients will go on to have further surgery to repair their PSH [40] due to increasing hernia size, discomfort, pain and cosmetic dissatisfaction.

    When a PSH hernia repair is undertaken the loops of herniated bowel are secured back inside the abdominal cavity. There are a number of methods that can be employed in corrective surgery and this can include minimally invasive corrective surgery involving closure of the defect or using a synthetic or biological mesh to reinforce the repair [40].

    The stoma position frequently remains unchanged following a PSH repair but stoma relocation may be required if the PSH is very large with significant intra-abdominal adhesions or if several repairs have already been attempted at the initial site (See Chap. 12).

Fig. 6.9 Parastomal hernia (courtesy of C Rudoni)

12. **Reversal of a stoma**

    Reversal of a temporary colostomy or ileostomy is performed to restore continuity of the bowel. Evidence surrounding the timing of stoma closure is limited, however there is agreement that is should not be performed prior to 8 weeks from the primary surgery, when intra-abdominal adhesions become more manageable and bowel oedema has resolved, to reduce the risk of complications [41].

    A loop stoma can be reversed without opening up the abdomen as both ends of the bowel are visible and this is considered to be a relatively straightforward procedure [41]. The loop stoma will be freed from the abdominal wall and the upper section of the bowel will be sutured or stapled securely to the remaining lower section of bowel.

    An end stoma is more difficult to reverse and will involve a laparotomy. The stoma will be detached from the abdomen and the distal bowel identified and mobilised from the abdominal cavity so the surgeon can reattach the two ends. It takes longer to recover from this type of surgery due to the surgery being more invasive [42] and there is also a greater risk of complications since the risk of anastomotic leakage is increased with full circumferential suturing [16].

    Prior to reversal it is important that the patient is prepared by the stoma or colorectal nurse specialist and understands that bowel function post reversal is often different to bowel function prior to stoma formation. Some patients experience constipation and others will experience loose, frequent bowel movements.

Conclusion

As we have established, colorectal surgery is performed for a wide variety of conditions. The SSCN has an important role to play in supporting the patients undergoing this type of surgery—as the patient's advocate it is vital to be able to offer accurate, up to date information on appropriate surgical procedures, as well as facilitating the patient's ability to make their own choice in respect to surgery and supporting their decision.

It is therefore important for all nurses to understand every aspect of the patient's journey, the rationale for the procedures and the implications for the patients' quality of life and how this can impact on their psychological and social well-being.

Appendixes

REVISED 2021
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WENDY OSBORNE (2019)
Reviewed: Yvette Perston 2021

Management of an ACE stoma (Adults)

An Antegrade Continence Enema (ACE) is performed for patients with chronic constipation/faecal incontinence requiring a conduit to enable colonic irrigation to achieve continence. The conduit can be formed from the appendix, ileum (Chéreau et al 2011) or caecum. Alternatively, a Percutaneous Endoscopic Colostomy (PEC) using a PEG (Percutaneous Endoscopic Gastrostomy tube) can be formed as the ACE (Duchalais et al 2015).

Statement:

Patients having undergone an ACE procedure within an expert centre will have been assessed and care prescribed by a Specialist Nurse with expert knowledge and experience of the ACE procedure.

Structure:

Evidence that a specialist assessment has been undertaken.
Evidence that care has been prescribed and care plan devised and communicated to other relevant healthcare professionals.
Evidence knowledgeable nurses have provided specialist care for patient with an ACE.
Evidence the patient will demonstrate safe management of their ACE.

Process:

- Ensure a private, confidential and safe environment where the patient can be assessed and appropriate advice given, and expectations managed.
- Preoperatively mark an appropriate site for the ACE/PEC stoma (refer to ASCN siting guideline). If no previous surgery this will usually be right iliac fossa or umbilicus.
- Post operatively:
    - Check the stoma to ensure it is pink and healthy and the skin is not compromised, and the catheter/device (e.g. button or tube) is secure.
    - Flush the catheter inserted into the ACE during surgery (as per local policy) this may be once a day with 20mls of tap water (body temperature 37 degrees) using a bladder syringe (make a note of the size of catheter inserted).
    - Discuss and commence a mutually agreeable teaching regime with the patient +/- carer as soon as possible once they are eating and drinking and preferably mobilising to bathroom.
    - Advise the patient to sit on the toilet and demonstrate how to irrigate the stoma via the catheter with 100mls of body temperature tap water via a bladder syringe. Increase the volume by about 50mls daily until the patient is able to have bowels open normally (this will vary from patient to patient depending on dietary intake and volume of water used - this may be about 500mls).
    - Reassure and advise evacuation may take up to 30 minutes. The patient may need to sit on the toilet for this period of time, or if they are able to control evacuation until they experience the 'urge'.
- Once independent/carer competent, discharge home from hospital with 10 day ward supply of bladder syringes for irrigation and dressings as per local policy to cover the ACE.This regimen may need to be delayed or slower if any anastomosis has been formed - as in the case when small bowel is used in the absence of an appendix.
- On discharge, advise patients to:
    - Continue daily irrigation of ACE.
    - Plan regular time (preferably morning, 30-60mins after coffee/meal).
    - Plan a convenient time when relaxed/undisturbed, as will take about 30mins.
    - Not strain.
    - Adopt a comfortable toilet position.
    - Recognise that mucus discharge around the ACE may occur.
    - Recognise signs of skin changes such as infection around the ACE site, if this occurs to contact the Specialist Nurse.

Continued on next page

Management of an ACE stoma (Adults) (Continued)

- Review the patient within 2-3 weeks (if a PEG tube is used this needs to be left for 3 months).
- Commence teaching the patient +/- carer independent intubation of ACE:
    - Check stoma and skin to ensure both are healthy.
    - Remove the catheter by deflating the catheter balloon and removal of suture if present.
    - Re-intubate with intermittent self catheter (ISC) (ISC size to correlate to catheter inserted in theatre).The positioning of the ISC will need to be manipulated to attain the correct angle through the valve into the caecum (this often creates a 'popping sensation' for the patient which is normal).
    - Encourage patient +/- carer to do this independently and self catheterise.
    - Insert a volume of water (about 500mls at body temperature) using a colostomy irrigation set or bladder syringe, sufficient to produce a normal bowel action.
    - Withdraw the ISC, clean the stoma site, dry thoroughly and cover with dry dressing.
- Advise patient of options of ACE stopper (see appendix 1) and/or stoma cap available and provide samples and/or prescription details as per patient preference.
- Advise of on-going management and possible complications (see appendix 2):
    - Advise time is required for bowel to settle into routine and effectiveness of ACE irrigation evaluated.
    - Once effective bowel management achieved on daily basis, alternate day irrigation of ACE may be trialled.
    - Additional medication may be required if water irrigation not effective on daily basis e.g. oral laxative and/or addition to irrigant on advice of consultant.
- Review patient as per local guidelines.
- Ensure the patient has the Specialist Nurse/SCN contact details for ongoing support and advice (NICE 2017).

Outcome:

- The patient makes a safe post operative recovery and +/- carer is able to demonstrate their ability to manage their ACE.
- Patient expresses they are satisfied with the effectiveness of their regime for bowel management.
- Completion of appropriate documentation as per local policy.

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Appendix 1: Equipment options for ACE

	Company and product details	Order Codes
Colostomy irrigation sets *(Compatible with intermittent self catheterisation (ISC) for ACE)*	Coloplast irrigator bag/tubing & flow control Dansac water container Dansac flow control clamp Dansac tubing	1511 95200-0000 95210-0000 95215-0000
Catheter options for ACE - ISC *(Shorter length usually preferable)*	Coloplast – ISC range from size 6-14 Wellspect – Lofric range from size 8-14 available in 2 lengths 15cm & 20cm	28506 – 28514 4041025 – 4041425 (15cms) 4030800 – 4031000 (20cm)
Adapter for gastrostomy button	 ENFIT to funnel adaptor Funnel to ENFIT adaptor *https://www.gbukenteral.com/enfit/*	UAD21SO TRN202
ACE stopper *Stoppers last a month just wash and reuse* *Order as single units or monthly packs of stopper and dressings, or dressings available as single item*	Aquaflush Medical Limited (Pharmacies/Delivery companies will need to obtain Aquaflush products via Bullen). *NOTE: stopper can be shortened if needed* Aquaflush Dressing (30 in pack) Corpak (Halyard) – Corstop (ACE stopper) New stopper - Wystopper Packs of 3 in 30mm or 60mm length sizes 10, 12, 14, 16	6fg ACE 6/100 8fg ACE 8/100 10fg ACE 10/100 12fg ACE 12/100 AFD30 Size 8 at sizes: 15mm, 30mm and 60mm CS8-15, CS8-30, CS8-60 Size 10 at sizes:: 15mm, 30mm and 60mm CS10-15, CS10-30, CS10-60 Size 12 at sizes: 30mm, 60mm and 100mm CS12-30, CS12-60, CS12-100 Size 14 at sizes: 30mm, 60mm and 100mm CS14-30, CS14-60, CS14-100 30mm WS0310 WS0312 WS0314 WS0316 60mm WS0610 WS0612 WS0614 WS0616

Continued on next page

Appendix 1: Equipment options for ACE (Continued)

	Company and product details	Order Codes
Stoma Cap options	Coloplast Dansac Oakmed Pelican Welland	2501 829-20 1120K 102382 MHSS 513
Meatal dilator	Peak medical ultrasmooth meatal dilators	12Ch USMDT12 14Ch USMDT14 16Ch USMDT16 18Ch USMDT18
Anal plugs	Peristeen Plug	1450/1451
	Renew inserts	
	Starter pack	702
	Starter pack - Regular size	706
	Starter pack - Large size	707

Appendix 2: ACE potential management issues

Potential concerns	Specialist Nursing Support
Difficulty instilling irrigation fluid	Leakage of fluid around the catheter while infusing and assess: Size of catheter Presence of abdominal cramps (see later) • Temperature of the instillation fluid (body temperature) Consider reducing the speed of fluid instillation Extended time to instil fluid, consider using: Larger catheter size • Irrigation kit
Constipation	Assess oral fluid and dietary intake and offer advice in accordance with diagnosis and bowel function. Reivew medication and assess appropriate laxative prescribed: Osmotic - Movicol, Laxido • Stimulant - Bisacodyl; Senna Softeners - Docusate sodium • Bulk forming - Fybogel Liaise with colorectal consultant for advice for alternative laxatives to be added to irrigant: Phosphate enema • Bisacodyl enema PEG solution (Movicol, golytely) • Liquorice Glycerin
Difficulty in intubation	Assess for stenosis (see later) Assess for peristalsis on insertion of catheter. if reported, advise the patient to: Relax, breathe deeply and perform abdominal massage • Consider changing position - ie insert catheter when lying or standing rather than sitting
Abdominal cramping	Reduce speed of infusion Check temperature of irrigant Review laxative/stimulants prescription Encourage abdominal massage
Bloating/flatus	Reduce speed of infusion Check temperature of irrigant Review laxative/stimulants prescription Encourage abdominal massage Review dietary and fluid intake Charcoal capsules Peppermint
Elimination problems	Extended time for evacuation: Review oral laxatives/medication • Review for irrigant stimulant • Discuss toilet positioning – not straining

Continued on next page

Appendix 2: ACE potential management issues and complications (Continued)

Potential concerns	Specialist Nursing Support
Soiling after the procedure	Assess effectiveness of irrigation • Ensure time to evacuate is taken • Review amount of instillation fluid – may require more for a complete evacuation or less if water residual leakage • Review laxative/stimulant regime Review need for: Anal plugs (see appendix 1) • Glycerine suppositories Rectal irrigation (mini)
Pregnancy	Assess for difficulty in catheterising due to: Change in body shape (vision for intubation) • Disturbance of channel Assess if changes in regime are needed such as: Reduction in volumes of water may be required • Review of alteration of stimulants Discussion between obstetrician and colorectal surgeon for assessment for caesarean section.
Child development to adulthood	Review effectiveness of evacuation Review oral laxatives/medication and or stimulants Review amount of irrigant used
Long-term implications	Reassessment required due to deterioration of original condition (e.g. spina bifida; multiple sclerosis) Reduced dexterity, mobility or eyesight Reduced response to stimulants – requires regular follow up to review effectiveness
Stenosis 6-59% (Soyer 2020)	May develop at skin level, anastomosis, from balloon dilation or previous refashioning Prevention can be gained with daily intubation (Soyer 2020), use of stopper or PEG button Dilation may be required under x-ray control Surgical revision may be necessary (Smith and Decter 2015) Use of graduated tip catheter may help when stenosis at skin level or caecum Consider use of meatal dilator (see Appendix 1)
Leakage from ACE	Assess for effectiveness of evacuation – increase fluid irrigant amount Review for addition of stimulant Consider the use of an ACE stopper Consider the use of a stoma cap
Local infection more common in PEC	Advice provided to patient for skin care Skin swab and treat as appropriate
False passage formation	Refer to colorectal consultant for review. Will probably need ACEogram (sinogram through ACE)
Granulation tissue formation (Sturkenboom et al 2018)	Topical steroid cream Silver nitrate
Prolapse	Is very rare, occuring in less than 1% (Chéreau et al 2011) Refer back to colorectal surgeon

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Anatomy and Physiology of the Urinary Tract and Associated Disease Processes

7

Jennie Burch

Learning Outcomes

There are four learning points for this chapter on urological anatomy and physiology; the reader will be able to:

- Describe the anatomy and physiology of the urinary system and identify why it might be necessary to remove the urinary bladder and form a urinary stoma or diversion.
- Identify common disease processes related to the urinary system.
- Recognise the common symptoms related to these disease processes
- Understand the function of the urinary tract to improve the care of patients with surgical changes such as the formation of an ileal conduit.

Renal System Development

During development in the womb the renal and genital systems develop from a collection of cells that are situated at the back of the abdominal cavity. While in the womb and during the initial development both systems drain into the foetal cloaca. At about 4 weeks, development of the renal system begins, first in the cervical region and then moving towards the pelvic region. By the second half of the pregnancy the kidneys have formed and have become functional. When the foetus swallows amniotic fluid the urine is excreted into the amniotic fluid, which is then removed by the placenta and passed in the mother's urine [1].

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Although unusual, it is possible during development for one or both kidneys to remain in the pelvis rather than move upwards towards the posterior abdominal area. If both kidneys remain in the pelvis they might be forced together and fuse, into a horseshoe shaped kidney. Alternatively there may be other malformations such as two ureters or both renal pelvises connected to a single ureter [2].

As the bladder and urethra form, the cloaca is split in two. During development within the womb, areas within the foetus grow and change becoming part of the urinary or sexual system. During foetal development, in rare situations, as the male penis develops there can be incomplete fusion resulting in the urethral opening being on the inferior aspect of the penis [2].

Urological Anatomy

There are four main parts to the urinary or renal system; kidneys, ureters, urinary bladder and the urethra (see Fig. 7.1).

Kidneys

The two kidneys are situated in the posterior aspect of the abdominal cavity, behind the peritoneum and within the retroperitoneal space [1]. The kidneys are positioned with one kidney on each side of the spine and extend from T12 to L3; with the nerves that relate to the kidneys being T10, T11 and T12 [2]. The right kidney is positioned slightly lower than the left kidney, being displaced by the liver. Jones [3] describes in relation to the other anatomical structures that the left kidney is posterior to the stomach, pancreas, spleen, jejunum and descending colon. The aorta is medial to the left kidney. The right kidney is posterior to the liver, the second part of the duodenum and the colon. The inferior vena cava is medial to the right kidney. The diaphragm is superior to both kidneys, as are the adrenal glands. The diaphragm as it contracts during inspiration moves the kidneys downwards. To protect the kidneys is a fibrous capsule. Additionally outside the kidney and adrenal gland is a covering of perirenal fat and around that the perirenal fascia [2].

In appearance the kidneys are coloured red-brown and they are the shape of a kidney bean. In size, the kidneys are about 11 cm in length, 6 cm wide and 3 cm in width; weighing about 135–150 g in adults [4].

A vertical dissection of the kidney reveals the internal structure (see Fig. 7.1). The dark, outer portion of the kidney is termed the cortex and the paler inner portion is termed the medulla. Centrally is the pelvis of the kidney, which is an irregular, branched cavity [4]. The medial border of the kidney is named the hilus. At the hilus the blood vessels, nerves and ureters enter and leave the kidney. The outer covering of the kidney is a fibrous capsule, which encloses all of the internal tissues.

The renal cortex is situated below the capsule and is highly vascularised, visible as a deep red-brown colour. Within the renal cortex are interstitial cells, some of which are responsible for producing erythropoietin [2]. The medulla is less well

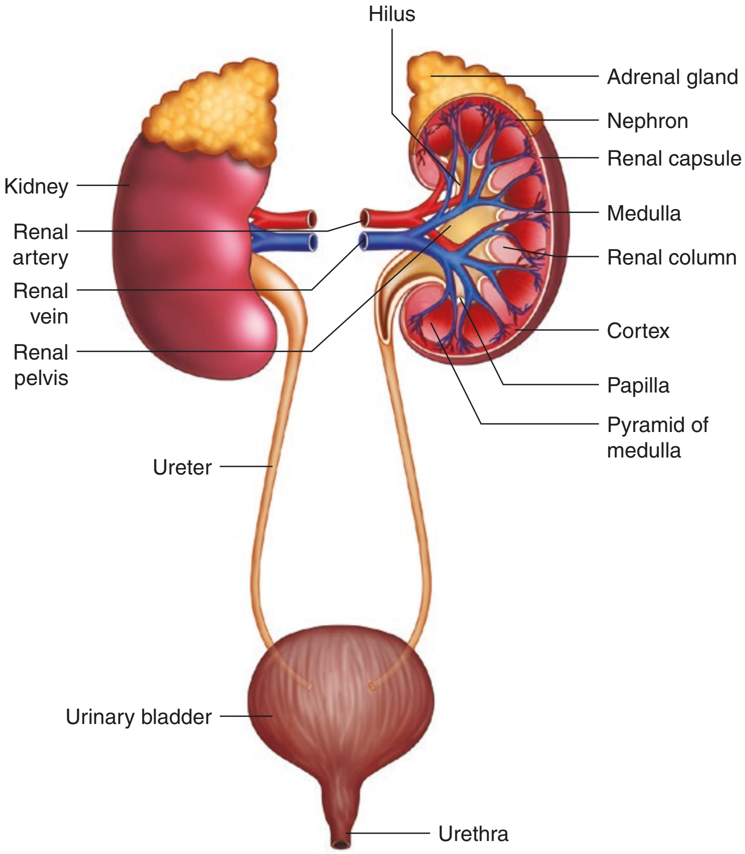

Fig. 7.1 The urinary system (courtesy of J Burch)

vascularised than the renal cortex and thus is visibly paler. The medulla contains about ten triangular structures, termed the pyramids of the medulla [5]. At the pyramid apex, also termed papilla, the urine pours into the kidney pelvis [4]. Within the pyramids of the medulla and the cortex are about a million, microscopic nephrons [6].

Nephrons

Nephrons are positioned within the medulla and the renal cortex [3]. Each nephron (see Fig. 7.2) consists of a blood supply and a network of ducts or tubules. The network of tubules within each nephron includes the renal corpuscle, proximal convoluted tubule, loop of Henle, distal cortex and straight collecting duct [5]. The renal corpuscle consists of the glomerulus, the glomerular capsule (also termed the Bowman's capsule) plus a network of capillaries [1]. The proximal tubule is lined with epithelial cells and many microvilli, which enable reabsorption of filtrate back

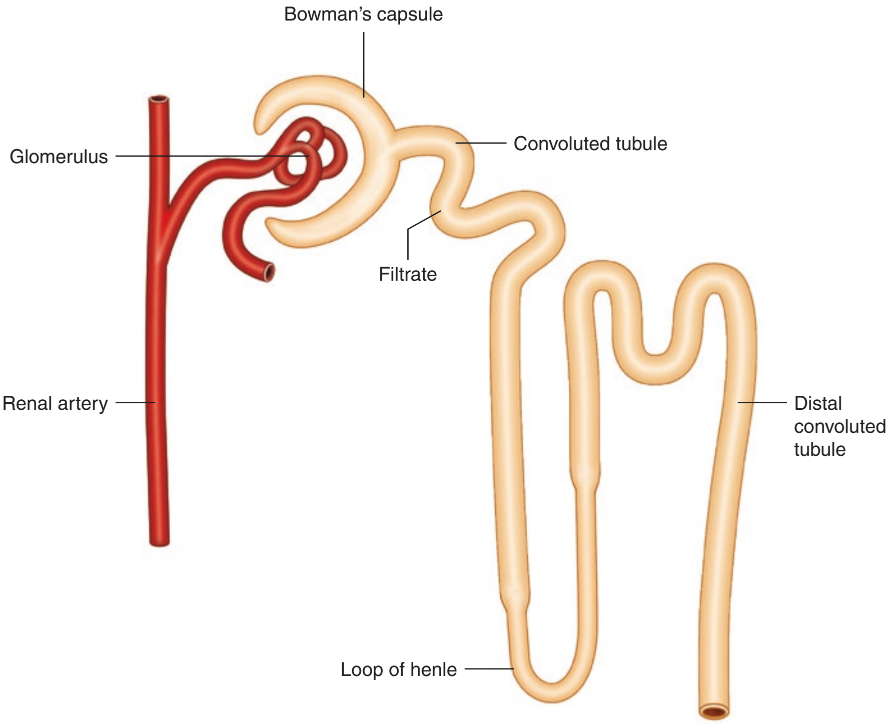

Fig. 7.2 Nephron (courtesy of J Burch)

into the circulating blood [2]. The straight collecting ducts at the apex of pyramids pass the urine into the branches of the minor and then the major calyces within the pelvis of the kidney.

The glomerulus is a sphere of capillaries that are surrounded by the Bowman's capsule, where the blood is filtered. Blood enters the glomerular capillaries via afferent arterioles and leave via efferent arterioles, not through the venous system [2].

There are two types of nephron the cortical and juxtamedullary [2]. The most common nephrons are the cortical nephrons, which have shorter loops of Henle. There are fewer juxtamedullary nephrons, which are longer and thus are situated deeper within the medulla; enabling them to concentrate the urine more effectively.

The blood supply to the kidneys comes from the abdominal aorta to the renal arteries. As the blood vessels pass through the kidney, the vessels travel between the renal pyramids in the area called the renal column. As the blood reaches the renal cortex it enters the glomeruli within the nephron.

Adrenal Glands

The pyramid shaped adrenal glands are superior to each kidney and covered in adipose tissue. There are two parts to the adrenal glands the inner medulla and the outer cortex. Although close in location to the kidney the adrenal glands are not part of the urinary system and function separately to the kidneys [7]. The adrenal glands secrete hormones that include cortisol, aldosterone, adrenaline and androgens. Aldosterone does have an effect on the kidneys, promoting sodium reabsorption.

Ureters

There are two ureters; each ureter joins one of the kidneys with the urinary bladder. The ureter is a muscular tube which in appearance is about 30 cm in length and 3 mm in diameter [6]. The ureters are lined with epithelial cells [2].

The ureters are situated with the kidneys, within the retroperitoneum [8]. The ureter, situated within the kidney is divided into two or three major calyces. Each major calyx then subsequently divides into smaller structures, termed minor calyces. The minor calyx is situated at the apex of each medulla [2]. The ureters enter the bladder at its base [5].

To move the urine from the kidneys towards the bladder the muscles within the wall of the ureter contract peristaltically about four to five times a minute [4]. To prevent urine from returning back up the ureters there are two bands of oblique muscle fibres that close the ureteric openings at the bladder end. The afferent nerves from the ureter enter the spinal cord at T11, T12, L1 and L2 [2].

Urinary Bladder

The urinary bladder is a reservoir for urine. The bladder is situated within the lesser pelvis when it is empty but moves as it begins to fills; upwards and forwards. The bladder is positioned above the pelvic floor (pelvic diaphragm). In appearance the bladder is an expandable sac, lined with transitional epithelial tissue that allows expansion [5]. The next layer of the bladder is smooth muscle, known as the detrusor muscle [9] and the outer layer is loose connective tissue. Expansion is also aided by rugae, which are folds within the bladder.

The bladder can hold over 500 ml of urine with discomfort, but the desire to pass urine is usually felt with a urine volume of 200–400 ml [1]. To maintain urinary continence there are internal and external sphincter muscles. The nerves that relate to the urinary system originate from the autonomic nervous system, predominantly parasympathetic nerves from the spinal cord (S3-S5), with nerve control from the pudendal nerve [2]. Urine leaves the bladder via the urethra.

Prostate

In men only, the prostate gland lies below the bladder and is attached to the bladder by connective tissue. The prostate gland surrounds the urethra; termed the prostatic urethra [3]. The prostate in appearance is 4 × 3 × 2 cm and is cone shaped. The gland secretes seminal fluid during ejaculation. With increasing age, the prostate gland enlarges and narrows the lumen of the urethra, reducing the urinary stream [3].

Urethra

The urethra is the passage from the bladder to pass urine via the external urethral orifice. The urethra as it passes from the bladder downwards will pass through the pelvic floor. In appearance, the urethra is a hollow tube. The urethra in males is about 20 cm in length, compared to females where the urethra is about 4 cm in length [6]. In males the urethra also is the passage for the reproductive system. In females the urethra just belongs to the urinary system. To maintain continence there are urethral sphincter muscles. There are internal and external urethral sphincter muscles; which are under involuntary and voluntary control respectively [9]. These sphincter muscles are controlled by nerves and nerve damage may result in urinary incontinence [4].

Pelvic Floor

The pelvic floor, also termed the pelvic diaphragm, is formed from a number of muscles and ligaments, specifically the levator ani and coccygeus [10]. The pelvic floor supports the organs within the pelvis; one of which is the urinary bladder. A competent pelvic floor ensures both urinary and anal continence. In women the pelvic floor surrounds the urethra, vagina and rectum. In men the pelvic floor surrounds only the urethra and rectum. Damage to the pelvic floor, such as during surgery, may therefore alter urinary continence.

Urological Physiology

The main function of the urinary system is to maintain homeostasis as well as to produce and eliminate urine. Homeostasis can be seen as maintaining the internal environment of the body at a constant.

Kidney Function

The kidneys perform a number of roles (see Box 7.1). The kidneys receive about a fifth of the blood that is passed from the heart every minute, equating to about 600-1000 ml [9].

Box 7.1 Role of the Kidneys

- Maintain homeostasis
- Maintain blood pressure
- Produce urine
- Remove metabolic waste, foreign substances and chemicals from the blood
- Secrete hormones
- Regulate of water and electrolyte balance
- Regulate of extracellular fluid volume and plasma osmolality
- Regulate of red blood cell production
- Gluconeogenesis

Homeostasis is achieved by the kidneys through the maintenance of a consistent composition and volume of body fluids, as well as maintenance of blood pressure [6]. Homeostasis is achieved by regulating the water content, mineral composition and acidity within the body, to ensure that the blood volume, pH and components remain balanced [7]. One way that regulation of the body is maintained is by secretion of substances to ensure that extra-cellular concentrations and blood levels remain within normal parameters. Another is the formation of urine to remove excess water and toxins such as drugs or food preservatives. It is also important to remove metabolic waste from the blood. Another role of the kidneys is to secrete hormones.

The kidneys produce four hormones. These hormones are renin, vitamin D, erythropoietin and prostaglandins [2].Renin is released by the juxtaglomerular nephrons and as a result angiotensin II is formed. Renin acts upon the proximal tubules to promote sodium retention [9]; additionally this hormone acts as a vasoconstrictor. Renin is necessary to help maintain blood pressure and blood volume. Vitamin D is a steroid hormone that is metabolised and activated in the kidney. This hormone promotes calcium and phosphate absorption from the gastrointestinal tract. Erythropoietin is a protein that is produced in the kidney to promote the formation of red blood cells within the bone marrow. Erythropoietin is secreted when it is necessary to increase the production of red blood cells such as in periods of hypoxia. Finally prostaglandins are produced in the kidney; one effect of this hormone is to alter renal vessel tone [2].

Hormonal Control

There are also a number of hormones that act on the kidney. Antidiuretic hormone (ADH) is a peptide that is released from the pituitary gland. This hormone promotes water reabsorption in the collecting ducts of the nephrons. Aldosterone is a steroid hormone produced in the adrenal glands. This hormone promotes reabsorption of sodium within the collecting ducts. To promote sodium excretion within the collecting ducts there are natriuretic peptides produced by cardiac cells. FGF23 is produced by bone osteocytes and promotes phosphate excretion and inhibits vitamin D production. Finally, the parathyroid hormone is a protein produced by the parathyroid gland that works to promote phosphate excretion, calcium reabsorption and vitamin D production [2].

Urine Production

Urine is produced in three stages; namely glomerular filtration, tubular reabsorption and tubular secretion. Considering first glomerular filtration; this occurs from the glomerulus to the glomerular capsule. The high pressure within the glomerulus forces water, ions and small molecules out of the blood, to become filtrate. Additionally the filtration barrier has a negative charge which means that negatively charged molecules are repelled and thus do not pass through the filter to become part of the filtrate. Only low molecular weight substances from the blood plasma can pass through the filter. Low molecular weight molecules include glucose, amino acids, sodium, urea and potassium [3]. Albumin is a reasonably large molecule which is negatively charged and thus very little will pass through the glomerular filter and all is reabsorbed in the proximal tubule in health. Thus, protein should not be seen in the urine; but if noted it is a sign of glomerular filter damage. The fluid that passes through the filter is termed glomerular filtrate. In composition this filtrate is similar to plasma; it contains glucose, amino acids, fatty acids, salts, urea and uric acid [4]. About 20% of the blood volume that passes through the glomerular capsule will become glomerular filtrate. The majority of this glomerular filtrate will subsequently be reabsorbed. The glomerular filtration rate (GFR) is the amount of filtrate that is produced in a certain time frame, such as a minute [3]. The GFR can be used to determine how well the kidneys are functioning.

The second stage of urine production is tubular reabsorption. Tubular reabsorption is the process of re-absorbing about 99% of the fluid that has been filtered. As well as fluid being reabsorbed, so too are many of the soluble substances that are still of use to the body [1]. About two-thirds of the primary filtrate is reabsorbed into the blood within the proximal convoluted tubule. Additionally, there is active reabsorption of ions through the ion channels. Also in the proximal convoluted tubule 100% of glucose is reabsorbed in health. Furthermore, other substances such as sodium, potassium, calcium, phosphate and amino acids as well as water are reabsorbed within the proximal tubule [2]. Water is passively reabsorbed with the reabsorbed solutes due to the osmotic pressure differences. The loop of Henle is the area where urea, water and additional ions are absorbed due to osmotic pressure differences. Reabsorption also occurs is the distal convoluted tubule of the nephron; where additional potassium ions and water are reabsorbed based on the needs of the body. The rate of absorption is controlled by the anti-diuretic hormone (ADH), which is secreted by the pituitary gland [4].

Tubular secretion is the third and final stage of urine production. The tubule and duct cells actively secrete substances such as waste and drugs as well as excess ions into the fluid within the renal tubule and collecting ducts [1]. This includes secretion of bicarbonate ions and urea with additional water reabsorbed if needed. Additionally, hydrogen is used to maintain the pH levels of the blood. The waste that passes from the collecting duct is now urine.

The function of the medulla is to collect the urine secreted in the cortex and transport it to the kidney pelvis. The urine will then move through the renal pelvis and be collected by the ureter. The function of the ureters is to transport urine from the kidney to the bladder. To enable movement of the urine through the ureters, towards the urinary bladder, a series of peristaltic contractions will occur several times each minute.

Voiding

In health the bladder will fill with urine; as this process occurs the pressure initially within the bladder will be low. To maintain continence the sphincter pressure is high, meaning that the sphincter muscles are closed [8]. The muscle layer of the bladder, the detrusor muscle is inactive. As the bladder fills the sensory afferent nerves respond to the stretching of the bladder wall signalling that the bladder needs to be emptied. To pass urine, also termed voiding, there needs to be coordination of a number of factors. The sphincters need to relax and the detrusor muscle needs to contract to allow the urine to leave the bladder. The bladder pressure will increase until the bladder is empty. The usual frequency of urination is to empty the bladder about four to six times a day.

Urine

Urine is sterile and a concentrated version of the primary filtrate consisting of water, salts and waste (see Box 7.2). In appearance urine is usually liquid and straw-coloured. The normal quantity of urine passed is 1000-1500 ml each day [3]. The volume of urine can vary due to a number of factors such as fluid intake, the amount of exercise undertaken and subsequent sweat produced. In health it is usual to consume 1500-2000 ml daily of oral fluids, this may need to be increased during sporting activities or when in hot climates. The specific gravity of urine ranges from 1015 to 1025. The acidity of urine varies from slightly acidic to slightly alkaline; with a pH between 4.5 and 8 most commonly 5.5–6.5 [8]. The pH will vary after eating a meal for example. Eating citrus fruits and vegetables will cause the pH to rise and become more alkaline, whereas the pH will become more acidic after consuming meat and cranberries [7]. Points to consider in respect of urine relate to its composition and acidity. For people with an ileal conduit, a high urinary pH (alkaline) can cause peristomal skin lesions [7].

Box 7.2 Constituents of Urine

Water (95%)
Salts consisting of:
    Sodium chloride
    Phosphates
    Sulphates
Urea (2%) consisting of:
    Uric acid
    Creatinine

Disease and the Urinary System

There are numerous diseases or conditions that can occur in the urinary system, some of which may result in the formation of a urinary stoma. It needs to be remembered that each kidney contains many more nephrons than are required to sustain life, thus significant renal damage can occur without any obvious symptoms [2]. Diseases of the urinary system that can occur include cancer of the bladder, overactive bladder, neurogenic bladder, renal stones, radiation cystitis, interstitial cystitis and kidney agenesis. Bladder cancer will be considered separately in Chap. 8. Additionally, other diseases can contribute to kidney disease, such as diabetes.

Acute Kidney Injury

Acute kidney injury (AKI) was previously termed acute renal failure [3]. AKI can be described as deterioration in renal function. This can be detected by an acute fall in glomerular filtration rate (GFR), resulting in substances that are usually removed from the blood and excreted via the kidneys not being removed from the circulating blood supply. There can be a number of reasons that an AKI can occur including kidney disease or an obstruction [2]. An AKI will result in a rapid increase in urea and creatinine, as well as oliguria. This may result in fluid overload, metabolic acidosis and hyperkalaemia (high potassium levels). When an AKI occurs following surgery this is usually due to fluid depletion, sepsis or drug toxicity [2]. AKI can also occur in people with a high output of their faecal stoma (see Chap. 12). People with known renal impairment, hypertension and diabetes are at risk of developing an AKI. Without the usual excretion of substances from the blood, such as potassium, it is possible that the combination of hyperkalaemia and severe acidosis can result in cardiac arrest. Thus potassium intake needs to be restricted. Within the hospital setting, careful monitoring of fluid input and output is necessary and oxygen may be needed. Treatment may include increasing oral or intravenous fluids, if the cause is an infection, antibiotics may be necessary.

Benign Prostatic Hypertrophy

Benign prostatic hypertrophy is a non-cancerous enlargement of the prostate gland. In men benign prostatic hypertrophy or an enlarged prostate can result in urinary dysfunction. Symptoms that men with an enlarged prostate report include; a poor stream of urine, frequency of passage of urine and nocturia; the latter is passage of urine at night. It should be noted that these symptoms can also be indicative of a urinary infection. Conservative treatment is often used to address symptoms such as reducing oral fluids in the evening. In addition it can be useful to limit consumption of alcohol, caffeine, carbonated drinks and artificial sweeteners; if conservative measures are ineffective medication may be necessary [3].

Chronic Kidney Disease

Chronic kidney disease is the result of progressive loss of nephrons. Initially there are no symptoms but as the disease progresses there can be accumulation of waste products within the blood, with symptoms that can include hypertension, anaemia, oedema and polyuria. Conservative treatment aims to control issues such as hypertension or high cholesterol through medication and by making dietary changes. If symptoms progress renal dialysis [3] or renal transplant may be necessary.

Congenital Abnormalities

There are a number of congenital kidney abnormalities. Kidney agenesis is the absence of one or both kidneys [3]. If only one kidney is present there is a risk that this kidney may become damaged, however, it will potentially function normally if disease is not present. Other abnormalities include multiple ureters or urethral abnormalities. Treatment will depend upon symptoms.

Hydronephrosis

Hydronephrosis is swelling of the kidney. Hydronephrosis is the result of an obstruction in the urinary tract that causes the renal pelvis to dilate due to the increased pressure exerted above the blockage. Hydronephrosis may present with renal colic, reported as severe pain, if there is a stone in the ureter for example. Treatment will depend upon the severity of symptoms, but may necessitate insertion of a urinary catheter or stent [3].

Neurogenic Bladder

A neurogenic or neuropathic bladder is an umbrella term for bladder dysfunction caused by neurological impairment [11]. Neurological conditions are associated with abnormal function of the urinary bladder and their sphincters [8]. It is possible that the condition only affects bladder function or urinary sphincter function but it is more likely to affect both.

Neurological diseases that affect bladder function include spinal cord injury (SCI), spina bifida and multiple sclerosis (MS). A spinal cord injury might occur as a result of a trauma such as an accident, where there is loss of communication between the nerves of the spinal cord and the brain. As a result this may affect how the urinary system functions. Spina bifida is a neural tube defect, where the spine and spinal cord do not develop properly within the womb resulting in a gap in the spine. People with spina bifida can have urinary or anal incontinence. Multiple sclerosis is a disease that generally progresses with time. In multiple sclerosis there is damage to the nerve cell sheaths within the brain and spinal cord potentially causing issues including problems with the urinary system.

For people with underlying neurological conditions there may be bladder related problems. An overactive bladder associated with neurological conditions is termed detrusor hyperreflexia. Overactive bladders are explained later. Alternatively, people with a neurogenic condition may have an underactive bladder termed detrusor areflexia. Detrusor areflexia results in a constant low pressure within the bladder when filling, remaining low even during voiding. Alternatively people with neurogenic bladder may have a bladder wall that is stiffer than usual, termed poor compliance [8]. The increased stiffness of the bladder walls means that as the bladder fills it is stored at higher pressures than usual. Some people with a neurogenic bladder have both detrusor hyperreflexia and poor compliance.

People with an underlying neurological condition may have urinary sphincter related problems. When there is an overactive sphincter it is termed a detrusor-external sphincter dyssynergia. In this situation the sphincter muscle contract all of the time, whereas usually the muscle contractions should reduce during voiding. A constantly contracted sphincter muscle will result in urinary retention. Whereas an underactive sphincter does not maintain adequate pressure to maintain urinary continence [8].

Treatment for these neurological conditions is usually conservative and might include intermittent self-catheterisation for people with urinary retention for example. For some people a urinary diversion may be necessary.

Nephritic Syndrome

Nephritic syndrome is a disorder of the kidney, due to damage to the glomerulus such as glomerulonephritis, which results in problems of filtering within the kidney. Glomerulonephritis may occur as a result of diabetes or bacterial endocarditis. Glomerulonephritis may be acute, chronic or asymptomatic. When symptoms do occur people can present with oedema of the face or legs. Conservative treatment for nephritic syndrome is to reduce the dietary intake of sodium, potassium and fluid and it might also be necessary to control blood pressure and inflammation. Kidney dialysis might be necessary in cases when kidney function is severely compromised.

Nephrotic Syndrome

Nephrotic syndrome occurs due to damage to the glomerular filter that results in increased permeability to albumin [3]. This additional permeability enables large molecules such as albumin to pass out of the body in the urine; potentially resulting in proteinuria, low serum albumin, tissue oedema and hypercholesterolaemia. Oedema is perpetuated by the loss of sodium, as well as water retention in peripheral tissues. Nephrotic syndrome can lead to further complications such as immunosuppression which increases the risk of infections and blood clots. Treatment of the underlying cause is needed such as using an ACE inhibitor (angiotensin-converting enzyme) to reduce proteinuria [3].

Overactive Bladder

For people with an overactive bladder the bladder does not function normally. An overactive bladder is a collection of symptoms that include urinary urgency, urinary incontinence, frequency of urination as well as passing urine at night [8]. Instead of the muscle wall of the bladder (detrusor muscle) being relaxed as the bladder fills, the muscle will intermittently contract. Thus, instead of the bladder pressure being low as it fills with urine, for people with an overactive bladder the increased pressures can lead to an unintentional passage of urine. The prevalence of overactive bladders increases with age. Treatment can include pelvic floor retraining, such as biofeedback. Additional factors that can improve symptoms of an overactive bladder include modifying fluid intake as well as avoiding beverages that irritate the bladder such as caffeine, alcohol and carbonated drinks. If these conservative measures are ineffective there are medications, which include anticholinergic drugs that may be of use [8].

Pyelonephritis

Acute pyelonephritis is a bacterial kidney infection resulting in inflammation of the kidney or the renal pelvis. Acute pyelonephritis can occur as infection ascends from the lower urinary tract to the kidney; affecting one or both kidneys. Alternatively there may be spread such as from septicaemia or infective endocarditis. Pyelonephritis can present with nausea, vomiting, pyrexia, flank pain, bacteria in the urine (bacteriuria), white blood cells in the urine (pyuria) as well as an increased white cell count [8]. Treatment in uncomplicated cases is usually antibiotics and increased oral fluid intake.

Renal Stones

Renal stones are the formation of crystals within the renal pelvis. Stones are formed from a number of substances such as uric acid. The lack of oral fluid consumption is a significant cause of renal stone formation. Alternatively, when the pH of urine is persistently alkaline and is associated with a urinary infection there is a risk of renal stones [8]. When the pH is below 6 in the presence of stones, the stones are more likely to be formed from uric acid. Whereas if the pH is above 5.5 when stones occur they are more likely to be formed from calcium phosphate. Renal stones are usually symptomless until they move from the renal pelvis into the ureter and at this point renal stones can cause intense flank pain that can radiate to the groin as a result of them causing an obstruction in the ureter [2]. The pain will fluctuate in intensity and may also be associated with dysuria. Treatment will depend upon the cause of the stone; symptoms will resolve once the stone has passed. Observation and adequate analgesia are necessary.

Urinary Incontinence

Urinary incontinence is the unintentional passage of urine. There are two main types; stress and urge incontinence.

Stress incontinence is associated with an increase in intra-abdominal pressure such as a cough or sneeze. Stress incontinence is more common in women than men. There are a number of reasons that stress incontinence may occur; weak pelvic floor muscles, weak sphincters, childbirth and surgery on the prostate for example. Pelvic floor exercises/biofeedback may be used to improve muscle function [7].

Urge incontinence occurs when the urge to urinate is too strong for the sphincter muscles. Urge incontinence may occur as a result of an overactive bladder, damage to the nervous system, inflammation or infection. Treatment relates to the cause of the urge incontinence.

Urinary Tract Infections and Inflammation

Urinary Tract Infection

A urinary tract infection (UTI) encompasses a variety of infections. Bladder infection/inflammation is termed cystitis, infection of the kidney is pyelonephritis, an infection of the ureter is ureteritis and finally an infection of the urethra is urethritis [8]. As urine should be sterile it is abnormal to see bacteria in the urine, termed bacteriuria. Women are more prone to UTIs than men due to having a shorter urethra; organisms, for example, from the bowel can enter the urethra and travel up the urinary system. Women have a 50% lifetime risk of experiencing at least one UTI [8]. Women are more likely to have a UTI if pregnant, sexually active or menopausal. People are more likely to have a UTI with increasing age, diabetes mellitus, if they have previously had a UTI with any urinary stone, if there is a malformation of the genitourinary tract, if there is an indwelling urinary catheter or if there are voiding problems such as caused by an obstruction [8].

Inflammation of the bladder or urethra that has resulted from an infection can present as frequent voiding of small volumes of urine, associated with urgency and discomfort on micturition (dysuria). There might also be offensive smelling urine, pain in the suprapubic area, blood in the urine (haematuria), pyrexia or urinary incontinence [8]. Lower urinary tract infection is restricted to the bladder and urethra, thus someone with an ileal conduit cannot have a lower urinary tract infection. An upper urinary tract infection affects the kidneys and ureters and can cause permanent kidney damage, so should be appropriately addressed. Antibiotic treatment is effect for simple UTIs.

Bladder Pain Syndrome (Interstitial Cystitis)

Bladder pain syndrome is the more recent term for what was previously called interstitial cystitis. A diagnosis of bladder pain syndrome is made by exclusion of other diagnoses. Bladder pain syndrome is characterised by pelvic or bladder pain as well as urgency, frequency and nocturia, but aetiology is unknown. Treatment can be bladder retraining and in rare situations treatment may include the formation of a urinary diversion [11].

Radiation Cystitis

Radiation cystitis is damage incurred to the bladder during pelvic radiotherapy such as to treat cancer of the prostate, rectum, cervix or uterus. The damage may be to the bladder and/or sphincters. The symptoms that can be associated with radiation cystitis include urinary incontinence, bleeding, poorly compliant bladder or painful sensations as the bladder fills [11]. Medical management is usually the first treatment option but a urinary diversion such as an ileal conduit formation may be necessary.

Diabetes and the Renal System

Diabetes is a disease that occurs when the body is unable to either produce or respond appropriately to the hormone insulin. Insulin is necessary to metabolise carbohydrates and if there is no insulin or an altered response to insulin, the result is an elevated blood glucose level.

Diabetes is the largest contributor to end-stage renal disease. Diabetes accounts for about a third of the cases of end-stage renal disease, which occurs in up to half of people with diabetes [2]. When changes to the kidney occur as a result of diabetes, this is termed diabetic nephropathy. Kidneys can enlarge and glomerular filtration rate (GFR) can increase as a result of increased pressures within the kidney. Increased pressure results in more water and substances passing through the filters within the kidney. This in turn means that there is an increase in urine formation. Also, as kidney disease progresses there can be protein detected in the urine although this might not be detectable on a urine dipstick test. As the renal disease progresses further it is likely to include hypertension, proteinuria noted on a dipstick test and a decline in the GFR. It is possible that people with severe proteinuria will develop nephrotic syndrome. People with nephropathy will generally also have retinopathy and hyperlipidaemia. This progression from proteinuria to end-stage renal disease takes up to 20 years to occur. However, death for people with diabetes and end-stage renal failure is usually from cardiovascular disease rather than the renal disease [2].

Conclusion

The urinary tract performs a number of different functions. The kidneys filter the blood to remove toxins. Additionally by filtering the blood the kidneys help to maintain the constituents of the blood within levels that enable the body to function optimally and maintain homeostasis. Finally, there is secretion of hormones and elimination of urine. The urinary tract can function even when diseased but it is important to enable good health by encouraging patients to take care of themselves holistically. Specific advice can be to drink appropriate volumes to enable the kidneys to perform their roles. As a Specialist Stoma Care Nurse (SSCN), having a detailed knowledge and understanding of the anatomy and physiology of the urinary tract is fundamental to ensure that the care of stoma patients is underpinned with a sound theoretical framework, enabling the Specialist Stoma Care Nurse (SSCN) to critically evaluate disease processes and treatments within their specialist field. This advanced level of knowledge leads to proactive management of patients and an intuitive recognition of potential complications or any deviations from a normal treatment trajectory which may occur.

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Urological Cancers

8

Diane Leach

Learning Outcomes

1. At the end of the chapter you will have an understanding of disease patterns in urological cancers.
2. Know the rationale for the different treatment options.
3. Be able to support patients through their decision making process giving them informed choice.
4. Understand how genetics affect a person's risk factors and how treatment can be personalised to that individual.

Cancer Pathways and Treatment Options

Urological cancer pathways and their treatments are based on the national guidance and recommendations, such as the European Association of Urology (EAU) [1] and National Institute for Health Care and Excellence (NICE) [2]. There are other associations that also promote high standards of care of urology patients, such as the British Association of Urological Surgeons (BAUS) [3], British Uro-oncology Group (BUG) [4], British Association Urological Nurses (BAUN) [5] and the urology site specific clinical reference group (SSCRG) [6]. Some regional areas produce their own local guidance based on their location.

As recommended by NICE [7], any patient presenting with symptoms such as haematuria that raise suspicion of a urological cancer should be referred to secondary care and have an appointment for review within two weeks.

It is also recommended that:

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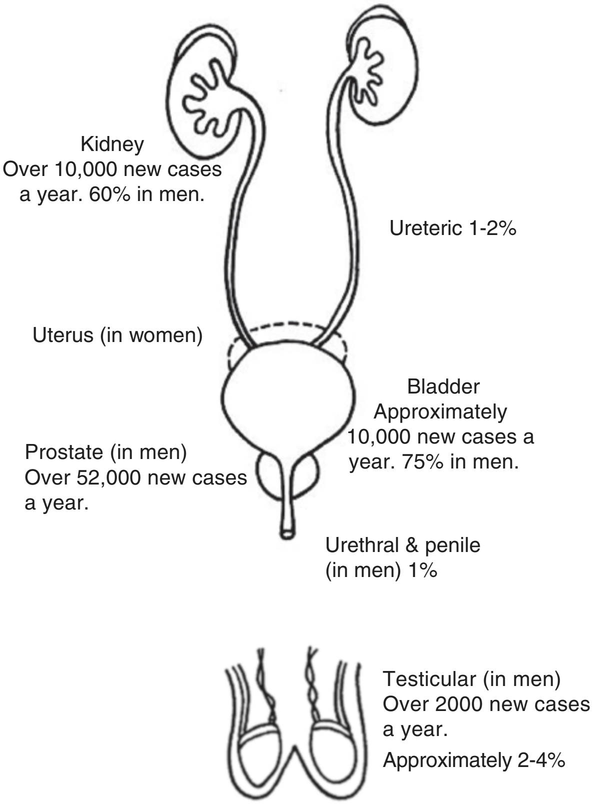
- Any patient with a urological cancer should be managed by dedicated specialist multidisciplinary cancer teams (MDTs). The patient's investigations and case notes should be reviewed using protocols agreed throughout each cancer network.
- Patients should be certain of a prompt diagnosis and treatment pathway with streamlined services to help minimise delays.
- The patient can make an informed choice by having the knowledge of treatment options supported by a clinical nurse specialist (CNS).
- There is improvement in the management of patients for progressive and recurrent disease.

Urological cancers are found in the urinary tract (bladder, ureter and kidney), prostate and the male reproductive system. Prostate, kidney and bladder cancers are the most prevalent urological cancers, with the incidences compared with other urological cancer shown in Fig. 8.1. Penile cases are rare with only 500 new cases diagnosed in the UK in a year [8].

Fig. 8.1 Location of urological cancers with their prevalence in the UK [8]



Prostate Cancer

Prostate Cancer is the most common type of cancer in men. More than 52,500 men were diagnosed in the UK between 2016–2018 according to Cancer Research statistics, with the number of patients rising each year [9]. Health screening and health promotion (looking for cancers before someone has symptoms) with blood tests, genetic screening and magnetic resonance imaging (MRI) is effective in detecting the cancer in its early stage. There is some controversy however regarding screening due to the anxiety it can cause and the undertaking of potential unnecessary procedures [10]. Patients need to have counselling regarding the implications of having tests with the potential of receiving an early cancer diagnosis which requires no immediate intervention. This situation can lead to a period of uncertainty for the patient.

Although the number of patients diagnosed with prostate cancer is rising, there is a 78% survival rate with more patients living with the cancer rather than dying from it [11].

Historically, someone may have been referred for further diagnostic tests following a routine digital rectal examination (DRE) in which the prostate felt abnormal alongside a raised blood test to measure the prostate specific antigen (PSA). PSA results vary depending on the individual and a raised result does not always indicate cancer [12] A number of factors can alter the PSA parameters, for example, a PSA goes up with age [13].

An enlarged prostate or inflamed prostate can also give a higher PSA reading, likewise, anyone who has had direct pressure on their perineal area, such as some exercises at the gym or bike riding, can cause a rise in the PSA level [14]. A significant analysis of the patient's history to help with the diagnosis is therefore crucial. A patient risk is 2–3 times higher than the average risk when they have a first degree relative with prostate cancer [15]. Genetics also play a role as, it has been found that African American men are more prone to a more aggressive form of prostate cancer and symptoms should be treated with a high level of suspicion [16]. A prostate biopsy may also be necessary if the PSA measurement is high.

The prostate biopsies are interpreted using a microscope and are graded. Each biopsy is given a grade between 1–5, based on how aggressive the cells appear. The closer to 5 indicates that the cells have mutated so much that they no longer resemble normal cells. An overall Gleason Score grade is obtained by adding together the two most common Gleason grades. The two numbers added together give the Gleason score, for example, 4 + 3 = 7. A Gleason total score of 6 is classed as a low grade tumour, 7 is classed as a medium grade tumour and 8, 9 and 10 classed as high grade tumours [17] (Table 8.1).

Another tool that is used for prostate cancer diagnosis to determine the degree of spread is by staging the tumour, nodes and metastasis (TNM staging system), whereby the prostate tumour is staged 1–4.

T1 = only detected on a biopsy—not visible or detectable.
T2 = organ confined disease (detectable on DRE).

Table 8.1 Prostate cancer grading—histopathology [18]

Biopsy Grade:	Cell appearance under the microscope
1 small, uniform cells. Normal prostate tissue	1 & 2 well differentiated
2 have more stroma between glands.	
3 distinctly infiltrative margins.	3 & 4 moderately differentiated
4 irregular masses of neoplastic gland	
5 only occasional gland formation.	5 poorly differentiated or Anaplastic

T3 = moved out from the prostatic capsule.
T4 = Fixed or invades adjacent organs.
NO = no nodes
N1 = regional lymph node metastases.
M0 = no metastatic disease
M1a = Non regional lymph nodes.
M1b = Bone metastasis.
M1c = other sites.

Treatment is based on the Gleason score [17], grading, staging and PSA level.

Treatment Options

- Surgery—Complete removal of the prostate for organ confined disease. This can be done robotically, laparoscopically or as an open procedure (see Chap. 9 for surgical procedures).
- Radiotherapy (External beam radiation) usually about 7–8 weeks of treatment with neoadjuvant androgen deprivation therapy (ADT).
- Brachytherapy (radioactive pellets)—one treatment.
- Focal tumour treatments such as cryosurgery or high frequency ultrasound (HIFU).
- Active surveillance—For patients with a low grade low volume disease. The patient will have frequent monitoring with PSA blood tests, possible repeat MRI and biopsies until the cancer starts to advance.

A patient’s risk factor can also be determined by the biopsies looking at the genetic makeup of the tissue. If a patients’s biopsy is benign but the PSA continues to be high the biopsy can be analysed to look at the DNA sequencing and determine the person’s risk of developing a cancer.

Recurrent prostate cancer is when the cancer has returned after treatment. Prostate cancer may recur within the same area, known as local recurrence or metastasised to another organ. This is usually detected by a rising PSA or localised symptoms. There are various second line treatments available, such as chemotherapy, hormone therapies, radium 223 and clinical trials.

Bladder Cancer

Aside from prostate cancer, bladder cancer is the most prevalent urological tumour. In the United Kingdom, bladder cancer is amongst the top 10 most common forms of cancer, eighth common in men and 11th in women [8]. Unlike prostate cancer there is less media coverage leading to a lack of public awareness and research funding. Consequently, there has been little change in treatment management and survival rates in the last 20 to 30 years.

Urothelial cancer, also known as transitional cell carcinoma (TCC), is the most common type of bladder cancer which results in 90% of urological malignancies identified [19]. Bladder cancers of this type start in the inner lining of the bladder, the mucosa and are capable of spreading either in an ascending direction involving the ureter and kidney, or take a downward route, involving the urethra and penis [20].

A urothelial cancer that originates in the kidney, although less common, is similarly capable of spreading in an antegrade direction involving the ureter and bladder. Early diagnosis and treatment are key to a better prognosis with these bladder cancers. The cancer stage at diagnosis is also an important factor that affects cancer outcomes, therefore health promotion and public awareness is paramount. On average patients with bladder cancers diagnosed at Stages 1 and 2 rather than stages 3 and 4 have a better prognosis [18] (see Table 8.2).

Statistics show that a higher number of men than women are diagnosed with bladder cancer. Risk factors include smoking, occupational exposures to certain chemicals and older age [21].

Any person presenting with symptoms such as haematuria that would lead to suspected urothelial cancer should be referred for review by a specialist urology secondary care team with an appointment given within a 2 week period [1]. A cancer diagnosis can be treated more successfully if caught at an early stage with a better prognosis.

Symptoms of urological cancers include:

- Painless visible or non-visible haematuria, with or without an infection.
- Persistent haematuria or recurrence after treatment for a urinary tract infection.
- Lower urinary tract symptoms (LUTS), such as frequency, urgency and pain when passing urine (dysuria). These symptoms may present with increased white cell count found on a urinalysis.
- Flank, supra pubic or pelvic pain.
- Unexplained fatigue or weight loss.

Table 8.2 5-year survival of bladder cancer patients diagnosed at each stage in England

Stage I	80 out of 100 people (80%)
Stage II	45 out of 100 people (45%)
Stage III	40 out of 100 people (40%)
Stage IV	10 out of 100 people (10%)

Investigations

If bladder cancer is suspected, a cystoscopy and transurethral resection of the bladder tumour (TURBT) should be performed within 31 days based on cancer guidelines. Depending on the patient's symptoms and presentation, a Computerised Tomography (CT) urogram +/− a CT/ magnetic resonance imaging (MRI) staging scan may be performed before the TURBT.

Other investigations would include blood tests, cytology using florescence in situ hybridization (FISH) and nuclear matrix protein (NMP22), x-ray of the kidneys: (CT) urogram if not already performed and a CT chest for staging. However, multiparametric magnetic resonance imaging (mpMRI) for bladder cancer is not advocated for all patients with bladder cancer, but may be useful to differentiate between a T1 and T2 bladder cancer or to determine response to chemotherapy and systemic approach [22, 23].

An MRI and positron emission tomography (PET) /CT provide superior sensitivity compared to CT for detection of positive lymph nodes in bladder cancer prior to cystectomy [24].

Consideration into performing a flurodeoxyglucose (FDG) PET-CT for people with muscle invasive bladder cancer (MIBC) or high risk non muscle invasive bladder cancer (NMIBC) should be made before radical treatment [25].

Histology

The sample tissue from the bladder resection is studied by the pathologist to determine if it is Non muscle Invasive (NMI) or Muscle Invasive (MI). Cancer cells lose their differentiation, therefore samples with a higher degree of undifferentiation present a poorer prognosis. The cancer cell is staged, graded and assessed for their risk of recurrence and progression (risk stratification). Candidate markers like carbonic anhydrase 9 and fibroblast growth factor receptors 3 (FGFR3) can predict how likely the tumour is to progress.

Bladder Cancer Staging and Grading: Pathology

A TNM system, similar to prostate cancer is used to stage bladder cancer [26], whereby:

- T—Tumour growth and it has invaded into the surrounding tissue.
- N—If any of the nearby lymph nodes are affected.
- M—If the cancer has spread to other parts of the body (metastasised).

The staging of the cancer determines how invasive the tumour is and indicates the patient's overall prognosis. See Fig. 8.2.

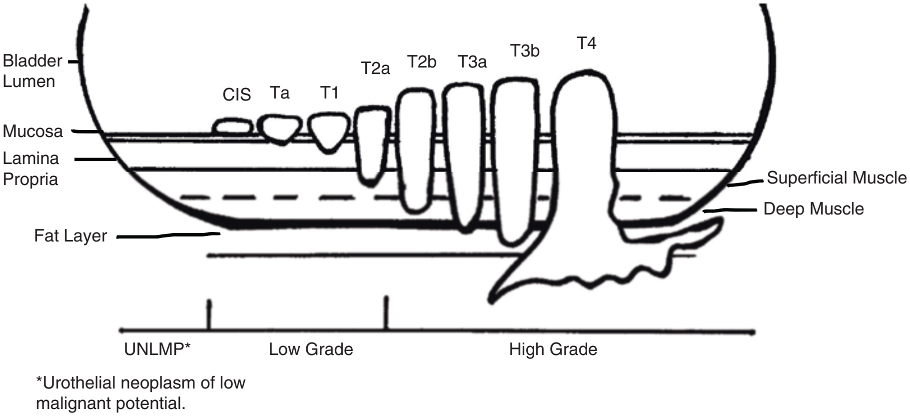


Fig. 8.2 Bladder cancer staging and grading [26]

Table 8.3 Bladder Cancer grouping [27]

Non muscle invasive (NMI)	Tis, Ta or T1
Muscle invasive (MI)	T2 or T3—penetrate muscle and fat layer but still contained within the bladder.
Locally advanced	T4
Advanced	T4—spread to lymph, liver, lung or bones.

T1, **TA** or **CIS**—used to stage non-muscle invasive (NMI) cancer which make up approximately 75% of bladder cancer cases.
T2—has gone through into the muscle layer.
T2a—superficial muscle.
T2b—deep muscle.
T3—has penetrated through the muscle layer and into the fat wall.
T3a—micro-invasion of fat layer.
T3b—macro-invasion of fat layer.
T4—The cancer has spread to adjacent organs such as the prostate in men and the vagina in women. T4 can indicate local spread, haematogenous spread or lymphatic.

Bladder staging is categorised into four main groups, as shown in Table 8.3.

There are three grades of bladder cancer depending on how aggressive the tumour is and how likely it is to grow and spread.

These are classed as:

- **Low risk NMI**—These are low grade, small solitary tumors.
- **Intermediate Risk**—These can be recurrent low grade tumors, multiple tumors/ Ta lesions or Ta >3 cm and high grade.

- **High Risk**—This includes any high grade tumor growing past the urothelial layer or a recurrent high grade tumor. Any tumor that is over 3 cm or multiple high grade Ta Tumors at diagnosis.

  TIS/CIS is automatically graded as high likewise, recurrent tumours after Bacillius Calmette-Guerin (BCG) induction (immunotherapy) therapy or BCG failure and tumours with a variant histology (more rare), for example, micropapillary, sarcomatoid, neuroendocrine, squamous differentiation or Local Vascular Invasion.

  Some of these variant tumours and where there is prostatic or urethral involvement are more difficult to stage.

Rarer bladder cancer types like squamous cell cancer and adenocarcinoma are less common forms of bladder cancer and are usually more invasive. Some of these variants can metastasise without local invasion.

Squamous cell cancers can be linked with repeated urinary tract infections and untreated bladder stones. This can be more common in people who are paralysed due to an injury of their spinal cord or the use of long term indwelling catheter increasing their risk of infection. Patients with bladder diverticulae may also be at risk due to stagnant urine that could irritate the bladder mucosa. Management for these cancers is less clear and radical cystectomy remains the mainstay of treatment to date [28].

Treatments

Treatments are tailored to the individual depending on the staging and grade of their tumour, therefore the quality of the biopsied tissue sample is important. The tissue needs to include the muscle layer to enable a full assessment.

If an inadequate tissue sample is obtained for example, there is no muscle layer present after the first resection, then a repeat TURBT will need to be performed.

Bladder cancer management focuses on whether the tumour is non-muscle invasive (NMI) or muscle invasive disease (MI). A single dose of intravesicular chemotherapy such as, mitamycin C may also be given at the time of cystoscopy and TURBT [28].

The TURBT is performed via a cystoscopy under a general anesthetic and the resected bladder cancer tissue is sent to pathology for staging to determine whether the tumour is non-muscle invasive (NMI) or a muscle invasive bladder cancer (MIBC).

Non Muscle Invasive Bladder Cancer: NMIBC

Low risk bladder cancer may simply require a TURBT and single dose of chemotherapy in the bladder following surgery to induce a cure.

Patients in the intermediate risk group have a higher recurrence rate than the low risk patients but still have a low risk of progression. The aim of treatment is to reduce the recurrence rate by 20–50%. BCG is given 3–4 weeks after TURBT with 6 weekly treatments. They have a maintenance course at 3 months with 3 weekly instillations and then a second maintenance course 6 months from induction. This has been a challenge, however with BCG shortages in recent years. Subsequent maintenance doses are given every 6 months for 2–3 years based on their risk.

Patients in a higher risk group have a greater risk of progression. Treatment therefore, is aimed at reducing the recurrence rate and more importantly progression to more advanced disease. They may need a repeat TURBT especially if no muscle was present in the original specimen and they may have further intravesical chemotherapy or cystectomy.

BCG

BCG is an immunotherapy intravesical treatment given over 6 weeks and has been the main stay treatment for high risk NMICs since 1976 [29]. However, patients on immunosuppressant drugs or steroids may not benefit from BCG. Intravesicular chemotherapy can be used but has a slightly lower effectiveness than BCG in terms of cancer recurrence and progression. If the cancer recurs there are a number of treatment possibilities. The patient can have another induction of BCG treatment or another intravesicular chemotherapy treatment.

Alternatively, another checkpoint inhibitor such as pembrolizamab can be used which targets the programmed cell death (PD-1) protein. This has been approved by NICE (2021) to treat bladder cancers that have been unresponsive to BCG treatment and the patient is not fit for or has decided not to have surgery. The approval was based on the efficacy data from the KEYNOTE-057 trial [30]. Further trials using checkpoint inhibitors are ongoing.

Although the mainstay of treatment, some patients do not respond and are known as BCG failures. BCG failures can be categorized into:

- BCG relapsing—This is where the tumour returns after 6 months disease free survival.
- BCG intolerance—When the treatment was stopped before the adequate amount was given usually due to toxicity.
- BCG refractory—If the tumour has returned and disease free survival is not achieved 6 months after initial treatment or 3 months if retreated
- BCG resistant—If the disease is still evident at 3 months, although improved but resolves after 6 months.

Patients with BCG failure have a 50% rate of progression to metastasis. For patients diagnosed with a high risk bladder cancer, a radical cystectomy is still gold standard treatment.

NICE have produced guidance on treatment for recurrence [28]:

Table 8.4 The incidence of recurrence and progression in NMIBC [27]

NMIBC	Recurrence	Progression
1 year	15–61%	Up to 17%
5 years	31–78%	Up to 45%

- A patient with intermediate or high risk disease that has recurrent Ta or CIS after a single course of intravesical BCG should be offered a second course.
- Patients with T1 disease recurrence after a single course of induction BCG should be offered cystectomy if they are fit for surgery.
- A patient who is intolerant of BCG or has a recurrence of high grade NMIBC and /or CIS within 6 months of two induction courses or induction BCG plus maintenance should not be prescribed further BCG treatment (Table 8.4).

Guidelines for BCG—Unresponsive patients or high risk NMIBC:

- Further intravesical BCG is unlikely to benefit patients who have not responded to initial treatment or have a new or persistent high grade recurrence at 6 months after starting. These are patients who have received at least two courses of BCG or relapsed within six months of the last installation with high grade NMIBC.
- If these patients are unfit for surgery or choose not to have a cystectomy they can be recommended for a clinical trial.

  Intravesical chemotherapy should be offered when trials are unavailable or chemo/radiotherapy can be discussed.

  Chemotherapies commonly used are Valrubicin (FDA approved), Gemcitabine and Mitomycin C.

  Modern trials showed that compared with the BCG treatment they were not so effective [31].

  Examples of chemotherapy trials are:

  – Mitogel (MMC in gel)
  – GemRISTM (gemcitabine released intravesical) and Radiofrequency-Induced Thermo-chemotherapy with MMC.

Muscle Invasive Bladder Cancer: MIBC

Patients diagnosed with muscle invasive disease will be offered neo adjuvant chemotherapy prior to a radical cystectomy and urinary diversion [32, 33]. The aim of the chemotherapy is to shrink the tumour prior to surgery and destroy any microscopic cancer cells not detected [34]. For these patients there is a narrow window of cure before the tumour can spread.

Post-surgery patients may be offered adjuvant chemotherapy to reduce the risk of the bladder cancer returning or if positive nodes or margins are identified on pathology.

An alternative to removing the bladder, or if surgery is not suitable, is a course of radiotherapy and/or chemotherapy.

Neoadjuvant immunotherapy may be offered within a clinical trial setting.

The specialist team should discuss with the patient all their treatment options, including the risks and benefits of radical surgery, chemotherapy or radiotherapy, so that they can make an informed choice. A CNS works as the advocate for the patient to ensure that the patient fully understands what they have been told and assist them with their choice.

Both NMIC and MIBC treatments are given with curative intent. The term, 'curative intent' is used because there is no guarantee of a cure or that the cancer will not return in the future. However, for the majority of patients they will remain disease free, but for a few the cancer will return.

Locally Advanced or Metastatic Bladder Cancer

Locally advanced and metastatic bladder cancer is where the cancer has spread outside of the bladder and the treatment is no longer curative. The treatment aim for these patients is to slow down the cancer growth and relieve any symptoms that the patient may experience. This is known as a palliative treatment or treatment with palliative intent.

There are various lines of treatment with chemotherapy and immunotherapy. For solid tumours there are biomarker based treatments [35]. A biomarker otherwise known as tumour genetic testing is carried out in order to profile the tumour and determine specific treatment options. Clinical trials are a good treatment option for eligible patients due to limited treatment options and should be encouraged.

The European Society for Medical Oncologists (ESMO) [36] recommend platinum based chemotherapy as first line treatment of locally advanced and metastatic bladder cancer for eligible patients in their guidelines.

NICE guidance for first line treatment licensed in the UK (NICE 2020) [2] are cisplatin and gemcitabine for patients who have a performance status of 0–1 which indicates baseline fitness and adequate renal function and combination chemotherapies, such as high dose methotrexate, vinblastine, doxorubicin and cisplatin (HD-MVAC) and a granulocyte- colony stimulating factor (GCSF).

Patients who are unable to have cisplatin and whose performance status is satisfactory (0–2) may have carboplatin and gemcitabine as an alternative.

Patients, who are unsuitable for cisplatin and are PD-L1 positive, could be offered an immunotherapy such as Atezolizumab.

For second line, treatment such as cisplatin and gemcitabine can be given to patients who have a performance status of 0–1 and adequate renal function or HD-MVAC and GCSF.

Patients who are unsuitable for cisplatin can be given carboplatin and paclitaxel or gemcitabine and paclitaxel or Atezolizumab.

Programmed cell death—lingand 1(PD-1/PD-L1) inhibitors such as pembrolizamab and atezolizumab, are licensed in the UK and are restricted to patients with high PD-L, expressing advanced urothelial cancer if they are cisplatin ineligible or following failure of platinum based chemotherapy. Some treatments are indicated for locally advanced disease; however these are not recommended by NICE, for example, Pembrolizamab for patients not eligible for cisplatin containing chemotherapy whose tumours express PD-L1.

Patients with locally advanced disease or where a tumour was unable to be resected, who also have had failure of prior platinum containing therapy, can be offered Nivolumab. Vimlurmine can also be used for patients with advanced or metastatic TCC of the urothelial tract after failure of a prior platinum containing regime.

The guidance in Scotland for immunotherapy (IO) treatments is different and local guidance should be checked.

Patients who are palliative may require treatment for symptom control, such as a temporary urinary diversion, for example if the tumour is obstructing the urinary flow or a nephrostomy can be inserted if the renal pelvis is obstructed. Palliative radiotherapy can also be given if the patient experiences bone pain, to reduce the size of a tumour that may be causing compression on nerves or soft tissue and often used to treat haematuria, which can prevent the patient requiring a blood transfusion.

Clinical Trials

Clinical trials are essential for finding improved ways to treat patients with bladder cancer and for developing new drugs.

Research trials into novel immune therapies have been introduced for patients with advanced urothelial cancer [37]. Avelumab is recommended within the ESMO guidelines [38] and has been recently approved in the UK as monotherapy for the first line maintenance treatment of adult patients with locally advanced or metastatic urothelial cancer who are progression free following platinum based chemotherapy trials such as the JAVELIN Bladder 100, investigated the role of maintenance therapies [39]. This trial demonstrated that maintenance treatment with BAENCIO (Avelumab) and best supportive care significantly prolonged the median overall survival than best supportive care alone. The drug had a manageable safety profile and harmful effects on clinically relevant patient reported outcomes.

At the American Society of Clinical Oncology (ASCO) the results of the up dated 5 year follow up of the Phase III KEYNOTE-045 trial was presented [40]. The results favoured pembrolizamab over chemotherapy in overall survival and reported minimal adverse effects.

Patient Follow Up

Even after successful treatment, bladder cancers can recur. Long term follow up is required so that if a recurrence is detected treatment can be given in a timely manner. What follow up is required will depend on the patient's initial grading and stage of cancer and what treatment was given. Patients with a high grade aggressive tumour will be on a more frequent follow up pathway than someone with a low grade less aggressive tumour. As time goes on without any signs of recurrence the frequency of the follow up reduces.

For Low Risk Disease

It is recommended by NICE [28], that the patient has a check cystoscopy at 3–4 months. If nothing abnormal is detected (NAD) the next check would be advised at 6–9 months and then yearly. It is not recommended to do any further imaging unless the patient reports any symptoms of concern, since tumours present in the upper urinary tract are rare. After a year NICE recommend patients with a low risk non-invasive bladder cancer can be discharged, however EAU guidelines extend the recommended follow up to 5 years [41].

For Patients in the Intermediate Risk Group

Follow up is with a cystoscopy and cytology 3 months after their TURBT, followed by 3–6 months for 1–2 years and then recommended yearly for life.

For Patients in the High Risk Category

For this group of patients, a more intense surveillance protocol is required.

If the patient has not had a cystectomy a cystoscopy and cytology is recommended every 3–4 months for 1–2 years, then every 6 months for the third and fourth year and yearly from 5 years. It is also recommended that they have imaging of the upper urinary tract at 1–2 years intervals. If at any point the cancer recurs the algorithm is changed accordingly.

For patients who have had a cystectomy for MIBC, it is recommended that they have a CT scan or MRI urography every 3–6 months. If metastatic disease is suspected, a FDG PET/CT (category 2b) and chest X-ray should be performed ever 3–6 months. After 3 years, patients should have an abdominal/pelvic CT or MRI annually up until 5 years. A category 2 b scan and chest X-ray is only necessary if metastatic disease is suspected. After 5 years an ultra sound scan (USS) is recommended annually to detect for hydronephrosis and after 10 years of follow up it only needs to be done if clinically indicated.

Psychological support is an important factor when caring for patients with bladder cancer and their relatives. Long-term follow up can create anxiety with the thought of the possibility of the cancer recurring; furthermore, patients with a higher stage bladder cancer have a poorer prognosis (Table 8.5).

For the purpose of a comprehensive understanding of urological cancers, the following cancers are discussed briefly. However, these cancers will rarely result in stoma formation.

Table 8.5 Bladder tumour stage with likely prognosis [35]

Tumour stage	Prognosis*
Tis	30–40%
Ta	90–95%
T1	40–75%
T2	55%
T3	25%
T4	5–10%

*percentage of patients likely to reach 5 years' survival.

Renal (Kidney) Cancer

Renal (kidney) cancer is a rarer cancer and tends to be diagnosed as an incidental finding when the patient is undergoing investigations for a different reason. Usually, the tumour is picked up on an ultrasound or CT/MRI scan [42].

Adenocarcinoma accounts for 80% of renal tumours, although, it is important to obtain a biopsy to rule out a urothelial carcinoma. Cancer of the kidney can spread either locally through the perinephric fat into adjacent organs or via the vascular system leading to spread to distant sites such as the lungs, liver, bones and brain.

The patient may have symptoms of haematuria, back pain or pains in the abdomen or flank and the tumour maybe palpable on physical examination. Other accompanying symptoms may include weight loss, fatigue, anaemia or a fever.

Risk factors include a family history, (especially if it's a first degree relative with a renal cancer), some medical conditions such as hypertension, people on long term dialysis, polycystic kidney disease and other chronic kidney diseases have also been linked to the disease. Certain analgesic medications that are used long term for example Naproxen, Celebrex, phenacetin and ibuprofen can also increase the risk together with smoking, obesity and an unhealthy diet.

Investigations

Patients with renal cancer may present with non-visible haematuria on urinalysis. Approximately 50% of patients with renal cancer have blood present in their urine. An USS can differentiate between a common cyst and a solid mass which may indicate a possible cancer. A CT scan is used to stage the cancer and identify any metastases. A biopsy is not required to diagnose renal cancer, however, if a nephrectomy is performed the tissue will be sent for histology.

In metastatic spread a biopsy can be taken from the malignant site to confirm the tumour type and to help with the decision in the plan of treatment. Blood tests are also done to check for kidney function or other signs of metastatic spread, such as raised calcium levels indicating that the cancer has spread to the bones.

Renal cell carcinoma has a similar TNM staging as bladder cancer.

Treatments

The best treatment is determined by assessing the patient's level of risk (risk stratification).

If the tumour is small and has not spread, some small low risk tumours can be observed and the patient is put on a surveillance pathway.

Surgical options involve a total or partial nephrectomy usually performed robotically or laparoscopically. Nephrectomies are performed sometimes in patients with malignant spread for symptom control, for example pain or excessive bleeding. For patients who are not well enough for surgery cryoblation or radiofrequency ablation (RFA) will be offered. Renal cancer can also be treated with targeted therapies, immunotherapy and anti-angiogenesis therapy.

From a biopsy a specific genetic mutation can be identified so that treatment is tailored to the individual for the best results.

Testicular Cancer

This cancer tends to be more common in younger men, although can also occur in older males.

Risk factors include men that have a history of having an undescended or late descending testicle, infections such as mumps or trauma to the scrotal area and having a family history slightly increases the risk.

Germ cell tumours are cells that grow from the reproductive cells. There are two main types of germ cell testicular cancer; Seminoma (GCT) and non-seminomas (NSGCT). Seminomas are the most common type of testicular cancer and carry the less risk.

Non-Seminomas can be:

- Teratoma
- Embryonal cancer
- Choriocarcinoma
- Yolk sac tumours

Patients may have a pure teratoma or present with a mixed histology, however non-seminomas are all treated the same way.

Patients usually present with a dull ache or swelling of the testes, however, occasionally the tumour can originate from elsewhere, such as the mediastinum, although these are rare.

Investigations

An USS will be performed on the testes and if there is a growth suspicious of cancer a biopsy will be taken.

Further investigations may include an MRI, CT or PET scan, also bloods to look for tumour markers—HCG and AFP (REF) although not all testicular cancer patients have raised tumour markers.

Treatments

- Surgery, such as an orchidectomy +/− peritoneal lymph node dissection.
- Chemotherapy—Carboplatin a single platinum based drug or a combination of bleomycin, etoposide and platinum (BEP) drugs are used.
- Radiotherapy.

Clinical trials are looking at the standard of care versus experimental arm in relation to overall survival and patient toxicity [43, 44].

Patients should be offered sperm banking prior to chemotherapy treatment due to potential implications for their fertility, especially if they have also had an orchidectomy.

Follow up

The follow up for these patients depends on the type and grade of cancer. A surveillance plan is draw up and bloods checked at planned times for tumour markers, HCP and AFP. Some patients will require occasional abdominal CT scans and others chest X-rays depending on their treatment pathway.

Penile Cancer

Penile cancer is a rare cancer that affects less than 1% of urological cancers in the UK. 63% are caused by an infection of the human papillomavirus (HPV) and can be prevented [45].

Symptoms

The skin of the penis and the foreskin are the most commonly affected areas of penile cancer; therefore the main symptoms are a sore or a growth on the penis which does not heal. The patient may present with bleeding or a foul smelling discharge from the penis or under the foreskin. The foreskin may become tight around the head of the penis making it difficult to retract (phimosis).

Other symptoms the patient may complain of are an ache or pain in their groin or abdomen, a swelling in the groin, a feeling of fatigue and/or unintentional weight loss.

Investigations

The main test for penile cancer is a biopsy of the affected area. Other investigations may include CT, MRI or PET scan. If there is a swelling in the groin then a lymph node biopsy may also be taken.

Treatments

As penile cancer is rare, treatment is usually given by a regional treatment centre that specialises in this type of cancer [46].

Treatment options for penile cancer include a chemotherapy cream to treatment early disease, patients may also have laser therapy, which is a powerful beam of light that can kill cancer cells or cryotherapy which freezes and kills cancer cells. Surgery may be required to remove the cancerous tissue. An alternative to surgery would be radiotherapy.

For cancer that has metastasised to other parts of the body a combination of radiotherapy and surgical lymph node dissection +/− chemotherapy maybe required.

Patients may also be eligible for clinical trials for targeted therapy or a combination of radiation therapy and chemotherapy drugs.

Genetics

Within a cancer cell there is a high rate of genetic mutations known as tumour mutation burden (TMB). A mutation is a gene that has changed and occurs in the DNA sequencing.

Genomics studies the interaction between genes and the environment, also the structure and function of the genome.

Identifying a connection with genitourinary cancers and their genetic association can assist in potential screening for disease and targeted treatment strategies [47]. Bladder cancer is not usually hereditary, however, a small number of people inherit a gene syndrome that increases their risk. Certain genetic mutations in some chromosomal genes, such as the mutation of retinoblastoma (RBI) or TP53 as well as others, can occur leading to cancers in the urinary system. Not all mutations are inherited however, and the cells can also be influenced by exposure to certain chemicals and/or smoking. Some of these can be prevented, although other risk factors like race, age, gender and personal history cannot be avoided.

Blood, tissue and bodily fluids like urine can be tested for the presence of gene mutations by using a specific molecular biomarker, or biological indicators. Researchers are looking at ways to determine a person's risk by incorporating genetic sequencing to classify tumours. With this person's risk profile, treatment can be personalised. From the Genome-Wide human array study (GWAS) it was identified that there were 40 common disease traits [48].

Through identification of the affected gene, treatments can be targeted to slow down a tumour growth and block the pathway.

Frequent FGFR3 mutations were found in NMIBC, which occur mainly in papillary disease. However, MIBC has a more diverse mutation spectrum. If the gene FGFR3 mutation is identified that patient may benefit from specific drugs [49].

Trials done with immune checkpoint inhibitor therapy favoured the patients' prognosis was improved compared to patients on standard care. In urothelial bladder cancer biopsies, TCGA researchers identified 64 significantly mutated genes. Interestingly, over half the tumours examined were taken from people who had a history of smoking. In patients that smoked the mutations in the ERCC2 gene and the ERCC2 mutation signature where more common.

Targeted therapies can treat cancer in various ways [50]:

- Assisting the immune system to destroy cancer cells.

  Cancer cells disguise themselves so that they can hide from the immune system. Certain targeted therapies affect the tumour so it can be identified by the body's immune system as foreign in order to destroy it. Other immunotherapies help to fight against the mutation by boosting the immune system.
- Stopping cancer cells from growing.

  Some targeted therapies interfere with the signal that instructs the cell protein to grow and consequently slow down cancer growth.
- Stopping signals which help form blood vessels.

  Targeted therapies, known as angiogenesis inhibitors interfere with the signal to make a new blood supply thereby preventing further growth and development. Targeted therapies can also cut off an existing blood supply causing the vessels to die and the tumour to shrink.
- Direct targeted therapies to eradicate the cancer cell

  Chemotherapy drugs, radiation and toxins are combined with a monoclonal antibody that attaches itself to the surface of the cancer cell. The cancer cell is poisoned and dies. Healthy cells are not affected because they do not have targets on their surfaces.

Conclusion

Cancers of the urinary system are complex with patients often requiring various treatments, sometimes with a combination of surgery, chemotherapy and radiation. Research has transformed the diagnosis outcomes for urology patients. With the greater understanding of tumour heterogeneity and evolvement, uro-oncology is advancing with new drugs and adaption in treatment techniques. Trials on immune checkpoint therapy have shown promising results. Due to these immune checkpoint inhibitors and use of targeted agents we are seeing an increased survival benefit in the metastatic setting. Ongoing research helps understand the sequencing of treatment offering the patient the most appropriate pathway resulting in the best patient outcomes.

All of these developments are not without challenges especially for the patient. Now that there is more treatment choice for patients this can be a cause for unnecessary anxiety. It is important therefore that patients are supported on their cancer journey by a CNS who can work as a patients advocate and can provide individualised patient centred care.

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Urological Surgery

9

Elizabeth Davis

Learning Outcomes
- Understand the different approaches to surgery and explain the rationale for each
- Describe different types of urinary diversion and the impact of the stoma for the patient
- Appreciate the post operative care for different types of urinary diversion

Introduction

Urological surgery resulting in the formation of a urostomy or ileal conduit may take many forms. In this chapter we will explore the following types of urological surgery, the indications for the surgery and the pre and post-operative care;

- Ileal conduit urinary diversion
- Simple cystectomy
- Radical cystectomy—open, laparoscopic and robotically assisted
- Types of urostomy

Background History

In 1887 the first complete cystectomy was performed in Germany by Bernhard Bardenheuser (1839–1913) but the subject died some 14 days later from complications associated with urine flowing freely into the abdomen and hydronephrosis due to the lack of a method of urinary diversion [1].

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The evolution of the cystectomy was further described by Brice and Marshall [2] when they described their experience of performing cystectomies and the outcomes of these from 1933 to 1950; at this time the ureters were commonly diverted into the sigmoid colon to form a ureterosigmoidostomy or brought to the surface of the skin to form a ureterostomy. As the earliest forms of urinary diversion these varying surgical techniques carried with them high morbidity and mortality rates particularly from sepsis, metabolic abnormalities caused by urine reabsorption, faecal incontinence and obstruction caused by high intrarectal pressures. Some improvements were made to patient outcomes by refinements to this surgical technique described by Goodwin et al. [3] and Leadbetter [4] in the 1950's.

In 1950 Eugene Bricker [5, 6] had pondered over the relative complications of the surgical options available to manage urinary output post pelvic 'evisceration' and described the development and construction of an ileal conduit diversion. This technique remains the most popular method of managing urinary output following cystectomy as it is relatively straightforward and has stood the test of time.

Modern developments and advancements in the available stoma appliances since the first urostomies were formed have also greatly improved patient quality of life outcomes.

The introduction and adoption of minimally invasive surgical techniques (MIS) in many hospital settings have significantly reduced the average length of stay and decreased overall recovery time [7] as well as reducing the incidence of perioperative complications.

Bladder cancer, both muscle invasive bladder cancer (MIBC) and high-risk non-muscle invasive bladder cancer (NMIBC) [8] remain the most common indication for the formation of a urostomy following a Radical Cystectomy (RC).

Ileal Conduit Urinary Diversion

Indication

The ileal conduit urinary diversion also known as the Bricker's loop and incontinent urinary diversion, was developed in the 1950's and remains the gold standard surgical technique used today to perform a urinary diversion primarily because it is a relatively simple procedure that most urologists are taught during their training and is the most common form of urinary diversion following cystectomy (removal of the bladder).

Patients may however, undergo a primary urinary diversion without a cystectomy being performed for a number of different reasons for both benign and malignant conditions.

Benign Indications

Urinary diversion is often considered when all other less invasive treatment modalities have been exhausted. The most common indications for performing this procedure are the preservation of renal function, reduction of recurrent infection and preventing the requirement for long term catheterisation [9, 10].

The most common indications are;

- Neurogenic conditions caused by spinal cord trauma, acquired disorders or congenital aetiologies. These include;
  - Spinal cord trauma as a result of traumatic injury
  - Congenital disorders including; Spina bifida, spinal dysraphism, dermoid cyst, bladder exstrophy
  - Acquired disorders secondary to disease; Multiple Sclerosis, diabetes mellitus and inflammatory processes.
- Intractable urinary incontinence in women
- Chronic pelvic pain syndromes
- Painful Bladder Syndrome (previously known as Interstitial Cystitis)

Indications with Malignancy

As with benign conditions the decision to perform a primary urinary diversion on a patient with a malignant condition will only be undertaken when all other conservative treatments have been exhausted.

Unfortunately, many radical treatments for pelvic cancers can result in irreparable damage to the bladder tissues and function.

The most common indications for primary urinary diversion are:

- Severe lower urinary tract symptoms (LUTS) associated with inoperable cancers, such as bladder pain, frequency and urinary incontinence
- The presence of a vesico-vaginal fistula resulting in urinary incontinence and recurrent infection, unless an adequate vaginal repair can be performed
- Severe radiation injury to the bladder

A urinary diversion may be carried out when a patient is found to have an inoperable bladder tumour at the time of surgery to allow for radical treatments to take place particularly when the patient already has severe LUTS that would significantly impact on their overall quality of life [11].

Ileal Conduit Formation: Surgical Procedure Description

As described by Bricker in 1950, a section of terminal ileum is selected close to the ileal caecal valve and approximately 15–20 cms is resected along with the mesentery to preserve blood supply and function (Fig. 9.1).

The terminal ileum is responsible for the reabsorption of vitamin B12 so the minimum amount is taken to preserve this vital function. When Bricker first described the procedure a longer segment was usually isolated; however this led to the formation of static reservoirs of urine which caused increasing and repeated infections.

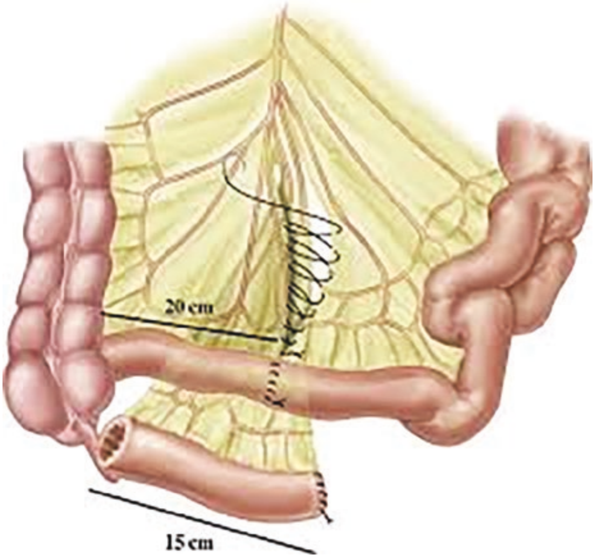

Fig. 9.1 Dissected section of terminal ileum on mesentery. https://doi.org/10.1016/j.eursup.2010.09.001 (with permissions from Colombo R, Naspro R. Ileal. Conduit as the Standard for Urinary Diversion After Radical Cystectomy for Bladder Cancer. European Urology Supplements: Volume 9, Issue 10, December 2010, Pages 736–744). (Colombo R, Naspro R. Ileal Conduit as the Standard for Urinary Diversion After Radical Cystectomy for Bladder Cancer. European Urology Supplements: Volume 9, Issue 10, December 2010, Pages 736–744. https://doi.org/10.1016/j.eursup.2010.09.001)

The remaining ends of the ileum are re-joined forming a ***primary bowel anastomosis.***

The segment of ileum is then mobilised as shown on diagram 1 and orientated in the natural direction of peristalsis of the bowel or the isoperistaltic direction. The proximal end of the segment is closed and the resected ureters are then implanted into the segment.

There are differing methods of ureteric anastomosis, Bricker describes the implantation of each ureter separately into the bowel segment as shown in Fig. 9.2.

However, in 1970 Wallace [12] described an alternative method known as the Wallace I where, the ureters are spatulated, that is divided and opened up, then sutured together side by side to form a ‘single’ ureter which is then sutured to the open end of the bowel segment as demonstrated in Fig. 9.3. A Wallace II anastomosis involves spatulation of the ureters which are then sutured together end to end before being anastomosed to the open end of the bowel segment.

The distal end of the bowel segment forms the stoma which is brought to the skin at a predetermined marked area on the skin (see Chapter on siting 11) through the lateral aspect of the rectus abdominis muscle and anchored to the abdominal wall.

The resulting stoma should protrude approximately 2–3 cms above the skin and be without tension.

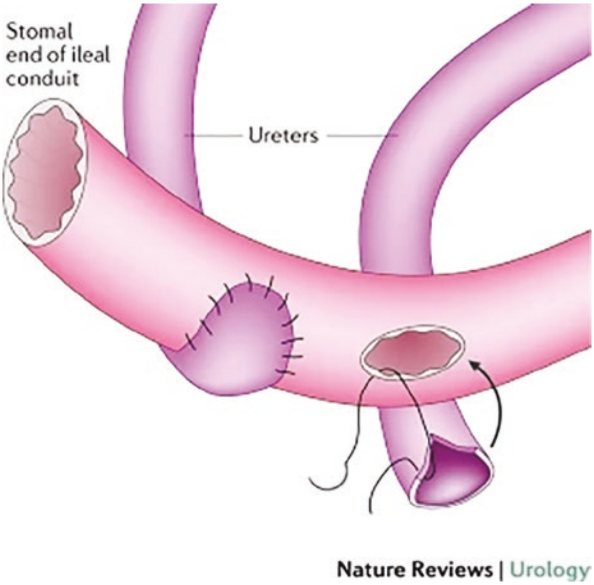

Fig. 9.2 Bricker implantation (with permissions from Lobo, N., Dupré, S., Sahai, A. et al. Getting out of a tight spot: an overview of ureteroenteric anastomotic strictures. *Nat Rev Urol* **13**, 447–455 (2016). https://doi.org/10.1038/nrurol.2016.104). (Lobo, N., Dupré, S., Sahai, A. et al. Getting out of a tight spot: an overview of ureteroenteric anastomotic strictures. *Nat Rev Urol* **13**, 447–455 (2016). https://doi.org/10.1038/nrurol.2016.104)

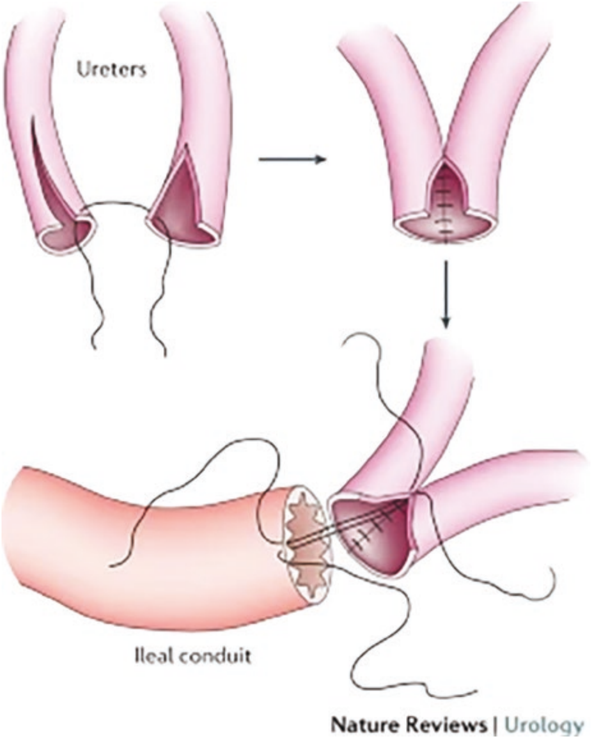

Fig. 9.3 Wallace I (with permissions from Lobo, N., Dupré, S., Sahai, A. et al. Getting out of a tight spot: an overview of ureteroenteric anastomotic strictures. *Nat Rev Urol* **13**, 447–455 (2016). https://doi.org/10.1038/nrurol.2016.104). (Lobo, N., Dupré, S., Sahai, A. et al. Getting out of a tight spot: an overview of ureteroenteric anastomotic strictures. *Nat Rev Urol* **13**, 447–455 (2016). https://doi.org/10.1038/nrurol.2016.104)

Ureteric Stents

Ureteric stents are placed inside the ureters during the procedure, secured using dissolvable sutures to protect the ureteric anastomosis during the initial healing phase. The number of ureteric stents correspond to the number of ureters present, for example patients with a single kidney would naturally expect to have a single stent and those with two kidneys, the corresponding two stents. However in patients with duplex kidney systems where they may have one or more complete ureters per kidney the patient may have multiple stents in situ.

Ureteric stents are not usually a permanent feature and are removed post operatively according to surgical preference although this is usually at or around day 10 post op [13]. Stents may be trimmed to facilitate easier pouch changes, however care must be taken not to trim them too short—due to peristaltic action of the bowel segment they may be drawn into the stoma out of sight.

Whilst still attached to the bladder the ureters have a one way valve that prevents urine from refluxing back into the ureter as the bladder contracts to empty however, once the bladder has been removed the ureters no longer possess this valve thus allowing some refluxing of urine back into the ureters in the direction of the kidneys. The presence of the stents within the ureters also bypasses the normal downward peristaltic action of the ureters that transports the urine away from the kidneys.

Prior to stent removal patients should be instructed to ensure that they remain well hydrated to reduce the opportunity for naturally occurring bacteria found within the bowel segment used to create the stoma, ascending toward the kidneys. Some urologists may suggest a stentogram is performed before stents are removed, but it is not a routine procedure in all centres. Following stent removal, it is important to review the patient within 48 hours as it is not uncommon for them to have developed a urinary tract infection (UTI) due to the presence of bacteria from the bowel segment that will always be present in the urine.

The use of prophylactic antibiotics in reducing the incidence of UTI post stent removal has not been fully proven, but however remains custom and practice by many surgeons.

It is important however to remember when antibiotics are prescribed that they are appropriate to treat an upper urinary tract infection, a **pyelonephritis,** and not those for a lower urinary tract infection particularly following a cystectomy.

Patients should be instructed to seek advice should they fail to pass urine, develop pain or note a sudden increase in the amount of fluid loss urethrally within an hour of having the stents removed.

Anuria and pain may signify an obstruction within the ureters and a sudden increase in fluid loss may be caused by an anastomotic leak.

Guidance on the management of stent removal can be found on the ASCN website and as part of the clinical guidelines [14].

Turnbull Loop Ileal Conduit

In patients with high body mass index and significant layer of adipose tissue it may not be possible to form a traditional stoma as it would potentially increase the risk of tension on the mesentery resulting in an increased likelihood of ischemia which may lead to stenosis of the stoma. Selecting a longer bowel segment may lead to pooling of urine and also increases the possibility of further electrolyte absorption [15].

The Turnbull Loop stoma as demonstrated in Fig. 9.4a shows how the bowel segment is brought to the skin surface and both ends of the segment are closed, with the ureters anastomosed using a Bricker method.

One completed it will have the appearance of a loop colostomy or flush loop ileostomy. Figure 9.4b.

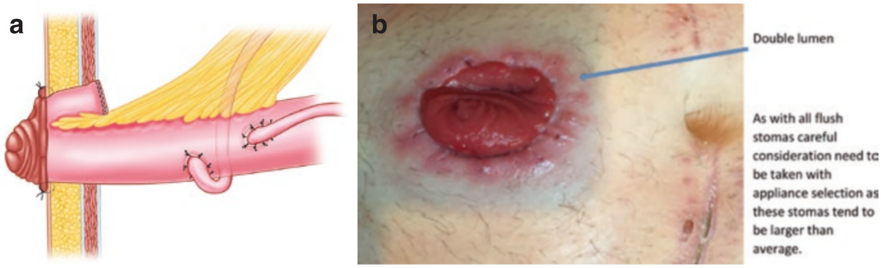

Fig. 9.4 (**a**) Turnbull loop urostomy with Bricker anastomosis. As with all flush stomas careful consideration need to be taken with appliance selection as these stomas tend to be larger than average. (**b)** Turnbull Loop Ileal conduit. (McGee, M.F., Cataldo, P.A. (2016). Intestinal Stomas. In: Steele, S., Hull, T., Read, T., Saclarides, T., Senagore, A., Whitlow, C. (eds) The ASCRS Textbook of Colon and Rectal Surgery. Springer, Cham. https://doi.org/10.1007/978-3-319-25970-3_55)

Simple Cystectomy

A simple cystectomy is defined as the removal of the bladder without the resection of any adjacent structures or organs.

Indications for Simple Cystectomy

This procedure is usually indicated in cases of patients experiencing functional and benign conditions of the bladder and is performed in conjunction with a urinary diversion reconstruction.

In cases where the bladder was not removed at the time of the urinary diversion, where the redundant bladder continues to cause problems such as recurrent infection a simple cystectomy may be performed at a later date.

Radical Cystectomy

Radical cystectomy (RC) with pelvic lymph node dissection (PLND) and formation of ileal conduit (IC) is considered the 'gold standard' technique for the treatment of muscle invasive bladder cancer and high grade recurrent non muscle invasive cancer.

Bladder cancer is the tenth most common cancer in the UK and is more common in men 1:50 than in women. 1:133.

Bladder cancer can be categorised as either non-muscle invasive bladder cancer (NMIBC) or muscle invasive (MIBC) and has the highest recurrence, progression and mortality rate of ***all cancers*** at 70% according to Cancer Research UK statistics.

Types of Bladder Cancer

- Transitional cell (urothelial) cancer or TCC accounts for 90% of all bladder cancers and develops from the cells of the bladder lining, the urothelium.
- Squamous cell bladder cancer or SCC accounts for 5% of all bladder cancers and develops within the squamous cells.
- Adenocarcinoma is a rare form of bladder cancer accounting for 2% of all bladder cancers and develops within the mucus producing gland cells found within the bladder lining.
- Sarcomas and Small Cell cancer of the bladder are the rarest forms of bladder cancer.

A radical cystectomy involves the complete removal of the bladder and the adjacent organs and structures to ensure the total resection of any cancer present in the bladder but also any that may have migrated out with the confines of the bladder wall.

In men the following organs and structures are resected; [16].

- Bladder
- Prostate
- Seminal vesicles
- Peri-vesical fat surrounding the bladder
- Bilateral inguinal lymph nodes
- Urethra—a urethrectomy is only performed when clinically indicated by the histological presence of cancer in the urethra at the time of the surgery.

In women the following organs and structures are resected where present;

- Bladder
- Total abdominal hysterectomy, uterus, ovaries, cervix and a portion of the anterior wall of the vagina.
- Peri-vesical fat.
- Bilateral inguinal lymph nodes.

Pre-operative counselling of younger women who are not premenopausal should include discussions about post-operative symptoms as the removal of the ovaries will precipitate a sudden onset of menopausal symptoms.

Sexual dysfunction to some degree is likely as a consequence of such invasive pelvic surgery for both men and women. As a result of this surgery it may be necessary for the specialist stoma care nurse (SSCN) to discuss with the patient the need for referral to a sexual dysfunction service where experts are available to support patients.

Preservation of the neurovascular bundles in men can be achieved but the preoperative counselling should include the possibility that this may not successfully lead to intact erectile function post operatively.

Bilateral resection of the lymph nodes is indicated both as a curative procedure and to aid with staging of the cancer histologically which will determine post-operative review and treatment.

Indications for Radical Cystectomy

There are specific guidelines which determine when a patient should be offered radical cystectomy, [17].

- Infiltrating muscle invasive bladder cancer without evidence of metastasis
- Cancer staging **pT2—T3** as demonstrated in Fig. 9.5
- Superficial bladder tumours characterised by any of the following:
  - Refractory to endoscopic resection and intravesical chemotherapy Mitomycin C (MMC) or Epirubicin or immunotherapy Bacillus Calmette-Guerin (BCG) treatment
  - Extensive disease not amenable to endoscopic resection
  - Invasive spread to the prostate or urethra

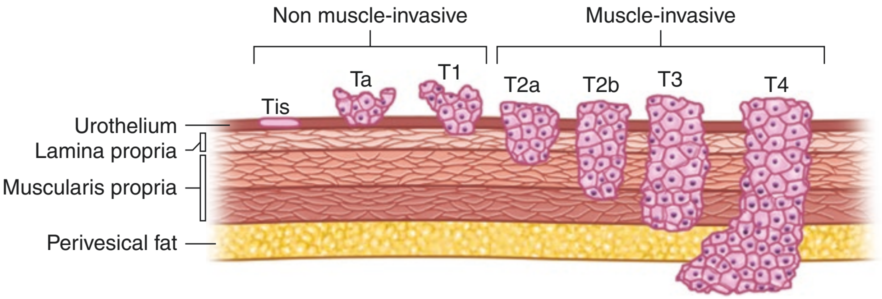

Fig. 9.5 Bladder cancer staging–Radical cystectomy indicated when the tumour has infiltrated into the muscularis propria layer of the bladder wall. T2a. *p* Primary. *T* referring to tumour. *N* lymph node. *M* Metastasis. *G* refers to the grade of the cancer in bladder cancer either 1, 2 or 3 where grade 3 would be considered aggressive cancer with a high likelihood of reoccurrence or significant growth

- Stage **pT1 G3** disease unresponsive to intravesical BCG treatment
  - CIS (carcinoma in situ) resistant to intravesical BCG or MMC
  - Palliative for symptom management, pain, bleeding or incontinence
  - Primary adenocarcinoma, squamous cell carcinoma SCC or sarcoma

Surgical Approaches in Radical Cystectomy (RC)

There are a number of surgical approaches to how a RC is performed such as: open (ORC), laparoscopic (LRC) and more recently robotically assisted (RARC), with LRC and RARC; both are considered as minimally invasive surgery (MIS).

Open Radical Cystectomy

Traditionally radical cystectomy has been performed as an open procedure and remains a surgical option to date.

The procedure is performed via a laparotomy, with the midline incision extending from the umbilicus to the pubis bone.

Indications for open cystectomy include;

- Surgical preference—not all surgeons are trained to perform MIS
- Patient selection and exclusion criteria—High BMI, multiple co morbidities, previous abdominal surgery.
- Previous pelvic radiotherapy
- Patients with stage T3b or T4 disease undergoing cystectomy as a palliative procedure in symptom control.
- Patients undergoing bladder reconstruction either orthotopic or neo bladder reconstruction. Orthotopic, by definition means ‘in the normal or usual position’

and here refers to the position within the pelvis and in the case of the newly reconstructed bladder meaning that it is placed where the diseased or dysfunctional bladder was removed.

In comparison to MIS techniques operating time is generally shorter therefore exposing the patient to a shorter general anaesthetic and the patient is positioned in a more traditional supine position therefore placing less stress on the patients physically compared to MIS.

In economic terms performing open procedures does not require the purchase of specialist equipment and disposables, so carries a smaller economic burden for a department; however this must be balanced by the potentially longer hospital stay post operatively and the longer recovery period expected.

Morbidity rates following ORC are high with the most common complications being gastrointestinal disturbance, wound infection and blood loss requiring transfusion as measured using the Clavien-Dindo scale [17].

However the high morbidity rate associated with ORC has led to the development and advancement of other surgical approaches with the express purpose of reducing these high rates.

Laparoscopic Radical Cystectomy (LRC)

The first early reported laparoscopy was performed on animals as far back as 1805. During the nineteenth century advancements in light sources, lenses and endoscopes evolved and the term ‘laparoscopy’ is credited to a Swedish surgeon Hans Christian Jacobaeus [18].

Despite the early development, laparoscopic or key-hole surgery fell out of favour with general surgeons. Its value as a minimally invasive diagnostic technique was recognised by gynaecologists and gastroenterologists, as it reduced the reliance on laparotomy as a means of diagnosis and investigation. Evolution of laparoscopic techniques was extremely slow due in part to the available technology of the day, most notably the lack of video technology to be able to adequately view the internal abdominal landscape to safely perform surgical procedures.

By the late 1980s laparoscopic surgery had gained momentum along with the evolution of the instruments, technologies and training to support its use and by the early 1990s laparoscopic cystectomy had made its debut [19].

Indications for LRC

- Reduced overall trauma to patient— < blood loss, quicker recovery time, shorter length of hospital stay—5-6 days
- Disadvantages include, prolonged anaesthetic and operating time.

Surgical Procedure

The patient is positioned in a supine lithotomy position with a 45 ° Trendelenburg tilt rendering the patient in a head down position on the operating table.

This severe position is necessary to allow the surgeons to adequately visualise and access the pelvic organs, particularly the prostate gland in male patients which is situated deep within the pelvic cavity.

Approximately 5–6 small incisions (port sites) are made in the abdominal wall to facilitate the insertion of the laparoscopic instrumentation into the patient. The abdomen is inflated with carbon dioxide to allow visualisation of the abdominal field.

The operative steps are similar to that of an open procedure, but will vary from surgeon to surgeon depending on their own preferred technique, [20]. In all cases the excision of organs is completed before the reconstructive techniques [21].

The excised organs are placed into laparoscopic bags and the lymph nodes are bagged separately from each side to allow for easy histological identification at a later stage. They are then usually brought out via an extended midline incision of the port site adjacent to the umbilicus. In female patients they can be delivered transvaginally.

Construction of the Ileal conduit can be performed either within—intra or outside extra-corporeal of the abdominal cavity, the method is determined by surgical preference and experience.

The extended midline port site incision is used to access a section of ileum as previously described and the technique to construct the stoma follows that of an open procedure.

Similarly if the patient is undergoing an orthotopic bladder reconstruction, this can be completed either intra or extra-corporeally but again the prolonged operating time involved with the intra-corporeal technique must be carefully considered with regard to patient safety.

Laparoscopic cystectomy can incur an operating time of 2–3 hours for the initial excision and a further 2–3 hours for the reconstruction. For this reason this surgery is usually performed with more than one surgeon to offset the potential of surgical fatigue and prevent complications.

The use of the laparoscopic technique has demonstrated favourable outcomes for the patient and it was not surprising that the next logical step was to introduce a robotically assisted surgical technique [22].

Robotically Assisted Radical Cystectomy (RARC)

By the late 1990s the technological development of a ‘robotic ‘system to assist surgeons in carrying out complex and intricate surgery was being adopted, initially in radical robotically-assisted prostatectomy (RARP) [23] The most commonly used system is Intuitive Surgical Inc’s da Vinci Surgical System [20, 21].

Indications for RARC

- Enhanced surgical accuracy
- Superior magnification thus improving visualisation
- Improved nerve sparing capabilities
- The elimination of ‘hand tremor’
- Improved manoeuvrability and dexterity
- Reduced blood loss, quicker recovery times and reduced hospital stay—average 4–5 days [24]

Operating time however remains lengthy with patients expecting to be under anaesthetic for approximately 5 hours and once again they are positioned as with laparoscopic surgery in a steep Trendelenburg position.

As with the LRC procedure the organs are excised first and then the reconstruction part of the surgery is undertaken resulting in the formation of the stoma.

From a nursing perspective the introduction of RARC has prompted a rethink of how stomas are sited and how care pathways to accommodate rapid discharge from hospital are implemented and designed.

Figure 9.6 represents the usual positions of the robotic arms. Whilst some slight variation of these can be accommodated by the surgeon it is evident that the proximity of the robotic arms to the ideal positioning of the stoma could lead to two incisions occupying the same area [23].

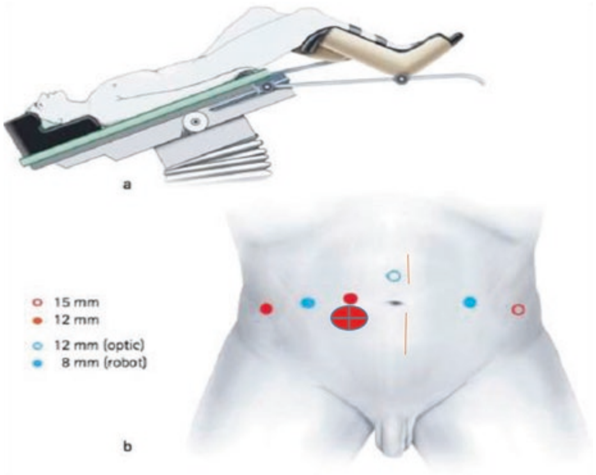

Fig. 9.6 Stoma siting for RARC (with permissions from Collins JW, Tyritiz S, Nyberg T, Schumacher M, Laurin O, Khazaeli D, Adding C, Jonsson M, Hosseine A, Wiklund P. Robotic-assisted Radical Cystectomy: Description of an Evolved Approach to Radical Cystectomy: European Urology 64(4) Oct 2013 654–663. https://doi.org/10.1016/j.eururo.2013.05.020). (Collins JW, Tyritiz S, Nyberg T, Schumacher M, Laurin O, Khazaeli D, Adding C, Jonsson M, Hosseine A, Wiklund P. Robotic-assisted Radical Cystectomy: Description of an Evolved Approach to Radical Cystectomy: European Urology 64(4) Oct 2013 654–663. https://doi.org/10.1016/j.eururo.2013.05.020)

Secondly, although the robot offers more manoeuvrability within the abdominal cavity the smaller incisions in the abdominal wall restrict the reconstructive process to some degree.

It is therefore essential that the siting of the stoma is agreed upon with the surgical team. A compromise has been to site the stoma in the same position as the intended site of the robotic port thus facilitating only one incision in that area.

Evidence to support stoma siting for RARC remains anecdotal and part of an evolving practice in stoma care.

Pre Operative Preparation and Care Considerations

Unlike other stoma types an ileal conduit is not reversible so all patients must be made aware of this. Patients undergoing surgery for benign indications are doing so to improve their quality of life, whilst patients with malignancy will undergo surgery with the intention of preservation of life. Psychological acceptance for both scenarios is likely to be positive.

Formation of an ileal conduit is rarely an emergency procedure so careful preoperative siting of the stoma is possible and required to ensure the optimum outcome for the patient. (See Chap. 11 Patient Assessment and Siting).

The development of enhanced recovery after surgery (ERAS) programmes have dramatically reduced the average length of hospital stay from an average of 10–14 days to 5–7 days depending upon the surgical approach.

The key principles of ERAS in urology include: [25–30].

- Pre operative counselling & stoma education
- Perioperative nutrition
- Avoidance of prolonged pre-operative fasting
- Carbohydrate loading
- Reduced or non-opioid analgesia regimes
- Reduced mechanical bowel preparation regimes
- Early mobilisation

Post Operative Care Considerations and Common Complications

As with all invasive surgical procedures there are risks that the patient should be made aware of preferably before the surgery takes place.

All patients undergoing the formation of an ileal conduit will have a ***primary bowel anastomosis*** which needs to be taken into consideration during the postoperative recovery period.

This must be managed with care and in the same way as for any patient who has undergone bowel surgery. Patients should be aware that they will need to avoid certain food groups, eat little and often and be encouraged to eat a high protein, low fibre diet for the first two weeks.

Unfortunately, some patients experience a post-operative ileus where the motility of the bowel is disrupted and there are a loss of bowel sounds initially leading to distension and sometime nausea and vomiting which unless treated can quickly lead to dehydration. Most post-operative ileus' resolve spontaneously within 24–48 hours but excessive vomiting may require management with a nasogastric tube and a prolonged ileus may require nutritional support via total parenteral nutrition (TPN).

The bowel should be monitored for the presence of bowel sounds via a stethoscope indicating that motility has returned and the passing of flatus should be noted.

Patients who have undergone a RARC (Robotically Assisted Radical Cystectomy) often report a change to their taste perception post operatively; *dysgeusia* is an abnormal or altered taste sensation associated with a metallic taste. This symptom is common in patients with an acute kidney injury and chronic kidney disease or when gastric motility is affected [31]. Little is written specifically with regard to post cystectomy patients and the cause of this symptom, it may be a combination of factors including patient positioning during surgery, disturbance of the GI tract and disruption to the urinary tract. In most cases this resolves quickly, however, any persistence, particularly following stent removal should not be disregarded, as this may indicate the onset of an acute kidney injury.

Altered Bowel Habit

As previously discussed some patients may experience an ileus post operatively. Once resolved many patients experience loose stools for a day or two until the oedema within the bowel resolves. However, not all patients manage to successfully move their bowels whilst in hospital but can be discharged once passing flatus if medically fit. It is common practice for the patients to be prescribed a mild laxative according to local policy to prevent constipation initially especially if they are observing a low fibre diet initially during the healing phase.

Once a full and normal diet has been re-established it is not uncommon for patients to experience some form of bowel disorder following surgery. Diarrhoea, flatulence and constipation are the most reported symptoms with 43% of patients reporting problematic symptoms in one study [32] and 46% of patients in another [33]. Patients should be made aware of the possibility of alterations to their bowel habit post operatively and that this may be a chronic complication requiring regular laxatives.

Post Operative Weight Loss

Some degree of weight loss should be expected post operatively and the patients should be made aware of this. The common reasons for this are,

- Loss of appetite due to dysgeusia, altered bowel habit and post op nausea
- Reduced calorie intake
- Increased calorific demand of tissue metabolism during the healing process. 35

Some patients can experience a dramatic weight loss in the first 6 week post-operative period, particularly if they have experienced any complications such as a UTI, with the average total loss being 9 kgs or 1.5 stones when weighed in a review clinic at 8 weeks post surgery [34].

Patients and their relatives can become distressed by the weight loss if they do not understand the causes for this as they often associate this negatively as being as a consequence of their cancer diagnosis rather than a common occurrence of the surgery [35].

Patients should be encouraged to eat small meals often and very importantly they must maintain an adequate oral fluid intake, 2 litres is recommended as a minimum. It must be remembered that many people are not natural water drinkers and therefore could struggle psychologically with the idea of consuming this volume of fluid even if it is necessary.

In order to help the patient they can be advised to drink a small volume 100-150mls every hour whilst up and about during the day on top of any other mixed fluids they can drink so that over a period of 8–10 hours they will have consumed 800–1500 mls.

Fluid Loss per Urethral/Vagina Post Cystectomy

Patients undergoing cystectomy and formation of ileal conduit often experience fluid loss per urethra in men and both urethrally and vaginally in women following removal of any catheters or abdominal drains post operatively. The fluid may leak on movement, coughing and bending as well as any straining involved in bowel movements. The fluid is usually serous fluid combined with lymph fluid in patients undergoing radical cystectomy secondary to the removal of the inguinal lymph nodes.

Initially the fluid may be heavily bloodstained but this gradually changes to become pink then a yellow resembling urine. Women who have undergone radical surgery including a hysterectomy may find this fluid becomes dark brown in colour resembling old menstrual blood. This fluid loss can persist for several weeks and the patient should be advised of this pre operatively in order to prepare as continence pads/containment devices such as sheaths will be required to manage this. It can completely stop for short periods only to return especially after mild exertion. Any sudden increase in this fluid, particularly following removal of the ureteric stents should be reported and investigated as this may indicate a ureteric anastomotic leak.

Patients not experiencing this type of perineal fluid loss may find that it leaks through their surgical incision sites or drain/port sites instead, affecting how the wounds heal.

Whilst inconvenient and often psychologically distressing for the patient, the fluid leakage should not be associated with abdominal pain, fever nor be malodourous as this could indicate an anastomotic leak within the small bowel and again this should be reported and investigated as a matter of urgency.

Although relatively common in this patient group it is often not well documented in academic studies nor in patient information leaflets.

Anticoagulant Therapy

Low molecular weight anticoagulant therapy should be administered for four weeks post operatively to reduce the risk of deep vein thrombosis and pulmonary embolism following any major abdominal surgery. This should be accompanied by the wearing of anti-embolic stockings [36].

Urinary Tract Infections

Urinary tract infections (UTI) are a common complication of cystectomy and urinary diversion surgery with the incidence rates documented in several studies being seen between 9% and 39% [37]. Whilst the patient is most at risk in the immediate post-operative period it is acknowledged that patients will remain at a higher risk of developing a UTI in their lifetime.

This is because patients undergoing any reconstructive surgical procedure of their urinary tract, that involves the use of segments of small or large intestine, will inevitably result in the introduction of naturally occurring gut bacteria into their urinary systems [37].

The presence of bacteria within urine is known as ***bacteriuria***.

Patients presenting with a systemic symptomatic infection should be considered to have an *ascending* upper urinary tract infection or pyelonephritis as their surgery has removed their native lower urinary tract. The obvious exception to this are patients who have undergone an ileal conduit diversion without cystectomy [38].

Patients whose bladder is not removed at the time of surgery are at risk of developing an infection in the ‘redundant’ bladder. Known as *Pyocystis,* this is caused when an accumulation of secretions from the bladder wall becomes infected as the bladder cannot or does not spontaneously empty. Whilst the bladder is surgically detached from the renal system it can nevertheless cause systemic cystitis type symptoms [39].

Mild to moderate pyelonephritis infections can quickly escalate into more serious episodes of urosepsis particularly in patients who have undergone neoadjuvant chemotherapy to reduce tumour bulk, or patients with underlying immunosuppressant therapy and diabetic patients [37]. The most commonly identified pathogens in patients having undergone an ileal conduit diversion are the Gram-negative, Klebsiella pneumonia, Escherichia Coli, Proteus and Pseudomonas and gram positive Enterococcus and Staphylococcus aureus and the most common fungal infection being Candida [38]. These bacteria are found to colonise the mucus secreted in bowel segment rather than adhering to the columnar cell epithelium lining the digestive tract. This mucus provides protection against invading bacteria and pathogens and is secreted by goblet cells [40].

Common Presenting Symptoms of a UTI

An increase in mucus production observed within the urine output can be an early indication of the development of a UTI, this is often accompanied by an increase in odour and a darkening in the colour of the urine; it should be noted however that these observations can also indicate dehydration.

Other common symptoms include;

- Headache
- Fever— > 38 °C
- Back pain/discomfort particularly in the region around the kidneys
- Nausea and vomiting
- Flu like symptoms, muscle and joint aches

Patients may describe feeling generally unwell with no specific acute symptoms with an initial low grade infection but these can quickly escalate into urosepsis.

Common Longer Term Conditions Leading to UTI

With any reconstructive surgery there is always an increased risk to the patient of them developing secondary complications over time, the most common are detailed here;

Hydronephrosis/hydro-ureter secondary to obstruction.

The accumulation of urine within the kidney is known as a *hydronephrosis* and can be accompanied by an accumulation of urine within the ureter itself which is known as a *hydro-ureter*.

A hydronephrosis is often a temporary problem within the first post-operative period within the first 2–6 weeks, often as a result of swelling of the uretero-ileal anastomosis either caused by infection or inflammation secondary to the stents which can obstruct or restrict the free flow of urine from the kidney.

A persistent hydronephrosis is usually as a result of ureteric obstruction and there are several potential causes for this which can be either intrinsic or extrinsic.

Intrinsic causes can include disease reoccurrence within the ureter, renal calculi, anastomotic stricture or a congenital abnormality of the ureter resulting in a stricture formation.

Extrinsic causes include intra-abdominal recurrence of cancers, constipation, benign abdominal tumours and pregnancy.

Most cases of uretero—anastomotic stricture can be treated endoscopically using balloon dilatation, stenting or incision although in some cases this may require further surgery.

Short term conservative management may include the insertion of a nephrostomy (to drain the urine directly from the kidney especially when renal function is compromised) or a temporary internal ureteric stent.

Long term permanent stenting is an option where the cause of the obstruction is benign in origin but does not resolve following temporary stenting. These stents are replaced at regular intervals during the year, the frequency of which is determined by the type of stent inserted.

- Ureteric reflux

  Ureteric reflux occurs when the urine is drawn back into the ureter because it is not able to drain easily. This is usually caused by two main factors in patients with an ileal conduit;
- Increased intraluminal pressure within the conduit secondary to stricture formation or the presence of a parastomal hernia causing an obstruction.
- Stricture formation at the uretero-intestinal anastomosis

If the urine descending from the kidney is restricted than this can cause the refluxing of urine back up the ureter and upwards towards the kidney. This urine contains a rich 'soup' of bacteria and this is inevitably introduced into the ureter facilitation an ascending infection [41].

Other Immediate Post Operative Complications Post RARC and LRC

Visual and Hearing Disturbance

Many patients can experience some transient symptoms of hearing and visual disturbance due to their positioning on the operating table in a deep Trendelenburg position (head down) they may also experience facial swelling particularly around the eyes due to the increased intraocular pressure [42].

Other Types of Urinary Diversion

Vesicostomy

Indication

This is a procedure normally only performed on neonates and babies when the upper urinary tract is at risk of damage due to neuropathic bladders where anticholinergic medication is contraindicated and intermittent catheterisation inappropriate.

Surgical Procedure

A small transverse opening is made in the abdominal wall between the pubis and the umbilicus. The fascia is incised and the peritoneum is pushed back from the dome of the bladder, the urachal remnant is then divided and the dome of the bladder is pulled up to the skin and the fascia is secured to the bladder wall to form an opening [43].

This is generally considered a temporary measure until the child is mature enough for reversal of other corrective surgeries or management.

Complications and Nursing Considerations

Managing this type of stoma in a neonate does not allow for the attachment of a stoma appliance and commonly the stoma will drain into the nappy that the child is wearing. A common complication is therefore peristomal dermatitis as the urine flows freely from the stoma onto the abdominal skin requiring adequate skin protection often found in the use of barrier wipes and creams. The peristomal skin must be monitored vigilantly to detect early signs of skin deterioration.

Bladder calculi and stomal stenosis are also commonly reported complications; any reduction in urine flow should be reported. Dilatation of the stoma may be necessary in cases of stenosis.

Cutaneous Ureterostomy

Indication

The formation of a cutaneous ureterostomy may be a permanent or temporary procedure depending upon the reasons for its formation and can be singular, bilateral or as a double—barrelled procedure. In much of the available scholarly literature they are mostly described in children [44].

Temporary ureterostomies are most commonly performed as an emergency procedure when a ureteric injury has been sustained following severe abdominal trauma, blunt or penetrating, when a formal repair is not immediately appropriate as the patient is too ill to tolerate complex surgery [45, 46].

Permanent ureterostomies are usually performed as a planned procedure as a form of urinary diversion following cystectomy where the formation of an ileal conduit or other reconstructive surgery is not possible. This may be as a result of an underlying bowel condition preventing the use of a bowel segment, previous bowel excision or previous extensive abdominal surgery resulting in dense adhesion or reduced or impaired renal function.

This procedure is also performed when patients are frail or have multiple co morbidities where less invasive surgery is a preferable option with a shorter anaesthetic time.

Complications and Nursing Considerations

Despite the relative benefits of performing this type of surgery there are a significant number of disadvantages [47].

The resulting stoma is small and flush to the skin which can present problems finding an appropriate appliance with which to manage the direct urine output from one/two kidneys and if the ureters have been sited bilaterally the patient will have two stoma sites to manage.

Pre-operative siting can be difficult as the actual length of the ureter/ureters cannot be determined accurately and in cases of planned surgery it is more appropriate to indicate the presence of skin creases and folds and areas to avoid rather than trying to accurately determine a precise spot for the stoma to be formed.

These stomas can also be prone to stenosis and are often managed with a long term ureteric stent in situ which requires changing on a frequent basis depending upon the type of stent selected. Stents can be subject to accidental removal during appliance changes and can also migrate down the ureter during daily movement and activity as they are held in place by a ‘pig tail’ this is a coil or loop at either end of the stent.

Ureterostomies without stents are prone to stenosis and may require intermittent dilatation using a small gauge sterile catheter designed for intermittent use.

Appliance Selection

Appropriate appliance choice is crucial when managing a ureterostomy particularly when there are stents in situ and they may not be easy to see on the abdominal wall.

The use of a two piece appliance is recommended as this allows better visualisation of the stent and makes it easier to thread through the skin barrier allowing for better positioning and safety of the stent. A two piece appliance also increases overall wear time of the skin barrier reducing the requirement to change the entire appliance thus reducing the risk of potentially dislodging the stent.

Conclusion

Surgery resulting in the formation of a urostomy can be complex and despite the revolutions in surgical techniques the recovery process can be slow taking several months. Urostomies are essentially high output stomas with an average healthy adult producing around 800 to 1800mls of urine in a 24 hour period. The appropriate appliance selection to manage such an output is important and many patients choose to use 2 piece appliances as these often offer better wear time and are more erosion resistant than 1 piece appliances.

Unlike colostomies and ileostomies a urostomy or ileal conduit cannot be reversed and is therefore a permanent stoma. Whilst the benefits of undergoing urostomy formation are evident, it is imperative the patient understands from the outset the radical change in functionality which will ensue.

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Stoma Management

10

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Learning Outcomes

- Identify the 3 main types of stoma and be aware of the appropriate appliance according to the output.
- Understand the dietary implications for any individual living with a stoma.
- Understand the normal range of output volume of a person living with an ileostomy and be aware of the consequence of any deviation from this
- Descibe the possible reasons for urinary infections and possible treatments for individuals living with a urostomy

Stomas

The word stoma comes from the Greek language and translates as 'mouth or opening' and is used in medicine to describe any opening into an individual's body. This chapter will focus upon the person with a stoma that has been created to allow faecal or urinary effluent to leave the body. There are 3 groups – the person living with a colostomy, termed a **colostomate** or colostomist, the person living with an

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ileostomy, an **ileostomate** or ileostomist and the person living with a urostomy or ileal conduit, a **urostomate** or urostomist. Each stoma is formed for a different reason and for a variety of different colorectal and urological diseases and conditions; as explored in the previous chapters. (See Chaps. 6 and 9).

Preoperative Assessment

Preoperative assessment is undertaken in accordance with ASCN UK standards [1] and local policy. A specialist stoma care nurse (SSCN) undertakes a holistic patient assessment. This should include an assessment of the physical, social and psychological needs of the person planning to have a stoma. One important physical assessment for example is the dexterity to be able to perform a stoma appliance change. In addition, prior to surgery, it is important to provide specific information about the actual surgery as well as information about adjustment to their lifestyle that may be experienced following stoma formation. It is important to not just provide good information, but to ensure that part of the assessment determines what level of understanding the patient has. This includes if they have any additional needs such as information in other languages or being blind or deaf that may affect them in the pre-assessment situation and beyond. It is important to ensure that information is presented at a level appropriate to the patient's needs. It is also important for the patient to have time to reflect on impending surgery, as well as have the opportunity to ask questions, and seek clarification on any aspects that concern them. Some patients may wish to meet an existing ostomate prior to surgery and a SSCN can facilitate this (Chap. 17). Marking the stoma site on the abdominal wall is also required whenever the clinical situation allows (see Chap. 11).

Preoperative Information

Prior to having a stoma-formed it is important for the nurse to provide information on the operation. The SSCN is an expert who focusses on survivorship that begins in the preoperative period, recognising that having a stoma is life-changing and adaption is necessary [2]. This is enabled through holistic nursing and education as well as expert skills and compassion. Thorpe et al. [3] explored the experiences of people who had undergone stoma formation; suggesting that to enable adaption to the stoma it is important to build a good relationship with healthcare professionals and be prepared for surgery. Information provided includes the reason for the operation and stoma formation as well as what changes having a stoma might mean to the individual. Additionally, information will be provided on diet, activities, relationships, recovery and where the stoma will be positioned.

Preoperative Stoma Care Training

To enable patients with a newly formed stoma to be safely discharged home from hospital after their operation, it is important to establish that independent care can be carried out by patients and/or carer. To enable a safe discharge home, preoperative practice is advocated; often using stoma teaching packs available from appliance manufacturers or providing alternative educational resources such as booklet, DVD or podcast will support this goal. Teaching packs enable the patient to wear a fake stoma and appliance prior to surgery and also to practice an appliance change on their abdomen without feeling any postoperative surgical pain. Undertaking preoperative training has enabled the length of hospital stay to be safely reduced, with patients still able to independently change their stoma appliance prior to discharge home from hospital [4]. These preoperative interventions are in line with the enhanced recovery after surgery principles; where evidence is used to guide the surgical pathway [5].

Postoperative Care

There are a number of stoma-specific elements of postoperative care including care of the appliance and also long-term expectations and considerations that are important. Postoperative stoma checks include assessing colour, temperature and output from the stoma [6] to ensure it is viable. Any deviation in colour or function of the stoma must be documented and reported as per local policy. The surgeon must be contacted immediately if there is any severe discolouration or concern for immediate review (see Chap. 12).

It is essential in the postoperative period that all healthcare professionals ensure that the patient is fully appraised of the surgical findings and actual procedure performed as this may differ from the planned operation. Clarifying the patients understanding is important in this post-operative phase. Further information may be required if there has been a significant deviation from the pre-operative information given.

Practical Stoma and Discharge Planning

Ward nurses with guidance from the SSCN need to ensure that people with newly formed stomas feel confident to go home and care for their stoma. Discharge preparation includes practical stoma care management; including the process of changing the stoma appliance independently. Additionally, discussion and information about the support mechanisms available locally help to ensure the patient does not feel isolated and alone following discharge from hospital. The SSCN should provide contact names and telephone numbers for the SSCN and other contact methods for on-going support services. When planning for discharge, it is essential to ensure that the correct appliance is used, enabling the output from the stoma to be collected and the skin integrity maintained [7]. There is no one perfect way to perform an appliance change (see Box 10.1) and each person will adapt their training to suit their individual lives once they are at home and gain greater confidence with their appliance.

Some patients and/or carers may benefit from a pictorial guide to assist them when changing their stoma appliance or an individualised care plan to remind them of the steps necessary to change the appliance (see Chap. 18).

Box 10.1 Practical Appliance Change

Collect all of the stoma equipment (appliance, warm tap water, cleaning cloths, and rubbish bag +/− any additional stoma products required, a measuring guide, pen and scissors).

Gently remove the appliance with or without the use of an adhesive spray/wipe from the skin of the abdominal wall around the stoma (peristomal skin).

Clean the faeces or urine from the skin with a cloth/wipe dampened with lukewarm water.

Thoroughly, but gently dry the skin.

Ensure that the appliance aperture is the correct size (about 2-3 mm larger than and the same shape as the stoma).

Remove the backing paper from the appliance or flange and ensure the closure is fastened if present.

Place the appliance over the stoma and gently press the adhesive flange onto the peristomal skin and hold in place for about 30 seconds.

Dispose of the waste as per local policy.

Wash hands.

Skin Care

Some fundamental points regarding skin care need to be shared with patients. This includes information about the appliance such as;

- The appliance adhesive is skin friendly and can help skin heal.
- Skin damage is not normal and all attempts should be made to ensure that the skin integrity is maintained.
- Soaps, deodorants and other chemicals are not recommended for use around the stoma.
- Seek timely advice from the SSCN if the peristomal skin alters from its usual appearance

It is also important to recognise the factors that may increase the risk of a person with a stoma having skin problems, such as having an ileostomy compared to a colostomy [8]. If problems do occur there are a number of skin tools that are available such as the Ostomy Skin Tool from Martins et al. [9], PLACED from the ASCN

UK [10], Stoma Care Ostomy Research Index by Williams et al. [11], Peristomal Lesion Scale by Menin et al. [12] and the Peristomal Skin Assessment Guide from the Wound, Ostomy and Continence Nurse Society [13]. All of these tools can be useful in the clinical situation, (particularly for the novice SSCN) to provide scores for example, but these tools are subjective (See Chap. 13).

Appliances

Patients need to be informed regarding the process for ordering their stoma supplies. In general people in the UK require a new order via prescription written by their general practitioner (GP) or an approved prescriber each month. This time frame is variable depending on local policy. Ostomy supplies in the UK are provided on prescription according to an approved body, The Drug Tariff (Part IX Section C FP10). Across the devolved nations of UK there are variations in prescription charges. In England, if the person is exempt from prescription charges, such as children or diabetics for example, the prescription for all ostomy supplies is free; other adults need to pay a prescription charge. Patients with a permanent stoma can apply for an exemption for all prescription costs, alternatively a pre-payment can be made for people who need to pay for prescription costs to reduce how much needs to be paid by them. In Northern Ireland, Wales and Scotland all prescriptions are free for ostomates. The ASCN UK in their guidelines recommend appliances should be changed between three times daily to twice weekly [10]. This variation is due to the stoma type and the individual's personal choice.

Diet

In general people with a stoma can eat and drink most foods [14]. Eating and drinking is encouraged immediately postoperatively as per local guidelines. Postoperatively some patients experience a delay in return to normal gut function (ileus). During this period, patients are advised to consume small quantities of a low residue diet and gradually return to normal diet once bowel function has returned. Any prolonged ileus may require intra-venous nutritional support until it resolves. Stoma-specific dietary considerations will be explored later.

Activities

In general a gradual introduction of activities back into the person's lifestyle is advocated. Walking will occur in hospital but more strenuous exercise will generally need to be postponed for a few weeks to months. However, in an Italian study by Maculotti et al. [15] most people with a stoma who answered the survey reported that they were undertaking exercise including swimming, walking and cycling. It is important to consider prevention of a parastomal hernia, seen as a bulge around the stoma. There have been several small research studies that show that abdominal exercises in conjunction with abdominal support can reduce this risk [10, 16–19].

Long-Term Care

It is important in the longer-term to encourage patients to return to the SSCN if there are any stoma-related issues [1, 20]. Marsden [21] suggests that regular reviews are necessary but acknowledges that there is no standardised protocol, but should include several contacts with the SSCN in the first year after stoma formation. Although dated Davenport [22] suggested a follow-up pathway to include telephone calls, home visits and annual reviews, with more contact in the first year after stoma formation as this is known to be when most issues will occur. Additional information provided in small groups can be useful in helping people recover faster and improve their quality of life. Danielsen and Rosenberg [23] undertook a study comparing people with newly formed stomas who attended additional educational sessions in small groups compared to usual follow-up. They concluded that encouraging patients to join a support group can enable peer support from other people with stomas and there are a number available in the UK. One of the ASCN UK quality statement suggests any person living with a stoma should have long term/lifelong specialist stoma care nurse support [1].

Colostomy

A colostomy can be fashioned/constructed in one of two ways (end or loop), using any portion of the colon (transverse, descending, sigmoid colon). An end colostomy is constructed when the colon is divided and the proximal end is brought through the abdominal wall and sutured to the skin. The distal end of the divided colon can also be exteriorised to create a mucous fistula, permanently removed or the end can be oversewn and placed back into the abdominal cavity. A loop colostomy is a loop of colon brought to the surface of the abdomen, partially divided and everted thus creating two visible lumens. It has a functioning end (proximal) which faeces pass through and a non-functioning end (distal) leading to the lower colon or rectum, which may produce mucus.

A colostomy is usually positioned in the left iliac fossa, but a loop colostomy may be created using any portion of the large bowel and exteriorised at an appropriate site on the surface of the abdomen. According to Lister et al. [24] the most common type of colostomy is formed in the sigmoid colon. A colostomy is usually minimally raised above skin surface and is pink/red in appearance, like the inside of the mouth and is soft and moist to touch.

Colostomy Output and Function

The output from a colostomy is normally a semi solid or formed stool but this may vary depending on the portion of the colon used to create the colostomy. A proximal colostomy will produce a looser stool than a colostomy created from distal colon. A colostomy is usually active on average 2 or 3 times a day but the frequency of defecation can vary between individuals. There is no control over the passing of wind or faeces through a colostomy as there is no sphincter mechanism to enable continence. A person with a colostomy may experience diarrhoea which may be due to diet or infection, but constant diarrhoea or watery faeces needs to be investigated. Equally constipation can result from poor diet or inadequate fluid intake, inactivity and/or medication in colostomates. Patients should be taught how to manage such issues.

Colostomy Appliances

An experienced SSCN has specialist knowledge regarding the needs of the patient, use of stoma appliances and additional products as well as being able to advise on appropriate appliance selection to prevent problems. It is important to assess the patient's physical and visual abilities and dexterity prior to choosing an appropriate appliance [10]. Using the correct appliance is a major contributing factor to the physical and psychological well-being of a person living with a colostomy.

People living with a colostomy usually use a closed bag. There are many different types of stoma appliances and appliances can either be a one or a two piece system. Appliances are available in transparent, opaque and other different colours and some have a split outer cover which allows the stoma to be observed without its removal. Appliances vary in size and capacity to enable patients to choose a suitable pouch according to their specific needs and wants. Most appliances have a filter to prevent a build-up of flatus in the pouch. The filters contain charcoal to absorb any odour. There are many manufacturers that produce a variety of stoma appliances and additional items, providing quality and choice which is paramount for each individual patient's needs.

The appliance is usually replaced when one third to one half full of faeces. An appliance is usually changed between 2–3 times a day and three times a week [10]. When using a two piece system the flange or base plate can be changed two to three times a week and the appliance replaced once to three times over 24 hours. It also allows patients to alternate using mini, standard or large appliances as appropriate and closed or drainable appliances may be used interchangeably. An overfull appliance needs to be avoided as the weight will pull the appliance away from the skin causing leakage. If the stoma output is loose some patients may opt to wear a drainable appliance which can be emptied as necessary and changed daily or according to the patient's wishes.

People with a colostomy need to be reassured that they will be able to do the activities they were able to prior to stoma formation, such as swimming. There are stoma caps available for a patient to wear when swimming and mini bags, which can be more discreet and suitable for short periods of time perhaps for sport or for more intimate moments. Hill [25] identified that stoma appliances will have an impact on the patient's body image and that intimate relationships may suffer. A discreet appliance can offer the patients confidence to live well with their stoma.

Varma [26] stated that colostomy irrigation is an option for people with a colostomy, who may consider it as an alternative to wearing an appliance to prevent leakage, odour and peristomal skin related problems. Colostomy irrigation is an option for patients that have an end colostomy formed in the sigmoid colon and should only be considered if the ostomate's consultant has consented to this option. Colostomy irrigation is usually performed every 24–72 hours [27] and it is important that physical, psychological and social needs are considered when discussing colostomy irrigation with ostomates. Williams [28] suggests that colostomy irrigation may be a positive way of restoring confidence through regaining bowel control, eliminating fears of odour and leakage and may result in reducing anxiety. However, it is important to understand that there are some contraindications for colostomy irrigation such as Crohn's Disease or radiation damage [10].

Dietary Considerations for a Person with a Colostomy

Following stoma surgery many people with a colostomy think they will need to restrict the variety of foods eaten and change their diet but for a person with a colostomy there are no dietary restrictions. Porrett and McGrath [29] state that when discussing food try to avoid using the term "diet" as this can be interpreted negatively by many patients as meaning rigid restrictions to their diet or that they have to be on a "special diet" now that they have a stoma.

Cronin [30] identifies that new stoma patients have many concerns about what they should and should not eat. It should be noted that some foods can cause a change in consistency of output or an increase in flatus and odour. Limiting intake of fibre and fizzy drinks may help to reduce flatus.

Challenges Specific to Managing a Colostomy

Pancaking is a common problem which can cause leakage and distress for the patient [31]. Pancaking is seen as when the faeces do not drop into the bottom of the appliance; instead the faeces pancake at the top and/or push under the stoma flange. Pancaking is thought to be caused by a vacuum occurring within the appliance; a lack of air in the appliance or possibly over activity of the integral appliance filter releasing gases from the appliance. A filter cover can be used to cover the filter to prevent too much flatus being expelled. This allows the stool to drop to the bottom of the appliance which can also be lubricated with a little oil or lubricating gel. Alternatively, trying to alter the consistency of the faeces by altering diet for example may help minimise the occurrence of pancaking. Some patients find it helpful to insert a tissue into the bag to keep it 'open'.

Ballooning of the appliance can occur if flatus builds up inside the bag. If the filter cannot cope with the flatus or if it becomes blocked due to faecal output it will result in ballooning. Ballooning can occur if air is swallowed with food or fluid. To reduce ballooning decrease the amount of air swallowed, eat small regular meals and chew food well. Advise patients to take time to eat and sip drinks. Patents should also be advised to avoid chewing gum and smoking as such activities may result in ingestion of air.

As with any individual with an intact gut, constipation can occur when the stoma does not function regularly and the faeces become dry and hard. Constipation can be due to diet, medication or reduced mobility. If drinking sufficient fluids, eating regular meals and taking regular exercise does not prevent constipation, a laxative may need to be considered.

Preventing or managing a parastomal hernia, a prolapsed colostomy, a retracted or stenosed stoma, granulomas and peristomal skin conditions are discussed in Chaps. 12 and 13.

Ileostomy

An ileostomy can be fashioned/constructed in two ways, using any portion of the ileum. An end ileostomy is constructed when the ileum is divided and the proximal end is brought through the abdominal wall and sutured to the skin. The distal end of the divided ileum can be also be exteriorised to create a mucous fistula or the end over-sewn and placed back into the abdominal cavity. A loop ileostomy is a loop of ileum brought to the surface of the abdomen, partially divided and everted thus creating two visible lumens. It has a functioning end (proximal) which is spouted [32] allowing loose faeces to pass through and a non-functioning end (distal) leading to the remaining bowel, which may produce mucus.

An ileostomy is usually positioned in the right iliac fossa [32]. Surgeons will aim to give an ileostomate a spouted ileostomy so that it its loose faeces avoid skin contact preventing leakage and skin damage (See Chaps. 6 and 13).

Ileostomy Appliances

Modern ileostomy appliances have continued to improve over the years but their fundamental purpose is to contain effluent from the ileostomy and ensure faecal leakage does not occur. Ileostomy appliances are drainable and have a filter. Filters were not introduced until 1997 [33] and each company has a filter made from different components which means that some filters will need to be covered if the appliance is worn in the shower or swimming if they do not contain a water proof protective membrane such as Gortex.

Most appliances nowadays have an integral closure that contain a Velcro™ type or plastic closing mechanism. Before integral closures on drainable appliances were introduced, plastic clips or soft ties (similar to bread/food ties) were used to fasten the appliance. These older fastenings were often difficult to open and fasten requiring good dexterity.

The latest additions to the ileostomy appliance range include ingredients added to the hydrocolloid wafer such as ceramide, manuka honey and aloe vera. As discussed earlier, appliances are available in transparent or covered with a fabric outer material. There are various appliances available in different colours. Additionally, appliances often have a 'split cover' so that the individual can view the stoma and contents if needed.

There are one and two piece ileostomy appliances available in a variety of sizes. Many ostomates use a smaller appliance for certain occasions including intimacy and if worn under particular clothes. A smaller appliance however needs emptying more frequently due to its reduced capacity.

Ileostomy Output

An ileostomy output can vary in consistency from watery to porridge-like depending on dietary intake; with porridge-like being the usual consistency. Therefore a drainable appliance is recommended as this allows faeces to be emptied from the appliance. The usual volume of faeces passed is most commonly between 600-800 ml daily. To contain a faecal output of over 1000mls [10], a high output appliance may be appropriate as it allows the outlet to be linked into a larger drainage system similar to a urinary night bag.

For people with a consistently high output from their ileostomy, over 1litre daily, it is important to consider reducing this faecal volume. Dietary manipulation may help (see later) alternatively use of anti-diarrhoeal medication such as Loperamide/Imodium is often used to control the output. For best effect the medication should be taken 30–60 minutes before a meal (see Chap. 12). It is also important to ensure that the high output does not affect kidney function by educating patients on signs to look for such as reduced urine output as well an understanding that a high output requires nursing and/or medical intervention.

Ileostomy Appliance Emptying

An ileostomy appliance should be drained regularly to prevent it from overfilling. An overfull appliance containing flatus and/or effluent can lead to it leaking, as well as being extremely difficult to empty especially for a new ostomate. It is common to empty the drainable appliance four to six times a day when about a third full [34].

Changing an Ileostomy Appliance

In the UK most patients choose to change their appliance daily or every two to three days depending on the type of skin barrier and the ostomate's choice [10]. This differs in other countries primarily due to costs.

Dietary Considerations for a Person with an Ileostomy

Many ostomates request dietary advice or diet guidance sheets; however this can often lead to eliminating many foods that may agree with the individual. Everyone is different and it is wise to try foods that the individual likes. Food should be chewed well and fluid taken after eating.

There are a number of foods that help to thicken the ileostomy output. These food types can be useful to take regularly; these include carbohydrates such as mashed potato. Also it can be useful to reduce the amount of wholemeal/whole wheat foods consumed and substitute for white versions such as bread and pasta. There is also some evidence that food containing gelatine found in wine gums, jelly/jelly babies and marshmallows [35] can help thicken and reduce the volume of the ileostomy output. However, some of these foods contain high volumes of sugar or artificial sweetener which can also contribute to a high output so care must be taken.

Postoperatively the gut is inflamed and so general advice is to keep meals fairly bland, rich in carbohydrate and low in fibre. It is important not to introduce too many fruit and vegetables initially, as this can lead to abdominal pain, an increase in flatus or even a blockage/obstruction. When re-introducing vegetables into the diet after stoma-forming surgery they should be well cooked. Carrots are well tolerated initially; whereas darker green vegetables such as cabbage, cauliflower and broccoli should be introduced gradually over a few weeks post-surgery. Introducing one new vegetable at a time is helpful, for example, broccoli one day, cabbage a few days later. It is good practice initially to remove the rind of the fruit such as apple skin and the pith around orange segments as this can lead to blocking a stoma. Stewed apples may be easier on the digestive system initially. Some ostomates report seeing pips in their appliance after eating strawberries and blueberry skin which has not been digested.

In the longer term there are certain foods that an ileostomate may find difficult to digest. Poorly digested food could potentially cause a mechanical blockage. Food types that are hard to digest and may block the ileostomy include pulses such as chickpeas and lentils as well as sweetcorn and nuts. It is important to ensure that a balanced diet is enabled; chewing or juicing foods can be useful for some ileostomates or taking multivitamins.

It is important to remember that all people are individual and food affects us all in slightly different ways. For example, if someone ate a lot of spices prior to surgery then their gut is well adjusted to these flavours and they will probably find that these spices are tolerated with their ileostomy.

Alcohol can be consumed by someone with an ileostomy although many report red wine and beer can make their stoma output very liquid. Fizzy drinks can lead to excessive gas. Additionally alcohol can be dehydrating to the body, so the ileostomate needs to be aware of this and take additional non-alcoholic fluids to rehydrate.

Certain foods may cause the faecal output to be malodourous such as eggs and fish. Whilst both of these are good sources of protein it may be advisable to use a deodorant spray when emptying the pouch if the ileostomate is bothered by the smell.

Ileostomy Related Issues

Some ileostomates do unfortunately experience some complications that can result in difficulties in stoma management, including parastomal hernia, a prolapsed ileostomy and/or retracted ileostomy (see Chap. 12). Alternatively, an ileostomate may gain or lose weight after their stoma is formed. Changes in weight can lead to skin creases occurring around the stoma site or the spout size reducing; either of these can cause issues with a stoma appliance fitting well, potentially resulting in a leaking appliance. There are many products such as skin filling pastes and rings (seals) that help "fill" creases and create a flat surface for the appliance to adhere to. For minimally spouted ileostomies a convex pouch with a soft or a hard rigid convex plateau may be appropriate. Convex appliances are available in both one and two piece systems but should be used with caution (see Appendix 1 ASCN Convexity guidelines).

Some ostomates with a loop stoma may report rectal faecal discharge. This can occur when the ileostomy output is particularly loose and an 'overflow' is created by the liquid faeces exiting the proximal limb of the loop stoma and overflowing down the distal limb and out through the anus. Rectal discharge can cause anxiety, particularly if the rectum expels faeces without control resulting in soiled underwear.

In cases of obstruction caused by food stuff the ileostomate will often report their stoma is not working, a bulge of the food bolus may even be evident at the site of the stoma. The blockage will often resolve itself with the help of the ileostomate drinking plenty of fluids to help dislodge the food bolus. Some ostomates find a hot water bottle applied to the site of pain will relax the bowel and also help the blockage to pass, although this advice should be given with caution to prevent undue physical harm e.g. scalding. However, if individuals experiencing symptoms of blockage start to vomit then medical advice needs to be sought immediately. Patients should be mindful of any food that could have caused the blockage such as mushrooms or sweetcorn and perhaps careful consideration needed in the future.

Urostomy

A urostomy is a permanent end stoma, and generally in the right iliac fossa unless there is a clinical or lifestyle reason why it cannot be positioned there. The ideal urostomy should be well spouted which assists in ensuring an optimal seal of the pouch is obtained to help reduce the risks of leakage [36]. The peristomal skin, on examination, should be intact and free from any signs of change in colour or skin integrity [37].

Urostomy Appliance

The appliances designed for the management of the urostomy have several differences to those designed for the management of a colostomy or ileostomy. The most obvious difference is the absence of an air/flatus filter. The design ensures that urine is contained safely within the appliance. This is achieved in a number of ways. Firstly, the presence of a non-return compartment within the appliance allows normal movement of the person without the risk of the urine seeping back to the aperture and potentially resulting in leakage. Several manufacturers have additional compartments within the appliance to allow for a more even distribution of urine which in turn allows for a more streamline profile of the appliance as it fills. The appliance is emptied via a tap or bung system.

It is important that a holistic assessment of the patient is undertaken. An assessment ensures that ostomates who may have specific dexterity issues are able to find a suitable appliance that meets their requirements to ensure they can be as independent as possible [38].

Due to the corrosive effects of urine on skin barriers, the skin barrier that is found on a urostomy pouch tends to be more long wearing than skin barriers on other pouching systems. Some stoma care manufacturers have developed skin barriers infused with ingredients such as Manuka honey, Ceramide and Aloe Vera to help maintain and improve the peristomal as mentioned earlier.

Many ostomates with a urostomy choose to use a transparent pouch. For ostomates that have recently had surgery it can help build confidence in ensuring the appliance has been positioned correctly as well as providing visual guidance as to when the pouch requires emptying. In addition to transparent appliances there are some available with a viewing option, as well as opaque in design. Recent design developments have ensured that ostomates that prefer to use appliances with a fabric covering have a variety of colours available to them to meet individual needs. Urostomy appliances are available as a one piece or two-piece system. Within the skin barrier range there is a wide choice of flat and a varying depth of convex skin barrier to manage a urostomy (see Appendix 1). On average the urostomy appliance will need to be emptied when it is a third full which can mean it being emptied every couple of hours. Overnight the use of a night drainage bag may be utilised.

Night/Drainage Bags

The use of a night bag or leg bag is of personal choice for ostomates who have a urostomy. The purpose of a night bag is practical; allowing urine to be collected into a 2 litre drainage bag. This allows for the person with a urostomy, to sleep, uninterrupted by the need to empty their appliance. Many people with a urostomy have reported how they are amazed at how much urine is collected at night in the drainage bag. Generally, the 2 litre drainage bags are used at night but some people with a urostomy might prefer a leg bag. Whilst there are generic night drainage bags, there are also some that have specifically been designed to attach to the urostomy appliance used. The benefit of using a specifically designed night drainage bag is the reduced risk of urine escaping through the universal adaptor port that the urostomy appliance is attached to. The 2 litre night drainage bags are generally changed weekly.

It is important to note that purple bag syndrome can affect urostomates that use night drainage bags, although it is rare. The drainage bag can become a blue purple colour [39]. A common cause for the change in colour is bacteria and thus an infection, for which antibiotics should be considered. Purple bag syndrome can also affect the urostomy appliance.

Leg Bags

The use of a leg bag for people with a urostomy is dependent on personal circumstances. Examples may include wheelchair users who may benefit from using a leg bag attached to the urostomy appliance to allow for increased confidence in the flow of urine away from the urostomy without the belt of the wheelchair interfering in the urine flow. Other ostomates who might benefit from using a leg bag include people that travel for either work or pleasure as well as people whose working patterns do not allow for flexibility to access toileting facilities [40]. Leg bags are available in different lengths. In addition, some ostomates may find the use of a leg bag preferable at night as opposed to a night drainage bag, as it might be easier to turn and move in bed.

Appliance Adaptors

An appliance adaptor facilitates the connection of the urostomy appliance to a night drainage bag or a leg bag, predominantly a universal drainage bag such as those found in hospitals. Appliance adaptors are provided within the manufacturer's appliance boxes. In addition, many who have a urostomy find that attaching the adaptor to the appliance allows ease of emptying the appliance into the toilet, as the adapter provides a little extra length of tubing.

Appliance Changing Interval

Urostomy appliances have been designed with a longer wearing hydrocolloid within the skin barrier, due to the effects that urine can have on the hydrocolloid. A one piece appliance is changed anywhere between one to three days [41], for ostomates using a two piece system, the skin barrier may be changed two to three times per week, the appliance itself can be changed more frequently. As a general rule most people with a urostomy may change their appliance on alternative days, however how the urine interacts with the hydrocolloid on the appliance will be a very personal experience and will be determined by several factors such a medication, hydration, skin health and activity. Appliances should be not be changed more frequently than daily unless there is a clinical reason which has been investigated by the SSCN. It is important to investigate any situation if the urostomy appliance is being changed more frequently than daily, especially if leakage is being experienced or the peristomal skin becomes damaged or compromised.

Stoma Output

Unlike people who have a colostomy or ileostomy, people with a urostomy will find that the stoma constantly produces urine both during the day and at night. This can be problematic when the person is learning the art of changing the appliance, but as skills and confidence develop the stoma functioning during an appliance change becomes something that the person learns to deal with. Although, it is advisable to plan an appliance change so that urine output is low, such as in the morning before drinking.

As a guide the colour of the urine will be straw coloured although certain foods and medication may alter the colouring slightly. Examples of medication that may alter the urine colour include antibiotics, senna, and warfarin. In terms of foods that may alter the urine colour, these include beetroot, red fruit such as blackberries, rhubarb and strawberries. In addition drinks that have a vibrant colour will alter the colour of the urine [30]. For many people with a urostomy the reason for surgery will have been bladder cancer, so they may be anxious about the colour of the urine, particularly if there is any evidence of blood. This may explain why the choice of an appliance is commonly transparent for people who have a urostomy as it allows them to keep a careful eye on the output and react quickly to any changes.

Challenges Specific to Managing a Urostomy

Following surgery, finding the optimum suitable appliance is of paramount importance to help the person become confident to resume normal activities. Unique to people who have a urostomy will be the presence of mucus mixed in with the urine, which occurs due to the stoma being constructed from an ileal segment. In addition, people having the formation of a urostomy may find the establishing of a regular bowel pattern problematic following surgery due to the bowel resection that is required in order to create the stoma (see Chap. 9).

For people with a urostomy, diagnosing a urinary infection may be difficult as gaining a clean sample of urine requires catheterisation of the stoma. Symptoms of an infection include lower back pain and cloudy foul smelling urine, as well as a possible increase in the amount of mucus that is produced and present within the appliance. A reduction in the amount of urine produced over 24 hours may also give cause for concern. In certain circumstances stenosis of the ureter can occur, leading to the need for a nephrostomy tube to be inserted into the kidney to allow for the passage of urine. People with a urostomy need to be educated as to when to urgently seek medical advice, as an urinary infection will be upper urinary tract rather than lower (as the bladder is removed) (see Chap. 9).

As with other types of stoma the advice of the SSCN should be sought in the event of leakages, changes to the output and peristomal skin.

Other Specific Issues

Bleeding

Unsurprisingly, the appearance of blood for a patient is very frightening and they will require assurance that a small amount of bleeding especially when cleaning the stoma is normal especially in the first few weeks after formation. Patients who are too enthusiastic at cleaning on or near the stoma need to be reminded that the blood vessels on the stoma are easily knocked and are just below the level of the surface of the stoma; consequently minor bleeding may result but should resolve quickly.

Patients on anticoagulant therapy may experience minor bleeding which occurs easily, usually at the time the pouch is changed and cleaning is undertaken. Bleeding is usually seen as just flecks of blood on the wipe. However, patients on long term anticoagulant therapy need to ensure that their medication is reviewed and their clotting times are checked regularly as bleeding can occur more readily, particularly if the stoma is traumatised in any way. A patient experiencing major bleeding from the stoma following any trauma requires emergency advice and support with an urgent surgical review. Bleeding varices and trauma are discussed in Chap. 12.

Medication Effects

Medication can affect the gastrointestinal or urinary system for any person. However, for the ostomist, the effects may be noticeable in their stoma appearance or function. The side effects of chemotherapy, for example, can affect the patient's ability to manage their stoma care. Specifically, peripheral neuropathy in the fingers or palmar-plantar erythrodyaesthesia can present a challenge by reducing the patient's independence with managing a stoma care regime [42]. Involving a carer or family member with stoma care can help to resolve this issue; however, this is not always possible and a more formalised support system may be required (see Chap. 18).

Chemotherapy can also induce oral and oesophageal stomatitis which may affect the patient's appetite. An alteration in their bowel and/or urinary function can therefore follow and the SSCN may need to give advice and reassurance regarding dietary replacements. Antidiarrhoeal or laxative medication can be suggested as a short term measure to manage these symptoms whilst the patient remains on treatment [43]. Any persistent disturbance to bowel function should be investigated and treated accordingly. Minor bleeding from the stoma after chemotherapy can also occur. It should also be noted that some chemotherapy treatments, as well as causing oral and oesophageal stomatitis can induce inflammation and swelling of an individuals' stoma. Alterations to the size of the appliance aperture may be required and continued monitoring and reassessment is recommended. Peristomal skin issues can also occur during chemotherapy treatments, the patient must be made aware to inform their SSCN if they experience any change in peristomal skin appearance/condition during treatment [42]. Chemotherapy may need to be postponed or even abandoned if side effects are severe and disabling.

Antibiotics are also known to cause GI disturbance and the patient should be advised accordingly.

Some tablets can be more difficult for an ileostomist to absorb especially those in Modified Release or Enteric coated capsule format and even more so if the ileostomist has a liquid output and/or rapid transit time or short gut. Obviously, this needs to be addressed as the individual will not be absorbing the correct dosage of prescribed medication. Digoxin, Levothyroxine and Oral Contraceptive Pill are specific medications that are usually absorbed in the small bowel; however if an individual living with a stoma has a particularly high output, quick transit time, short gut or perhaps the ileostomist has eaten something causing faster transit time such medications may not be fully absorbed resulting in incorrect dosage which could be harmful, therefore ensuring that all patients are aware of this is paramount.

Cultural Issues

It is important for SSCNs to be sensitive and responsive to any cultural needs that may impact patients undergoing stoma formation and their subsequent care. It is vital for every nurse to have an awareness and a baseline understanding of their patient's religion and how any beliefs and needs can be affected by the formation of a stoma.

Most hydrocolloids used in stoma appliances and accessories contain a form of gelatin. The gelatin is commonly porcine in origin and therefore should be discussed with the patient prior to use. Gelatin is also found in some medications such as capsules e.g. Loperamide capsules.

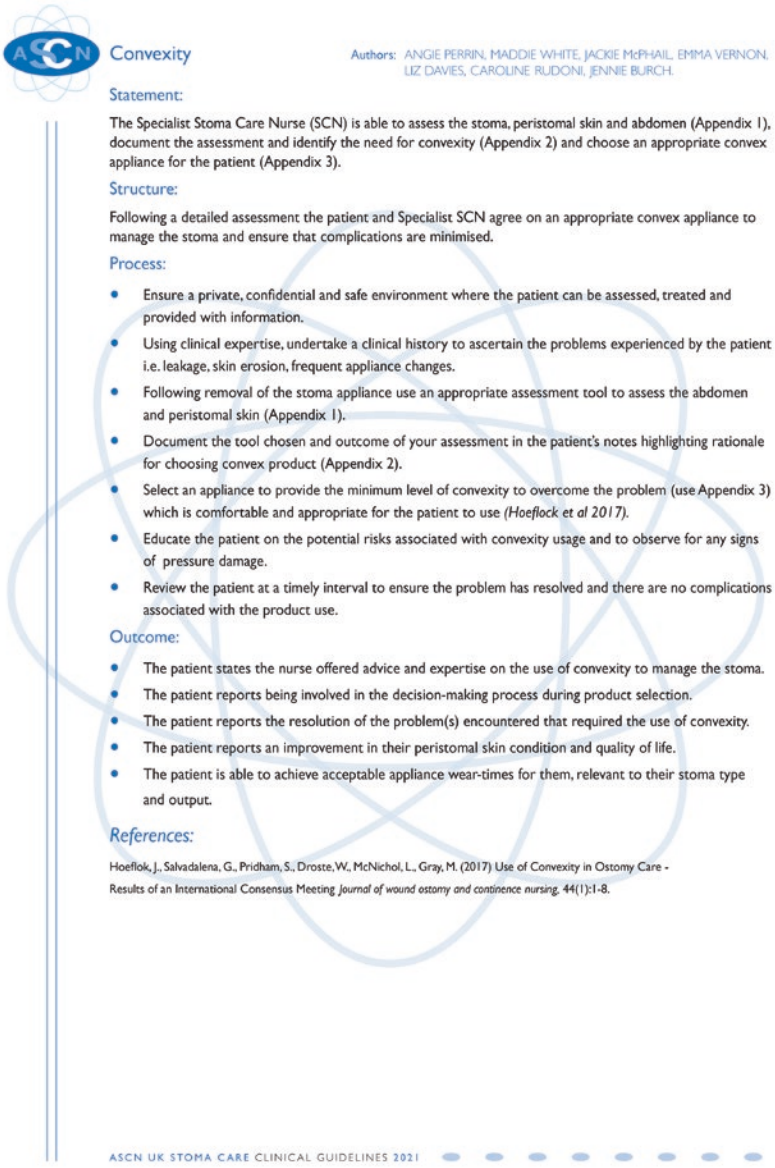
Detailed information is available from the ASCN UK guideline 2022 on Cultural and Religious implications relating to stoma care (Appendix 2).

Conclusion

The three main types of stoma, the colostomy, ileostomy and urostomy each require slightly different care needs. Life with a newly formed stoma may bring challenges and new patients have many concerns. SSCNs play a key role in offering people with a stoma and their family, information, support, guidance and counselling. This is provided in the peroperative and long-term scenario. The SSCN role also encompasses advising on management of a stoma with appropriate appliances and supporting products if necessary due to a clinical need.

It is important to understand what diets people with a stoma may consume as there is often confusion about diet. Additionally, it is important to understand stoma specific needs. For example, food types that can cause the individual with an ileostomy to have issues with a food bolus blockages. New stoma appliances are continually being developed and improved to meet the needs of ostomates, therefore ostomates may find newer products are more suitable to their needs. It is also essential for the SSCN to understand the effects that medication can have on the stoma and the patient's ability to manage their stoma in circumstances which affect their normal stoma routine.

Appendix 1. ASCN UK (2021) Convexity Guideline



Convexity

Authors: ANGIE PERRIN, MADDIE WHITE, JACKIE McPHAIL, EMMA VERNON, LIZ DAVIES, CAROLINE RUDONI, JENNIE BURCH.

Statement:

The Specialist Stoma Care Nurse (SCN) is able to assess the stoma, peristomal skin and abdomen (Appendix 1), document the assessment and identify the need for convexity (Appendix 2) and choose an appropriate convex appliance for the patient (Appendix 3).

Structure:

Following a detailed assessment the patient and Specialist SCN agree on an appropriate convex appliance to manage the stoma and ensure that complications are minimised.

Process:

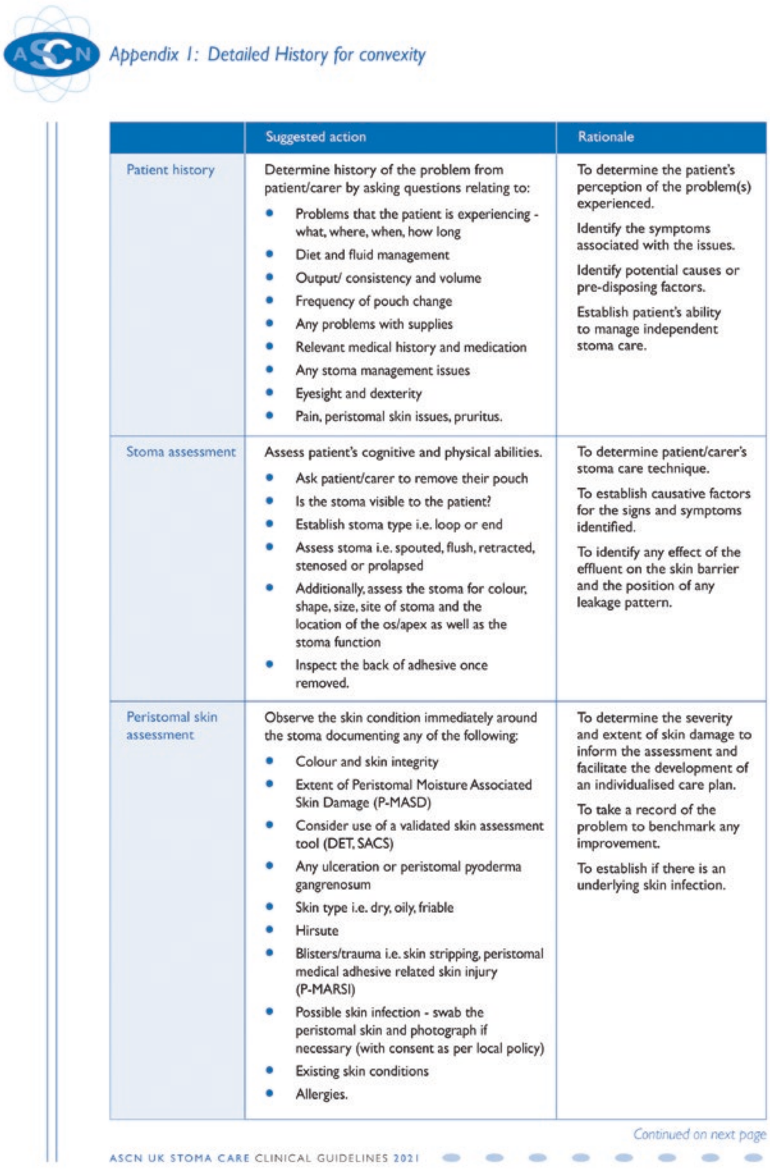
- Ensure a private, confidential and safe environment where the patient can be assessed, treated and provided with information.
- Using clinical expertise, undertake a clinical history to ascertain the problems experienced by the patient i.e. leakage, skin erosion, frequent appliance changes.
- Following removal of the stoma appliance use an appropriate assessment tool to assess the abdomen and peristomal skin (Appendix 1).
- Document the tool chosen and outcome of your assessment in the patient's notes highlighting rationale for choosing convex product (Appendix 2).
- Select an appliance to provide the minimum level of convexity to overcome the problem (use Appendix 3) which is comfortable and appropriate for the patient to use *(Hoeflock et al 2017).*
- Educate the patient on the potential risks associated with convexity usage and to observe for any signs of pressure damage.
- Review the patient at a timely interval to ensure the problem has resolved and there are no complications associated with the product use.

Outcome:

- The patient states the nurse offered advice and expertise on the use of convexity to manage the stoma.
- The patient reports being involved in the decision-making process during product selection.
- The patient reports the resolution of the problem(s) encountered that required the use of convexity.
- The patient reports an improvement in their peristomal skin condition and quality of life.
- The patient is able to achieve acceptable appliance wear-times for them, relevant to their stoma type and output.

References:

Hoeflok, J., Salvadalena, G., Pridham, S., Droste, W., McNichol, L., Gray, M. (2017) Use of Convexity in Ostomy Care - Results of an International Consensus Meeting *Journal of wound ostomy and continence nursing*, 44(1):1-8.



Appendix 1: Detailed History for convexity

	Suggested action	Rationale
Patient history	Determine history of the problem from patient/carer by asking questions relating to: • Problems that the patient is experiencing - what, where, when, how long • Diet and fluid management • Output/ consistency and volume • Frequency of pouch change • Any problems with supplies • Relevant medical history and medication • Any stoma management issues • Eyesight and dexterity • Pain, peristomal skin issues, pruritus.	To determine the patient's perception of the problem(s) experienced. Identify the symptoms associated with the issues. Identify potential causes or pre-disposing factors. Establish patient's ability to manage independent stoma care.
Stoma assessment	Assess patient's cognitive and physical abilities. • Ask patient/carer to remove their pouch • Is the stoma visible to the patient? • Establish stoma type i.e. loop or end • Assess stoma i.e. spouted, flush, retracted, stenosed or prolapsed • Additionally, assess the stoma for colour, shape, size, site of stoma and the location of the os/apex as well as the stoma function • Inspect the back of adhesive once removed.	To determine patient/carer's stoma care technique. To establish causative factors for the signs and symptoms identified. To identify any effect of the effluent on the skin barrier and the position of any leakage pattern.
Peristomal skin assessment	Observe the skin condition immediately around the stoma documenting any of the following: • Colour and skin integrity • Extent of Peristomal Moisture Associated Skin Damage (P-MASD) • Consider use of a validated skin assessment tool (DET, SACS) • Any ulceration or peristomal pyoderma gangrenosum • Skin type i.e. dry, oily, friable • Hirsute • Blisters/trauma i.e. skin stripping, peristomal medical adhesive related skin injury (P-MARSI) • Possible skin infection - swab the peristomal skin and photograph if necessary (with consent as per local policy) • Existing skin conditions • Allergies.	To determine the severity and extent of skin damage to inform the assessment and facilitate the development of an individualised care plan. To take a record of the problem to benchmark any improvement. To establish if there is an underlying skin infection.

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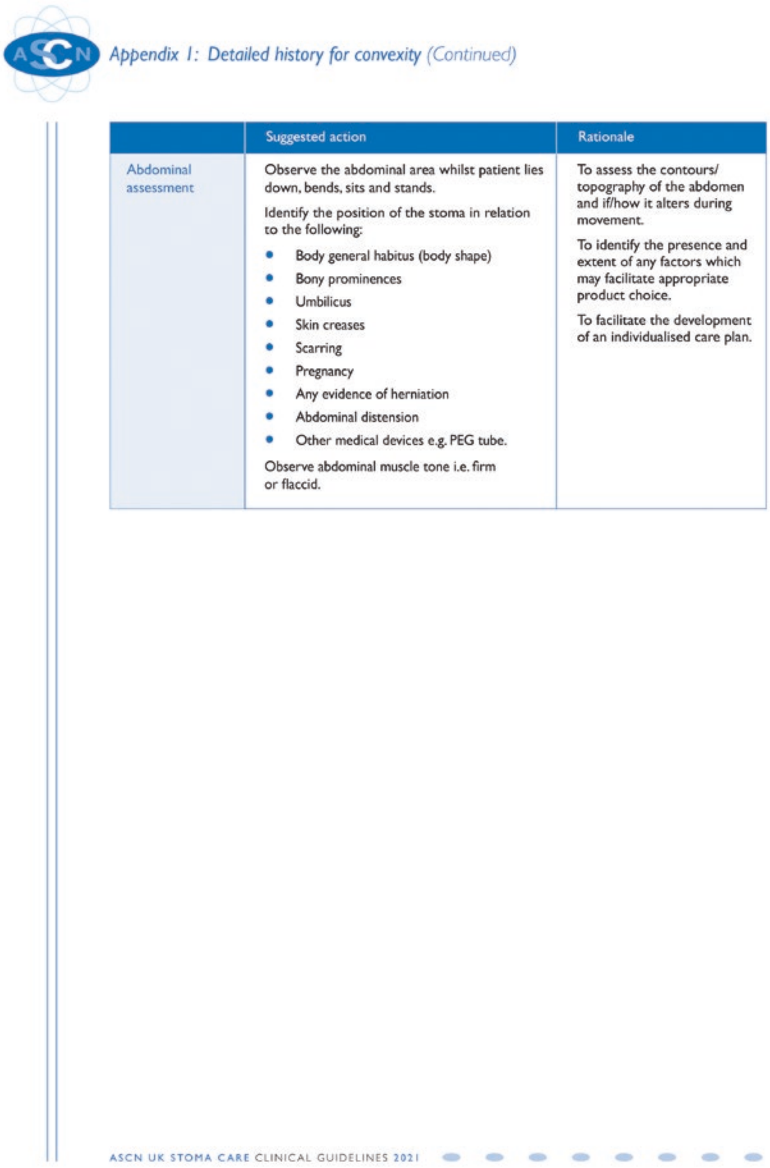
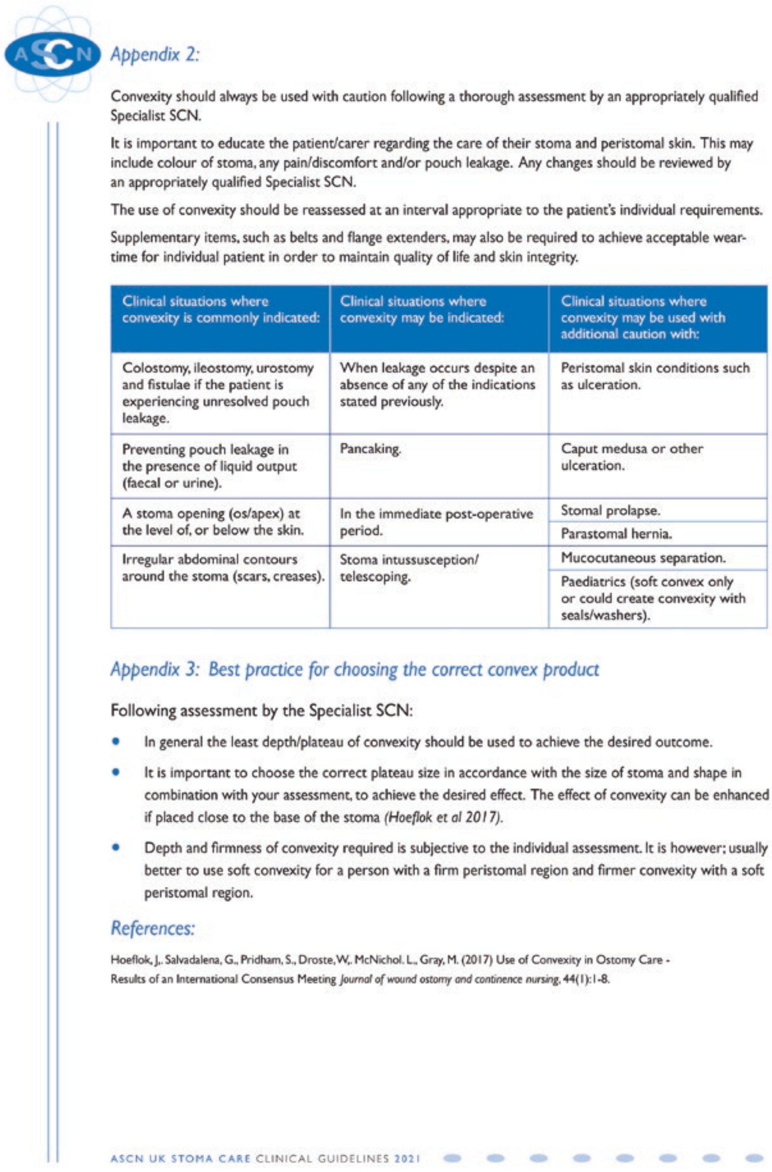
ASCN UK STOMA CARE CLINICAL GUIDELINES 2021



Appendix 1: Detailed history for convexity *(Continued)*

	Suggested action	Rationale
Abdominal assessment	Observe the abdominal area whilst patient lies down, bends, sits and stands. Identify the position of the stoma in relation to the following: • Body general habitus (body shape) • Bony prominences • Umbilicus • Skin creases • Scarring • Pregnancy • Any evidence of herniation • Abdominal distension • Other medical devices e.g. PEG tube. Observe abdominal muscle tone i.e. firm or flaccid.	To assess the contours/topography of the abdomen and if/how it alters during movement. To identify the presence and extent of any factors which may facilitate appropriate product choice. To facilitate the development of an individualised care plan.



Appendix 2:

Convexity should always be used with caution following a thorough assessment by an appropriately qualified Specialist SCN.

It is important to educate the patient/carer regarding the care of their stoma and peristomal skin. This may include colour of stoma, any pain/discomfort and/or pouch leakage. Any changes should be reviewed by an appropriately qualified Specialist SCN.

The use of convexity should be reassessed at an interval appropriate to the patient's individual requirements.

Supplementary items, such as belts and flange extenders, may also be required to achieve acceptable wear-time for individual patient in order to maintain quality of life and skin integrity.

Clinical situations where convexity is commonly indicated:	Clinical situations where convexity may be indicated:	Clinical situations where convexity may be used with additional caution with:
Colostomy, ileostomy, urostomy and fistulae if the patient is experiencing unresolved pouch leakage.	When leakage occurs despite an absence of any of the indications stated previously.	Peristomal skin conditions such as ulceration.
Preventing pouch leakage in the presence of liquid output (faecal or urine).	Pancaking.	Caput medusa or other ulceration.
A stoma opening (os/apex) at the level of, or below the skin.	In the immediate post-operative period.	Stomal prolapse.
		Parastomal hernia.
Irregular abdominal contours around the stoma (scars, creases).	Stoma intussusception/ telescoping.	Mucocutaneous separation.
		Paediatrics (soft convex only or could create convexity with seals/washers).

Appendix 3: Best practice for choosing the correct convex product

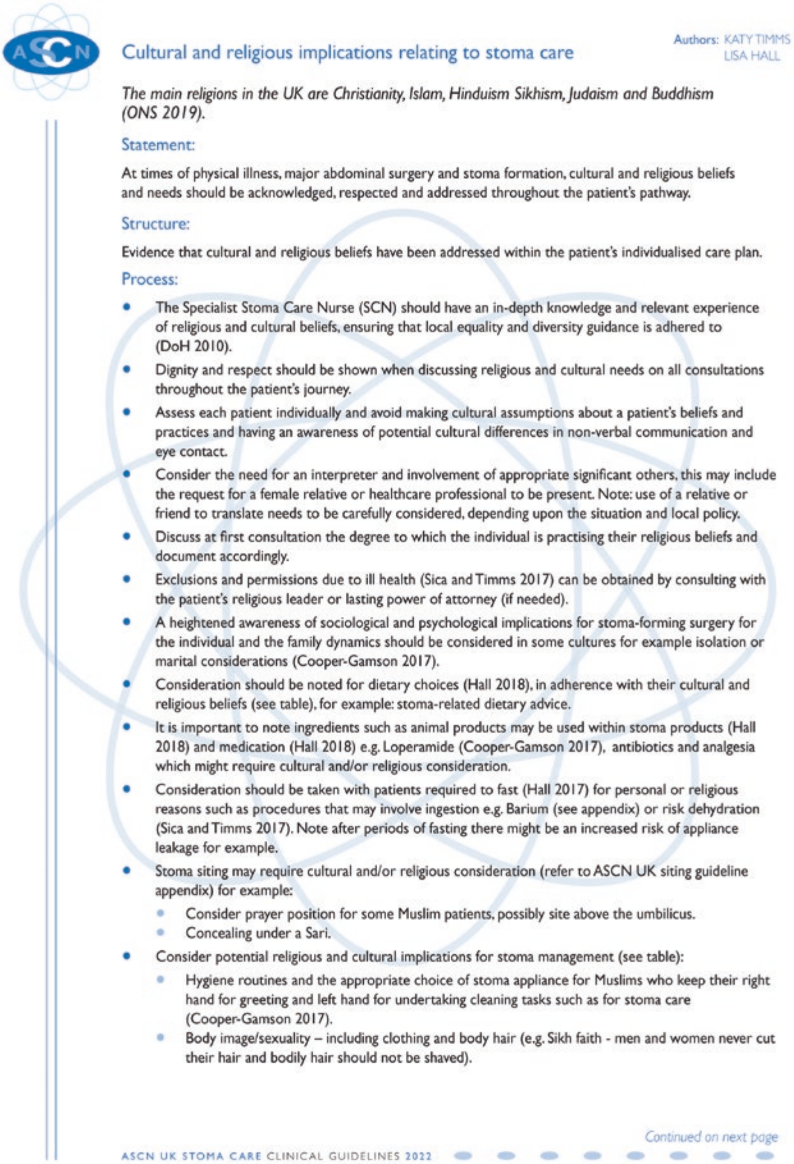
Following assessment by the Specialist SCN:

- In general the least depth/plateau of convexity should be used to achieve the desired outcome.
- It is important to choose the correct plateau size in accordance with the size of stoma and shape in combination with your assessment, to achieve the desired effect. The effect of convexity can be enhanced if placed close to the base of the stoma *(Hoeflok et al 2017)*.
- Depth and firmness of convexity required is subjective to the individual assessment. It is however; usually better to use soft convexity for a person with a firm peristomal region and firmer convexity with a soft peristomal region.

References:

Hoeflok, J., Salvadalena, G., Pridham, S., Droste, W., McNichol. L., Gray, M. (2017) Use of Convexity in Ostomy Care - Results of an International Consensus Meeting *Journal of wound ostomy and continence nursing*, 44(1):1-8.

Appendix 2. ASCN UK (2022) Cultural and Religious implications relating to stoma care.



Cultural and religious implications relating to stoma care

Authors: KATY TIMMS
LISA HALL

The main religions in the UK are Christianity, Islam, Hinduism Sikhism, Judaism and Buddhism (ONS 2019).

Statement:

At times of physical illness, major abdominal surgery and stoma formation, cultural and religious beliefs and needs should be acknowledged, respected and addressed throughout the patient's pathway.

Structure:

Evidence that cultural and religious beliefs have been addressed within the patient's individualised care plan.

Process:

- The Specialist Stoma Care Nurse (SCN) should have an in-depth knowledge and relevant experience of religious and cultural beliefs, ensuring that local equality and diversity guidance is adhered to (DoH 2010).
- Dignity and respect should be shown when discussing religious and cultural needs on all consultations throughout the patient's journey.
- Assess each patient individually and avoid making cultural assumptions about a patient's beliefs and practices and having an awareness of potential cultural differences in non-verbal communication and eye contact.
- Consider the need for an interpreter and involvement of appropriate significant others, this may include the request for a female relative or healthcare professional to be present. Note: use of a relative or friend to translate needs to be carefully considered, depending upon the situation and local policy.
- Discuss at first consultation the degree to which the individual is practising their religious beliefs and document accordingly.
- Exclusions and permissions due to ill health (Sica and Timms 2017) can be obtained by consulting with the patient's religious leader or lasting power of attorney (if needed).
- A heightened awareness of sociological and psychological implications for stoma-forming surgery for the individual and the family dynamics should be considered in some cultures for example isolation or marital considerations (Cooper-Gamson 2017).
- Consideration should be noted for dietary choices (Hall 2018), in adherence with their cultural and religious beliefs (see table), for example: stoma-related dietary advice.
- It is important to note ingredients such as animal products may be used within stoma products (Hall 2018) and medication (Hall 2018) e.g. Loperamide (Cooper-Gamson 2017), antibiotics and analgesia which might require cultural and/or religious consideration.
- Consideration should be taken with patients required to fast (Hall 2017) for personal or religious reasons such as procedures that may involve ingestion e.g. Barium (see appendix) or risk dehydration (Sica and Timms 2017). Note after periods of fasting there might be an increased risk of appliance leakage for example.
- Stoma siting may require cultural and/or religious consideration (refer to ASCN UK siting guideline appendix) for example:
  - Consider prayer position for some Muslim patients, possibly site above the umbilicus.
  - Concealing under a Sari.
- Consider potential religious and cultural implications for stoma management (see table):
  - Hygiene routines and the appropriate choice of stoma appliance for Muslims who keep their right hand for greeting and left hand for undertaking cleaning tasks such as for stoma care (Cooper-Gamson 2017).
  - Body image/sexuality – including clothing and body hair (e.g. Sikh faith - men and women never cut their hair and bodily hair should not be shaved).

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Cultural and religious implications relating to stoma care *(continued)*

  - Be aware of religious practice; including wearing of cultural clothing for particular ceremonies, religious symbolic items (Hall 2018), rituals, worship and festivals.
  - For home visits consider; timing of visits in relation to religious practices and ask about the need to remove shoes on entering the home.
- Utilise materials and teaching techniques culturally relevant for the patient and family for example the need for interpreters and written information in the relevant language.

Outcome:

The patient states the SCN has offered appropriate advice and consideration in relation to their cultural and religious needs.

References for cultural and religeous implications:

Akgül, B. & Karadag, A. (2016) The Effect of Colostomy and Ileostomy on Acts of Worship in the Islamic Faith. *Journal of Wound, Ostomy, and Continence Nursing* 43(4) 392-397

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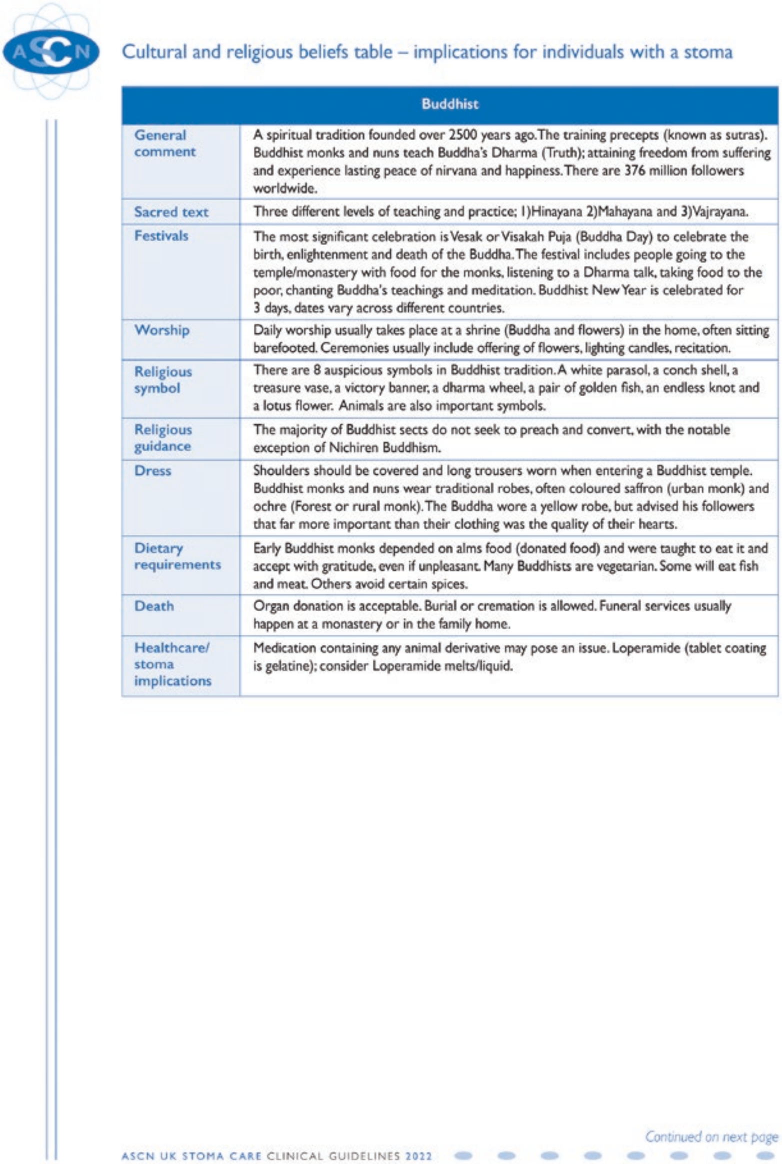
Sica, J. and Timms, K. (2017) A guide to stoma care for Jewish patients. *Gastrointestinal Nursing* 15 (1) 26-29 https://www.magonlinelibrary.com/doi/abs/10.12968/gasn.2017.15.1.26?journalCode=gasn



Cultural and religious beliefs table – implications for individuals with a stoma

Buddhist	
General comment	A spiritual tradition founded over 2500 years ago. The training precepts (known as sutras). Buddhist monks and nuns teach Buddha's Dharma (Truth); attaining freedom from suffering and experience lasting peace of nirvana and happiness. There are 376 million followers worldwide.
Sacred text	Three different levels of teaching and practice; 1)Hinayana 2)Mahayana and 3)Vajrayana.
Festivals	The most significant celebration is Vesak or Visakah Puja (Buddha Day) to celebrate the birth, enlightenment and death of the Buddha. The festival includes people going to the temple/monastery with food for the monks, listening to a Dharma talk, taking food to the poor, chanting Buddha's teachings and meditation. Buddhist New Year is celebrated for 3 days, dates vary across different countries.
Worship	Daily worship usually takes place at a shrine (Buddha and flowers) in the home, often sitting barefooted. Ceremonies usually include offering of flowers, lighting candles, recitation.
Religious symbol	There are 8 auspicious symbols in Buddhist tradition. A white parasol, a conch shell, a treasure vase, a victory banner, a dharma wheel, a pair of golden fish, an endless knot and a lotus flower. Animals are also important symbols.
Religious guidance	The majority of Buddhist sects do not seek to preach and convert, with the notable exception of Nichiren Buddhism.
Dress	Shoulders should be covered and long trousers worn when entering a Buddhist temple. Buddhist monks and nuns wear traditional robes, often coloured saffron (urban monk) and ochre (Forest or rural monk). The Buddha wore a yellow robe, but advised his followers that far more important than their clothing was the quality of their hearts.
Dietary requirements	Early Buddhist monks depended on alms food (donated food) and were taught to eat it and accept with gratitude, even if unpleasant. Many Buddhists are vegetarian. Some will eat fish and meat. Others avoid certain spices.
Death	Organ donation is acceptable. Burial or cremation is allowed. Funeral services usually happen at a monastery or in the family home.
Healthcare/ stoma implications	Medication containing any animal derivative may pose an issue. Loperamide (tablet coating is gelatine); consider Loperamide melts/liquid.

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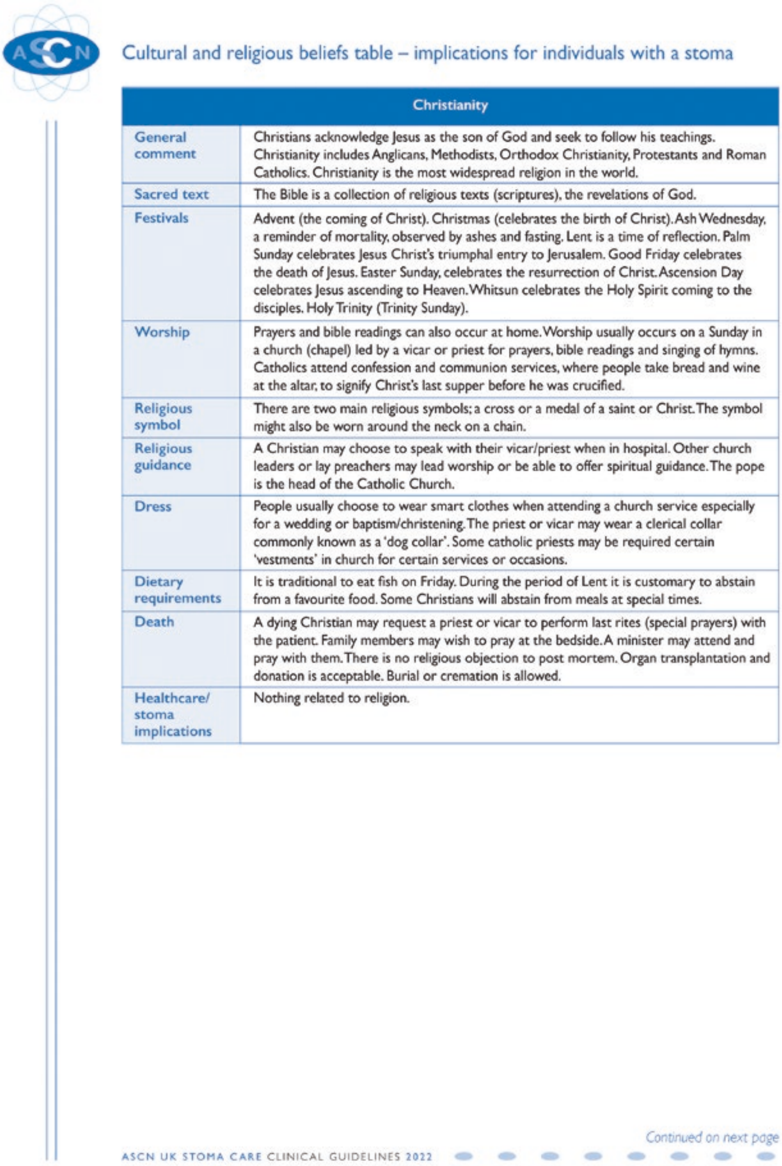

Cultural and religious beliefs table – implications for individuals with a stoma

Christianity	
General comment	Christians acknowledge Jesus as the son of God and seek to follow his teachings. Christianity includes Anglicans, Methodists, Orthodox Christianity, Protestants and Roman Catholics. Christianity is the most widespread religion in the world.
Sacred text	The Bible is a collection of religious texts (scriptures), the revelations of God.
Festivals	Advent (the coming of Christ). Christmas (celebrates the birth of Christ). Ash Wednesday, a reminder of mortality, observed by ashes and fasting. Lent is a time of reflection. Palm Sunday celebrates Jesus Christ's triumphal entry to Jerusalem. Good Friday celebrates the death of Jesus. Easter Sunday, celebrates the resurrection of Christ. Ascension Day celebrates Jesus ascending to Heaven. Whitsun celebrates the Holy Spirit coming to the disciples. Holy Trinity (Trinity Sunday).
Worship	Prayers and bible readings can also occur at home. Worship usually occurs on a Sunday in a church (chapel) led by a vicar or priest for prayers, bible readings and singing of hymns. Catholics attend confession and communion services, where people take bread and wine at the altar, to signify Christ's last supper before he was crucified.
Religious symbol	There are two main religious symbols; a cross or a medal of a saint or Christ. The symbol might also be worn around the neck on a chain.
Religious guidance	A Christian may choose to speak with their vicar/priest when in hospital. Other church leaders or lay preachers may lead worship or be able to offer spiritual guidance. The pope is the head of the Catholic Church.
Dress	People usually choose to wear smart clothes when attending a church service especially for a wedding or baptism/christening. The priest or vicar may wear a clerical collar commonly known as a 'dog collar'. Some catholic priests may be required certain 'vestments' in church for certain services or occasions.
Dietary requirements	It is traditional to eat fish on Friday. During the period of Lent it is customary to abstain from a favourite food. Some Christians will abstain from meals at special times.
Death	A dying Christian may request a priest or vicar to perform last rites (special prayers) with the patient. Family members may wish to pray at the bedside. A minister may attend and pray with them. There is no religious objection to post mortem. Organ transplantation and donation is acceptable. Burial or cremation is allowed.
Healthcare/ stoma implications	Nothing related to religion.

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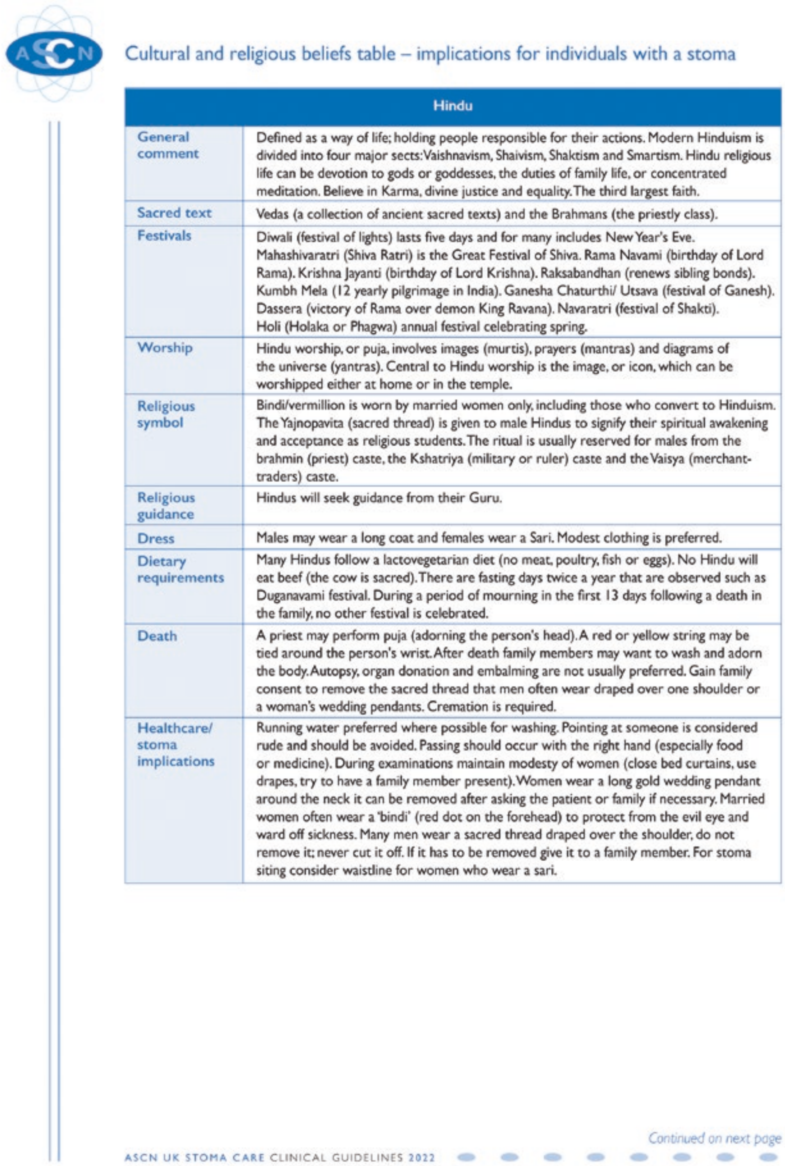

Cultural and religious beliefs table – implications for individuals with a stoma

Hindu	
General comment	Defined as a way of life; holding people responsible for their actions. Modern Hinduism is divided into four major sects: Vaishnavism, Shaivism, Shaktism and Smartism. Hindu religious life can be devotion to gods or goddesses, the duties of family life, or concentrated meditation. Believe in Karma, divine justice and equality. The third largest faith.
Sacred text	Vedas (a collection of ancient sacred texts) and the Brahmans (the priestly class).
Festivals	Diwali (festival of lights) lasts five days and for many includes New Year's Eve. Mahashivaratri (Shiva Ratri) is the Great Festival of Shiva. Rama Navami (birthday of Lord Rama). Krishna Jayanti (birthday of Lord Krishna). Raksabandhan (renews sibling bonds). Kumbh Mela (12 yearly pilgrimage in India). Ganesha Chaturthi/ Utsava (festival of Ganesh). Dassera (victory of Rama over demon King Ravana). Navaratri (festival of Shakti). Holi (Holaka or Phagwa) annual festival celebrating spring.
Worship	Hindu worship, or puja, involves images (murtis), prayers (mantras) and diagrams of the universe (yantras). Central to Hindu worship is the image, or icon, which can be worshipped either at home or in the temple.
Religious symbol	Bindi/vermillion is worn by married women only, including those who convert to Hinduism. The Yajnopavita (sacred thread) is given to male Hindus to signify their spiritual awakening and acceptance as religious students. The ritual is usually reserved for males from the brahmin (priest) caste, the Kshatriya (military or ruler) caste and the Vaisya (merchant-traders) caste.
Religious guidance	Hindus will seek guidance from their Guru.
Dress	Males may wear a long coat and females wear a Sari. Modest clothing is preferred.
Dietary requirements	Many Hindus follow a lactovegetarian diet (no meat, poultry, fish or eggs). No Hindu will eat beef (the cow is sacred). There are fasting days twice a year that are observed such as Duganavami festival. During a period of mourning in the first 13 days following a death in the family, no other festival is celebrated.
Death	A priest may perform puja (adorning the person's head). A red or yellow string may be tied around the person's wrist. After death family members may want to wash and adorn the body. Autopsy, organ donation and embalming are not usually preferred. Gain family consent to remove the sacred thread that men often wear draped over one shoulder or a woman's wedding pendants. Cremation is required.
Healthcare/ stoma implications	Running water preferred where possible for washing. Pointing at someone is considered rude and should be avoided. Passing should occur with the right hand (especially food or medicine). During examinations maintain modesty of women (close bed curtains, use drapes, try to have a family member present). Women wear a long gold wedding pendant around the neck it can be removed after asking the patient or family if necessary. Married women often wear a 'bindi' (red dot on the forehead) to protect from the evil eye and ward off sickness. Many men wear a sacred thread draped over the shoulder, do not remove it; never cut it off. If it has to be removed give it to a family member. For stoma siting consider waistline for women who wear a sari.

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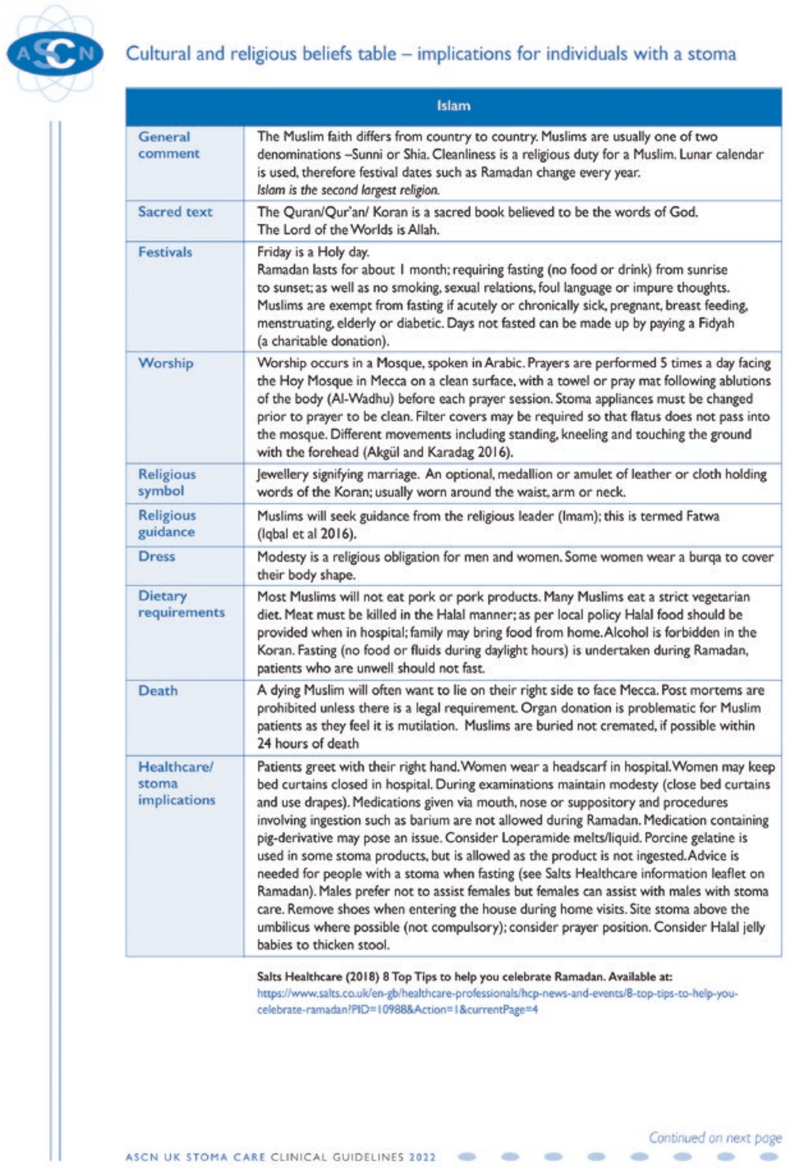

Cultural and religious beliefs table – implications for individuals with a stoma

	Islam
General comment	The Muslim faith differs from country to country. Muslims are usually one of two denominations –Sunni or Shia. Cleanliness is a religious duty for a Muslim. Lunar calendar is used, therefore festival dates such as Ramadan change every year. *Islam is the second largest religion.*
Sacred text	The Quran/Qur'an/ Koran is a sacred book believed to be the words of God. The Lord of the Worlds is Allah.
Festivals	Friday is a Holy day. Ramadan lasts for about 1 month; requiring fasting (no food or drink) from sunrise to sunset; as well as no smoking, sexual relations, foul language or impure thoughts. Muslims are exempt from fasting if acutely or chronically sick, pregnant, breast feeding, menstruating, elderly or diabetic. Days not fasted can be made up by paying a Fidyah (a charitable donation).
Worship	Worship occurs in a Mosque, spoken in Arabic. Prayers are performed 5 times a day facing the Hoy Mosque in Mecca on a clean surface, with a towel or pray mat following ablutions of the body (Al-Wadhu) before each prayer session. Stoma appliances must be changed prior to prayer to be clean. Filter covers may be required so that flatus does not pass into the mosque. Different movements including standing, kneeling and touching the ground with the forehead (Akgül and Karadag 2016).
Religious symbol	Jewellery signifying marriage. An optional, medallion or amulet of leather or cloth holding words of the Koran; usually worn around the waist, arm or neck.
Religious guidance	Muslims will seek guidance from the religious leader (Imam); this is termed Fatwa (Iqbal et al 2016).
Dress	Modesty is a religious obligation for men and women. Some women wear a burqa to cover their body shape.
Dietary requirements	Most Muslims will not eat pork or pork products. Many Muslims eat a strict vegetarian diet. Meat must be killed in the Halal manner; as per local policy Halal food should be provided when in hospital; family may bring food from home. Alcohol is forbidden in the Koran. Fasting (no food or fluids during daylight hours) is undertaken during Ramadan, patients who are unwell should not fast.
Death	A dying Muslim will often want to lie on their right side to face Mecca. Post mortems are prohibited unless there is a legal requirement. Organ donation is problematic for Muslim patients as they feel it is mutilation. Muslims are buried not cremated, if possible within 24 hours of death
Healthcare/ stoma implications	Patients greet with their right hand. Women wear a headscarf in hospital. Women may keep bed curtains closed in hospital. During examinations maintain modesty (close bed curtains and use drapes). Medications given via mouth, nose or suppository and procedures involving ingestion such as barium are not allowed during Ramadan. Medication containing pig-derivative may pose an issue. Consider Loperamide melts/liquid. Porcine gelatine is used in some stoma products, but is allowed as the product is not ingested. Advice is needed for people with a stoma when fasting (see Salts Healthcare information leaflet on Ramadan). Males prefer not to assist females but females can assist with males with stoma care. Remove shoes when entering the house during home visits. Site stoma above the umbilicus where possible (not compulsory); consider prayer position. Consider Halal jelly babies to thicken stool.

Salts Healthcare (2018) 8 Top Tips to help you celebrate Ramadan. Available at:
https://www.salts.co.uk/en-gb/healthcare-professionals/hcp-news-and-events/8-top-tips-to-help-you-celebrate-ramadan?PID=10988&Action=1&currentPage=4

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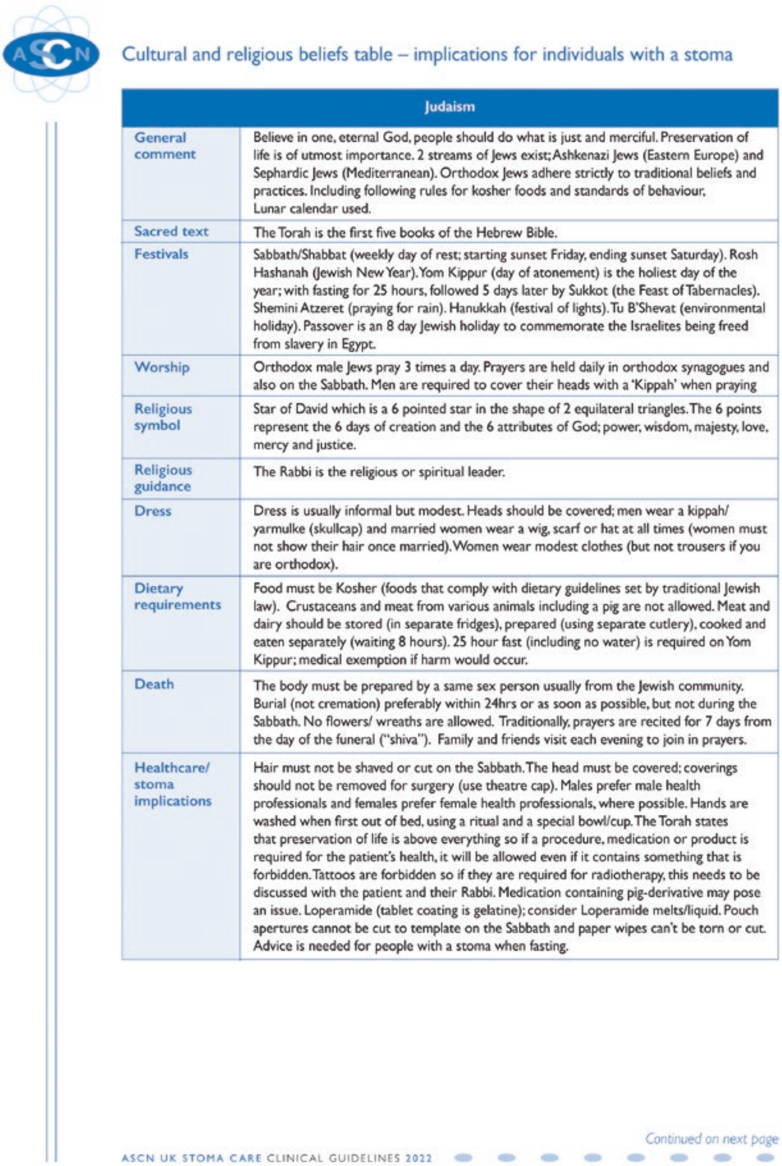

Cultural and religious beliefs table – implications for individuals with a stoma

Judaism	
General comment	Believe in one, eternal God, people should do what is just and merciful. Preservation of life is of utmost importance. 2 streams of Jews exist; Ashkenazi Jews (Eastern Europe) and Sephardic Jews (Mediterranean). Orthodox Jews adhere strictly to traditional beliefs and practices. Including following rules for kosher foods and standards of behaviour. Lunar calendar used.
Sacred text	The Torah is the first five books of the Hebrew Bible.
Festivals	Sabbath/Shabbat (weekly day of rest; starting sunset Friday, ending sunset Saturday). Rosh Hashanah (Jewish New Year). Yom Kippur (day of atonement) is the holiest day of the year; with fasting for 25 hours, followed 5 days later by Sukkot (the Feast of Tabernacles). Shemini Atzeret (praying for rain). Hanukkah (festival of lights). Tu B'Shevat (environmental holiday). Passover is an 8 day Jewish holiday to commemorate the Israelites being freed from slavery in Egypt.
Worship	Orthodox male Jews pray 3 times a day. Prayers are held daily in orthodox synagogues and also on the Sabbath. Men are required to cover their heads with a 'Kippah' when praying
Religious symbol	Star of David which is a 6 pointed star in the shape of 2 equilateral triangles. The 6 points represent the 6 days of creation and the 6 attributes of God; power, wisdom, majesty, love, mercy and justice.
Religious guidance	The Rabbi is the religious or spiritual leader.
Dress	Dress is usually informal but modest. Heads should be covered; men wear a kippah/ yarmulke (skullcap) and married women wear a wig, scarf or hat at all times (women must not show their hair once married). Women wear modest clothes (but not trousers if you are orthodox).
Dietary requirements	Food must be Kosher (foods that comply with dietary guidelines set by traditional Jewish law). Crustaceans and meat from various animals including a pig are not allowed. Meat and dairy should be stored (in separate fridges), prepared (using separate cutlery), cooked and eaten separately (waiting 8 hours). 25 hour fast (including no water) is required on Yom Kippur; medical exemption if harm would occur.
Death	The body must be prepared by a same sex person usually from the Jewish community. Burial (not cremation) preferably within 24hrs or as soon as possible, but not during the Sabbath. No flowers/ wreaths are allowed. Traditionally, prayers are recited for 7 days from the day of the funeral ("shiva"). Family and friends visit each evening to join in prayers.
Healthcare/ stoma implications	Hair must not be shaved or cut on the Sabbath. The head must be covered; coverings should not be removed for surgery (use theatre cap). Males prefer male health professionals and females prefer female health professionals, where possible. Hands are washed when first out of bed, using a ritual and a special bowl/cup. The Torah states that preservation of life is above everything so if a procedure, medication or product is required for the patient's health, it will be allowed even if it contains something that is forbidden. Tattoos are forbidden so if they are required for radiotherapy, this needs to be discussed with the patient and their Rabbi. Medication containing pig-derivative may pose an issue. Loperamide (tablet coating is gelatine); consider Loperamide melts/liquid. Pouch apertures cannot be cut to template on the Sabbath and paper wipes can't be torn or cut. Advice is needed for people with a stoma when fasting.

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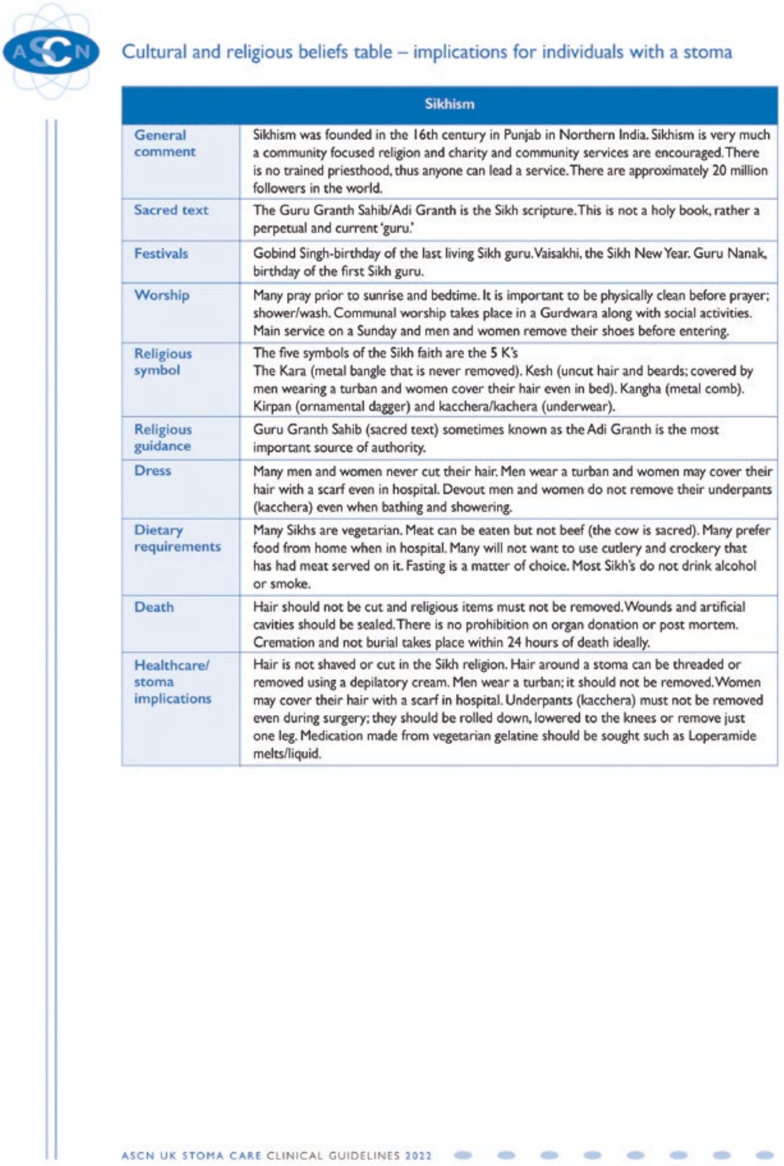

Cultural and religious beliefs table – implications for individuals with a stoma

Sikhism	
General comment	Sikhism was founded in the 16th century in Punjab in Northern India. Sikhism is very much a community focused religion and charity and community services are encouraged. There is no trained priesthood, thus anyone can lead a service. There are approximately 20 million followers in the world.
Sacred text	The Guru Granth Sahib/Adi Granth is the Sikh scripture. This is not a holy book, rather a perpetual and current 'guru.'
Festivals	Gobind Singh-birthday of the last living Sikh guru. Vaisakhi, the Sikh New Year. Guru Nanak, birthday of the first Sikh guru.
Worship	Many pray prior to sunrise and bedtime. It is important to be physically clean before prayer; shower/wash. Communal worship takes place in a Gurdwara along with social activities. Main service on a Sunday and men and women remove their shoes before entering.
Religious symbol	The five symbols of the Sikh faith are the 5 K's The Kara (metal bangle that is never removed). Kesh (uncut hair and beards; covered by men wearing a turban and women cover their hair even in bed). Kangha (metal comb). Kirpan (ornamental dagger) and kacchera/kachera (underwear).
Religious guidance	Guru Granth Sahib (sacred text) sometimes known as the Adi Granth is the most important source of authority.
Dress	Many men and women never cut their hair. Men wear a turban and women may cover their hair with a scarf even in hospital. Devout men and women do not remove their underpants (kacchera) even when bathing and showering.
Dietary requirements	Many Sikhs are vegetarian. Meat can be eaten but not beef (the cow is sacred). Many prefer food from home when in hospital. Many will not want to use cutlery and crockery that has had meat served on it. Fasting is a matter of choice. Most Sikh's do not drink alcohol or smoke.
Death	Hair should not be cut and religious items must not be removed. Wounds and artificial cavities should be sealed. There is no prohibition on organ donation or post mortem. Cremation and not burial takes place within 24 hours of death ideally.
Healthcare/ stoma implications	Hair is not shaved or cut in the Sikh religion. Hair around a stoma can be threaded or removed using a depilatory cream. Men wear a turban; it should not be removed. Women may cover their hair with a scarf in hospital. Underpants (kacchera) must not be removed even during surgery; they should be rolled down, lowered to the knees or remove just one leg. Medication made from vegetarian gelatine should be sought such as Loperamide melts/liquid.

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Patient Assessment and Stoma Siting

11

Emma Vernon

Learning Outcomes
1. Explain the consequences of a poorly sited stoma
2. Describe why a holistic assessment is important during the pre-operative phase
3. Understand the rationale for stoma siting and the information required by the patient.
4. List ways in which you could record/document the stoma siting.

Introduction

Why is stoma siting important? To maximise the patient's quality of life with a stoma, the optimum site should be chosen. By observing the patient lying flat, sitting, standing, and bending, a flat abdominal surface is identified. This is to ensure that there are no leaks after stoma formation. It is also to ensure the patient agrees with the proposed position of the stoma in relation to being able to undertake self-care, making decisions relating to their lifestyle and clothing [1]. Preoperative stoma siting is ideally performed by a suitably qualified Registered Nurse to identify the preferred position in order for the surgeon to create a stoma, by marking the patient's abdomen following informed consent [2]. Usually, a colostomy is sited in the left iliac fossa and an ileostomy and urostomy are sited in the right iliac fossa of the abdomen.

The 2011 census highlights that 13% of the population (7.5 million people) in England and Wales were born overseas [3], thus it is advisable for the Stoma Care Nurse to have awareness, knowledge and understanding of the patients religious and cultural beliefs and how this might affect the way they care for their stoma. When

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considering the religion of the UK population, 59% were Christian, 5% were Muslim, 0.4% were ‘other’ religion, with 25% having no religion [3]. Black [4] highlights that in the Muslim faith, when a stoma is positioned above the level of the umbilicus the output is considered dirty and defiling and so cannot be touched. Another factor to consider with Muslim patients is that they use their right hand to eat food and greet others and their left hand for cleaning themselves [4, 5]. These aspects will need to be discussed and considered during the pre-operative and siting counselling session(s). It is important to remember that everyone is individual, and that it should not be assumed that any faith should affect how a patient manages their stoma care. People follow and acknowledge their faith in different ways, the specialist stoma care nurse (SSCN) should always ask the patient if they feel that any aspect of their faith might affect their ability to manage their individual stoma care.

History

The principle of stoma siting has not differed over the years since SSCNs accepted responsibility for this role to take over from the surgeon. The first stoma recorded was a Colostomy in 1710 which was located in the patient’s left groin area [1]. There is a paucity of data in relation to stoma siting with no specific year mentioned within the literature. Leyk et al [1] discuss early papers and research referring to stoma siting as the “stoma location” or “stoma placement”. Norma N Gill, an American Nurse, as early as 1958 suggested stoma siting preoperatively should be commonplace for any Stoma Care Nurse [1]. In the UK, SSCNs started to site patients soon after 1989; Wade [6] claimed that as late as 1989, it was still the role of the surgeon to site patients once they have been anaesthetised. Rust [7] however states within her research review, that following the development of the nurse specialist role, stoma siting became a fundamental aspect of role of the SSCN. Patients were seen to be better psychologically prepared for surgery and their stoma after consultation with a SSCN as this provided a more holistic approach.

Prior to 1980’s there was very little evidence to suggest that a SSCN’s pre-operative education and siting offered better outcomes than the surgeon siting the patient on the operating table. Burke [8] examines the rate of post-operative complications and length of stay if the patient is reviewed pre-operatively for counselling, education and siting by a SSCN. Burke [8] identified that patients who were seen prior to surgery had less post-operative stoma complications and a decreased length of stay within a hospital setting.

The consequences of a poorly sited stoma are well identified in clinical practice and within the literature [5, 7–9]. A poorly sited stoma will have a detrimental effect on a patient’s quality of life and is a familiar issue to SSCNs within their clinical practice. A poorly sited stoma can lead to difficulties with pouching the stoma causing leakages and consequently sore peristomal skin. This can be due to the stoma being situated in a crease or the patient not being able to visualise the stoma [7, 9, 10]. Rust [10] states that if the bowel is under tension following an emergency colorectal procedure, this can have a harmful effect on the blood supply. The author suggests that in some instances this can lead to the stoma becoming necrotic, which may lead to a complete dehiscence of the stoma from the mucocutaneous junction and consequently stenosis. Elcoat [11] identifies that any of these complications can lead to psychological frustration, resentment, and possible social isolation.

Holistic Assessment

As SSCNs we need to consider and acknowledge all aspects of the patient's life and their needs; it is the reason why pre-operative siting is a fundamental part of our role. Historically patients' physical needs have been focussed upon, however, since the SSCN role evolved to undertake stoma siting the patients have been viewed holistically with psychological and social aspects of care addressed more readily. A holistic pre-operative patient stoma care assessment is vital to complete for many reasons including:

- Equipping the SSCN with the information they need, to effectively manage the patient's care,
- To provide the patient with adequate information so that they can be better be prepared for this life-changing surgery,
- To highlight any potential issues which may impact upon the patient's ability to deliver self care regarding stoma care [9, 12]

Preoperative counselling and stoma siting can lead to improved successful post-operative recovery by facilitating the dispelling of any myths and pre-conceived ideas from the patient, their friends or family [12] The patient's pre-operative assessment and siting can be undertaken at different sessions if there is adequate time within the patient pathway [13]. Slater [13] advocates that early siting can give the patient an opportunity to go home and observe how the proposed stoma site is appropriate for their activities of daily living. This may also give the patient an element of acknowledgement and help them to reconcile with the idea of having a stoma. However, it needs to be recognised that there is a fine balance between ensuring that the patient is fully informed and prepared for surgery, whilst also acknowledging that there might be some indication for some patients as to how much information they can comprehend and retain [14].

> *A holistic assessment should include all aspects of the patient needs including physical, psychological, and social well-being. This preoperative discussion should be undertaken in "consultation with the patient, thus enhancing their sense of control over their changed body image"* (Burch [14] p. 42).

The acknowledgement of a holistic approach and the consideration of the patient's quality of life comes down to the patient's own view of their body and how they feel others will view them. Black [4] discusses the impact of a stoma being an alteration to a patient's body, leading to a change in appearance and function as an individual. The patient's social situation and past experiences can impact upon their acceptance of the situation, further highlighting the need for a holistic assessment. A discussion is required with the patient and their significant others, to discuss the rationale for surgery, proposed operation and stoma formation. It is imprtant to be mindful of the patient's psychological needs and social well being; there may be many other issues for the patient apart from a new diagnosis and proposed surgery and stoma to consider. Other events may be important in the patient's life at the same time.

> Thompson [15] pg. 20 states "*the ostomy is only a part of the picture, the individual is facing much more, such as a diagnosis, effects of disease or treatments and whatever is going on in their lives*".

Highlighted below in Table 11.1 are the considerations needed for a full holistic assessment:

Table 11.1 Considerations for holistic assessment

	Suggested action	Rationale
Patient medical history Physical assessment	• Reason for operation and stoma formation. • Proposed operation and stoma formation. • Identify any physical factors which might hinder the patient's ability to care for their stoma – Manual dexterity – Visual impairment – Level of independence with daily activities – Skin condition such as psoriasis or eczema [9]	Identify disease process, reason for surgery and other members of the multidisciplinary team who will be required to be involved with patient's care. To be able to give the correct information and guidance. To ensure the stoma site situated in the correct abdominal quadrant and is appropriately marked [15]. Establish patient's physical ability to manage stoma care independently. Identify any problems which will lead to a Delay in healing
	• Identify any physical factors which might affect healing – Disease process affecting skin healing e.g. diabetes – Obesity – Radiation affects [4]	
Psychological assessment	• Identify the patient 's understanding of proposed surgery • Identify if the patient has any concerns regarding the intended operation and stoma formation • Identify any existing conditions such as dementia, mental illness	To determine the patient's perception and knowledge of their possible diagnosis, operation, and stoma. To determine the patient's level of anxiety and fear. To help the SCN to identify aspects of stoma management which may require more emotional support. To determine the patient's cognitive ability and factors which may impede learning

Table 11.1 (continued)

	Suggested action	Rationale
Lifestyle assessment	• Identify aspects of the patient's lifestyle that need to be considered following stoma formation; – Sport – Travel – Dietary requirements – Hobbies – Religion/culture – Family support – Clothing – Occupation – Home arrangement – Sexuality/function/ reproductive concerns	To determine if any lifestyle choices will hinder stoma function, stoma care or appliance selection.

Pre-Operative Assessment

The preoperative assessment will initiate the SSCN/patient relationship, allowing for support and education regarding forthcoming surgery. Blackley [16] considers that the patient and family should be encouraged to express how they feel, any concerns they might have, and identify causes of anxiety. If English is not the patient's first language and the SSCN feels that the patient might find it difficult to understand this important first interaction, then a professional interpreter should be considered [17]. This element of education could be enhanced by utilising written material available in the patent's preferred language, which can be obtained from stoma pouch companies/manufacturers.

The process of pre-operative assessment prior to stoma siting by a suitably qualified registered nurse is as follows:

- Introduce yourself and your role in the patients care. Confirm with the patient who they are and that they are expecting to discuss a specific operation and the rationale for that procedure.
- Provide a private space equipped with chairs and a bed or couch to allow the patient to lay flat for adequate stoma siting.
- Explain the rationale for the meeting, outline the length of time it might take and obtain verbal informed consent to proceed with the assessment. Verbal and non-verbal cues should be observed throughout the consultation [12]. This will allow you to determine what the patient might be thinking and/or feeling.
- Try to ascertain what the patient already knows. Use questions such as "tell me what the surgeon said about your surgery?", "what do you understand about the surgery you are about to have?"

- Discuss the intended operation with the patient, the part of bowel to be removed and whether any segments of bowel will be joined together to form an anastomosis, using simple language. Discuss the stoma type, where it will be located and what it will look like [11], utilising booklets, and software apps with pictures and diagrams to inform the patient. Also inform the patient that a newly formed stoma will have sutures around the circumference stitching the stoma to the skin. These may be dissolvable or made of a material that will require removal after 7–10 days. If a loop stoma, especially a transverse colostomy or colostomy, there might be a bridge or rod, a plastic device to support the stoma to stay in position until the stoma is adhered to the skin [12]. For urostomy patients you should inform the patient that they will have two stents coming out of the urostomy to keep the conduit patent. Discuss why these devices are required, the length of time they are in-situ and when they are to be removed. Educate the patient that the newly formed stoma will be swollen, oedematous and will gradually get slightly smaller in the first 5–11 weeks [12].
- Provide a level of information appropriate to the individual patient's needs utilising written, verbal, social media options as applicable [16].
- Discuss the stoma output consistency, the number of times that the stoma will be active and the production of gas, flatus and odour [12].
- Discuss what to expect post operatively, especially in relation to mild exercise to strengthen abdominal muscles and limit any heavy lifting to prevent the risk of a parastomal hernia [16]. Recognise if there are any lifestyle activities which might increase the risk of the patient developing a parastomal hernia, this could be weightlifting, gardening, and any household activities which involving heavy lifting. If any concerns are raised, the SSCN might need to consider discussing the need for a hernia support garment for when the patient returns to their normal activities.

Considerations of Stoma Siting

ASCN UK [1] clinical guidelines provide guidance for the suitably qualified registered nurse to be able to effectively mark a suitable stoma site. The following issues should be considered;

- The patient must be able to visualise and reach the proposed stoma site.
- There are some areas of the body which need to be avoided:
  - Skin creases
  - Scars
  - Bony prominences (hip bone, rib cage, and symphysis pubis)
  - Umbilicus
  - Groin
  - Natural waistline
  - Pendulous breasts [5, 9]

- There are a number of areas on the abdomen that are used to help identify the ideal stoma siting location:
  - Rectus abdominis muscle
  - Upper curve of the abdomen
  - Below the umbilicus, ideally below the waistband on clothes [5]
- The rectus muscle is a paired muscle running vertically on each side of the abdominal wall, this muscle should be identified. The stoma site should be within the rectus muscle to give the stoma strength and support. Research suggests that this helps to reduce the risk of a parastomal hernia and prolapse [9].
- If two stomas are required to be sited, it is best practice to site one slightly above the other should the patient be required to wear a stoma belt attached to one or both of the pouches [18].
- A transverse colostomy if required is usually positioned in the right upper abdomen within the rectus muscle. If the SCN is asked to site a transverse colostomy it is commonly sited above the umbilicus avoiding the waistline but where the patient can easily see it [1]. If siting is a challenge, a collaborative approach is advocated [17].
- A patient with an increased Body Mass Index (BMI) should ideally be sited higher on the abdomen [5]. It is vitally important that a patient can see their stoma, even if it means siting above the waistline [9]. However, this can present the surgeon with intra-operative difficulties; the surgeon might not be able to mobilise the bowel to the proposed stoma site. If the SSCN is not sure regarding any siting, this should be discussed with the surgeon. If the patient is unable to visualise the stoma, the patient will need to be taught to manage their pouching system using a mirror [9].
- Patients who use a wheelchair should be sited in their wheelchair to ascertain the optimum position for the patient to manage their stoma [5, 9, 10].
- The patient's preference and style of clothing, as well as hobbies should all be considered when identifying the stoma position. Ideally the stoma should be located below the waistband, this can allow for the top of the pouch to sit slightly above the waistline and not be too visible [8]. Occasionally, the patient might need to make clothing modifications especially if they wear low cut style trousers as seen over the last decade [9].
- It is important to inform the patient that the stoma siting is a guide for the surgeon [19]. The surgeon makes the final decision on where the stoma is positioned especially if this is an emergency procedure, this will depend on what happens intra-operatively. The patient may require a different stoma type, not sited for or the surgeon might not be able to mobilise the bowel adequately to reach the marked site. Blackley [16] identified that a discussion might be needed with the surgeon if there are any uncertainties related to the stoma siting, the patient might require multiple sites with a preferred site which can be numbered. It would be advisable to site both sides of the abdomen if the operation and stoma type required is not clear [16].
- The 2011 census highlights that 13% of the population (7.5 million people) in England and Wales were born overseas [3], thus it is advisable for the SSCN to

have awareness, knowledge and understanding of the patients religious and cultural beliefs and how this might affect the way they care for their stoma. When considering the religion of the UK population, 59% were Christian, 5% were Muslim, 0.4% were 'other' religion, with 25% having no religion [3]. Black [4] highlights that in the Muslim faith, when a stoma is positioned above the level of the umbilicus the output is considered dirty and defiling and so cannot be touched. Another factor to consider with Muslim patients is that they use their right hand to eat food and greet others and their left hand for cleaning themselves [4, 5]. These aspects will need to be discussed and considered during the pre-operative and siting counselling session(s). It is important to remember that everyone is individual, and that it should not be assumed that any faith should affect how a patient manages their stoma care. People follow and acknowledge their faith in different ways, the SSCN should always ask the patient if they feel that any aspect of their faith might affect their ability to manage their individual stoma care.

- During this pre-operative session, the patient should be asked if they have a sensitivity to adhesive plasters or tapes. If the patient states that they do have an allergy or sensitivity the SSCN should consider undertaking a skin test during the pre-operative period. Sections of different manufacturers pouch flanges can be applied to the patient's skin to ascertain if there is a reaction. The timeframe might depend on how quickly a patient's skin reacts to the adhesive ingredients. The main ingredients in any pouch flange are pectin, agar, and gum, although the quantities might vary and some pouch manufacturers have added ingredients such as aloe vera, manuka honey and ceramide (to name but a few) [9].
- Most literature discusses the need to site patients for a stoma who are going to have an emergency colorectal procedure [4]. Cronin [12] expresses the importance of the need to meet with the emergency patient, introducing yourself and your role within their care. If the patient has abdominal distension or is unable to move into the sitting and standing position required for optimal stoma siting, then this can be challenging. Recent literature recommends that the patient is sited to the best of the SSCN's ability, this is documented in the patient notes and the patient is made aware that this proposed site might not be used by the surgeon [5].

Stoma Siting Practice

The process of pre-operative stoma siting by a qualified and experienced Nurse is as follows:

- Gain verbal and/or written consent (in line with NHS Trust policy) prior to a physical assessment for marking of the stoma site [1].
- Observe the patient in their usual clothing in the sitting and standing position, if appropriate. Notice the position of the waistband, a belt, or braces. You should ask the patient if this is where they normally wear their waistband [2].

- Ask the patient to lay flat on a bed/couch to accomodate the abdominal assessment. This will enable the SSCN to identify scars, skin creases and all the other anatomical landmarks mentioned previously. The SSCN should locate the rectus abdominis muscle. To facilitate this, ask the patient to lift their head placing their chin on their chest, and gently raise their shoulders off the bed/couch. This exercise will tense the this muscle which will facilitate identification whilst palpating the abdomen [13].
- Identify the halfway point on imaginary diagonal line between the iliac crest and the umbilicus. The SSCN can use some medical tape to mark the initial siting of the stoma [7].
- Ask the patient to sit, stand, bend, and twist (if able to) to identify any creases or problem area(s) and move the marked medical tape up or down considering all the factors which have already been identified [7]. Occasionally, with a patient with an increased Body Mass Index (BMI), this initial siting becomes concealed and will need to be moved up higher until the patient can see the marked site. Leyk et al. [2] considers cultural issues and asking the patient to kneel and bow as they would during worship, if appropriate.
- The patient should be given the opportunity to place an appliance over this proposed site to make sure it is suitable, considering the patient's clothing and lifestyle. It is important to inform the patient that they will have a clear drainable appliance within the initial post- operative phase irrespective of the stoma type; explain that this is temporary for the surgeon and nursing staff to be able to monitor the stoma and output. Once the surgeon and SSCN are satisfied with the stoma's colour, function, and output then a more appropriate appliance can be used [12].
- Ideally the siting should be approximately 2 inches or 5cms away from any bony prominences, scars, creases, waistline, and midline. The site should be placed on a flat even abdominal surface visible by the patient [1].
- Allow an opportunity for the patient to ask questions and seek clarification in relation to the site chosen [1].
- Once the SSCN and the patient have agreed on the optimum site for the stoma, the SSCN should mark the site with a permanent marker pen. If the surgery is not imminent the site could be marked and covered with a waterproof clear dressing according to local policy. Where possible, the stoma site should be checked on the day of surgery [1]
- Aim to involve a patient's carer(s) in the pre-operative process as much as possible especially if the patient will need help to manage their own stoma care needs or is unable to care for the stoma themselves [4].
- Finally, explain the stoma care service to the patient and next steps. Following the operative procedure, the patient will be reviewed post-operatively in hospital and the SSCN will commence stoma care teaching. On going follow up should be offered to the patient once discharged.

Documentation

The ASCN UK guidelines [1], highlight the requirement to record the outcome of stoma site marking in relevant medical records. It is a trained nurse's professional responsibility and accountability to record all events formally and in a timely manner [20]. All documentation is treated as a permanent legal record of that patients care [20]. Consider taking consented photographic evidence to be included in the patient's medical notes if the siting procedure is particularly challenging. The SSCN could also consider drawing an abdominal diagram to including findings such as creases and old scars. Cronin [12] has considered a siting checklist which was completed during the pre-operative counselling session. The patient then signed this document when satisfied with all that was discussed [12]. The documentation of the pre-operative session and siting can also specify any issues identified with the stoma siting or future considerations during the post-operative period.

Conclusion

Pre operatively there should be evidence that the patient expressed verbal and or written consent for siting and confirms that they are satisfied with the marked site for stoma formation [1]. It is also essential that the patient and/or significant others were able to ask questions they may have had regarding the stoma, and that any questions were answered satisfactorily. It is important that the patient understands that the pre-operative marked site is a guide only and that the final decision on siting is determined by the surgeon at the time of operative procedure [1].

It is vital that an appropriate pre-operative assessment and stoma siting is undertaken by a suitably qualified and registered nurse according to ASCN UK guidelines [1].

Refer to Chap. 9 for siting for robotic cystectomy.

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Managing Difficult Stomas

12

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Learning Outcomes

- To understand complications which may arise in stoma care (excluding peristomal skin conditions)
- To assist in recognising stoma complications and actions that can be undertaken to resolve, improve or manage the situation.
- To appreciate the impact of the complication on the patient's wellbeing

Introduction

There are many complicating factors that an individual living with a stoma may experience which will cause a challenge in their stoma management. Support for such situations is provided by the specialist stoma care nurse (SSCN) as well as other health care providers. Difficult stomas can result in lower wear time for stoma appliances, increased appliance usage, increased costs of care and complicated routines for management. This can undoubtedly also affect the patient's quality of life [1, 2].

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Necrosis

If the blood supply to the stoma is compromised, this can lead to a stoma which may appear dusky pink or at worse black in appearance (see Photo 12.1). This may occur in the early post op period [3] and is likely to be due to tension in the mesentery at the time of surgery. The mesentery contains blood vessels which supply oxygenated blood to the bowel. This is commonly seen in obese patients who have a high body mass index (BMI) as the creation of a stoma can cause traction on the mesentery as the bowel is brought up to the surface of the abdomen. Patients who are malnourished or immunocompromised may also be at a higher risk of developing necrosis and subsequent complications. The long term complication can be retraction and possibly stenosis or narrowing of the stoma [4]. The necrotic stoma will ideally require surgical refashioning but if this is not possible due to the health of the patient, then the stoma will need to be closely monitored for further signs of deterioration in colour, warmth and output. The patient's general condition must also be closely monitored as infection or sepsis may rapidly ensue.

If the necrosis is superficial, the top layer of the stoma mucosa may slough off and reveal healthy mucosa underneath which is well perfused [3]. If the necrosis is more extensive, the stoma above the level of necrosis may slough off and leave a retracted stomal opening or cause mucocutaneous separation (MCS) which may in turn lead to stenosis [3]. It may also result in an extremely retracted stomal opening which may or may not require stomal dilatation to prevent complete stenosis.

Photo 12.1 Necrosis (courtesy of M White)

Partial/Full Retraction

Stomal retraction is defined as a stoma that is 0.5 cm or more below the skin surface within 6 weeks of construction, typically as a result of tension on the stoma [5]. Retraction can occur even if the stoma is viable, well spouted and functional in the initial post operative period. This has been reported in 1–6% of patients after stoma creation [6] and is thought to be due to poor placement of the stoma or a lack of full mobilisation of the bowel which can lead to inadequate suture fixation of the bowel intra abdominally. A subsequent mucocutaneous tension and ischaemia can lead to retraction; the best method to prevent this is to ensure adequate mobilisation and blood supply to the stoma as well as a suitable sized skin opening to facilitate the delivery of the stoma to the skin [7].

It is particularly important for ileostomy and urostomy stomas to have a reasonable sized spout as this helps to ensure that the stomal output, either faeces or urine, goes straight into the pouch, rather than pooling near the stoma which can undermine the appliance leading to skin breakdown. Brooke in 1952 described the spouted ileostomy; an ideal ileostomy should protrude from the anterior abdominal wall by approximately 2.5 cm [8].

Sliding retraction or "telescoping" can occur when the opening in the abdominal wall is too large and allows the stoma to fall below skin level when the patient is prone [9]. Surgical technique is therefore extremely important requiring adequate experience and an appreciation of the patient's quality of life after stoma surgery.

Stenosis

Stenosis can occur following retraction and separation in the early post operative phase. Any circumferential skin wound arising from the separation granulates and heals slowly by secondary intention. This causes contracture of the wound resulting in a shrinking and stenosing of the stoma which causes stoma management problems and may necessitate surgical revision [7].

Mucocutaneous Separation (MCS)

MCS can occur between 1–4 weeks post operatively with 10–14 days being the most common [10]. In 1 study, 24% of patients were identified as having MCS within 3 weeks of surgery [11]. MCS can also commonly be seen when individuals are nutritionally deficient, have been on immunosuppressants and/or are diabetic, and when there is evidence of fistulation or abscess formation. Insufficient suturing of the stoma to the skin at the mucocutaneous (MC) junction can also lead to a separation. It may also occur following the use of a rod or bridge which can cause tension at the junction [12]. MCS is commonly seen following emergency surgery due to the potential presence of infection. The degree of separation may be classed as superficial, intermediate or deep [10] or, combining this with a peristomal skin assessment, classed as mild, moderate or deep [13], providing the nurse with a more comprehensive evaluation of the separation. The principles of wound management apply [14] such as;

- Provide a moist environment
- Manage excess exudate
- Protect the wound from trauma and contamination which may be challenging with a stoma regime
- Maintain a wound interface i.e. appropriate dressing or the wafer
- Allow gaseous exchange

The SCN should be aware of local policy for wound management and seek advice from other specialities such as a Tissue Viability Nurse if further guidance is required. Some separations will exhibit wound exudate to some degree and a wound swab is recommended. Guidance and recommendations for MCS and stoma management can be followed as shown in Table 12.1. Evidence to support these recommendations can be found within the literature [10, 13, 15–19].

Table 12.1 Assessment and Management of Mucocutaneous Separation as suggested by White and Perrin 2022 (unpublished) (photos courtesy of M White and A Perrin)

MILD	MODERATE	SEVERE
		
Assess Dust with stoma powder if moist (10) Re-measure template and incorporate separation into appliance if exuding (15), but cover if not (16) Cut appliance to size. Review in 48hrs	Assess Apply ostomy powder or hydrocolloid paste depending on the amount of exudate (17) Use a seal or hydrocolloid wafer as a secondary dressing (18) Cut appliance to size. Consider use of two-piece Review in 48hrs	Assess Irrigate or clean the separation according to local policy Pack the cavity with an appropriate primary dressing, such as an alginate (19) Use a seal or hydrocolloid wafer as a secondary dressing Cut appliance to size. Consider use of two-piece Review in 48hrs

One peristomal skin disorders classification [13] states; Mild with 1-5 mm of skin involvement, Moderate with over 20 mm of skin changes/involvement and Severe as substantial amounts of skin involvement, requiring immediate attention. This classification use in collaboration with the guidance and recommendations provided in Table 12.1 offers a comprehensive and evidenced based management tool for treatment of MCS.

Signs and Symptoms

These 4 issues are summarised within Table 12.2 (Necrosis, Retraction, Stenosis and MCS) and can lead to a variety of symptoms or management issues for the patient requiring SSCN knowledge and expertise to alleviate. (See Table 12.2).

Table 12.2 Signs and symptoms of necrosis, retraction, stenosis and MCS (as suggested by M White unpublished)

	Signs and symptoms	Treatment
Necrosis	Black, dusky pink colouration Cool to touch Non functional Odorous	Surgical revision if appropriate Clear appliance for stoma review
Retraction	Non protruding spout Leakage from appliance Sore skin	Convex appliance or additional items Skin management
Stenosis	Ribbon like stools Leakage from appliance Obstructive symptoms Sore skin	Stool softener (colostomy) Convex appliance or additional items Dilation Skin management
Mucocutaneous separation	Leakage from appliance Sore skin Cellulitis Infection	See Table 12.1

Granulomas

Granulomas are friable, tender papules often occurring at the MC junction of an abdominal stoma which can bleed easily [20]. These can be treated with 75% silver nitrate sticks following a specific assessment by a SSCN (see Appendix 1). Patients may experience excessive bleeding if there are multiple granulomas. Some individuals may experience pain as a symptom, more commonly if the granulomas are situated on the mucocutaneous junction (MCJ). Any concern with regard to the appearance of the colour or surface aetiology of the stoma should be discussed with a medical colleague as this could potentially be something more sinister (see Chap. 13).

Stomal Prolapse

This is when the length of the stoma increases, causing it to protrude further out from the abdomen (see Photos 12.2). It can occur with any type of stoma but more commonly with a transverse colostomy or loop stoma [3]. This may be due to the size of the opening made for the stoma in the abdominal wall.

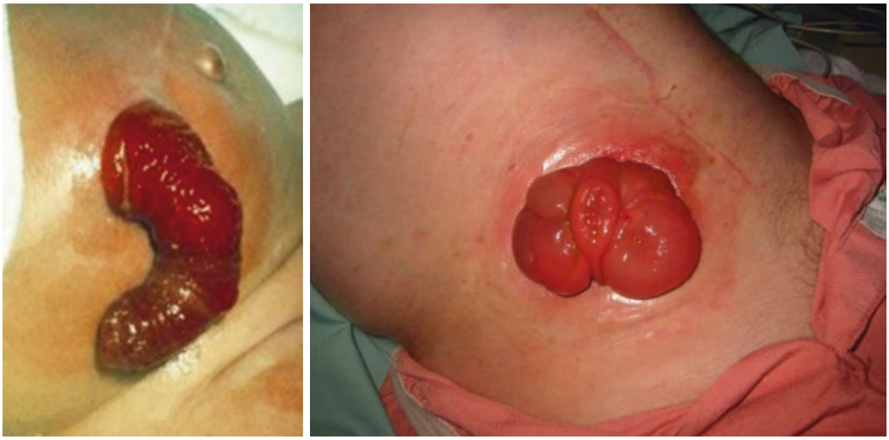

Photo 12.2 examples of stomal prolapse (courtesy of M White)

Signs and Symptoms

- More of the bowel is seen on the surface of the abdomen than normal.
- The surface of the stoma may be more prone to bleeding due to rubbing against the pouch.
- Wear time of the pouch may be affected and the skin may be affected if exposed to effluent.
- Management difficulties if the prolapse is large.
- If the appliance is too small and the aperture too tight for the prolapsed stoma, the stoma may become swollen.
- The colour of the stoma should be reviewed as it may possibly change (see necrosis or ischaemia above) due to the blood supply being affected.
- The resulting bulge from a prolapsed stoma may appear unsightly under clothes.
- The stoma may be at its largest during the day and retract back into the body at night. Lying prone reduces intra abdominal pressure.
- Patient distress at the appearance of the prolapsed stoma.

Treatment

1. Non surgical
   - The patient may be alarmed by the sudden change in size of the stoma but should be reassured [21] that this is only serious if the appearance has altered from a healthy appearance i.e. the stoma becomes dusky, bluish or dark pink in colour. The patient needs to understand that should this occur they will require an urgent medical review [21].
   - The surgeon may be reluctant to operate on the stoma especially if the patient is undergoing chemotherapy or it is less than 3 months since the formation of a loop stoma.
   - Use a larger appliance to accommodate the length of the stoma and possible larger stoma aperture.
   - It is important that the aperture cut into the flange fits correctly around the stoma, preventing constriction to the prolapsed stoma [21]
   - Vaseline gauze wrapped around the stoma may prevent rubbing of the stoma against the pouch film.
   - The application of granulated sugar has been shown to facilitate the reduction of an acutely prolapsed stoma by using osmosis to reduce the oedema of the prolapsed stoma [22]
2. Surgical
   - Emergency surgery is required if the stoma is severely compromised, often seen as a blue/dusky appearance and cool to touch or the patient shows signs of obstruction.
   - The Surgeon may decide to operate and reduce the enlarged/prolapsed stoma. If the stoma is temporary, this may be dealt with at time of reversal. However, the patient would need to be supported by the SSCN to ensure they are able

to cope with the prolapse until then. If the stoma is permanent, the surgeon may discuss the operation to reduce the stoma, especially if the stoma becomes ischaemic [3].

Parastomal Hernia

A hernia is a protrusion of tissue through the wall of the cavity in which it is normally contained [23]. For example, the opening created in the abdominal wall at the time of initial abdominal surgery for a stoma creates a weakness allowing bowel to protrude into the space behind the stoma. Parastomal hernia is the term used to describe this herniation. A hernia usually occurs gradually and may increase in size over time and can vary in size (see Photo 12.3). Large parastomal hernias can lead to management complications; sometimes the use of a wound manager or an extra large stoma appliance is required to accommodate the size of the stoma.

The impact on the individual with a parastomal hernia needs to be considered as it affects body image and may cause psychological difficulties for the patient [24].

Causes

There are many factors that contribute to causing a parastomal hernia [25] including;

- Chronic Cough
- Smoking

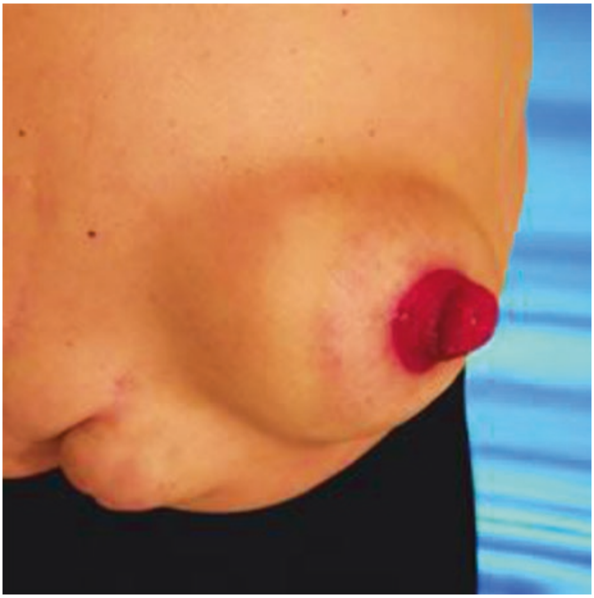

Photo 12.3 Parastomal hernia (courtesy of M White)

- Manual occupation or with young family
- Straining on lifting heavy objects or strenuous activities
- Infection at the site of the stoma or abdominal wound
- Muscle weakness related to age (sarcopenia)
- Obesity and high BMI
- Diabetes

Frequency of Occurrence

The incidence of a parastomal hernia can be up to 48.1% in particular with a loop or end colostomy [25].

Signs and symptoms include;

- A noticeable bulge around the stoma
- A dragging dull ache around the stoma, particularly at the end of the day or after exercising
- As the hernia increases in size, the shape and size of the stoma can change and the surrounding skin can become tightly stretched with a shiny appearance.

Practical management problems;

- Securing a stoma appliance can become difficult around the tightly stretched skin
- Skin trauma can occur
- Leakage from an ill-fitting appliance due to hernia shape
- Frequency of appliance change may increase
- Concealment and body image issues
- Disruption to normal bowel function and possible obstructive symptoms

Complications

If a hernia cannot be manually reduced, the bowel trapped within the hernia sac can become incarcerated and die. The patient presents acutely with bowel obstruction, pain and a discolouration of the stoma. Emergency surgery is required to restore blood supply and reduce the hernia thereby preventing the loss of a large quantity of previously viable bowel.

Management

Initially, following an assessment and diagnosis of a parastomal hernia, it may be helpful for the patient to wear a support belt to help reduce the hernia and symptoms. The SSCN needs to assess (see Appendix 2) the patient for an appropriately sized support belt and show the patient how to apply it. Encourage the patient to lie down as this allows the hernia to reduce spontaneously and then apply the belt. This helps to keep the hernia in once the patient gets up.

The patient can be referred to the Consultant Surgeon who will assess the risk of strangulation and consider whether surgery to reduce the hernia is necessary. Success rates vary depending on how many hernia repairs the patient has undergone as well as the patient's individual risk factors. North and Osborne [26] state; 'Having a repair does not guarantee the hernia could not reoccur'.

Osborne, North and Williams [25] focussed on a risk assessment tool to ensure consistency of care and management of parastomal hernia. This work has informed the ASCN UK (2019) guidelines on Hernia management (see Appendix 2) and prevention (Appendix 3).

High and Low Stoma Output

High Output Stomas (HOS)

Definition

This is usually associated with an ileostomy or jejunostomy. Daily stoma output will depend on numerous factors, for example: duration since surgery to form the stoma, position (proximal bowel length), presence of disease such as inflammatory bowel disease, infection, recent dietary intake and medication. Defining a HOS is normally based on the volume produced in the previous 24 h. According to ASCN UK Clinical Guidelines (2019) [27, 28], a HOS is considered to be when the stomal output is greater than 1500 mL in 24 h. However, different guidelines and hospital trusts use different criteria for defining a HOS, possibly starting at 1200 mL in 24 h for an adult. For the purposes of this chapter, the author considers a HOS to be more than 1200 mL in 24 h. The consistency of the output would be liquid with possibly undigested food and may be brown or green in colour. A useful resource can be found on the ASCN UK website (ASCN UK ileostomy output chart) [29].

HOS can further be classed as acute following surgery, or sub-acute and chronic [30]. The consequences of a HOS are dehydration leading to Acute Kidney Injury (AKI) [31] with electrolytes outside of normal parameters, especially sodium and magnesium [32], and a reduced quality of life for the patient [33].

Acute HOS

This is usually a short-term occurrence, occurring in the immediate post-operative period following colorectal surgery with stoma formation. The majority of these patients are managed in hospitals, with full recovery and no complications [34] as stomal output settles within days—weeks.

Sub-Acute HOS

A subacute HOS can result from a number of conditions that affect the gastro-intestinal tract [34] including:

- Intestinal resection, e.g., extensive resection of the bowel resulting in short gut syndrome. The small intestine (ileum) will be unable to re-absorb water and electrolytes secreted. Malabsorption of dietary vitamins, minerals and macronutrients (fat, protein, carbohydrate) may also occur depending on the extent of the resection.
- Surgical (intra-abdominal) sepsis; an infection is present following surgery; this may cause increased gastrointestinal secretions which are not reabsorbed until the sepsis resolves.
- Inflammation or fistula development.
- Mechanical or functional intestinal obstruction. This can result in an increased output from the stoma following removal or resolution of obstruction.
- Stoma stenosis
- Medication that can alter intestinal function: a previously normal stoma output can be altered by chemotherapy, sudden withdrawal of anti-diarrhoeal medication and some antibiotics.

Some of these patients can progress from an acute presentation of high output to a more chronic condition and would therefore need long-term management.

Chronic HOS

This is due to intestinal failure and therefore, requires input from a multi-disciplinary team including medical staff, pharmacists, dietitians, specialist nurses and psychologists. Patients may require intravenous fluid and electrolyte support alone or as parenteral nutrition (with intravenous administration of nutrients) if significant malabsorption is seen [35].

Management of HOS

The management of these patients includes identifying the cause of the high output, monitoring and treatment of any associated complications.

Local Trusts may have their own policies for managing HOS and guidance can be found from ASCN UK (2019) [27, 28] whose management guidelines cover both the hospital and community settings. Any guidance used should include situations where ongoing referral is required for more specialist input, determining roles and responsibilities for monitoring and also weaning off HOS treatment if the stoma function returns to normal.

The general principles for managing HOS in the acute setting, once any potential cause such as sepsis has been investigated and treated, are outlined in Table 12.3;

Stoma Care Equipment: Management

A high output appliance in one or two-piece format is recommended and is available on Part IXC of the Drug Tariff [38], which is capable of being attached to a fistula/night drainage bag (currently appears in Part IXB Incontinence Appliances, Faecal Collectors, [39], to aid measurement and containment of the faecal output. Care should be taken to help prevent the effect of ileal output on the peristomal skin as the skin is at high risk of breakdown with the enzymatic contents in the output. The

Table 12.3 High output stoma management

Assessment and monitoring

- Accurate monitoring of stomal losses and urine output (using a strict fluid balance chart and daily weight if possible).
- Monitoring of renal function and electrolytes (serum urea & electrolytes including magnesium. A urinary sodium measure of less than 20 mmol/litre is indicative of sodium depletion even if serum sodium is normal [36].
- For community patients assess signs of dehydration and electrolyte depletion:
  - Reduced, concentrated urine output
  - Thirst and dry mucous membranes,
  - Tiredness and lethargy,
  - Muscle cramps
  - Feeling faint, especially when position changes (sit to stand) as this may suggest postural hypotension due to reduced blood volume
  - Headaches.
  - Risk of falls
  - Confusion

Replacement of stoma fluid & electrolyte losses

- Replacement of fluid and electrolytes with the use of oral rehydration solutions such as St Marks solution [37] or dioralyte®, oral magnesium supplements and/or intravenous fluid and electrolyte replacement
- Refer to dietitian if malnutrition present or if advice is needed to modify the diet, for example alter the fibre content to modify stoma function.

Reduction in stoma output

- Reduction of stomal losses with the use of oral fluid restrictions (500 to 1000 ml daily used in conjunction with an oral rehydration solution)
- Use of anti-diarrhoeal and anti-secretory medication. Local guidance should include an initial dose, followed by build-up and maximum dosages, plus preparation type and when to take in relation to meals.

output may be very alkaline [33] due to the content containing intestinal enzymes, bile and contents from the pancreas. To improve fit around the stoma, and help prevent peristomal moisture associated skin damage (PMASD), a barrier ring/seal may be required in conjunction with the high output pouch. As the high output subsides, patients can return to a more conventional drainable appliance.

Patients are encouraged to be as independent as possible. This includes learning to manage their medication, fluid and nutrition regimes as well as their stoma. Education and support is vital.

Low Output Stomas

There is also concern when patients do not have any output or have a low output from their stoma. There is no formal definition currently for a low output stoma but the features are described in Table 12.4;

Table 12.4 Features of low output stomas [40]

Stoma type	Signs and symptoms	Causes
Urostomy	• Less output than they drink, the patient would be in a positive fluid balance. • Dark coloured urine • Malodorous urine • Loin or back pain • Fever • Generally unwell • Blood in urine—Visible haematuria • Increased abdominal girth	• Renal failure, or kidneys not working properly • Mechanical obstruction • Physical obstruction such as a ureteric stone • Anastomotic leak, (extravasation) this would more likely occur in the early post op period • Circulatory issues if the urine is less during the day but increases at night so that most of their urinary output occurs when they are lying down. • Blocked stent if immediately post-op or stent fallen out too soon if sent home with stent in • Dehydration and acute kidney injury (AKI) • Sepsis • Upper urinary tract infection, this would be a complicated urinary tract infection as their urinary tract is not intact.
Ileostomy	• Less than (600 ml approx or no output. Normal output ranges from 600–800 ml [34] • Abdominal pain • Generally unwell • Nausea or vomiting • Abdominal distension or bloating • Abdominal cramping • Changes to the appearance of the stoma. • Pain behind the stoma • Intermittent subacute obstruction due to the presence of parastomal hernia	• Physical obstruction ie bolus of high fibre food such as mushrooms, nuts for example • Mechanical obstruction such as twisted bowel, or possible recurrence of cancer • Paralytic ileus • Dehydration and AKI • Sepsis NB a high output stoma can occur following resolution of a sub-acute small obstruction
Colostomy	• Constipated i.e., no output for more than 3 days • Abdominal pain • Generally unwell • Nausea or vomiting • Abdominal distension/bloating • Abdominal cramping • Changes to appearance of the stoma • Pain behind the stoma • Output is hard like rabbit droppings (scybala or type 1 on the Bristol stool chart) [41] • Changes to colour of stool • Intermittent subacute obstruction due to the presence of parastomal hernia	• Slow transit bowel • Constipation • May occur following bowel prep for a scan, or commencement of chemotherapy, initially the patient may have had diarrhoea and then stoma may not work for a couple of days. • Physical obstruction ie bolus of food • Mechanical obstruction—Twisted bowel, or recurrence of cancer • Not eating enough, low appetite • Dehydration and AKI • Sepsis

Management of Urostomy

Strict fluid balance is essential to establish the amount of urine output in last 24 h and the timing of urinary output. It is also necessary to check the patient's input in order to determine that urine output is equivalent to the output and the patient is not retaining fluids. Recording the colour of the urine can help staff to recognise the signs of dehydration (see Table 12.4). Ward staff should also establish baseline observations when the patient is admitted and report them according to National Early Warning Signs (NEWS) [42]. Any visible haematuria should be recorded and a review of medication with Urology team can help to determine their effect on the urine output.

If the urine output is mainly at night, ask the patient to put legs up during the day when sitting down to aid circulation and renal perfusion. An urgent referral to the urological team may be required for further investigation and management.

Management of Ileostomy

A strict fluid balance for output in 24 h is essential as well as noting the consistency of output according to ASCN UK guidelines [34]. Both fluid and food intake must be recorded in order to establish the effect they can have on the output. Baseline observations may show discrepancies which require correcting. If the patient is unable to pass stool or wind they will be very uncomfortable and will require suitable analgesia. Physical assessment of the abdomen for tenderness and abdominal tension is indicative of bowel obstruction. Anti-diarrhoeal medication must be stopped immediately if this is suspected.

If the patient is nauseous and not vomiting it may be sensible to stop eating and drink as tolerated. Other measures to relieve symptoms include having a warm bath, using a warm heat pad placed onto the abdomen, or walking and abdominal massage to try activating bowel function.

Once the stoma has started working low fibre foods can be reintroduced. Depending on the cause of the low stoma output they may need to avoid certain foods long term or modify the preparation of them. For example, remove skins and pips from fruit and vegetables and choose low fibre cereal products. It is always helpful to encourage patients to chew their food well.

If the patient continues to vomit for more than 24 h then they should be reviewed in hospital for treatment by the relevant surgical team. Following this review a nasogastric tube may be required as well as radiological imaging.

Management of Colostomy

Again it is essential to establish the patient's normal output in terms of frequency, amount and consistency. Hardened stools would indicate constipation and may need treatment; this may include oral laxatives if the patient is not vomiting or a colostomy washout as per local guidelines.

If this is a new colostomy and the output has previously been loose, the output may be thickening up post operatively as they are eating more normally and is therefore to be expected.

An abdominal assessment will help the SSCN to ascertain whether this is the case or whether distension and bowel sounds are absent (SSCNs must follow local procedure if they are not able to undertake an abdominal assessment). If the patient is vomiting, they may require a nasogastric tube and an abdominal x-ray.

Check the output for any signs of blood in the stool and stop patient taking antidiarrhoeal medication if they are prescribed.

The patient may need ongoing treatment for chronic constipation with a slow increase in dietary fibre and adequate fluid intake. However, he/she will require urgent hospital review by their surgical team if they are unwell and vomiting.

Caput Medusa (Parastomal Varices) (See Photo 12.4)

These are swollen blood vessels that form around the stoma from a central point. It is caused by portal hypertension and typically has a bluish appearance and sometimes visible veins [43]. Bleeding from these veins can be dramatic and acute, with patients requiring attendance at an emergency department. The vessels may stop bleeding abruptly and the patient may require blood transfusion or suturing of a bleeding vessel. Bleeding small varices may respond to pressure with a cold water compress but the patient should be assessed as to whether further interventional treatment is required.

Torrential bleeding can be extremely frightening for the patient and the nurse alike, but it is important to reassure the patient that the bleeding is not arterial and usually responds to conservative management.

Photo 12.4 Examples of caput medusa (courtesy of MWhite)

Trauma

A stoma can be traumatised in a number of ways and the patient may present with a variety of different symptoms including;

- Bleeding
- Laceration to the stoma
- Swelling
- Bruising

Treatment

If a stoma skin barrier is too tight around the stomal opening this can cause a laceration, particularly if this is from a firm convex appliance situated too close to the stoma. The patient should be assessed for the correct size and type of convex product to prevent this from occurring. Lacerations usually resolve, however if there is a bleeding point which will not stop bleeding, emergency treatment is required. Silver nitrate and /or suturing may help.

Patients who are too enthusiastic at cleaning on or near the stoma need to be reminded that the blood vessels on the stoma are easily damaged as they are just below the level of the surface of the stoma. Therefore, minor bleeding may result and resolves spontaneously.

Stomatitis is defined as inflammation of the surface of the stoma which can lead to bleeding. Although a small amount of bleeding when cleaning is normal, bleeding may be exacerbated if inflammation is present, for example following chemotherapy [44]. This resolves spontaneously once the effects of chemotherapy have subsided.

Conclusion

The management of difficult stomas may arise from issues with the construction of the stoma, stoma effluent or internal or external influences.

Difficult stomas can have a negative effect on the psychological wellbeing of the patient.

However, identifying the issue and understanding the causes can assist the SSCN in offering appropriate treatment, referral or stoma management, leading to resolution or control of the issue.

Difficult to manage stomas have implications on costs for treatment, time taken by the SSCN and others when managing certain complications, impact on weartime and consequently psychological adjustment to having a stoma. The SSCN is ideally situated to assist the patient with management of the challenging stoma providing, not only physical advice and support but also offer psychological provision which may help the patient during this difficult time to readjust to life with a challenging stoma. Ultimately this will improve their quality of life as the SSCN is a key advocate for patients' overall health and wellbeing [45].

Appendix 1 ASCN UK (2019) Granuloma Management, *ASCN UK Stoma Clinical Guidelines* www.ascnuk.com

Granuloma Management

Authors: EMMA MALTBY
CLAIRE LOWTHER
GILLIAN TOMSETT

Statement:

Patients with stomal granulomas are assessed by a Stoma Care Nurse (SCN) and an individualised stoma care plan is formulated.

Structure:

- Ensure a private, confidential and safe environment where the patient can be assessed, treatment given and provided with information
- Using clinical expertise undertake a clinical history of the granuloma in line with the guidelines for stoma treatment as overleaf
- Assess the granuloma as per guideline (Appendix 8). Document and photograph as per local policy
- Identify any allergies to silver - silver nitrate to be omitted from treatment option
- Provide advice to the patient or carer on how to monitor for complications from the granulomas and ensure they understand when to contact medical staff if concerned
- Involve family and carers, where appropriate, and in agreement with the patient
- Feedback appropriate information to referring healthcare professional
- Evaluate the patient's understanding of the information given.

Outcome:

The patient states the nurse offered advice and expertise on the management of their granulomas.

If granulomas do not resolve, consider alternative causes - e.g. Peyers Patches.

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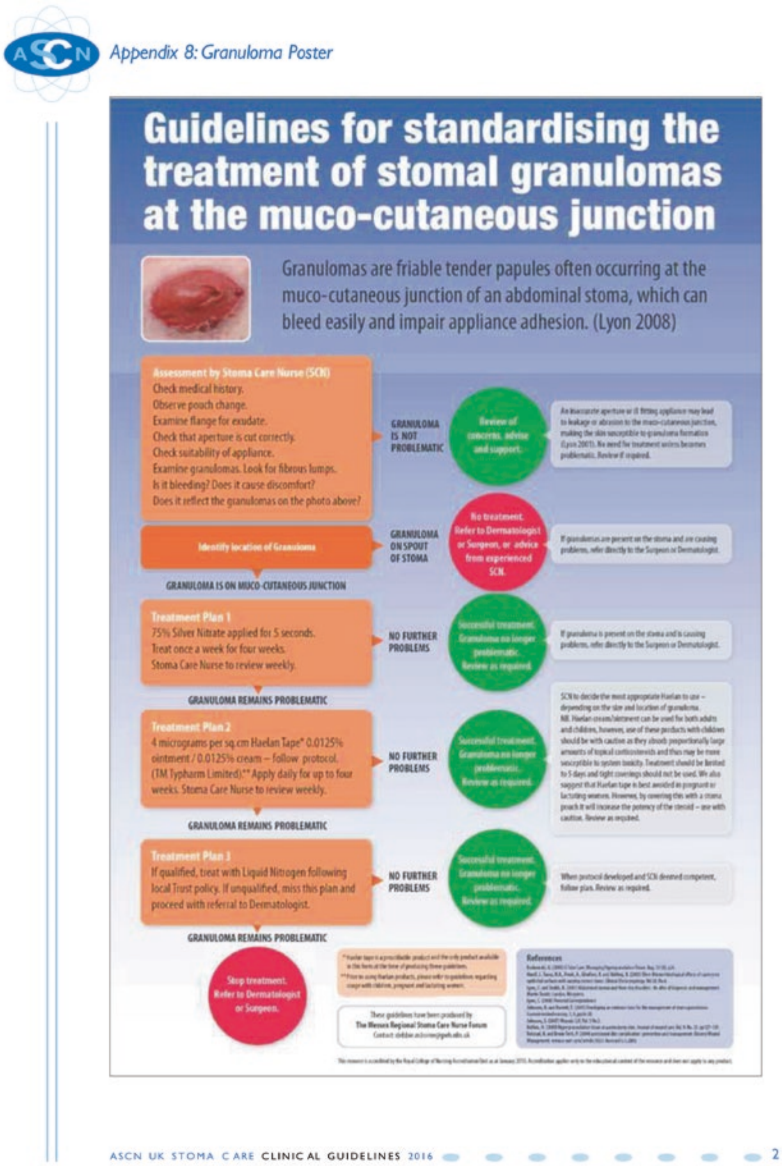


Appendix 8: Granuloma Poster

Guidelines for standardising the treatment of stomal granulomas at the muco-cutaneous junction

Granulomas are friable tender papules often occurring at the muco-cutaneous junction of an abdominal stoma, which can bleed easily and impair appliance adhesion. (Lyon 2008)

Assessment by Stoma Care Nurse (SCN)
Check medical history.
Observe pouch change.
Examine flange for exudate.
Check that aperture is cut correctly.
Check suitability of appliance.
Examine granulomas. Look for fibrous lumps.
Is it bleeding? Does it cause discomfort?
Does it reflect the granulomas on the photo above?

GRANULOMA IS NOT PROBLEMATIC

Review of concerns, advise and support.

An inaccurate aperture or ill fitting appliance may lead to leakage or abrasion to the muco-cutaneous junction, making the skin susceptible to granuloma formation (Lyon 2001). No need for treatment unless becomes problematic. Review if required.

Identify location of Granuloma

GRANULOMA ON SPOUT OF STOMA

No treatment. Refer to Dermatologist or Surgeon, or advice from experienced SCN.

If granulomas are present on the stoma and are causing problems, refer directly to the Surgeon or Dermatologist.

GRANULOMA IS ON MUCO-CUTANEOUS JUNCTION

Treatment Plan 1
75% Silver Nitrate applied for 5 seconds.
Treat once a week for four weeks.
Stoma Care Nurse to review weekly.

NO FURTHER PROBLEMS

Successful treatment. Granuloma no longer problematic. Review as required.

If granuloma is present on the stoma and is causing problems, refer directly to the Surgeon or Dermatologist.

GRANULOMA REMAINS PROBLEMATIC

Treatment Plan 2
4 micrograms per sq.cm Haelan Tape* 0.0125% ointment / 0.0125% cream – follow protocol. (TM Typharm Limited).** Apply daily for up to four weeks. Stoma Care Nurse to review weekly.

NO FURTHER PROBLEMS

Successful treatment. Granuloma no longer problematic. Review as required.

SCN to decide the most appropriate Haelan to use – depending on the size and location of granuloma.
NB. Haelan cream/ointment can be used for both adults and children, however, use of these products with children should be with caution as they absorb proportionally large amounts of topical corticosteroids and thus may be more susceptible to system toxicity. Treatment should be limited to 5 days and tight coverings should not be used. We also suggest that Haelan tape is best avoided in pregnant or lactating women. However, by covering this with a stoma pouch it will increase the potency of the steroid – use with caution. Review as required.

GRANULOMA REMAINS PROBLEMATIC

Treatment Plan 3
If qualified, treat with Liquid Nitrogen following local Trust policy. If unqualified, miss this plan and proceed with referral to Dermatologist.

NO FURTHER PROBLEMS

Successful treatment. Granuloma no longer problematic. Review as required.

When protocol developed and SCN deemed competent, follow plan. Review as required.

GRANULOMA REMAINS PROBLEMATIC

Stop treatment. Refer to Dermatologist or Surgeon.

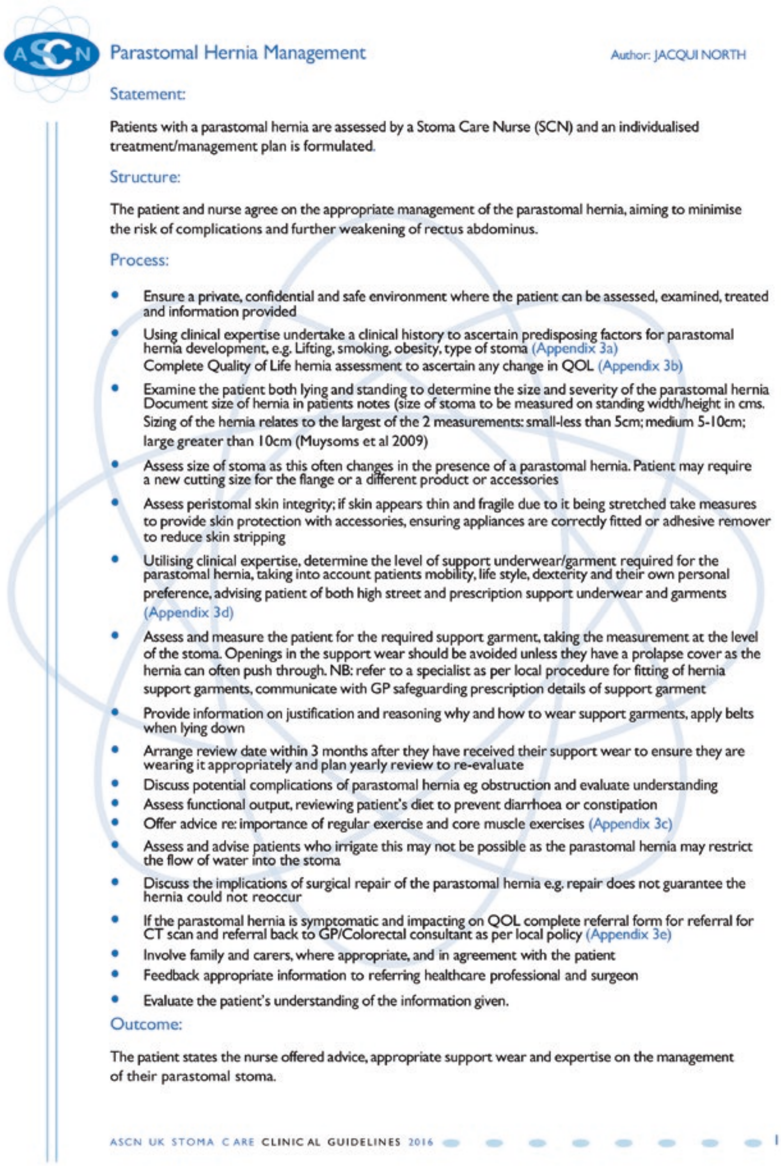
*Haelan tape is a prescribable product and the only product available in this form at the time of producing these guidelines.
**Prior to using Haelan products, please refer to guidelines regarding usage with children, pregnant and lactating women.

These guidelines have been produced by
The Wessex Regional Stoma Care Nurse Forum
Contact: [illegible]

References

ASCN UK STOMA CARE CLINICAL GUIDELINES 2016 2

Appendix 2 ASCNUK (2019) Hernia Management, *ASCN UK Stoma Clinical Guidelines* www.ascnuk.com



Parastomal Hernia Management

Author: JACQUI NORTH

Statement:

Patients with a parastomal hernia are assessed by a Stoma Care Nurse (SCN) and an individualised treatment/management plan is formulated.

Structure:

The patient and nurse agree on the appropriate management of the parastomal hernia, aiming to minimise the risk of complications and further weakening of rectus abdominus.

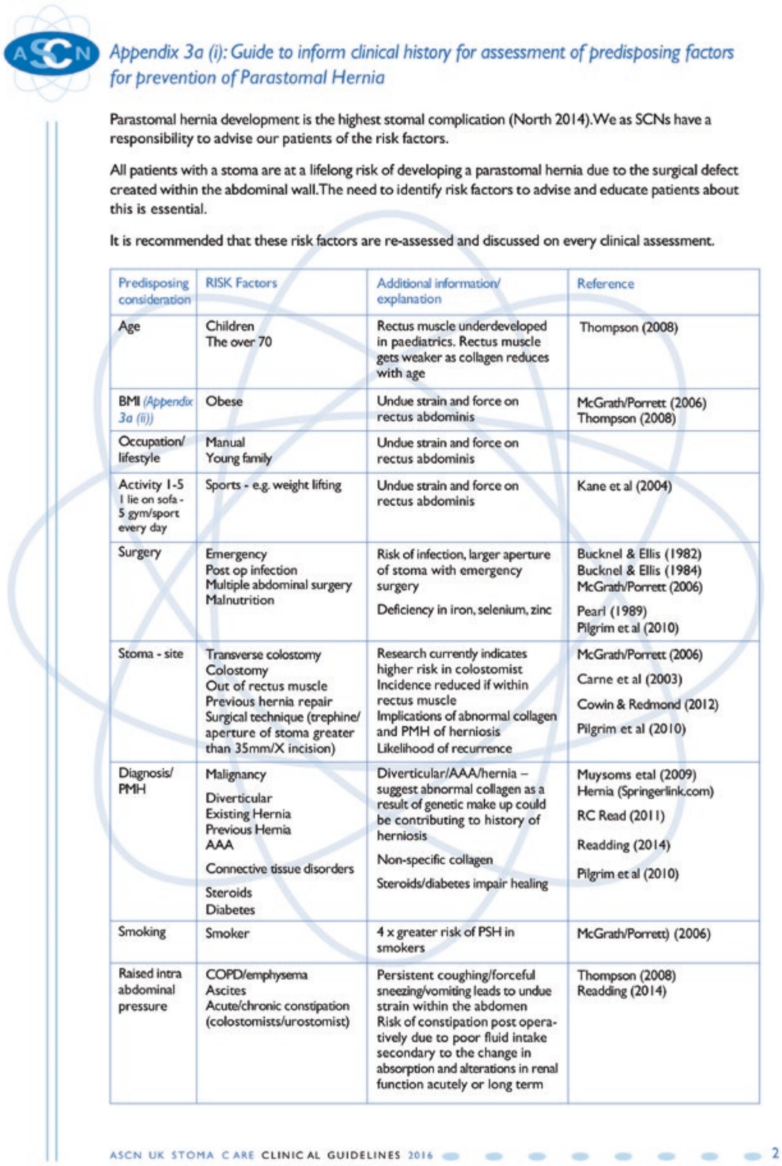
Process:

- Ensure a private, confidential and safe environment where the patient can be assessed, examined, treated and information provided
- Using clinical expertise undertake a clinical history to ascertain predisposing factors for parastomal hernia development, e.g. Lifting, smoking, obesity, type of stoma (Appendix 3a)
  Complete Quality of Life hernia assessment to ascertain any change in QOL (Appendix 3b)
- Examine the patient both lying and standing to determine the size and severity of the parastomal hernia Document size of hernia in patients notes (size of stoma to be measured on standing width/height in cms. Sizing of the hernia relates to the largest of the 2 measurements: small-less than 5cm; medium 5-10cm; large greater than 10cm (Muysoms et al 2009)
- Assess size of stoma as this often changes in the presence of a parastomal hernia. Patient may require a new cutting size for the flange or a different product or accessories
- Assess peristomal skin integrity; if skin appears thin and fragile due to it being stretched take measures to provide skin protection with accessories, ensuring appliances are correctly fitted or adhesive remover to reduce skin stripping
- Utilising clinical expertise, determine the level of support underwear/garment required for the parastomal hernia, taking into account patients mobility, life style, dexterity and their own personal preference, advising patient of both high street and prescription support underwear and garments (Appendix 3d)
- Assess and measure the patient for the required support garment, taking the measurement at the level of the stoma. Openings in the support wear should be avoided unless they have a prolapse cover as the hernia can often push through. NB: refer to a specialist as per local procedure for fitting of hernia support garments, communicate with GP safeguarding prescription details of support garment
- Provide information on justification and reasoning why and how to wear support garments, apply belts when lying down
- Arrange review date within 3 months after they have received their support wear to ensure they are wearing it appropriately and plan yearly review to re-evaluate
- Discuss potential complications of parastomal hernia eg obstruction and evaluate understanding
- Assess functional output, reviewing patient's diet to prevent diarrhoea or constipation
- Offer advice re: importance of regular exercise and core muscle exercises (Appendix 3c)
- Assess and advise patients who irrigate this may not be possible as the parastomal hernia may restrict the flow of water into the stoma
- Discuss the implications of surgical repair of the parastomal hernia e.g. repair does not guarantee the hernia could not reoccur
- If the parastomal hernia is symptomatic and impacting on QOL complete referral form for referral for CT scan and referral back to GP/Colorectal consultant as per local policy (Appendix 3e)
- Involve family and carers, where appropriate, and in agreement with the patient
- Feedback appropriate information to referring healthcare professional and surgeon
- Evaluate the patient's understanding of the information given.

Outcome:

The patient states the nurse offered advice, appropriate support wear and expertise on the management of their parastomal stoma.

ASCN UK STOMA CARE CLINICAL GUIDELINES 2016 1



Appendix 3a (i): Guide to inform clinical history for assessment of predisposing factors for prevention of Parastomal Hernia

Parastomal hernia development is the highest stomal complication (North 2014). We as SCNs have a responsibility to advise our patients of the risk factors.

All patients with a stoma are at a lifelong risk of developing a parastomal hernia due to the surgical defect created within the abdominal wall. The need to identify risk factors to advise and educate patients about this is essential.

It is recommended that these risk factors are re-assessed and discussed on every clinical assessment.

Predisposing consideration	RISK Factors	Additional information/ explanation	Reference
Age	Children The over 70	Rectus muscle underdeveloped in paediatrics. Rectus muscle gets weaker as collagen reduces with age	Thompson (2008)
BMI *(Appendix 3a (ii))*	Obese	Undue strain and force on rectus abdominis	McGrath/Porrett (2006) Thompson (2008)
Occupation/ lifestyle	Manual Young family	Undue strain and force on rectus abdominis	
Activity 1-5 1 lie on sofa - 5 gym/sport every day	Sports - e.g. weight lifting	Undue strain and force on rectus abdominis	Kane et al (2004)
Surgery	Emergency Post op infection Multiple abdominal surgery Malnutrition	Risk of infection, larger aperture of stoma with emergency surgery Deficiency in iron, selenium, zinc	Bucknel & Ellis (1982) Bucknel & Ellis (1984) McGrath/Porrett (2006) Pearl (1989) Pilgrim et al (2010)
Stoma - site	Transverse colostomy Colostomy Out of rectus muscle Previous hernia repair Surgical technique (trephine/ aperture of stoma greater than 35mm/X incision)	Research currently indicates higher risk in colostomist Incidence reduced if within rectus muscle Implications of abnormal collagen and PMH of herniosis Likelihood of recurrence	McGrath/Porrett (2006) Carne et al (2003) Cowin & Redmond (2012) Pilgrim et al (2010)
Diagnosis/ PMH	Malignancy Diverticular Existing Hernia Previous Hernia AAA Connective tissue disorders Steroids Diabetes	Diverticular/AAA/hernia – suggest abnormal collagen as a result of genetic make up could be contributing to history of herniosis Non-specific collagen Steroids/diabetes impair healing	Muysoms etal (2009) Hernia (Springerlink.com) RC Read (2011) Readding (2014) Pilgrim et al (2010)
Smoking	Smoker	4 x greater risk of PSH in smokers	McGrath/Porrett) (2006)
Raised intra abdominal pressure	COPD/emphysema Ascites Acute/chronic constipation (colostomists/urostomist)	Persistent coughing/forceful sneezing/vomiting leads to undue strain within the abdomen Risk of constipation post operatively due to poor fluid intake secondary to the change in absorption and alterations in renal function acutely or long term	Thompson (2008) Readding (2014)

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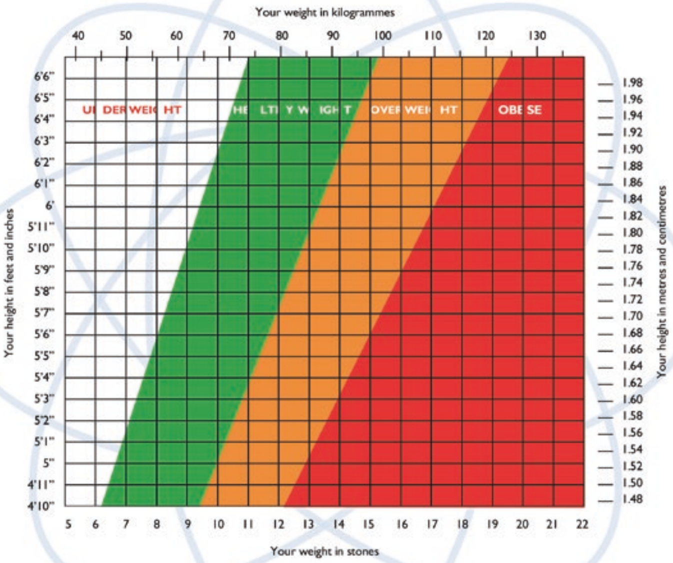
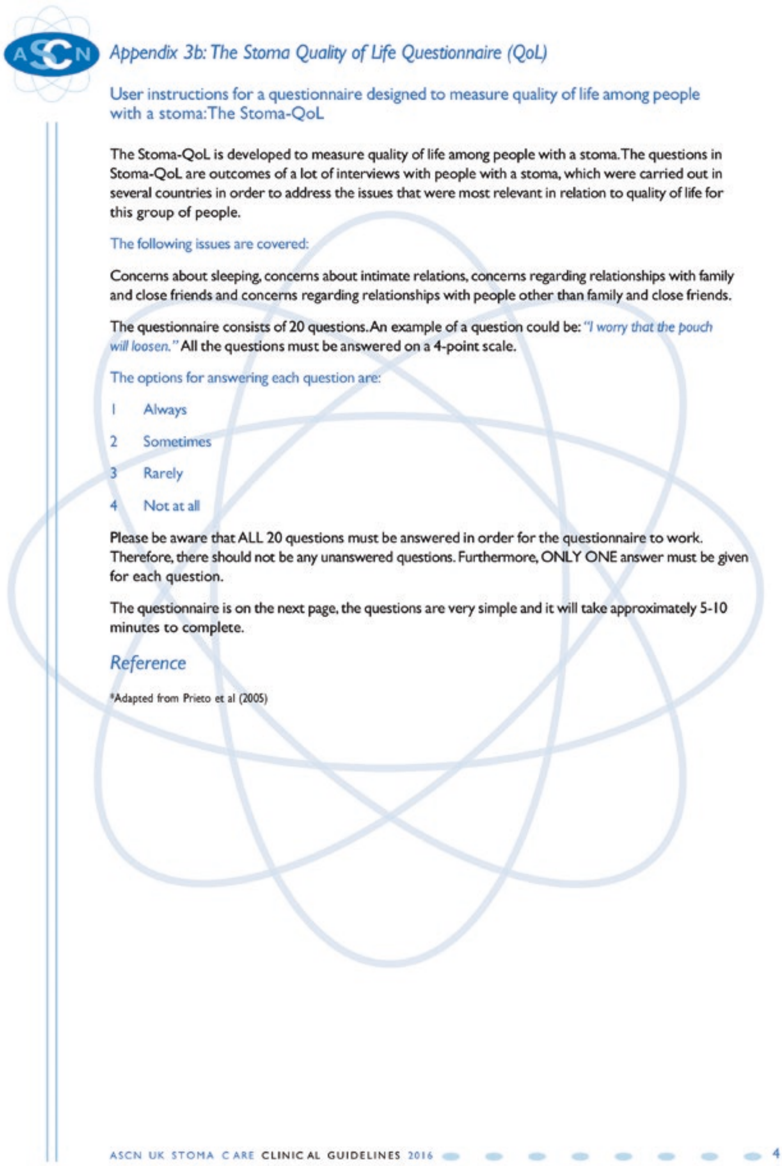
Appendix 3a (ii): BMI Chart





Appendix 3b: The Stoma Quality of Life Questionnaire (QoL)

User instructions for a questionnaire designed to measure quality of life among people with a stoma: The Stoma-QoL

The Stoma-QoL is developed to measure quality of life among people with a stoma. The questions in Stoma-QoL are outcomes of a lot of interviews with people with a stoma, which were carried out in several countries in order to address the issues that were most relevant in relation to quality of life for this group of people.

The following issues are covered:

Concerns about sleeping, concerns about intimate relations, concerns regarding relationships with family and close friends and concerns regarding relationships with people other than family and close friends.

The questionnaire consists of 20 questions. An example of a question could be: *"I worry that the pouch will loosen."* All the questions must be answered on a 4-point scale.

The options for answering each question are:

1 Always

2 Sometimes

3 Rarely

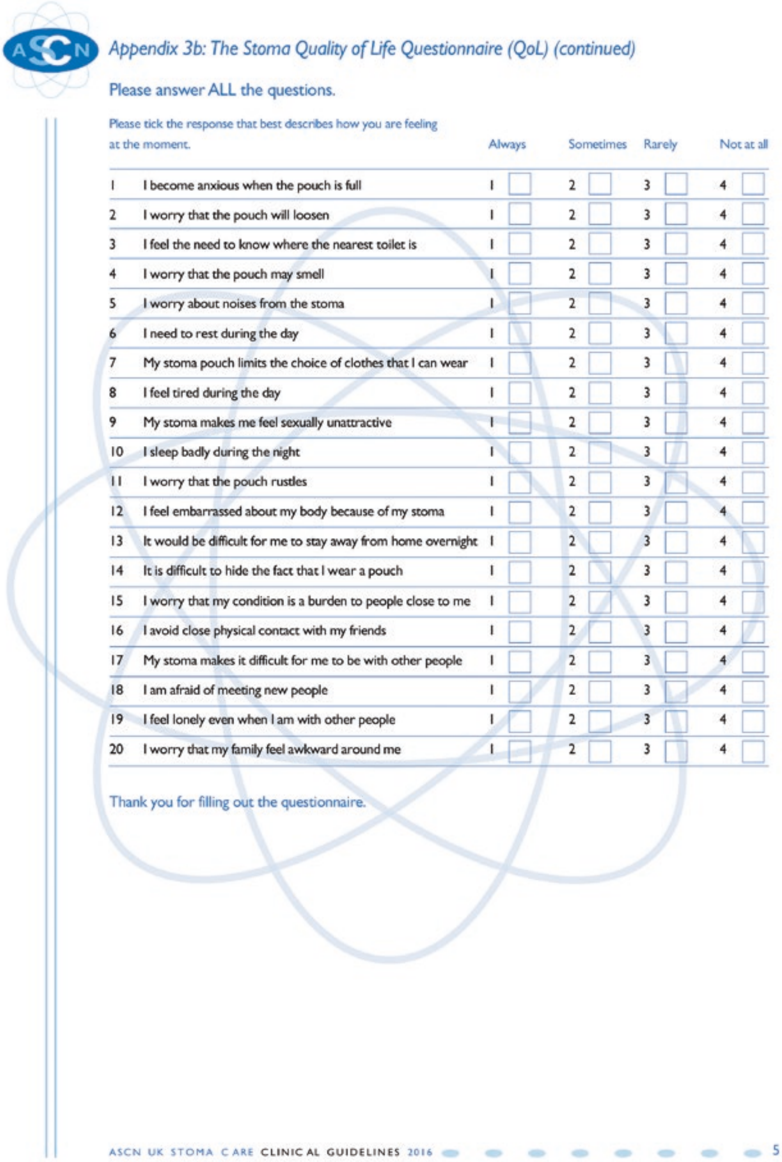
4 Not at all

Please be aware that ALL 20 questions must be answered in order for the questionnaire to work. Therefore, there should not be any unanswered questions. Furthermore, ONLY ONE answer must be given for each question.

The questionnaire is on the next page, the questions are very simple and it will take approximately 5-10 minutes to complete.

Reference

*Adapted from Prieto et al (2005)

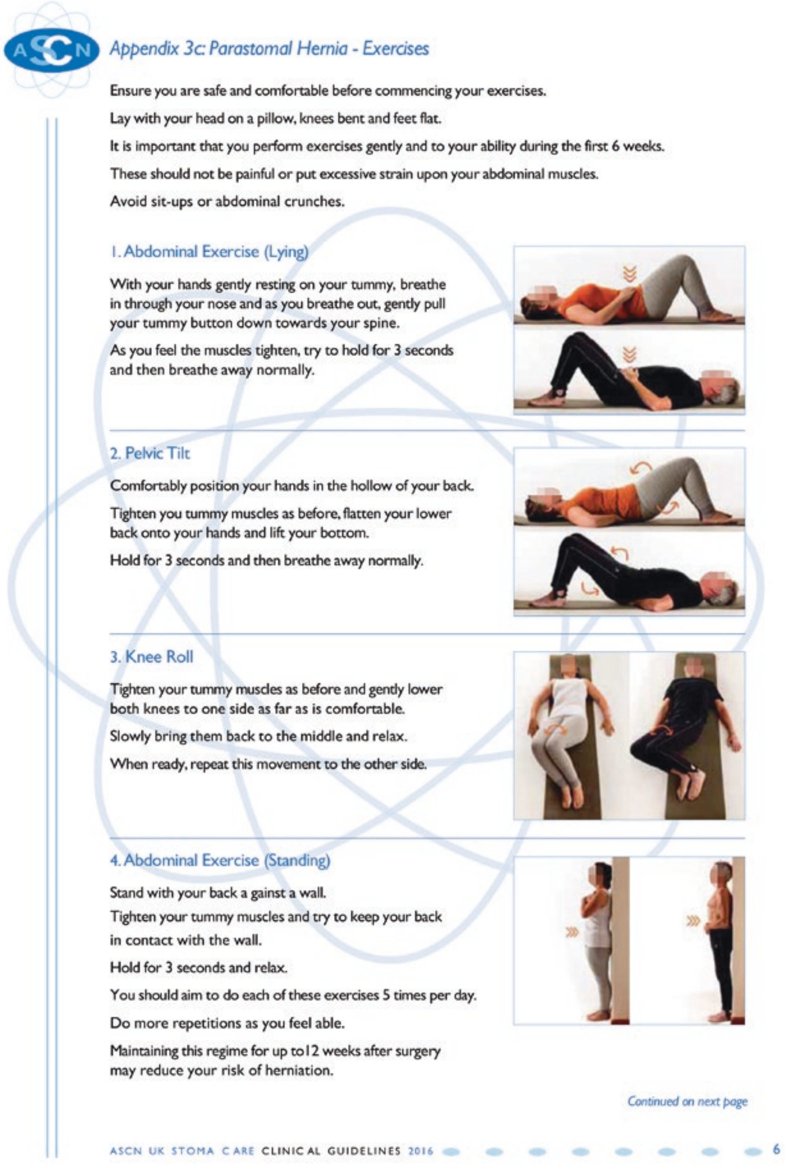


Appendix 3b: The Stoma Quality of Life Questionnaire (QoL) (continued)

Please answer ALL the questions.

	Please tick the response that best describes how you are feeling at the moment.	Always	Sometimes	Rarely	Not at all
1	I become anxious when the pouch is full	1 ☐	2 ☐	3 ☐	4 ☐
2	I worry that the pouch will loosen	1 ☐	2 ☐	3 ☐	4 ☐
3	I feel the need to know where the nearest toilet is	1 ☐	2 ☐	3 ☐	4 ☐
4	I worry that the pouch may smell	1 ☐	2 ☐	3 ☐	4 ☐
5	I worry about noises from the stoma	1 ☐	2 ☐	3 ☐	4 ☐
6	I need to rest during the day	1 ☐	2 ☐	3 ☐	4 ☐
7	My stoma pouch limits the choice of clothes that I can wear	1 ☐	2 ☐	3 ☐	4 ☐
8	I feel tired during the day	1 ☐	2 ☐	3 ☐	4 ☐
9	My stoma makes me feel sexually unattractive	1 ☐	2 ☐	3 ☐	4 ☐
10	I sleep badly during the night	1 ☐	2 ☐	3 ☐	4 ☐
11	I worry that the pouch rustles	1 ☐	2 ☐	3 ☐	4 ☐
12	I feel embarrassed about my body because of my stoma	1 ☐	2 ☐	3 ☐	4 ☐
13	It would be difficult for me to stay away from home overnight	1 ☐	2 ☐	3 ☐	4 ☐
14	It is difficult to hide the fact that I wear a pouch	1 ☐	2 ☐	3 ☐	4 ☐
15	I worry that my condition is a burden to people close to me	1 ☐	2 ☐	3 ☐	4 ☐
16	I avoid close physical contact with my friends	1 ☐	2 ☐	3 ☐	4 ☐
17	My stoma makes it difficult for me to be with other people	1 ☐	2 ☐	3 ☐	4 ☐
18	I am afraid of meeting new people	1 ☐	2 ☐	3 ☐	4 ☐
19	I feel lonely even when I am with other people	1 ☐	2 ☐	3 ☐	4 ☐
20	I worry that my family feel awkward around me	1 ☐	2 ☐	3 ☐	4 ☐

Thank you for filling out the questionnaire.



Appendix 3c: Parastomal Hernia - Exercises

Ensure you are safe and comfortable before commencing your exercises.

Lay with your head on a pillow, knees bent and feet flat.

It is important that you perform exercises gently and to your ability during the first 6 weeks.

These should not be painful or put excessive strain upon your abdominal muscles.

Avoid sit-ups or abdominal crunches.

1. Abdominal Exercise (Lying)

With your hands gently resting on your tummy, breathe in through your nose and as you breathe out, gently pull your tummy button down towards your spine.

As you feel the muscles tighten, try to hold for 3 seconds and then breathe away normally.

2. Pelvic Tilt

Comfortably position your hands in the hollow of your back.

Tighten you tummy muscles as before, flatten your lower back onto your hands and lift your bottom.

Hold for 3 seconds and then breathe away normally.

3. Knee Roll

Tighten your tummy muscles as before and gently lower both knees to one side as far as is comfortable.

Slowly bring them back to the middle and relax.

When ready, repeat this movement to the other side.

4. Abdominal Exercise (Standing)

Stand with your back a gainst a wall.

Tighten your tummy muscles and try to keep your back in contact with the wall.

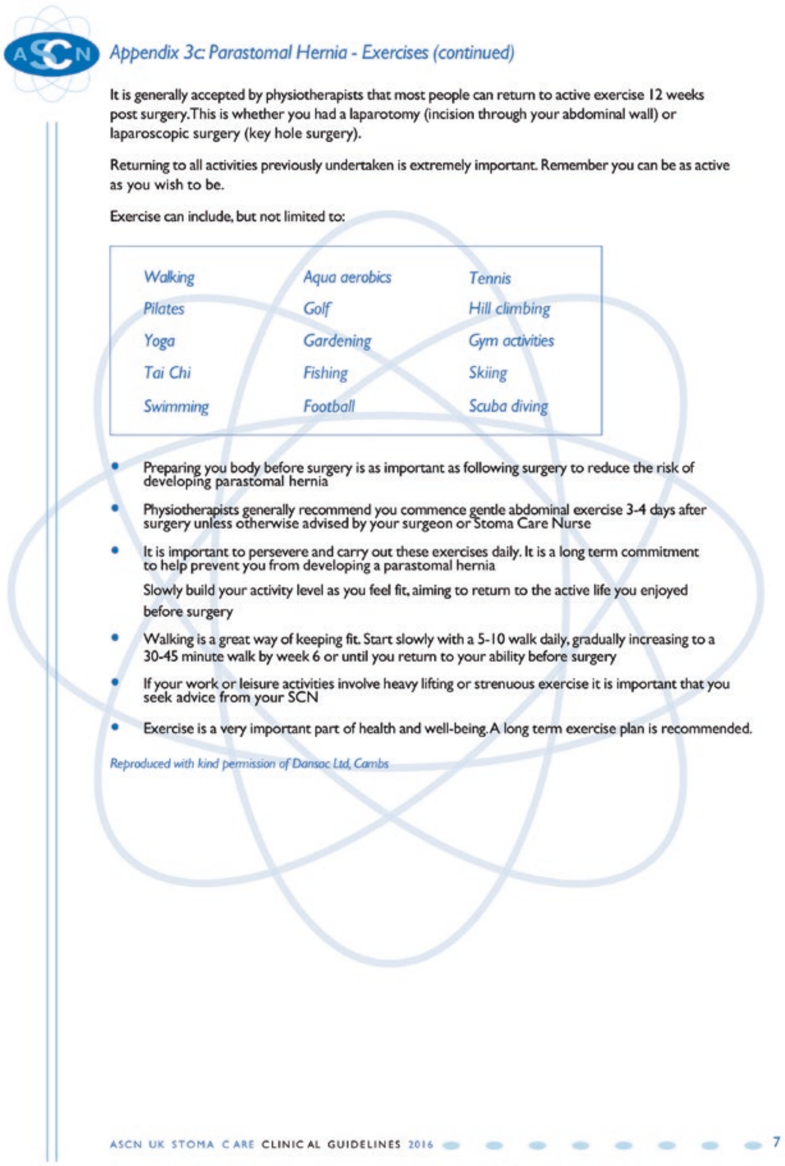
Hold for 3 seconds and relax.

You should aim to do each of these exercises 5 times per day.

Do more repetitions as you feel able.

Maintaining this regime for up to12 weeks after surgery may reduce your risk of herniation.

Continued on next page



Appendix 3c: Parastomal Hernia - Exercises (continued)

It is generally accepted by physiotherapists that most people can return to active exercise 12 weeks post surgery. This is whether you had a laparotomy (incision through your abdominal wall) or laparoscopic surgery (key hole surgery).

Returning to all activities previously undertaken is extremely important. Remember you can be as active as you wish to be.

Exercise can include, but not limited to:

Walking
Pilates
Yoga
Tai Chi
Swimming
Aqua aerobics
Golf
Gardening
Fishing
Football
Tennis
Hill climbing
Gym activities
Skiing
Scuba diving

- Preparing you body before surgery is as important as following surgery to reduce the risk of developing parastomal hernia
- Physiotherapists generally recommend you commence gentle abdominal exercise 3-4 days after surgery unless otherwise advised by your surgeon or Stoma Care Nurse
- It is important to persevere and carry out these exercises daily. It is a long term commitment to help prevent you from developing a parastomal hernia

  Slowly build your activity level as you feel fit, aiming to return to the active life you enjoyed before surgery
- Walking is a great way of keeping fit. Start slowly with a 5-10 walk daily, gradually increasing to a 30-45 minute walk by week 6 or until you return to your ability before surgery
- If your work or leisure activities involve heavy lifting or strenuous exercise it is important that you seek advice from your SCN
- Exercise is a very important part of health and well-being. A long term exercise plan is recommended.

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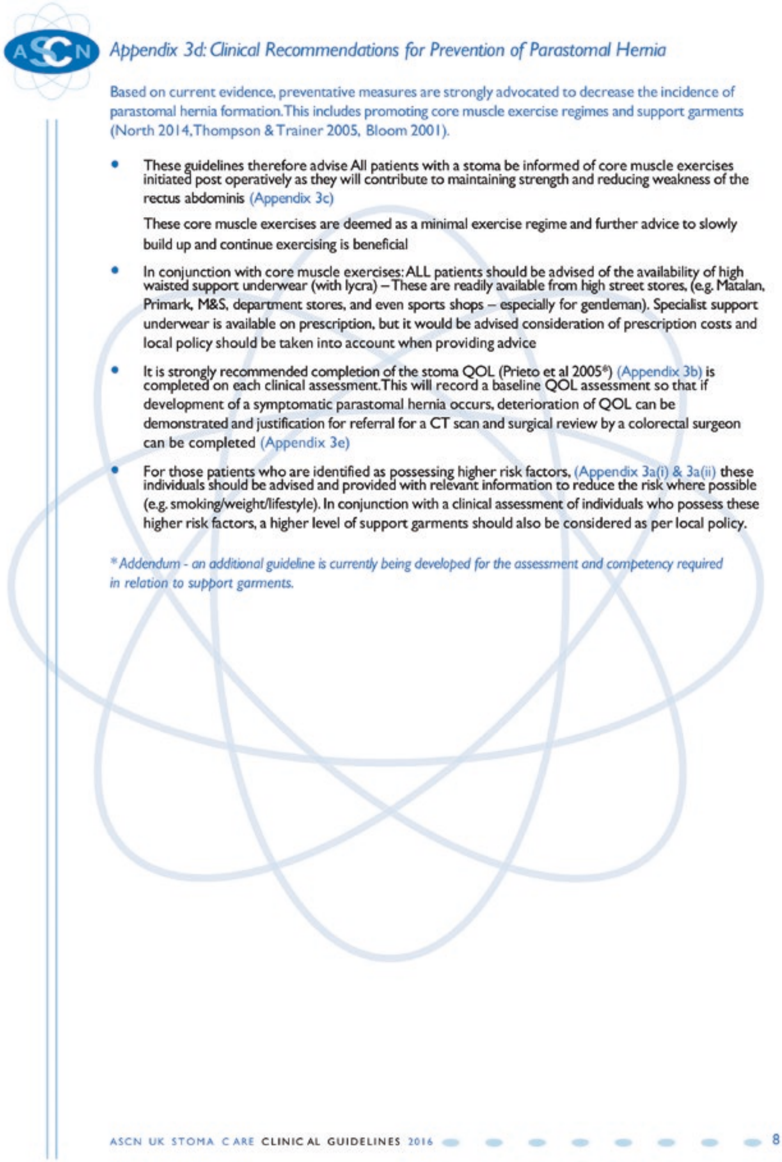


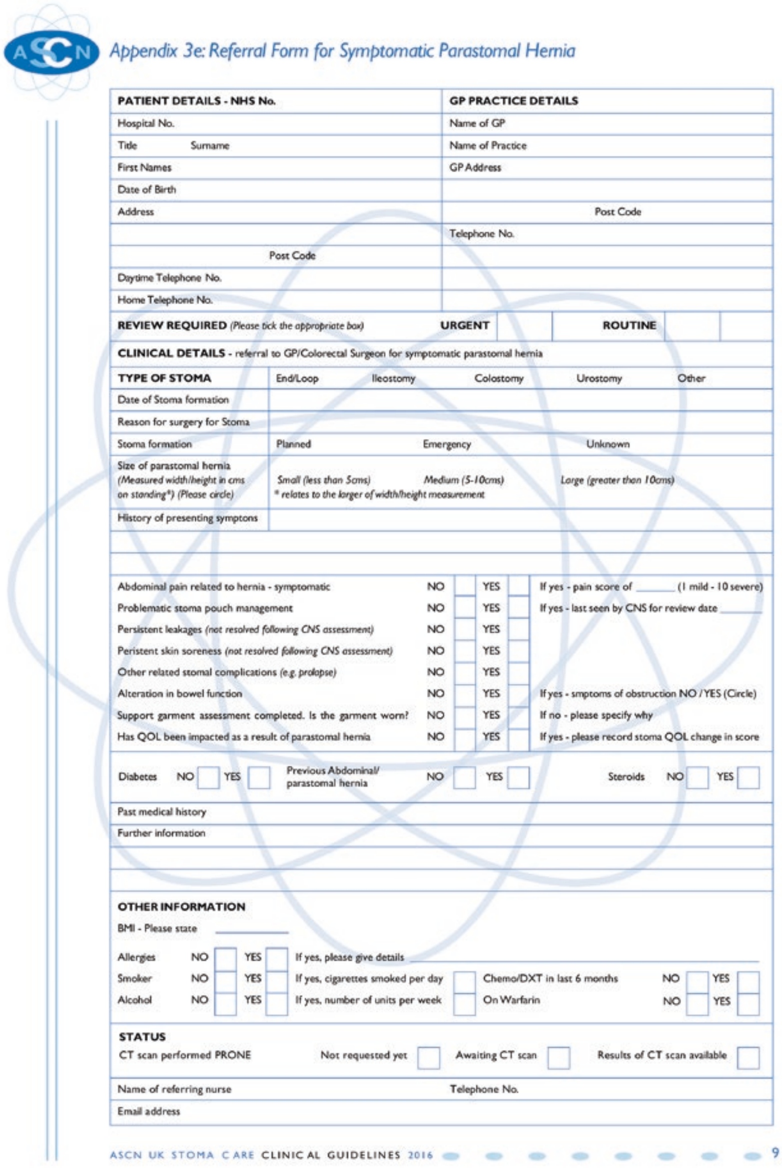
Appendix 3d: Clinical Recommendations for Prevention of Parastomal Hernia

Based on current evidence, preventative measures are strongly advocated to decrease the incidence of parastomal hernia formation. This includes promoting core muscle exercise regimes and support garments (North 2014, Thompson & Trainer 2005, Bloom 2001).

- These guidelines therefore advise All patients with a stoma be informed of core muscle exercises initiated post operatively as they will contribute to maintaining strength and reducing weakness of the rectus abdominis (Appendix 3c)

  These core muscle exercises are deemed as a minimal exercise regime and further advice to slowly build up and continue exercising is beneficial
- In conjunction with core muscle exercises: ALL patients should be advised of the availability of high waisted support underwear (with lycra) – These are readily available from high street stores, (e.g. Matalan, Primark, M&S, department stores, and even sports shops – especially for gentleman). Specialist support underwear is available on prescription, but it would be advised consideration of prescription costs and local policy should be taken into account when providing advice
- It is strongly recommended completion of the stoma QOL (Prieto et al 2005*) (Appendix 3b) is completed on each clinical assessment. This will record a baseline QOL assessment so that if development of a symptomatic parastomal hernia occurs, deterioration of QOL can be demonstrated and justification for referral for a CT scan and surgical review by a colorectal surgeon can be completed (Appendix 3e)
- For those patients who are identified as possessing higher risk factors, (Appendix 3a(i) & 3a(ii) these individuals should be advised and provided with relevant information to reduce the risk where possible (e.g. smoking/weight/lifestyle). In conjunction with a clinical assessment of individuals who possess these higher risk factors, a higher level of support garments should also be considered as per local policy.

** Addendum - an additional guideline is currently being developed for the assessment and competency required in relation to support garments.*



Appendix 3e: Referral Form for Symptomatic Parastomal Hernia

PATIENT DETAILS - NHS No.	**GP PRACTICE DETAILS**
Hospital No.	Name of GP
Title Surname	Name of Practice
First Names	GP Address
Date of Birth	
Address	Post Code
	Telephone No.
Post Code	
Daytime Telephone No.	
Home Telephone No.	

REVIEW REQUIRED *(Please tick the appropriate box)* **URGENT** ☐ **ROUTINE** ☐

CLINICAL DETAILS - referral to GP/Colorectal Surgeon for symptomatic parastomal hernia

TYPE OF STOMA	End/Loop	Ileostomy	Colostomy	Urostomy	Other
Date of Stoma formation					
Reason for surgery for Stoma					
Stoma formation	Planned		Emergency	Unknown	
Size of parastomal hernia *(Measured width/height in cms on standing*) (Please circle)*	*Small (less than 5cms)* ** relates to the larger of width/height measurement*		*Medium (5-10cms)*	*Large (greater than 10cms)*	
History of presenting symptons					

Abdominal pain related to hernia - symptomatic	NO	☐	YES	☐	If yes - pain score of ______ (1 mild - 10 severe)
Problematic stoma pouch management	NO	☐	YES	☐	If yes - last seen by CNS for review date ______
Persistent leakages *(not resolved following CNS assessment)*	NO	☐	YES	☐	
Peristent skin soreness *(not resolved following CNS assessment)*	NO	☐	YES	☐	
Other related stomal complications *(e.g. prolapse)*	NO	☐	YES	☐	
Alteration in bowel function	NO	☐	YES	☐	If yes - smptoms of obstruction NO / YES (Circle)
Support garment assessment completed. Is the garment worn?	NO	☐	YES	☐	If no - please specify why
Has QOL been impacted as a result of parastomal hernia	NO	☐	YES	☐	If yes - please record stoma QOL change in score

Diabetes NO ☐ YES ☐ Previous Abdominal/ parastomal hernia NO ☐ YES ☐ Steroids NO ☐ YES ☐

Past medical history

Further information

OTHER INFORMATION

BMI - Please state ______

Allergies	NO	☐	YES	☐	If yes, please give details				
Smoker	NO	☐	YES	☐	If yes, cigarettes smoked per day ☐	Chemo/DXT in last 6 months	NO ☐	YES	☐
Alcohol	NO	☐	YES	☐	If yes, number of units per week ☐	On Warfarin	NO ☐	YES	☐

STATUS

CT scan performed PRONE Not requested yet ☐ Awaiting CT scan ☐ Results of CT scan available ☐

Name of referring nurse	Telephone No.
Email address	

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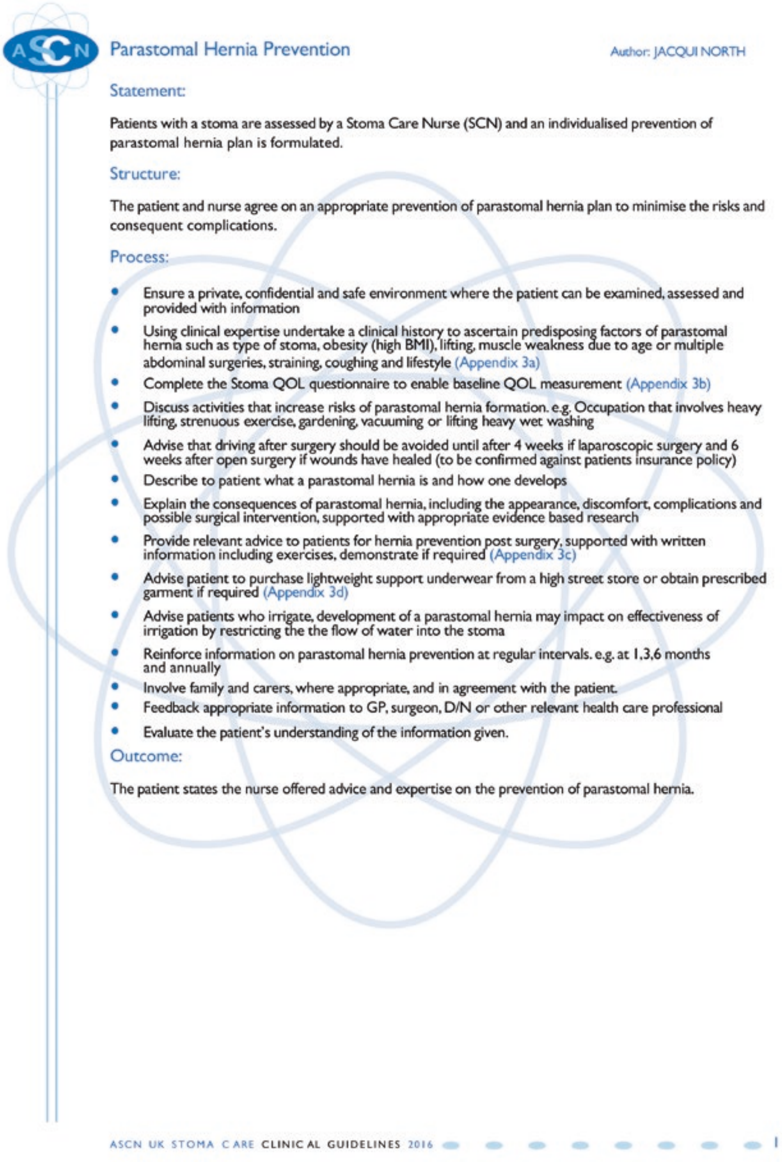
** Size classification for parastomal hernia has been derived from a literature review of abdominal hernia classification. A consensus of opinion was determined within the parastomal hernia project group, which will be evaluated within subsequent studies.*

Appendix 3 ASCNUK (2019) Hernia Prevention, ASCN UK Stoma Clinical Guidelines www.ascnuk.com



Parastomal Hernia Prevention

Author: JACQUI NORTH

Statement:

Patients with a stoma are assessed by a Stoma Care Nurse (SCN) and an individualised prevention of parastomal hernia plan is formulated.

Structure:

The patient and nurse agree on an appropriate prevention of parastomal hernia plan to minimise the risks and consequent complications.

Process:

- Ensure a private, confidential and safe environment where the patient can be examined, assessed and provided with information
- Using clinical expertise undertake a clinical history to ascertain predisposing factors of parastomal hernia such as type of stoma, obesity (high BMI), lifting, muscle weakness due to age or multiple abdominal surgeries, straining, coughing and lifestyle (Appendix 3a)
- Complete the Stoma QOL questionnaire to enable baseline QOL measurement (Appendix 3b)
- Discuss activities that increase risks of parastomal hernia formation. e.g. Occupation that involves heavy lifting, strenuous exercise, gardening, vacuuming or lifting heavy wet washing
- Advise that driving after surgery should be avoided until after 4 weeks if laparoscopic surgery and 6 weeks after open surgery if wounds have healed (to be confirmed against patients insurance policy)
- Describe to patient what a parastomal hernia is and how one develops
- Explain the consequences of parastomal hernia, including the appearance, discomfort, complications and possible surgical intervention, supported with appropriate evidence based research
- Provide relevant advice to patients for hernia prevention post surgery, supported with written information including exercises, demonstrate if required (Appendix 3c)
- Advise patient to purchase lightweight support underwear from a high street store or obtain prescribed garment if required (Appendix 3d)
- Advise patients who irrigate, development of a parastomal hernia may impact on effectiveness of irrigation by restricting the the flow of water into the stoma
- Reinforce information on parastomal hernia prevention at regular intervals. e.g. at 1,3,6 months and annually
- Involve family and carers, where appropriate, and in agreement with the patient.
- Feedback appropriate information to GP, surgeon, D/N or other relevant health care professional
- Evaluate the patient's understanding of the information given.

Outcome:

The patient states the nurse offered advice and expertise on the prevention of parastomal hernia.

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Peristomal Skin Issues and Their Management

13

Maddie White, Jackie McPhail, and Ben McDermott

Learning Outcomes

- To understand the anatomy and physiology of the skin
- To understand the classifications of skin conditions and complications
- To help identify the different types of skin conditions and complications
- To help aid in the potential treatments or need for referral for different types of skin conditions and complications

Introduction

Skin is the largest organ in the body, and is complex, consisting of three layers; epidermis, dermis and hypodermis. The very outer layer of the epidermis, which can be seen, is the stratum corneum which regulates the water loss from skin. Skin can also be referred to as the integumentary system. Skin health can reflect the patient's general health status. The rate of skin loss is dependent on age, however, on average, the skin renews itself every 26–42 days. The skin is a sensory organ, which has a natural acid mantle, which plays an important role in preventing bacterial penetration and growth.

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Skin has several functions; it acts as a protective barrier between the internal and external environments; it is responsible for thermoregulation and insulation as well as a sensory perception and synthesis of Vitamin D.

Skin Health in Stoma Patients

Peristomal skin is the skin immediately surrounding the stoma. Maintaining healthy peristomal skin is the aim for the stoma patient and the professionals who care for them. Peristomal dermatoses (diseases) are a significant problem affecting more than one-third of colostomy patient and two-thirds of urostomy and ileostomy patients [1]. People living with a stoma who have severe peristomal skin complications no longer have intact skin therefore they experience the following;

- Increased trans-epidermal water loss (TEWL);
- Alteration in skin pH;
- Loss of their protective barrier.

Functions of Skin

Skin's main priority is to maintain a barrier between the internal body structures and the external environment. It protects against invasion by pathogens, such as bacteria, and environmental irritants. These could include irritants associated with products used on the skin; for people with a stoma this may include the effluent that is excreted or the skin barrier on their stoma appliance.

The ability of the skin to control blood flow is vital for thermoregulation and maintenance of normal body temperature. Skin responds rapidly to restore equilibrium when there is an increase or decrease in core body temperature. If it is too hot, the blood vessels in skin enlarge helping heat to escape. If it is cold, blood vessels will constrict to help prevent heat from escaping; this is seen when the hairs on the skin stand on end to help trap warm air.

The hypodermis layer otherwise known as the subcutaneous layer or adipose layer, also helps to conserve heat through insulation.

Skin has the ability to sense the external environment. Skin can detect heat and degrees of heat, the cold and degrees of coldness. The skin can determine between hardness and softness of items in the surrounding environment. There are also pain receptors in skin to allow skin to determine painful stimuli. Skin can also sense itchiness, although the skin may appear intact and normal. Skin also synthesises Vitamin D from sunshine which is needed for calcium absorption in the body.

Anatomy

The skin has three layers; epidermis, dermis and hypodermis (see Fig. 13.1).

The epidermis is broken down into 5 layers (see Fig. 13.2);

- Stratum corneum (outermost layer)
- Stratum lucidium
- Stratum granulosum
- Stratum spinosum
- Stratum basale

The stratum corneum containing skin cells and waxy lipids consists of a matrix-like structure similar to bricks and mortar, with the skin cells (corneocytes) being the bricks, and waxy lipids being the mortar [2, 3]. Waxy lipids consist of ceramides, fatty acids and glycerol with ceramides being the major lipid component in the intercellular spaces of the stratum corneum [4]. Their function is to help minimise trans-epidermal water loss (TEWL).

TEWL can be defined as the measurement of the amount of water that passes from inside the body to the outside via the epidermis. TEWL can increase with both physical skin damage such as stripping, and with pathological conditions such as

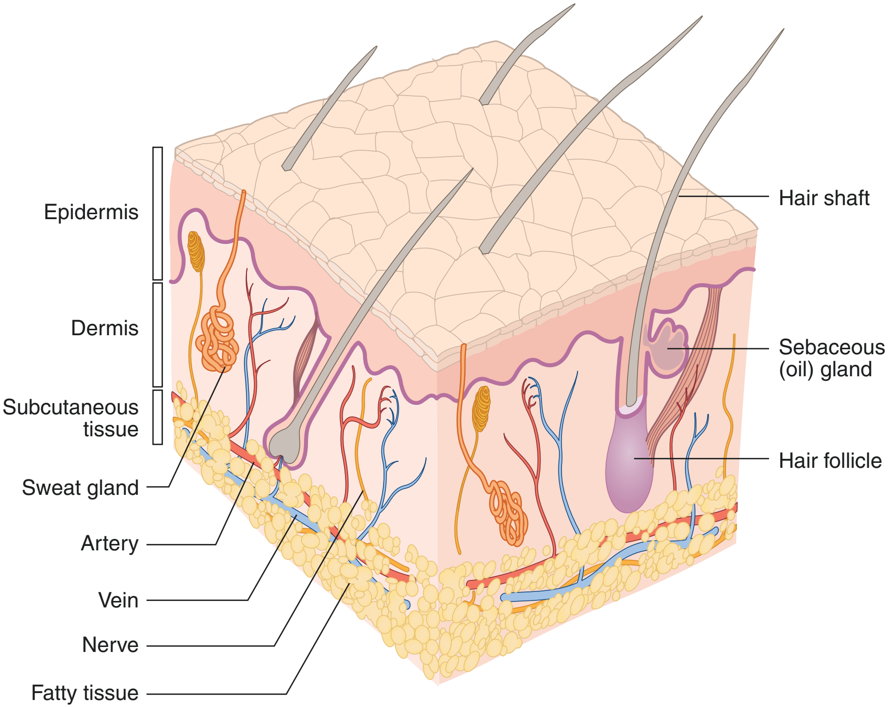


Fig. 13.1 The structure of the skin (copyright UHB NHS FT)

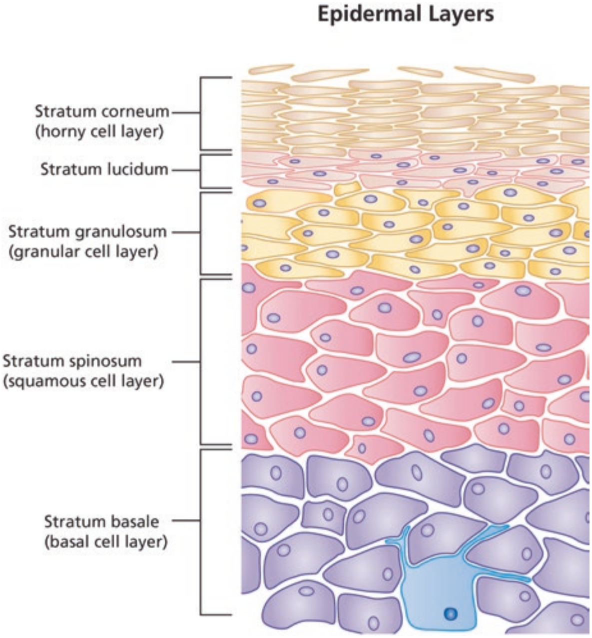


Fig. 13.2 Epidermal layers (copyright UHB NHS FT)

eczema and psoriasis. In peristomal skin, physical skin damage can occur due to peristomal moisture associated skin damage (PMASD) from contact with stomal effluent. Ceramides have a role in minimising TEWL, and is important in maintaining the moisture level within the stratum corneum. According to Coderch et al. [4], ‘It is well known that ceramides play an essential role in structuring and maintaining the water permeability barrier function of the skin’ which is supported by Feingold [5]. Most skin disorders that have a reduced barrier function, have a decrease in ceramide content and pattern [4].

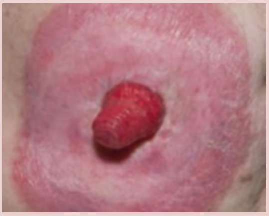
The arrangement of the corneocytes and lipids help to slow down water loss from the subcutaneous layer and impedes the absorption of water or other fluids in contact with the skin’s surface [6]. These lipids are hydrophobic and help to form the waterproofing of the skin. A reduction in the barrier lipids occurs when solvents or detergents are used, or following the removal of tape leading to skin stripping, which leads to a significant increase in water loss through the upper layers of the skin [4].

It is known ageing affects the integrity of the skin; it loses it’s protective function because the sebaceous glands produce less sebum making older people more prone to bacterial, viral and fungal infection [7]. Further discussion in relation to stoma patients will be discussed later in this chapter.

Skin Issues/Complications

24% of General Practitioner (GP) appointments were patients presenting with skin conditions requiring medical intervention [8]. LeBlanc et al. [9] state that 80% of patients will present with a stomal or peristomal skin complication within 2 years of their surgery. Skin conditions can be complex. Some are related to other diseases such as extra intestinal manifestations of Crohn's disease. Others are related to the environment or trauma to the skin, considered to be as a result of intrinsic or extrinsic factors [10]. Skin issues may be classified as mild, moderate and severe. The literature also classifies skin disorders into categories including rash, ulceration or a raised lesion. These three categories will be used to look in depth at peristomal skin conditions (see Fig. 13.3).

Fig. 13.3 Classifications of skin lesions common in stoma patients (photos by kind permission from Salford Hospital)

Classification	Examples include;
1. Rashes 	Folliculitis Infection i.e. Impetigo, Cellulitis and Fungal infection i.e. candidiasis Psoriasis (see photo) Pemphigoid Bullous Peristomal Medical Adhesive Related Skin injury (PMARSI) leading to skin stripping (9) Allergies Irritant and contact dermatitis
2. Erosion/ulceration 	Pyoderma Gangrenosum Gangrene and Necrotising Fasciitis Nicorandil induced ulcer (see photo)
3. Raised lesions 	Granuloma (papular overgranulation) Malignancy (see photo) Cutaneous Crohn's Disease Chronic papillomatous dermatitis (around urostomy)

Many patients still present to a Stoma clinic or GP appointment with skin which they feel is ‘normal’ and yet shows inflammation and erythema. The skin around the stoma should be free from any areas of soreness or inflammation. Appliance leakage may occur if the skin barrier does not adhere properly thereby increasing the opportunity for skin problems.

The development of Moisture Associated Skin Damage (MASD) is well recognised in the field of wound care and involves more than bodily fluids alone. Rather, skin damage is attributable to multiple factors, including chemical irritants within the moisture source (e.g. proteases and lipases in faeces, drug metabolites), its pH, associated microorganisms on the skin surface (e.g. commensal skin flora), and mechanical factors such as friction [2].

Cleansing the skin should be undertaken using warm tap water. If soap is required to remove effluent, it must be thoroughly rinsed off the skin as it may contain irritants which if left on skin, can lead to irritant contact dermatitis. It is also essential to dry the skin effectively once it is clean.

Assessment

Identifying skin complications is vital in understanding peristomal skin health. There are several skin tools available for specialist stoma care nurses (SSCNs) to aid with this process. A diagnostic tool such as that described by Lyon and Smith [1] or measurement via a peristomal skin tool such as the Ostomy Skin Tool [11] which measures Discolouration, Erosion/Ulceration and Tissue overgrowth (DET), help SSCNs to accurately judge the condition of peristomal skin and provide objective evidence before initiating a treatment plan [11, 12]. Peristomal skin should always be swabbed to rule out any underlying infection. Seeing a patient face-to-face is indispensable for a holistic assessment of the entire situation including other possible factors such as the patient’s underlying health problems, medication history and stoma technique when removing and changing an appliance. Using a validated assessment tool can also aid in removing local clinical variations. With widespread usage, this should help standardise clinical practice, resulting in improved patient care [13]. A score is useful for identifying a problem, but a holistic assessment, which includes touching the peristomal skin is necessary to determine the extent of the problem as well as causes and solutions [14]. Once the peristomal skin has been assessed and scored it is important to identify the cause of the problem and manage this effectively, otherwise the skin will further deteriorate [15].

It is also important to understand that skin damage looks different across the range of skin tones. Much of the evidence on peristomal skin complications comes from research on people with caucasian skin. However, due to the variations in the structure and content of the skin layers, particular skin pigmentations handle and respond to TEWL differently and therefore may respond differently to damage ([16] cited in [17]). In addition, observing for subtle changes in the skin, such as erythema, may be more difficult in people with darker skin pigmentations. Burch et al. [17] suggest that further research is required in this area for a fuller understanding of the implications of this.

An abundance of terminology is used by SSCNs some of which are often used incorrectly or confused with other terms. As understanding the cause of a peristomal skin condition is usually essential to resolving it, this confusion regarding terminology poses a real risk to the quality of patient care, potentially leading to misdiagnosis and/or use of inadequate or ineffective treatments [17]. This lack of consensus has also led to ASCN UK reviewing current literature and suggesting an evidence-based assessment tool integrating common terms which concur with a global perspective [18]. This tool is called PLACED and available to use from the resource section on ASCN UK website, alongside a glossary of approved terminology to increase the consistency and appropriateness of descriptions used and documented.

There are three main categories of skin lesions, the most common of which will be discussed in more depth (see Fig. 13.3).

Categories and Descriptions

Group 1.Rash: Folliculitis

The skin contains tiny hair follicles situated in the dermis. The follicle is a tube like structure which surrounds the hair, which grows up and out, exiting through the epidermis. The area swells with pus around the hair follicle or base. (It is not a boil as they tend to be larger and appear singularly.)

Symptoms
The rash appears as a crop of small rounded yellow/red spots at the sites where hair follicles have been damaged or blocked.

Causes
Pustular inflammation of the hair follicles can be caused by staphylococcus aureus infection or streptococci infection or occasionally both. The most common cause is frequent shaving; this is why it is frequently seen in male stoma patients with hairy abdomens (hirsutism). In addition it could be caused by skin stripping from frequent pouch changes introducing infection.

Treatment
The folliculitis may be mild and clear up on its own after 7–10 days. When the appliance is changed and after cleaning the peristomal skin, stoma powder may be used to make a moist area dry. Excess powder should then be removed before applying the stoma appliance.

A swab of the peristomal skin should be taken for culture and antibiotic sensitivities if the folliculitis is severe. It is important not to use antibiotics unless absolutely necessary to prevent resistance developing [19].

Alternatively, a steroid cream can be applied to the affected area. This should be used under the guidance of the patient's doctor and SSCN, who can assess the peristomal skin. It is important that treatment does not impede the adhesion of the stoma appliance therefore the patient needs to be advised to use sparingly then remove the excess. Steroids can cause thinning of the skin as they impair healthy anabolic processes that build up organs and tissues making it more prone to skin stripping [20], so should always be used with caution.

Prevention

If the abdomen is hairy, shaving with a clean razor is advisable and in the direction of the hair growth. Care must be taken using depilatory creams as the ingredients can irritate the skin and may not allow the skin barrier to adhere to the body.

Encourage the person with a stoma to not share towels, which may be used to dry the skin around the stoma.

The use of an adhesive remover spray or wipe when removing the appliance can also help to prevent folliculitis [21].

Group 1. Infection: (a) Impetigo

Description

Impetigo is a superficial infection caused by staphylococcus or streptococci. The bacteria infects the upper layer of the skin causing superficial sloughing resulting in denuded or blistered skin.

A thorough examination of the patient is necessary as impetigo is highly contagious and more than one body site may be involved.

Symptoms

Impetigo starts as blisters which burst and leave a broken area of skin with a characteristic honey-coloured crust. On peristomal skin the blisters and honey coloured crusting may not be seen as the skin barrier removal will cause the blisters to burst and remove the crusting.

Treatment

A swab of the peristomal skin should be taken for culture and antibiotic sensitivities. It is important to use the correct antibiotic for this skin condition to prevent delay of treatment and antibiotic resistance [19].

Group 1. Infection: (b) Cellulitis

Description

Cellulitis is an infection of the subcutaneous tissues and upper dermis usually caused by Streptococcus. It can be seen in patients who have had recent surgery, or who are chronically unwell or patients who are immunosuppressed. The patient may otherwise appear well.

Symptoms

The onset is sudden. The affected skin is erythematous (blanching redness), tender and oedematous (swollen).

Treatment

This type of infection requires urgent treatment with antibiotics, usually given intravenously then orally once the infection is under control.

Group 1.Infection: (c) Candida

Description

It is a cutaneous or mucosal yeast infection caused by candida albicans [1], which thrives in warm humid environments. This type of organism is found in the mouth, gut and vagina. This fungal infection mostly affects the elderly, immunosuppressed patients and those with diabetes or on high doses or prolonged treatment of antibiotics [1].

Symptoms

An erythematous rash on the peristomal skin can be seen particularly underneath a skin barrier. The patient is also likely to have a rash in the groin area or underneath pendulous breasts for example.

Treatment

This type of infection responds to oral antibiotics [1]. Topical treatment such as creams can cause issues with adhesion of skin barriers and further affect peristomal skin. An antifungal in a powder form could be considered if it does not affect skin barrier adhesion.

Group 1. Pemphigoid Bullous

Description

Pemphigoid Bullous (PB) is an autoimmune condition, mostly seen in people from middle age onwards [22]. The pathogenic mechanisms and aeitiology are unknown but IgG and IgE autoantibodies are involved in disease pathogenesis [23]. The presence around a stoma can affect appliance adhesion.

Symptoms

It begins as an itchy erythematous rash then develops tense fluid filled blisters which can take weeks to months to develop. Blisters can occur anywhere but are very likely to occur at sites of trauma such as peristomal skin. It occurs when the immune system attacks the thin layer of tissue below the outer layer of skin.

Treatment

The patient should be referred to a Dermatologist for treatment. The patient may be treated with oral corticosteroids to relieve symptoms as it cannot be cured. The SSCN may therefore need to review the type of skin barrier being used to prevent any exacerbation of the condition leading to further management problems.

Considerations;

PB does not usually affect the stoma mucosa and it does not just occur around the stoma. The patient should be checked to see if they have this anywhere else on their body. It can be life threatening if left untreated.

Group 1. Psoriasis

Description

Psoriasis is defined as a benign hyperproliferative skin condition with well-defined red adherent thick plaques [1]. It is a chronic condition which may have remissions and flare ups.

Cause

Lyon and Smith [1] found that those with a diagnosis of inflammatory bowel disease (IBD) are twice as likely to have psoriasis than those without. The aetiology is unknown, but it is thought that there is an underlying genetic involvement.

Symptoms

The skin replacement process speeds up, taking just a few days to replace skin cells that usually take 21–28 days. The accumulation of skin cells builds up and form raised ‘plaques’, which can also be flaky, scaly, red on Caucasian skin, or darker patches on other ethnicities with darker skin tones, and itchy.

The diagnosis is made on its’ appearance, but biopsies may be taken to determine this skin condition.

Treatment

There is no cure for Psoriasis, but symptoms can be treated. Treatment may involve topical steroids or if it does not respond, phototherapy may be used. In severe cases systemic treatment may be required [24].

The SSCN may need to review the skin barrier being used on the peristomal skin to ensure adhesion and prevent worsening of the condition caused by stomal leakage.

Further Information

Psoriasis Association www.psoriasis-association.org.uk [25]

Group 1. Peristomal Medical Adhesive Related Skin Injury (PMARSI)

Description

When assessing any stoma patient, it is important to document the specific type of PMARSI that occurs: skin stripping, tension blister, skin tear, irritant contact dermatitis, allergic dermatitis, maceration or folliculitis. PMARSI is well recognised as a contributor to peristomal skin damage and is defined as the removal of one or more layers of the stratum corneum following removal of medical adhesive. It appears as erythema (blanching redness), epidermal stripping or skin tears, erosion, bulla, or vesicle observed after removal of an adhesive ostomy pouching system [9].

Symptoms

Areas of skin stripping appear as epidermal loss, or a rash as discussed previously. Stripped skin may appear shiny and a skin tear can be partial or full thickness.

Treatment

The patient should be advised to use an adhesive remover (either a wipe or a spray) to help with removal of the flange. Supporting the skin with the other hand whilst removing the flange is also helpful.

Group 1. Dermatitis: Contact Irritant and Contact Allergy

Description

Irritation, particularly from stoma effluent is the commonest cause of skin problems, whilst allergy is one of the rarer causes [26]. Both cause a rash, but the pathological response is different. Dermatitis (inflamed skin) is the skin's reaction to an irritant, either contact or allergic. The skin's response is to become hyperplastic (increase in the number of cells produced) and hyperkeratotic (thickening of the stratum corneum). (Please see Fig. 13.4).

Fig. 13.4 Dermatitis: Contact irritant and Contact Allergy Courtesy of M White

Cause

Peristomal skin is ideal for developing either an allergy or irritation due to the stomal effluent, repeated appliance removal and the occlusion of the skin with the appliance. This humid environment increases the risk of sensitisation [26].

Symptoms

Irritant contact dermatitis typically presents as a well defined erythema, which can be oedematous with blister formation. Necrosis can occur in severe cases.

Acute allergic dermatitis is also erythematous, but the margins are indistinct and blurred. Lesions (these include papules/raised lesions and vesicles/small blisters) can become eroded and crusted. Symptoms increase in their evolution if the skin is increasingly exposed to the same causative agent. The patient usually complains of an itch with both conditions and a secondary infection may also occur, because the patient scratches and damages the skin.

Treatment

A correctly fitting appliance will prevent skin damage by reducing the area of peristomal skin exposed to stoma effluent. This may be an appliance with a smaller aperture, a convex appliance or the use of a hydrocolloid sheet or ring under the appliance. Corticosteroids can be applied topically and sucralfate powder has been widely used. Removing the irritant permanently prevents further damage and allows the skin to recover. True allergic contact dermatitis is rare but will subside once the responsible factor is removed. Patch testing may be necessary before introducing a suitable alternative [27].

Group 2. Ulceration: Pyoderma Gangrenosum (PG)

Description

This is a rare autoimmune disease of the skin [28] and commonly presents as ulcerations that appear as well defined ulcers with purple edges, which are painful to touch and may exhibit webbing or skin bridges. A definitive diagnosis of PG is often delayed because of clinical confusion with other peristomal skin ulcerative aetiologies [29] (Please see Fig. 13.5).

Cause

The aetiology is unknown (idiopathic), however it may be exacerbated in patients with inflammatory bowel disease by trauma or psychological stress [30]. It is an autoimmune disease and affects 50% of patients with inflammatory bowel disease (IBD), although it can occur in patients who have had a colostomy or ileostomy for other conditions such as cancer or diverticular disease [1].

Symptoms

It is usual to see painful ulcers down to the dermis with characteristic bluish edges around the ulcers [31]. The diagnosis is determined by eliminating any other cause. If non- healing, a biopsy is required to ascertain the diagnosis.

Fig. 13.5 Ulceration - Pyoderma Gangrenosum (PG) (Courtesy of Salford Hospital)

Treatment

If the patient has any other underlying disease such as IBD they will need to be referred to the Gastroenterology team or relevant team for additional treatment. This may involve a combination of topical steroids and topical immunomodulators and systemic biologic treatment under the guidance and advice of both gastrointestinal and dermatology teams [32]. It is important to treat the area with PG only, and not apply the topical steroid on the entire area of peristomal skin. Stoma equipment should be selected which will both protect and prevent worsening of the peristomal skin and allow for application of treatment prescribed.

Group 2. Gangrene

Description

Gangrene is a serious condition where a loss of blood supply causes body tissue to die. It can affect any part of the body, but it typically starts in the toes, feet, fingers and hands, although may be seen as a peristomal skin lesion in patients who have an injury (surgery, burn or frostbite for example), an infection in an open wound or an underlying condition that affects circulation. The term gangrene includes a group of conditions including necrotising fasciitis (NF). It is rare, but is a serious bacterial infection that affects the tissue below the skin and surrounding muscles and organs. It is sometimes referred to as the “flesh eating disease”. The bacteria which cause this release toxins that damage the nearby tissue [33]. Fournier’s Gangrene is a specific gangrene which affects the immunocompromised, those who have poor circulation or comorbidities such as HIV or diabetes. Weight fluctuations such as obesity or malnourishment may also put patients at risk of developing this. Gangrene may arise as the result of a traumatic skin issue around the perineum and genitalia and may be the underlying reason why a stoma is created [34].

Symptoms

Progressive necrotising cellulitis with erythema and swelling appear after a few hours or days. The patient is usually systemically unwell and showing signs of sepsis with disproportionate pain and a pyrexia. The original injury, sores or blisters, will bleed easily releasing a malodorous pus like discharge. These are similar symptoms to cellulitis and require prompt attention.

After a few hours or days [33] the following symptoms may occur; swelling and redness in the painful area, and firmness to touch. The patient may also experience diarrhoea and vomiting and show dark areas on the skin that turn into fluid filled blisters.

Cause

It is caused by either Clostridium or a combined bacterial infection [1].

Treatment

This type of infection responds to high doses of antibiotic; however, if gas gangrene is present this will require emergency surgical debridement [1].

Group 2. Nicorandil Ulceration

Description

A nicorandil induced ulcer is a non-inflamed bland ulcer [1]. This can occur within weeks of commencing nicorandil [35], and as late as 23 months after the patient has commenced on nicorandil [36].

Nicorandil is a vasodilator and has elements of a nitrate and a potassium channel activator and is used as a third line therapy for angina [37]. Lyon and Smith [1] state that cutaneous eruptions account for 15% to 20% of adverse reactions to systemic medications. Fake et al. [38] further state that nicorandil ulcers are not well recognised, stressing the need for vigilance and a holistic patient assessment.

Cause

It is still unclear how Nicorandil causes mucosal ulceration. Lyon [36] highlighted patients who developed peristomal ulcers were on high doses of nicorandil, at least 20 mg twice a day; Donaldson et al. [39] reported a patient commenced on nicorandil 20 mg daily developed a peristomal ulcer after 2 weeks. These studies show that peristomal ulceration can develop in patients ingesting both high and low dose nicorandil and are more at risk. Nicorandil ulcers can also present like PG.

Symptoms

The condition appears as a non-inflamed bland ulcer, usually with defined looking edges.

Treatment

A skin swab is needed to rule out any underlying infection and microbiological sensitivities [1]. The best treatment is to refer to a cardiologist for alternative cardiac therapy so that the nicorandil can be stopped [40, 41]. Lyon [1] indicates the use of topical sucralfate powder which helps to protect the peristomal skin as it turns into a gel preventing the ulcer becoming contaminated by faeces. Sucralfate also doesn't affect the adherence of the stoma appliance. Ongoing assessment of the ulcer is needed to monitor treatment and document progress as the ulcers can take up to 3 months to heal [1]. Regular SSCN reviews are therefore essential.

Group 3 Raised Lesions: Granulomas

Definition

The excessive proliferation of granulation tissue to the point that it becomes elevated above the skin or mucosal surface is the basis of a granuloma. These are friable, tender papules which frequently appear at the mucocutaneous junction [1]. (Please see Fig. 13.6).

Cause

This is regarded as a consequence of aberrant healing and can be secondary to factors including chronic irritation and infection [42]. Williams and Lyon (2010) however, regard faecal irritation as the principal causative factor.

Symptoms

These papules are asymptomatic but friable and bleed very easily which patients find very distressing. Bleeding can dislodge the appliance and more will occur if the aperture in the appliance is increased to accommodate them as this exposes more surface area to stomal effluent.

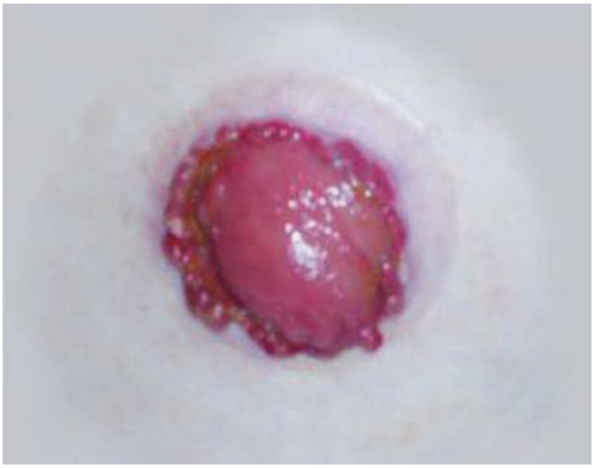


Fig. 13.6 Raised lesions. Courtesy of M White

Treatment

Treatment is reserved for granulomas if they become large, painful or uncomfortable or the bleeding causes lifting of the appliance. Silver nitrate treatment can be instigated; the guidelines for a treatment plan can be found at www.ascnuk.com/userfiles/pages/files/nationalguidelines.pdf [43] as well as an appropriate effective stoma management plan. Some patients may require cryotherapy with liquid nitrogen or photocoagulation [26].

Group 3 Chronic Papillomatous Dermatitis

Definition

These are defined as warty papules occurring around urostomies as a reaction to urine irritation of the skin. The skin thickens and the greater the alkalinity of the urine, the more chance they develop. This can be seen with patients who suffer chronic urinary infections [26].

Symptoms

A whitish cobblestone appearance on the immediate peristomal skin around the stoma is evident.

Causes

Constant saturation of urine on the immediate peristomal skin due to seepage underneath the skin barrier over a period of time is responsible for this chronic appearance.

Treatment

A treatment regime includes cleaning of the peristomal skin with vinegar solution; normally one part vinegar (ordinary malt vinegar), to four parts water. Alternatively vinegar soaks can be applied to the area following each pouch change. The SCN and patient must also consider a suitable appliance to prevent seepage of urine onto the peristomal skin.

Group 3 Malignancy (Metastatic Adenocarcinoma)

Description

This is a rare cutaneous metastasis following surgery for bowel [44] or bladder cancer leading to stoma formation.

Cause

If a stoma is formed for bowel or urinary tract malignancy, patients may develop secondary deposits around their stoma. There are rare reports of primary adenocarcinoma affecting long-standing ileostomies and/or peristomal skin.

Symptoms

It may present as cutaneous or subcutaneous nodules or an unusual lesion or as a rash, commonly on the anterior abdominal wall.

Treatment

Urgent referral to the surgical or oncology team is required. The surgical or oncology team may decide to biopsy the site, however if there is a risk of bleeding or the patient is undergoing chemotherapy this may not be possible. Consideration will then be given to the patient's fitness regarding further treatment. Surgical intervention such as excision of the lesion or refashioning of the stoma may be required if it will influence the management of the patient's disease trajectory or improve their quality of life.

Hydrocolloid barrier rings or seals that are able to absorb any fluid or mucin arising from the lesions or nodules may help to facilitate satisfactory stoma management. The SSCN will need to revise the template for the stoma regularly and provide advice appropriate to protect any exposed skin and manage uneven areas of the peristomal skin; healing can be delayed due to the patient's underlying state of health.

Group 3 Cutaneous Crohn's Disease (CD)

Description/Cause

It is associated with active CD which can be confirmed histologically following a biopsy of the lesion (see Chap. 4 for a more detailed description of Crohn's disease).

Symptoms

CD on the peristomal skin can manifest in three different ways;

- Ulceration (See Sect. 2)
- Fistulae/fissures
- Granulomatous inflammation

Ulcers form around the stoma on the peristomal skin especially at sites of injury or surgery. The patient will also have poor wound healing.

Treatment

The patient needs to be referred to a dermatologist, but they will also need referring for treatment and wider investigation of their CD. Treatment with biological therapy is usually most successful. Stoma management may be compromised and the SSCN needs to assess the patient and offer an effective solution.

Documentation

The description of peristomal skin conditions needs to be assessed and documented in a consistent and accurate way. Patients may see more than one SSCN and for the sake of continuity, an established assessment tool can help to maintain the language and descriptive terminology used. ASCN UK [18] have devised a skin assessment tool to help with this. Called PLACED, it outlines the assessment in a graphic and descriptive way to ensure that the information observed is captured accurately [18]. Consecutive photographs of the peristomal skin help to establish a baseline and monitor the progress [45]. They can be used to document the patient's skin avoiding any miscommunication associated with subjective or vague terminology in written descriptions of skin conditions [1]. Local policy will require that consent is obtained for the use of the photos before sharing with other health care professionals for clinical or educational purposes.

Quality of Life and Implications for Patient Care

Peristomal skin complications have been shown to affect patients' quality of life negatively, affecting their health, wellbeing and social interactions [46]. Studies have shown that social interactions are fundamental for individuals, as communication and social connections with others positively influences their outlook on life. Negative adaptation to life with a stoma is a possibility if patients experience ongoing or persistent peristomal skin complications [47]. Quality of life issues have been explored and results obtained can be reviewed by SSCNs to improve their own knowledge and understanding of the psychological and adaptative issues patients may experience (DIALOGUE, ADVOCATE, SCOR studies). More than 80% of patients living with a stoma will experience some form of peristomal or stomal complication within 2 years of stoma formation; the risk of complications are increased in those with additional co- morbidities [48]. There also appears to be little difference between patients in the UK and other countries such as Canada and the USA [46]. However, it is not clear whether quality of life is worse in other nations and how this correlates with spend on health care, access to Specialist nurses and other social factors.

Conclusion

Peristomal skin rashes account for one fifth of all peristomal skin issues which is more than any other group, and emphasises the importance of thorough history taking and physical examination [49]. Any peristomal skin complication can affect the patient's quality of life and wellbeing [50]. It is important that the SSCN has knowledge of the anatomy and physiology of skin so that they understand and can identify skin complications in order to manage and/or refer appropriately. A swab of the peristomal skin should be taken for culture and antibiotic sensitivities. When a peristomal lesion appears it is imperative to undertake a full assessment of the patient and stoma including a photograph of the peristomal area to establish a baseline [45]. Lyon and Smith's [1] ulceration diagnostic guide, The DET scoring system [11] or ASCN UK's PLACED [18] are excellent tools to help diagnose and describe peristomal ulcers and skin lesions. Using a tool ensures the patient gets the right diagnosis and treatment in a timely way in order to prevent worsening of the condition and patient's symptoms.

In the current health climate, the financial impact of persistent peristomal skin conditions resulting in frequent pouch changes and additional products and /or medicines, must be acknowledged. SSCNs have a responsibility to prevent wherever possible both skin issues and rising prescription costs (see Chap. 3).

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14 The Management of Enterocutaneous Fistula

Maddie White

Learning Outcomes

- To understand the principles of fistula management.
- To provide the patient with a safe structured plan of care.
- To understand gastrointestinal anatomy and physiology in order to plan care for the fistula patient.
- To explain the role of the multidisciplinary team in the care of a fistula patient.
- Explain the clinical role of the SSCN in the patient's care pathway.
- Describe the benefits of enteral versus parenteral nutrition and understand the rationale for fistuloclysis.

Introduction

The care of EFs has become the responsibility of Specialist Stoma Care Nurses (SSCNs) due to their clinical expertise in colorectal problems and their practical 'bag' management skills. Regardless of the cause of a fistula, the type of effluent and it's integrity with a wound, the overarching aim is to provide a leak free, skin protective and odour proof management system to ensure a high level of quality patient care, comfort and dignity. This chapter will discuss the causes and types of abdominal fistulas a SSCN may encounter and a structured careplan which will enable successful management, resulting in a satisfactory outcome for the patient. Some references are seminal pieces of work and remain relevant today.

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Background

'The ultimate goal in managing enterocutaneous fistulas is restoration of gastrointestinal continuity while minimising morbidity and mortality' [1].

A fistula may be a simple tract between the bowel (entero) or bladder (vesico) and the abdominal wall (cutaneous). Alternatively a complex fistula may have multiple visible outlet points on the abdominal wall and involve a complex conundrum within the abdominal cavity. Conditions such as Crohn's disease or cancer are associated with sepsis and erosion and can cause spontaneous fistulae. Haack [1] quotes a figure of 15–20% of fistulas occurring spontaneously in the setting of underlying pathology. A leak from a surgical anastomosis or damage from instrumentation (iatrogenic) at operation can also be the underlying cause for fistulation, with a figure of 75–85% of fistulas occurring as a result quoted in the literature [2].

Although fistulas are rare, they are associated with considerable morbidity and mortality with sepsis, electrolyte imbalance and low serum albumin concentrations being the main precursors to death [3]. They can also present a management conundrum to SSCNs and are often seen as a challenge! Resuscitation with intravenous (IV) fluids and antibiotics to stabilise the patient may be required and will allow for more essential interventions such as imaging. It is important for the team to ascertain the exact location and cause of the fistula in order to plan appropriate care. Radiological assessment will provide this important information and may be undertaken as a computerised tomography (CT) scan or fistulogram, with contrast inserted through the fistula opening via a catheter to outline the length and extent of the tract as well as the location and position of the fistula.

A decision can then be made as to whether the treatment course will be conservative with a typical patient having parenteral nutrition (PN) and nil orally to rest the gut or a surgical one. A multidisciplinary approach is essential in the successful management and this has led to closure rates ranging from 5% to 20% following conservative management and 75–85% with operative treatment [4].The principles of fistula management by an MDT team are seen as essential—this ensures a multidisciplinary approach delivers care based upon evidence based guidelines [5].

The basic principles for fistula management are interconnected and are continuously being reviewed. All the elements are essential and interchangeable to ensure that the care delivered is holistic and responsive to the changing condition of the patient. Individual elements may need to be revisited therefore at any time.

The principles can be seen in Diagram 14.1.

Diagram 14.1 The principles of fistula management (unpublished, suggested by Maddie White)

Holistic Patient Assessment

Table 14.1 highlights the information that should be considered when undertaking a patient assessment. The physical condition of the patient is vital—a poorly nourished patient will require intensive nutritional support in order for healing to take place; this may be over many weeks, with PN and no oral intake which can have a huge impact on the patient both socially and psychologically. Many patients have undergone multiple surgical procedures, leaving them nutritionally and physiologically compromised [3]. Baseline observations should therefore include the patient's weight and Body Mass Index (BMI) as well as fluid losses and blood chemistry values.

It is important to thoroughly assess a fistula to obtain significant information which will influence it's clinical management and provide prognostic information. For the SSCN, it is important to assess the fistula for it's characteristics as this is important when treatment is being planned. For example, a fistula producing small bowel (SB) contents or urine is likely to require a bag with a tap outlet and a continuous drainage system. It is almost certainly going to cause skin damage in a very short space of time due to the composition of the effluent. The pH value of SB effluent determines the effect on the surrounding skin; small bowel secretions contain active digestive enzymes, such as trypsin, lipase and peptidase, that will erode the skin [6]. Exposure of the epidermis to fluid, digestive enzymes and pH extremes will thus lead to maceration, erythema and erosion [7]. A large bowel fistula is likely to have a lower output compared to a SB fistula and possibly thicker fluid which

Table 14.1 Assessment considerations

	Considerations	Rationale
Nutritional state	Weight BMI Serum Albumin	Consider routes of nutrition; PN or NG feeding Liaison with wider MDT
Type of fistula	Simple or complex Faeces or Urine Volume and consistency of output (small bowel, large bowel or urine)	Determine the type of fistula and the appliance and outlet required for management
Skin assessment	Skin health and assessment Consider swab Contours/scars/wounds	Treat underlying skin infections/ conditions Determine need for accessory items
Wound/fistula site	Position and extent of wound with fistula	Determine the type of appliance required
Other considerations	Stoma Drain/s External fixator/medical device	Determine the positioning of management device in relation to others
Psychological state	Underlying conditions affecting patient's mood	Establish a baseline Assess regularly for signs of deterioration

may allow for a more conventional drainable bag. Sampling the effluent for the presence of pathogens can also yield further important information to be considered such as whether the patient has *clostridium difficile* and requires barrier nursing. Local policy procedures should be followed for requesting stool specimens.

The skin assessment should include a detailed examination of the size and area affected by the leakage, the degree to which the dermis is damaged as well as the presence of ulcers, bleeding and other adverse features such as allergies to adhesive products. The patients's body shape may have changed dramatically from their 'normal' shape due to significant weight loss if they have become malnourished. This is not unusual in patients with ongoing sepsis and disease activity. If the patient is well enough, assessing their shape whilst sitting, lying and standing will provide valuable information regarding skin creases, dips and recesses which may need to be filled (see Table 14.1).

It is helpful to use a recognised skin assessment tool - there are several available from manufacturing companies such as the Ostomy Skin Tool [6, 8] as well as the ASCN UK PLACED skin assessment tool [9]. A swab from the peristomal skin should be taken to rule out underlying skin infections for which antibiotic use may be required. Any underlying bacterial infection will need to be addressed. Good practice dictates that care is well documented in the patient's notes and/ or photographed with permission and consent from the patient.

The fistula site may be integral within a wound such as a laparotomy wound which may be closed or open. A standard sized appliance may be ample for a laparotomy wound with a small opening. However, the management of a large open abdominal wound can be made easier by 'bridging' the wound to reduce the size of

Table 14.2 ‘Bridging’ a fistula wound (ASCN UK 2019)

	**Step 1** Prepare all equipment Adhesive Remover Wound manager Hydrocolloid paste Large hydrocolloid Seal Hydrocolloid wafer		**Step 5** Apply the strip of hydrocolloid to wound edges with join at the top of the wound
	**Step 2** Clean skin and wound well with water and dry thoroughly		**Step 6** Apply hydrocolloid wafer to top half of the wound
	**Step 3** Apply hydrocolloid paste with spatula or gloved finger moistened with water		**Step 7** Cut the new bag according to the template
	**Step 4** Cut a large hydrocolloid seal into one long strip		**Step 8** Apply bag to wound and allow patient to keep still for 20 minutes to allow the paste to set.

the appliance required (see Table 14.2). The presence of scars/dips and creases will require the use of additional items such as paste or seals to create and ensure a smooth flat platform for an appliance to adhere without leakage.

The management system selected may need to fit alongside other appliances such as those used for a stoma, wound drain or something as complex as an external fixator following a pelvic fracture for example. Please refer to ASCN UK clinical guidelines Fistula management (2021) www.ascnuk.com for further guidance (Appendix 1).

The psychological impact for the patient cannot be underestimated. A depression scale [10] can be used to determine the need for support services such as psychology and the involvement of the family can help to set care goals and boost the patient thereby maintaining morale. Patients, if they are willing, can be helpful in managing a successful fistula regime allowing them to feel involved in their care. For example, assisting with suctioning whilst paste and seals are being applied can help to support the SSCN and keeps the patient both engaged and involved in their care.

The SSCN should aim to achieve a successful plan of care that can be reproduced by staff when he/she is not available and an expectation that this can be followed clearly. A photographic careplan can support nurses' learning whilst providing step by step instruction for fistula management [11].

Resuscitation

The patient's overall physical wellbeing is fundamental to recovery and should include all aspects pertaining to physiological performance. Many patients will be nutritionally depleted due to chronic illness or failure to recover after surgery. Fluid resuscitation and the correction of electrolyte imbalance with micronutrients is vital if the patient is to make physical progress and adjust socially and emotionally. These patients are often in hospital for a prolonged period of time; motivation and goal setting can help to keep the patient focussed and in control particularly if they are able to self care with some aspects of their fistula management.

Surgical or disease complications such as sepsis need to be treated as per the local Trust sepsis guidelines with rapid antibiotic infusion and fluid resuscitation [12]. Other possible measures that need to be considered are whether a fluid collection needs draining radiologically as a percutaneous procedure or in theatre as a more formal procedure. Reducing the losses from the fistula may require the addition of medication such as loperamide, codeine phosphate, omeprazole or octreotide which act to slow the gut transit times or by reducing the secretions [13]. Some of these may be administered subcutaneously whilst others are oral or sublingual medications. Strict fluid balance monitoring is essential as, along with blood chemistry analysis, it provides information to inform clinical decisions about the patient's nutritional requirements.

Imaging

Radical imaging is essential to establish the exact nature of the fistula and the surrounding affected body structures. All modalities of imaging may be considered and include CT scan, Magnetic Resonance Imaging (MRI), fistulogram and a contrast enema. Acute changes in the clinical picture need to be addressed quickly ensuring that the correct intervention will improve the patient's condition. CT drainage of an abscess or collection in a septic patient will rapidly improve the patient's clinical condition and allow further stages of a management plan. Supporting the patient with a fistula who requires a CT scan includes reassurance that the fistula management system will remain intact or that the SSCN or other competent professional will be available to change the appliance should it leak.

Once the patient is stabilised, radiological investigation of the fistula to define its anatomy and characteristics can be arranged [1]. This may be after 7–10 days when the fistula has matured enough to support a thin catheter being inserted [12]. A fistulogram provides vital information not obtainable with other techniques, predominantly about the length and position of the fistula tract in relation to the anatomy and surrounding tissues. A water soluble contrast enema through the rectum or stoma will rule out any distal bowel obstruction which will prevent the healing of a fistula.

Nutritional Support

The choice whether to deliver nutritional support via the gut or a vein will be made according to the location of the fistula, the type of output and the general condition of the patient. The safest route to use is an enteral one and enteral nutrition (EN) can be commenced, provided the patient is not vomiting and is able to tolerate a naso gastric tube and is not obstructed in any way. However, the fistula output should be <500 mL/24 h. Nutritional support is important but must be appropriately implemented. Feeding too quickly may result in refeeding syndrome (RFS).

RFS broadly encompasses a severe electrolyte disturbance (principally low serum concentrations of the predominately intracellular ions; phosphate, magnesium, and potassium) and metabolic abnormalities in undernourished patients undergoing refeeding whether orally, enterally, or parenterally [14]. Patients can experience a sudden shift from fat to carbohydrate nutrition once put on EN or PN. The consequences may include neurological, pulmonary, cardiac, and hematologic complications and the patient needs careful monitoring.

The delivery of PN through an intravenous catheter (this must be a dedicated peripheral or central line) will include essential macro nutrients (fats, carbohydrates, amino acids) as well as a fluid volume and micronutrients (vitamins, minerals and trace elements) [15]. Constant monitoring is essential to identify and manage catheter related complications such as sepsis as well as the response in terms of the reduction in the fistula output [15]. This must include the patient's weight and daily fluid balance to prevent dehydration and possible acute kidney injury (AKI). The preservation of this line is therefore essential and aseptic techniques to clean and change attachments must be rigidly observed.

PN is an effective route to deliver nutritional support if the output exceeds >500 mL/24 h but has associated risks such as the possibility of a line infection and sepsis and longer term complications such as liver damage leading to death [16]. It has been shown in published studies that it can however, decrease gastro intestinal secretions by 30–50% [3].The decision for PN should therefore not be taken lightly but considered in light of the clinical findings and patients should be closely monitored under the auspices of a dedicated nutritional support team [5]. Some patients if well and stable may go home on PN until they are fit enough to undergo further surgery. This requires both planning and funding.

In cases where there is mucocutaneous continuity at the site of an intestinal fistula (which indicates that spontaneous closure will not occur), the intestine distal to the fistula can be intubated and used to deliver enteral feed [17]. This provides an alternative choice to PN or NG feeding and is called fistuloclysis. The process involves placing a catheter into the distal bowel in order to reinfuse the fistula

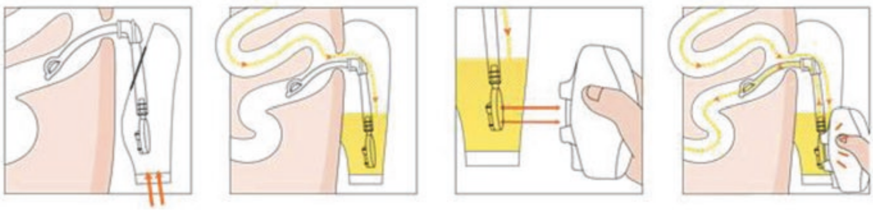

Diagram 14.2 Chyme reinfusion system (reproduced with kind permission of The Insides Company)

contents. This can be done by syringing the fluid directly down the catheter and into the distal bowel and may require the catheter to be brought through an appliance using an access device or using a windowed appliance to enable easy access. It has the advantage of maintaining the integrity of the distal bowel before any reconstructive surgery as it enables the bowel below the fistula to absorb nutrients that are not absorbed up to the point of the fistula [16]. Studies have shown that using this method to feed the patient improves both nutritional status and liver function [18]. A new method to enable this process is currently available in the UK. The Insides System [19] is a chyme reinfusion system which enables diverting enterostomy, and enterocutaneous patients to reinfuse chyme back into their intestine, allowing them to recommence oral feeding and reduce length of stay in hospital. This can be seen in Diagram 14.2. The catheter is placed in the distal bowel and the balloon dilated to keep it in place. A hand held external device is utilised to then push effluent from the bag along the catheter into the distal bowel. Patients who are well motivated can readily learn this technique allowing them to be discharged from hospital.

Conservative or Surgical Treatment

Some low volume fistulas will spontaneously close. If the fistula remains open after 2 months then surgery is likely to be required to close the fistula [3]. Many patients will be discharged home and further surgery planned electively. Certain criteria for surgery should be met—the patient's nutritional status must be optimised and consideration should then be given to discharge and community requirements for fistula care. Collaboration with community services will ensure that the patient's care is maintained at home and patients will therefore require referral to other agencies such as District and community nurses and the patient's GP. A photographic care plan as discussed earlier, provides a care plan for community staff who will also require access to the acute team for ongoing support and advice.

Surgery can be extensive and requires an 'open' rather than laparoscopic approach. Refistulation figures are quoted as ranging between 5% and 21% and mortality following definitive surgery between 0% and 11% [20]. Ideally, patients should be referred to a specialist intestinal failure unit for reconstructive surgery.

Skin Integrity

The importance of skin integrity cannot be over emphasised and a thorough assessment of the skin has been discussed previously. The distress and discomfort of sore skin can affect the patient's morale and mood, leading to a decline in physical and mental health. The care of the skin around the fistula wound is therefore a vital component of fistula management.

There is a vast amount of literature written about skin care and wound management. Preventing sore skin from occurring and maintaining skin integrity are key to successfully providing a high quality level of care. Skin protection with a barrier wipe and using calamine lotion on sore skin will establish a base layer on which to build. Paste and seals can be used in conjunction to level the skin surface before applying an appropriate appliance to collect the effluent (see ASCN UK 2019- fistula management guidelines www.ascnuk.com). Individual care plans will require a bespoke combination of products. The choice of products should be appropriate to the situation. Involving ward nurses and providing photographic care plans allows for teaching of skills and promotion of self reliance when the SSCN is not available.

Conclusion

The art of fistula management comes from the SSCN's experience and ingenuity as well as an understanding about the anatomy and physiology of the GI tract and the effect of a disease process upon it. Many nurses will have limited experience of caring for patients with fistulas therefore a set of guidelines to support them are integral to planning and executing a successful care regime. Both physical and psychological aspects of care must be considered to ensure that a unique holistic careplan is devised for the individual patient. The care provided by the SSCN and the MDT continues until a definitive conclusion is reached—either closure of the fistula or surgery undertaken to repair it. The positive relationship that evolves over time between the patient and the team remains vital to sustain the patient's morale.

Appendix 1. Fistula_management

Fistula Management

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Statement:

Patients with a faecal/urinary fistula are seen and assessed by the Stoma Care Nurse (SCN) and an individualised care plan formulated.

Structure:

The patients and SCN agree a plan to manage the fistula in order to contain the effluent, prevent skin breakdown and provide comfort.

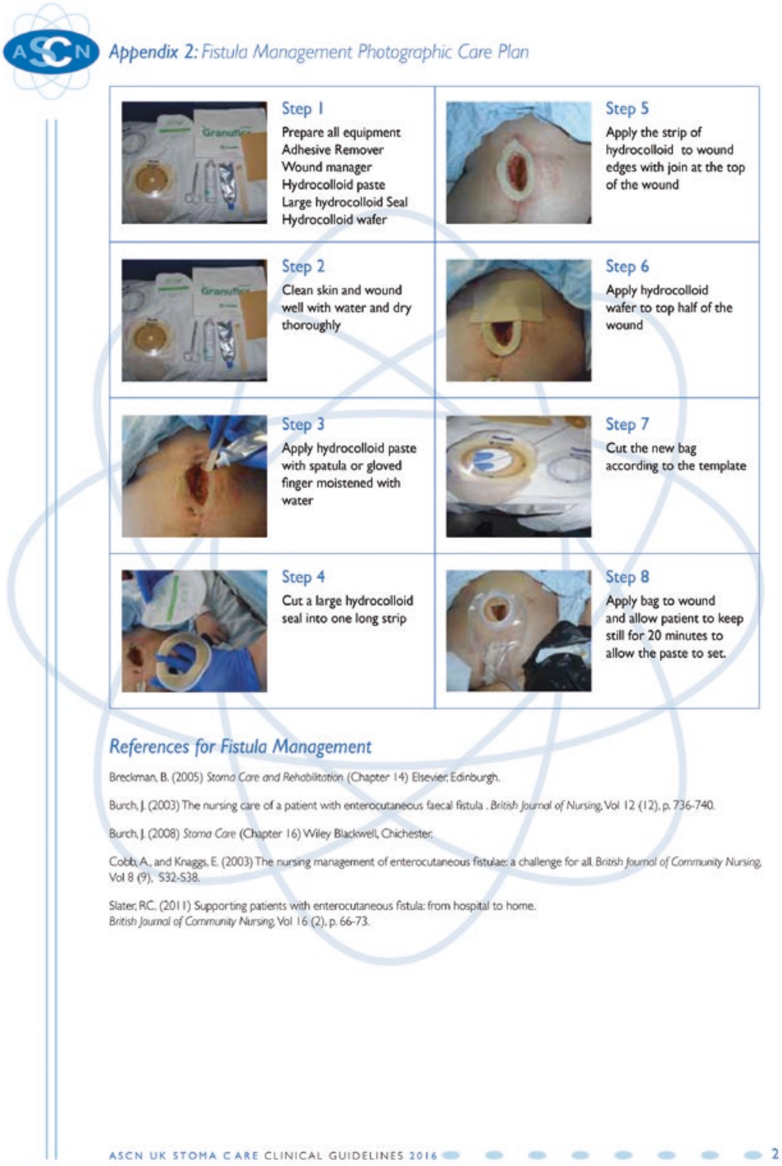
Process:

- Ensure a private, confidential and safe environment where the patient can be assessed, treatment given and provided with information
- Using clinical expertise undertake/review a clinical history to ascertain the cause of the fistula, the type and amount of effluent, and the extent of skin breakdown
- Document all findings with photographic evidence as per local policy with patient consent
- If the output is high, use suction to keep effluent away from skin edges whilst undertaking wound care
- Clean the skin with warm tap water and dry thoroughly
- If skin is broken, protect with barrier product, otherwise apply a layer of adhesive paste around the edges of the wound using gloved finger or spatula
- Apply additional paste or hydrocolloid strips to fill any creases or skin folds
- Apply a strip of double sided hydrocolloid on top of the paste to 'Picture Frame' around the wound edges to protect the skin edges and promote seal
- Using the clear template in the wound manager packet (or alternative transparent piece of paper), place over the wound and draw around the wound edge
- Cut out so that you have a template of the wound
- Apply the template to the appliance, (ensuring it corresponds to shape of wound) draw an outline and cut out the appliance taking care not to cut the front of the appliance
- Remove the wound manager backing and apply paste directly to the cut edges of the wound manager to enhance the seal between the appliance and skin edges when applied
- Position the wound manager carefully over the wound ensuring no creases or folds (it may be advantageous for the patient to be lying as flat as possible during this process)
- If you are using a windowed appliance - you can add a layer of paste to the inside of the wound manager. Either use as a syringe or gloved finger to apply the paste
- You may need retention strips to secure the appliance edges down
- Attach night drainage bag if output high to keep wound manager empty
- Advise the patient to rest in the same position for 20 minutes following the procedure to allow the paste to dry and to promote adherence of the wound manager
- Provide verbal and written advice to the ward staff on the importance of monitoring the output and ensure they understand when to contact medical staff if concerned
- Develop a photographic care plan if possible to assist ward staff with fistula management, outlining step by step management of the fistula (Appendix 2)
- Involve family and carers, where appropriate, and in agreement with the patient
- Refer to appropriate allied professionals e.g. Dietician; and feedback appropriate information as required
- Evaluate the patient's understanding of the information given
- Arrange a review at appropriate intervals as the wound may change and the template may need to be reduced.

Outcome:

The patient states the nurse offered advice and expertise on the management of their fistula and provided a care plan to outline the process.

Ward nurses express the specialist nurse offered advice and support to enable them to manage the wound/fistula management effectively.



Appendix 2: Fistula Management Photographic Care Plan

Step 1 Prepare all equipment Adhesive Remover Wound manager Hydrocolloid paste Large hydrocolloid Seal Hydrocolloid wafer	**Step 5** Apply the strip of hydrocolloid to wound edges with join at the top of the wound
Step 2 Clean skin and wound well with water and dry thoroughly	**Step 6** Apply hydrocolloid wafer to top half of the wound
Step 3 Apply hydrocolloid paste with spatula or gloved finger moistened with water	**Step 7** Cut the new bag according to the template
Step 4 Cut a large hydrocolloid seal into one long strip	**Step 8** Apply bag to wound and allow patient to keep still for 20 minutes to allow the paste to set.

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Paediatric Stoma Care

15

Claire Bohr, Jason Beyers, Kate Mills, and Hilary Kennard

Learning Outcomes

- To be able to identify some of the common conditions that require the formation of a stoma in paediatrics and compare differences with the formation of stomas in adults.
- Associate types of paediatric stoma formation with appropriate appliances, understanding the function of a mucus fistula.
- To summarize both physical and developmental changes in paediatrics that impact on paediatric stoma care.

Introduction

Not all specialist stoma care nurses (SSCNs) will look after paediatric stoma patients on a regular basis but may at some point and so need to understand the particular requirements for this group of patients. Understanding the differences in anatomy and physiology as well as developmental considerations such as changes in the skin, allows nurses to plan and deliver care effectively. Further understanding the stoma care needs of this group is vital to address their needs. This chapter will concentrate on these factors.

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Conditions that May Require Formation of a Stoma in Paediatrics

Anorectal Malformations

The majority of stomas formed in children are temporary. One of the most common causes is when a child is born with an anorectal malformation. This is when a child is born with no anal opening, it is in the wrong place, or it is stenosed. It occurs in 1in 4000–5000 live births [1].

There are different variations of the anomaly which are usually classified as high or low depending on where the rectum ends, and if there is a fistula between the rectum and the urethra and the vagina in girls [1].

If there is no opening at all and the colon reaches the anus the surgeons may be able to do a minimal operation to break through the skin covering. A high malformation usually requires a colostomy and mucus fistula within the first two days of life to provide an outlet for the stool. The mucus fistula enables contrast medium to be administered into the distal bowel to assess the severity of malformation before the stoma is closed. Once this has been established the baby will have a posterior sagittal anorectoplasty (PSARP) to form a surgical anal opening [2]. An electrical stimulator is used to identify the position and function of the muscle sphincter and establish the correct position within the muscle complex to form a new anal opening. In some centres the parents are taught how to dilate this new anal opening for a few months following surgery to prevent stricturing of the anal opening. There is no national consensus of how often or who undertakes the dilatations. Local policy should be followed, and staff must be competent to undertake the task. The SSCN plays a huge role in supporting parents and carers with education and stoma management.

Once the child has had the PSARP they will then have the stoma closed ideally within the next 3–6 months. The child should be followed up by the surgical team and paediatric nurse specialists in order to provide support regarding continence and bowel management.

Cloaca is the most severe form of malformation. During normal foetal development in females intestinal, genital, and urinary tracts should form into three separate channels. In rare cases (1 in every 50,000 babies), this process fails and these tracts do not separate from one another completely. A female is said to have developed a “persistent cloaca” when these three tracts open into one common cavity, with one opening from the body. This malformation will require many operations by a specialised unit to establish the best outcome in continence as the child develops.

Necrotising Enterocolitis

Necrotising enterocolitis (NEC) mainly occurs in premature babies or babies with low birth weight. It is a condition where the lining of the bowel becomes inflamed which leads to the affected tissue becoming necrotic. This can subsequently cause perforation of the bowel [3].

Symptoms include vomiting, distended abdomen and passing bloody stools. The baby will show signs of sepsis with an increased respiratory rate, tachycardia and pyrexia. If conservative management fails, the baby will require explorative surgery and a stoma may be created if the bowel has perforated or is necrotic [4].

The baby will be allowed to recover from the surgery and grow before the stoma is closed. This will generally be no sooner than 4 to 6 weeks after the initial surgery.

Malrotation with Midgut Volvulus

Malrotation is an abnormality of the bowel which occurs during foetal development at about 10 weeks gestation. The bowel is not fixed into position as it enters the abdomen during foetal development leaving it to float freely on its blood supply (the superior mesenteric artery (SMA). As a result, after birth the midgut can twist around the SMA causing loss of blood supply to that part of the bowel. This is known as a volvulus and in turn can lead to necrosis and death to a large proportion or all of the small intestine and part of the colon [5].

A stoma will be created if a large part of the bowel is ischaemic. This will typically be temporary and can be closed as soon as the child is well enough. Closure of the stoma will generally be required for the child to gain weight and develop. The stoma is often formed from the jejunum where the output is often very watery and can cause severe excoriation of the skin as well as dehydration and renal failure if not managed appropriately [6].

Intussusception

Intussusception occurs when the bowel slides into an adjacent section of bowel causing a telescopic effect. This can cause bowel obstruction and if untreated can lead to ischaemic bowel (see Chap. 6). Initial investigation is an air enema to establish anatomy as well as an attempt to reverse the telescoping effect, but if this fails the child will require surgery [7]. If ischaemia has occurred and the part of the bowel is felt unsalvageable the surgeon will aim to perform an end-to-end anastomosis. If the bowel is too severely damaged the surgeon will bring out a stoma, usually an ileostomy and allow the child to recover then reverse the stoma at a later date.

Hirschsprung's Disease

Hirschsprung's disease is a congenital condition, which in a samll percentage may be hereditary resulting in the absence of ganglionic cells in the distal colon. This results in the lack of peristalsis and normal function in the affected portion of gut. It most commonly presents in newborns as functional intestinal obstruction and in older children as constipation, distended abdomen and failure to thrive. It usually only affects the colon, but it can involve the whole intestine, although this is very rare [8]. While it used to be common practice for children with Hirschsprung's to have a formation of a stoma to decompress the bowel until they could remove the affected bowel, more recently the objective is to decompress the gut with regular rectal washouts before definitive surgery [9]. This may be twice a day to prevent the build-up of stool and Hirschsprung's enterocolitis [10]. Depending on the centre's policy the parents may be taught how to undertake these at home until a definitive operation to remove the affected section of the gut is preformed [11].

Chronic Intestinal Pseudo-Obstruction

Chronic intestinal pseudo-obstruction is a rare disorder where the bowel's normal action of peristalsis become inefficient; this can be neurogenic (unsynchronised) or myogenic (weak or absent). The child will present as if there is a mechanical obstruction but without the presence of a physical obstruction. The treatment is generally the formation of an ileostomy and minimal feeding often via a jejunostomy and long term total parenteral nutrition [12]. Bowel resection may be offered but this is generally ineffectual as a treatment and the problem will persist. Some patients may require a bowel transplant [13].

Crohn's Disease and Ulcerative Colitis

It is known that 25% of adult patients with inflammatory bowel disease (IBD) had symptoms in childhood. A UK study in 2001 showed that the incidence was 5.2 per 100,000 children per year. The percentage of those with Crohn's disease was 60% compared with 28% with ulcerative colitis (UC). 12% were said to be indeterminate colitis [14]. The incidence of IBD diagnosed in adults is much higher than that in the paediatric population. This is reflected on the advancement of the surgical management in adults to that in paediatrics.

There are several reasons why medical management of IBD is not as successful in paediatrics compared to adults. The main factors being the disease is more aggresive in paediatrics, lack of significant data and trials, noncompliance of rectal medication, restriction of the child's growth, and delayed puberty, unacceptance of exclusive enteral nutrition because of taste and body image if having a nasogastric tube as a young adult .

Many paediatric centres now utilise the experience of the surgeons in the adult field when undertaking pouch surgery in paediatrics. Because of the low numbers there isn't a gold standard operation in paediatrics. The preferred technique is usually determined by the age/size of the child and the surgeon's preference.

The surgical treatment for Crohn's, UC and Familial adenomatous Polyposis in paediatrics is similar to the adult group; consideration in the timing of ileal pouch formation differs in each centre. Older children may be transitioned to adult services before the formation of the pouch. This may mean the child has a stoma for a longer period if initial surgery is performed at an early age (see Chap. 6 re pouch surgery).

Table 15.1 Gestational ages

Pre-term	Born before 37 weeks gestation
Neonate	Born at term to 1 month
Infant	1 month to 2 years
Child	2–12 years
Adolescent	12–16 years

Paediatric Considerations

Unlike caring for an adult with a stoma who falls into one human age category, children fall into 5, all of which have different body shapes, physical, developmental, and care needs. As the child is still developing this should be taken into consideration when planning and delivering appropriate stoma care that is not purely based on the child's age (see Table 15.1).

The Preterm and Neonate

Neonates, particularly preterm neonates pose their own set of challenges. Their delicate skin and small size can make fitting and changing stoma bags an intricate procedure. In the early days, this can also be complicated by the fact that stoma formation in the neonate is often an emergency procedure, carried out on an unwell and unstable baby, making risks such as wound breakdown and infection more likely to cause complications.

A preterm baby born before 34 weeks will have skin that is not fully formed, with infants born extremely preterm (before 28 weeks' gestation) having an almost absent stratum corneum [15]. This results in skin with a reduced barrier function leading to high trans-epidermal water loss (TEWL) and increased risk of topical absorption [16]. To reduce TEWL the preterm neonate is often nursed in an incubator that provides a high humidity environment. This can present challenges to the adhesion of stoma appliances as the hydrocolloid bases absorb water from the environment affecting the adhesive properties and resulting in frequent leaks. A decreased barrier layer makes it more likely that the infant will sustain damage from stoma effluent on the skin. Skin immaturity, and the development of the stratum corneum in particular is accelerated by birth. However, once born, the exposure to an air filled, rather than fluid filled environment, barrier functions will equal that of a full-term skin by the time they are 2–4 weeks of age for most preterm neonates [15].

Immature barrier function is not the only challenge of preterm skin. The bonds between the skin layers are also weaker than in adults [17] increasing the risk of skin stripping when dressings or stoma appliances are removed. It may seem beneficial to leave the stoma appliance on for longer periods of time to avoid the risk of damage to the skin as the bag is removed; however, the hydrocolloid will degrade in time leaving the skin exposed to the stoma content. A barrier film can aid protection of the skin, although this should be used according to the instructions and left to fully dry before the appliance is applied. A well-documented plan with agreed timings of appliance changes should be provided for ward staff. With the use of adhesive remover and gentle cleansing of the skin (using gauze and water) this should be sufficient to protect the skin whilst also maintaining good stoma care. Although the stoma may be left uncovered immediately after formation, it requires an appliance once it begins to function. Gauze should not be used over a functioning stoma as it will not absorb fluid away from the skin causing further skin breakdown from contact between the effluent on the gauze and the skin.

The immaturity of the skin, along with risks from a poor clinical condition, poor nutrition and a reduced immune system can put the neonate at a higher risk of generalised oedema, poor wound healing and wound infection. This can further increase the challenges of ensuring a well-fitting stoma bag. Problems caused by wound breakdown around the stoma often require a multidisciplinary approach to stoma care and may need to involve input from the neonatal team, stoma nurse and tissue viability specialists to create an integrated care plan.

The size of a preterm neonate also presents challenges. The availability of stoma bags designed for neonates is limited. Most preterm neonates are likely to have an ileostomy or high colostomy resulting in fluid stools. A bag designed for a urostomy may be suitable to accommodate high output fluid stool. As the neonate grows the range of bags available will expand. Parents should be taught to recognise what is a normal volume and consistency of stoma loss for their baby. It is not usually necessary for them to measure the output once discharged home.

Another major challenge that preterm neonates with a stoma present is ensuring fluid balance is adequately managed. As necrotising enterocolitis is the most common reason for formation of a stoma in this population the preterm neonate is likely to have an ileostomy and may also have required a bowel resection. This is likely to result in at least some degree of malabsorption of feed and higher than usual stoma loss. This can lead to a risk of dehydration, electrolyte imbalance and poor growth [18]. To avoid this, it is important that stoma losses are measured accurately in the neonate, particularly as they recommence their feeds after surgery, starting supplements or feed additives and when changing feed type (for example from breast milk to formula). It is important that all areas that manage the neonate with a stoma have a guideline or care plan in place for the management of stoma losses that includes an agreed upper limit for losses and a plan for replacement of excessive losses. Losses above 20–30 mls/kg/day are generally regarded as high and in need of management [19, 20]. Management of high losses may require replacement of excessive losses with IV fluid, decreasing feed volume, increasing parenteral nutrition and re-referral back to the surgical team. Breast milk should be the feed of choice for neonates with a stoma due to the many protective factors it confers, particularly against necrotising enterocolitis [21]. Formula feeds are likely to be harder to digest than breast milk [22] and so may lead to a higher rate of malabsorption. If breastmilk is not available a hydrolysed formula may need to be considered [20].

Stoma refeeding (fistuloclysis *see* Chap. 14), where losses from the proximal stoma are infused into the distal stoma via a catheter can be used to promote intestinal maturation and improve growth prior to stoma closure. Techniques vary and published evidence on the practice is sparse and limited to single centre trials and case studies. Stoma refeeding should only be performed under the direction of a paediatric surgeon and following local guidelines.

Babies and Children

Babies and childrens' body shapes differ to adults. Children have a more rounded abdomen as their livers take up 4% of its body weight compared to 2.5% in adults. The anterior abdominal wall also bulges forwards to accommodate the bladder, uterus and ovaries, which are in the pelvis in adults [23].

New born babies may still have the umbilical cord attached for up to 10–14 days after delivery. This will also have to be considered when applying the stoma appliance.

If a stoma is sited too low down on the baby's abdomen the hydrocolloid from the appliance may end up in the leg crease, affecting appliance adhesion and possible injury to the skin.

It is important to take into consideration the changing shape of the child as they grow when siting a stoma in a young child/baby.

To be able to establish a positive therapeutic relationship with the child/young person and the family/carer there must be a high level of trust, respect and communication with the SSCN [24].

The nurse should be aware of the level of understanding that the child has of their condition and situation. A simple explanation may be all that is required to satisfy the child's questioning. i.e., "your *bottom isn't working probably, so the doctors are going to make you a new bottom hole on your tummy"*. Children of similar age may be at different developmental levels both physically and developmentally which will need to be considered to provide the best care.

Visual aids can help a child to focus on what is being verbalised, it will give the child time to process what is being said about their condition or treatment. It may take time and empathy in several short session using books, videos, puppets, dolls/soft toys before the child clearly understands or accepts what information is being given [25].

If the child has limited verbal communication due to development or impairment the SSCN must be aware of any non-verbal clues as to how the child is reacting. The child may withdraw in their body language, by turning away, or hiding behind an object or person. They may cry because they are frightened not because it hurts. Understanding this and using positive communication will help to overcome a negative response. Other tips include maintaining eye contact, using exaggerated facial expressions, speaking in a positive tone of voice and approaching the child at their level. All these will help to form a trusting relationship [26].

Points to Remember

- Build a relationship with child and family.
- Create the right environment.

- Get down to their level.
- Do your homework.
- Let them help [27]

Children should be encouraged to take part in their stoma care to enhance their self-esteem and acceptance of the stoma. Young children can help by getting the equipment out ready, peeling off the backing of the appliance, moulding the appliance to their skin once reapplied.

They can be encouraged to draw or write on the appliance; this is something all the family can do to stay involved. Being encouraged to name the stoma will remove the clinical aspect and have a positive effect on acceptance [28].

Teenagers/Young Adult

Teenagers without health issues have difficulty coping with changes in their biological growth and development, adjusting to increased pressure of decision making, confusion of status, and their body image. Coping with the added stress of a chronic illness at this age can by challenging for the young adult, family members and the professionals delivering the care.

Having a chronic illness and having to spend time in hospital jeopardises their new found independence; suddenly they are having to rely on parents and carers to undertake or assist with personal care. Teaching a teenager/young adult how to care for their own stoma will gain back their independence.

Teenagers are very focused on the physical changes to their body and body shape. Having a stoma and surgical scar may cause negative emotions such as fear, anger, and rudeness. Encourage the teenager to share their thoughts and feelings. If there is availability use the expertise of a psychologist to help the teenager expresses these either verbally or through an art form [29].

It is important to gain trust by giving them honest answers to any questions. It may take several visits before trust is obtained. They may speak more openly if their parents aren’t in the room as they may feel they have to protect their parents from being exposed to their true feelings and fears.

Make time to listen, use open questions, humour (if appropriate) positive body language, silences don’t need to be filled. Importantly, encourage them to continue to be teenagers and make their own decisions. These will not always be the right ones but they were at the time for that person.

Use of Social Media—Positives and Negatives

The use of social media for teenagers with chronic medical conditions can have both positive and negative outcomes. Social media is a powerful medium that is used in educating, information sharing, expressing fears and feelings and communicating, but negatively, also worryingly, harassment and bullying. By using social media, patients have the ability to seek information and share experiences worldwide. Information must therefore be reliable and composed of attractive messages tailored to meet teens' diverse needs. Teenagers and young people should be guided to reliable and factual information to minimize misunderstandings and misconceptions [30].

The Law

In the United Kingdom a child is defined as anyone who has not yet reached their 18th birthday even if they are living independently [31]. There are laws and guidelines in place to protect children and ensure they have a right to a say in the decisions that affect them. There are also legislations and laws to assist health care professionals to determine if a child is mature enough to make these decisions. Two of these are the Gillick competency and the Fraser guidelines. The Fraser guidelines apply to treatment about contraception and sexual health, and the Gillick competency applies mainly to medical consent, implications on decisions and medical care [32].

All health care professionals who have a direct responsibility for reporting and recording safe guarding concerns need to be adequately trained. E.g. Level 3 Safe Guarding Children and Young People will incorporate these aspects [33].

If a practitioner does not hold level 3 Safe Guarding a joint visit should be arranged with an appropriately trained professional to fulfil their duty to work within the NMC code which states "*raise your concerns immediately if you are being asked to practise beyond your role, experience and training 16.2*" [34].

Nutrition

Apart from the child's age the site of the stoma predicts tolerance to feeding and likelihood of appropriate nutrient absorption and corresponding growth velocity. The intestinal lumen will begin to adapt 24–48 h after surgery and the remaining functional length of gut to the site of the stoma will predict the duration of nutritional therapy to establish intestinal absorption. A proximal stoma (e.g. distal jejunum) will likely result in earlier and higher degree of malabsorption as the feed volume increases toward normal fluid targets compared to a stoma at the distal ileum. The ileum has a greater capacity to adapt, has a slower peristaltic rhythm and can efficiently absorb more nutrients and fluids compared to the jejunum. In neonates who have a mucous fistula the neonatal unit may initiate refeeding of digestive secretions from the proximal stoma to protect the disconnected bowel's integrity. As previously stated, this practice has varying efficacy and is not a standard practice across all Trusts.

A neonate or younger child with a permanent stoma will have greater capacity for the immature gut to adapt, lengthen and increase in surface area due to many years of growth ahead. Children of breastfeeding age are likely to receive the greatest benefit for gut adaption owing to hypertrophic factors if receiving breastmilk which contains human milk oligosaccharides (HMOs), IgA, nucleotides, growth hormone and essential long chain fats. Breast fed children predominantly come off parenteral nutrition sooner and achieve feeding targets earlier compared to that of formula milks. It is also important to recognise the benefits to the mother and child bond by encouraging breastfeeding. However if breastmilk is not an option, a formula milk which contains 25–50% medium chain triglycerides (MCTs), fats and hydrolysed proteins as part of their formulation should be used to achieve better absorption than a standard formula in the early stages of feeding after surgery.

It might be perceived that an amino acid or elemental formula that is broken down into the basic nutritional components provides the optimal formula to improve gastrointestinal (GI) absorption in the paediatric gut. However, this is not the case as the recovering digestive tract will yield a greater level of gut adaption to an intact formula due to the longer term ‘conditioning or stimulating growth affect’ on gut mucosa. Also, amino acid or elemental formulas carry a higher osmolarity, risking significant intra luminal fluid imbalances due to hyper osmotic gradient leading to higher stoma output and risk of dehydration.

Younger children require a higher amount of energy, protein, and fluid per kilogram (kg) of body weight when compared to older children and rely on higher fluid intakes to achieve their nutrition targets, risking greater fluid losses. Stoma losses need to be less than 20 mls/kg/bodyweight per day to indicate appropriate intestinal absorption. If a child cannot reduce losses to <20 mls/kg the formula osmolarity will need reviewing and the feed frequency may need to be adjusted e.g. changed to a period of continuous feeding, or the bolus volume may need to be changed to lower volume and given more often. In cases where the rate is reduced to where it was last tolerated, IV fluid maintenance may be required to achieve adequate nutrition support. If unable to deliver >50% of targets over the ensuing days, then parental nutrition (PN) may be initiated to top up nutrition support until the digestive tract has adapted appropriately.

The most common method of nutrition support to restart feeding after a stoma formation is continuous nasogastric tube (NG) feeding (rather than bolus oral feeding) with the view to increasing the feeding rate slowly to establish tolerance. However, bolus feeding stimulates gall bladder contraction and intestinal secretions, and it also important to consider that neonates and infants have developmental needs associated with oral feeding that can be delayed if unable to progress oral feeding. These include muscle tone, parent infant bonding, swallowing and language development. In older children and adolescents normal eating patterns can be initiated and if required, NG feeding support commenced if unable to gain suitable control over stoma losses in the early stages.

If unable to reduce stoma losses to appropriate levels the gastroenterology or surgical team may initiate medication such as Loperamide hydrochloride to slow the stoma output. Some dietetic interventions to improve output volume and consistency have been used with equivocal results such as pectin, Partially Hydrolysed Guar Gum (PHGG) or glutamine. Pectin must be sugar free and meet food safety standards. PHGG is a form of soluble fibre and can be gradually added to fluids or foods to reach the desired stoma output consistency, and glutamine can improve gut adaption. However, a case-by-case trial for these interventions should accompany dietetic support to ensure that it is appropriately initiated and monitored.

In older children the resumption of a low residue diet at the early stages may deliver benefits to normalise stoma output consistency. Initial avoidance of foods that reduce gut transit time e.g. food with high insoluble fibre content, or contain high lactose or fructose content should be avoided. Lactose may require a temporary restriction and should be restored to normal dietary patterns as time progresses (lactose intolerance is not an allergy and should not be confused with cow's milk protein allergy). Insoluble fibre must also be reintroduced up to a point of tolerance. It is important to note that a plan to resume a near normal diet to ensure appropriate food choices and a varied and balanced diet.

Some food groups that need discussing with the older child or parent/carer can have an adverse effect on stoma management. These include;

- Highly indigestible carbohydrates (e.g. tough skins on fruits/vegetables, pips, seeds).
- High sulphur/odour content (e.g. fish, eggs, garlic, onions).
- Strong colourants (e.g. beetroot, red berries) that give a red output.

Children may have an innate desire for salty foods when stoma losses are high, and it may be useful to monitor urine sodium levels for any child with consistently high stoma losses. (a low urine sodium of <20 mmol/L will not allow for growth in a child). A change in dietary patterns towards salty food preferences may become apparent in children with high stoma outputs.

It is vital to include the parent or carer in the decision-making process for nutritional support. However some challenges to initiate optimal nutrition support plans may be generated from parenteral resistance or lack of understanding, which will require an MDT approach. In some cases failure of parents to adhere to sensible nutrition interventions may warrant child protection measures to ensure appropriate interventions for stoma management. The SSCN is pivotal in supporting the child and family and social factors should also be considered.

Stoma Products Used in Paediatrics

Neonates and preterm babies' skin is more susceptible to chemical irritation and systemic infections than adults because of the reduced barrier function of their developing skin [35].

The epidermis of a preterm baby is very fragile so particular care must be taken when using and removing adhesives. To prevent epidermal stripping and transepidermal water loss (TEWL) when changing a stoma pouch, an adhesive remover should be used and a liquid barrier film can be applied under the stoma adhesive for protection. Silicon and hydrocolloid appliances are recommended to prevent skin damage in this age group [36]. New-borns of 37 weeks gestations or less are at risk of topical drug absorption due to the immature function of the stratum corneum; this is not the case in infants of 37 weeks gestation and above [37]. To prevent toxicity it is advised to use products without any supplementary additives such as scented chemicals or vitamins.

Due to milk only diet babies who are not yet weened produce stools that are soft, seedy or at times thick fluid. If leakage becomes a problem, an absorbent sachet, strips or crystals may be added to the stoma bag to absorb water from the stool within the bag. This will help to keep the stool at the bottom of the bag, preventing or minimizing leaks. If the baby is in hospital it is important that the addition of the crystals is clearly documented as the consistency of the stool reported may have an impact on the medical treatment that the baby receives. The weight of the dry crystals must be deducted from the output if a fluid balance chart is used. Care must be taken to avoid ingestion of this product by either the baby or siblings.

Although the availability of specifically designed paediatric bags have increased over the years the choice still remains limited compared to the selection available for the adult group.

The size of the baby doesn't always determine the size of the bag used. If the stoma and mucus fistula are formed side by side they may not fit into the cutting area of a paediatric bag and a small adult bag may be more appropriate.

Conclusion

Children should not be treated in the context of a "small adult". For a child to grow into an adult they develop through distinctive stages. They develop physically, developmentally and biologically. They have differing medical conditions and pathologies to that of adults. They are vulnerable, both physically and mentally, and will need protecting both environmentally and socially. As with adults they are not all standard shapes and sizes; each child will need to be assessed individually as they all respond in different ways.

To care for a baby, child or young adult appropriately it is important to have a basic understanding of the fundamental development process and presenting medical condition and treatments.

As with most stoma care the nurse must be adaptable, resourceful, and knowledgeable when advising on appropriate appliances and products. SSCNs must deliver care within the scope of professional practice, seeking advice and support to increase knowledge and provide best practice.

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Body Image and Sexuality

16

Nicola Tonks

Introduction

This chapter will discuss how patients living with a stoma may experience altered body image and sexuality. Having a permanent stoma means living with a body alteration in the way the body looks, feels and functions. The expression of body image and sexuality are virtually inseparable and this chapter aims to offer some understanding of the challenges patients may face and ways in which the nurse can enable patients to understand and navigate their perceived change. It will discuss how surgery can affect the functional aspect of sexuality. As it is of great importance for the nurse to discuss changes in body image and sexuality, there will be some discussion of models that can be used in practice to support both practical advice and psychological support.

Sex and sexuality are complex and encompasses multiple components. The accumulated impact of parents, family, friends, religion, media, gender roles, gender identity, sexism, heterosexism and sexual issues will have shaped, to some degree, our attitudes towards sex and influenced who we are sexually [1]. It will be experienced differently by individuals. For many, it is a significant part of life and having a stoma can have a significant impact upon their sexual well-being and identity. The World Health Organisation [2] provides an understanding of sexuality as experienced and expressed in thoughts, desires and fantasies and describes sexuality as a central aspect of being human. It is often essential to who a person is and how they describe themselves. It is associated with quality of life, with some studies supporting a reduced sexual function as diminishing quality of life for patients who have a stoma [3].

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With sexual functioning being a part of quality of life, it is essential that the nurse can support patients and ensure that they have access to information to understand the effects of surgery and treatments such as chemotherapy and radiotherapy on the physical impact on the body as well as changes to anatomy. These physical changes coupled with the emotional response to changes in sexual confidence can affect the experience of sex.

Functional Problems Following Stoma Surgery

Treatments such as pelvic radiotherapy and pelvic surgery can significantly influence sexual health for both men and women. Rectal surgery impacts sexual functioning differently in men and women.

Rectal surgery in males may cause erectile dysfunction. It may cause damage to the sympathetic and parasympathetic nerves, which enable erection and ejaculation as well as a change in sexual function. The amount of nerve damage depends on the location of ligation during surgery. When the rectum is removed, the most common problem experienced is the inability to have or maintain an erection. However, this does not mean that males cannot experience orgasm since erection and ejaculation are controlled by different sets of nerves. They may experience retrograde ejaculation, a decrease in the intensity of orgasm or a dry orgasm may occur.

Some of the biomedical strategies for functional sexual problems include the following:

- Drug therapy—PDE5 inhibitors (e.g. Sildenafil, Tadalafil and Vardenafil).
- Intracorporeal injection or pellets.
- Vacuum erection device.
- A combination of therapies or
- Penile implants.

Dyspareunia and loss of libido are the most common sexual problems for females. Pelvic surgery may damage the autonomic nerves causing a decrease in lubrication of the vagina. Increased friction caused by vaginal dryness can be painful. The rectum acts as a ‘shock absorber’ for the vagina against penetration during sexual activity. As a result of rectal surgery, bands of scar tissue may form around the vagina, which also decreases its diameter and length. This effect may be heightened if surgery has also resulted in partial removal of the vagina. If this occurs, penetration can be painful (dyspareunia) or even not possible. Chemotherapy and radiotherapy may also result in drying of the vaginal and vulval tissue and cause scarring and vaginal stenosis. There may also be complications regarding fertility, pregnancy and normal vaginal birth.

Some biomedical strategies for functional sexual problems for women include:

- Vaginal lubricants or moisturisers.
- Vaginal dilators.

Anal intercourse may not be possible if there has been a low resection or removal of the rectum. Anal intercourse may damage a low anastomosis. In addition to these anatomical problems, individuals may experience fears and anxieties about the security of their stoma appliance, leakage and odour during sexual intercourse.

If possible, there should be a preoperative discussion with the patient and their partner about the potential impact of surgery and treatments such as chemotherapy and radiotherapy on sexual functioning and its management. It may be appropriate during the counselling session preoperatively to include psychological factors, relationship issues and any social context factors that impact sexuality or that may / are affected by sexual dysfunction.

What is Body Image?

Body image is a complex concept with no one agreed meaning. In the twentieth century, the conceptual development of 'body schema' emerged within the field of neurology with clinical attempts to understand neuropathological forms of body experience such as phenomena of 'phantom limb' [4]. It organized the body's sensory experience into the preconscious body schema and postural model to be termed the *body percept*. Schilder [5] later coined the term "body image", and a broader view of body image involving psychological functioning. The social significance of appearance and a person's attitudes and feelings towards their own body emerged. Schilder's definition can be loosely defined as the mental representation of our bodies that we hold in our minds. However, more recent literature suggests that body image is strongly influenced by a variety of factors including, but not limited to psychological, social, cultural, biological, historical and individual factors [6]. The concept of body image is used across many disciplines, including psychology, psychoanalysis, medicine, and cultural studies. Across these disciplines, there is no one consensus definition.

Broadly speaking body image consists of how people view themselves and how others think they see them and can be defined as how we see or perceive our body. Familiar within the nursing literature is the work of Bob Price [7], who defined body image as 'the picture we form in our minds of how our body looks and the experience we have of how our body feels and behaves'. This perception is influenced by various factors such as personal attitudes, beliefs, social norms, media, to name just a few. The formation of a stoma will alter our perception and our evaluation of the physical integrity of our body, which may have psychological implications for the ostomate. The ostomate may have problems with the self-concept, self-esteem, and self -worth [8]. Our self-concept is related to ideas, values and perceptions that characterise the person and can include the behaviour, attitude and well-being of a person. Our body image is part of our identity and if the body changes, then this can change the person's experience of their self in their world [9]. With a body that looks different and behaves differently the patient will have concerns and worries about how life will be with a stoma and how their lack of control over bowel function may impact their social, work and personal relationships [9–11].

Body image can be broken down into three main components [12, 13]:

1. Body reality: that is the physical presence of the body, the way the body has been affected by surgery, for example, having a stoma formed.
2. Body ideal: that is the person's desired body image. This refers to personal ideas about how the body should look, feel, smell, or function, referenced against cultural and social norms.
3. Body presentation: the body that is presented to the world by the way the individual adjusts their appearance.

Any change in these components can have an effect on other body image concepts for the patient. For example, having a stoma may affect the individual's body reality; this may challenge the person to review whether their body ideal is sustainable. To manage this the patient may make adjustments to their body presentation such as changing their clothing, or how they manage their stoma in the type of pouch used. How the individual manages this will help to support their self-esteem. The seminal research undertaken by Price relates to patients living with a stoma, and his body image model provides a helpful way to describe body image [7, 13].

Many factors may increase the risk of distress associated with a change in body appearance or function [13] which are relevant for the patient with a stoma:

- Sudden and extensive body change: for example, patients who must undergo emergency stoma surgery.
- Change that affects body function that the person links to their livelihood, status, ability or reputation: for example, feeling unable to enjoy social occasions or continue with work.
- Change that affects the individual's sexuality, to express their identity and maintain relationships: for example, relationship or sexual difficulties that they may perceive as a result of the stoma/ surgery.
- Change that makes the person's body behave in unpredictable ways: for example, worry that the stoma will be active at work, or during intimacy.
- Recent contextual changes to life that undermine the person's perception of self as competent, adaptive and resilient: for example, not feeling confident to manage their stoma.

An altered body image can be associated with several feelings that may include degradation, mutilation and restriction [14]. It has even been described as reverting to emotions of regression to a baby state [11]. In the initial period following stoma surgery, the perception of body image may be based on the immediate social situation and previous experiences [14, 15].

Body Image with a Stoma

Life with a stoma can profoundly change a person's life. The transition from life before and after stoma surgery can take time and be different for each person. The consequences of illness and a change in bodily function can change a person's sense of their body, altering their self-image, relationships and experiences of sexuality. The specialist stoma care nurse (SSCN) needs to take a holistic perspective when assessing the impact of having a stoma on an individual's body image and sexuality.

Patients will have many concerns that may impact their perceived body image. With their body looking and behaving differently, they will be concerned about how life will be and how this will impact upon work, social and recreational life, relationships, and sexual life [9, 11, 16] Patients may not feel comfortable with the changes to their body leading them to feel worried about other people's reactions leading to rejection or even being viewed with disgust [10].

Assessing Perceived Changes in Body Image

As described above, many factors can affect the ability to adapt to the altered body image, including diagnosis, treatment, medical and nursing care, and the disease process [14, 15]. Although the variables associated with how one perceives their body image are complex, it is important to evaluate with the patient how significant a bodily change with a stoma is for the individual, particularly for new patients. The two most frequently reported difficulties for individuals with a 'visible' bodily difference relate to negative self-perceptions and problems with social interactions [17].

Assessment should therefore explore:

- The patient's self-perception: the importance patients place on their appearance and their level of current satisfaction or dissatisfaction.
- Any difficulties with social interactions.
- Any compensatory behaviours such as social avoidance or concealing the body and emotions they associate with shame or self-consciousness [18, 19].

Although there are limitations to the relatively few studies that have investigated the effect of a stoma on body image with patients who have a stoma, it is suggested that the degree to which the stoma impacts body image is what is most likely to affect psychosocial outcomes and can be a predictor of anxiety, depression and distress following surgery [20]. It is also suggested that although there may be an improvement in the patient's quality of life following stoma formation, problems with body image or adjustment to the stoma and new bodily functions may persist over time [11, 15].

Addressing Concerns About a Change in Body Image

Patients need to have access to ongoing psychological support from the preoperative period if possible and ongoing to support them with the challenges both physically and psychologically. Psychological support should be offered to understand the significance of an altered body image for them. It is important for the nurse to assist the patient in coping with these changes. This can be achieved by supporting the patient to discuss their experiences and fears through active listening to facilitate emotional expression. It is also essential to understand that some patients may experience a grieving process for their old sense of self or loss of a body part, and the patient may experience a difficult transition through loss, denial, anger and depression before they can move forwards towards acceptance [21].

Table 16.1 Model of psychological change [13]

Stage	Emotions expressed	How the nurse may support
Stage 1: psychological shock	Patient may ask questions of themselves	Information about illness, treatment and recovery, How other patients adjust. Information on support groups, charities
Stage 2: Managing emotions	Patient may blame themselves or others, feelings about illness, health and the future. Concerns about body reality	Allowing the patient to discuss their emotions, identifying what distresses them most, what challenges they have overcome before
Stage 3: Investigating needs: offering direction	May be inpatient to regain some control, need to revise their identity. May feel hurt or bewildered	Focus on what the patient wishes to do. Suggest support groups, websites, help the patient identify places or people that can support and understand
Stage 4: Consolidating acceptance	Reflecting on experiences	Celebrate what has been shared and achieved

Price [13] offers an adaption of the Kübler-Ross [22] grief response model for psychological change (Table 16.1) associated with altered body image distress. The nurse must take time to explain to patients that it may take time for them to assimilate and adjust to their new body reality. How patients adjust to altered body image is highly individual. Although there are no models that have been tested in clinical practice for stoma patients, Price's model offers the nurse an understanding of the process of change and the stages that a patient may progress through (Table 16.1).

There may be practical suggestions that may help, such as alterations in their pouch management system. It may include other methods that the patient may wish to consider such as stoma irrigation or a stoma plug for the those who have a colostomy. It is important that patients see alternative pouches, with options in colour and size of pouches and are informed about the availability of types of underwear garments or clothing.

Depending upon a patient's relationship, they may have concerns about telling a partner that they have a stoma and worry about how their partner may react to this revelation. This may include concerns or worries that their partner will no longer find them attractive or may lose interest [23, 24]. The patient themselves may perceive themselves as less attractive, and patients with a stoma report a more significant reduction in social functioning [25]. Nurses may need to consider how they will support both the patient and the partner. Partners may feel that their main concern is for the health of their loved one [11], but it is also possible that they may also experience sexuality concerns [26]. If the patient agrees, it may help to encourage discussion with the partner as soon as it is known that stoma surgery is necessary.

Providing advice about eating out, going to the pub, and advice about emptying the pouch when out socially are all relevant issues to assist the patients with adaptation to their new body image. Discussing the subject freely helps to create an understanding which will hopefully help to promote acceptance. Table 16.2 summarises some common body image concerns.

Table 16.2 Body image concerns

Body image concerns for the patient with a stoma
Loss of confidence when in social situations, fear of the stoma becoming active or noisy and needing to attend to it or worries of leakage
Embarrassment over changes in appearance, others noticing the bag underneath clothing
Worries about sexual attractiveness and fear of intimacy

Stigma: Some patients may feel stigmatized by family, society or employers. Loss of control of elimination is generally unacceptable to society, and we are taught this from an early age. This will have an impact on how an individual feels able to participate in their life activities, amongst others. Stigma-related sensory phenomena such as odour, sound and appearance are associated with a decreased satisfaction with the body [27].

Difficulties Exploring Sexuality After Stoma Surgery

Sexuality and sexual activity have often been taboo subjects, and this varies between cultures and time periods. Cultural attitudes towards sex have rendered sexuality a private matter making talking about it embarrassing. It is a subject that patients and health professionals find embarrassing or uncomfortable to discuss. Unfortunately, the literature suggests that patients want to discuss issues around sexuality and are waiting for the health professional to bring the subject up [28]. Patients may find the thought of resuming sex with a newly formed stoma frightening. Therefore, it is an important aspect of the SSCN's nurse's role to ensure that patients are given an opportunity to discuss and receive support should they want it. By not making your patients aware that sexuality is open for discussion, you may leave your patient with anxiety, frustration and unmet needs that could and should be addressed. It is important to open discussions early in the therapeutic relationship, conveying interest and willingness to talk about the issue.

A therapeutic relationship can be structured using the PLISSIT model [29, 30] and is based on a problem-solving approach to address an individual's particular problem. The PLISSIT model has four levels to help the practitioner identify their role in assessing and evaluating an individual's sexual well-being needs.:

1. Permission (P)—Allowing individuals to express their thoughts/concerns about sexuality. The nurse should provide the feeling of openness and a non-judgmental relationship with them.
2. Limited information (LI)—Involves giving information to patients directly related to their problems. An open therapeutic relationship based on trust must first be established. Nursing interventions at this level aim to increase the patient's knowledge level. It may include giving information about the effects of treatments, changes to emotions and the impact of living with a stoma.
3. Specific Suggestions (SS)—before giving specific information, the nurse should obtain specific information. This may relate to specific suggestions regarding the type of appliance or vaginal dryness, for example.
4. Intensive Therapy (IT)—This is the last level of the model. It involves referring the individual and the partner to specialists, such as a psychologist, sexual or relationship counsellor.

Table 16.3 The Ex-PLISSIT model by Davis and Taylor (2006) [31, 32] shows the role of permission-giving is integral to each stage (with permission from [31, 32] copyright Elsevier)

	P	LI	SS	IT
Intervention level	Permission giving	Limited Information	Specific Suggestions	Intensive Therapy
Intervention	**Permission** Normalise sexuality and explicitly open discussion about concerns/ problems that patients may experience with a stoma /after surgery	**Permission** Relevant general information about problems and solutions	**Permission** Problem solving approach to address the individuals particular problems. Assessment of problem/ concerns and expectations	**Permission** Referral for specialist intervention e.g. urogynecologist, urologist, psychologist or psychosexual / relationship counselling.
REVIEW and REFLECT				

More recently, Davis and Taylor [31] have extended Annon's original PLISSIT model to emphasise the role that permission-giving plays at all stages of the model. It also includes elements of reflection and review, enabling practitioners to use this to develop their own practice. The Ex-PLISSIT model from Davis and Taylor, as shown in Table 16.3 below, puts explicit 'permission' at the beginning of all interventions, giving individuals the opportunity to ask questions or voice their concerns. It encourages patients and their partners to discuss sexual issues with their clinicians openly.

Each stage of Limited Information, Specific Suggestions and Intensive Therapy are underpinned by permission-giving. All interventions begin with Permission, and it is essential that this Permission giving is explicit, providing individuals with the opportunity to ask questions or voice their concerns. This makes it clear to patients that it is appropriate to discuss their sexual well-being.

Let's take a look at how the levels of interventions may work in practice:

Permission giving: This involves normalising sexuality for the individual [31]. ***You may say, "… men/ women who have a stoma have concerns about sexuality or their relationships. Is there anything that you would like to talk about or ask?* "*Or…. "some men may have problems with maintaining an erection, or some women may find sex uncomfortable or even painful. Is this something you have experienced?"*** Having given permission once, Taylor and Davies [32] stress that the nurse should not assume that a lack of enquiry by the patient indicates a lack of concern about their sexual well-being and further permission giving is needed. The permission-giving stage needs to be addressed; otherwise, the provided information will be general and will not address each individual's specific needs or concerns. It needs to be inclusive and not restricted to assumptions about the patient or sexual preferences. For example, if the information is given to a woman about different sexual positions and only discusses vaginal intercourse, it would not meet the needs of a woman who practised anal intercourse.

So that the information given is relevant to the needs of the individual and to recognise that the individual may not disclose all their issues, it is necessary to offer further permission-giving. Some patients may worry about attitudes towards their sexual identity and fear prejudice, making it even more difficult to disclose anything about their sexuality [33]. Providing *Limited Information* in the form of a booklet containing some written information about the impact of a stoma on the individual's sexual well-being without further permission giving is to presume that the patient would raise the subject of their sexual well-being. This would not be adequate to signal to patients that it is appropriate to discuss their sexual wellbeing.

The *Specific Suggestions* stage is based upon a problem-solving approach to address an individual's particular problem and requires more knowledge and skill than providing Limited Information. Here, the practitioner would need to take a sexual history to identify issues, concerns, and expectations. Examples of specific suggestions may include conception advice, lubrication, sexual aids, contraception and alternative positions. It is important to realise that specific suggestions do not just relate to sexual behaviours; for example, a patient who is frightened that her partner may find her unattractive may also be referring to her sense of loss, and so it may be necessary to assess how she perceives herself and this may need some interventions to manage her depression as a result of a change in body image. When the practitioner talks about ways to help sexual well-being, the practitioner may be implicitly indicating their acceptance of sexual activity with a stoma, which suggests to the patient that it is okay to talk about sexual issues when they have a stoma.

Intensive Therapy may be offered at any stage. It is often assumed that the nurse can only move to Intensive Therapy when the intervention via the lower three levels has not been effective [32]. It is essential that the practitioner is aware of their strengths and limitations and can recognize when they are outside their limits of comfort or competence. It may involve complex interpersonal and psychological or physical issues and require a referral for specialist intervention such as a urologist or gynaecologist, psychosexual therapist or psychologist. Again, this will involve further permission-giving and may involve Limited information or Specific Suggestions.

The nurse needs to understand when using the model that it is a two-way dialogue allowing the patient to engage in discussion and review the usefulness and appropriateness of the information given. Sexuality is fluid and dynamic, so patient concerns may change in response to their physical, social, and psychological circumstances. Therefore, patients must be given the opportunity to review interventions both at the end of a consultation and at future consultations by asking questions such as:

> ***"Is there anything else that concerns you, or how helpful was the information I gave you in answering your questions?"***

The model does not need to be used linearly, it may be necessary to return to previously addressed levels, or some levels may not be necessary.

As previously touched upon, it is necessary for the nurse to challenge their assumptions to develop their knowledge and self-awareness around the subject of sexuality and body image. The ExPLISSIT model encourages this by promoting a learning cycle of reflection and review (Table 16.3). Davis and Taylor [32] describe two elements to reflection and review; the first is to focus upon the patient and then secondly the practitioner. This will ensure ongoing learning for the practitioner and develop their skills to discuss sexual information in a non-judgmental way.

Practical suggestions for physical intimacy with a stoma:

- Ensure the appliance fits correctly.
- Empty the appliance before having sex.
- Consider options to cover the appliance such as underwear, waistband or a pouch cover.
- Experiment with different positions that keep your partners weight off the stoma.
- Let your partner look at your stoma, allow them time to adjust.
- Share your thoughts.
- Maintain physical closeness, show affection in other ways, touching, caressing and kissing.

Lesbian Gay Bisexual Transgender Intersex Queer (LGBTIQ)

Being lesbian, gay or bisexual is an example of sexual orientation, whereas being transgender is a gender identity. 'LGBTQ' is used as a more collective term for all sexual orientations and gender identities, but variations of this initialism make this more apparent. Sometimes you may see a plus to refer to 'others' (LGBT+) and culturally specific versions with third gender representation such as Two-Spirit. All forms are valid [34].

There should be a consideration for all a patient's individual needs following stoma surgery regarding the effects on:

- Sexual practices.
- Sexual role.
- Relationships.

The UK Equality Act 2010 says that LGBTQ people must be treated fairly and without discrimination. But in a government survey (2018), there was a disproportionate dissatisfaction with NHS services, with respondents stating that staff were ignorant of their health needs, specifically about mental and sexual health services. Nurses who care for lesbian, gay, bisexual and transgender individuals are best prepared when they are aware of and sensitive to issues specific to the LGBTQ community [35]. Amongst those issues may be a history of stigma, victimisation and or discrimination, with individuals experiencing feelings of fear, isolation, stress and anxiety, depression and distrust [36, 37].

Treatment modalities for colorectal and urological diseases with stoma formation have potential sexual adverse effects for men, such as orgasmic and erectile dysfunction [38]. If the rectum has been removed, anal intercourse will not be possible. This may have a profound, often permanent and unanticipated impact on sexual practices [39], and so other methods of sexual pleasuring need to be discussed and researched. The LGBGT community has the same concerns and fears about sex after stoma surgery as anyone else. It is important to find ways to support the psychosocial needs of LGBT + patients as they are generally less satisfied with written information provided and report more negative interactions with a lack of additional support [40]. The use of peer support through LGBT+ specific support groups can be a crucial source of information for patients, and an example is the charity 'Live Through This' (2021). The 'Live Through This' Charity also provides advice for health care staff about providing inclusive care.

The clinical implications for the nurse are to:

Include a discussion of the individual's sex-role in sex counselling.
Respectfully explore sexual identity and practices with all patients.
Create healthcare spaces inclusive of sexual identities.

Conclusion

This chapter has highlighted sexual and body image challenges patients may experience following stoma formation. The SSCN must be willing and able to discuss these issues openly with patients. The Psychological Change and Ex-Plissit models offer the SSCN approaches that can assist with assessing sexuality and body image issues, provide the appropriate support, and know when to refer for more specialised assessment.

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Supporting Patients Beyond the Clinic

17

Richard Biddle and Libby Herbert

Learning Objectives

1. To develop an appreciation of the historic and current relationship between charities and the healthcare profession.
2. To understand the broad and varied support charities offer patients and how this complements and enhances the care patients receive in a clinical setting.
3. To examine how charities exploit technology to support patients.

Introduction

What, you may wonder, is a chapter about charities and patient associations (hereafter referred to as charities) doing in a book about clinical practice? It is a legitimate question to ask and one that is tackled in depth below. The discussion is divided into two parts. The first outlines aspects of the historical relationship between charity and medicine, locating charities of today in what we might call the ‘landscape of care’. The second uses a case study of Colostomy UK to examine in detail the ways in which a modern charity supports people with stomas and also the friends, family and, where applicable, carers of ostomates. Reference is made to the projects Colostomy UK run, and their campaigning and advocacy work too. As a healthcare professional, it is important for you to understand how charities complement the care you give patients in a clinical setting. Although the focus of this chapter is on Colostomy UK, readers are encouraged to visit the websites of the other stoma charities (Ileostomy and Internal Pouch Association and Urostomy Association).

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As you will see, to varying degrees, they are all adept at engaging with and tailoring their support to different patient groups. They are also responsive to the needs of patients at different stages in their stoma journey. To achieve this, charities have had to become increasingly dynamic in their use of technology. The chapter concludes by considering opportunities for collaboration between clinicians, charities, and patients. It reflects on how we can learn from one another and, through working together, better support people as they go through life-changing surgery and afterwards as they learn to adapt to life with a stoma.

Locating Charities in the Landscape of Care

The relationship between charities, medicine, and patients is a long one. If you are based at a hospital, then there is a strong chance that your hospital will have started life as a charity. Back in the nineteenth century, donated funds were used to build and run ‘voluntary’ hospitals up and down the country, each of which was a charity in its own right. In return for making an annual donation or ‘subscription’, donors were given the right to send sick people of their choosing for treatment at their hospital’s in-patient and out-patient departments. The number of patients a subscriber could send was determined by the size of their donation. Before the NHS, this system helped local business owners keep their workforce fit and able. The hospitals themselves were staffed by a mixture of paid employees and medical practitioners working on a voluntary basis. An honorary position in a voluntary hospital was an excellent way for a physician to build his private practice, mixing as he did, with the charity’s wealthy supporters [1].

Of course, things are very different now, but one of the key motivations behind the voluntary hospital movement are to work for the benefit of sick people; this remains as strong as ever. So too does the close bond that has developed over the centuries between charities and the healthcare profession. It is visible today in many guises. Specialist stoma care nurses (SSCNs) are involved with local support groups for example, as organisers or attending to give talks and answer patient questions. The three main stoma charities also maintain strong links, from board level right through to the carrying out of their everyday operations. The ileostomy and Internal Pouch Association (IA) has two healthcare professionals who act as liaison co-ordinators between the charity’s board of trustees and professional forums such as the Association of Stoma Care Nurses (ASCN UK) and the Royal College of Nursing Gastrointestinal Nursing Forum [2]. The president of the Urology Association (UA) is a consultant urologist [3], while the current president of Colostomy UK for example, is just one in a long line of eminent consultant colorectal surgeons to hold this voluntary position [4].

The founding of each of the aforementioned charities also owes much to the input and backing of healthcare professionals. In part this was driven by the latter’s deep understanding of the limits of what can be achieved in a clinical setting versus the wider and ongoing needs of people with stomas. The IA has been supporting people with ileostomies since 1956 and started life as a patient visiting service at the

Queen Elizabeth Hospital in Birmingham, with Professor Bryan Brooke (who developed the Brooke ileostomy) their founding president [2]. The UA emerged some years later in 1971, when Laurie Kenefick, a charge nurse at the Christie Hospital met with patient Valerie Kings who was having problems with her appliance following a recent urinary diversion. What began as a simple consultation ended up with a patient association being formed in early 1972, with Mr. Raymond Carroll, a urologist at the hospital becoming the association's first national president [3]. Colostomy UK can trace its origins to the early 1960s when a surgical registrar at a London hospital, recognising the therapeutic value of human contact, approached an ostomate and asked if she would visit his colostomy patients on the wards. It quickly became clear that her visits encouraged recovery. She provided the reassurance that patients needed living proof that it was possible to lead an active life after stoma surgery. Three years later, and with the involvement of Frances Goodhall (retired general secretary of the College of Nursing), the King Edward's Hospital Fund (now The King's Fund) provided the money to conduct a pilot study into the need for a national service for colostomates. 29 hospitals in London took part. The findings of the study led to the establishment of the Colostomy Welfare Group which, after several name changes in the decades that followed, became Colostomy UK in 2017 [5]. As the next section demonstrates, charities are not in competition with healthcare professionals, nor do they offer patients an alternative to clinical care. Instead, they complement the work of clinicians. They support patients in ways that are not always possible or practical in a clinical setting.

A Charity Offering: A Case Study of Colostomy UK

Colostomy UK was founded on the outcome of a study that showed peer-to-peer experience-based support and advice was (and is) not just desirable for stoma patients but also of great benefit to them as well. In simple terms, this translates as follows: discussing stoma surgery, recovering from stoma surgery, and living life with a stoma afterward. This experience, puts volunteers in a unique position to empathise, advise and support fellow ostomates. The finding, which is now well established in the medical literature [6] and applies similarly in other settings and to many patient groups in addition to ostomates, has resulted in Colostomy UK developing as a volunteer-centred charity. It now has volunteer representation across the United Kingdom, with volunteers involved in the delivery of all its core support services. As we saw above, the original Colostomy Welfare Group began by providing support through volunteer ostomates visiting patients on the ward. This suggests the support was given to people who were pre-op and to people in the immediate post-op period or returning for further surgery. It also kept things in a medical/surgical context e.g. a hospital ward. The charity of today looks very different. In the last fifty years, it has learned much about the types of support ostomates want, when they want it and where they want it, all of which are reflected in Colostomy UK's current offering.

Support

Colostomy UK delivers support in a number of key ways, each of which is examined in turn. All that is described below, is freely available to your patients. Similarly, Colostomy UK supports all patients, regardless of the type of stoma they have (colostomy, ileostomy, urostomy).

24-Hour Stoma Helpline

The charity has been running its stoma helpline for over two decades. It is free to call and currently operates 24 h a day, 365 days a year. Callers are guaranteed to speak to a person. During office hours this will normally be a member of the Colostomy UK team. Outside of office hours (and at weekends and bank holidays) calls are taken by fully trained and DBS checked volunteers, all of whom either have a stoma(s) or have had a stoma. This makes peer-to-peer experienced-based support and advice easily accessible to ostomates; callers can choose when they phone. Similarly, they have control over where they phone from e.g. home, work, and who, if anyone, is present. Callers can also choose to remain anonymous. All this amounts to a very different service and experience to what patients might expect in a clinical setting. Additionally, there is no time limit put on calls, which is particularly beneficial for people looking for emotional support.

As one might expect, a high proportion of calls are from people with stoma management issues. Everything from pancaking and leakage to sore skin and diet, crops up regularly. Enquiries about irrigation (What is it? What are the benefits? etc.), as well as ‘I might be able to have a reversal, can I speak to someone that has had one?’ are common too. Many of the issues callers face can be addressed through experience-based advice (such as imparting tips), or by directing them to the appropriate Colostomy UK literature. Helpline operators do not, however, provide medical advice. Where this is required, callers are encouraged to contact their GP or stoma care nurse. If the situation warrants it, they are advised to call 111 or the emergency services instead. Instances where medical advice is needed tend to be easy to spot, as do calls from people seeking ‘confirmation’ that they need to see a healthcare professional.

As was alluded to earlier, some ostomates call the helpline looking for emotional support. With the outbreak of Covid-19 and knowing that many people with stomas would fall within the ‘shielding’ category, Colostomy UK further enhanced its offering in this area, by launching its **Telephone Befriending service**. Rather than being simply reactive e.g. waiting for people to call, all those who answer helpline calls have now been trained to spot and offer proactive telephone contact to ostomates who may be lonely or alone and might benefit from a weekly call and chat with a fellow ostomate (e.g. one of the charity’s volunteers). The service is still in its infancy but is explained fully on the Colostomy UK website. Details of how healthcare professionals can make referrals can also be found here [4].

Calls that can be categorised as ‘lifestyle related’ are received too. These range widely, including everything from enquiries about entitlements to financial support and eligibility for a blue badge to queries about travel and the return to sports, hobbies and other pastimes. Questions such as: ‘I am about to go abroad for the first time since my surgery, do you have any advice?’, or ‘Is it safe for me to do the garden now?’ are typical. Again, the experience of the charity’s volunteers is invaluable. If we take the travel example, then linking the caller with a volunteer who has travelled extensively can lead to the ostomate jetting off with practical tips around preparing for travel (quantities of stoma supplies to take etc.) as well as the feeling of comfort derived from having spoken to a fellow ostomate that has done it before, that has been through airport security, has changed their bag during a flight and so on.

The social characteristics of ostomates who call the helpline are varied, but sway towards people who are over 60. Although not scientifically tested, this is probably a generational thing, with older people more likely to engage using ‘traditional’ methods. This view is supported by the number of calls received to the stoma helpline which peaked some years ago, at over 6000 per annum. In 2019 3861 calls were received, but this fall needs to be set against an ever-increasing number of electronic contacts (e-mail and website) received from people seeking support. In the same period these amounted to 4475, with some, but not all of these latter types of contact, serving as the prelude to a telephone discussion. One function that electronic contact seems to serve, is as an ice breaker. It takes some of the fear out of telephoning a helpline. For ostomates who seek help in this way, it gives them control over how Colostomy UK responds to their need (they can specify if they want an e-mail or telephone response).

Private Facebook Support Group

Colostomy UK launched its private Facebook Support Group in 2012 and within 12 months it had over 1000 members. The broader trend of patients increasingly seeking support and guidance online (which was hinted at earlier) is reflected in the group’s continued expansion. Today, this vibrant and ever-growing community stands at nearly 9000, having almost doubled in size since 2017. A snapshot taken at the end of 2020 (see Fig. 17.1) revealed members to be from a broad spectrum of ages, with the numbers of females significantly higher in all groupings. It is also notable how prominent membership is for people under the age of 55, which contrasts with the profile of callers to the charity’s helpline. Most members have, or have had, a stoma. The group is also open to the families/ friends of ostomates and to carers and healthcare professionals. Extending membership in this way has many benefits. For example, it can help non-ostomates develop a better understanding of what a loved one is going through or living with. Similarly, it can help reduce the isolation often felt by the parents of young children with stomas.

The group is administered by the Colostomy UK team and a handful of specially trained volunteers. Their role includes giving support to members, such as

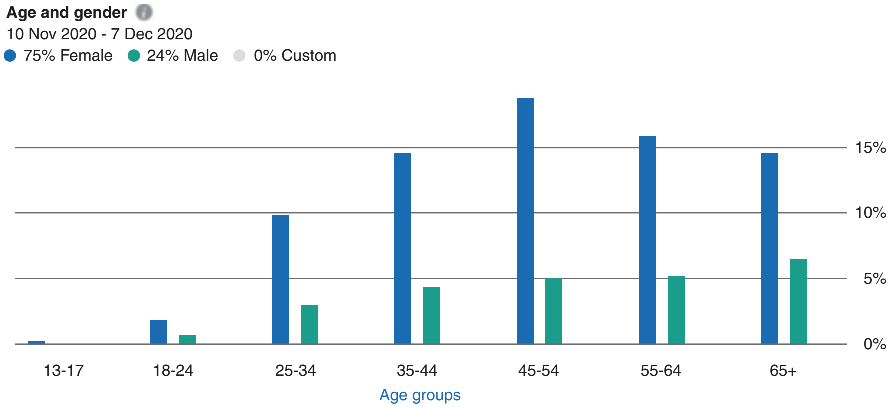

Fig. 17.1 Membership of Colostomy UK's Private Facebook Support Group (extracted December 2020) with permissions from Colostomy UK. https://www.colostomyuk.org/ [Accessed 20 December 2020]

signposting them to appropriate literature. It also involves ensuring that members adhere to the group's rules. On joining the group, people have to agree to rules around 'netiquette' and are reminded about internet safety. They are also cautioned about giving medical advice in posts and warned about the risks of taking advice from unqualified sources. Policing this is taken seriously, with offending posts removed if necessary.

The group provides a safe and confidential space for ostomates and people associated with them to 'meet' and support one another. At a general level, this can help to reduce the isolation many people with stomas feel, living with hidden and often poorly understood conditions. Anecdotally, it is known that many fruitful friendships and connections have been made via the group. Often these remain purely 'online' but some develop further (hence the need to remind new members about safe use of the internet) [7]. Before the Covid 19 pandemic of 2020, Colostomy UK hosted a number of face-to-face Facebook Group get togethers, which were popular and well supported.

In terms of the 'conversations' that go on in the group there are some similarities with the charity's helpline. Members seek experience-based advice on stoma management issues and life-style matters. They also look for emotional support. The differences lie in how this support is accessed and the form it takes. This is best illustrated through an example. A recently discharged ostomate for instance might be wondering about post-operative recovery times and whether they themselves are 'on track'. As a member of the Facebook Support Group, they would have several options. Firstly, they could just follow the group's feed, in the hope that the topic crops up, thus deriving support and advice from reading other people's posts. In the process, it is highly likely that their overall 'stoma' knowledge, and awareness of some of the challenges that might lay ahead for them, would increase significantly too. This sort of 'passive' engagement is of course very different to calling a helpline. Recent research conducted into online health support groups, terms this as 'lurking' and has demonstrated that, over time, 'lurkers' can accrue benefits from such behaviour [8]. The Colostomy UK Facebook Support Group has many 'lurkers'. Long-standing members often talk about how much they learned from 'lurking' in early days, before finally plucking up the courage to post something themselves [7].

This brings us back to the other option our imaginary ostomate has, which is to make a post themselves. Research shows that people who are active in this way and also actively respond to the posts of others, derive greater benefits than lurkers [8]. In the present example, 'posting' would be guaranteed to elicit two types of response. The first would be experiential in nature, from which our ostomate would learn that post-operative recovery times vary considerably from person to person. This in itself is helpful and supportive. The second type of response ticks the box for emotional support. This would take the form of words of encouragement, as well as people just 'liking' the post. Support of this nature is very prominent in the Colostomy UK Facebook Support Group. A simple post of a member telling the group that they are nervous because they will learn the next day if they are finally free of cancer, or are fearful perhaps of having a colonoscopy through their stoma, can result in literally hundreds of likes and messages of support.

Others have concluded that online support can be especially '*advantageous to individuals who are living with rare, hidden, stigmatised or misunderstood health conditions, because finding others who can understand and appreciate what they are going through is likely to be much more challenging in the offline world*' [8]. This is certainly borne out by the experience of Colostomy UK's private Facebook Support Group, which gives ostomates the opportunity to access support and information on their own terms.

Tidings Magazine

It is likely that many reading this chapter will be familiar with Colostomy UK's free quarterly support magazine. This is because *Tidings* has been a feature of the stoma world for over two decades. In itself, this says something about the magazine's enduring success as a vehicle for supporting ostomates. Tidings' current editor is an academic who has published and researched widely in the field of medical humanities. The remainder of the editorial board is made up of members of the Colostomy UK team, a senior stoma care nurse specialist and a number of Colostomy UK volunteers, all of whom have stomas. The magazine's current circulation stands at around 24,000 hard copies each quarter (it is also free to download on the charity's website) with the readership of each edition estimated to be in excess of 69,000. Subscribers tend to be over 55, although there are signs of younger ostomates starting to engage. In 2019, 90,650 copies of Tidings were distributed to a mailing list comprised of ostomates, healthcare professionals and stoma care departments. In the same year, the publication won a 'Highly Commended' award at the British Medical Association's Patient Information Awards. In their comments, the judging panel said: ‘This is a great resource pretty much written by patients for patients. Patients as experts seem to be the main focus and articles are written by them in an authoritative and professional but patient-focused way.’

Tidings’ popularity with patients lies in its content as with other Charities’ magazines. This comprises a mix of charity news, readers’ letters and emails, articles from healthcare professionals and ‘real lives’ stories. The latter two are particularly valued by subscribers. The magazine’s ‘dear nurse’ feature addresses common (and sometimes less common) stoma and stoma-related issues. Recent editions have tackled rectal discharge, stoma bleeding and blocked stomas/bowel obstructions. These pieces are often presented in a ‘question and answer’ format, which breaks down the information they contain, making it more accessible and easier to understand. There is an obvious synergy here with the needs of callers to the charity’s helpline and members of its private Facebook Support Group, albeit that the support is being accessed via a different medium. Through ‘dear nurse’ articles, ostomates are able to construct their own stoma reference library and this is indeed what many do. Long-standing subscribers report keeping their copies of Tidings for many years and using them as a ‘go to’ resource when they have concerns about their stoma, or when other related problems strike.

Real lives stories function more as a form of emotional support. Reading about the experiences of others, eases the burden of loneliness (real or imagined) that many ostomates testify to feeling, and helps create with readers a sense of belonging to a wider community. In recent years, the editorial team have also used real lives stories as a means to explore a whole range of different themes and issues, including everything from the impact of stoma surgery on mental wellbeing, and the experience of having a reversal, to more practical concerns, such as returning to work after surgery or preparing for your wedding. Thus, as well as providing emotional support there is an empowering element embedded in many of the stories too. Tracking an ostomate’s history, from symptoms to diagnosis and then surgery, also allows discussion of topics such as patient responsibility, the importance of seeking help early (rather than ignoring symptoms) and the virtue of preventative measures such as bowel cancer screening. Collectively, the stories speak to people at all stages of their journey, from the pre-op patient worried about what life might ‘look like afterwards’, to the post-op patient struggling to come to terms with what they have been through, to the ostomate who is ready to get their life back on track and beyond.

Support Literature

Studies of colorectal patients have shown that access to good information is vital both pre-operatively and afterwards [6]. This is something that stoma charities in general recognise. The provision of high-quality literature has been a central pillar of Colostomy UK’s support offering since the charity’s earliest days. Its current library comprises 20 titles, all of which are freely available both in hardcopy and as downloads from the charity’s website. While some titles relate to the charity’s campaign work and fundraising, the library's emphasis is squarely on the ostomate. To give a flavour, the booklets 'Living with a Stoma' and 'How Will a Stoma Affect Me?' focus on the needs of patients who are pre-op or have just had their surgery. Common issues are covered by titles such as 'Healthy Eating', 'Rectal Discharge' and 'Parastomal Hernias', while booklets including 'Colostomy Irrigation', 'Active Ostomates™: Sport and Fitness After Stoma Surgery' and 'Travel Advice' are more about empowerment, making them of greater relevance to patients who have passed beyond the initial post-op stage. Recent collaborations with Target Ovarian Cancer and Dementia UK have led to important new titles being added to the range, with 'Caring for a Person With a Stoma and Dementia' working well with the more general booklet 'Caring for a Person with a Stoma'. As the title of the latter suggests, this is aimed at people with caring responsibilities, be they friends, family, or care home staff.

Although most Colostomy UK literature is written in-house, it is peer-reviewed by ostomates. Similarly, all medical content is either sourced from, or reviewed by, healthcare professionals. Unlike with the membership to its private Facebook Support Group or the readership of Tidings, Colostomy UK cannot be as precise about who reads their literature. However, the volume of hardcopy literature distributed suggests that it is widely read and valued as a resource. In 2019, almost 31,000 items of literature were posted to stoma care nurses, colorectal departments and ostomates. This was an increase of 25% on 2018. The quality of the literature has also been recognised. The aforementioned 'Active Ostomates' booklet won a Highly Commended award at the BMA Patients Awards in 2017, while 'Parastomal Hernias' (also mentioned above) is currently used by the Royal College of Surgeons in an e-learning module.

Website and Live Chat

The Colostomy UK website is a vital resource for ostomates, their families and friends, healthcare professionals, and people/agencies with caring responsibilities. Similar can be said of the IAs [2] and the UAs [3] websites, making a visit to them a must for patients and healthcare professionals alike.

As should be apparent from the discussion so far, Colostomy UK's entire literature suite along with the Tidings magazine archive is freely available to all visitors, regardless of whether they are registered with the charity or not. The website contains a searchable database of support groups across the United Kingdom, with contact details of group organisers and information about the frequency, times, and locations of meetings. The website also functions as a news portal, both for the latest updates from Colostomy UK (projects, fundraising, campaigns and advocacy work) and more broadly for news and issues topical in the stoma world. During the pandemic, ostomates visiting the 'coronavirus landing page', were (and are) able to access up-to-date government information and see the latest medical guidance on issues such as whether the vaccines are safe for ostomates, which was a concern for many. The page was/is also used as a tool for communicating important messages, such as encouraging ostomates to seek help for stoma-related issues in the normal way, rather than delaying treatment.

The website is a popular resource, with the year-on-year trend being towards ever-increasing engagement. In 2019, 119,452 people visited the site viewing a total of 332,448 pages, with the support and information pages being most popular. The age range of visitors has been stable for a number of years now, being spread evenly across the 24 to 65 age range, with 64% being female and 36% male. This highlights the vital role the website plays in supporting younger people who, as was noted earlier, are less likely to call the stoma helpline.

Given the growing importance of the website and the trend towards accessing information and support electronically, the charity invests resource accordingly. Most recently, this has led to an expansion of the support offering available via the website with the introduction of a **Live Chat** function. This enables visitors to chat via on-screen text messages with a member of the Colostomy UK team. Outside of office hours, they can use the facility to message the charity via e-mail instead. The facility thus offers another means through which people can access support and information and, again, they can access this on their terms. They can remain anonymous and they can terminate the 'chat' at any time. The service has been used almost daily since its launch in spring 2020. At this stage it is still not understood the extent to which this activity is being driven by the pandemic and the effect that government restrictions have had on things such as support group meetings.

Campaigns and Projects: Active Ostomates

In addition to the support services outlined above, Colostomy UK campaigns relentlessly on behalf of ostomates and runs various projects, aimed at empowering people with stomas and supporting their health and wellbeing. The project most pertinent to this discussion is **Active Ostomates**. As you will see from the summary below, the project illustrates how patients who come to the charity can be helped and supported in ways not possible within the constraints of a busy clinical setting. It also highlights once again the part technology can play in this and re-states the complementary role charities have alongside clinicians in responding to the ongoing needs and concerns of patients.

The link between exercise and health is well established [9]. And, as we know, for ostomates, being active and keeping weight in check has the added benefit of aiding post-operative recovery and preventing parastomal hernias. Research conducted by Colostomy UK in 2016 revealed however, that while ostomates in general recognised the benefits of being active, many were unsure what types of exercise were safe for them. Many also cited fear of the public 'gaze' as being a barrier to undertaking physical activities. These findings mirrored those of Russell's 2017 research [10].

It was against this backdrop that the charity launched its Active Ostomates project in 2016, with the aim of improving the mental and physical wellbeing of people with stomas, empowering them to get their lives back on track as soon as possible. The project has two key elements. The first, which is the provision of up-to-date, freely and easily accessible information, is delivered by the previously mentioned 'Active Ostomates' booklet. This is designed to encourage and give patients the confidence to exercise and get involved in sports and other activities. Written in collaboration with, amongst others, a senior clinical nurse specialist and colorectal physiotherapist, it contains a whole range of safe exercises for ostomates (some can even be done sitting in an armchair in front of the T.V!). The booklet also sets out the benefits of being active, gives stoma management advice for the periods before, during and after physical activity, and signposts readers to a range of sports and other activities. The information is also shared extensively on the charity's website and social media platforms, with the Active Ostomates project having a two-page feature in each edition of Tidings magazine as well. Broad dissemination across a range of channels is a conscious policy of the charity, given what is known about the ways in which patients of different ages prefer to seek information and support.

The project's second element is the provision of different activities for ostomates. Prior to the coronavirus pandemic, many of these were delivered in partnership with stoma support groups. In order to reduce the barriers to participation all activities to date have been provided free and, in the case of swimming, organised as 'ostomate only' swim sessions at local pools in order to remove as far as possible the previously cited 'fear' factor. Since the project's launch, members of support groups across the United Kingdom have enjoyed participating in everything from chair yoga, swimming, and archery, to Creative Minds art sessions, aimed at getting people mentally as well as physically active. Colostomy UK also has its own Rugby League team, which ostomates can join. In 2019 the team played four fixtures, all of which were well supported. Feedback from ostomates who have participated in activities has been universally positive. After a swimming event held for ostomates and their families at Sheppey Leisure Centre, one participant reflected on how he had lost confidence after stoma surgery in 2003 and had not been in the pool since. For him, the session was especially poignant as it was the first time that he, his wife and young son, had ever been swimming as a family [11].

The pandemic had obvious implications for the project. With support group meetings across the country suspended the delivery of face-to-face activities was forced to stop as well. Rather than call a temporary halt to the project, Colostomy UK turned to technology for help, launching 'Active Ostomates: At Home' in spring 2020. By the start of 2021, the offering included: Mindfulness and Meditation; Yoga; Pop to the '80s Dance; Chair Yoga; Art. The activities are advertised on the Colostomy UK website, social media and in Tidings magazine. All sessions are delivered using Zoom and remain free to join.

Conclusion

People have stoma surgery for a whole range of reasons and, while their medical needs may be different, there is common ground to be found in the support they need before and afterwards. Research has shown that easy access to high-quality information and peer-to-peer experienced-based support is beneficial to patients [6]. It is here that stoma charities are able to work alongside healthcare professionals, complementing all that is achieved by clinicians in a clinical setting.

As the case study of Colostomy UK shows, this charity has been successfully fulfilling this role since the late 1960s. During this time, it has learned much about the needs of stoma patients, and its support offering has developed accordingly. Today's charity is highly responsive to the requirements of different patient groups, with its core services designed in a way which ensures that all people, regardless of their social characteristics or stage in their stoma journey, can access the help they need. They can also choose how, when and where they access it.

For good reason the discussion has foregrounded technology throughout. Experience shows that in the digital age, patients are increasingly turning to the internet for support, be this via forums, online support groups, or interactive ZOOM sessions. The coronavirus pandemic has undoubtedly accelerated this trend. There will probably always be a place for traditional forms of support (e.g. face-to-face support groups, open days etc.), but we can speculate that now 'technology' has been forced on the previously reluctant, it is here to stay. People seeking support and advice in an online environment is likely to become a new 'norm'. Ignoring this development is not an option for either the healthcare profession or the charity sector. Recognising this, Colostomy UK has been quick to respond, offering more and more technological solutions to make support more widely accessible than ever before.

What else might the future hold? It is the hope of this author that the links between the healthcare profession and stoma charities will continue to grow in strength and that patients will benefit as a result. The three stoma charities mentioned at the start all have a considerable pedigree and are keen to share their knowledge with, and learn from their colleagues, in the healthcare profession. It is also important to point out that tens of thousands of patients are registered with these charities. This opens the door to fruitful collaborations between patients, charities and the healthcare profession on everything from patient-led research to discussions around central prescription services and the future direction of stoma care in the UK.

Reflective Questions

1. How do you think the work of the stoma charities complements your work as a clinician?
2. Which of your patients might benefit from engaging with one or more of the stoma charities?
3. What opportunities are there for collaboration between healthcare professionals and the stoma charities?

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Living with Long Term Conditions

18

Carolyn Swash, Maddie White, and Michaela Parker

Learning Outcomes

- Understand the impact of stoma surgery upon health inequalities.
- Understand the implications of stoma surgery for a patient with dementia.
- Draw on key points regarding the involvement of other care agencies to support patients living with a stoma.

Introduction

The importance and value of long-term health has never seemed greater than at this time. The Department of Health acknowledges that up until most recently, there has been minimal change to the focus on wellbeing in the United Kingdom (UK). However, healthcare policy over the last decade has been influenced by a variety of data to address and support methods for achieving this. There is now a strong realization by healthcare leaders and policy makers that wellbeing very much *does* matter to health [1].

More recent emphasis on health and well-being, as well as significant advances in science, medicine and technology, has resulted in the gradual emergence of an increasingly aging population; a group within society that are living with various

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health challenges that are often multiple, complex and long-term in nature. Such advances relating to the impact upon health have paved the way for 'cutting edge' treatments; some of these have the potential to reduce or delay illness and even eradicate and cure disease, often by-passing the need for major intervention. An example of this may be coronary artery angiography rather than open heart surgery.

As a result many people live with health conditions over the longer term, as opposed to acute illness and even though a disease process may be evident, this becomes something that is manageable [2].

According to the Colostomy UK 2021 [3], it is now estimated that within the UK approximately 21, 000 people have a new stoma formed each year with the estimated number of people who live with a stoma having increased from traditionally quoted figures of 120,000 to approximately 200,000 people [4]. For some patients undergoing surgery, the stoma planned was a permanent stoma. An intended temporary stoma may well become permanent as a result of post-operative complications and social outcomes that are assessed as having the potential to negatively impact upon health and well-being, if reversal were to take place. As a result those living with a stoma should now be considered to be living with a long term health condition.

What is a Long Term Health Condition?

A long-term health condition or illness can be described as a state of health that requires self-management and often treatment over an extended period of time; usually years or even life entirety. A long-term condition involves an individual often being responsible for symptom control, medication or treatment compliance, with possible lifestyle adjustments as a consequence [5]. The ability to care for numerous health needs may well force a compromise in personal care; whether that be due to disability, lack of support and/or collaboration in relation to care and is influenced by numerous and often complex issues. Long term health and well-being continue to be manipulated by economic and political agendas, with many areas seeing greater support from the medical industry and charitable organisations. Government agenda and policy continues to underpin healthcare budgets and specialist guidelines for the best possible care. Key documentation describes good care being something that is closer to home, collaborative in nature and practiced in an open and honest environment, where individuals feel involved in any decision-making and offered choice and detail that facilitates informed consent along the complete care pathway [2]. For those who have a long term health condition, access to healthcare professionals with both the knowledge and the skills to support them is of paramount importance to ensure that health optimisation, whether mental health or physical health, is achieved.

The measurement of health and wellbeing is multifactorial and can be very subjective. In 1948, the World Health Organization defined health as 'A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' [6]. As with health, wellbeing is also multifactorial and is both a subjective and objective concept. Subjective wellbeing considers how someone feels about their own health and wellbeing and is based on personal satisfaction with life, feeling positive about events as well as whether life is meaningful. Objective wellbeing considers basic human needs and rights such as access to food or education [7]. Personal health and wellbeing is therefore much more than the absence of dysfunction and disease; it is based on mental and emotional health, physical health and a healthy lifestyle as well as having access to support to cope with life in all its complexities. Good health and wellbeing involves a person being able to balance, optimise and cope with diseases and conditions that will be present long term as well as being able to access a health care professional with the skills and knowledge to support them in achieving this. The measurement of good health and wellbeing is reflected in the quality of life a person feels he/she has [8].

The Impact of Health Inequalities

Health inequalities are the differences in health between people or groups of people that may be considered unfair [9]. Health inequalities are more prevalent in those who have a long term health issue. Within England, Public Health England has a statutory duty to try and reduce the inequalities between groups of people to ensure that everyone has an equal opportunity to live a healthy life no matter who they are or where they live [10]. This is also echoed within the devolved nations of the UK. Having a long term-health condition is considered one of the major factors that leads to poor quality of life and if not managed effectively, ill-health has a direct impact on people achieving what they wish to achieve in life [9]. In trying to address health inequality there are four main factors that are taken into consideration that influence government policy decisions. They are:

- socio-economic factors, for example, income
- geography, for example, region or whether urban or rural.
- specific characteristics including those protected in law, such as sex, ethnicity or disability.
- socially excluded groups, for example, people experiencing homelessness. Williams et al. 2020.

Stoma Care

Within stoma care there are many factors which may affect quality of life and could thereby increase the notion of health inequalities. These include the type of surgery performed (elective versus emergency), stoma position and type, stoma health as well as the condition of the peristomal skin [11]. In addition, for many having a stoma formed, there is a likelihood that there may be the presence of one or more health conditions, which although may not have directly lead to the stoma formation, may prevent possible reversal of a temporary stoma. For example those with chronic respiratory conditions or cardiac conditions may struggle in pursuing stoma reversal given the high risk as demonstrated by the American Society of Anaesthesiologists Physical Status Classification System (ASA) [12]. ASA risk has been used for over 60 years and is a predictor of perioperative risk, based on a person's health; the higher the score the higher the risk. For some this may lead to a defunctioning stoma for symptom control in an example of bowel obstruction rather than the surgeon being able to remove the cause for the obstruction.

The role of the specialist stoma care nurse (SSCN) in ensuring health optimisation starts with the pre-operative preparation of the patient for surgery and it is about having honest conversations with the patient to ensure that they have realistic expectations of what the outcomes of the surgery may be. Following surgery, in the immediate post-operative period, the teaching of good stoma management is critical to ensure that knowledge and skill are attained to help the patient adapt to living with a stoma. Access to long term support for those with a stoma is crucial to ensure that any health inequalities as a result of the stoma being formed are managed. In addition to having access to a SSCN, peer support is also essential and is often provided by the various stoma associations such as Colostomy UK, Ileostomy and Internal Pouch Association (IA) and Urostomy Association (UA) (ASCN UK 2021 [13] and see Chap. 17).

Reducing the Health Impact of Stoma Formation in the Elective Patient

Although previously discussed in earlier chapters within this book it is worth highlighting the aspects of having a stoma formed that can contribute to worsening health inequalities. For individuals undergoing elective surgery resulting in stoma formation the knowledge and skill of the SSCN can help mitigate some of the risks. The pre-operative preparation and holistic assessment of the patient including home circumstances is crucial to identifying what patient support will be required post-surgery and beyond [13]. For those that live alone, this could be recommending that the patient have a package of care to support them on discharge until fully recovered. Similarly, it could be that a family member is identified as the person who will be managing the stoma in those who have some form of disability in order to assist with stoma independence. In addition, pre-operative assessment of the patient also ensures that any medical conditions are treated and optimised in order to attain the best surgical outcome for the patient [14].

The pre-operative siting of the stoma in elective patients, apart from providing guidance to the colorectal surgeon where the optimal position for the stoma should be also ensures that the stoma is positioned where it can be most easily managed by the patient/carer (see Chap. 11). Assessment of the abdomen not only provides an opportunity to provide siting guidance with regards to the position of the stoma but also provides an opportunity to highlight areas to the surgeon to avoid positioning the stoma in the event that the stoma cannot be brought out where the marking guide is located ie deep skin creases that may not be apparent in a lying position [15].

The skill of the surgeon in forming the stoma should not be underestimated and a well-constructed stoma is crucial to ensure a positive outcome following surgery in terms of management of the stoma. However, co morbidities such as obesity, another long term health condition, may prevent the creation of a well spouted or well fashioned stoma leading to inequalities in health and wellness as the patient is at increased risk of experience leakage and sore skin for example. Cottam and Richards [16] describe a problematic stoma as one that requires more than one product or accessory to ensure that the pouch did not leak for 24 h (see Chap. 12).

Peristomal skin health is of importance to ensure that the pouch of choice adheres correctly to the skin. A thorough assessment of the patient which includes a history of existing skin conditions helps the SSCN to plan post operatively. Skin health is dependent on both intrinsic and extrinsic factors. Intrinsic factors are factors such as disease, nutrition and the aging process. Extrinsic factors consist of how the environment affects the health of the skin for example sun exposure as well as the effects of treatments such as radiotherapy. In the very young the skin is immature and in the older person a combination of disease as well as medication coupled with the aging process can weaken the strength of the skin making it more easily damaged [17]. In relation to stoma care, if the adhesion of the pouch to the skin is too strong then the bond between the skin cell to skin cell will weaken and skin health damage can occur [18]. For those that require the use of a convex pouch, there is additional pressure on the peristomal skin which will require ongoing assessment by the SCN to ensure that the need for the convex pouching system continues to be the right product for the patient [19]. The use of additional items to help with the management of the stoma should be kept to a minimum and should be reviewed on a regular basis along a pathway of care, in order to prevent wastage and stockpiling of equipment which has an economic impact for the NHS. Education needs to be provided to patients to ensure that there is recognition of peristomal skin complications and that they seek assistance from the SSCN rather than self-treat if symptoms develop, persist or worsen. This is also a global issue not just a UK issue (see Chap. 13).

The Health Impact of Stoma Formation in the Emergency Patient

The health impact of emergency treatment for the stoma patient can predispose the patient to an increased risk of health inequalities. The fact that the patient requires emergency surgery suggests that the systems within the body are already stressed and the ability to optimise pre-existing health conditions could be difficult requiring more intensive medical input and support. It also suggests that the patient may have been unwell for a while and so known health conditions could be unstable. Nutritionally the patient may also be compromised increasing the risk of delays to attaining well-being in the post operative period [14]. The risk of stoma formation in a patient undergoing emergency bowel surgery is higher and even with the skill of the SSCN it may be impossible due to abdominal distension to site the stoma in the most optimal position. Often for those requiring emergency surgery marking the position of skin creases is helpful thereby giving the surgeon an indication of areas to avoid may be all that the SSCN is able to do [11].

Following surgery in this situation the condition of either or both the stoma and peristomal skin could be compromised due to poor circulation and poorly controlled medical conditions. In addition the nutritional health of the patient may result in delays in wound healing and general recovery from the surgery will take longer. Long hospital stays are often experienced and the ability of achieving independence in relation to the stoma may also be delayed requiring packages of nursing and social care to be implemented in some circumstances. The input from the medical teams will additionally be more intense and may need to be present for a longer period of time in order to try and achieve the baseline health of the person although in some this may never be achieved.

Considerations of Having a Stoma as a Long-Term Health Condition

As highlighted earlier in the chapter, long term health conditions may have a financial impact on the patient and their family. In the elective patient, treatments that were required to be carried out prior to surgery may well have meant that the person was unable to work for a considerable period of time due to risk to health. Post-operatively, in both the elective and emergency patient, due to the time it takes to recovery, treatment plans undertaken or complications, may result in a reduction of pay increasing the reliance on statutory sick pay. At a time when there is an increased burden on people's finances this may add considerable stress to families. The SSCN is ideally situated to signpost patients to get support and advice. For those with a cancer diagnosis it may be via or other cancer based charity. For those without a cancer diagnosis it will be through referral to social services for assessment. A continuing health care fund is also available to those who have a very brittle condition that requires intense support within the community such as a carer's allowance. The SSCN needs to be familiar with how to support and signpost the patient and their family to appropriate agencies particularly in regard to social services and financial support. In addition, in England unlike the rest of the UK, prescriptions are not free and for those that pay for their prescriptions, an exemption certificate is available if the stoma is permanent. Exemption certificates can also be obtained for those who have been diagnosed with cancer. These certificates need to be renewed every five years. For those who may not have a permanent stoma and are obliged to pay for their prescriptions, obtaining a pre-paid certificate of either three months or one year can ease the financial burden [20].

Annual Clinical Review (ACR) and Appliance User Reviews (AUR)

As with any medication that is prescribed, there is a requirement to ensure that the stoma patient has an annual review to ensure that prescription medication is still current and effective [21]. An appliance user review can be undertaken at any time and focuses more on whether the product (s) are clinically suitable for the patient and an example of this is when reviewing a patient if they are experiencing leakage. Any review should consider the following areas

(a) the stoma
(b) the peristomal skin health
(c) suitability of the appliance and other items that may be used for the stoma type and output to ensure they are still effective and are required
(d) the stoma template to the ensure the pouch fits accurately
(e) the stoma output
(f) the impact of other health conditions and prescribed treatment
(g) agreeing the prescription template in terms of items and quantities to be prescribed
(h) checking storage of stoma items as well as stock levels and where needed offer advice
(i) ensuring the patient is aware of what is a healthy stoma and peristomal skin
(j) ensuring contact numbers are correct and that the patient knows how and when to contact the SSCN
(k) recognising any other conditions that need to be referred to the GP for investigation or management [13].

There are many benefits to having these reviews; for example the ‘lost ostomist’ in communities may be overlooked and no longer under surveillance, living with problems which they accept as normal including appliance leakage and skin damage [22]. Through the annual clinical reviews the SSCN is ideally placed to ensure that the impact of having a stoma in terms of having a long-term health condition and the stoma as a health inequality is managed. Although ideally it may be beneficial to review people in person, in some instances a telephone or virtual review may also be acceptable. The development and use of digital technology within the NHS has grown as a means of reviewing and supporting patients since the beginning of the Covid-19 pandemic. For some it is helpful, for others it may be inappropriate and should be judged on a person by person basis.

Mental Wellbeing and Quality Life

For some patients following surgery, the impact of having a stoma can result in anxiety about interaction with people as they feel self-conscious about having the stoma or uncomfortable in the presence of others. For others it may be because they feel that the stoma is loud or just very unpredictable. This may result in withdrawal and isolation from situations that they may have previously enjoyed. As part of the recovery process the SSCN would generally ask about the transition through the recovery pathway and may become alert to the fact that there is reduced social interaction. This may be voiced by the person themselves or by others within the family household. Completing quality of life questionnaires with the person may appear daunting but incorporating them into daily practice and informing the person at the onset that they will be completed as part of the routine care pathway can help the SSCN develop confidence in undertaking them with the patient. Quality of life questionnaires such as those provided by ASCN UK (see Appendix 1) are easy to complete with the patient and would provide a benchmark with regards to the person's mental health. Depending on the results, liaising with the GP for onward referral to specialist support may be appropriate. For people with long-term health conditions, social isolation is a recognised complication and can contribute to worsening health. Referral to the GP for assessment would therefore be beneficial. One fairly new initiative is that of social prescribing which any health care professional can utilise to access services relevant for the patient (www.england.nhs.uk). The referral is generally through the GP practice and the aim is to introduce and support the patient into becoming more integrated back into society via an interaction that works for them ie social gardening or health and wellbeing services. This initiative works well in both rural as well as urban areas where social isolation may contribute to poorer health outcomes [23]. Support groups and access to the relevant patient associations can also be beneficial.

The Stoma Patient with a Diagnosis of Dementia

It is evident that as patients get older, their physical health and wellbeing can only be sustained if their mental health is also nurtured. The increasing incidence of dementia and the growing global challenge raise the issue of whether the stoma patient with dementia is able to learn or maintain self management in both the short and long term. The learning of a new skill may be beyond the patient's cognitive understanding, particularly in light of the fact that memory loss is a significant symptom of dementia (see ASCN dementia guideline 2022 Appendix 2). Many symptoms associated with dementia, such as memory loss, communication difficulties, attention and concentration deficits, difficulty learning and retaining skills, can all add to the challenges in stoma management [24]. Adopting a person centered approach and positive strategies for teaching such as reflection are strategies discussed in the literature and help the SSCN plan practically for caring for patients with these increased needs [25]. Coston and Pullen [25] describe developing a patient diary for stoma patients living with dementia which could help to support patients as it includes visual prompts and repetition of instructions but also supports relatives and carers with up to date feedback. Ward staff can check the diary for a progress on training needs utilising a traffic light system. Utilising hints and tips from relevant organisations such as the Alzheimer's Society [26] (www.alzheimers.org.uk) will also enhance the care delivered and support families caring for patients with cognitive issues who may need to undertake stoma care themselves.

Conclusion

Within the current health care setting there is a requirement that patients are supported with living with long terms conditions to reduce the impact of the health inequalities that may manifest as a result. As a health care professional, the SSCN's role is pivotal when holistically assessing the patient to equip them with the knowledge and skills to ensure that they are able to adjust to life with a stoma. There is also a requirement to ensure that the patient is aware that ongoing support is available and that, as with other health conditions, a yearly review is undertaken to ensure that the clinical aspects of their care are reassessed and the AUR as a requirement for medicines management is met.

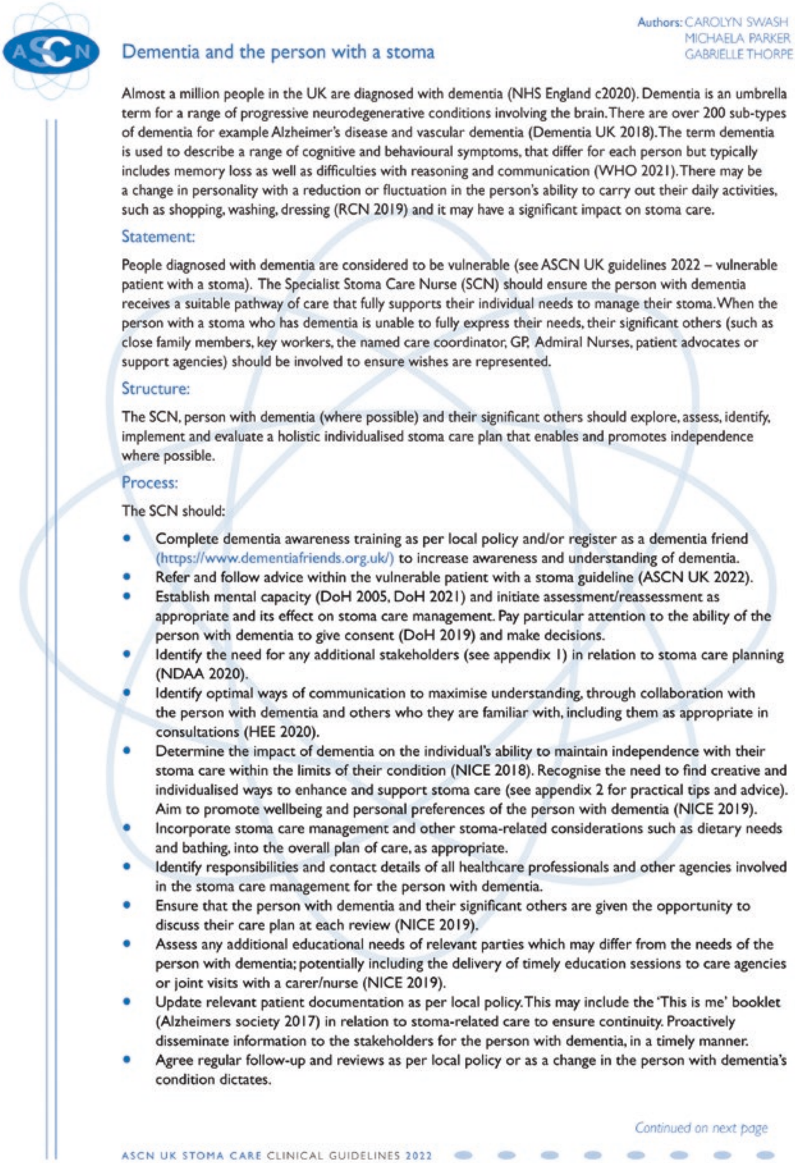
Appendix 1 Quality of Life Questionnaire

Please answer ALL the questions.

	Please tick the response that best describes how you are feeling at the moment.	Always	Sometimes	Rarely	Not at all
1	I become anxious when the pouch is full	1 ☐	2 ☐	3 ☐	4 ☐
2	I worry that the pouch will loosen	1 ☐	2 ☐	3 ☐	4 ☐
3	I feel the need to know where the nearest toilet is	1 ☐	2 ☐	3 ☐	4 ☐
4	I worry that the pouch may smell	1 ☐	2 ☐	3 ☐	4 ☐
5	I worry about noises from the stoma	1 ☐	2 ☐	3 ☐	4 ☐
6	I need to rest during the day	1 ☐	2 ☐	3 ☐	4 ☐
7	My stoma pouch limits the choice of clothes that I can wear	1 ☐	2 ☐	3 ☐	4 ☐
8	I feel tired during the day	1 ☐	2 ☐	3 ☐	4 ☐
9	My stoma makes me feel sexually unattractive	1 ☐	2 ☐	3 ☐	4 ☐
10	I sleep badly during the night	1 ☐	2 ☐	3 ☐	4 ☐
11	I worry that the pouch rustles	1 ☐	2 ☐	3 ☐	4 ☐
12	I feel embarrassed about my body because of my stoma	1 ☐	2 ☐	3 ☐	4 ☐
13	It would be difficult for me to stay away from home overnight	1 ☐	2 ☐	3 ☐	4 ☐
14	It is difficult to hide the fact that I wear a pouch	1 ☐	2 ☐	3 ☐	4 ☐
15	I worry that my condition is a burden to people close to me	1 ☐	2 ☐	3 ☐	4 ☐
16	I avoid close physical contact with my friends	1 ☐	2 ☐	3 ☐	4 ☐
17	My stoma makes it difficult for me to be with other people	1 ☐	2 ☐	3 ☐	4 ☐
18	I am afraid of meeting new people	1 ☐	2 ☐	3 ☐	4 ☐
19	I feel lonely even when I am with other people	1 ☐	2 ☐	3 ☐	4 ☐
20	I worry that my family feel awkward around me	1 ☐	2 ☐	3 ☐	4 ☐

Thank you for filling out the questionnaire.

Appendix 2 ASCN UK Dementia guideline 2022



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Dementia and the person with a stoma

Almost a million people in the UK are diagnosed with dementia (NHS England c2020). Dementia is an umbrella term for a range of progressive neurodegenerative conditions involving the brain. There are over 200 sub-types of dementia for example Alzheimer's disease and vascular dementia (Dementia UK 2018). The term dementia is used to describe a range of cognitive and behavioural symptoms, that differ for each person but typically includes memory loss as well as difficulties with reasoning and communication (WHO 2021). There may be a change in personality with a reduction or fluctuation in the person's ability to carry out their daily activities, such as shopping, washing, dressing (RCN 2019) and it may have a significant impact on stoma care.

Statement:

People diagnosed with dementia are considered to be vulnerable (see ASCN UK guidelines 2022 – vulnerable patient with a stoma). The Specialist Stoma Care Nurse (SCN) should ensure the person with dementia receives a suitable pathway of care that fully supports their individual needs to manage their stoma. When the person with a stoma who has dementia is unable to fully express their needs, their significant others (such as close family members, key workers, the named care coordinator, GP, Admiral Nurses, patient advocates or support agencies) should be involved to ensure wishes are represented.

Structure:

The SCN, person with dementia (where possible) and their significant others should explore, assess, identify, implement and evaluate a holistic individualised stoma care plan that enables and promotes independence where possible.

Process:

The SCN should:

- Complete dementia awareness training as per local policy and/or register as a dementia friend (https://www.dementiafriends.org.uk/) to increase awareness and understanding of dementia.
- Refer and follow advice within the vulnerable patient with a stoma guideline (ASCN UK 2022).
- Establish mental capacity (DoH 2005, DoH 2021) and initiate assessment/reassessment as appropriate and its effect on stoma care management. Pay particular attention to the ability of the person with dementia to give consent (DoH 2019) and make decisions.
- Identify the need for any additional stakeholders (see appendix 1) in relation to stoma care planning (NDAA 2020).
- Identify optimal ways of communication to maximise understanding, through collaboration with the person with dementia and others who they are familiar with, including them as appropriate in consultations (HEE 2020).
- Determine the impact of dementia on the individual's ability to maintain independence with their stoma care within the limits of their condition (NICE 2018). Recognise the need to find creative and individualised ways to enhance and support stoma care (see appendix 2 for practical tips and advice). Aim to promote wellbeing and personal preferences of the person with dementia (NICE 2019).
- Incorporate stoma care management and other stoma-related considerations such as dietary needs and bathing, into the overall plan of care, as appropriate.
- Identify responsibilities and contact details of all healthcare professionals and other agencies involved in the stoma care management for the person with dementia.
- Ensure that the person with dementia and their significant others are given the opportunity to discuss their care plan at each review (NICE 2019).
- Assess any additional educational needs of relevant parties which may differ from the needs of the person with dementia; potentially including the delivery of timely education sessions to care agencies or joint visits with a carer/nurse (NICE 2019).
- Update relevant patient documentation as per local policy. This may include the 'This is me' booklet (Alzheimers society 2017) in relation to stoma-related care to ensure continuity. Proactively disseminate information to the stakeholders for the person with dementia, in a timely manner.
- Agree regular follow-up and reviews as per local policy or as a change in the person with dementia's condition dictates.

Continued on next page

Dementia and the person with a stoma (continued)

- Allocate and agree appropriate duration for clinical appointments, taking into consideration the possible need for joint visits or a relevant advocate to be present.
- A specific named SCN (NICE 2019) should be identified in regards to stoma care issues. They have a duty of care to liaise with the stakeholders for the person with dementia to ensure stoma care needs are met and maintained.

Outcome:

The SCN will assess, develop and implement, with the person with dementia and significant others, a plan of care that is tailored to the stoma care needs and management of the person with dementia.

The person with dementia and their significant others will express stoma care needs have been met.

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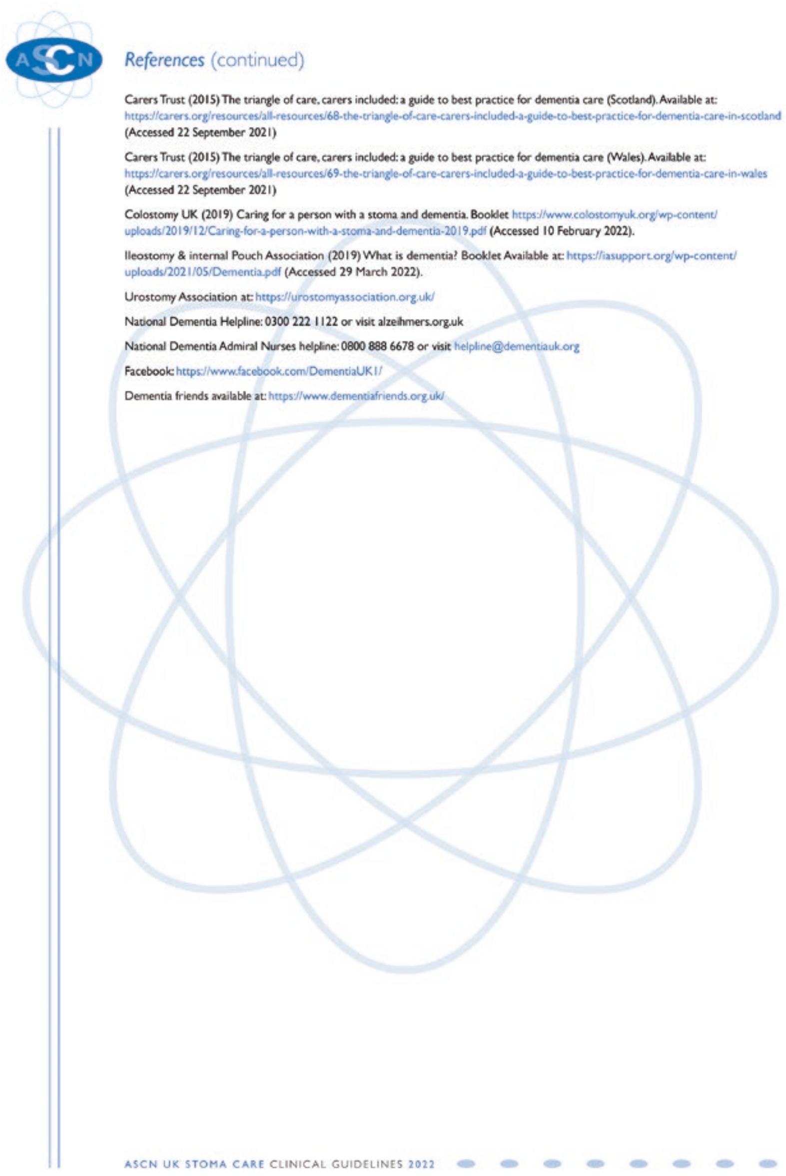

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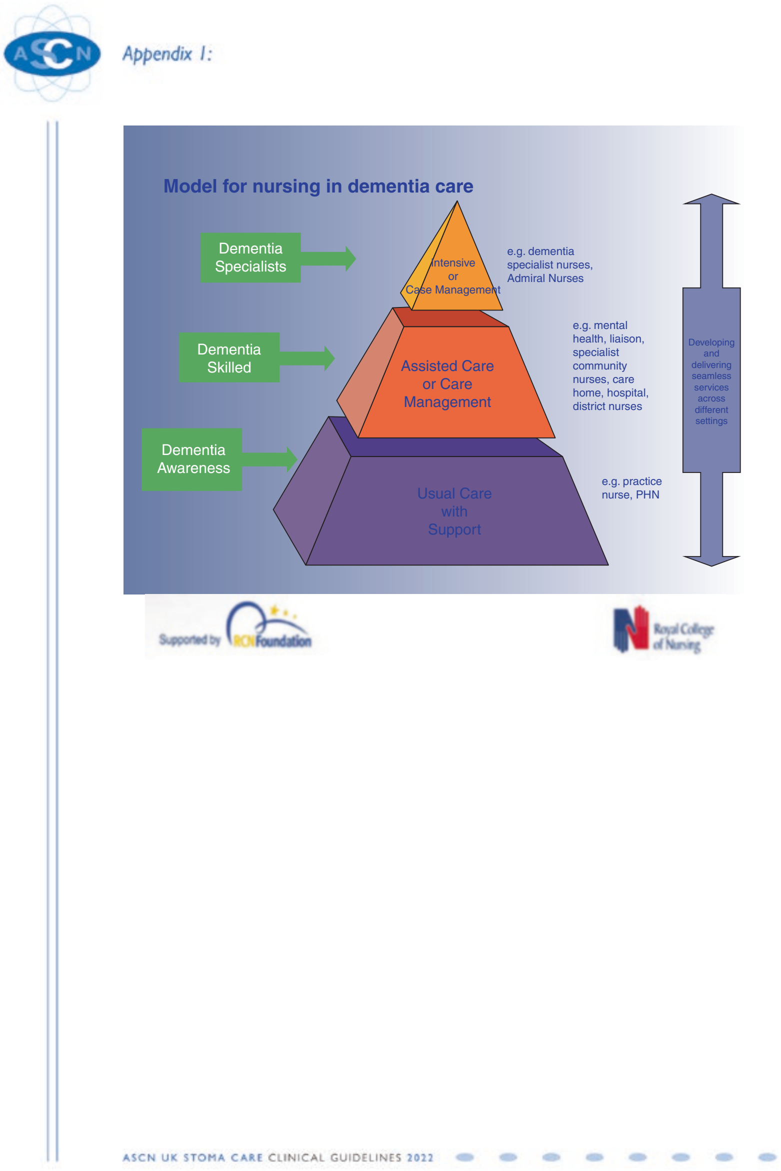
National Dementia Helpline: 0300 222 1122 or visit alzeihmers.org.uk

National Dementia Admiral Nurses helpline: 0800 888 6678 or visit helpline@dementiauk.org

Facebook: https://www.facebook.com/DementiaUK1/

Dementia friends available at: https://www.dementiafriends.org.uk/

ASCN UK STOMA CARE CLINICAL GUIDELINES 2022



Appendix I:

Model for nursing in dementia care

Dementia Specialists

Dementia Skilled

Dementia Awareness

Intensive or Case Management

Assisted Care or Care Management

Usual Care with Support

e.g. dementia specialist nurses, Admiral Nurses

e.g. mental health, liaison, specialist community nurses, care home, hospital, district nurses

e.g. practice nurse, PHN

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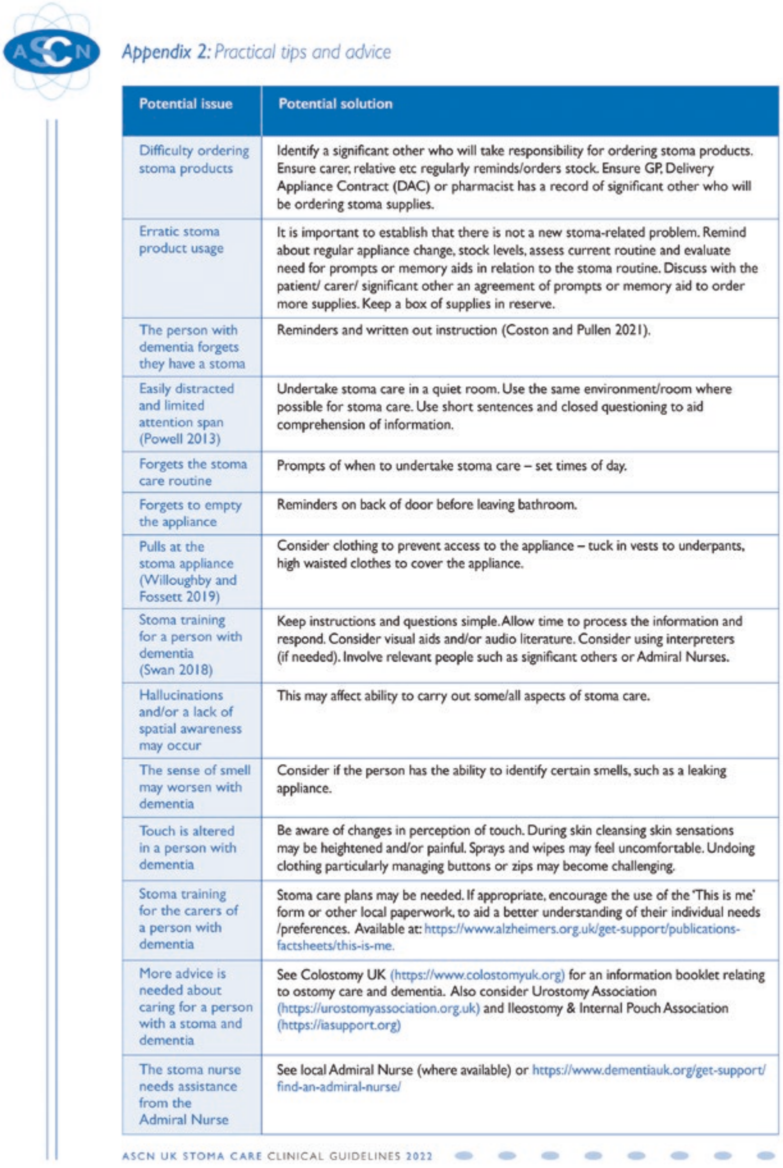

Appendix 2: *Practical tips and advice*

Potential issue	Potential solution
Difficulty ordering stoma products	Identify a significant other who will take responsibility for ordering stoma products. Ensure carer, relative etc regularly reminds/orders stock. Ensure GP, Delivery Appliance Contract (DAC) or pharmacist has a record of significant other who will be ordering stoma supplies.
Erratic stoma product usage	It is important to establish that there is not a new stoma-related problem. Remind about regular appliance change, stock levels, assess current routine and evaluate need for prompts or memory aids in relation to the stoma routine. Discuss with the patient/ carer/ significant other an agreement of prompts or memory aid to order more supplies. Keep a box of supplies in reserve.
The person with dementia forgets they have a stoma	Reminders and written out instruction (Coston and Pullen 2021).
Easily distracted and limited attention span (Powell 2013)	Undertake stoma care in a quiet room. Use the same environment/room where possible for stoma care. Use short sentences and closed questioning to aid comprehension of information.
Forgets the stoma care routine	Prompts of when to undertake stoma care – set times of day.
Forgets to empty the appliance	Reminders on back of door before leaving bathroom.
Pulls at the stoma appliance (Willoughby and Fossett 2019)	Consider clothing to prevent access to the appliance – tuck in vests to underpants, high waisted clothes to cover the appliance.
Stoma training for a person with dementia (Swan 2018)	Keep instructions and questions simple. Allow time to process the information and respond. Consider visual aids and/or audio literature. Consider using interpreters (if needed). Involve relevant people such as significant others or Admiral Nurses.
Hallucinations and/or a lack of spatial awareness may occur	This may affect ability to carry out some/all aspects of stoma care.
The sense of smell may worsen with dementia	Consider if the person has the ability to identify certain smells, such as a leaking appliance.
Touch is altered in a person with dementia	Be aware of changes in perception of touch. During skin cleansing skin sensations may be heightened and/or painful. Sprays and wipes may feel uncomfortable. Undoing clothing particularly managing buttons or zips may become challenging.
Stoma training for the carers of a person with dementia	Stoma care plans may be needed. If appropriate, encourage the use of the 'This is me' form or other local paperwork, to aid a better understanding of their individual needs /preferences. Available at: https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me.
More advice is needed about caring for a person with a stoma and dementia	See Colostomy UK (https://www.colostomyuk.org) for an information booklet relating to ostomy care and dementia. Also consider Urostomy Association (https://urostomyassociation.org.uk) and Ileostomy & Internal Pouch Association (https://iasupport.org)
The stoma nurse needs assistance from the Admiral Nurse	See local Admiral Nurse (where available) or https://www.dementiauk.org/get-support/find-an-admiral-nurse/

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