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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Part 5

The natural progression of brain cancer

Why do I need to know about common symptoms in the final weeks and options?

This section is written with the caregiver in mind. It will help you, the caregiver, to understand a little more about:

- why it is important to know what to expect
- what to expect during the end-of-life care phase
- how to ask for help
- what you can do to help yourself and the patient
- how not to be afraid.

It is difficult to exaggerate the importance of good end-of-life care. After all, we only ever have one chance to get it right.

At some point in the course of a malignant brain tumour, it is likely that treatment options will run out. Best supportive care should always be the focus from diagnosis. 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 on 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 three guiding principles that should help make any decision-making easier, but not easy:

1. Plan as much as you can in advance so that the patient's wishes are clearly stated and can be followed.
2. Pursue the most appropriate treatments, but if there comes a point when these treatments are causing more harm or are not extending the life or quality of life, then they should be withdrawn.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.

What are the likely side effects of treatments?

If the treatments are not going to prolong life and are going to have a negative impact on quality of life, or if they add significant risk and complication to an already compromised state of health, then these factors need to be considered as part of the decision-making process. Only your consultant will know what the likely side effects are going to be, depending on the treatment and current state of health. Talk, ask, and talk and ask some more.

What are the options for stopping treatment?

Some patients prefer to stop treatment and let the disease take its course. This should be respected but is not irreversible if the patient changes their mind. The focus should always be on the goals and priorities of care; this should define the type of treatment and helps with decision-making. Equally, doctors can override the order if resuscitation is needed for an unrelated cause, or if they think it is within the patient's best interest. You can change your mind about treatments or refusal of treatment. In *Living with a Brain Tumour*, Peter Black says:

> *There is no way to predict with certainty how a person's disease will progress or how he or she will feel about further treatment at any given point. Sometimes a patient who has lived with a tumour that has been considered inoperable may begin to have more and more problems because of it. At that point, it's not too late to consider surgery as an option in order to stabilise the person enough so that he or she can have a better quality of life.*

He goes on to explore options in best supportive care:

- Choosing not to treat with antibiotics. People with fragile health are more susceptible to infections such as pneumonia or a urinary tract infection. Choosing not to take antibiotics means that the patient is likely to succumb to infection.
- Choosing not to resuscitate. If the patient has a cardiac arrest, then the medical team would not attempt to restore the heartbeat.
- Choosing to withdraw a breathing tube or feeding tube. If a patient is dependent on a ventilator or a feeding tube, then withdrawing this support will hasten death.
- Choosing to give increasing doses of morphine. Morphine is used to treat pain, but it also slows the patient's breathing.

What do I, as a caregiver, want to do?

This is the most important question. Of course we are frightened of dying. Or are we? Isn't it more how we might die that frightens us the most? By looking the tiger in the eye, we can have more control over how we die. There was a time when it was left to the medical practitioners. Not any more. This next section should help you understand a little better about what to expect, what changes you might see and how you might deal with any symptoms. Remember, you can ask for help at any point when you feel out of your depth, overwhelmed or upset. Ask for assistance in any of the following circumstances:

- The patient is in pain and is not responding to prescribed pain relief, or you are unable to provide medication.
- There are signs of discomfort, such as fidgeting, grimacing, moaning.
- There is difficulty with breathing and the patient is upset.
- The patient is unable to pass urine or open their bowels (steroids and pain relief can disrupt bowel movements).

- The patient has fallen.
- The patient is very depressed or talking about committing suicide.

The patient's GP and practice nurse should be your first port of call. They will be able to unlock key resources for you, such as Marie Curie nurses. You might also find it supportive to involve a spiritual leader if you have strong religious beliefs.

What to expect

One of *brainstrust*'s guiding principles is to be truthful. Before you explore the next section, you need to know that there may be things in here that will be upsetting. We believe in facing the unknown so that you know what you are up against. This can help to alleviate some fears and will build the psychological flexibility that you'll need. You'll feel, and be, more resilient.

At *brainstrust*, these are the areas that we are asked about the most. You may want to know about them too but do not want to ask or do not know who to ask.

What is the natural progression of brain cancer, so that I know what to expect?

In our experience, which is based here on talking with many caregivers and reading research evidence, the patient with brain cancer can remain stable for a while, but then deterioration happens very quickly, sometimes over a matter of hours.

The natural progression is that the patient will spend more and more time in bed, will become withdrawn and sleep more, and eventually, the patient slips into a coma. Hearing is the last sense to go, so keep talking gently to the patient as much as you can while you hold their hand. In the last stage of disease, brain tumour patients can present severe symptoms due to the growing tumour or to treatment side effects, which require adequate best supportive care management and supportive therapy.

Not every brain tumour patient will experience every symptom, nor does the presence of the symptoms mean that the patient is near death. Much depends on where the tumour is located. For example, a tumour in the speech area will affect someone's ability to talk. As the tumour progresses, these symptoms will become more obvious. If you have any concerns, discuss them with your clinical nurse specialist first. This person will know your context better than your GP will.

The most frequent symptoms observed in the last four weeks of life are:

- increased sleepiness
- difficulty swallowing (dysphagia)
- decreased ability to move around
- trouble speaking or understanding conversation
- loss of memory and the ability to form new memories
- impaired judgement – for example, how much help is needed to move around
- seizures
- headaches
- extreme mood changes.

Other signs that could suggest that the disease is progressing include prolonged confusion (delirium), visual hallucinations, withdrawal from socialising, loss of appetite, slowing down of bladder function, a cooling of the skin, loss of vision (the patient will turn towards a light source), increased pain and involuntary movements.

Motor and sensory problems are likely to happen over the course of the tumour progression. Symptoms can progress to the point that it may be difficult for the patient to walk, to feed themselves and maintain regular bowel function. This can be distressing for everyone, and for the patient. Losing the ability to go to the toilet could be their worst fear. It can be the cause of burnout for the caregiver too. Patients may lose the ability to sense when they need to urinate, leading to retention. Certain medications can also lead to urinary retention. When this happens, ask for an evaluation so that the appropriate management can be chosen. Sometimes, for comfort, the patient can have a catheter, which drains urine from the bladder into a bag close to the patient's bedside. These are easy to manage. Commodes at the bedside, bedpans (in which the patient can urinate or have a bowel movement while lying down on the bed) and incontinence briefs may be utilised to help with this important and distressing problem. Ask your clinical team for help.

Language and communication can be affected by brain tumours. Patients may struggle to find the right word, to speak words in a logical pattern or to read and/or write. They may also struggle to understand. This can cause frustration for everyone – patient, caregiver, friends and healthcare practitioners.

You can help by:

- giving the person time to talk
- speaking slowly
- using pictures or objects to help (things the patient can see)
- acknowledging the frustration (talk about it for the patient)
- talking to other caregivers who might have strategies (use social media).

Swallowing can become difficult. This can cause food and drink to enter the lungs, which may increase congestion and impact on breathing. Eating can become an issue too. Liquids, which you might think are easier to swallow, are actually harder to control and swallow. Liquids can spill into the back of the throat and cause coughing. Then there is the added stress that is caused when you think the patient isn't getting enough food and drink. Eating and drinking are associated with care, with nurturing, so it can be distressing if a person stops eating and drinking or can't eat or drink. Mostly, people at this point lose their appetite and desire to drink. Sometimes it causes the body more stress trying to process food and drink, as the body is shutting down and cannot cope with the burden of processing sustenance. And of course, steroids can increase hunger, so a fine line has to be trodden between satisfying hunger and helping the patient eat when swallowing is hard. These problems may be lessened by offering assistance with feeding and offering small bites of pureed or soft food or thickened liquids.

Unfortunately, problems with eating and drinking are likely to get worse. When a person is not able to eat or drink due to progression of a brain tumour, it is likely that other symptoms (such as inability to communicate, altered level of consciousness or seizures) will worsen as well, and that the end of life is approaching. Sometimes caregivers consider providing food and liquid through a feeding tube (through the nose or the stomach) or through an intravenous line. Artificial nutrition and hydration will not treat the cancer and, importantly, has not been shown to improve quality of life or prolong life. In addition, providing artificial food or fluids near the end of life may worsen secretions, swelling or breathing difficulty. Most patients who are actively dying do not experience hunger or thirst. The sensation of thirst is most likely related to having a dry mouth, which can be addressed by using moistened swabs or ice chips.

Headache is experienced by about 50% of brain tumour patients at some point during their illness. A patient's headaches can be variable in frequency, intensity and quality. Typically, headaches that are caused by the build-up of pressure in the skull from the brain tumour are worse in the morning (or at night) and can be worsened by bending over or coughing. Headaches from the tumour itself and from increased brain swelling can be any type of headache – the most common being a dull ache. Steroids are the key treatment for increased brain pressure, and the dose should be adjusted to maximise pain relief and minimise side effects. Ibuprofen can be used as needed. It is better to stay on top of the pain, and therefore keep to a regular dose, rather than take it in response to an increase in pain. Headaches may become more severe as the cancer progresses, at which time opioids are used. Some headaches may be associated with other neurological changes, such as changes in strength, sensation, ability to speak, etc.

Fatigue can be caused by a variety of things. For more detailed information about fatigue, have a look at our fatigue resource (brainstrust.org.uk/fatigue). Fatigue can manifest in a variety of ways, including poor concentration, irritability, sleeping more and participating in fewer activities. It is natural that as the brain tumour progresses, the patient will likely become increasingly tired and spend much of their time sleeping. The focus at end of life should be on enjoyable experiences and may need to be creatively reconfigured to meet the patient's energy level, mobility and desires in their final days. So consider things like visitors for short periods, just being a presence in the room, listening to music and reading to the patient.

Agonal breathing (previously called Cheyne–Stokes respiration, and often misspelled as 'chain stoking') is common in the terminal phase of life. This is a pattern of breathing typical of dying patients. Breathing becomes rapid and shallow; then the diaphragm flutters and stops. The patient doesn't take another breath; then they gasp suddenly and breathe very rapidly for a few seconds until their breathing returns to a shallow, rapid pace again. It can go on for days.

Seizures (a sudden attack or convulsion caused by an abnormal burst of electricity in the brain) are caused by pressure in the brain from the tumour. Seizures at the end-of-life phase happen in up to 50% of patients, and about 25% of patients will have a seizure in the week prior to dying. It often leads to rehospitalisation and a worsening of the patient's quality of life, so it is important to deal with them so that the patient is comfortable. Swallowing difficulties and impaired consciousness, in particular, can interfere with giving anti-epilepsy medication. Ongoing seizures may cause additional distress for caregivers as well, who are already experiencing a heavy burden of care. There are a variety of methods for giving AEDs if the patient can no longer swallow, such as rectally or an oral dissolving tablet. Just ask your clinical team.

You can help by:

- clearing the area of dangerous objects
- staying with the patient
- protecting the head
- keeping the mouth clear
- not restraining limbs or movement
- laying the person on their side after the seizure has finished
- talking with the patient (tell them where they are, who you are)
- allowing time for recovery (the patient will feel drowsy and want to sleep).

When it is safe to leave the patient, call the appropriate person in your clinical team and ask for advice about what to do next. It may be necessary to alter the medication. If seizures just won't stop or are too frequent and debilitating, then sedation can be given.

The goal here is comfort and relief of suffering. This reduces stress for everyone.

Delirium is an acute change in mental state. It can be confusion, disorganised thinking or a change in the level of consciousness (very sleepy or agitated). Sometimes delirium can be caused by infection and can simply be treated by dealing with the infection. See also 'Symptoms in the week before dying' below.

Symptoms in the week before dying

The majority of patients will be drowsy in the last week of their life and will also have difficulty swallowing. Just over 25% of patients will experience a seizure in this week.

What can I do to help?

You do not need to be alone for this phase. Consider having someone there to help you. This person can provide you with comfort and support and make sure you are okay. If you are at home, you should ensure that the patient's GP is informed so they can assess whether pain relief is needed. As a caregiver, you should:

- talk calmly and quietly to the patient; let them know you are there
- keep the patient warm with blankets
- leave soft lighting on
- keep the bed clean (a catheter and management of a catheter will be provided)
- use ice chips for keeping the mouth moist; lip balm and swabs are also useful to freshen the mouth.

The following are some symptoms that might be experienced and their treatments.

Symptom	Treatment
Raised intracranial pressure	Steroids (dexamethasone). These help to reduce brain swelling but cannot be used for prolonged periods, because of known side effects.
Seizures	Anticonvulsants
Nausea and vomiting	Antiemetics
Headache	Analgesics (including opiates in the terminal phase)
Anxiety or depression	Antidepressants. These take time to work.

Top tips

- Be prepared. Know who is in your team who you can call upon.
- Use your GP. Ask about what help is available.
- Use as much help as possible. This will enable you to be a partner, a son, a daughter, etc. rather than a caregiver.
- Have someone organise a rota for visitors.
- Appoint someone as a spokesperson who can update friends and other family members.

Sources used in this section

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How will I know when the patient has died?

Signs to be aware of

Instinct will tell you. Prior to death, you will probably have noticed a change in the rate and rhythm of breathing. Breathing may be shallow and infrequent, with episodic, awkward gasping (see 'Agonal breathing' on page 53). At the point of death, breathing ceases completely, as does the blood circulation. There is no detectable pulse. The patient is unresponsive. The eyelids may be slightly open, and the eyes do not move or blink. Pupils dilate, and they don't constrict when bright light is shone in them. The face becomes very pale, and lips become purple. The skin of the body also becomes very pale and blotchy, as the circulation has stopped. The jaw relaxes, so the mouth will be slightly open. The body has relaxed, so there may be a final bladder and bowel expulsion.

Rigor mortis (stiffening of the body) does not happen until a few hours later, and it normally only lasts a few hours before the body becomes limp again. Some family members like to be involved in the last washing as a final act of caring and saying goodbye. You might like to think about keeping a lock of hair or making a handprint cast if small children are involved, to help them with grieving and memories. There is nothing to do for now. Take a deep breath, and have some quiet moments of calm. Your loved one is at peace. There is no rush to act now.

Sources used in this section

Consultant neurologist

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
x.com/brainstrust, **facebook.com/brainstrust**
and **@brainstrustuk**.

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