



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 diagnosis, this can mean that you will have regular medical appointments and check-ups at any stage of the pathway. They are a key part of your clinical care and are where you will get key information about your condition and treatment plan. These appointments may have been planned for months or arranged at the last minute.

We are currently living in a time when appointments with clinicians may also be conducted via an online video call or telephone call rather than face to face, which may bring more challenges in itself. This Know How will help you to prepare for your appointment so that you get the best out of it.

What does this mean?

Living with 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. 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 to help you feel more relaxed and in control.

How can I prepare?

Preparing for a medical appointment can come in different forms. You may want to use some strategies before, during and after your appointment.

Before and during your appointment

 You may want to think about implementing some relaxation or mindfulness techniques in the build-up to your next appointment. By making strategies like this part of your daily routine, it can help to give you the space that 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 care with your clinician. What would be a good goal for the appointment? What would make you feel it was time well spent? Preparing the questions that you 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: <u>brainstrust.org.uk/</u> patient-guides.
- You may feel more comfortable taking someone else along to your appointment. Think about what their role will be when they are in the appointment with you. They may be able to take notes during the appointment, or they can ask your questions on your behalf if you are happy for them to do so.
- If you go to your appointment alone, you may find it helpful to record the appointment so that you have a record of the discussion. This means you can focus in the moment and can refer back to the recording if you have any uncertainty around what was discussed. If you plan to record your appointment, seek the consent of the healthcare professional before doing so.
- You may find that more questions arise as a result of your appointment. Ask your 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 care to be sent to you.

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

- Make sure you have the right technology and applications downloaded if your appointment is over 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 your appointment.
- You can still record an appointment if it is over a video call or on a mobile phone. Again, be sure to seek consent of the healthcare professional before doing this.

After the appointment

Medical appointments can often feel exhausting and may at times be very emotional. Often, if family and friends know you have an appointment, you can find yourself having to tell lots of people what was discussed. This can keep you in a place you'd rather not be in, as you are reliving the consultation. Think about having a spokesperson who can share information on your behalf, or send out one email to people who want to know how it went. You may also find it helpful to plan to do something nice or relaxing afterwards. Some things you could do include:

- meeting a friend
- 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/brain-tumour-support/

brainstrust.org.uk/knowhows

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