brainstrust
the brain cancer people

End-of-life care

a resource to help you understand and manage the end-of-life care pathway for brain tumours

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Shifting the focus of care

Making decisions that are best for you

This section will help you understand a little more about:

- making decisions that are best for you, including shared decision-making (SDM) and options for stopping treatment
- making sure that you are in control and your wishes are met.

Shared decision-making (SDM)

A cancer diagnosis, whether it is a new diagnosis or a recurrence, is frightening. A common theme is the sense of isolation, a lack of voice, and the disempowerment that you feel. You aren't sure who to turn to, when and for what, and there is a general feeling of loss of control. You don't know what support is available, where to seek help or what questions you should ask. A shift to being empowered begins at the point of diagnosis, with a collaborative and interactive relationship between you and your healthcare team. This empowers us to take responsibility for our condition with the appropriate clinical support. This is called **shared decision-making**.

Life-changing decisions will need to be taken as end of life approaches. These decisions will include whether to continue or withdraw treatment, where to die and shifting goals of care to avoid futile treatment, and they should always be decisions based on a partnership. Among the most powerful interventions are our relationships with our doctors. Feeling seen, being heard and knowing our values and beliefs are valued at end of life help everyone to retain a sense of meaning and a rooted human connection during a time of fear and uncertainty. When we are seen and cared for as individuals beyond brain cancer, we retain a sense of ourselves and intrinsic worth in an otherwise unpredictable storm.

Why is shared decision-making important?

Shared decision-making is important for the following reasons:

- It can create a new relationship between individuals and professionals based on partnership.
- People want to be more involved than they currently are in making decisions about their own health and healthcare.
- Both individuals and clinicians tend to consistently overestimate the benefits of treatments and underestimate the harms.
- It has the potential to enhance the way resources are allocated and reduce unwarranted clinical variation.

There remain major challenges to this approach – for example, from moving from the position of seeing the healthcare professional just as an expert giving advice, to seeing them as an enabler who supports us to achieve our goals. There is also the challenge for us to move from seeing ourselves as passive recipients of care, to becoming active and taking responsibility for our own contribution to improving our health and well-being outcomes and being empowered to do so. Understanding the principles of shared decision-making will help you to be an equal partner in any discussions, and not just around the critical phase of end-of-life care.

What is shared decision-making?

Shared decision-making ensures that you are supported to make decisions that are right for you. Only you know what your context is, what your appetite for risk is and what your values are. You are the expert on you, and the clinician is the expert on treatment options, if the options are appropriate. Shared decision-making is a collaborative process through which a clinician supports you to reach a decision about treatment, which could be no treatment.

We know that shared decision-making and weighing up the pros and cons of treatment help people to reframe problems, generate insights, shift dynamics and change practice. Using shared decision-making allows everyone to become a co-pilot in their care, so that we see a new model of maintenance of wellness as well as treatment of illness. At end-of-life care, the focus should be on ensuring that the patient is comfortable, not in distress, and that the care is seamless.

The shared decision-making conversation brings together:

- the clinician's expertise, such as treatment options, evidence, risks and benefits
- what we know best about our preferences, personal circumstances, goals, values and beliefs.

How does shared decision-making happen?

Shared decision-making focuses on achieving specific, immediate goals that relate to precise challenges – for example, weighing up the pros and cons of having a particular treatment, overcoming a problem with caring, or coming to terms with entering the next stage of treatment. All of these are effective forms of self-management, and all rely on effective communication, which is in our DNA.

There are a variety of tools available that enable shared decision-making. People can use decision aids when there is more than one option and neither is clearly better, or when options have benefits and harms that people value differently. Decision aids may be pamphlets, videos or web-based tools. They state the decision, describe the options and help people think about the options from a personal view – for example, how important possible benefits and harms are.

The most accessible tool is the Ask 3 Questions approach. This approach encourages you to ask three simple questions that lead clinicians to provide higher-quality information about options and their benefits and harms. The questions are:

- What are my options?
- What are the possible benefits and risks?
- How can we make a decision together that is right for me?

Options for stopping treatment

At some point in the course of a malignant brain tumour, it is likely that treatment options will run out. Best supportive care should become the focus. But this sounds easier than it is. Decisions are complex enough without the added difficulty of highly charged emotions, which may differ between family members, so it does help to have some guiding principles. If these can be discussed and agreed well in advance, it enables the family, which includes the brain tumour patient and the caregiver, to be proactive and more in control, rather than reactive.

We believe there are four guiding principles that should help make any decision-making easier:

1. Plan as much as you can in advance so that the patient's wishes are clearly stated and can be followed.

2. Pursue treatments, but if there comes a point when these treatments are causing more harm or are not extending life or improving quality of life, then they should be withdrawn. But care continues.

3. Be firm. Know what you need in the way of support and ask, no, *demand* it. And if you don't know what you need, speak with your GP. Tell them what you are struggling with. They will help you to work out what your priorities are.

4. Know what is important to you. What are your values? If you are feeling conflicted, it will be because your values are being compromised. If you want to know more about this aspect, then talk to *brainstrust*. We can help you understand values better and work out what is important to you. Knowing your values will help you make decisions that work for you.

With the individual's agreement, make sure any discussions are:

- documented
- regularly reviewed
- communicated to key people, including healthcare practitioners, family and friends.

These discussions should include any concerns you may have, important values and goals, and understanding about the illness and prognosis.

There is a gap between what people say they want and what actually happens, so it's good to start with what the patient wants. But how do you begin the conversation? Try starting with 'When I come to the end of my life, I want it to be ...'

There is a fantastic website called The Conversation Project (theconversationproject.org), which is dedicated to helping people talk about their wishes for end of life. You can download a starter kit, which will help you organise your thoughts so that you can then have the conversation. This isn't about filling in a medical form; it's about talking to your loved ones about what you or they want for end-of-life care. One of the areas to talk about is the preferred place to die – in hospital, at home or in a hospice – and we'll explore that in another section.

Another resource that you may find helpful is our guide to having a difficult conversation (brainstrust.org.uk/difficult-conversations). This resource helps you to talk about what you are facing, gather your thoughts and clarify your thinking. It will help prepare you for conversations that could be easier not to have, but that can be transformative if planned.

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brainstrust resources that can help you

At *brainstrust*, we create resources to help you feel less alone, more resilient and better able to cope. They are easy to access, and they provide clear, concise, impartial advice. As with all our resources, where they involve health information, everything written follows our rigorous process, so you know that the information is trustworthy and reliable.

Here are some of our resources that you may find useful when managing end-of-life care.

Patient guide: End-of-life care

Our patient guides outline the standard of care that you can expect at different stages of the brain tumour pathway.

brainstrust.org.uk/patient-guide/eolc

How to hold a difficult conversation

Managing end-of-life care involves holding difficult conversations. These need to be planned. This handy guide outlines things you might want to think about as you plan the conversation.

brainstrust.org.uk/difficult-conversations

Walking a mile in our shoes

When you are managing a difficult situation, offers of help can be an additional burden. There is an expectation that you will think of things for others to do, when your head is already full to overflowing. You'll find lots of tips in this little leaflet.

brainstrust.org.uk/walking-a-mile

Acceptance

Acceptance helps us to make peace with the difficulties that come with life and what is out of our control. It is about living with painful and negative thoughts and feelings, understanding that they are part of the challenges we are facing, and not being overwhelmed by them to the extent that we become trapped and unable to move forward in our lives.

brainstrust.org.uk/acceptance

Know Hows

Our Know Hows are published 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. Here are some that are relevant to managing end-of-life care.

Lasting power of attorney

brainstrust.org.uk/knowhows/lpa

How to make the best of the time I have left

brainstrust.org.uk/knowhows/time-left

Coping with bereavement

brainstrust.org.uk/knowhows/bereavement

Support and help for caregivers

It's tough being a caregiver. Often this is not a role you applied for, nor is it one for which you have had any training. There is a wealth of resources available on our website to help caregivers feel more resilient, less alone and better able to cope.

brainstrust.org.uk/caring

And of course, you can pick up the phone (01983 292 405) or email hello@brainstrust.org.uk for a chat at any time.

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To find out more about our work, call **01983 292 405**, email **hello@brainstrust.org.uk**, visit **brainstrust.org.uk** or follow us on **@brainstrust**, **facebook.com/brainstrust** and **@brainstrustuk**.