know how How to have a voice as a caregiver

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 feel trapped. I can't go to college, because of my mum's brain tumour. She has no one else. If I speak out, she'll think I don't love her.'

Teenage caregiver

'I wish I knew the prognosis. I know nobody knows – but a ballpark would be good. We've so much we still want to do, and I don't know whether to plan for 3, 6, 12, 24 months. I can't ask the consultant. He might get the wrong impression.'

Caregiver of a person with a glioblastoma

Why do we need this Know How?

As a caregiver, how many times have you not been able to ask the questions you want to in a consultation, or express an opinion openly without fear of causing upset? Or even just say, what about me? Where is my voice in all of this? It is hard to have a voice as a caregiver. You have to be:

- an enabler for others
- secure around uncertainty
- open with not knowing
- sure that your inner dialogue is constructive.

All of this when most likely your world inside has fallen apart. It's a daunting role – you need compassion, fortitude and a fierce resilience. And more often than not, you are living these values on behalf of your close person, but never for yourself.

What does this mean?

A tip from the airline industry: 'secure your own oxygen mask before assisting others.' If you are to help others, then you need to look after yourself first. It's so much easier asking for something for someone else than it is for you. We attach feelings and emotions to things we'd like for ourselves, in a way that we don't when doing something for someone else. Hold on to this thought, as this will become a strategy for being heard (see point 5 below). But over time, this erodes who we are: our purpose is lost; we become a shadow of who we were; we deny our own needs to meet those of others. This leads to psychological distress, undermining our health and well-being. And then this also prevents us from being effective, not just as a caregiver but in all aspects of life. You are not a superhero – you will be weathering the storm of fear, denial, anger, guilt, hope, uncertainty. And if you don't acknowledge this, you will be starved of oxygen.

How can I have a voice?

1. Information is power. Keep notes, order a brain box (www.brainstrust.org.uk/the-brain-box), talk to *brainstrust*. Before a consultation, sit down with your close person and ask what you both need from the appointment. If your needs are different and you want more, or less, information, agree that one of you will leave the room while the information is sought. The clinical team won't mind. Or arrange a separate call with the clinical nurse specialist. The important thing is to talk beforehand and be open about your needs. It doesn't matter if you know different things. And you can also talk with *brainstrust*.

2. Pick one person to be your spokesperson. Relay all information to friends and family through your spokesperson. This means you do not have to report on scans, treatment updates, appointments, etc. There is nothing worse than having to keep repeating information or telling the same story – it means you become stuck in that space. And this takes up valuable time when you could be doing more important things.

3. Plan what you want to say. Conversations work better if they are planned and rehearsed (even if it is just in your own head). You don't need to plan it word for word, just the key points you'd like to get across. Make sure you have a full understanding of the situation from your perspective. It might also help to try and see it from the other person's point of view. You can't plan much more than that. Remember that you have very little control over how the person you're talking to will respond. Do your best and believe it will help. More information about how to have a successful conversation can be found in our 'How to have a difficult conversation' resource.

4. Focus on what it is you need. What does the other person need to hear? There are some things you can do to give yourself the best chance. Be firm in your request – instead of saying, 'I can't do this any more,' say, 'I'm exhausted and need a rest.' Or say, 'I would like to speak to you about some respite care,' rather than, 'I was wondering if I could have a break.'

5. How to silence the inner critic. This is the voice that tells you not to seek help, that you should be able to cope. Let's reframe this. Imagine you have a friend who has been caring for someone and who is at breaking point. Then imagine you are in the same situation. What would you say to yourself? What is the learning here?

Your friend	**You**
What do you think about your friend's situation?	What do you think about your situation?
How do you feel about your friend's situation?	How do you feel about your situation?
What would you suggest your friend does?	What would you want a friend to suggest to you?
How would you want to help them?	How would you want them to help?
How could your friend help themselves?	How could you help yourself?

Ask yourself

- What specifically am I struggling with?
- What do I need to be different?
- What do I want for the other person?
- What do I want for myself?
- What do I need for myself? For them?
- What does a good result look like?
- When's the right time to talk?
- What are the reasons to hold the conversation? And to not?
- What can go wrong?
- What do I sense?
- What do I know?

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

www.brainstrust.org.uk/wp-content/uploads/2018/01/how-to-have-difficult-conversations-guide.pdf

www.brainstrust.org.uk/brain-tumour-support/quality-of-life/practical-help/knowhows

References/resources

https://www.carersuk.org/images/publications/Self-advocacy_UK/How_do_you_see_your_own_needs.pdf (accessed February 2020)

Expertly checked and updated March 2020.

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