



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 living 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 feel lost, undone, fearful of loss or what lies ahead. It is at these moments, when you feel vulnerable and fragile, that it is easy to lose sight of what is important to you. Having boundaries brings back a sense of control, of ownership, and helps you to navigate what is important to you.

What are personal boundaries?

Boundaries are the limits and rules we set for ourselves, particularly in relationships. It's healthy to say no, but you need to know your boundaries to be able to do this. Boundaries should be based on values, or things that are important to you. For example, being with family may be one of the most important things to you, so you would set boundaries about other demands on your time so that you are with your family. Finishing a task might be important, so you say no to an invitation that would stop you finishing off the work you have to do. Reflecting on boundaries can also bring insights about who you are and

what your purpose is – these are things that are thrown into relief when you are living with a brain tumour. Ask yourself 'What am I tolerating?' Your answers will give you a guide to where your boundaries could be clearer. For example, you could be a caregiver who finds themselves spending more time in the kitchen, making tea for the constant stream of visitors, than you do sitting with your loved one. Having a boundary would enable you to limit the number of visitors so that you can spend your time how you want.

What does this mean?

We have different kinds of boundaries:

Physical boundaries. You'll know when someone invades your physical, personal space. This could be someone standing too close or opening a letter that isn't addressed to them, reading a text on your phone.

Intellectual boundaries. It's healthy to debate things, but not at the expense of our own beliefs and values. We should always respect someone's point of view, even if we don't agree with it. If you are belittled or dismissed, your intellectual boundary is violated.

Emotional boundaries. These boundaries relate to our feelings. Your brain tumour diagnosis is yours to own. If you tell someone in confidence, it is not their information to share. But you also need to be aware that as soon as you share personal information, you risk the right to own it, even if you think you are telling someone in confidence.

Material boundaries. Healthy material boundaries set limits on what you will share and with whom. If someone 'borrows' something that belongs to you without asking, this violates your boundary.

Time boundaries. We set aside time for different aspects of our lives, such as work, family and relaxation. When someone doesn't observe these boundaries – for example, they call when they know you are having a family meal, or they keep you waiting for a meeting – this violates the way we use our time.

Sexual boundaries. We all know what we feel comfortable with when it comes to sex and relationships. Being touched in a way that makes us feel uncomfortable, or being belittled or pressured, crosses boundaries.

How can we set boundaries?

Knowing your personal boundaries means that you own the situation. You take control. You live the life you want despite living with a brain tumour. It means you won't tolerate things that make you uncomfortable. 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.

 Know your boundaries. Boundaries should be based on your values, the things that are important to you. Boundaries are yours, and it is important to 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.

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- We all have the right to say no. But how we say no is important. Say no clearly, and without ambiguity, so that the meaning is clear and people know what it is you want or don't want. Some phrases that are useful include:
 - I'm not comfortable with that.
 - No, not right now.
 - I'm not going to do that.
 - I can't do that for you.
 - This isn't working for me.
- Use confident body language. Look the person in the eye. Use a steady tone at an appropriate volume.
- Be politely firm. Stick to the facts and avoid emotion.
- Plan what you want to say. You might find our difficult conversations guide useful.
- Consider compromise give and take is always welcome and gratefully received.

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

How to be assertive Know How

Living well with a brain tumour

How to build a supportive team around you Know How