



# 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**.

### Why do we need this Know How?

When you are diagnosed with a brain tumour, or you are caring for someone living with a brain tumour, it undoes everything you have spent your life building. You cycle through the emotions of fear, anxiety, sadness and anger. The reaction is unguarded and visceral. Inevitably, the values and beliefs that have made you the person you are come into question – your sense of identity and purpose, and your relationships with those around you. Patients feel remorse and guilt. Caregivers feel isolated and lost. Some professionals feel ill-equipped and uncertain. These challenges resonate:

- threat to way of life
- the certain knowledge of neurocognitive decline
- lack of control over behaviour
- impact on relationships
- problems leading to isolation
- access to support.

To cope, you need to think about a different mindset – what has worked in the past when you were facing change doesn't seem to be working now, so you have no alternative but to step away for a moment and think about how you have survived in the past. What did you do that saw you through? How do you need to adapt now to make sure that you don't become lost? It's also important to remember that you have been, and always will be, a person first and a patient second.

# Why is this important?

- You spend more time being a person than you do a patient.
- As a person, you are inherently resourceful.
   You turn to help outside the clinical setting when you are a person rather than a patient.
- Emotions and values drive the great decisions, not clinicians alone.
- As a person, you look for possibilities; as a patient, you focus on problems.

#### What does this mean?

If you can find a new normal, it means that you own the situation. You take control. You build a team around you who can help. You know where to go to solve problems. You live the life you want despite living with a brain tumour. It means you won't tolerate things that drain your energy. It means you are in charge, making the decisions that reflect your values, your situation and your attitude to risk. It means that people will listen – and you will be heard.

#### How can I find a new normal?

It's easy to say all these things – harder to do them. There are some simple things you can do to find a new normal. Above all, be kind to yourself. There will be days when it feels like the whole world is against you; as you become more accustomed to what has happened to you, these days will become fewer. Here are some strategies:

- Think about your life as a story and this as the next chapter in your book. Yes, it's a hard chapter, but it will come to a close – this will help you to stop feeling engulfed. This isn't the chapter you will always be in. What will you miss about this chapter? What will you want to hold on to and value?
- Adjust your expectations. Give yourself a break.
  Lower your expectations. Focus on what you
  can do, what you are achieving, not what you
  can't do and have lost. If you hold on to the
  expectation that you're going to be able to do
  everything you did before the diagnosis, you
  are going to be frustrated. So be flexible.
- Accept. You can find out more about acceptance <u>here</u>. Accepting the situation means that you have recognised reality, and this will enable you to move on, to stop being stuck in the moment. New ways of seeing things will appear. You'll problem solve, share, learn, re-evaluate and reflect.

- Make positive choices every day this will make this your chapter and not someone else's.
- Don't view everything that you had or that you were doing as essential.
- Know where your sanctuary is. Your sanctuary is a place where you feel safe, where you are not dancing to someone else's tune, where you can just 'be'. It doesn't need to be exotic it could be sitting on a bench feeling the sun on your face, an hour with a good book, a walk with a friend. Gift yourself this time and space. You'll feel stronger for it.
- Know your boundaries. Boundaries should be based on your values, the things that are important to you. Boundaries are yours they will help you write your chapter. Know your boundaries before you enter a situation. Knowing what your bottom line is will mean that you're less likely to do something you are uncomfortable with.

### Ask yourself

- What's important to me?
- What are my values?
- How do I want to be in the weeks, months, years ahead?
- What am I tolerating?
- What's my bottom line?

#### **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

Living well with a brain tumour

How to bring structure to your day Know How

Mindfulness Know How

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