

Behaviour and personality change

A resource to help you understand and manage behaviour and personality change when living with a brain tumour

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Behaviour and personality change (BPC)

“Mood swings take careful controlling; I have to disappear to keep control.”

Patient

“I’ve known this man for 46 years and now feel as if I know nothing about him.”

Caregiver

“From the perspective of a neuro nurse, I would like to know how to manage personality change and help partners, caregivers and family to adapt to these changes. This is a huge need in my clinical setting, and I would like to implement strategies to improve things and include this in the service I provide.”

Neuro-oncology clinical nurse specialist



About this resource

We know that living with a brain tumour is challenging – on so many fronts. We know, too, that dealing with behaviour and personality changes makes life distressing – for everyone involved. We know this from our daily interactions with our community. Patients feel remorse and guilt. Caregivers feel isolated and lost. Some professionals feel ill-equipped and uncertain. The following challenges resonate:

- threat to way of life
- lack of control with behaviour
- impact of behaviour and personality changes on relationships
- systemic problems leading to isolation
- access to support.

Managing BPC is one of the biggest challenges facing anyone who is living with a brain tumour – you have told us it is. Not only that, but researchers also tell us it is. BPC carries a considerable burden for patients and families living with a brain tumour, with between 16% and 60% experiencing behaviour and personality change.¹ It is one of the key themes that has emerged from our daily interactions with everyone in our brain tumour community, whether they are a patient, a caregiver, a clinician, a nurse or an allied health professional. This is hardly surprising: when illness strikes, a number of structural and emotional skews will follow. Belief systems are challenged, roles are upended, and identities shift. The onset of a brain tumour diagnosis forcefully challenges the emotional and physical boundaries that we have spent a lifetime building. The tumour is an uninvited guest that we must somehow build into our lives while at the same time living with the undercurrent of threatened loss. This loss and distress is not a cause of BPC, but it is a factor that comes into play.

¹ Gofton, T., Graber, J. and Carver, A. (2012). Identifying the palliative care needs of patients living with cerebral tumors and metastases: a retrospective analysis. *Journal of Neuro-Oncology*, 108(3), pp.527–534.

How this resource can help

This is an informative, supportive resource, written to help people living with a brain tumour. It's written to help you understand:

1. what we mean by BPC
2. how it is different from other psychological disorders
3. how to self-manage BPC so that you:
 - have independent, reliable, factual information on BPC
 - have the information you need so that you can understand and make informed decisions about BPC and how to manage it
 - talk openly about the challenges around BPC.

Having read this resource, you will:

- feel more confident about managing BPC, why it happens and what it is
- be more informed and engaged in your situation
- be reassured you are doing the best you can to cope with BPC
- feel comfortable and confident in exploring further options, should you wish
- understand how *braintrust* can help
- know where to go for further help.

You will find links throughout this resource. These links take you to the relevant area of our website, where you will find even more information about certain aspects; for example, chemo brain and fatigue.

Understanding behaviour and personality change (BPC)

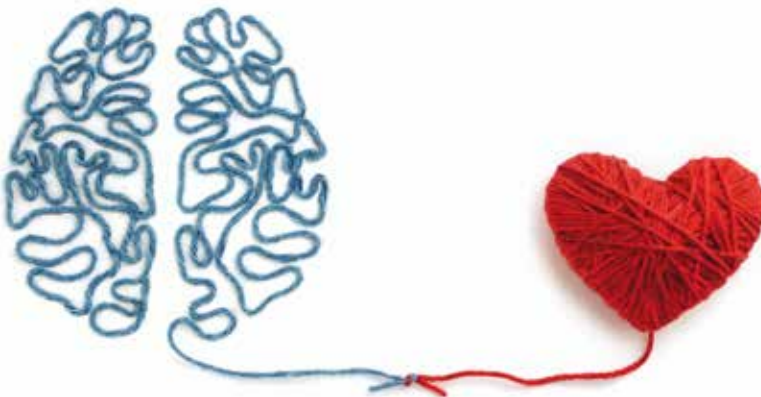
What do we mean by ‘BPC’?

It is changes in the way people think or act.

Behaviour is the way a person responds to certain situations or conditions. It is how they act.

Personality describes the combination of unique qualities that forms a person’s character.

BPC isn’t directly related to movement and physical sensations, such as balance, coordination and numbness. These are affected by the parts of the brain that control motor functions. It isn’t depression and it isn’t anxiety. Yes, these are changes, and they can also impact on the way someone living with a brain tumour behaves. But these may be part of a bigger jigsaw. It’s a very messy field of knowledge. For example, we could ask, what’s the difference between depression and personality change? We don’t really know for certain; it depends how the key aspects of each are defined. It is therefore very hard to define.



Causes of BPC

Sometimes BPC is due to *the tumour itself*. Brain tumours can cause a variety of symptoms. These can be neurological symptoms (headaches, dizziness, loss of speech or movement) or behavioural changes (changes in the way people act). These changes can be due to the brain tumour or the treatment for the brain tumour. Changes in behaviour, personality and cognition could be related to the type of tumour, its location, size and rate of growth or grade. For example, a brain tumour can cause a person to be disinhibited – to behave in ways that are completely out of character and at times inappropriate. More information about the classic view of brain tumour location and the impact it could have can be read about in a review by Madhusoodanan.² An overview may help:

- Frontal lobe: movement, intelligence, reasoning, behaviour, memory, personality, planning, decision-making, judgement, initiative, inhibition, mood.
- Temporal lobe: speech, behaviour, memory, hearing, vision, emotions.
- Pituitary gland: hormones, growth, fertility.
- Parietal lobe: intelligence, reasoning, telling right from left, language, sensation, reading.
- Occipital lobe: vision.
- Cerebellum: balance, coordination, fine muscle control.
- Brain stem: breathing, blood pressure, heartbeat, swallowing.

However, many researchers now think this rigid view of how the brain works is no more than a rule of thumb. Because the brain is also organised in higher networks, many cases have been reported where tumours caused behaviour symptoms that would be unexpected.

2 Madhusoodanan, S., Sinha, A., Moise, D. and Sinha, S. (2006). Psychiatric Manifestations of Brain Tumors. In: A. Yang, ed., *Trends in Brain Cancer Research*. New York: Nova Science Publishers, Inc., pp.281–301.



A malignant tumour is more likely to cause BPC changes. A large tumour can cause more changes, but a small tumour in a sensitive location can also cause big changes. So it's very complex.

Treatments can also cause BPC. Radiation therapy, surgery, medication, chemotherapy – all of these can have an impact. '*Chemo brain*', for example, is a recognised side effect. After treatment, a spaced-out feeling lingers; impaired memory and an inability to concentrate or multitask dogs some patients. It is suggested that the cause lies deep within the brain, in regions where immature and newborn cells (progenitor cells) are proliferating. These self-renewing cells, part of the complex structures needed for memory and other normal functions, are particularly vulnerable to toxic chemotherapy drugs. On the other hand, the very stress of a brain tumour diagnosis or depression may also contribute to memory loss, so it is hard to say whether chemo brain exists or is exaggerated, and if it is, whether it is prolonged and progressive. *Fatigue* can also be a legacy of radiotherapy. For in-depth information, a good read is 'Psychiatric symptoms in glioma patients: from diagnosis to management'.³

3 Boele, F., Rooney, A., Grant, R. and Klein, M. (2015). Psychiatric symptoms in glioma patients: from diagnosis to management. *Neuropsychiatric Disease and Treatment*, 11, pp.1413–20.

Mood disorders cover a range of different problems. Some of these may be pre-existing, so there already. It is hard to know if these are made worse by the brain tumour or by the stress of living with a brain tumour. These are characterised by low mood, in the case of unipolar depression, or mood instability, in the case of bipolar disorders. Other symptoms include problems with self-worth, sleep, appetite, concentration, changes in energy levels, and in some cases, thinking about death and suicide. Mood disorders are very common, affecting about one in five people, with a greater proportion of women and those facing the greatest adversity and disadvantage. This includes living with a brain tumour.

Thinking ability (aka cognition) is also a key part of behaviour and personality change. Cognition includes how we think, what we remember and how we reason, or make decisions. You may have heard the words 'cognitive deficit' being used. This refers to a loss of cognitive ability, so, for example, a loss in the ability to make a reasoned judgement, or not being able to do more than one thing at a time.

TO DO LiST

1. **SO**
2. **MANY**
3. **THiNGS**



What is different about BPC in a person living with a brain tumour?

The brain is organised into areas and also networks – a ‘small world’ organisation with discrete areas linked into broader networks. Each area or network controls specific mental and emotional functions. We know that these areas can be affected by the tumour – its location, type and size – and the treatment given. But a brain tumour is not like any other diagnosis. Unfortunately, with progression of a brain tumour, or effects of treatment (some of which can happen years after the treatment has finished), BPC can worsen and become more difficult to manage. Also, it can at times feel like you are living on shifting sands. Some patients will have insight into what is happening to them, while others will not. In some cases, changes in BPC can be very subtle, and the patient is more aware of the difficulties, creating a workaround to hide the change so that caregivers don’t notice it. Changes in BPC can mean that the caregiver doesn’t recognise the person they know and love – that they have already ‘lost’ the person.

“I’ve known this man for 46 years and now feel as if I know nothing about him.”

Caregiver

Some symptoms can be managed with therapy, but seizures, infections and other medical problems can precipitate symptoms. It is important to take advantage of the times when everything is working well, as we cannot predict the future. Being comfortable with uncertainty and accepting what is happening is key. You can find out more about these on pages 19–29.

How does BPC manifest?

“We are all adjusting to the new us. Looks like quite a few of us have something in common (besides the obvious): frustration, anger, guilt for relying on others.”

Patient

BPC can show itself in a variety of ways. Some of these can be subtle, some less so.

Disinhibition – disinhibited behaviours are actions that seem tactless, rude or even offensive. They occur when people don't follow the usual social rules about what or where to say or do something. People who show disinhibition can make poor assessments about risk, so would do things that put themselves (and others) at risk. These behaviours can place enormous strain on families and caregivers.

Apathy – this is a state of indifference, or the suppression of emotions such as concern, excitement, motivation or passion. An apathetic individual has an absence of interest in or concern about emotional, social, spiritual, philosophical or physical life and the world.

Aggression – depression, anxiety, obsessive–compulsive behaviour, changes in emotional control, irritability, mood swings, withdrawal, inappropriate behaviour.

“My wife says that everything makes me angry now, and she hates it. I don't want to be angry, and I'm not an angry person at heart, but so many things just seem to stress me out and irritate me, and that comes out as me being grumpy or angry. It's horrible.”

Patient

“My father broke a plate on our dog's head because Rufus was after his food; he wasn't aware that what he had done was wrong. I don't know who was more shocked, me or the dog.”

Caregiver

“At first diagnosis, Dave went through a period of intense anger, mostly directed at me. At one point, severe enough that I walked out of the house and told him afterwards that I had seriously been looking in estate agents’ windows for a place to live on my own, as I wasn’t sure our marriage could survive this. I had never done this before and haven’t since.”

Caregiver

Attention and concentration – confusion, being distracted and difficulty multitasking, planning and thinking strategically.

“My daughter was always the reliable child. If you wanted a letter posting, then Sophie was the one to ask. Then one day, she presented her bedding to me and asked me where she should put it. The next day, she asked me where the kitchen was. It was unnerving, as I really felt she was vulnerable.”

Caregiver

Learning and memory – difficulty processing, storing and retrieving information, short-term memory loss.

“Memory issues control my life, and my waking hours involve a note attached to my forehead with a tick list.”

Patient

“Memory loss – I find it really upsetting. Makes me question myself. Did I or didn’t I say that? Did I or didn’t I do that? I often ask myself these questions. Yes, my confidence is at an all-time low, but I think I have lots of reasons for this, not just the memory loss.”

Patient

Executive functioning – decreased reasoning and organisational ability, impaired judgement.

“I can't rely on my husband now to do some of the things he has always done – like paying bills on time. I love my husband so much but feel I'm letting him down by saying, 'You can't do that,' and other things I say. Then I think he's not a child, but I just can't help it.”

Caregiver

Language and communication – difficulty finding the right words, using words in the right order, reading and writing.

“The loss of words that I need to use as well! I did business studies, was a PA, so needed to be organised. Now I can't organise a fight in a paper bag!”

Patient

“My son forgets nouns. So he makes up phrases to describe things. Yesterday he couldn't remember the word 'escalator', so he described it as a moving staircase. It's sad, but also it can be quite amusing – and then I feel guilty for laughing.”

Caregiver

“Since my brain surgery, I can't see the left-hand side of the page, so reading left to right has needed a rethink. I just have to turn my head further to the left so I can see the left-hand side. It looks a little odd, but I am just happy I can still read.”

Patient

“I have stopped going out now. I can't remember the most basic words, and it's embarrassing. I used to go to my bowls club and do the shopping – but I don't do either of these any more.”

Patient

The thread that underpins all of these changes is the impact on life context. It is pervasive and impacts in a variety of ways – physical, social, concentrative, emotional, spiritual. All the things that enable us to be who we are. What does this look like?⁴

Physical:

- reduced energy level
- diminished strength or endurance
- difficulty sleeping.



Social:

- changes in roles or relationships
- altered responsibilities within the family
- reduced ability to perform job responsibilities
- changes in sexual relationships or sexual response
- reduced interest in affection.



4 Conn-Levin, N. (2008). *Fatigue and Other Symptoms after Brain Tumour Treatment*. [PDF] London, Ontario: Brain Tumour Foundation of Canada. Available at: <https://biak.us/wp-content/uploads/2016/06/Brain-Tumors-and-Fatigue.pdf> [Accessed 4 Dec 2019].

Concentrative:

- difficulty concentrating
- inability to understand new information
- being distracted by sensory input (i.e. noise, activity, etc.)
- feeling overwhelmed by daily tasks
- finding that typical activities of daily living are more difficult to do.

**Emotional:**

- changes in mood
- reduced feelings of self-esteem or confidence
- diminished sense of control about daily life
- fears or anxiety about the future
- concerns about body image changes (i.e. facial differences, hair loss, etc.).

**Spiritual:**

- questioning one's purpose
- disinterest in previous religious or spiritual practices
- feelings of 'Why me?' related to diagnosis
- indifference about prayer, meditation or other mindfulness.



People stop going out. Their world becomes smaller as they become more isolated. Relationships suffer. Confidence is eroded until one day you realise that you are grieving for the person that has been lost – whether you are a patient or a caregiver.

How do we measure BPC?

The short answer is it's not easy. But we know that accurate assessment of neurocognitive status as early as possible helps everyone to understand what is happening. Assessment will tell us what the strengths and weaknesses are. This is important for anyone living with a brain tumour, as it helps with the emotional adjustment needed. Families will have a better understanding of what the patient can and cannot do, and so expectations can be managed better. Informed decisions can be made about life events, such as the level of support needed for the person with the brain tumour to maintain their independence and find the 'new normal'.

The National Institute for Health and Care Excellence (NICE) outlines clearly what you should expect when you are diagnosed with a brain tumour. It recommends 'regular clinical reviews to assess changes in your physical, psychological and cognitive well-being', and having access to specialist neuropsychology and neuropsychiatry services is part of the optimum standard of care.^{5,6} However, resources are stretched, and it isn't always a given that assessments will be offered, so you may need to ask explicitly for an assessment from your GP or from your clinical team.

For a detailed description of the range and type of assessments used, you should read 'Neurocognitive deficits and neurocognitive rehabilitation in adult brain tumors'.⁷ Objective assessment can be carried out either by using a neurocognitive screening test or by administering a longer, more detailed neuropsychological assessment. Both approaches have strengths and limitations; it is never 'one size fits all'. The type of assessments that are used include:

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- 5 NICE. (2019). *Brain tumours and metastases – NICE Pathways*. [online] Available at: <https://pathways.nice.org.uk/pathways/brain-tumours-and-metastases> [Accessed 4 Dec 2019].
 - 6 *brainstrust* (2018). Patient Guide. [PDF] Cowes: *brainstrust*. Available at: <https://brainstrust.org.uk/brain-tumour-support/navigating-your-pathway/patient-guides/> [Accessed 4 Dec 2019].
 - 7 Day, J. et al. (2016). Neurocognitive Deficits and Neurocognitive Rehabilitation in Adult Brain Tumors. *Current Treatment Options in Neurology*, 18(5), p.22.

Assessment type	Advantages	Disadvantages
Screening tools	These have the advantage of being quick to use and require little specialist knowledge to administer. They can be completed when patients feel low, unmotivated, depressed or fatigued.	They can be limited and overlook some neurocognitive domains, such as executive function.
Neuro-cognitive test batteries	These tests provide more comprehensive assessments of cognitive strengths and weaknesses. They can also be supplemented with additional tests.	These tests need to be administered and interpreted by practitioners who have been trained.
Self-reporting assessment (also called subjective assessment)	Increasingly, data provided by patients and their caregivers is becoming validated. It is valuable, as it provides information about the everyday problems that patients and their caregivers attribute to their brain tumour.	Some patients may have poor insight into their condition and not see that there is a problem. This is difficult for the caregiver, and it is important that caregivers know how to create the space to have conversations with the clinical team about the challenges. Likewise, a patient may only be too painfully aware of an issue and may not want their loved one to know. They will create a workaround to hide the issue, and so it is never addressed until it becomes apparent, and then it is often too late to do anything about it.

Mood journals and how to use them

A mood journal logs the emotions that someone may feel over a specific time period. Mood journaling can help you understand the connection between what you're feeling and your environment. As a starting point, you might want to use the journal to see if there are any patterns to the BPC.

Capture as much information as you can over a few days. This will help you to identify what might be making things worse or better. You can then complete the journal again once you have made changes, and compare the two to see if the changes have made a difference. Think about marginal gains – they might seem to be insignificant, but if you make two or three changes, the impact could be big. Try to give as much information as you can. This will help you identify what helps and whether there is a pattern.

We suggest that you note the emotions you feel during every two-hour period. For each emotion experienced, rate the intensity on a scale of 1 (low) to 10 (high), along with any notes about anything that was going on at the time. This should include physical symptoms, e.g. headache, nausea, tiredness. You can also include other emotions, such as fear or insecurity. It's important that you make this journal your own.

When you have some data to look at, see if there are any patterns. For example, anger commonly manifests as a cover-up for other emotions. You might be able to connect a trigger to an underlying issue or problem. Is behaviour more erratic and unpredictable in the evening, or before lunch? This could be related to tiredness or feeling hungry.

Other things to consider:

- Are you finding your home too noisy or cluttered?
- Do these changes happen when you are being challenged or asked to do something you may not want to do?
- Are you in a situation that is not usual for you?

You can photocopy the mood journal (it's also on page 44) so that you have blanks to complete, or download it from the *brainstrust* website at brainstrust.org.uk/wp-content/uploads/2020/01/mood-journal.pdf.

	Happy	Sad	Angry	Tired	Excited	Anxious	Other	Notes
6 a.m. to 8 a.m.								
8 a.m. to 10 a.m.								
10 a.m. to 12 p.m.								
12 p.m. to 2 p.m.								
2 p.m. to 4 p.m.								
4 p.m. to 6 p.m.								
6 p.m. to 8 p.m.								
8 p.m. to 10 p.m.								
10 p.m. to 12 a.m.								
12 a.m. to 2 a.m.								
2 a.m. to 4 a.m.								
4 a.m. to 6 a.m.								

What are the strategies to help me cope?

Treatment options

Let's deal with what might seem the obvious way to manage BPC but is actually probably the least straightforward – drug treatments. They are complex, with many things at play. Firstly, neurorehabilitation is in its infancy. It is only in the last few years that this area of quality of life has been considered to be important, and so in the past, it has largely been ignored. This means that there is little research evidence available to suggest what treatments do and don't work. It is all a bit 'finger in the wind', but it is important to understand this so that we don't expect quick fixes. Clinicians would love to have the answers to a very complex problem, but they don't. We need more controlled trials so that the clinical management of BPC is informed.

Secondly, no drug treatment has been compared to placebo for the treatment of BPC (which includes depression and anxiety) in people living with a brain tumour. This means that there is very little evidence that drugs will improve BPC in people living with a brain tumour. An added complication is that drug treatments could cause adverse drug interactions. For example, although antidepressants generally do not trigger epilepsy in healthy individuals, the risk of causing seizures in patients with a brain tumour is unknown. So both doctors and patients may be reluctant to initiate new drug treatments.⁸ Always discuss the pros and cons with your clinical team before starting drug treatments.

8 Boele, F., Rooney, A., Grant, R. and Klein, M. (2015). Psychiatric symptoms in glioma patients: from diagnosis to management. *Neuropsychiatric Disease and Treatment*, 11, pp.1413–20.

Bottom line? At the moment:

- No drug treatment has been compared to a placebo in this group of patients.
- There is limited evidence for the use of certain drugs.
- There is some, but limited, evidence for specific complex psychosocial interventions, but these would be difficult to implement widely so that everyone living with a brain tumour has access to them.⁹

What is recommended is that people living with a brain tumour who have changes in behaviour and personality should be assessed whenever possible by neuropsychiatry or neuropsychology services. This is the optimum standard of care outlined by NICE in 2018.¹⁰

We cannot stress strongly enough that if you think you are living with BPC and have not been assessed, then you should be assessed by a specialist neuropsychiatrist or diagnostic neuropsychologist. Your GP or your clinical team should be able to refer you, but resource is limited. Some hospitals don't have access to these services.

Self-help strategies

Self-help is exactly that – you have a toolkit at your fingertips from which you can ‘help yourself’ to deal with the situation as it arises. There are many benefits to self-help for people who are living with a long-term condition, illness or disability, as well as their caregivers. People can suffer less pain, anxiety, depression

9 Day, J. et al. (2016). Neurocognitive Deficits and Neurocognitive Rehabilitation in Adult Brain Tumors. *Current Treatment Options in Neurology*, 18(5), p.22.

10 NICE. (2018). *Brain tumours (primary) and brain metastases in adults*. [online] Available at: <https://www.nice.org.uk/guidance/ng99> [Accessed 4 Dec 2019].

and fatigue, have a better quality of life, be more active and independent, and live longer.

So the next section is to help you feel supported so that you:

- can build knowledge, skills, confidence and resilience to manage the impact that BPCs are having
- are able to know where to access the support you need within and beyond our National Health Service so that you can better manage your situation
- are active partners in working out what is important to you.

Relaxation

Relaxation doesn't just happen. You will need to develop your body's ability to relax through breathing or physical relaxation, or both. If you are not used to gifting yourself the time to relax, start to build the skill of relaxation when you are relaxed, rather than when you are stressed. It is a skill to be learned, and like any new skill, it will take time. Try to do this every day.

Breathing

1. Choose a space that is quiet and warm and not too bright. Set a timer for five minutes.
2. Lie on your back, arms by your side, palms facing upward. Let your feet fall out naturally. If you are uncomfortable lying down, then sit in a comfortable chair.
3. Bring gentle attention to your breathing. Close your eyes; otherwise, you'll be spotting cobwebs and other things that distract.
4. Breathe slowly and steadily and deeply – in through your nose and out through your mouth. Breathe into your belly rather than your chest, and let your belly rise and fall as you breathe. You can place a hand on your belly, just below your ribs, so that you can feel the rise and fall.

5. Breathe in for three counts and out for five counts.
6. Pause between each breath.
7. Notice how the air feels and how your body moves as you breathe in the air.

Physical relaxation

This builds on relaxing by breathing. Follow steps 1 and 2, then:

Bring awareness to your body. Starting from the top of your head, work all the way down your body to your toes. As you pass over each part of your body, label it; then soften and relax it.

Let the tension go in each body part – so, forehead, eyes, jaw, neck, shoulders, etc. Pay particular attention to the areas where we tend to hold tension – neck, shoulders, jaw, forehead, scalp.



Mindfulness

Putting your day to bed.

There is a transition point in every day when the day's activities end and the evening begins. Use this time to think about the day that has just passed. Find a quiet space to reflect. Take fifteen minutes, and capture the following:

- What have you achieved today? It doesn't matter how small, note this down. Be kind to yourself and champion yourself. Who else deserves to be championed? Make sure you let them know.
- What loose ends are there? You might not be able to tie all of the loose ends up here and now; just acknowledge that they are there. When might you deal with them? Who can help you? Once you have done this, put them to bed until you are ready to deal with them.
- What might stop you sleeping well tonight? What positive actions might you take to deal with this? One of the things you can do with negative thoughts is to accept them, acknowledge that they are there and then let them go. This is the brain processing. Just let them go, and bring your mind back to the task in mind.

After fifteen minutes, put your notes to one side and enjoy your evening.

Pleasurable activities

In the busyness of our lives, sometimes we lose sight of pleasure. We are so busy trying to sort, manage, orchestrate, drive that we forget that we need a balance. Make a list of things you like to do that make your heart sing. These will give you energy. Many do not use much energy; many are actually quite small things, like sitting with a favourite piece of music or feeling the sun on your face, listening to birdsong or having a cuddle. Page 43 has plenty of suggestions. Write yours in a beautiful notebook. Look at them often to remind yourself. And promise to do one every day. Gift yourself this moment.

Creating a sanctuary

Think about creating a space that truly is a sanctuary for you. What does this look like? It doesn't have to be exotic, expensive or a room on its own. It could be as simple as designating a space in the kitchen where electronic devices are plugged in when you come into the house in the evening. It could be turning off the TV and turning on some relaxing music instead. It could mean stopping what you are doing to make eye contact with your children while they talk to you. It could be saying no to some plans so that you can spend time together as a family or time on your own. A sanctuary is a space where you can breathe, take a break from performing, and where you can be who you are in a safe place. But it is only a sanctuary if you use it. You may want to let others know that when you are in this space, you'd rather not be disturbed.

Acceptance

Acceptance helps us to accept the difficulties that come with life and what is out of our control, while at the same time committing to action that will improve our quality of life.

Life brings joy and pain, and learning the skill of acceptance – to accept things as they are without evaluation or attempts to change them – can bring freedom and help us to become 'unstuck'. It is about living with painful and negative thoughts and feelings, understanding that they are part of the unhappiness of the life challenges we are facing, and not being overwhelmed by them to the extent that we become trapped and unable to move forward in our lives.

Acceptance allows you to understand that being human means that you feel emotions that can allow you to move forward, whereas obsessively and unhappily playing things over and over in your mind keeps you stuck. So, for example, being frustrated and angry because you can't do the things you used to do may mean that your frustration and anger become the focus, and this is using

energy you could be using more positively. Accepting the reality of your situation and working with what you have now, living in the present rather than constantly asking ‘Why?’ about the past, reduces helplessness and despair. It can open your eyes to new opportunities, new ways of doing things, new hobbies and new forms of exercise.

Acceptance means allowing the painful feelings and sensations to come and go as part of the natural process of loss, while dropping the struggle with them. By giving the feelings permission to exist in the present moment, but not getting caught up in them and being dragged back to the past, it becomes easier for your feelings to come and go without you getting stuck within them. And so, over time, they lose their impact on your everyday psychological and emotional well-being.

How to accept BPC as part of your day

One way to do this is to use the metaphor of a sailing boat.¹¹ Imagine that life is like sailing a small sailing boat. During your life, you have picked up the skills necessary to sail your boat, and you have a sense of where you are taking this boat. At some point in your learning to sail, you have learned that from time to time, waves may wash over the bow, and you will find yourself with wet feet. The usual response that people have learned is as follows: when you have water around your feet, use this bailer to bail out the water.

So you’ve learned about the bailer, but when it has not been needed, it has been put away in a locker, ready to be used if needed. And at some point along your journey, you have had waves come over your boat, and there is now water in the bottom of your boat. So you have started to do the thing that is sensible and logical to do: get rid of the water. You have been using that

11 Gillanders, D. (2011). *The Sailing Boat Metaphor*. [Blog] BABCP ACT Special Interest Group Blog. Available at: <https://actsig.wordpress.com/2011/05/22/the-sailing-boat-metaphor/> [Accessed 4 Dec 2019].

bailer a lot, sometimes bailing quickly, sometimes bailing carefully, sometimes bailing wildly, sometimes bailing desperately, and in your experience, have you managed to get rid of the water yet? And all this time that you have been bailing, what has been happening to the direction of your boat and the progress it has been making? Is it fair to say that you have been bailing more than you have been sailing this boat?

Now, what if you were to one day really look at the bailer and see that it is full of holes? What if it was a sieve? What would you have to do first? You'd have to find a different bailer, one that is more effective. It may be that you have already tried different bailers, and none of them are effective any more. So you need to develop a different approach to the water in your boat. What if this approach could be about accepting that there will always be water in your boat, and the time has come to put a hand on the tiller and choose to pull in the sails and get the boat moving in whatever direction you choose? Once you get the boat moving, then you might be able to investigate some other ways of bailing, if they prove to be useful strategies in helping you to take this boat where you want it to go.



The question to ask yourself is this: which would you choose?

1. To have this boat with only a little water in the bottom, but the boat is drifting because you are bailing so much and you do not have the capacity to look up to steer the boat. In other words, you are not choosing the direction you sail in.
2. To have a boat that has water in the bottom, maybe sometimes so much water that you wonder how it is still afloat, but you are taking this boat, however slowly, in the direction that you most want to take it in.

Acceptance can allow you to move forward, whereas obsessively and unhappily playing things over and over in your mind keeps you stuck. Accepting the reality of living with BPC and working with what you have now, living in the present rather than constantly asking ‘Why?’ about the past, reduces helplessness and despair over time. If you feel unable to adjust to the mood swings or other consequences of having a brain tumour to a point where it is significantly impacting your day-to-day life, you may want to think about accessing professional support through *brainstrust* or your GP.

Exercise

There is evidence to show that exercise can help your body to work at its best when you are living with a brain tumour.¹² Exercise improves strength, fitness, mood and general well-being. But exercise isn’t always straightforward when you have a brain tumour. The brain controls voluntary movement, balance and gait, all essential elements of physical activity. When the brain’s occipital lobe is affected, some vision can be lost as well, making mobility more difficult. In addition, therapies can cause fatigue, dizziness, weakness and lack of balance, making the situation worse. And long-term use of steroids, which may be given to

12 Ruden, E. et al. (2011). Exercise behavior, functional capacity, and survival in adults with malignant recurrent glioma. *Journal of Clinical Oncology*, 29(21), pp. 2918–23.

counteract chemotherapy side effects, also causes muscle-wasting. So exercise may be particularly difficult for some people living with a brain tumour. Equally though, exercise may bring the greatest benefit. The most important thing is to do what works for you. Walking is easy to build into daily activity. Others choose yoga, t'ai chi, cycling, swimming or dance classes like Zumba.

Exercise in short sessions for three to five minutes a few times a day, rather than longer single sessions. Add gentle stretching exercises to your regimen. Yoga is great for building strength and for relaxation.

The easiest, cheapest form of exercise is going for a walk. The payback is huge, but pace yourself. If you haven't been for a walk in a while, set a realistic goal of five minutes, gradually increasing the time until you are walking for thirty minutes. Walking will help you to:

- improve your mood
- be happy
- improve your balance and coordination
- maintain a healthy weight
- increase your energy levels
- prevent or manage various conditions, including heart disease, high blood pressure and type 2 diabetes
- strengthen your bones and muscles.

Rest

The antithesis of exercise. What does rest look like for you? It means different things for different people and is never a case of 'one size fits all'. Rest is important. It stops you getting to the point of exhaustion so that you have to stop what you are doing, regardless of what you are doing. It stops you being irritable. It gives you space to just be. Planning for rest is a critical part of BPC management; by planning your activities, you can plan to rest too.

Only you know what type of rest break works for you, for how long and when. It could be:

- a few short rests, or power naps
- one longer rest at the same time each day
- resting between activities.

Try not to nap after 3 p.m., and only nap for up to twenty minutes. The quality of rest is key though. Try to make your rest as complete as possible. This means aiming to switch off your mind and body, and more importantly, asking those around you to understand how valuable this time is for you. You need to be quiet and undisturbed.

Diet

It is well known that there is a strong relationship between mood and food. We know that unhealthy eating patterns can cause mood swings. Blood sugar fluctuations and nutritional imbalances are often to blame. Without a steady source of fuel from the foods we eat, our minds and bodies don't function well. Here's how some unhealthy eating habits can alter your mood and emotional well-being:

- Skipping meals. Missing a meal, especially breakfast, can lead to low blood sugar. This will likely leave you feeling weak and tired.
- Cutting out entire food groups. If you reduce the variety of foods in your diet, it can be more difficult to get all the essential nutrients you need. Low levels of zinc, iron, B vitamins, magnesium, vitamin D and omega-3 fatty acids are associated with worsening mood and decreased energy.
- Eating too many refined carbohydrates. High intakes of unhealthy, processed carbohydrates, such as white bread and pastries, cause blood sugars to rise and fall rapidly. This can lead to low energy and irritability.

Beyond mood and general well-being, the role of diet and nutrition in mental health is very complex and has yet to be fully understood. Some evidence shows that food can contribute to the development, prevention and management of mental health conditions, including depression and anxiety disorders.

Things to ask yourself are:

- How regularly do I eat? If your blood sugar drops, you might feel tired, irritable and depressed. You need to eat regularly to keep your sugar level steady, and choose foods that release energy slowly.
- Do I stay hydrated? If you don't drink enough water, you may find it difficult to concentrate or think clearly. You might also start to feel constipated (which puts no one in a good mood).
- Do I eat five a day? Vegetables and fruit contain a lot of the minerals, vitamins and fibre we need to keep us physically and mentally healthy.
- Am I eating enough protein? Protein contains amino acids, which make up the chemicals our brains need to regulate our thoughts and feelings. It also helps to control blood sugar levels.
- Am I eating the right fats? Our brains need fatty oils (omega-3 and -6) to keep them working well. It's important to eat the right ones.
- Do I drink too much caffeine? Caffeine is a stimulant. Having too much can make you feel anxious and depressed, disturb your sleep or give you withdrawal symptoms if you stop suddenly.¹³

13 Mind (2017). Mood and Food. [PDF] London: Mind. Available at: <https://www.mind.org.uk/media/34727115/food-and-mood-2017-pdf-version.pdf> [Accessed 4 Dec. 2019].

Looking after someone with BPC

“I love my husband so much but feel I’m letting him down by saying, ‘You can’t do that,’ and other things I say. Then I think he’s not a child, but I just can’t help it.”

Caregiver

Meeting your own needs

This next section outlines how you, as a caregiver, can help the patient and make life a little easier for yourself. Much of the previous section is as relevant to you as it is to others. For example, as a caregiver, you have a right to rest too. Being a caregiver is not a role you applied for, nor is it one for which you have had any training. You need to know your sanctuary, know how and who to ask for help, and be comfortable in gifting yourself the time to be the person you were before you became a caregiver. What is important to you?

So, diet, rest, exercise, knowing where your sanctuary is, doing things that make your heart sing – all of these are about the magic of the ordinary but will make a huge difference to your quality of life.

BPC can be unpredictable. So a key part in being a caregiver living with someone who has a brain tumour is to be agile and tolerant, accepting of uncertainty and to manage expectations – your own and those of your loved ones. This is quite a tall order when, as a caregiver, you are already digging deep. You may find yourself having to dig even deeper, but remember, too, that you can build a team around you to help you.

The golden rule? Never be afraid to ask for help. If you were in the position of being able to reach out and help someone in your shoes, you would. People are only too happy to help, but sometimes it helps to go with a specific ask. Download our caregivers leaflet, which outlines some things you could ask of those around you. bit.ly/walkamilecarer.



The second golden rule? Always remember that this behaviour, no matter how hurtful it is, is not directed at you personally. They are not being deliberately difficult; their sense of reality may be very different from yours, and they are responding to their own needs.

Communication challenges

Language and communication can be affected by brain tumours. Patients may struggle with finding the right words to use, speaking words in a logical pattern, reading and writing, or understanding language, depending on the location of the tumour. This is referred to as aphasia. This can lead to frustration, guilt, anger, embarrassment, inadequacy and helplessness. It can be disempowering for both the patient and the caregiver. Here are some simple tips to help:

- Give the patient time to talk. Speak slowly and clearly, and stay calm.
- Use visual prompts to help get the message across.
- Acknowledge and verbalise the emotion the patient feels at being unable to communicate in the way that they want.
- Seek professional help if necessary.

Managing and reducing out-of-character behaviour

It is important not to see the behaviour as just another symptom that needs treating. Try to work out why the person's behaviour has changed. Here are some clear steps to help.

1. Define the problem:

- Is the person's behaviour really a problem?
- Is the problem the reaction of others towards the person, or is it towards the behaviour?
- Is it a response to an interaction with the person?

2. Consider the situation and look at the circumstances. The mood journal may help here.

- When and where does the behaviour happen?
- Are there times when the behaviour doesn't happen?
- Does the person always behave the same way in the same place?
- Are there patterns to the behaviour?

3. Assess the person in the situation. Do they seem to be:

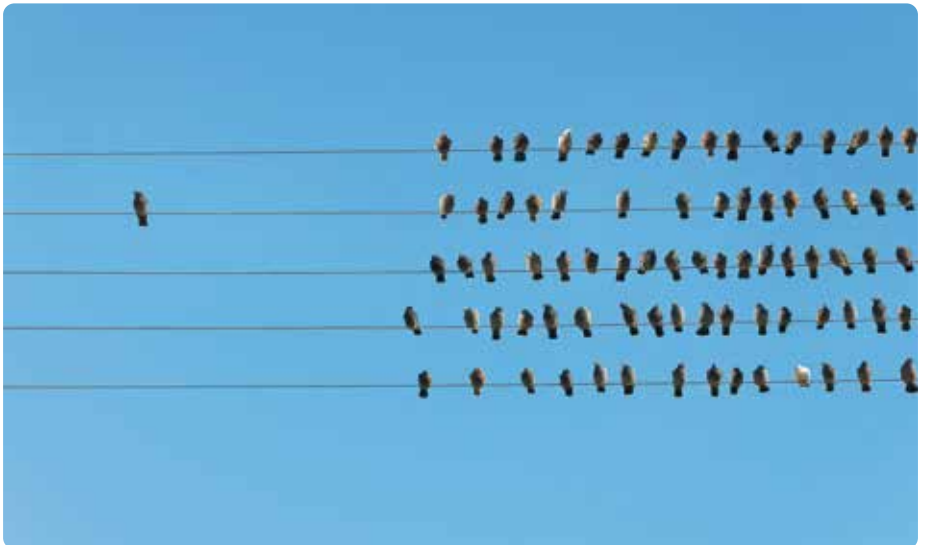
- in pain or discomfort
- unwell or tired
- overstimulated
- bored
- lacking in social contact
- anxious
- embarrassed
- ignored
- misunderstood
- responding to an unpleasant incident, a change or a provocation?

Once all these have been considered, you may be able to develop a strategy to manage the behaviour. Talk to the person and those around them, and come up with a plan. Start to make some changes, and review whether they have made a difference. It might take some trial and error to find effective solutions.

Reducing the likelihood of out-of-character behaviour

Simple measures include:

- ensuring continued social relationships
- encouraging the person to engage in meaningful activities
- reducing unnecessary noise and clutter
- providing people with familiar personal items
- maintaining a comfortable sleeping environment
- engaging the person in enjoyable and meaningful activities
- spending quality time with the person – perhaps chatting or sharing a task together
- developing a structured day.



Aggressive or combative behaviour

Some behaviours present special challenges. In rare cases, behaviour can become aggressive or combative. Aggressive behaviour is particularly difficult when safety becomes an issue. The best strategy is to pay attention to warning signs of growing anger or threats of violence. Tell your doctor, and try to resolve the problem before it escalates. Sometimes just moving to a different space can help. When dealing with an agitated person:

- Try to create a calm environment. Reduce noise, bright lights, excess movement and the number of people in the vicinity. Alternatively, remove your loved one from stressful situations.
- Speak calmly and maintain eye contact. Assure the person of his or her safety. Ground the person by identifying yourself and stating your intentions.
- Find out if something specific is bothering the person, and resolve the problem. For example, the person may be hungry, thirsty, tired, afraid of something or may need to go to the bathroom. Try to calm the person by encouraging him or her to talk and by listening to his or her complaints. Don't disagree or argue with the person. Let the person talk until he or she calms down.
- If the person becomes combative, remain calm. Take a few steps back and give the person plenty of room. Continue to agree and assure the person that he or she is safe.
- Assess the level of danger. If the person is about to hurt himself or herself or someone else and it is safe to intervene, step in and say 'Stop' or 'No' in a calm but firm voice. Gently restrain the person if possible.
- If you believe your own safety or the safety of others is at stake, do not hesitate to get help. If you call for outside help, make it very clear that your loved one is very ill and confused.
- Inform your doctor immediately of episodes of uncontrolled rage, violence or any dangerous, impulsive behaviour.



Dealing with emotion – react or respond?

“My wife says that everything makes me angry now and she hates it. I don’t want to be angry, and I’m not an angry person at heart, but so many things just seem to stress me out and irritate me, and that comes out as me being grumpy or angry. It’s horrible.”

Patient

Emotional maturity and emotional intelligence are key skills we use daily in maintaining healthy relationships. But these skills can be impacted by a brain tumour and its treatments. This can lead to a breakdown in communication and, ultimately, complications in or even the break-up of relationships. There is no way to navigate relationship politics without these skills.

An interaction may appear to be happening between two people in the here and now, but the reactions, the language and the emotions being expressed are all deeply rooted in two very separate histories and two unique experiences.

In the white heat of the moment, try to remember two words: react or respond. Choose 'respond'. When you find yourself in a disagreement with another person, it is natural to feel some sort of emotional response – particularly a negative one. Acknowledge the emotion (anger, fear, frustration) and respond; don't react. This is how you respond:

1. Walk away

Just knowing this can help you as a caregiver. There will be times when you feel you are being tested to the very limit. Nothing triggers us as emotionally as our relationships with other people. And the closer the relationship, the more likely we are to be affected. We may feel set off by each other's words, a tone of voice or facial expressions. We may read between the lines and infer all kinds of meaning from our partner's behaviour. We may just be bone-tired and fed up and wishing we were anywhere else than in the place we are in now. That's okay – it's a human reaction to a human situation. Walk away, move to a different space, breathe – this will create a shift in the way you are feeling.

2. Offer reassurance

“I don't want sympathy, just understanding. Every day is a learning curve and an adjustment.”

Patient

When you re-enter the space, you will probably find the moment has passed. Try to think about how the person is feeling, what they are trying to express and how to support their emotions. It may help to validate the person's feelings (e.g. 'I can see that this is difficult for you.'). They are likely to respond to your behaviour and communication, so if you are frustrated or angry, it may exacerbate the situation. Offer the person gentle reassurance. Humour can also deflate a situation.

3. Is it really a problem?

Consider whether the behaviour is really a problem. If it is disrupting a particular activity, such as washing or dressing, ask yourself if this task really needs to be done right now or if you could come back to it later. Sometimes ensuring a safe environment and leaving the person to do what they want may be the best option.

4. Have I had enough?

If you are exhausted by the person's behaviour, ask friends and relatives to spend some time with the person so that you can have a break. Build these breaks in regularly; you'll feel better able to cope. If the person is frequently or persistently behaving out of character, consult your GP.



How not to feel guilt and resentment

“Why do I feel I am letting the patient down with the help I can and can't give?”

Caregiver

Guilt might be an ‘overrated trip’, but we all know it’s there. And it can be crippling. It can fuel the vicious cycle of resentment, which fires guilt, until it impacts on the warp and weft of the fabric of our lives.

When put into a situation that we didn’t choose, it’s not uncommon to feel negative and resentful. And when you spend so much time and energy caring for the person, it’s natural to experience caregiver resentment – no matter how much you love or care about them.

For example, you might resent the overall situation, their illness, certain behaviours, unhelpful family members or unsupportive friends. It’s pervasive and increases stress.

How to break the cycle

There are two types of guilt. The first is healthy and appropriate guilt, when you know you’ve done something wrong (eating that whole packet of biscuits). This is known as ‘healthy’ or ‘appropriate’ guilt, because it serves a purpose in trying to help redirect our moral or behavioural compass. Your brain is telling you that what you did is just wrong. The other type of guilt is less healthy. This guilt happens when you have done nothing wrong. There’s nothing to feel guilty about, yet we still do. This is known as ‘unhealthy’ or ‘inappropriate’ guilt, because it serves no purpose. This is the type of guilt that comes with being a caregiver.

No amount of being told ‘you have nothing to feel guilty about’ will make any difference.

So what can you do?

Here are some tips:

1. Recognise that your struggle is valid, no matter what you're struggling with.

Don't be ashamed of how you feel – you're not the first to have felt like this, and you won't be the last. Talk to other caregivers about the way you feel.

2. Realise the ways in which you're already resilient.

You will have been through something in your life that was challenging. Think about two of the toughest times in your life before this. How did you get through these? What strategies did you use? You will already know something about what it means to be resilient – you just haven't thought about it before.

3. Don't wait for the situation to fix itself.

Ask yourself 'What am I going to do about this?' rather than 'When will I be released from all of this?' It may not be solved overnight, but reframing the problem can help.

4. Know your strengths. Use them.

If you are feeling so lost you don't know, ask someone close to you. Grab onto these people – they will see you through.

5. Don't do it alone.

One thing resilient people do is seek support. They use other people and seek help. They build a team around them.

6. Know your sanctuary.

You may not be able to fix the problem, but you can protect yourself from being overwhelmed by the situation. Know your escape and use it often. It doesn't have to be anything remote, hard to access or expensive. It could be a walk in the sun, an hour with a good book or friend, listening to music. Learn to take a mental break.

7. Be kind to yourself.

By learning to cope with negative feelings and having that experience, we grow in confidence and in preparation. It's easy to see how broken you are rather than how strong you are. See yourself as someone who is already better prepared for life's stressors, as you have already lived through so much.

8. When conflicted, go back to your core values.

If something is askew in your world and you feel stress, list your core values. One or more of them will be compromised.

Finally, pick up the phone to talk with or email *brainstrust*. We can help.

Who's in your team?

That's easy. List the people who are in your team. These are people who you know would be only too happy to help out, who will go the extra mile for you. Get out there and feel like there are people who see you and understand you, and who care. People want to help. And you can help them by being specific in your ask. It's not always easy to ask for help when it's offered, but give people the opportunity to step up to the mark. By asking, you will be helping them too. They want to be involved.



Questions to ask

Remember why you are asking. Asking is not a sign of weakness or helplessness. It's a sign of strength, of organisation, of wanting to get on with things. Think about things you'd like help with.

For example:

- Do you need someone to sit with the person for a couple of hours?
- Are there things you hate doing that someone else could do?
- Would you like to have dinner with friends or family so you can be you for an evening and not a caregiver?
- Would it be good to have someone on standby who you could just call upon?
- Are there practical things you would like help with, e.g. collection of prescriptions by someone who is often in town and has access to a pharmacy?

Good questions are key – they elicit information and drive forward action. But they require effort. A good question requires time to think about it, to write out and to rethink it. The extra effort is worth putting in; the return you will get is huge.

Here are some good questions:

- What are you struggling with the most?
- Who's in your team?
- What's important to you?
- What are you frightened of?
- What's your life motto?
- Where's your sanctuary?
- Where's your anchor?
- What helps you most?
- What do you need?
- What is already in place?

- What are you missing?
- Who are the people who can help?
- What's important to get right?
- What's going to get you through?
- What questions do you need answers to?

What to do in a crisis

If at any point you feel that life is in danger, then call 999. Try to remove yourself from immediate danger and seek help.



What makes your heart sing?

Which of these do you like to do? Highlight key ones and build them into your activity planning. Promise yourself to do one a day, as a minimum. Add your own.

Phone a friend	Paint your nails
Watch a favourite film	Treat yourself to something new
Have a massage	Light a candle
Curl up with a good book	Have clean sheets on the bed
Play word games	Thump a cushion
Enjoy a walk in the sun	Declutter a cupboard
Sit by the sea	Stretch
Watch people from a café	Make a list
Go out for dinner or have a takeaway	Promise yourself to do something new this week
Walk a dog	Have a bath
Watch a comedy	Look at photographs
Cuddle someone or be cuddled	Share a smile
Surf the internet	Plan a weekend away
Wear something cosy	Dance
Have someone wash your hair	Clear out an in-tray
Tell someone what is special about them	Meet a friend for coffee and cake
Bake a cake	Plan a get together with friends

Mood journal

	Happy	Sad	Angry	Tired	Excited	Anxious	Other	Notes
6 a.m. to 8 a.m.								
8 a.m. to 10 a.m.								
10 a.m. to 12 p.m.								
12 p.m. to 2 p.m.								
2 p.m. to 4 p.m.								
4 p.m. to 6 p.m.								
6 p.m. to 8 p.m.								
8 p.m. to 10 p.m.								
10 p.m. to 12 a.m.								
12 a.m. to 2 a.m.								
2 a.m. to 4 a.m.								
4 a.m. to 6 a.m.								

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Links

Support can be found in all kinds of places, ones that maybe you haven't considered. Some of the mental health charities can help, as can other charities that support neurological conditions.

www.mind.org.uk

MIND is the national mental health charity. It has a network of local MINDs. Services include talking therapies, crisis helplines, drop-in centres, employment and training schemes, counselling and befriending.

www.alzheimers.org.uk

This charity has a separate section on managing behaviour changes.

www.stroke.org.uk

Having a stroke changes so many aspects of behaviour and emotion. The Stroke Association has some tips on how to manage BPC. Caregivers are also supported.



www.encephalitis.info

The Encephalitis Association has a section written by a clinical neuropsychologist and has downloadable fact sheets.

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To find out more about our work, call **01983 292 405**, email **hello@brainstrust.org.uk**, visit **www.brainstrust.org.uk** or follow us on  **twitter.com/brainstrust** and  **facebook.com/brainstrust**.

Behaviour and personality change: A resource to help you understand and manage behaviour and personality change when living with a brain tumour, edition 2, published by *brainstrust*, September 2024, due for review September 2027.