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Surviving a Brain Tumour Diagnosis and Living Life Well: The Importance of Patient-Centred Care

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17.1 Background

> Your loved one is diagnosed with a brain tumour. Suddenly, the world you have inhabited until now comes crashing down around you within a matter of minutes. You feel like you are standing on the edge of a huge precipice, about to be pushed off without a parachute. And then you're falling…falling fast. You don't speak the language of medicine. You don't know how to get from A to B. You have no map, no compass to guide you. You are filled with fear and dread of the unknown road ahead.
>
> (A brain tumour caregiver)

The diagnosis of a brain tumour is one of the most shocking pieces of news that people can receive. Brain tumours know no geographic boundaries. They strike people of all ages with equal ferocity—from tiny babies to the elderly. They intersect three major disease areas:

- they are a rare disease [1]
- they are a progressive neurological disease, resulting in significant physical and cognitive deficit
- and brain tumours are, of course, a cancer, with the most malignant types such as glioblastoma, resulting in survival times ranging from 6 to 21 months [2].

Brain tumours remain one of the most intransigent of all cancers with a 5-year survival rate for glioblastoma, for example, of just 5.5% [3]. Little progress in improving survival has been made in the last 30 years because the treatment of brain tumours involves unique challenges not associated with other cancers, not least of

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which is the ability of effective therapies to successfully cross the blood brain barrier.

Brain tumours are also the biggest cancer killer of children and adults under 40 years old [4]. Additionally, brain tumours are responsible for the highest number of per person life years lost—approximately 20—of any cancer [5].

Against this stark background, and given the devastating impact that a brain tumour diagnosis has on a person's everyday lived experiences, maintaining a good quality of life is absolutely crucial. Lehman et al. [6] highlighted that there is a need for rehabilitation in 80% of central nervous system tumours, in comparison to 60% in bone, prostate and bladder cancer. Mukand [7] identified the following neurological complications in brain tumour inpatients:

- cognitive deficits 80%
- weakness 78%
- visual-perceptual deficit 53%
- sensory loss 38%
- bowel/bladder dysfunction 37%
- cranial nerve palsy 29%
- dysarthria 27%
- dysphagia 26%
- aphasia 24%
- ataxia 20%
- diplopia 10%

Seventy-five percent of inpatients will have three or more of these neurological complications; 39% will have five or more.

Key to achieving a good quality of life while living with a brain tumour is a comprehensive, sustained rehabilitation programme, tailored to each patient's needs, goals and personal preferences.

Services offering rehabilitation across a wide spectrum of activities (work, leisure, interpersonal relationships, physical exercise, emotional resilience) should be delivered by a multidisciplinary team and form the backbone of a comprehensive survivorship plan for each brain tumour patient. It goes without saying that such a plan should also be relevant to the caregivers of these patients because a brain tumour diagnosis deeply affects not only the patient but also the family and friends of that patient.

Pivotal to such a survivorship plan is an understanding by researchers, healthcare professionals, regulatory bodies and others of what really matters to patients and what is of value to them. In other words, the patient perspective must be completely integral to the way brain tumour care—including rehabilitation—is planned, delivered and evaluated.

This kind of approach is central for the patient to successfully live well with and beyond a brain tumour diagnosis and demands not only a focus on the costs of delivery but on the outcomes that need to be achieved so that what patients value is at the core of treatment pathways.

17.2 Defining Patient Value

A recent review [8] on "Patient Value: Perspectives from the Advocacy Community" highlighted that value frameworks (such as those developed by ASCO, ESMO, NCCN and others) which are used to determine the value of medicines, need to reflect what matters most to patients.

The review found that: "It is difficult to define one single homogeneous set of patient values as these are shaped by social, religious and cultural factors, and health-care environment, as well as many factors such as age, gender, education, family and friends and personal finances" [9]. Nevertheless, despite varying opinions on what constitutes value, perspectives across a wide range of patients, caregivers and patient advocates need to be considered.

The value review concluded that: "Patient input is necessary to define the response to the full range of outcomes that patients may experience, whether this is at an aggregated level or a personal level, rather than the limited set of outcomes considered relevant by researchers. The patient perspective cannot be inferred by expert panels, but needs to be provided by patients and advocacy groups" [9].

17.3 Building a Framework for Survivorship and Rehabilitation in Brain Tumour Care: Some Definitions

For the purposes of this chapter, we have adopted the definition of survivorship used in the European Commission's Cancer Control Joint Action (CANCON). This was an EU Member State effort to "harmonise the way we fight cancer in Europe…" and to "reduce the cancer burden in the EU by creating a European Guide on Quality Improvement in Comprehensive Cancer Control." CANCON succeeded the first Joint Action on cancer, called the European Partnership Action Against Cancer—EPAAC. The CANCON definition of "survivorship" is "*anyone with a diagnosis of cancer and who is still alive*" [10].

Additionally, the definition of "rehabilitation" for this chapter is based on that provided by the UK National Institute for Health and Care Excellence (NICE). NICE's guidance for *Improving Supportive and Palliative Care for Adults with Cancer* defines rehabilitation as the "*attempts to maximise patients' ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individual's physical, psychosocial and economic functioning*" [11].

Many experts in the field of cancer rehabilitation also acknowledge that rehabilitation can be *preventive, restorative, supportive and palliative*.

When it comes to building a framework for survivorship and rehabilitation for brain tumour patients, considerations pertaining to health-related quality of life (HRQoL) are crucial. There are varying definitions of HRQoL [12]. But for the purposes of this chapter, HRQoL as described by the European Organisation for Research and Treatment of Cancer (EORTC) covers "*the subjective perceptions of the positive and negative aspects of cancer patients' symptoms, including physical, emotional, social, and cognitive functions and, importantly, disease symptoms and side effects of treatment*" [13].

17.4 What Brain Tumour Patients and Caregivers Say

Based on two important, patient-advocacy group-led research projects in the UK, we know that there can be significant gaps for brain tumour patients in accessing neuro-rehabilitation and neuro-psychosocial support [14, 15].

Sometimes, patients and caregivers simply don't know what services are available to them because they have not been provided with a care or survivorship plan once discharged from hospital.

The brainstrust paper "*Quality of Life: what the brain cancer community needs"* [16] states: *"Carers and patients don't understand the purpose of neuro-rehabilitation or how the emphasis is placed on restoring maximum independence with activities of daily living, mobility, cognition and communication. Rehabilitation interventions can be applied in all stages of the disease, although rehabilitation goals change as the stage of illness advances."*

Sometimes rehabilitation facilities don't exist in a particular geographic area, necessitating the patient to travel to another city or region. Sometimes, this *"isn't just a resource issue, but also an attitude of mind of all involved"* [17]. This, according to brainstrust, can be related to a clinical mindset that "*once the patient is through a particular phase of their care pathway, they are no longer [the doctor's] problem. And again, once discharged home, the secondary care team assumes that the primary care team will pick up the support and rehabilitation. This is not always the case, particularly if the caregiver and patient don't know what to ask for, who to ask or where to go*" [16].

In the UK, the National Cancer Patient Experience Survey, which is conducted every year, highlighted in the 2016 survey [18] the fact that only:

- twenty-six percent of people with a brain tumour received a care plan
- forty percent felt supported by their GP
- forty-two percent felt happy with the provision of care and support post treatment

Unfortunately, these statistics represented a decline from the results in the 2015 National Cancer Patient Experience Survey.

In 2015, The Brain Tumour Charity (TBTC) released a report called "Losing Myself: the Reality of Life with a Brain Tumour" [15]. The report was the result of an initial survey involving 1,004 people between 13 February and 13 March that year. Following the survey, face-to-face, in-depth interviews were held with 15 people, and an additional 25 people kept reflective diaries over the course of a week.

The resultant report highlighted levels of access to neuro-rehabilitation in the United Kingdom. Of the 1,004 survey responders, 52% had access to physiotherapy, 50% had access to occupational therapy and 43% had seen a psychologist. Only 25% of those surveyed had accessed speech and language therapy.

The report further found that the main difficulties regarding access to rehabilitation were finding these services in the first place, long waiting lists and poor communication between healthcare professionals and patients. The report also found that "*people with a high grade brain tumour are significantly more likely than those with a low grade brain tumour to have had access to speech and language therapy, occupational therapy and physiotherapy*" [15].

If these shortcomings are occurring in an advanced society like the United Kingdom, it would not be unreasonable to assume that in developing areas of Europe and the rest of the world, access to rehabilitation and survivorship plans is either very low or totally non-existent. Brain tumour patients and their families in these geographic areas must surely be suffering significantly as a result of this lack of rehabilitative support.

This chapter will discuss—from the perspective of patients and caregivers—the specific themes emerging in the brain tumour community in connection with rehabilitation, survivorship and quality of life so as to highlight the unique challenges we face. Policy-makers and healthcare commissioners must be aware of these challenges so that improvements can be made which will result in better outcomes for brain tumour patients based on what matters most to the people living with this disease.

17.5 Themes Reported by Patients, Caregivers and Health Professionals

To understand the issues in more depth, UK data has been gathered over a period of years from patients, caregivers and healthcare professionals, through online and offline channels. This has allowed for an accessible and open discussion, as real-world experiences and opinions have been shared, built on and contested. This evidence has provided research, stories, insights and ideas that can be provided to healthcare professionals and policy makers to help shape their thinking, as people work to collectively and collaboratively solve the issues that need addressing.

Themes that have emerged from offline and online interactions with brain tumour patients, their caregivers and healthcare professionals are the sense of isolation, lack of voice and the daily challenges they face. Patients are concerned about vitality, their identity and role, limitations, personal relationships and sexual issues, mental health and emotional wellbeing. All of these are important factors for patients.

Some of the highly challenging hallmarks of a brain tumour journey are:

- varying survivorship
- variable trajectory, even for benign brain tumour diagnoses
- high frequency of disabling complications

- high severity of disabling complications
- knowledge of increasing cognitive dysfunction
- life context—whether there is resilience or a lack of ability to cope

There is little available through the usual channels of clinicians for addressing these challenges—for example, only 43% of neuro-oncology multidisciplinary teams in the United Kingdom have access to neuropsychiatry services [19].

Catt et al. [20] have identified that, in the United Kingdom (where a substantial amount of research on rehabilitation has been carried out):

- Supportive care pathways for patients and their families differ between hospitals.
- Guidelines either omit important aspects of care and follow-up or are based on assumptions with little empirical support.
- As treatment of patients is often palliative, more efforts are needed to ensure good continuity of care.
- Current follow-up is failing to meet the psychological needs of patients and their caregivers.
- There is a need for developing innovative and integrated interventions that effectively support caregivers, such as proactive counseling or problem solving services.

These points are echoed in the findings of a crowdsourcing project undertaken by brainstrust and createhealth.io [21]. Brain tumour patients and caregivers highlighted four main themes that would improve the quality of care for them post surgery [16]:

- a desire to know what to expect
- better mentorship, home care, and personal support
- the importance of understanding and accessing long term care
- increased uniformity in standard of hospital care from place to place.

The two sentiments that were repeated more than any others were:

1. the desire to know what to expect during rehabilitation:
   - *"I now realise that stuff like memory loss, not being able to articulate what's in your head and the bone-aching tiredness that comes on without warning, are not just my symptoms. Knowledge is coping, for me."* (Patient, 60–70 years)
   - *"Community caregivers need a lot more education on the effects of brain tumours. This is an area that falls down in far too many areas."* (Patient, 40–50 years)
   - *"If doctors would continue the dialogue and engage with the patient more to build a good rapport I believe that would improve many patients' situations." (*Patient, 40–50 years)
2. calls for better mentorship, home care and personal support - this includes a more equal relationship with clinicians through more effective conversations:

- *"There should be a dedicated social worker for this client group and they should also be educated about the complexities of brain tumour patients."* (Nurse, 30–40 years)
- *"It would be nice to have a mentor or support worker allocated to each family after diagnosis. This person could visit or phone the family on a regular basis to check on how things are going, answer questions and offer pointers to further support and help."* (Caregiver, 40–50 years)
- *"Simply never happened. Went for a very thorough assessment but then kept getting appointments to see various people, physios, etc which were always postponed so that I didn't actually see anyone. After a year of this I just gave up. Resorted to speaking with colleagues and being treated by them which meant I had to share my diagnosis. Live in central London and worked in oncology for 15 years so know my way around the system well. I really feel for patients."* (Patient, 30–40 years)

Two other challenges that were identified during the crowdsourcing project were:

1. the importance of understanding the long-term effects of brain tumour surgery, and the subsequent neuro-rehabilitation required:
    - *"For me, it would have been more information about what to expect during recovery. I mean not only immediately post operative but in the months and even years after."* (Patient, 60–70 years)
    - *"I would have liked to have known about the possibilities of late effects rather than wait until they appeared." (*Caregiver, 50–60 years)
    - *"There is perhaps a place for an annual neuro-rehab MDM [multi-disciplinary meeting], where people who are 'stable' after treatment are seen in clinic once or twice per year after having an assessment to cover areas that the patient/carer feel important or lacking."* (Doctor, 50–60 years)
    - *"We didn't hear about 'late effects' until they started to become evident. We might have got on with doing some of the travelling we hoped to do while things were easier."* (Caregiver, 60–70 years)
2. the varying degree of hospital care that they receive from place to place:
    - *"All departments we visit for monitoring his condition are all different, some good, some bad, some lazy, some exceptional. The problem is that there is little to no coordination between these healthcare professionals."* (Caregiver, 40–50 years)
    - *"Having lived three separate places post diagnosis the care varies widely from place to place. We need to create minimum standards."* (Patient, 40–50 years)

The most repeated comment in the crowdsourcing project was in relation to holistic and long-term care, for example:

> "*It would be good to see a more holistic approach. After my treatment for a brain tumour had finished I was left to my own devices. It would be helpful to have a road map for the patient how to get back to… normality - if there is such thing. Many things required are of a fairly practical nature - moving from independent to assisted living, travel support, dietary support, exercise planning and tracking, hair dressing.*"
>
> (Patient, 40–50 years)

In the crowdsourcing project, caregivers strongly supported the provision of specific neuro-psychosocial support to help with the patient's

- short term memory
- personality and behaviour changes
- difficulty in decision making
- pain management
- depression (including feelings of despondency)
- hemiparesis (and the safety issues that come with this)

Caregivers are concerned, too, about the potential for the patient to suffer falls and mobility problems. This is a limiting factor which results in caregivers feeling that they are unable to leave the patient alone at home. Whilst fatigue is mentioned, caregivers do not see this to be a particular problem, nor do they relate this to a quality of life issue. Fatigue limits the activities they could do together with the patient, but the upside is that it means that the caregiver *"could get on with things"* (caregiver of patient with a glioblastoma). Research demonstrates however, that fatigue is a significant issue for patients [22, 23].

Caregivers also feel that they have significant unmet needs and that support and rehabilitation services should address these, particularly where the caregiver is the primary source of support for the patient.

Brain tumour caregivers have confirmed that they, themselves, suffer from a wide range of emotions and mental stress [24] such as:

1. Feelings of Despondency

This includes feelings of hopelessness and fear of recurrence, fear of treatment, fear of losing a loved one and what the future holds.

"Watching your best friend's life be snatched away from under feet, and not being able to do a single thing to stop it." (Caregiver, 30–40 years)

"Watching my beautiful wife fight so hard yet slowly deteriorate over the weeks and months. My heart is breaking. Where has our life together gone?" (Caregiver, 60–70 years).

2. A Sense of Loss

This includes—but is not limited to—loss of identity and loss of normality and life as it was. Some caregivers mourn the loss of the person they loved because that person is no longer the same person they once knew.

"The tumour has changed my wife's personality so much I no longer see the person I married and love … I feel so alone and trapped." (Caregiver, 40–50 years).

3. Lack of Psychological Strength

"I can't be strong for my family all the time. Sometimes I need a shoulder to cry on." (Caregiver, 40–50 years).

4.'Scanxiety' [25]
The agony of waiting for scans, for results, for treatment to start and to work, for recurrence.

*"The worst part of having a brain tumour is waiting for things to happen with your treatment … the waiting is mental torture." (*Caregiver, 30–40 years).

5. Feeling Alone/Isolated
"…I am a mother, a daughter, a sister, an employee. I am surrounded by many, yet so alone…I'm lost." (Caregiver, 40–50 years).

6. Brain Tumours Are Unique
People may not understand that in the world of brain tumours, 'benign' does not mean harmless as in other cancers. Friends and family may assume the patient is 'cured' after treatment and that they will return to 'normal' after treatment. This is rarely the case in brain tumours. There is also a need for recognition that living with a brain tumour brings disability. Patients are also affected by epilepsy, changes in personality and other side effects unique to brain tumours.

"Knowing that my brain just doesn't work the same anymore since surgery." (Patient, 40–50 years)

"[I'm] looking for support from the government to recognise that a brain tumour is a disability and not just a condition." (Caregiver, 50–60 years).

7. Unresourced
There is not enough help in the way of support and information for patients and caregivers on the brain tumour journey.

"No follow-up after release from hospital. I had to contact a brain tumour charity to ask what happens next as hospital and GP didn't offer any help/support." (Caregiver, 40–50 years)

"Nobody from the hospital gives you any information about brain tumours when you are diagnosed. You are just left to try and find it all out for yourself and struggle through." (Caregiver, 40–50 years).

17.6 Challenges

From the perspective of patient-centred brain tumour care—which includes rehabilitation—empowerment models such as choice and entitlements are generally seen as ways of better responding to a person's needs.

The 'asset-based' community development approach is an interesting one. Originating in the United States, it takes a different starting point. It rejects the view of the citizen as principally a service user with needs that the state must meet. The citizen-as-service-user model tends to infantilise and disempower people, creating dependency cultures in which the best hope for improving a person's situation is to wait for a paid professional to step in. Instead, asset-based approaches see capabilities in everyone and seek to mobilise these. In particular they seek to mobilise people's 'relational power'—that collective impetus which achieves social change and which develops when communities come together to achieve their goals [26].

Such approaches are still generally counter-cultural in some of our health systems. But moving in the direction of shared decision-making begins at the same starting point. In particular, care planning for such services as rehabilitation under this model must start by discussing a patient's needs and aspirations—and importantly, what is of value to that person. Then there must be consideration of what resources are available to help meet these requirements, taking into account a person's own skills and capabilities, as well as resources from the local community before looking at what should be provided by the wider state.

For example, inpatient care may be very cohesive and coordinated but patients and caregivers may not know what range of services is available to them following discharge from hospital. A patient returning to the community needs to be more proactive and have a comprehensive care plan in place [27]. It's interesting to note that even in the UK (according to 2016 statistics) 74% of patients never received a care plan [18].

With regard to brain tumours specifically, there usually comes a point when additional resources are needed for the patient and caregiver due to the devastating nature of this progressive neurological disease. There can be a disconnect between what happens in hospital and what happens after discharge and once at home. At home, patients and caregivers will need to address such substantial issues as:

- speech deficits
- balance issues
- visual problems
- seizures
- swallowing issues
- challenges of daily care including bathing, insomnia, dressing, eating and physical activity

Caregivers and patients may be completely unaware of the range of rehabilitation services available to them which can diminish the impact of these issues. In many cases, there are district nurses, social services, physiotherapists, speech therapists, occupational therapists, counseling facilities and complementary therapists—to name but a few—who can help.

There is a significant shortage of rehabilitation facilities, particularly for those patients with brain and spinal cord tumours. Supportive care and rehabilitation for these people is of key importance and requires development and consolidation with commissioned rehabilitation facilities.

There are over 150 different types of brain tumours and prognoses can vary from very short term to longer-term. Access to appropriate levels of neuro-rehabilitation is vital for people with brain tumours but rapid referral for those patients with palliative and end-of-life care needs is particularly crucial. For these patients rehabilitation can be complicated by a prolonged period of physical and cognitive disability with distressing symptoms that are hard for patients and families to endure. This group of patients often requires a different rehabilitation approach, with care and support being given closer to home. Collaboration between health and social care is required to develop appropriate placements for those people who need ongoing institutional care and may have challenging symptoms.

In addition, patients and caregivers frequently have no idea how to access rehabilitation services [16]. A caregiver said:

> *My son (aged then 28) was told, after surgery and while still in hospital, that he was waiting for a bed in rehab and would stay in hospital until the bed was available. Then he was discharged - without warning. No rehab. No home visits. He was offered physio and OT [occupational therapy] as an outpatient but because of depression would not go. So it never happened, was never followed up. No support offered to us, as his carers, at all. And because of our ignorance at the time - we just accepted it. Bitterly regretted. I had to trawl the internet to find out what was available and was fortunate to find a good support group - that was where I learned what we needed to know.*

And on a more pragmatic level, another caregiver said:

> *Just to advise that I had to take Natalie into hospital last Tuesday due to severe headaches etc. The scan highlighted that the tumour was active again and she had a huge one-off dose of chemo last Friday evening. The plan is to allow her to return home, however I need a certain hospital bed to fit into a downstairs room. In your list of contacts, do have anyone who might be able to help? The hospital has offered a normal size hospital bed but it is about 4 inches too long. I also need a wheelchair. What else will I need?*

In addition, caregivers sometimes feel that non-specialist nursing services have little understanding of the specific needs of a brain tumour patient and that caregivers' concerns are not acknowledged.

One caregiver, Simon, was anxious to keep his wife at home when she was in the end-of-life phase but the district nurse accused him of being selfish, which led him to take extreme action at a time when he needed to be building a rehabilitation team around him. He said:

> *I have decided to take control. I am going to change doctors, as I should stop getting frustrated by the situation. I am going to change to a practice that is closer to home and apparently has a robust procedure for fast tracking those critically ill to either a doctor's visit or at the least a phone call…I will request that another district nurse is appointed. I am very low at the moment and do not need to be advised by the district nurse (who has only just appeared on the scene) that I am being selfish and very unkind to Jane by not allowing her to use a commode. I only read this in Jane's notes. So I am angry. A lack of tact I fear!*

17.7 Future Directions

Qualitative studies [16, 24, 28, 29] show that some patients and the majority of caregivers want to be fully involved in:

- understanding their illness
- exploring their options for treatment and for living with the illness
- sourcing information, knowledge, help and advice

Following diagnosis and treatment for a brain tumour, patients will have differing trajectories which may be predicted, ranging from recovery, stable situation or progression. Research shows that neuro-rehabilitiation and neuro-psychosocial support improves outcomes for patients diagnosed with a brain tumour [30].

For improved survivorship and to plan transition points in care, close collaboration is required between clinicians involved with neuro-rehabilitation, supportive care, quality of life, psychological and palliative care. This entails coordination of different specialties and expertise—from symptom management to end-of-life care.

Furthermore, engaged patients and caregivers are better able to manage the complexity of their journey, have more resilience and a better quality of life. Patients and caregivers who are fully involved in shared clinical decision-making processes also do better. They are significantly more likely to attend screenings, regular check-ups, and much more likely to engage in healthy behaviours like eating a healthy diet [31, 32] or taking regular exercise [33–37].

Conversely, less engaged patients are significantly less likely to have prepared questions for a visit to the doctor, to know about treatment guidelines for their condition or to be persistent in asking if they don't understand what their doctor has told them [33]. They are also two to three times more likely to have unmet medical needs and to delay medical care compared with more highly engaged patients, regardless of income, education and access to care [35]. There is a straightforward moral case for empowering people in health and care—but there is an enabling case as well.

Empowerment of patients and caregivers creates a range of positive factors:

Autonomy

- Having greater control over our health and care is a good thing. Autonomy, or the ability to exercise control over the forces that affect our lives, is an essential part of a good life. In healthcare, self-directed support is only now starting to break through into mainstream services, but there are strong grounds for extending it. Healthcare services should support people to lead independent lives, rather than forcing them to fit their lives around the services on offer.

A Better Quality of Life

- Research has shown that patient 'activation' (having the knowledge, skills and confidence to manage one's own health) is strongly correlated with a broad and positive range of health-related outcomes, which suggests that improving activation has great potential' [31]. This is because patients with chronic conditions like brain tumours live with their disease 24/7 and only spend a fraction of their time visiting clinical experts. The rest of the time they have to manage their condition themselves [38]. Studies show that shared decision-making processes are more likely to result in people adhering to treatments and actions.

Patient Satisfaction

- In addition, research has shown that patients who are engaged in their health and healthcare—through health literacy, shared clinical decision-making and self-management—are more likely to say that their healthcare is of high quality, and are less likely to report experience of medical errors [39].

Saving Money

- Giving people the support and information they need to avoid getting ill, or when they have a chronic condition to self-manage it effectively, should save money by reducing demand on acute care. If people are not equipped and supported to self-manage, they are effectively left on their own and can end up with complications, health crises, preventable trips to the primary care clinician or emergency care, avoidable suffering and even premature death. Around 20% of emergency admissions to hospital are thought to be potentially preventable, and many of these involve chronic conditions [40]. In this era of cash-strapped national health services and the vital need to develop sustainable and affordable models for healthcare, this is an approach which certainly has the potential to avoid inefficiency and therefore eliminate wasting precious resources.

The most robust evaluations of empowerment programmes focused on peer support and redesigned consultations have been estimated to reduce acute care costs by 7%. Nesta (a global foundation focusing on innovation) estimates conservatively that this would save the NHS £4.4 billion a year across England [41].

The Health Foundation in the UK has found that:

- Self-management programmes can reduce visits to health services by up to 80%.
- Although shared decision-making approaches can lead to extended consultations, in the long term they are associated with higher satisfaction levels and can reduce the need for further future consultations.

17.8 Coaching: A Navigational Aid for Patients

Navigation to support decision making, improve understanding and information has been shown to be associated with better knowledge and understanding of diagnosis and treatment, better ability to cope and improved distress levels [28].

‘Coaching’ is a one-to-one relationship in which the patient is supported by a coach to identify, focus on and achieve what is important to that patient. Patients felt that, by preparing for consultations through coaching, a discussion of personalised key issues, broader than the prime focus of the consultation, resulted. Patients felt more informed and utilised coaching materials to aid memory, information gathering and understanding.

Clinical feedback revealed that coaching led to more effective consultations and facilitated communication within consultations by giving insight into information gaps. Telephone follow-up was effective for information and support and psychoeducation increased feelings of mastery [42]. Through a focus on achieving specific immediate goals which relate to specific areas—for example, weighing up the pros and cons of having a particular treatment, or overcoming a problem with caring—patients and caregivers can also experience a sense of healing, as they make courageous decisions about their lives and work.

17.9 Conclusion

Unsurprisingly, there are gaps in neuro-rehabilitation and neuro-psychosocial support as the evidence from patients diagnosed with a brain tumour and their caregivers reveals. The causes for this are complex; it isn't just a resource issue but is also an attitude of mind of all involved.

Preventive rehabilitation (rehabilitation that is proactive and aims to prevent problems rather than treat problems) can help maintain independence in brain tumour patients who undergo treatment and who have potential loss of function. When tumour progression causes a decline in functional skills, or the disease causes neurological deficit, rehabilitation assumes a supportive role, with goals adjusted. If patients and caregivers are more informed in advance about the progression of the disease they could be better prepared sooner with helpful interventions.

During terminal stages of illness, palliative rehabilitation can improve and maintain comfort and quality of life until the end of life. Brain tumour patients and caregivers need to be more specific and more proactive in asking for help from support services, outlining definitively what the problem is so that additional assistance can be targeted effectively. It is difficult to ask for support if you don't know what is available or where it is available.

This could so easily be addressed. A simple, key question: "What are you struggling with the most?" elicits unmet needs. Once this is articulated it is easy to clearly define what is needed.

The lack of identification of needs and the absence of documentation regarding these is worrying because funding and resource allocation follows need. Patients and caregivers should be more proactive and confident about what it is they need. They don't need to fix the problem; they just need to identify it and share it with a healthcare professional (HCP) who can fix it. HCPs need to identify for themselves the range of rehabilitation and support services offered, the uptake of services and any barriers to service use. Only then can the gaps begin to be addressed.

Brain tumour patients and their caregivers have the capacity to take control of their situation to secure the best possible outcomes. Empowering the patient and caregiver community results in autonomy, a better quality of life, more patient satisfaction, and a strong health economic argument. Everyone has capabilities and we should seek to mobilise these.

By creating the space to explore a person's needs and aspirations, their values, context and appetite for risk, resources can then be identified which meet the needs of the patient and caregiver.

This is patient-centred care.

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