



How to hold a difficult conversation



Living with a brain tumour can mean that our values and beliefs, our sense of identity and purpose, and our relationships with those around us come into question. This can lead to a desire to have some tricky conversations with those closest to us. This guide will help you to talk about what you are facing.

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Introduction

Many people are unsure about how to talk with someone who might be distressed or in difficulty. It can also be hard to know how to talk when you are in crisis. Questions about the illness, its symptoms, its meaning or its impact can be challenging to ask. Other people are involved in this journey too, with whom you might need to talk. This guide will help you talk to a close person, such as a main caregiver or partner, check in with a child's sibling, break news to family and friends, speak to an unsupportive friend, or to a doctor or school that you're having difficulty getting onside, and so on.

Often, anxiety around a conversation is due to worrying about how the other person will react to what you want to say. Be assured that thinking about the conversation is often scarier than the conversation itself. Have courage and be ready to 'go there'.

We can't help you know exactly what to say, or predict how it will go. You may decide you or the other person is not ready to take on the conversation, and choose to drop it. Or it may be the start of many conversations. If you haven't come to terms yourself with what it is you need to talk about, then take some time to get it straight in your mind first. Taking time to process your thoughts is time well spent.

This guide will help you get your thoughts together and clarify how you feel about what it is you're facing.

Aims

If you or your child has a brain tumour, we know you can be faced with conversations that are hard. Use this guide to decide whether or not to tackle a difficult conversation, and to prepare yourself if you do decide to go for it.

Here we help you to:

- 1. step back and reflect**
- 2. plan the conversation**
- 3. have the conversation**
- 4. think about children and consultations.**

There is not much research out there to help you in this. This guide has been written with the training and experience of expert authors: a psychiatrist with experience of talking to brain tumour patients and their families, an expert coach at Thrive Partners, two parent caregivers who have trodden the same path as you, and the trained coaches in *brainstrust's* support team.



Step back and reflect – does this conversation need to go ahead?

1. Step back and reflect – does this conversation need to go ahead?

You may be unsure as to whether to have the conversation or avoid it. It is important to think about what a good outcome would be.

Consider carefully the following questions to help you know whether you should go ahead with it or not:

- What do you want for the other person?
- What do you want for you?
- What do you need for yourself? For them? Want and need are different.
- What does a good result look like?
- When is the right time?
- What are the reasons to hold the conversation? And to not?
- What can go wrong?
- What do you sense?
- What do you know?

You could consider writing answers to these before you have the conversation. Or maybe put it in a letter.

Where are you now?

Are you in a place where you're thinking, 'No, this is not for now'? If so, what are your choices? If you're not going ahead with the conversation, how will you (or the other person) get your needs met? Give *braintrust* a call if you want to talk it through: **01983 292 405**. Or drop us an email at **hello@braintrust.org.uk**.

Or are you in a place where you're thinking, 'Yes, I must say something'? Read on.



2

Plan the conversation

2. Plan the conversation

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 to 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. Our experience shows it does!

- a. **When and where** – when talking to someone, including children, it is important not to force a conversation on them. Even if you're certain that the time is right, you might find that once you start, it really isn't. Children in particular will engage with the issue or ask questions when they're ready, and stop when they don't want to continue.

If you're planning on talking to a teenager or adult, you can think about when might be a good moment. Also, consider how you'd both be most comfortable. There is a lot to be said for talking while being next to someone rather than directly in front of them, which can sometimes feel confrontational or too intense.

And of course, think about the physical space where you could have the conversation. It should be free from distractions, have comfy seating and be quiet. We live in a very busy world, and sometimes we aren't aware of the distractions around us.

When you're ready, centre yourself: sit down, place both feet on the ground, and breathe deeply to calm yourself. This can help you to stop fidgeting and seeming nervous.

b. **Planning your opening** – set a concrete start point.

Here are some questions for you to think about. They are suggestions, and not all might be relevant to your situation:

- What is your intention for having this conversation?
- What do you want to achieve from this conversation?
- What do you want or need to say about how you feel at this time?
- What do you want for the person you're talking to?
- What do you want to say about what you think they're feeling at this time?
- Who do you need to spend time with?
- Who do you need to ask questions of? Get information from? Ask for help from?
- What do you most need to be different?
- How can you get what you need?
- What are you most frightened of?

c. **Exploration** – what do you need to know?

What do you need to have covered by the end of the conversation? Think about what questions you want to ask. Always try to ask an open question, using:



2. Plan the conversation

Avoid 'why' questions – they can make the other person feel defensive, and the answer is often 'I don't know'. Here are some examples of open questions. These aren't necessarily the right questions for you to ask, but they give you an idea of what open questions might be.

What ...?

- What are you spending a lot of time thinking about?
- What is worrying you?
- What is scary?

How ...?

- Right now, in this conversation, how do you feel?
- How do you see yourself?
- How can you get what you need?

Who ...?

- Who do you feel most able to turn to?
- Who else is important in this?
- Who helps you most?

Where ...?

- Where do you feel safe? (The place or people you go to when you need comfort or rescuing.)
- Where are you happiest? (Somewhere you enjoy going to clear your head, and that makes you feel better.)

When ...?

- When do you feel strongest?
- When are you most frightened?

d. **The decisions** – the actions or reflections that follow the conversation.

- What decisions would help?
- What is now needed?
- How can you both help each other at this time?

e. **Acknowledge and appreciate** – before the conversation closes, it is vital to acknowledge and voice appreciation. You could acknowledge the effort made in having a conversation, or highlight one of the positive qualities in the other person that you admire. Some examples are:

- ‘It’s taken courage to have this conversation.’
- ‘I know this has been hard for us.’
- ‘How you’re approaching this inspires me.’
- ‘You’ve brought honesty and compassion to this.’
- ‘I really appreciate us talking like this.’

f. **The closing** – the final words that you want to leave the conversation on and the words you hope they will come back to.

A photograph of two young women with long brown hair, seen from behind, embracing each other in a grassy field. The woman on the left is wearing a dark grey leather jacket over a maroon top. The woman on the right is wearing a blue denim jacket and a tan leather backpack. The background is a bright, hazy sunset or sunrise over a field, with a blurred building in the distance. A blue circle with the number 3 is in the top right corner.

3

Tips to improve the quality of any conversation

Listen

Listen, listen, and listen some more. This is particularly important when talking to children. Give them a chance to ask questions, and check for understanding. It will let them know that their views are important and you're taking their questions seriously. This will help minimise any unnecessary worry they have.

If the person you're talking to is visibly displaying emotion but not talking about it, react to it. For example, if they're crying, you could ask, 'What's hurting?' or 'What are they tears of?' (for example, hurt, pain, sadness). Again, you're allowing them the space to talk it through, and to be heard.

Ask questions

Conversations are a two-way dialogue, so allow time for the person you're talking with to ask questions. If you feel they need encouragement, you could ask open questions beginning with 'How ...?' or 'What ...?'

Don't be afraid of silence

Let silences occur, and give the other person time to say what they need to say. When you ask a question, be prepared to wait two to three minutes for a reply. Maybe even an hour, or a day. They may not be able to respond straight away, so be prepared to pick the conversation up when they're ready. If it's a good question, they will.

3. *These tips can help improve the quality of any conversation*

It's very easy to jump in as soon as there is a silence in a conversation, but it can be a golden time for reflection. The person you're talking with might be busy thinking or processing what you have told them. It's usually fairly easy to tell when someone is thinking, as they may look away from you and be still. Don't put words in their mouth.

Try to be aware

A valuable gift you can offer someone is to give them the space to talk. Allow them the moment to express what they're feeling. In this conversation, you need to be really aware of what is not being said.

Try to be aware of how the person you're talking with is thinking, feeling and behaving. Being aware of their body language and non-verbal signs can give helpful clues about what is really going on in their thoughts. This non-verbal communication – facial expressions, gestures, eye contact, posture and tone of voice – can convey much more than what is being said aloud. Say something like 'I notice that you are ...' name the emotion or response that you *see*'.

You also need to be aware of how you are thinking and feeling, and of your own body language. When your body language matches up with what you are trying to say, it helps build trust, making communication clearer and easier. If it doesn't, then tension, mistrust and confusion can arise. Try to remain open (don't cross your legs and arms) and be in rapport. For example, if they are talking quietly, talk quietly. If they are particularly difficult to talk to, you can try to copy their body language to make them feel more comfortable.

Voice what you sense

Voicing what you sense can be a powerful way to get started – never be afraid to trust your instincts. How do you think the other person is feeling? Simply let them know what you sense, ask them about it, and truly listen to the answer. For example, ‘I sense you’re not okay. Can we talk about it?’ gives them room to talk it through (and shows how attentive you are). They may try to shrug it off with ‘I’m fine’. If you believe they’re not, say so gently, but be ready to back off; they may not be ready to talk, now or ever. Sometimes talking is just not possible. Allow the other person total freedom to talk, or not. This might mean that you have to recognise, and then let go of, your own need to have the conversation.

Be yourself

Ask yourself: ‘What is really important here, for them and for me?’ How do you want the conversation to be remembered? Be authentic and speak from the heart.

When the conversation is slipping away from you or there is a lot of emotion

If you feel the conversation is veering away from you, let the person you’re talking with know you’re listening. Breathe slowly and deeply, and remind them you care.

If they are becoming very emotional, it helps if you can try to get to the bottom of what is making them feel upset, angry, scared. A useful word to use here is ‘specifically’, to get down into the root of the emotion and to make it less overwhelming and more understandable – for both of you. For example, ‘You say it is all very confusing. What specifically is confusing you?’ or ‘You say you are scared. Which part specifically is scariest to you?’

3. These tips can help improve the quality of any conversation

Don't take it personally. If the person you're talking to reacts badly, this is unlikely to be directed at you. Rather, it is the situation.

Use your instinct to judge the temperature – what is the emotion being displayed? And know that it will pass. You can use silence to buy time. If it gets too challenging, take a break or have a wander together. Move to a different physical space.

There may be times when the issue simply won't be resolved, and despite the hard work you put into the conversation, the other person won't accept the situation, particularly when the issue is emotionally charged. This is completely normal. It is important not to take it personally. Acknowledge that you tried your best.

Be resilient

You are bigger than the mood they're in. If they react badly or unexpectedly, remember it's not about you but what they're going through. When it's tough, they're not rejecting you but blocking the illness or the fear. This is normal too.

Who can help you?

You don't have to do this alone. If it's appropriate, have another person there. Is there someone who can sit with you during this conversation, either as a silent supporter or to help you get across what you're trying to say? Or if they can't be there for the conversation itself, can they help you plan what to say? Or be there to sound off to afterwards about how it went? Don't forget *brainstrust* can help you with this. Just call **01983 292 405**, or email **hello@brainstrust.org.uk**.



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Children and consultations

4. Children and consultations

Whether or not your child attends a consultation depends on their age and your sense of their understanding. Ultimately, it has to be a personal decision for your family to decide who to include in consultations. Research shows that it is good for the child if they are present, as it makes them feel included and reassures them that information is not being kept from them.

However, it also brings added difficulties for the parents or caregivers, who have to split their concentration between the clinician and the child, meaning that important information can be missed. You may also feel reluctant to ask certain questions that you don't want your child to hear the answers to.

Also, it may help if you can digest any distressing information before sharing it with your child, so that you're ready to answer any questions they may have. Therefore, you might want to consider seeing the clinician without your child when you are learning new and complicated information, but at regular check-ups, it would be good for them to be included. The clinician can help you manage communication of this information to your child. Don't be afraid to ask a member of staff if they would look after your child while you're talking with the clinician. Play specialists or other staff are often only too happy to do this.

Of course, you might not know which consultations will include new information, so discuss with the clinician as early as possible what you want your child to be present (and not present) for, so they are aware and can advise accordingly.

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