



Transition to Adulthood: Shifting Roles Between Young People with Chronic Conditions and Their Parents

6

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6.1 Introduction

Transitional care is that which is provided by parents and health professionals throughout adolescence and emerging adulthood. It is characterised as a time of change whereby young people move towards assuming responsibility for their chronic condition, in line with their development and in preparation for the transition to adulthood and adult healthcare services.

For many years, parents were either absent from the transitional care literature or conceptualised as a barrier to young people's independence; a view that still pervades contemporary narratives. More recently, there has been a discernible shift that repositions parents as key enablers in transition and protective factors in young people's health and wellbeing. This positive stance is increasingly reflected in policies for transitional care, which now define parents as legitimate stakeholders, key informants and service users. These recognise that parents have an influential role in young people's health and development. However, they also acknowledge that parents are widely critical of care provision during transition. Improving parental support is, therefore, an explicit priority for service improvement. Unfortunately, while policy makers are keen to drive-up standards in care, they provide scant detail about what effective parenting in transition looks like, or how to support families in transferring caring responsibilities for optimal benefit.

In response, this chapter brings together the latest evidence about parenting in the context of transition. In doing so, we make an important distinction—that

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parents are involved in two interrelated transitions: (1) the transfer of healthcare responsibility from parents to young people — *health transition* and (2) the relocation of young people’s healthcare services from paediatric to adult providers — *transitional care* [1].

The first part, *Parenting in Transition*, explores what it means to be a parent of a young person with a chronic condition during health transition. This explains why transition cannot be understood as a young person-only phenomenon. We then draw upon existing literature to demonstrate how parents and young people can, and do, work together to shape the emotional environments necessary for positive realignment of roles and responsibilities. This highlights the potential of parents to play beneficial and protective roles in young people’s transition, rather than problematizing parenting, which has historically been the case. However, we also reveal the unmet support needs of parents that place them and their children at risk of poor outcomes. Drawing upon psychological theory, we discuss why a ‘whole family approach’ is now warranted.

The second part, *Parenting and Transitional Care*, examines parental roles in relation to service provision and the adequacy of current arrangements to offer meaningful support. We discuss the different ways in which parenting has been conceptualised in relation to adolescent health (generally) and transitional care (specifically). In doing so, we explore a strengths-based approach that views parents as assets in transitional care; arguing that improving parental capabilities will benefit young people’s health, wellbeing and transition readiness. We highlight a number of ways to foster positive relationships with parents in transitional care settings and challenge the prevailing view that young people are expected to manage their condition independently.

The final part, *Key Recommendations for Practice* presents a range of evidence-based strategies to accommodate family support appropriately throughout paediatric and adult healthcare, including priorities for research and development.

At this point, it is important to note that the term ‘parent/s’ is used in this chapter as an umbrella term to include all primary caregivers responsible for parenting during transition, which includes (but is not limited to) biological parents, other guardians such as step-parents and foster parents, and other adult family members such as grandparents and older siblings.

6.2 Parenting in Transition

It is expected that children will incrementally increase responsibility for managing their chronic condition as they move through adolescence and into adulthood. This usually involves a shift from parental to shared responsibility, followed by a shift to young people themselves, where capacity allows [2–4]. For parents, this represents a change in their role from ‘care provider’ to that of ‘care consultant’ [5], while embedding this new role within an adult-adult relationship [6]. This realignment of roles and responsibilities is central to the Shared Management Model (introduced in Chap. 3) which is enacted within clinical contexts, but evolves as part of everyday family life.

Studies examining the changing roles of parents during transition [1, 6–12] conceptualise the problem as: adaptation to a marginalised role, appropriate allocation of treatment responsibilities and managing anxieties related to their child’s illness trajectory [13–15]. It is unsurprising, therefore, that effective change from parental management to self-management is tricky. It requires fine balancing [8, 10, 13, 15] and sharing care is both a source of support and conflict for young people and their parents [2, 4, 9, 13, 16–18]. Getting the balance right is important; having too little responsibility for self-care or being ‘forced’ to take on responsibility prematurely can impact on young people’s health and use of healthcare, including non-compliance, missed appointments and delays in transfer [19]. Thus, there is much need to understand how parents and young people can be supported to manage the shift in responsibilities, starting with a better understanding of the roles that parents play in young people’s transition readiness. This section therefore draws together research that describes the supporting roles that parents perform in their children’s transition and the impact this can have on their own health, wellbeing and personal development. It also demonstrates how parents understand their changing roles and responsibilities, explaining why they enact them as they do. Importantly, this includes evidence from parents themselves (e.g. [4]).

6.2.1 Experiences and Impact of Parenting in Transition

Typically, parents hold a number of roles and responsibilities in transition; not least functioning as scaffolds, supporting young people to develop the skills they need to become independent and effective health service users. Where there are complex health conditions and additional care needs, these roles have been shown to be intensified and extended to include the roles of nurse, student, teacher, detective, guard, advocate [20]. Parenting roles in transition have also been shown to extend beyond what would be considered usual in adolescence. A recent study by Shaw et al. [15] that included mothers and fathers of adolescents with a range of chronic conditions (asthma, epilepsy and osteogenesis perfecta), showed that parents experience their roles as time-consuming, stressful and unrelenting; but necessary to protect children from harm in the face of multiple risks and uncertainties. This is heightened further where young people have profound and multiple learning difficulties and have a continuing dependency on parents to meet and advocate for them across ecological levels [21–23]. For some parents, transition is also a time where their children may be experiencing deteriorating health due to physical changes [22]. Parents are therefore required to engage in both ‘ordinary’ parenting that is not directly linked to their child’s condition and ‘extraordinary’ parenting which is specific to their child’s healthcare needs [24].

It is important to remember that these parenting demands also exist within a wider context. Parents may have other caring responsibilities (e.g. siblings, partners or ageing parents) and need to maintain relationships with partners, work commitments and engagement in other valued activities. Parents may also have preexisting issues to contend with (e.g. their own health conditions) or be facing major

life-events (e.g. divorce, bereavement) that can impact on parenting. It is not surprising, therefore, that some parents describe transition as a ‘stressful’ and ‘difficult process’ [4, 15]. Indeed, a number of systematic reviews and meta-analyses have found that parents of children with chronic conditions (including adolescents) report significantly more parenting stress, anxiety, depression and physical health issues than parents of healthy children [25, 26]. Parents also describe how such ‘extended’ parenting can impact on important aspects of personal development as mid-life adults, making it more challenging to pursue goals relevant to this stage of life (e.g. vocational and financial security, increased opportunities to develop new interests or socialise) [15].

Despite this, the available evidence also suggests that parents value their parenting roles and see them as essential in transition for the immediate and longer-term benefit of their children [4, 15]. A systematic review and thematic synthesis of parenting in transition shows that parents understand the importance of independence-building, as well as young people’s acquisition of self-care skills, including disease-management and self-advocacy [4]. It also reveals how parents consciously begin the process of transferring responsibility for managing their condition outside of the clinic context; as part of wider decisions about a young person’s developmental readiness and in response to other events in a young person’s life (e.g. school residential trips) or family circumstances (e.g. being home alone while parents are working). The timing of this is often based on parental beliefs about a young person’s competence and motivation to undertake self-management tasks as well as the stability of the child’s condition [4]. Thus, the transfer of responsibility usually occurs incrementally through a ‘process of mediated condition management’ (p. 82) where parents employ multiple strategies to promote young people’s health and development, for example: information-giving, modelling self-care behaviours, prompting, monitoring condition management, allowing young people to experience (non-severe) consequences of their actions [4].

Findings and recommendations from this review certainly support the idea that parents can be key facilitators of their child’s transition to adulthood and independent self-management [4, 27], and suggest that parents should be conceived of as assets or resources who can promote the child’s adaptation to self-care through a process of family management [28, 29]. This approach is consistent with Social Development Theory [30] which suggests that learning occurs during the interaction between individuals and more knowledgeable others (e.g. parents or health professionals), and that a greater range of skills are developed with adult guidance than would be attained alone. Thus, outcomes for young people are likely to be better when parents are able and willing to support their child’s acquisition of skills; moving towards a state of inter-dependence as a bridge to young person independence.

Research is clear on the protective and enabling nature of parental involvement in terms of disease control and reinforces the value of a parent–adolescent partnership in the management of chronic conditions [1, 31–33]. For example, there is

now a substantial body of evidence that indicates that compassionate parental involvement can support better glycaemic control in adolescents with diabetes. However, getting the balance right is critical, as research also reveals that parents can experience increased levels of stress and depression that are related to the burden of diabetes management and this negative impact on parents can subsequently place young people at risk of poor outcomes [34–38]. For example, a longitudinal study of parents and young people aged 8–15 years ($n = 174$) with diabetes found almost a third of parents reported low wellbeing which was associated with unsupportive diabetes parenting behaviour, parental distress and behavioural problems in young people, which in turn was linked to reduced glycaemic control [35]. The authors therefore concluded that interventions to help young people manage their condition may also need support for parents.

Thus, it appears that parental involvement in transition can protect young people's health, but may require support to ensure positive outcomes. Research is less clear about how parental involvement fits with increased young person autonomy and other goals in transitional care (e.g. lone consulting). Indeed, there are tensions between the adolescent health literature which emphasises the benefits of independent self-management, and evidence that continued parental involvement contributes to better health outcomes. This tension is mirrored by parents themselves who, on a daily basis, struggle to strike the right balance between protecting young people's health and facilitating their independence [11, 13, 15]. While parents have described wanting to move towards more indirect forms of parenting as their children mature (e.g. through monitoring, teaching self-care skills, guidance and advocacy), they find it difficult to shift from a 'hands on' approach when risks to health are felt to be high or uncertain [15]. This is consistent with some theories about parenting in adolescence, which suggest that parents are driven to protect children's 'physical, psychological, spiritual, ethnic and cultural integrity', but protecting health and survival precedes most other goals ([39], p. 456). From this stance, many parents who at first, appear to be 'over-involved' in young people's care, may be better viewed as following natural parenting imperatives to protect their children from real and anticipated dangers [15].

Health transitions are therefore just one of many overlapping transitions that parents are attempting to navigate and support in adolescence and emerging adulthood. This point has been made by Farre and McDonagh [3] who discuss the 'interrelated nature of health transitions' in detail; explaining how young people undergo multiple transitions (biological, psychological, social, health, educational) which occur alongside, and in connection with one another—with different implications at different developmental stages. However, the way in which parents approach and enact their changing roles has important implications for young people. Indeed, parents' beliefs, expectations and behaviours are known to influence young people's behaviours and subsequent health outcomes [40, 41], and also health professionals' thoughts and behaviours [42]. Understanding how parents can shape young people's outcomes is therefore relevant.

6.2.2 Parenting Capabilities in Transition

New ways of conceptualising parents' roles in transition suggest that a strengths-based approach to parenting is appropriate and needed [43]. This assumes that parents and young people are capable of working together in transition, if they are enabled and supported to do so. The intention is not to ignore or minimise problems, or to set aside young people's safety as the main priority. The focus is, however, on helping parents to use their personal knowledge, skills and potential capabilities to inform positive strategies for transition. Indeed, the literature provides ample evidence that many parents have considerable expertise in their child's condition, are motivated to support their children in transition and have valuable insight into their lives [4]. That said, it is important to recognise that individual capacities can vary considerably, which may cause parenting roles to be expressed in many different ways. As such, parents will differ in their abilities to promote young people's health, wellbeing and transition readiness. Although this has received only limited attention in relation to transitional care [44], evidence from other literatures suggest a number of factors that influence parents' abilities to support young people, including: (a) the personal and psychological functioning of the parent, (b) the characteristics of the young person and (c) the contextual sources of stress and support [39, 45]. Core concepts outlined by these literatures are summarised here, although their implications for practice are revisited later in the chapter.

1. *Personal and psychological functioning of the parent*: In terms of personal and psychological attributes, *connection (or warmth)* is considered to be an important determinant of positive adolescent development, including in families where children/adolescents have a chronic condition [44]. This refers to the emotional closeness of the relationship between parents and their children and constitutes a range of behaviours that parents use to express that young people are loved and accepted. Thus, while an important goal of adolescent development is to form relationships outside of the family, maintaining ongoing connections with parents remains important. Parental *behavioural control* (or regulation, limit-setting) is also important. This involves parents using a range of reasonable techniques to encourage or limit young people's behaviours, in ways that are developmentally appropriate and responsive to their abilities. It includes knowledge and understanding of young people's behaviour, ongoing supervision and monitoring of their activities, communicating clear expectations for behaviour, setting rules and imposing appropriate consequences if these are broken. However, it is also important that parents *respect individuality*; promoting their children's positive self-worth and identity. This involves an appropriate balance of power (where young people can express their opinions, contribute to family decisions, assert their individuality) and the avoidance of psychological control (excessive criticism, invalidating feelings, constraining self-expression, or control through guilt or withdrawal of affection). Parents can also promote better outcomes through *modelling appropriate behaviours*; adopting behaviours and attitudes that are supportive of health and wellbeing, and helping young people

interpret wider social and cultural norms. Although the views of peers begin to have increasing weight, parents still remain an important source of influence for young people. Thus, parents can convey important values through their words and actions. They can also teach young people skills that will support self-management, and increase more generic aspects of their physical safety and psychological wellbeing.

2. *The characteristics of the young person* can also affect parenting, including gender and age, personality and condition. While some of these may remain stable over time, others may change and require new types of parental response. For example, children may develop new symptoms with age or lose abilities as health deteriorates. Recent neurological evidence also reveals that the brain changes more during adolescence than any other time (apart from infancy). These changes also go on for longer than previously thought, with brain ‘maturity’ not reached until the mid-to-late twenties [46]. However, because changes do not always process smoothly, it is likely that behaviour will be influenced by whichever region is exerting the most power. Thus, there may be times where young people are more vulnerable to the effects of new environmental stresses, are less able to think about the consequences of their actions and have heightened sensitivity to other people’s reactions [46–48]. Parenting may be easier when parents have insight into these changes and are able to adapt their approach to ensure a good fit between the young person’s characteristics and their own.
3. *Contextual sources of stress and support* are important aspects of parenting in the context of transitional care, but often overlooked. Whatever their circumstances, parents cannot provide all of the support and opportunities that young people require to successfully transition into adulthood. While parents can certainly support their children to access other enabling resources that exist outside of the family (e.g. education, healthcare, formal and informal social networks), other factors can affect their ability to do so. Parenting may be more difficult when there are other caring commitments, physical or mental health issues, lack of financial resources, poor housing, and personal histories that affect caring abilities. It may be difficult for parents to engage in tasks to model and effectively teach self-management strategies when, for example, they are preoccupied with providing basic protections, such as a safe place to live or adequate food.

Many aspects of parenting are therefore amenable to change, for the benefit of parents and young people. This may be particularly important, given evidence that parents who have children and young people with chronic physical conditions may find it harder to adopt positive parenting styles, when compared with parents of healthy children [49]. Helping these parents to recognise and build on their existing strengths within these domains, and foster new parenting skills, will undoubtedly support their ability to promote better outcomes for young people. The Family Management Style Framework [50] offers one such approach. This framework was developed to enhance understanding of how families incorporate the work of managing a child’s chronic condition within family life and has provided the conceptual

underpinnings for studies of family life in the context of childhood chronic conditions. The framework outlines four major components that can influence family management style and outcomes for individual and family functioning—and which align with the above domains of parenting capacity: (1) contextual influences (social networks, care providers, resources), (2) definition of the situation (child identity, view of the condition, management mindset, parental mutuality), (3) management behaviours (parenting philosophy, management approach) and (4) perceived consequences (family focus, future expectations). Of course, family management changes over the course of a child's life as they mature and develop the skills, cognitive ability and social confidence to manage their own health care activities [28]. However, it is clear that incorporating a flexible approach that supports positive realignment of roles and responsibilities is more consistent with how adults successfully manage their conditions, with support from friends and family. As Morris et al. [51] and others [52, 53] suggest, many of the practices of chronic condition management in adulthood involve the support and/or negotiation of multiple supportive actors and relationships (family focused, friend focused or health care professional focused). This challenges the prevailing notion of 'self'-management as an individual construct and instead highlights the importance of relationships which represent the context in which condition management practices, such as appointment attendance, medication and lifestyle management, are integrated into everyday life.

6.3 Parenting and Transitional Care

6.3.1 Changing Conceptualisations of Parenting in Transitional Care

The World Health Organisation (WHO), in their global overview of adolescent health, states that policies and programmes should 'focus beyond the individual' to improve young people's outcomes [48]. This includes parents and caregivers, who are considered to be major determinants of young people's health, development and wellbeing [48]. Indeed, parents are described as an important protective factor for adolescent health and wellbeing, and as such, the WHO calls for greater understanding and support for positive parenting.

This view has also been expressed in relation to healthcare transition, with several authors emphasising the value of socio-ecological models [54] as a conceptual basis for improved service provision [3, 4, 23, 55–57]. These approaches emphasise how young people with chronic or life-threatening conditions live within the context of their families, peers, social networks, service providers, social values, national policies, laws and resources that interact to influence their health and health-related behaviours. Young people's choices, goals and actions in transition are therefore shaped by a range of actors, relationships and exposures in their immediate and wider environments—not just their own individual characteristics. Healthcare transition can therefore be characterised as a multifaceted process that (at the very least) requires the engagement of patients, families and healthcare providers [55].

Evidence for the appropriateness of this model comes from Schwartz et al. [55, 56] who used stakeholder input to develop and validate the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART). The model contends that transition involves numerous stakeholders (adolescents and young adults, parents, providers), psychological factors that are amenable to change (e.g. self-efficacy) and less modifiable factors (e.g. age, gender, medical status). Further evidence comes from a systematic review that synthesised qualitative findings using an ecological model to understand transition from school to adult services for young people with severe or profound intellectual disability [23].

However, this systemic view has not always been evident in the transitional care literature, where the role of parents has been somewhat marginalised. Until recently, parental inclusion in transition-related research and service development has generally focused on parents' views of the quality of young people's care or providing proxy ratings for young people's outcomes, rather than exploration of parenting roles and needs [4]. Instead, evidence for transition has focused on the perspectives of young patients [58–60], transitional care models [61–63], healthcare practices [21, 64–68] and barriers to transition [19]. Where parents have been considered, their roles in transition care have often been positioned as problematic. This is evident in several systematic reviews of studies across a range of conditions that have identified 'helicopter', 'over-involved' and 'excessive' parenting as a threat to successful transition [19, 69]. Gray et al. [19] suggest that such parenting styles limit young people's opportunities to develop self-management skills and recommend education and guidance for parents. One could argue that such recommendations imply that parents are at fault and their parenting styles require correction. The reality, however, is far more complex. Parents cannot be conceived of as merely observing their child's transition, or as an impediment to it. Rather they are an integral component. They affect the process, and are reciprocally affected by it [55, 56].

This shift in the way parents are constructed in their child's transition is beginning to gain traction. Clinical guidance in the UK, for example, recognises the positive role of parents in managing childhood onset chronic conditions at many levels throughout transition and calls for improved parental support as a key component of transitional care [70]. However, there remains scant advice about what positive parenting looks like and how it can be facilitated in practice. The following sections therefore examine how parents experience current models of transitional care, highlighting areas of inadequacy, and discuss how the conceptualisations of parenting described here offer a useful starting point for service improvement.

6.3.2 Parents Experiences of Transitional Care

While parents are responsible for adapting their role to support their children, healthcare providers are responsible for providing transitional care that addresses the needs of both parents and young people. This is an explicit expectation of policy makers [70, 71] who assert that the active and appropriate involvement of parents in

transitional care will lead to better outcomes. This premise has been supported by existing research for some time [6, 72, 73]. More recently, Suris et al. [74] showed that parental satisfaction with their involvement in transitional care was associated with easier transition from the young person's point of view. 'Appropriate parent involvement' was also found to be a feature of transitional care associated with better outcomes in a UK-based longitudinal observational study of 374 young people and their parents/carers across three conditions [75]. Unfortunately, less than half of these participants experienced their transitional care as satisfactory, echoing earlier studies of parental (dis)satisfaction [76]. Others have also found shortfalls between policy and practice with respect to parental involvement and support. A UK report by the Care Quality Commission found that health professionals showed little concern or support for parents in their roles as carers and concluded that there was 'a culture of overreliance on partner agencies to recognise and assess the demands on family members as carers' ([22], p. 11).

Therefore, despite acknowledgement of the need for parent-targeted transition support, this is one aspect of transitional care that remains poorly addressed. Even when available, the provision for parents is often withdrawn at the time they need it most [7]. Parents have described stark contrasts between paediatric and adult care cultures; portraying the journey as one that moves them from care that is tailored to the child's 'unique and complex' needs [77] within a 'warm, familiar, cosy and trusted' environment [78] to a service environment where parents experience 'loss' of support, resources and trusted relationships [79]. As such, the process of transition and the transfer between services have been regarded by parents as a form of 'abandonment and rejection' by paediatric professionals [22, 80], with parents subsequently 'left to get on with it' by adult providers [22].

What is evident, is that parents display extensive knowledge about their children's conditions and play a crucial role in shoring-up current deficiencies in transitional care. A systematic literature review [4] and quality assessment [22] both reveal how parents often act as transition coordinators for their children's care and services; assuming responsibility for communicating between providers; organising orientation visits, clinic appointments at new places of care and transfer of clinical notes. This is even more pronounced in parents whose children have profound and multiple learning difficulties or complex health care needs [22, 23, 81]. Reasons for adopting this role have included: having no lead professional responsible for transition, insufficient service resources and capacity, and fragmented provision. Thus, while parents value the expertise and dedication of their healthcare teams, they perceive transitional care to be complex, confusing and lacking continuity in personnel [4, 15, 22]. They also highlight a lack of joined-up care working within and across sectors, including health, social care and education [4, 15, 22]. To compensate, parents employ a wide range of 'proactive' strategies, including the compilation of hand-held records to document young people's medical histories and service use, and evidence of symptoms and side effects (e.g. video recordings) [15]. Nevertheless, a plethora of parental concerns remain about the current state of transitional care [4, 19, 22] including:

- Lack of information about transition arrangements and the services available to young people and their families
- Loss of long-standing relationships professionals in paediatric care, who provide important support systems for them and their children
- Timing of transfer, which parents prefer to be at times of (relative) stability or wellness
- Developmental readiness of young people, given expectations of reduced parental involvement
- Reduced quality of care in adult services (e.g. beliefs that professionals lack knowledge about conditions with childhood/adolescent onset, reduced time allocated for clinic appointment, loss of specialist services)
- Changes and differences in funding/insurance arrangements and eligibility criteria for medical and social care, services (e.g. respite), specialist equipment and supplies
- Concerns about changes regarding consent and mental capacity
- Lack of parental facilities/involvement (e.g. ability to stay with young person during inpatient admissions)

It is no wonder, therefore, that parents perceive care providers as having insufficient understanding of the impact of transition upon them [22]. It is also unsurprising that they call for rapid improvement including: better collaboration between paediatric and adult sectors; joint visits; starting the process of transition earlier; increased information provision, transition preparation and access to emotional support [4]. These findings and improvement strategies are echoed in many studies [24, 74–76, 82–88] and appear relevant across conditions and countries [4]. The consistency of these findings over the years amply supports the idea that parents are not just integral to the provision of good transitional care, but *need* transitional care themselves.

6.3.3 Parent-Friendly Transitional Care

Although criteria exist to assess youth friendly care [89–92], there are no comparable frameworks to judge the extent to which transitional care is responsive to parental needs. There are however, a number of important concepts that the literature suggests are important.

Models of care provision that recognise parents as determinants of young people's health and wellbeing The models of care in which transitional care services are embedded matter. Existing services may be set up in ways that do not always lend themselves to developmentally appropriate care and appropriate parent involvement. Although 'appropriate parent involvement' has been associated with improved outcomes of transitional care [75], arguably, this is not a feature specific to transitional care, but rather a defining feature of developmentally appropriate healthcare for all young people [93]. Therefore, a model of care rooted in good, routine devel-

omponentally appropriate healthcare for all young people should, by definition, incorporate appropriate parent involvement for those requiring transitional care. Concepts that underpin developmentally appropriate care and implications for transitional care practice are discussed further in Chaps. 3 and 8 and by Farre and McDonagh [3].

Valuing parents as assets Healthcare practitioners need to work in partnership with parents in order to help them to facilitate their child's transition and to maintain their own psychological wellbeing during a stage of parenting that is characterised by ambiguity, uncertainty and risk. Importantly, parents need to be acknowledged for all the good work they do and the expertise they bring. They possess unique insights into their child and their condition, in contexts that extend beyond the consultation room. Thus, while transitional care should be centred on young people and promote their own agency, it is also important to view parents as having expertise that can support the individualised nature and practical implementation of transitional care. Working together as a group, where everyone's good intentions are validated, offers opportunities for less adversarial and more constructive approaches in transition. Indeed, integration of young people's perspectives with those of their parents and professionals is a central tenet of family-centred care [94]. Unfortunately, while young people, parents and professionals generally value collaborative practices, in reality, misalignment of expectations and motivations can make this hard to achieve [94]. Indeed, sharing care is often experienced as tensions between parents and young people (e.g. [17]) and parents and professionals [15]. Parents in the same households/families may also have divergent views about the best ways forward [13]. Transitional care that values parents as assets, therefore requires collaborative and compassionate working practices that include: listening to parents, respecting their expertise, acknowledging the stresses and challenges of parenting in transition, supporting unmet needs and integrating parental roles in ways that support young people appropriately [4, 94].

Developmentally appropriate transition plans—for young people and parents The importance of providing a holistic and planned approach to transitional care is well established [95, 96] and assessing the readiness for transfer is a key defining feature of transitional care. In this context, there has been some interest and debate around the use of checklists and measurement tools to assist with this process [97, 98]. However, despite the well documented multi-stakeholder nature of transitional care and multifaceted nature of judging readiness, most tools focus solely on the young person's perception of their own readiness. Only a few tools acknowledge the role and impact of parents on health transition by encompassing parent-reported assessments of their children's readiness or assessments of their own parental readiness. These include some generic tools [97, 99–101] as well as some condition-specific tools [102–104]. These can be excellent conversation starters to assess the understanding and needs of parents in relation to young people's transitional care and prompt appropriate support responses. However, they do not in themselves promote a partnership approach and can become tick-box exercises that inadvertently reinforce the message that parents are a barrier to transitional care. They can also have a

narrow focus (i.e. parent understanding and skills in relation to the transition process and self-management), rather than encompassing factors that impact on their experience of transition or parenting capacity. However, when used as part of a well-designed programme, in combination with other initiatives, they can help young people, parents and professionals assess their needs, develop shared expectations, review progress and plan ahead for a range of foreseeable scenarios. Ideally, these should outline and support appropriate parent involvement in relation to all three stages of transition, including the initial preparation phase spanning adolescence, the shorter phase around transfer and the third phase when young people engage with the new adult services [105]. They should be used within a family-centred approach [106] that facilitates dialogue and understanding about what matters to young people and their parents, including their preferences for involvement in transitional care and ambitions for the future. Thus, the focus is not on having a ‘one size fits all’ model, but on gaining information within a flexible collaborative relationship, to guide the plan (remembering that the checklists are not the plan!).

Supporting parents in relation to young people’s rights Young people have important patient rights in transitional care, including the rights to be seen alone, confidentiality and consent to treatments (where capacity allows). These are a cornerstone of transitional care and key to enabling adolescent autonomy. However, stakeholders’ attitudes around this remain controversial and ambivalent, even among parents [87]. Parents have described confusion about changes regarding consent and mental capacity during adolescence, which are not always explained or understood [22]. Adjusting to being excluded from consultations is also a difficult process for parents, particularly when they perceive their child is not coping well [14]. In addition, there is an implicit tension arising from two bodies of evidence that must be carefully balanced in practice; namely the importance and benefits of young people being seen alone [8, 12] versus the protective nature of parental involvement in terms of disease control [1, 31]. Healthcare providers may be able to resolve some of these issues by introducing families to the concept of *inter-dependence* (rather than solely focusing on individual *independence*) and supporting them to practice a partnership approach which incrementally engages the young person in developmentally appropriate self-care and advocacy. In terms of lone consultations, one could argue that most adult patients are afforded the right to attend consultations with family members or other trusted individuals. Young people should certainly have opportunities to be seen alone and given support to instigate this safely and without negative repercussions (given the power imbalances that usually exists in relation to young people and their parents). However, the focus should not be on insisting that young person are seen alone, unless there are very good reasons for this. Instead, health professionals need to ensure that both young people and parents understand their rights as patients and carers, and that young people have opportunities to develop and practice self-advocacy skills, make informed decisions about who is involved in their care (including consultations) and have support to access to specialist services (e.g. patient advocacy services, family mediating services).

Further research on how to effectively balance these two sets of recommendations is still needed [31], with greater consideration of these ethical aspects of transitional care [107]. In the meantime, there is the potential for better addressing the journey towards young people's independence without undermining parental involvement by starting preparation for transition early on in adolescence [78]. Alongside this, current best practice guidelines also emphasise the need to regularly discuss with young people how they would like their parents to be involved throughout their transition [70].

Support to manage risk, uncertainty and vulnerability An important component of effective transitional care is supporting families to cope with risk and uncertainty. Indeed, parents who face higher levels of illness-related uncertainty are likely to perceive their child as vulnerable [108] and engage in more activities to protect their children from harm [15, 109, 110]). It was shown earlier in this chapter that parents often want to foster increased independence in their children, but struggle to transfer responsibilities when they perceive that the risks to health are high or uncertain. While this can have a protective function for their health, there are also important reasons why families should be supported to manage risk and uncertainty. These additional care-giving demands can negatively impact on parents' wellbeing, which further reduces their capacity to promote young people's development and wellbeing [34–38, 109, 110]. Research also suggests that parents' strategies to manage uncertainty can be counterproductive by exacerbating uncertainty, diminishing hope or increasing distress [15, 111]. For example, constant monitoring of young people's health can highlight symptoms and signs that parents are unsure how to respond to, causing additional anxiety and straining relationships as young people become frustrated with parental surveillance [15]. Health professionals therefore need to provide regular opportunities for parents and young people to discuss issues around risk, uncertainty and vulnerability, and work collaboratively to prioritise their concerns and make developmentally appropriate plans to manage anticipated scenarios. Existing frameworks (e.g. [112]) may help them to understand the different types of uncertainty that might be relevant to families. This may involve addressing uncertainties related to the young person's condition, generic adolescent health and wellbeing issues, role of parents in transition, and the organisation of services [15]. A positive youth development approach [113] (Chap. 2) may be particularly beneficial by demonstrating that young people have the potential to manage risk and explaining how parents and other people (including care providers) can support them to achieve this. A promising resource in relation to this is The Skills for Growing Up (SGU) communication tool (Chap. 8), which aims to promote autonomy and empowerment for young people in hospital or rehabilitation care [114–116]. This is age appropriate, covers a broad range of aspects of daily life and is underpinned by a shared management approach where young people and their parents work together to identify and set goals [114–116]. Importantly, the SGU is considered relevant to conditions where managing risk is a core concern for parents, including epilepsy [115]. The focus is not on avoiding all risks, but developing the knowledge, skills and confidence that allow young people to recognise and prepare

for risk, including insight about when to act for themselves and when to seek help. This is likely to require (1) the identification of different risks, (2) awareness of how these affect young people, parents and others around them, (3) understanding the benefits of addressing risks, including the reduction of harm, personal growth, increased opportunities and reduced parental stress, (4) support to develop self-management skills and (5) the provision of ‘safe’ opportunities to experience manageable levels of risk and responsibility in ways that are demonstrable to parents. Healthcare providers could encourage problem solving in clinics, offer skills workshops, signpost wider opportunities (e.g. those offered by charities/youth organisations), and encourage families to create opportunities at home for their children to learn and practice skills. This will be an essential part of a young person’s transitional readiness, which is an important predictor of successful transition to adult healthcare [33, 117].

Support for parenting capacity Despite acknowledgement that transition impacts on parental health, wellbeing and development, and evidence that positive parenting can promote better outcomes for young people, transitional care services rarely include processes to assess or address parental support needs [22]. Even when parents’ needs are assessed, it can feel like a ‘tick-box exercise’ [22], particularly when focused narrowly (e.g. on disease education) rather than a more holistic assessment of their wider emotional and practical needs. However, it is also evident that many professionals have no training in assessing the needs of parents and lack the resources to address any needs identified [22]. Unfortunately, intervention studies specific to parenting and transition remain limited. Most research has focused on interventions to improve parental management of treatments [44]. There are, however, some limited systematic and scoping reviews that have examined psychological interventions for parents of children and adolescents with chronic illness [118] and medical complexity [119]. These have examined the effect of a range of therapies (e.g. cognitive-behavioural therapy, family therapy, motivational interviewing and problem-solving therapy) on parents’ physical and mental health, parenting skills and behaviour. The findings are not easy to apply, as the results pertaining to parents of adolescents cannot be separated from that of younger patients. In general, the findings suggest that *some* parents can experience modest benefits from interventions, but the heterogeneity of the data and other design limitations (such as explicit criteria about the goodness of fit between parents’ needs and interventions) makes it difficult to draw firm conclusions. However, Bradshaw et al. [119] conclude that the results confirm that parents have ‘significant and diverse support needs, and are likely to benefit from a number of interventions targeting specific issues and outcomes across their child’s condition trajectory’. Less attention has been placed on parenting styles and behaviours. Johnson et al. [120] have highlighted the need for effective family therapy interventions, especially those addressing parenting in healthcare settings.

Parents themselves have often called for more opportunities for parent-to-parent support during transition; the potential of which has been suggested for some time

across different types of support and conditions [15, 121–127]. Networking support typically includes peer support groups, parent-led transition groups, befriending, internet support groups, and lay-led or specialist workshops. Recent studies show that such initiatives can be an important source of hope, motivation and connection to resources for parents during transition, particularly as they offer opportunities for shared experience; a critical element of support that health care providers often lack [85]. Reported benefits include new knowledge, becoming more future-oriented, being more active in their transition preparations, decreased feelings of isolation, opportunities to discuss nonclinical issues [123, 128–130]. It also appears that supporting others can be as beneficial as receiving support, enabling parent mentors or befrienders to recognise how much they have developed since their child's diagnosis [131, 132]. However, the benefits are less substantiated in a review of quantitative research studies [126]. Thus, while interventions in this area have shown promise, further research is needed to find effective ways to help parents and young people shift their roles and responsibilities [1] and cope with the impact of transition.

6.4 Key Recommendations for Practice

This chapter provides strong evidence that young people's outcomes are likely to improve if transitional care also includes a focus on parent outcomes. This includes their physical and mental health, and parenting capacity. The evidence also points to the relevance of a strength (or empowerment) based approach which 'explores, in a collaborative way the entire individual's abilities and their circumstances rather than making the deficit the focus of the intervention' ([43], p. 24). As such, transitional care should be based on a holistic picture of young peoples' lives and work with others who are likely to shape their outcomes, including parents and other key people/organisations in their networks such as siblings, teachers and social workers. This approach aligns closely with the theoretical frameworks highlighted previously in the chapter as relevant to transition, including the ecological, developmental, positive youth development, positive parenting and family management models. Existing evidence and theory thus supports the notion that transitional care needs to look beyond the individual patient to optimise their outcomes.

In line with this approach, transitional care providers will need to identify both the strengths and difficulties within the family by undertaking holistic assessments. This should explore the young person's development, the parents' capacity to meet their child's needs, and the impact of wider contextual factors. Although these approaches are more established in social work and mental health provision, they are explicitly relevant to families [133] and are beginning to gain traction in health care. For example, the UK Department for Health and Social Care [43] has developed a framework and handbook to support practitioners understand strengths-based interventions and implement them in practice, including case studies that focus on families and transition to adulthood. The handbook also includes helpful practitioner reflections that explain the rationale, application and benefits of using a strengths-based approach. In terms of parent involvement, this approach goes

beyond the assessment and support of skills related to the transfer of self-management skills, but extends more widely to support general parenting capacity. In reality, no single agency is likely to provide all the help that will be required (e.g. addressing barriers related to poverty). However, health professionals, in partnership with families and other agencies, can support parents to develop the skills and resources to begin to address these issues and judge what services and interventions may be relevant.

Providers of health and social care also need to adopt a life-course approach to adolescent health [47]. Not only does this suggest that interventions in adolescence will support better outcomes in adulthood, but also acknowledges that positive or harmful parenting begins long before adolescence [48]. While discussion of this is beyond the scope of this chapter, it is important to recognise that early support for parents will benefit families in transition. Therefore, in addition to improved collaborative working between adolescent and adult care providers, it will also be important to collaborate with early year providers to ensure that parents, whose children are diagnosed with a chronic condition in childhood, have access to parenting support as early as possible. Early year providers can also inform transition planning by communicating important information about specific family needs as part of any their handover to adolescent services. This may not remove all challenges associated with adolescence and transition. However, parenting support received pre-transition and awareness of their ongoing needs may support better outcomes; by equipping parents with the skills to anticipate their children's needs and respond appropriately.

Ensuring dedicated time and effort to supporting parenting capacity will be particularly important. We have already identified some key targets that are amenable to change and offer some practical strategies in Table 6.1. This is not to ignore the limitations of insufficient healthcare funding that can constrain new or extended work. However, there is much that can be done to support parents within existing resources, referral routes and community level networks. Much of this is about cultural changes that require people to think and behave differently. It will require new conversations with young people and their parents such as: What does a good life look like for you and your family? What do you enjoy doing? What level of independence would you/your child like to have? What can you manage now? What would you like to manage soon? In your opinion, what might work better? What support do you need? How can we help?—followed by meaningful action (e.g. [43]). Practical guidance to explore individual's needs, aspirations and capacities have been developed (e.g. [43]) and include examples of strength-based questioning that may be of value to health professionals involved in transitional care.

Realising these ambitions is likely to require new research, interventions and initiatives. It will be important to embed these within coproduction models of involvement [138] to ensure that parents, young people and professionals are equal partners in decision-making. Indeed, it is evident that parents have been largely marginalised in the development of transitional care and rarely involved in developing interventions designed to meet their needs, which may account for the slow progress in finding effective approaches [119]. Yet, there is considerable evidence

that young people and their parents are able and willing to comment on their care and services, given the opportunity (e.g. [4, 22]). One mechanism to improve service provision may be through ‘learning collaboratives’ where professionals and families work together for set periods of time to learn about, coproduce and try new processes. Guidelines to support such approaches in health care are available and are easily transferable to transitional care [139]. Targets for further research and service development, based on this Chapter, are likely to include how to: assess parental capacity and support needs; target interventions to parents/young people at

Table 6.1 Practical suggestions to improve parenting capacity

Personal needs of parents

- Address the developmental changes of mid-life adults and explore how these changes impact on their parenting abilities and relationship with their child. Help them to identify personal goals in transition (e.g. increased independence in young people not only benefit their children but may also mean more time for them to pursue valued activities, such as hobbies, or improve opportunities for employment). Where possible, link these opportunities to wider benefits for them, their children and families. Help them to access relevant support (e.g. career guidance).
- Distinguish between parents who normally cope well, but are overwhelmed with specific problems, and those who have more complex or deep-seated needs (e.g. mental health problems or learning disabilities) and may need referral to specialists or multi-agency input (e.g. counselling, community drug and alcohol services).

Parenting capacity

- **Connection:** Provide parents with advice and practical strategies to improve communication with their children that focus on warmth and respect for individuality, including understanding adolescent communication styles, managing arguments and conflict. Provide opportunities for young people and parents to work together on goal setting and help them to celebrate as they move towards their goals.
 - **Support for behaviour control:** Help parents to promote positive adolescent behaviour using strategies that recognise their increasing needs for autonomy and privacy. Help them to: establish rules that are specific to young people’s condition and related to wider aspects of adolescent health and wellbeing; communicate expectations, limits and reasonable consequences; and strategies to effectively monitor behaviours. Provide specific information that explains how their child’s condition and development may reciprocally affect one another. Also provide information about normal adolescent development (e.g. teen brain, sexual health), including stressors associated with this period and symptoms of important adolescent problems (e.g. self-harm, anxiety, depression, eating disorders, bullying, substance abuse). Show parents how to teach important protective skills (e.g. self-care, dealing with peer pressure). Support parents to respond appropriately to their children’s emotions and behaviour (e.g. anger, anxiety) and their own feelings in response to these (including where to seek help for them and their children). Facilitate the development of parental networks to help parents learn about and establish positive social/cultural norms.
 - **Respect for individuality:** Help parents and young people to gain/maintain mutual respect by acknowledging each other’s knowledge, abilities and good intentions, but also their concerns, fears and vulnerabilities. Help parents understand their rights and responsibility to advocate for their children, and children’s own rights as patients/young people. Teach parents the skills and knowledge necessary for advocacy, helping them to model these. Help parents to shift from being the main source of information to helping their children find these resources on their own.
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Table 6.1 (continued)

• **Modelling appropriate behaviours:** Encourage parents to adopt attitudes and behaviours that support health and wellbeing (e.g. non-smoking, clinic attendance), noting that that young people are also able to spot inconsistencies between what parents say and do! Support them to be a confident and direct source of information (adolescent health and condition specific). Expose parents and young people to other positive role models. Provide opportunities for parents to learn and practice guidance competencies. Strategies to prepare young people for assuming healthcare autonomy might include: parents encouraging, supporting and allowing their child to experience self-care [134]; modelling self-care behaviours, monitoring condition management and prompting treatment administration; actively teaching their children self-management skills, including condition and treatment management, self-advocacy and “self-surveillance” of symptoms [135]; ensuring awareness/access to their own medical history and practicing asking questions for consultations; active provision of practical support with key tasks such as filling prescriptions, making appointments or commuting with clinics [136]. Support young people to plan for/achieve goals beyond their health (e.g. introduction to career counsellors, volunteering).

Contextual sources of stress and support

Assess and address material and financial resources that can impact on parenting capacity (e.g. by actively facilitating access to advice and state/community level programmes that will help parents find the resources they need to adequately support their children). Facilitate care close to home where possible and schedule clinics/programmes/interventions at convenient times, considering access to transportation and costs. Explore and address the impact of family structure and dynamics (e.g. challenges associated with being a single-parent, caring for siblings/aging parents, shared care between parents in two households). Provide parents with opportunities to meet, talk with, and develop meaningful relationships with other parents of adolescents e.g. parent support groups, community parenting programmes, befriending schemes, parenting helplines, safe social media forums. Interventions that support young people are likely to reduce the stress that parents experience e.g. young person support groups, community youth groups, self-management workshops, befriending groups.

Organisational barriers

Minimise sources of uncertainty for parents by providing consistent care (seeing same professionals), joining-up services (within and between health, social and education agencies), continuity at transfer, and transfer at times of health stability. Support families to understand how services are organised, how to access them and strategies for healthcare use and help-seeking. Self-assessment and benchmarking tools to support organisations assess their own practice in transitional care are available (e.g. [70, 137]). However, developing a competent workforce will be important. Many professionals lack training to assess and support the needs of parents [22]. Professionals may benefit from training about family dynamics and how to create safe environments for young people and their parents to discuss and agree transition goals. This should include communication training to support discussions about sensitive/challenging issues and to avoid/resolve conflicts. When discussing transition, staff also need to promote and model positive norms, decision-making and collaborative practices (e.g. listening, respect, compromise). Wider initiatives to promote public understanding of chronic conditions in adolescence are also needed.

most risk and promote optimal benefit; improve workforce competency and collaboration. Attempts to address these will also benefit from using frameworks that support robust design, implementation and evaluation (e.g. [140–143]) to ensure they target parents appropriately, align to outcomes that matter to families and provide optimal benefits.

6.5 Conclusion

In this chapter, we have shown that there has been a discernible shift in our understanding of transitional care, highlighting it as a process that involves young people and their parents who reciprocally shape the experience of transition and influence outcomes. It thus repositions parents as key enablers in transition and protective factors in young people's health and wellbeing, rather than barriers to young person autonomy, as traditionally conceived. We argue that taking a family-focused approach, that recognises the strengths and potential of young people and their parents, is more conceptually appropriate and more likely to bring about better outcomes for all involved. In line with this, we have suggested a number of general principles and practical strategies to help care providers align their practices to models of transitional care policies that recognise parents as major determinants in adolescent health. Such approaches are likely to promote the positive involvement of parents in transitional care and help young people to flourish in transition. It may also address the dissatisfaction that parents and young people express in relation to their care, and explain why even structured programmes often fail to deliver their promised benefits.

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