



How to live with uncertainty

brainstrust information sheet

Know Hows are published by *brainstrust* to help people living with a brain tumour to understand current topics. They are produced with input from relevant scientific and clinical experts and are written in a way that should help you to understand often complicated topics.

If you have an idea for a Know How, then please let us know.

If you have any queries, don't forget you can talk to one of our support specialists on **01983 292 405**, or email **hello@brainstrust.org.uk**.

'I've learned that some poems don't rhyme, and some stories don't have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious ambiguity.'

Gilda Radner

Why do we need this Know How?

Living with uncertainty is when we live with the anxiety that something bad may happen. When you have been diagnosed with a brain tumour, you feel that your life is less secure, more fragile than it once was. You find yourself living in a space where nothing seems certain any more. It's a scary place to be, and it can leave you feeling out of control, helpless and overwhelmed.

Living with a brain tumour brings uncertainty from a variety of things:

- There is the knowledge that at some point your tumour could progress, so is that latest headache a sign things are changing? Or is it just dehydration? You find yourself paying attention to every potential symptom.

- Maybe you are living with seizures and the uncertainty they bring.
- Or perhaps you are anticipating nausea and pain from treatment and are anxious about becoming less independent.
- Maybe you are a caregiver who has called home, and the phone isn't being picked up. You drop everything to see what's happened. In the past, before diagnosis, would you have done the same thing? Probably not.
- You may wonder if the treatment you are receiving is the best. Are you missing something?
- And your job – what happens if you can no longer do the job you have? Or are you worried about redundancy now that you have a brain tumour?
- As a caregiver, you may be anxious about having to reduce hours, or give up something that gives you purpose, to look after your loved one.

These are all real, valid anxieties that undermine your confidence. The negative chatter in your head becomes a loud voice; you stop making

plans just in case you can't make it – that holiday, that lunch with friends, that trip to see the family. And so your world becomes smaller. Also, these feelings may develop into physical symptoms – your sleep becomes affected, or you find it harder to concentrate. Your mood changes and your heart rate increase – all impact on your health and well-being. So how do you cope? How do you silence the anxious voice? How do you manage to live with uncertainty without dissolving into stress and worry? How can you protect yourself?

What does this mean?

Although each of us differs in how much uncertainty we can tolerate, being diagnosed with a brain tumour can challenge even the most risk-tolerant among us. We love a sense of order, of predictability, and so randomness and chaos can be very frightening. Finding a way to live comfortably with uncertainty means that you can lead a fulfilling life, one where you are at peace with uncertainty and can focus on what is important to you. Being comfortable living with uncertainty, building emotional resilience, will not stop you feeling stressed or experiencing challenging emotions. These are what make us human. But they will mean that you cope better, that you feel more in control and less overwhelmed.

How can I become comfortable living with uncertainty?

- *Think about what matters most to you.* It's easy to lose sight of your purpose and direction when living with a brain tumour. Ask yourself, who are the most important people in my life? What are the values that drive me? If you want help finding out what these are, then contact *brainstrust* – we can help you. Checking in on your values can help you get back on track and give you renewed purpose. These values will then become your beacon to help you decide where you are going to invest your time and energy.
- *Let go of the struggle.* We love to be in control. But we can lose sight of what we can control and what we can't when everything feels

like it is slipping away from us. You cannot change the fact that you are living with a brain tumour, but you can change how you respond to this. Acceptance can be a gift. Find out more about acceptance www.brainstrust.org.uk/acceptance.

- *Understand that we can never achieve total certainty.* Certainty is an illusion. Life before your brain tumour was not necessarily any more certain than it is now. We take for granted that things will stay constant, but the reality is that our lives can be turned upside down at any moment. It's how we deal with this that is important. Just because uncertainty now has its name up in flashing neon lights doesn't mean that it wasn't there before; it's just that you are more aware of it. Once you see this, it's easier to loosen the grip of uncertainty.
- *Exercise.* Animals shake themselves to relieve tension and energy; we could learn so much from the way animals respond to stress. Running, walking, yoga, swimming, weight training – all are good for discharging the stress we carry around.
- *Mindfulness.* Allocating time to being mindful gives you the opportunity to create space between you, your thoughts and your reactions. Just finding a few minutes every morning, or at the moment when the day ends and the evening begins, will provide a space for you to calm your mind and reduce anxiety. There are plenty of apps that can help, or just a focus on breathing:
 1. 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.
 2. Breathe in for three counts and out for five counts.
 3. Pause between each breath.
 4. Notice how the air feels and how your body moves as you breathe in.

- *Get help.* It's easy to feel alone. But it is part of being human to suffer. So the feelings you have are the same feelings that millions of others have had. Everyone is dealing with uncertainty in their lives. Find a friend who has been through a tough time. Talk to us at *brainstrust*. No matter who it is, find someone who can help you reconnect with yourself when you start to hear that negative chatter.

Learning to live with uncertainty is one of the greatest challenges in life. It's hard, but learning to live with it is an essential skill for living a fulfilling life. We can learn so much from uncertainty, and even more about ourselves in the way we manage it. So be open to uncertainty, live in the moment, and act on your values.

Ask yourself

- What specifically am I struggling with?
- What makes it hard?
- What are my values?
- Who's in my team?
- Who can I talk to?
- When can I weave my next 'pause' into my day?

Contact

Talk to *brainstrust*. We can help. You can call, write, type, text. Email for help and support: **hello@brainstrust.org.uk**. Telephone: **01983 292 405**.

Other helpful links

www.brainstrust.org.uk/brain-tumour-support

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Production of *brainstrust*'s information is supported by the Anna Horrell fund. Anna, wife and mum, tragically passed away in August 2017 after a valiant fight against a glioblastoma. Throughout her life and her illness, she was an inspiration to us all, fighting bravely and cheerfully in the face of adversity. She was the beating heart of our family, and her loss left a hole in our lives that can never be replaced. In her incredible memory, we are passionate about helping others diagnosed with a brain tumour to navigate this most difficult of journeys.

Mike, Tom, Rebecca, Charlie & Sophie