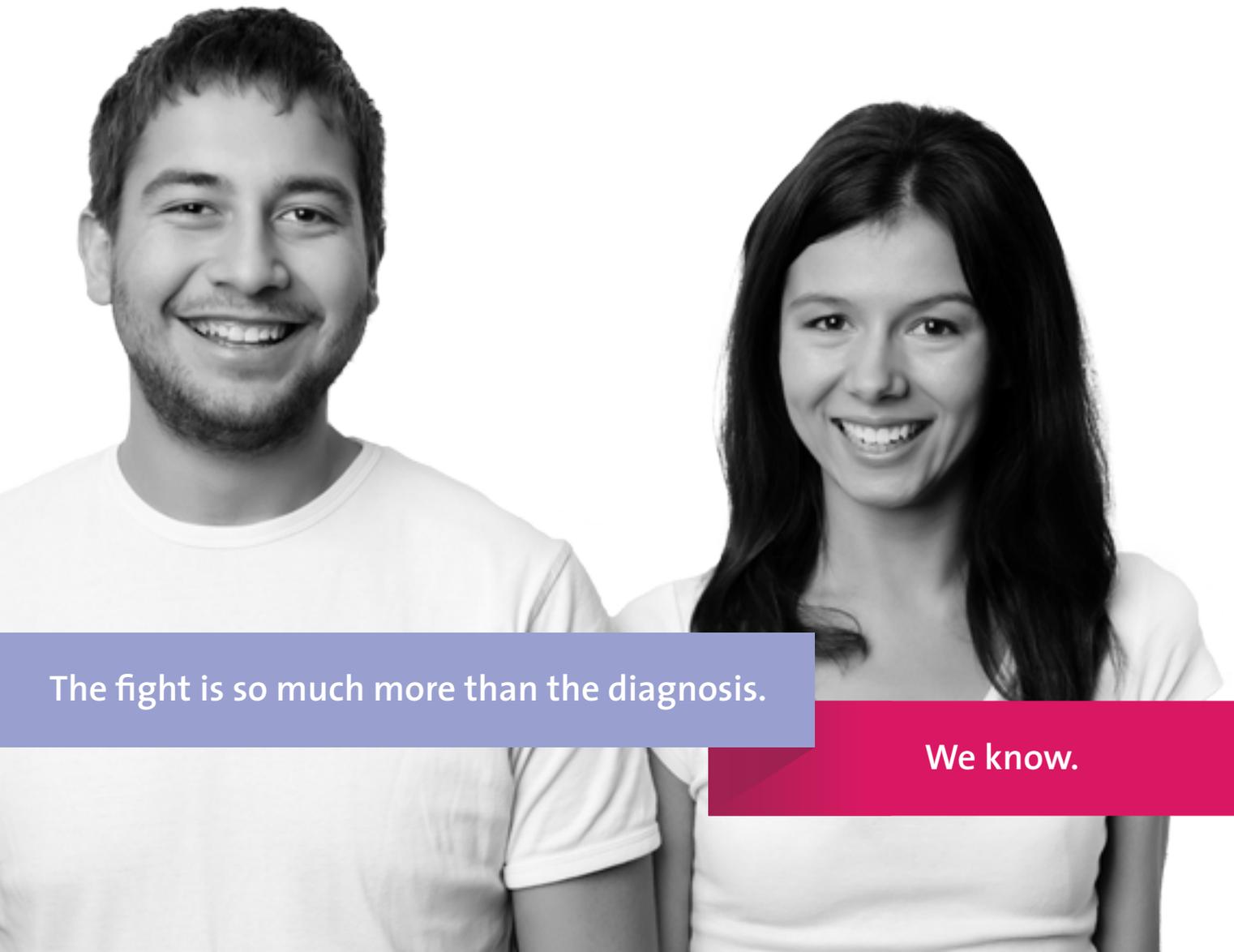


Quality of life: what the brain cancer community needs



The fight is so much more than the diagnosis.

We know.

‘A disproportionate focus on surgical and oncological outcomes’

National Peer Review: brain and CNS cancer services report 2012/2013

‘The fight is so much harder than the diagnosis’

Carer 2013

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Introduction

Let's start with what this paper is not. It is not an academically rigorous paper on the current state of play in the neuro-rehabilitation/neuro-oncology world. It is not representative of everyone's views. It is not a polemic establishing the truth of one position, or falsifying another. It is more about setting our collaborative sights on tackling an area that is lacking in focus, that is fragmented and could offer so much more – to our patients, their carers and the healthcare professionals who look after this vulnerable group.

The challenge?

- To improve patient outcomes by facilitating effective collaboration between clinicians working in different specialties
- To engage patients and carers in their care so that they are more proactive on their journey – should they so choose.

Who is *brainstrust*

brainstrust is the only brain cancer charity dedicated to helping patients and carers. We know a brain tumour diagnosis is confusing, isolating and overwhelming. We know these problems are exacerbated by not being able to access care and information quickly and easily. And we also know that access to proactive support, and good information can improve knowledge and understanding, reduce anxiety, increase preparedness for events, instill control and improve satisfaction with treatment in brain tumour patients. That's why we're here.

brainstrust

1. Enables patients to stand up for themselves, and therefore secure better outcomes
2. Solves real problems collaboratively
3. Creates the vision for patients and carers to help them understand how their care should be
4. Provides the patient/carer voice.

We believe that every brain tumour patient and carer should feel in control of their situation. We give this community the means to have a voice at the time when they need it most. The result? A feeling of being in control, and better outcomes for brain tumour patients.

Here at *brainstrust* we know good neuro-rehabilitation and psychological care improves quality of life for people with a brain tumour. And a better quality of life often means a better outcome. But we know that this care is hard to get right. Our work to understand the real issues that people with a brain tumour face has shown us this. Despite having had excellent treatment, people feel lost, confused and isolated. And this isn't right.

We know that when people play a more collaborative role in managing their health and care, they can have better clinical outcomes^{1,2}. They are less likely to use emergency hospital services³. We know too that patients who have the opportunity and support to make decisions about their care and treatment in partnership with healthcare professionals are more satisfied with their care⁴. And we know that patients are more likely to choose treatments based on their values and preferences rather than those of their clinician⁵. They also tend to choose less invasive and costly treatments⁶.

Methodology

We want to make things better. To do this we need to understand the issues in more depth. So we have created a conversation with our community, one element of which was a crowd sourcing campaign. Simply by joining a conversation, our community has helped us to understand more about the problem, so we can make things better for people who have had treatment for a brain tumour.

We have used online and offline channels to have the conversation. Gathering the views and ideas of patients, carers and medical professionals over a period of time and in this way allows for an accessible and open discussion. This method has allowed us to gather the real-world experiences and opinions on healthcare consumers. Online participant channels include:

- The *brainstrust* Facebook community
- CreateHealth.io twitter followers
- *brainstrust* twitter followers
- The NHS CHAIN community
- Share aware pinboard
- National Cancer Patient Experience Survey (NCPES) 2014 (appendix A).

Offline channels include:

- Face to face conversations at Meet Ups, patient and carer events and clinical conferences
- Daily interactions with our community.

¹ De Silva D. Helping people help themselves. London: The Health Foundation, May 2011, p6. www.health.org.uk/publications/evidence-helping-people-help-themselves

² Hibbard J, Gilbert H. Supporting people to manage their health: An introduction to patient activation. The King's Fund, 2014.

³ De Silva D. Helping people help themselves. London: The Health Foundation, May 2011, p6. www.health.org.uk/publications/evidence-helping-people-help-themselves

⁴ De Silva D. Helping people share decision making. London: The Health Foundation, July 2012, p.9. www.health.org.uk/publications/helping-people-share-decision-making

⁵ O'Connor AM, et al. Modifying unwarranted variations in health care: shared decision making using patient decision aids. Health Affairs, web exclusive, 7 October 2004.

⁶ De Silva D. Helping people share decision making, The Health Foundation, June 2012, p.12. www.health.org.uk/publications/evidence-helping-people-help-themselves

This project has shared ideas that will improve the quality of life and care for people living with a brain tumour. It has given us stories, insights and ideas that we can take to doctors and other decision makers to help shape their thinking – they know there’s a gap here too and they want us, and our incredible community, to help them fill it.

Our community is a conduit for people to solve collectively and collaboratively the issues that need addressing. And so this paper is a ‘thought piece’ about the current state of the nation, pulling together the views that have been expressed to date by people who are motivated to create change in the neuro-rehabilitation/neuro-oncology phase of the patient journey. It has been written to start the conversation. The challenge, outlined above, is not insurmountable and could be addressed by:

- Creating the space and presence for a group of people, which has an interest in neuropsychosocial care for people and carers who are living with a brain tumour
- Supporting the establishment of a group of experts who want to work collaboratively on an agenda around this vulnerable group of people
- Facilitating the sharing of collective intelligence
- Being a physical presence to keep neuro-rehabilitation front of mind, including a presence at key clinical events.

Context

Brain cancer is different to other cancers; not only do patients and their carers have to come to terms with the diagnosis of brain cancer, but they do so in the knowledge that this diagnosis will certainly mean progressive neurological and cognitive deficit. Lehman et al⁷ acknowledge that in 80% of central nervous system tumours there is a need for rehabilitation. This compares to 60% in bone, prostate and bladder.

As it is, brain cancer is an unrecognised clinical problem. It is one of the most lethal human diseases; only 27% of people diagnosed with a glioblastoma will be alive at the end of the second year following diagnosis⁸. At five years this drops to 9.8%. Brain cancer is also the most prevalent form of solid tumour in children and the most common cause of cancer death in them⁹. We also know that there are over 60,000 people living with a brain tumour diagnosis in England¹⁰.

When you’re faced with a wall of information, it’s easy to feel overwhelmed. *brainstrust* empowers brain tumour patients and carers to be engaged in their care so that they can take control and be confident that they are working towards the best possible outcome

⁷ Lehmann J, DeLisa JA, Warren CG, et al. Cancer rehabilitation assessment of need development and education of a model of care. *Arch Phys Med Rehabil* 1978; 59:410-419.

⁸ Stupp R, Hegi ME, Mason WP, van den Bent MJ, Taphoorn MJ, Janzer RC, et al. Effects of radiotherapy with concomitant and adjuvant temozolomide versus radiotherapy alone on survival in glioblastoma in a randomised phase III study: 5-year analysis of the EORTC-NCIC trial. *Lancet Oncol*. May 2009;10(5):459-66.

⁹ Watts, C, ‘Brain Cancer: An Unrecognised Clinical Problem’ Colin Watts, in *Oncology News*, vol 5, issue 2, May/June 2010.

¹⁰ ‘Living with a brain tumour: prevalence of intracranial brain tumours’ *brainstrust* and National Cancer Registration Service, 2013.

for their situation. Our ethos revolves around creating a supportive, helpful community for these people where they can interact as much, or as little, as they need to both in the real world and online. We offer a range of support services that embrace the ways that brain tumour patients and carers want to communicate, and that are accessible when people need to use them. To this end, we provide 24/7 phone and email support, face to face 'Meet Ups', printed information (NHS England approved) and support tools, as well as an online community and two websites that each meet a very specific, predetermined set of needs: www.brainstrust.org.uk and www.braintumourhub.org.uk

Elemental to our work is high performance coaching. This sets us apart. When we are no longer to able to change a situation we are challenged to change ourselves. You are the person who is ultimately going to have the greatest impact on your life. Our coaching relationship with the patients and carers whom we support enables them to face their challenges, so that they learn how to develop resilience and utilise resources to their full potential.

Themes that have emerged from our daily interactions with brain tumour patients, their carers and healthcare professionals is the sense of isolation, lack of voice and the daily challenges that they face. Patients are concerned about vitality, their identity and role limitations, mental health, emotional well being – all of these are important decision factors for patients.

These considerations resonate:

- 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 – where there is resilience or a lack of ability to cope.

Mukand¹¹ (2001) identified the following neurological complications in brain tumour inpatients:

- Cognitive deficits 80%
- Weakness 78%
- Visual-perceptual deficit 53%
- Sensory loss 38%
- Bowel/bladder 37%
- Cranial nerve palsy 29%
- Dysarthria 27%
- Dysphagia 26%
- Aphasia 24%

¹¹ Mukand, Am J Phys Med Rehabil 80(5): 346-350, 2001.

- Ataxia 20%
- Diplopia 10%.

75% of inpatients will have three or more of these neurological complications; 39% will have five or more.

There is little available through the usual channels of clinicians for this support – only 47% of UK neuro-oncology multidisciplinary teams have access to neuropsychiatry services¹².

Catt et al¹³ have identified that:

- 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 treatments 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 counselling or problem solving services.

These points are echoed in the findings of a crowdsourcing project undertaken by *brainstrust* and createhealth.io in August 2014. Brain tumour patients and carers highlighted four main themes that would improve the quality of care for brain tumour patients post surgery¹⁴:

- 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.

Themes – what our community thinks

brainstrust asked its brain cancer community to comment on the question “What has been your experience of neuro-rehabilitation”?

This question was posted on our Facebook site, on our forum, on other community social networking sites, twitter, crowdsourcing and was asked, when relevant, during our email and telephone conversations with patients and carers. Whilst quantitative data is available, it would be hard, therefore, to quantify exactly the number of people who have engaged with the topic and who have responded.

¹² Rooney, A. ‘Challenges and Opportunities in Psychological Neuro-oncology’ in *Oncology News* vol 6 issue 4, Sept/Oct 2011.

¹³ Catt, S., Chalmers, A., Critchley, G., Fallowfield, L., ‘Supportive follow up in patients treated with radical intent for high grade glioma’ in *CNS Oncology* 1(1), 39-48 2012.

¹⁴ Fellgate, T., Bulbeck, H., Hill, M., Jones, W., Patient Crowdsourcing: Ideas that will improve the quality of life for people living with a brain tumour, October 2014.

Our community wants:

- To be able to get hold of a nurse specialist
- Clear signposting of care in the community
- Access to rehabilitation
- Quicker scan results
- The right information at the right time
- Equality of care across hospitals
- Public understanding
- The tools to deal with fatigue
- Clear expectations
- A more equal relationship with my doctor
- Early diagnosis
- To be able to get around
- More honest discussions sooner
- To know how to get what I want out of a discussion
- To not be alone
- To feel in control
- To know how to deal with death and dying.

The two sentiments that were repeated more than anything else were:

1. The desire to know what to expect during rehabilitation
2. Calls for better mentorship, home care and personal support. This includes a more equal relationship with clinicians through more effective conversations.

Two other challenges that resonated during the discussion were:

3. The importance of understanding the long-term effects of brain tumour surgery, and the required neuro-rehabilitation
4. The varying degrees of hospital care that they receive from place to place.

The highest rated comment in the crowd sourcing campaign was focused on holistic and long-term care:

'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 as much normality – if there is such thing. Many things required are of a fairly practical nature – Moving from independent to assist living, travel support, dietary support, exercise planning and tracking, hair dressing.'

Generally, responses identified gaps or commented on what has worked:

1. A desire to know what to expect:

'More information about what to expect would be helpful.'

Patient 60 – 70 yrs

'Driving license – despite having obvious double vision, I was never informed I would need to send it back!'

Patient 30 – 40 yrs

'My care was excellent, I received a lot of information about how the oncology treatment – i.e. radiotherapy – would affect me in the short and long term, ditto for the steroids.'

Patient 20 – 30 yrs

'A general impression that no question was too unimportant, sufficient time given to discussing issues before discharge. Plenty of encouragement to stay in touch if any problems arose. Excellent communication with local oncologist and hospice at home team.'

Carer 40 – 50 yrs

'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 yrs

'I strongly feel that each patient should have someone assigned to explain what practical and financial help there is available in full.'

Carer 60 – 70 yrs

'Community carers need a lot more education on the effects of BT's. This is an area that falls down in far too many areas.'

Patient 40 – 50 yrs

'If doctors would continue the dialogue and engage with the patient more to build a good rapport – I believe – that would improve many patient's situation.'

Patient 40 – 50 yrs

2. Calls for better mentorship, home care, personal support:

'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 yrs

'We think that there should be someone who oversees all medical evidence and makes contact annually to check if the best care is being administered or discuss new medication advances if applicable.'

Carer 40 – 50 yrs

'I felt very alone, I did not have a clue where to turn to. Fortunately as my son was on a clinical trial I rang the trial nurse, who rang the oncologist. But without that link we were lost.'

Carer 50 – 60 yrs

'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.'

Carer 40 – 50 yrs

'We were put in contact with a Macmillan nurse locally and met a doctor and a social worker on her team at one point. It was good to have a number to ring 24/7.'

Carer 60 – 70 yrs

'I strongly feel that each patient should have someone assigned to explain what practical and financial help there is available in full.'

Carer 60 – 70 yrs

'... good follow up care from specialist doctors, psychologists or psychiatrists if necessary, specialist nurses.'

Patient 20 – 30 yrs

'I'd like someone I could meet face to face to talk through my biggest fears and get practical support for myself and my family.'

Patient 20 – 30 yrs

I did see the psychotherapist at the hospital, who got Macmillan involved and I now see one of their counsellors, but this only happened after my treatment had finished and to be honest I could have done with it quite quickly after diagnosis. Thank goodness for the Samaritans... No practical help available with things like cleaning or gardening which would have allowed me to focus on fighting the cancer and on those days when I couldn't do anything as I felt too ill would have been really useful. I cannot fault the care I am receiving medically... but there is a lot of practical aftercare that could be improved on, especially for those who live on their own. The Government just seem to want to get me to attend a "back to work/get a new job" interview as soon as possible.'

Patient 40 – 50 yrs

'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 yrs

3. The importance of understanding and accessing long term care:

'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 yrs

'I would have liked to have known about the possibilities of late effects rather than wait until they appeared.'

Carer 50 – 60 yrs

'My scar extends from the top of my head down to my neck. I have since had physiotherapy which has involved scar tissue massage to prevent soreness and tightening, which I could have been doing myself for a long time before I got to see a neurophysio. It would be good to have some practical tips for long-term expectations and exercises.'

Patient 60 – 70 yrs

'I went for many years without any neurological outpatients visits and was diagnosed with chiari malformation and syringomyelia 6 years ago. I could have been receiving treatment for this condition sooner rather than thinking for many years that my symptoms were related to the tumour.'

Patient 50 – 60 yrs

'There is perhaps a place for an annual Neuro-Rehab MDM "MOT", where people who are "stable", after treatment, but just seen in clinic once or twice per year after have an assessment to cover areas that the patient/carers feel important or lacking.'

Doctor 50 – 60 yrs

'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.'

Carer 60 – 70 yrs

4. Varying degrees in standard of hospital care 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 none coordination between these healthcare professionals.'

Carer 40 – 50 yrs

'King's College Hospital set up contact with the local palliative care team. They were immensely helpful, withdrawing as we got better at living with brain cancer. We could press for this to happen everywhere.'

Carer 60 – 70 yrs

'Having lived in 3 separate places post diagnosis the care varies widely from place to place. We need to create minimum standards.'

Patient 40 – 50 yrs

What carers think

Common themes which have resonated from carers and ones for which they wished specific neuro-psychosocial support had been made available are concerns around short term memory, difficulty in decision making, pain management, depression (including feelings of despondency), hemiparesis and the safety issues that come with this. Carers were concerned about falls and mobility; this is a limiting factor in carers being able to leave the home. Whilst fatigue was mentioned, carers did not see this to be a particular problem, nor did they relate this to a quality of life issue. It limited the things they could do together with the patient, but the upside was that it meant ‘they could get on with things’ (carer of patient with a GBM 4.) Research demonstrates however, that fatigue is significant to patients^{15,16}.

Carers too felt that they had needs that were not met and that the support and rehabilitation services should encompass this in some cases, particularly where the carer was the primary source of support for the patient. These include:

1. Feelings of despondency – fear, hopelessness, lack of strength, scanxiety and isolation
2. Challenges faced due to brain cancer being unique
3. Feeling unresourced¹⁷.

1. Despondency

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

‘Knowing that when treatment is over, it’s never really over. The damage done by chemo and radiotherapy never goes away. The fear never goes away. Life is changed forever.’

Carer

A sense of loss includes – but is not limited to – loss of identity and life as it was. Some carers mourn the loss of the person they loved, who either died or has had such a personality changed, they are no longer 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.’

Carer

‘Having to face losing the person you thought was your future, when your peers are buying houses, getting married and starting families. Will these things happen for us?’

Carer

¹⁵ Armstrong, T. S., S. G. Cron, et al. (2010). “Risk factors for fatigue severity in primary brain tumor patients.” *Cancer* 116(11): 2707-2715.

¹⁶ Armstrong, T. S. and M. R. Gilbert (2012). “Practical strategies for management of fatigue and sleep disorders in people with brain tumors.” *Neuro-Oncology* Suppl 4: iv65-72.

¹⁷ *braintrust* Share Aware Pin Board, spring 2013.

Hopelessness and powerlessness: The sense of being unable to do anything but stand by as loved ones struggle with this disease.

'Watching your best friends [sic] life be snatched away from under feet, and not being able to do a single thing to stop it.'

Carer

'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.'

Carer

Lack of strength: Psychological strength in themselves

'I can't be strong for my family all the time. Sometimes I need a shoulder to cry on.'

Carer

Scanxiety¹⁸: 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 treatment... the waiting is mental torture.'

Carer

Feeling alone/isolated: The sense that they are alone on this journey.

'...I am a mother, a daughter, a sister, an employee. I am surrounded by many, yet so alone...I'm lost.'

Carer

2. Brain cancer is unique

Lack of understanding from others: Examples include others not understanding that 'benign' does not mean harmless; friends and family assume the patient is 'cured' after treatment; will return to 'normal' after treatment; others don't realise it is cancer.

*'When you say "At least it's just a tumour" don't be surprised when I reply "IT'S GOING TO B****Y KILL HER!'*

Carer

Dealing with side effects: This includes personality changes, epilepsy, tiredness, becoming disabled, brain "not working" the same anymore, hair loss, and more.

'When the person who you care for becomes too violent and unpredictable to live with it is heart breaking having to put them in an "old folks" care home.'

Carer

¹⁸ Andrykowski, Michael and Maria Kangas. "Posttraumatic Stress Disorder Associated with Cancer Diagnosis and Treatment." In Holland, Breitbart, et. al, eds. Psycho-Oncology. New York: Oxford, 2010, p. 353.

A brain tumour is a disability:

'Looking for support from the government to recognise that a brain tumour is a disability and not just a condition.'

Carer

3. Unresourced

Not enough help: This refers to having to fight for help navigating the brain tumour pathway.

'No follow up after release from hospital. I had to contact a brain tumour charity to ask what happens next as hospital & GP didn't offer any help/support.'

Carer

Not enough information: A large number of these refer to lack of information from hospital and perceived lack of information from consultant, such as not being given options, or finding things out on notes instead of being told:

'Reading the word 'palliative' on your son's notes.'

Carer

'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.'

Carer

There were issues around changed identity, which impacted on the patient's lifestyle. In some cases, once diagnosed, the person would become a 'patient', even though nothing had physically changed in the last 24 hours:

'Before it all happened Dad would holiday every month with Mum and go to the gym 3 times a week. In fact he had a 2 week wait from his scan at our local hospital til his biopsy and he still went to the gym during that time for a run. Needless to say he asked me to cancel his membership the day after prognosis but he still tries to get out for a walk each day. Mum also said he's been doing his Sudoku the last 2 days to keep his mind sharp. He used to do them daily before this so at least he's trying to get a sense of normality in his life and keep his mind as active as possible.'

Carer

Range of services used

Carers and patients do not know the range of services available to them when a patient has been discharged. Inpatient care is more cohesive and coordinated and patients are able to be more reactive as services are organised on their behalf. A patient living in the community needs to be more proactive and whilst a patient on discharge may not need to have rehabilitation services available, and should have a care plan in place¹⁹ there usually comes a point when additional resources are needed due to the progressive neurological disease that brain cancer causes. There is a disconnect between what happens in hospital and what happens once home. Frequent questions we are asked are about speech therapy, balance issues, visual deficit, seizures and practical, daily care like bathing, swallowing, insomnia, dressing and exercise. Carers and patients are unaware of the range of services available – district nurses, social services, physiotherapists, occupational therapists, counselling, complementary therapies to name a few. And when they do recognise a need usually it is needed immediately and the ask comes to late, so they give up.

And carers have to balance the needs of others too:

'I spoke to the specialist last night and again this morning and have persuaded them to allow me to drop the daily Clobazam tablet. I have previously used them when Anne experienced fits and they have always knocked her for six. The idea of a daily Clobazam tablet was suggested by Janet last year and I argued against for this reason. Gary suggested on Monday that Anne should perhaps go on a daily dose, but it is making her feel terrible and sleepy so no quality of life. I hope it helps her, to at least get to the toilet independently. Emma was quite upset last evening regarding the idea of an endless stream of carers visiting the house. She expressed that this was hindering her GCSE revision. As a result, I have cancelled the weekend carers.'

Carer

Access to services

There is a national shortage of rehabilitation facilities, particularly for those patients with spinal cord tumours such as ependymomas and other tumours with a longer term prognosis. Almost all neuroscience centres in England and Wales (96%) reported having access to a specialist neuro-rehabilitation unit. Access to specialist neuro-rehabilitation units was much lower for oncology/radiotherapy units (60%)²⁰.

Supportive care and rehabilitation is of key importance and requires development and consolidation with commissioned rehabilitation facilities. Significant disability can result from brain and CNS tumours and bulky rehabilitation equipment, a gym, and a high staffing ratio per patient are required.

¹⁹ Although the NCPES (2014) states that only 21% of patients diagnosed with a brain tumour were offered a care plan.

²⁰ NICE Improving Outcomes for People with Brain and Other CNS Tumours 2006.

Equally, rapid access to appropriate levels of neuro-rehabilitation is required for those patients with palliative care needs and those with shorter prognosis CNS tumours. For these patients rehabilitation can be complicated by a prolonged period of physical and cognitive disability with a profile of distressing symptoms that is hard for patients and families to endure. These groups of patients often require a different rehabilitation approach and those with a shorter prognosis would require care 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 carers have no idea how to access rehabilitation services:

'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 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.'

Carer

And on a more pragmatic level:

'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 you 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 wheel chair. What else will I need?'

Carer

It does not occur to them that their primary care could unlock rehabilitation services for them. Our job is made difficult because what may be available in one CCG may well not be in another. One example is the role of the Community Rehabilitation Neuro Nurse, who is not available in all areas:

'This nurse was amazing. I went to my GP as I was desperate for help with my daughter. She had a grade 2 brain tumour but the biggest impact on her life was her epilepsy. This made her forgetful – she couldn't go out because she couldn't remember where to go, why she was going, or how to get there. The rehab nurse came to the house and went through everything with us and signposted services. She then fixed up an appointment for us to see a neuro-psychologist so that my daughter could be assessed and strategies developed.'

Carer

In addition, when additional resource is drafted in carers sometimes feel that the nursing services have little understanding of the specific needs of a brain tumour patient or they feel unheard. Simon was anxious to keep his wife at home when she

was in end of life phase but was accused by the district nurse of being selfish, which led him to take extreme action at a time when he needed to be building a rehabilitation team around him:

'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 am also in the belief that 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!'

Carer

Summary

Unsurprisingly, there are gaps in neuro-rehabilitation and neuro-psychosocial support as our interactions with carers and patients diagnosed with a brain tumour reveal. The causes for this are complex but it isn't just a resource issue but is also an attitude of mind – of all involved.

Carers and patients don't understand the purpose of neuro-rehabilitation, or how the emphasis is placed on restoring or maximising 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. Preventive rehabilitation can maintain independence in 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 carers were more informed about the progression of the disease they could be better prepared and intervene earlier. During terminal stages of illness, palliative rehabilitation can improve and maintain comfort and quality of life until the end of life. Carers and patients need to be more specific and more proactive in their asks of the support services, outlining specifically what the problem is so that additional help can be targeted effectively. It is difficult to ask for support if you don't know what is available. This could so easily be addressed. A key question which we ask regularly is 'what are you struggling with the most?' Once this is articulated it is easy to define what it is needed.

There is a mindset with some clinicians that once the patient is through a particular phase of their care pathway, they are no longer their problem. At a cancer network meeting, when reviewing the progress against the IOG, a neurosurgeon stated that once the patient has had neurosurgery 'they become someone else's problem'. Never mind that the surgery may leave the patient with complex rehabilitation needs. And again, once discharged home the secondary care team assumes the primary care team will pick up the support and rehabilitation. This is not always the case, particularly if the carer and patient don't know what to ask for, whom to ask or where to go.

This could be easily addressed with information provided to patients and carers. The lack of identification of needs and the lack of documentation is worrying as funding and resource allocation follows the need. Patients and carers need to 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, and the uptake of services and any barriers to service use. Only then can the gaps begin to be addressed.

Future directions

Qualitative studies^{21, 22, 23, 24} show that some patients and the majority of carers 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-rehabilitation and neuro-psychosocial support improves outcomes for patients diagnosed with a brain tumour²⁵. For improved survivorship, close collaboration is required between clinicians involved with neuro-rehabilitation, supportive care, quality of life, psychological and palliative care to plan transition points in care. This requires coordination of different specialties and expertise from symptom management to end of life care. It is imperative that improvement in prognosis is associated with improvement in the quality of survivorship.

Suggested actions for taking the agenda forward, based on conversations (online/offline) to date:

1. Build the community – this is happening with the development of a neuro-psychosocial/neuro-rehabilitation database and website (www.neurooncologyrehabhub.org.uk), plus facilitated meetings at BNOS

²¹ *brainstrust* Share Aware Pin Board, spring 2013.

²² Shepherd, S.C, Cavers, D, Wallace, L.M, Hacking, B, Scott S.E, and Bowyer, D.J, Edinburgh Cancer Centre, UK. Coventry University, UK; University of Edinburgh, UK, BNOS poster, 2012. 'Navigation' to support decision making for patients with a high grade brain tumour. A qualitative evaluation.

²³ Cavers D, Hacking B, Erridge S, Kendall M, Morris PG & Murray SA. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ*, 2012; 184 (7).

²⁴ Cavers D, Hacking SE, Kendall M, Morris PG, Murray SA. Adjustment and support needs of glioma patients and their relatives: serial interviews. *Psycho-oncology*, in press.

²⁵ Bartolo et al. Early rehabilitation after surgery improves functional outcome in inpatients with brain tumours. *J Neurooncology* (2012) 107:537-544.

2. Special interest groups e.g.:
 - Communication
 - Young people
 - Mood
3. Audit current provision (see Lance Sloan's data.)
 - What percentage of primary brain tumour patient or primary spinal cord tumour patients get referred to neuro-rehabilitation units?
 - What evidence is there that they benefit post-operatively?
 - Survey MDTs
4. Establish pathways and protocols for referral, rehabilitation and transitions between rehabilitation and palliative care, and also early rehabilitation e.g. post resection. Do this through 'experienced based co-design', so co-construction and design of care pathways
5. Raise the profile at neuro-oncology and rehabilitation conferences
6. Ensure it is on the agenda at the Brain and CNS CRG
7. Identify effective practice where strong links exist between neuro-oncology and rehabilitation and create a case note (Surrey: Anne Arber, UCL: Jane Neerkin, Hereford: Macmillan)
8. Collect data on patient/carer experience through online and offline channels
9. Understand and raise awareness around real patient issues
10. Establish a spokesperson/spokespeople – from all stakeholder groups.

And for *brainstrust*? We have a very clear plan of forward action now that will deal with the list of 'wants' from our community. We have never been more clear about what we need to do to help. This work has provided the foundation on which *brainstrust* and our stakeholders need to work to make, shape and drive change so that together we can improve the quality of life and care for people living with a brain tumour, and also for those who work so tirelessly with this vulnerable community.

Appendix A

National Cancer Patient Experience Survey 2014

The 2010 National Cancer Patient Experience Survey²⁶, repeated in 2011/12, 2013, and 2014 has been designed to:

- monitor national progress on cancer care
- provide information that could be used to drive local quality improvements
- assist Multi Disciplinary Teams, Commissioners, and NHS Trusts in improving services for patients
- inform the work of the charities supporting cancer patients.

Brain/CNS is one of the tumour groups with the lowest scores (this group gave the lowest scores on 5 questions). Relevant data appertaining to neuro-rehabilitation from the survey:

After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists?)

54% of patients diagnosed with a brain tumour felt that they had been given enough care/help from health or social services. Scores ranged from 67% (colorectal/lower gastrointestinal) to 51% (urological cancer).

Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?

55% of patients diagnosed with a brain tumour said that the staff at their general practice definitely did everything they could to support them. Scores ranged from 72% (prostate cancer) to 55% (brain/CNS).

Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?

76% of patients diagnosed with a brain tumour felt that the different people treating and caring for them always worked well together. Scores ranged from 89% (skin cancer) to 76% (brain/CNS).

Have you been offered a written assessment and care plan?

21% of patients diagnosed with a brain tumour were offered a written assessment and care plan. Scores ranged from 25% (colorectal/gastrointestinal cancer) to 18% (other cancer).

Sometimes people with cancer feel that they are treated as 'a set of cancer symptoms rather than a whole person. In your NHS care over the last year, did you feel like that?

76% of patients diagnosed with a brain tumour did not feel that they were treated like a set of symptoms. Scores ranged from 89% (skin cancer) to 76% (brain/CNS).

²⁶ <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

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Suggested reading

brainstrust: A new guide to patient care – your pathway explained
www.brainstrust.org.uk/news-detail.php?id=344&year=2013

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