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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About this resource

Why it is needed, what it aims to do

This resource has been produced to help with end-of-life care for people who are dying with a brain tumour. We only have one chance to get this right, and how we die lives on in the memory of those left behind. We know that our end-of-life care page is one of the most visited pages on our website, so there is a need for more specific information and support about this phase.
If, at any time, you would like to talk things over, then please email hello@brainstrust.org.uk or call 01983 292 405.

Patients and their relatives are often anxious about what will happen in the last phase of life. This anxiety can be magnified, as there can be a team of people involved, which needs orchestrating. So a key part of this resource will be about enabling people to engage in shared decision-making and understand the role coaching can have in supporting meaningful conversations. This means that decisions can be made that are right for you, for your family, for anyone who is living with a brain tumour. It puts the person at the centre of the conversation – before we are patients, we are people. Sometimes it is easy to lose sight of this.

This resource will provide information on good end-of-life care, how to achieve it, who can help you and how to ensure that you are being informed and making the right decisions that are personal to you. It will take you through options for stopping treatment through to looking at making decisions for where the patient wants to die. Having as much information to hand as possible allows you to be in control, certain that you are making the right decisions for those concerned. Death is the one sure certainty for us all, yet we rarely discuss end-of-life care and what our final wishes would be. Having all the relevant information allows you to open up the conversation, make sure any requests are in place and ensure that you feel in control.

This resource aims to:

- have independent, factual information available on end-of-life care when living with a brain tumour for patients, caregivers and stakeholders
- ensure that you have the information you need so that you can make informed decisions about end-of-life care and how to manage it
- help you understand what happens in end-of-life care quickly and easily, with evidence supporting the information
- build trust in clinical judgement and in stakeholder decisions
- articulate the challenges around end-of-life care so that you can be more open in your discussions.

Once you have read the resource, we hope you will:

- feel more confident about the end-of-life phase of the disease trajectory and what it is
- be more informed and engaged in your situation
- be assured that you are doing the best you can to cope
- feel comfortable and confident in your decisions
- understand how *brainstrust* can help
- be aware of where further help and information may be available.

If you have any thoughts, feedback or tips you would like to share, then please let us know.

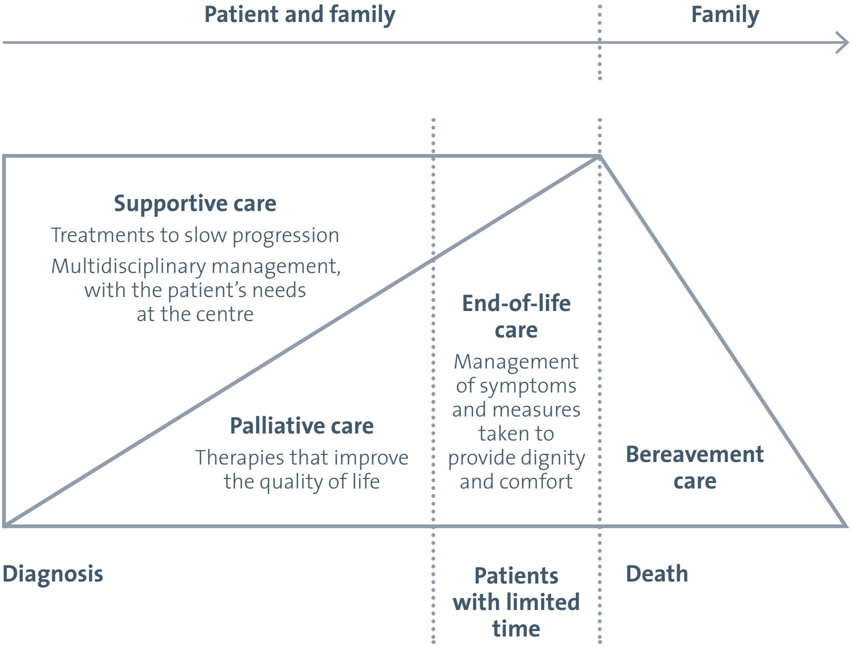
What do we mean by ‘end-of-life care’?

How is this different from palliative care? And how does this fit in with supportive care?

First things first. Let's sort out some definitions. The language used to describe the different phases of the brain tumour pathway can be confusing. Traditionally, the words 'palliative care' have been linked to end of life. Why is this? In the 1960s, hospice and palliative care came of age, often established outside mainstream acute care, and so the primary focus of palliative care was end of life. And this has stuck.

However, in the last 60 years, things have shifted. While palliative care and oncological care remain separate, we now know that integrated care produces the best results, where the focus is centred on the person living with cancer and their family. Everyone works together to achieve the best outcomes – called 'supportive care'.

What does this mean? The best approach is one where all the needs of the patient and their family are met for the whole pathway – from diagnosis through to end of life, and for the family, beyond. We'd call this supportive care. This means that the starting point is at diagnosis and the focus is on improving quality of life, with the patient very much at the centre. So improvement of function, the best symptom management, active use of resources and family involvement throughout become cornerstones of the pathway, all guided by the patient's needs. This means that interventions are seen as a positive sign, rather than entering a phase that signifies end of life.



In summary, supportive care is care that begins at diagnosis, and it is an approach that is multiagency, with the patient and their family very much at the centre. The aim of best supportive care is to help the patient to have a good quality of life so that they can have their best possible day. This includes being as well and active as possible through the brain tumour pathway. It should be based on a person's needs and not their prognosis. It can involve:

- managing physical symptoms, such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing and eating
- support for family and friends.

A life-limiting illness is an illness that can't be cured and that you are likely to die from. You might hear this type of illness referred to as 'life-threatening' or 'terminal'.

You can receive best supportive care at any stage in your illness. It doesn't mean that you are at end of life – some people receive best supportive care for years. You can also have best supportive care alongside treatments, therapies and medicines aimed at controlling your illness, such as chemotherapy or radiotherapy. Best supportive care includes end-of-life care, and palliative care is part of this, but it also entails much more.

End-of-life care

When treatment against cancer is no longer effective, or would cause more harm than benefit, this marks a transition point. You cannot put a timescale on this, but generally, it applies to people who are thought to be in the last year of life. This time frame can be difficult to predict. Some people might only receive end-of-life care in their last weeks or days.

End-of-life care aims to help you to live as comfortably as possible in the time you have left. It involves managing physical symptoms and getting emotional support for you and your family and friends. You might need more of this type of care towards the end of your life.

End-of-life care also involves talking to you and your family and friends about what to expect towards the end of your life. The people looking after you will talk to you about your needs and wishes. The goal of this should always be to maintain quality of life. With the right conversations, planning and support, it is still possible to have your best possible day at end of life. However, our daily engagement with our community (patients, caregivers, clinicians, allied health professionals) tells us that this phase comes with very specific challenges, and these are outlined in the next section.

Sources used in this section

Voltz, R. and Borasio, G. 1997. Palliative therapy in the terminal stage of neurological disease. *Journal of Neurology*, 244(S4), pp.S2-S10.

Why is end of life different for brain tumour patients?

Explaining the differences

We know that end of life is different for those suffering with a brain tumour. There aren't just the physical effects as the disease progresses. There may also be an effect on a specific area of the brain or on the whole brain, which may be caused by swelling and the tumour. These challenges are different from death caused by other diseases for these reasons:

- People with a high-grade glioma have a poor prognosis and cannot be cured.
- Focal neurological deficits, symptoms of increased intracranial pressure, epilepsy, and cognitive dysfunction are key symptoms in people with a high-grade glioma, and they may arise in any stage of the disease.
- Fatigue, mood disturbances and anxiety are often reported. These factors all negatively affect health-related quality of life of patients and their relatives.
- Anti-cancer treatment and supportive medication – often steroids and anti-epilepsy drugs (AEDs) – may cause side effects, which may further diminish quality of life.

Different areas of the brain control different body functions. A tumour in an area associated with a certain function will affect that function. For example, a tumour in the area that controls speech can affect someone's ability to talk. Also, as the tumour grows, these symptoms can become more obvious. The swelling due to the growing tumour can produce symptoms such as:

- sleepiness
- lack of mobility
- difficulty speaking
- memory problems
- impaired judgement

- weakness
- seizures
- headaches
- behavioural changes.

This table gives an overview of the typical symptoms that someone may experience as they near end of life. This data is drawn from a sample of 55 patients.

Symptoms	**Number of patients (%)**
Drowsiness/progressive loss of consciousness	48 (87)
Dysphagia (difficulty swallowing)	39 (71)
Progressive focal neurological deficits (motor, dysphasia)	28 (51)
Seizures	25 (45)
Incontinence (before the patient is confined to bed)	22 (40)
Progressive cognitive deficits	18 (33)
Headache	18 (33)
Confusion	16 (29)
Bodily pain	14 (25)

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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**.