



# How to prepare for medical appointments 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**.

### **Why do we need this Know How?**

When someone you love is living with a brain tumour diagnosis, they will have regular medical appointments and check-ups at every stage of their pathway. These appointments are a key part of your loved one's clinical care and are an opportunity for you to get key information and ask questions about their condition and treatment plan.

It's not always easy as a caregiver to find your voice in a consultation. In this Know How, we will explore how you can feel prepared for medical appointments as a caregiver, how you can make the most of the time you have with your loved one's clinical team, and some strategies to help you feel more resilient and on top of things.

### **What does this mean?**

As a caregiver, you may find yourself taking on more of an administrative and advocacy role when it comes to your loved one's medical appointments. You may feel a responsibility to ask the correct questions and take notes, while also being emotionally supportive. It's a lot to ask of you.

A brain tumour diagnosis can often come with a lot of uncertainty, and often the outcome of a medical appointment can be a key factor in this. Waiting for an appointment can bring feelings of anxiety and fear for yourself as a caregiver and for your loved one with the brain tumour.

In order to feel like you are getting what you need out of a medical appointment, the key is to feel as prepared as you can and use strategies that can help you feel more relaxed and in control.

## How can I prepare?

The role of a caregiver comes with many different responsibilities. This can depend on your loved one's diagnosis and the relationship you have with them. As you prepare for medical appointments, it is important to make sure that both of you feel as prepared as you can. To support your loved one, it is important that you, as a caregiver, feel supported too.

### Before and during the appointment

- You may want to think about implementing some relaxation or mindfulness techniques in the build-up to your loved one's next appointment. You can do this together or separately. By making strategies like this part of your daily routine, it can help to give you the space you need to feel more prepared and in control. You can find some good suggestions here:

[Mindfulness Know How](#)

[Dealing with the overwhelm Know How](#)

- Medical appointments are an opportunity for you to ask questions and discuss your loved one's care with their clinician. Before the appointment, sit down with your loved one and discuss what would be a good goal for the appointment. What would make them feel it was time well spent? Then think about this from your own perspective. If, from this discussion, you find that you have different goals for the appointment, suggest that you have five minutes alone with the clinician. This allows you both to feel more in control of the situation, and it will mean that you both feel like you have a voice.
- Preparing questions that you and your loved one want to ask may sound simple, but it can help to refocus your mind if you have something written down to refer to. Our patient guides have some good suggested questions in them, covering different stages of the patient pathway: [brainstrust.org.uk/patient-guides](#).

- Discuss with your loved one what your role in the appointment is. It may be to take notes during the discussion, to take the lead and ask questions, or to be there as emotional support.
- You may find that more questions arise following the medical appointment. Ask the clinician for the contact details of someone you can get in touch with to ask any further questions you may have.
- If you like to keep a record of your appointments and notes, ask for copies of any letters that are sent regarding your loved one's care to be sent to your loved one. Our brain box contains 'my brain book', which allows you to have one place to keep details about your loved one. Order yours here: [brainstrust.org.uk/the-brain-box](#).

If the medical appointment is going to be conducted via a video call or telephone conversation, there may be a bit of practical preparation you and your loved one can do:

- Make sure you have the right technology and applications downloaded if your appointment is via a video call. You may want to do a test call with a friend or family member to check your sound and video beforehand.
- Choose a room or area of your home that is quiet and without distractions. You may want to place your phone on silent as well, to avoid any other phone calls interrupting the appointment.

## After the appointment

Medical appointments can often feel exhausting and may at times be very emotional. Often, if other family and friends know your loved one has an appointment, you may find yourself having to tell lots of people what was discussed. As a caregiver, you may be used to acting as a spokesperson for your loved one and relaying information about their condition to others around you. This can be emotionally challenging, as it could keep you in a place you would rather not be, reliving the consultation. Think about the best way for you to communicate information that works for everybody. This could be a group text or email that you could send to multiple people at once, or you might have a close friend who could take on this role for you. This means you can spend time doing things that are less emotionally draining.

You may also find it helpful to plan to do something nice or relaxing afterwards, and you could encourage your loved one to do the same. You could do something together or separately.

Some things you could do include:

- meeting a friend for coffee and a chat
- taking a nice walk
- treating yourself to something new
- curling up with a good book
- watching a favourite film.

## Ask yourself

- What specifically am I struggling with?
- Who's in my team?
- What do I need?
- Where is my sanctuary?
- What information do I need to help fill the gaps?

## 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

[brainstrust.org.uk/caring](https://brainstrust.org.uk/caring)

[How to build a supportive team Know How](#)

[How to get a carers assessment Know How](#)

[How to have a voice as a caregiver Know How](#)

[brainstrust.org.uk/knowhows](https://brainstrust.org.uk/knowhows)

[brainstrust.org.uk/difficult-conversations](https://brainstrust.org.uk/difficult-conversations)

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