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 1

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.

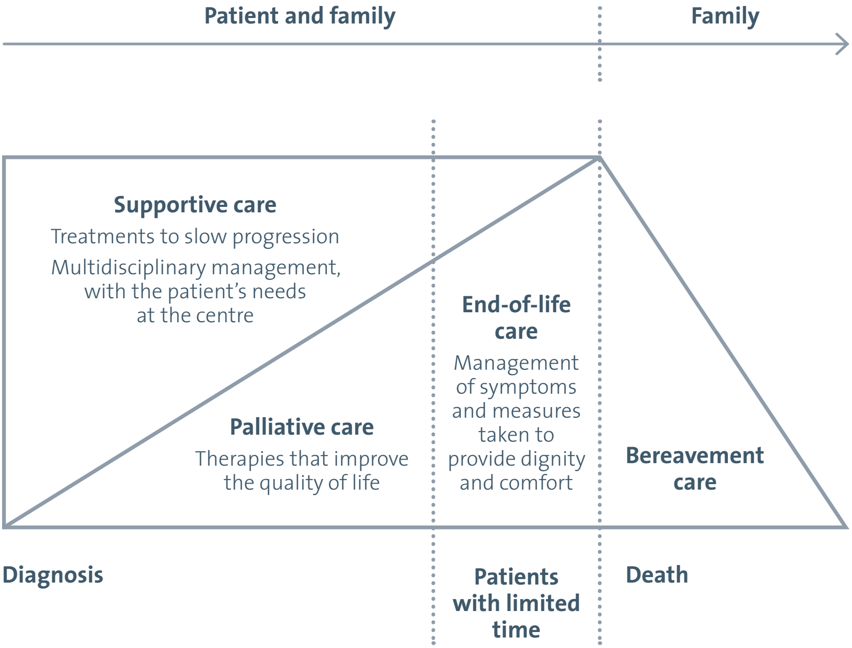
What do we mean by 'end-of-life care'?

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)

Sources used in this section

Batchelor, T. and Byrne, T. 2006. Supportive Care of Brain Tumor Patients. *Hematology/Oncology Clinics of North America*, 20(6), pp.1337-1361.

Behin, A., Hoang-Xuan, K., Carpentier, A. and Delattre, J. 2003. Primary brain tumours in adults. *The Lancet*, 361(9354), pp.323-331.

Correa, D. 2006. Cognitive Functions in Brain Tumor Patients. *Hematology/Oncology Clinics of North America*, 20(6), pp.1363-1376.

Heimans, J. and Taphoorn, M. 2002. Impact of brain tumour treatment on quality of life. *Journal of Neurology*, 249(8), pp.955-960.

Janda, M., Steginga, S., Langbecker, D., Dunn, J., Walker, D. and Eakin, E. 2007. Quality of life among patients with a brain tumor and their carers. *Journal of Psychosomatic Research*, 63(6), pp.617-623.

Leidy, N., Elixhauser, A., Vickrey, B., Means, E. and Willian, M. 1999. Seizure frequency and the health-related quality of life of adults with epilepsy. *Neurology*, 53(1), pp.162-162.

Osoba, D. 2000. Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neuro-Oncology*, 2(4), pp.221-228.

Pelletier, G., Verhoef, M., Khatri, N. and Hagen, N. 2002. Quality of life in brain tumor patients: the relative contributions of depression, fatigue, emotional distress, and existential issues. *Journal of Neuro-Oncology*, 57(1), pp.41-49.

Sizoo, E., Braam, L., Postma, T., Pasman, H., Heimans, J., Klein, M., Reijneveld, J. and Taphoorn, M. 2010. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Neuro-Oncology*, 12(11), pp.1162-1166.

Taillibert, S., Laigle–Donadey, F. and Sanson, M. 2004. Palliative care in patients with primary brain tumors. *Current Opinion in Oncology*, 16(6), pp.587-592.

Part 2

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.

Sources used in this section

brainstrust. 2014. *How to hold a difficult conversation*. Cowes: *brainstrust*.

Bulbeck, H. 2020. Measuring What Matters to the Brain Cancer Community. In: W. Grisold, R. Soffietti, S. Oberndorfer and G. Cavaletti, ed., *Effects of Cancer Treatment on the Nervous System, Volume 1*, 1st ed. Newcastle upon Tyne: Cambridge Scholars Publishing, pp.329–356.

Bulbeck, H. 2020. Quality of Life in People Living with a Brain Tumour. In: W. Grisold, R. Soffietti, S. Oberndorfer and G. Cavaletti, ed., *Effects of Cancer Treatment on the Nervous System, Volume 1*, 1st ed. Newcastle upon Tyne: Cambridge Scholars Publishing, pp.300–328.

The Conversation Project. 2021. *Have You Had The Conversation? – The Conversation Project*. [online] Available at: <https://theconversationproject.org/> [Accessed 27 July 2021].

Da Silva, D. 2012. *Evidence: Helping people share decisions*. [ebook] London: The Health Foundation. Available at: <https://www.health.org.uk/publications/helping-people-share-decision-making> [Accessed 27 July 2021].

Dying Matters. n.d. *Talking about death and dying*. [online] Available at: <https://www.dyingmatters.org/page/TalkingAboutDeathDying> [Accessed 27 July 2021].

The Health Foundation. 2012. *A simple tool to facilitate shared decisions*. [online] Available at: <https://www.health.org.uk/newsletter-feature/a-simple-tool-to-facilitate-shared-decisions> [Accessed 27 July 2021].

Hibbard, J. and Gilburt, H. 2014. *Supporting people to manage their health: An introduction to patient activation*. [PDF] London: The King's Fund. Available at: <https://www.kingsfund.org.uk/publications/supporting-people-manage-their-health> [Accessed 27 July 2021].

Kissane, D. 2011. *Handbook of communication in oncology and palliative care*. Oxford: Oxford University Press.

NHS England. 2018. *Shared decision making*. [online] Available at: <https://www.england.nhs.uk/shared-decision-making> [Accessed 27 July 2021].

NICE. 2021. *Shared decision making: NICE guideline [NG197]*. [PDF] London: NICE. Available at: <https://www.nice.org.uk/guidance/ng197/resources/shared-decision-making-pdf-66142087186885> [Accessed 27 July 2021].

Seal, R., Kynaston, J., Elwyn, G. and Smith, P. 2013. Using an Option Grid in shared decision making. *Practical Neurology*, 14(1), pp.54-56.

Stacey, D., Légaré, F., Lewis, K., Barry, M., Bennett, C., Eden, K., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R. and Trevena, L. 2017. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 2017(4).

Part 3

How to talk about death and dying

Why we don’t talk about death and dying

Communication is central to human interaction, to everything we do. Without it, we cannot relate to those around us, make our needs and concerns known or make sense of what is happening to us. We all die, and yet death is not openly discussed. We would rather talk about anything other than dying. We use euphemisms such as ‘passed’, ‘passed on’ or ‘passed away’, or ‘resting in peace’, ‘eternal rest’, ‘asleep’. We say our loved one has departed, gone, lost the battle or slipped away.

We shy away from talking about death for a whole host of reasons. Relatives and friends find it difficult to talk about what’s happening, and those who are dying often find it very hard to express what they are feeling or what they would like.

Why relatives and friends won’t talk about it

Reasons for not talking about death and dying may include:

- fear of saying the wrong thing and making matters worse
- fear of loss
- collusion (refusing to face the truth, or pretending everything is all right) with relatives, doctors and caregivers
- fear of what other relatives might say
- the notion that professionals know best, so nothing is addressed
- fear of one’s own mortality
- guilt or shame about what has happened in the past
- denial – the inability or reluctance to face the truth of what’s happening.

Why people who are dying won’t talk about it

The ability or willingness of someone who is dying to talk openly about what they are going through may be affected by some or all of the following:

- fear of being a burden to family and friends
- lack of privacy, particularly in hospital wards
- inner conflict and unfinished business
- fractured, strife-ridden families
- secrets that have never been shared
- denial – the inability or reluctance to face the truth of what’s happening
- fear of upsetting relatives
- having never been a talker and not wanting to start now
- trusting the right person (a dying person may choose who they want to talk to, and this might not be a relative, trained nurse or doctor).

So how do you talk about it?

The most important thing is not to push anyone into talking if they don’t want to. Just make sure they know you are willing to listen if and when the time is right.

This does mean that at times you have to be agile and responsive. There is no right or wrong way to talk about death and dying, and it probably won’t be one ‘heavy’ conversation but one that unfolds over time. There are some key questions you can explore together that are open and invite reflection on what’s important:

Dealing with a life-limiting prognosis

What's going to be hard to talk about? What makes it hard?

What's important to get right?

What's going to get you through tough decisions? How involved do you want to be?

What milestones do you want to achieve?

What do you need to hear?

Coming to terms with a life-limiting prognosis

What do you not want to regret?

What do you want to remember about the next few weeks?

Who do you want to be in the time you have left?

What questions do you need to ask?

What will help you be prepared?

What do you do with emotion?

The rule is always to respond to emotion. Just acknowledging the emotion that is in the room can reduce emotional tension. Here are eight techniques for responding to emotion when talking about death and dying:

Technique	Example
Silence	When someone is upset, shared silence is a way of providing safety and saying, ‘I understand.’ Silence can be comforting. It is also often needed for information to be processed.
Normalising/ validation	‘It is okay to be upset at such a moment.’ ‘It’s understandable that you are angry after all that has happened.’
Empathy	‘You’ve had such a tough time.’
Name the emotion	‘I sense you are sad.’ ‘I can see you are angry.’
Gesture or touch	Touching the patient’s arm or hand.
Encourage expression	‘Tell me more about how you are feeling.’ ‘What’s going through your mind at the moment?’
Paraphrase or playback	‘I think you’re saying you’re angry because you thought this chemo would work.’ ‘This is what I have heard you say …’
Acknowledge the person	‘You’ve done so well for so long now.’ ‘I admire you for fighting your corner like you have.’

Sources used in this section

Bostock, P. 2011. Useful questions when using GROW. *High Performance Coaching, Module 1*. Horsham: Zinnia Consulting.

Bulbeck, H. 2019. Communication Skills: The Patient as Co-pilot. In: I. Oberg, ed., *Management of Adult Glioma in Nursing Practice*, 1st ed. Cham: Springer, pp.177–193.

The Conversation Project. 2021. *Have You Had The Conversation? – The Conversation Project*. [online] Available at: <https://theconversationproject.org/> [Accessed 27 July 2021].

Dying Matters. n.d. *Talking about death and dying*. [online] Available at: <https://www.dyingmatters.org/page/TalkingAboutDeathDying> [Accessed 27 July 2021].

Kissane, D. 2011. *Handbook of communication in oncology and palliative care*. Oxford: Oxford University Press.

Oliver, K. and Bulbeck, H. 2019. Surviving a Brain Tumour Diagnosis and Living Life Well: The Importance of Patient-Centred Care. *Neurorehabilitation in Neuro-Oncology*, pp.239-254.

Emotional and practical support

Who is in your team?

This section will help you understand about:

- what kind of support you can expect to receive from healthcare professionals
- who they are and how they can help you
- your other support team – family and friends.

For end-of-life care, you will be provided with support from healthcare professionals. This support will be provided at home, in hospital or in a hospice, and it will ensure that the patient is kept as comfortable as possible, with support for the family too.

Support from healthcare professionals

For end-of-life care, there are services available to support you and your family.

GP

Your first-line contact is your GP. Your GP is the primary caregiver. If end-of-life care is at home, it is led by a GP. They can help by:

- telling the patient where to find information about their condition and any support services available
- prescribing medications and other treatments to manage pain and symptoms
- liaising with the district nurses regarding care at home
- arranging for hospice staff to get in touch and explaining how they can help
- helping the patient and family manage physical needs
- making sure the patient has access to the medical and nursing care that they need 24/7.

District nurses

The district nurse organises and coordinates home care and can arrange for services to be provided if the person wishes to be cared for at home.

Community nurses

These vary from area to area but can include Marie Curie nurses and Macmillan nurses.

Both the district and community nurses organise and coordinate home care and can arrange for services to be provided if care is at home. They can also help by coordinating the patient's care, linking to other services, overseeing the medical care, managing pain relief, giving advice on eating and drinking, prescribing medications, helping with advance care planning and helping to keep the patient comfortable. They can also provide information about local services.

Healthcare assistants

Healthcare assistants work in homes, care homes, hospitals and hospices. Although not registered nurses, they are trained to help patients with keeping clean and dressing, eating and drinking, incontinence care and dressings. These people are key; they can enable the caregiver to be the person they want to be – partner, son, daughter, friend – rather than a caregiver.

Best supportive care team (palliative care team)

You will also have a best supportive care team consisting of a best supportive care clinical nurse specialist, physiotherapist and occupational therapists. The best supportive care team is based in the community, hospital and hospice. Sometimes this team is called the palliative care team.

Your other team

There is also another important team, and that is your family and friends. People, by nature, want to help and support but are unsure how to. People tend to overthink things and think that there is little they can do, but it's the little things that make the big difference. Don't be afraid to be direct with your asks. Could someone bringing a hot meal really help you out? Could collecting a prescription help out? Would doing the laundry or shopping help? Even just visiting to give the caregiver a few hours of respite would be a great help.

It's sometimes helpful to have someone in charge of sharing updates. Having one person either phoning or emailing takes the strain off the main caregiver and saves passing the same news to many well-meaning family members and friends. CaringBridge (caringbridge.org) is a website that gives you all the tools that you need to keep family and friends up to date during a difficult time. It lets you post updates and is a private place to keep caring family and friends updated.

Sources used in this section

CaringBridge. n.d. *Personal Health Journals for Recovery, Cancer & More*. [online] Available at: <https://www.caringbridge.org> [Accessed 27 July 2021].

National Institute for Health and Care Excellence (NICE). *End of life care for adults*. Quality standard [QS13]. Published: 28 November 2011. Last updated: 02 September 2021. https://www.nice.org.uk/guidance/qs13/chapter/Quality-statements [accessed September 2021].

Part 4

Where should I die?

Exploring available options

This section will help you to understand about:

- advance care planning (ACP)
- how to make the right decision for hospice or home care
- the pros and cons of both
- things to take into consideration to know you are making the right decision for you.

Healthcare professionals involved in your care are always keen to hear your views. In the case of planning your end-of-life care, they call this ‘advance care planning’ (ACP). It mostly takes the form of a conversation with a healthcare professional involved in your care. This may be your own GP or your best supportive care nurse. It may be a different healthcare professional, but the important point is that someone you feel comfortable with hears your views.

The conversation about writing an advance care plan can contain as much or as little detail as you feel you need to give. It will make all future decisions much easier if people around you know your wishes. An ACP can reduce the stresses for the family. You can also find more resources about ACPs on page 75 and lasting power of attorney (LPA) here. If you feel that you are ready to talk about an advance care plan, you can make an appointment with anyone involved in your care. The timing is up to you, and any time you feel ready to talk will be the right time. Once you have made your wishes known, either your GP or best supportive care nurse can then document your advance care plan and share it with other agencies, such as ambulance control, out-of-hours GP services and community nurses. A useful website is advancecareplan.org.uk.

You may hear the terms ‘preferred place of care’ or ‘preferred place of death’. These terms are used to help professionals make sure that they understand what your wishes are throughout your cancer journey. Many people want to be cared for as long as possible in one environment and then, at the end of life, move to a different setting. For example, from home or a nursing home to a hospice. You may not feel able to make these kinds of choices, but you may have a strong wish that will influence that decision. Examples of less clear plans that are equally useful to know are feelings such as 'I don't want to be on my own', 'I want my partner with me', 'I don't want to trouble my partner too much'. If the healthcare professionals around you know what is important to you, they will be able to support you in the way that you would most like. The more you can share now with people around you, the easier the decisions will be later on.

Most advance care plans would like to know what your first and second choices are for your preferred place of care and your preferred place of death. It is sensible to try to think of two choices, even if you feel very strongly that you want your first choice. Sometimes plans need to be flexible, and it applies more pressure to your loved ones if they don't know what your second choices are. It may be that your preferred place of care is home, but your preferred place of death is the hospice. An example of a second choice may be including a nursing home in part of this plan. The healthcare professionals you speak to will know what choices are available in your area.

When thinking about your advance care plan, you are bound to be full of emotions and worries. The reality is that any small amount of information you feel able to share about your wishes is going to help your family and healthcare professionals make timely and quick decisions that everyone will be happy with. The plans you make are always flexible and subject to change. All the agencies involved in your care, such as the hospice and your GP, are used to adapting and changing the plan as the situation requires. Don't let the idea of a plan being fixed stop you from advance care planning. Nothing is set in stone. In fact, the opposite is true: knowing your wishes can allow people around you to be more flexible.

Does having a brain tumour make advance care planning different?

Everyone facing a life-limiting illness benefits from advance care planning. However, there can be two main challenges for patients with a brain tumour. These are reducing mobility and cognitive impairment. This can make your end-of-life care a little more complicated and challenging to plan for. Flexibility is a must, and no one should feel disappointed if plans have to change. Cognitive impairment can be a distressing symptom, and advance care planning becomes more important to plan for your wishes. Your flexibility may be needed. For example, if what you want for your preferred place of care is dependent on your ability to stand, what would be a second choice for you if you are no longer able to stand? These are the choices that benefit from advanced planning.

Is it possible to plan for my care to remain at home?

It is very much a personal decision where end of life is to take place, and this next section explores different aspects of where to die. There is a list of the pros and cons of both home and hospice care, which may help you make the right decision for you.

Many people choose to stay at home for end-of-life care, and this can be done with the support of the local community team. Your GP is central to your end-of-life care at home. They will usually continue to prescribe for you and maintain clinical involvement, even if other clinical teams are involved. The local community team consists of community nurses, occupational therapists and physiotherapists, and they will also be key to supporting you at home. Your local hospice is usually involved in your care and provides a community best supportive care clinical nurse specialist team. The best supportive care nurses liaise with other teams and help to plan and manage your end-of-life care at home.

The hospice will also have a multidisciplinary team, who will be available for home support, such as consultants, physiotherapists and other therapy services.

Care at home is frequently achieved and can be a rewarding and peaceful experience. If you can spend a moment considering the practicalities of remaining at home, you are more likely to make a successful plan for your care at home. The practicalities influencing your choices around end-of-life care at home can be divided into two broad subjects for you to consider: the environment and the capabilities of both yourself and your partner or caregiver. If you are thinking of making home your preferred place for your end-of-life care, you may want to consider some of the following factors:

Environmental practicalities to consider in your home

- What is your living space like?
- How do you feel about rearranging your living space to accommodate you?
- Do you have space for a bed downstairs?
- Do you have space for equipment that may be needed around a bed downstairs?
- What is your downstairs bathroom like?
- Does the bathroom have space for any equipment? (Only having a loo and washbasin downstairs is workable, but you need to accept only having a wash with a flannel and washbasin or bowl. A caregiver can teach you how to do this.)
- Is the environment free of clutter and trip hazards?
- How do you feel about having professional caregivers coming into your home?

Environmental practicalities to consider in your home *(continued)*

- Is your house easy to find?
- Do you have a key safe or easy access to your home?
- Who else lives in the home, and what are their needs?

Considerations about how you and your partner or caregiver will manage at home

- What is your mobility like?
- Do you become easily muddled or confused?
- Are you likely to be confused if you are moved?
- Do you and/or your caregiver find it distressing when you are confused or muddled?
- Do you have symptoms, such as headaches or seizures, that may benefit from increased nursing or medical input?
- Is your mobility gradually reducing?
- How do you currently move around your home?
- Is your partner planning on performing some physical care for you at home?
- How physically fit and able is your partner?
- Do you have any other people in your support network who could help you at home?
- Do you both feel comfortable having your partner performing intimate care?
- Can you be left alone? Consider that you and your caregiver may become housebound while you are at home.

What are the advantages of moving to a hospice?

Hospices have many advantages for you for delivering your end -of-life care. They are supportive, secure environments designed with the purpose of making end-of-life care the best it can be. The planning and delivery of care is handed over to the hospice, and this can feel very reassuring for families.

In reality, there are advantages and disadvantages to both hospice care and home care. It is quite usual for patients to want to stay at home, but then they find it too much and decide to go into a hospice. On the other hand, many people come into the hospice and then find a routine they think will work at home. A discharge home can be planned, and care can continue at home. As well as admission for end-of-life care, hospices also admit people for symptom management. This may be while care is planned at home. Medications are altered in the secure environment of the hospice, and the patient returns home again.

Hospice – advantages

- The hospice offers a secure environment where nursing care is on hand 24 hours a day.
- It can be very reassuring having the professional guidance of the nurses and doctors planning and implementing the care. Any medication can be given quickly and reviewed.
- The environment is perfectly suited to caring for people with a variety of needs.
- All the equipment needed will be there for you.
- There are therapy services such as complementary therapies, counselling and physiotherapy, which can be accessed more easily in the hospice inpatient environment.

Hospice – advantages *(continued)*

- The time you spend with family becomes more quality time. Visiting times are flexible, and the room is large enough for more family members to visit than in hospitals.
- The environment is homely and comfortable. Hospices try to be less clinical and cosier than hospitals.
- If there are children in the family, the hospice environment and staff can be very supportive. The counselling team can be on hand for some interaction if needed. There is usually a family room with games for children to use.
- The hospice will allow family members to spend some time with the patient once they pass away.
- Family may begin to meet and benefit from counselling services, which can be helpful to plan for bereavement care in the future.

Home – advantages

- You can remain in your own familiar environment.
- If there is any cognitive impairment, remaining in a familiar environment can be more settling and preferable for you.
- It is possible to stay on your own bed, but if there are professional caregivers involved, manual handling has to be reviewed. This means the safety of caregivers and you when moving you around at home.
- You will be able to lie on the bed together.
- Therapy services such as counselling, physiotherapy and complementary therapies are available for home visits.

Home – advantages *(continued)*

- You should be visited by a community best supportive care nurse, who will help to plan and coordinate your care at home.
- Your community best supportive care nurse can review your symptoms and needs at home and liaise with other healthcare professionals to keep you comfortable at home. Your GP will continue to support you at home during your end-of-life care.
- All the same medications and drugs can be administered at home by district nurses and best supportive care nurses in their injectable form.
- You can have a continuous infusion of medication at home, which community nurses can set up and monitor.
- Once the patient passes away, they can remain in the home for a reasonable length of time with the family until they are all ready for them to be transferred to the care of the undertakers.

Hospice – disadvantages

- Family members may have to travel in to visit every day.
- It is not your familiar home environment. This may be distressing if you have memory or cognitive impairment.
- You and family members may wish to lie on a bed together, and there may not be space in the hospice bed. The hospice will, of course, allow people to lie on the bed together, but it may be uncomfortable and only suitable for a short cuddle.
- Some hospices have large beds for you to lie on together, but this is rare and exceptional.

Home – disadvantages

- Although support is available to you at home, you will be on your own for a good proportion of the time. Nights can be especially long if you are having problems, and help can take some time to arrive.
- There may be a delay between you requesting medication to be administered via an injection and the nurse arriving to administer it. It will take at least the nurse's travel time to get to you before it can be given.
- If you have a change in medication, it can take some time to have the prescription changed and then collected from the pharmacy.
- There will be some time between ordering equipment as your needs change and the equipment arriving.
- If caregivers are needed to come into the home to do physical care, they will need the environment to be safe for them to work in. This means, for example, when nursing you in a bed, a hospital bed is needed to prevent caregivers injuring themselves. These aspects of manual handling need to be considered.
- As much as it is comforting being in a familiar environment, cognitive impairment can be a distressing symptom towards the end of life, and this is more easily managed by nurses in a hospice environment.
- When the patient passes away, a healthcare professional, such as the district nurse, needs to come and verify the deceased. This means to confirm that they have died. Some people find waiting for this distressing.

Sources used in this section

Ariadne Labs and The Conversation Project. 2020. *What Matters to Me: A Guide to Serious Illness Conversations*. [PDF] Boston: Ariadne Labs and The Conversation Project. Available at: <https://theconversationproject.org/wp-content/uploads/2020/12/WhatMattersToMeWorkbook.pdf> [Accessed 27 July 2021].

Best supportive care neuro-oncology nurse

Thomas, K., Lobo, B. and Detering, K. ed. 2017. *Advance Care Planning in End of Life Care*. 2nd ed. Oxford: Oxford University Press.

National Institute for Health and Care Excellence (NICE). *End of life care for adults*. Quality standard [QS13]. Published: 28 November 2011. Last updated: 02 September 2021. https://www.nice.org.uk/guidance/qs13/chapter/Quality-statements [accessed September 2021].

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

Black, P. 2013. *Living with a Brain Tumor*. New York: Henry Holt and Company.

Cohn, M., Calton, B., Chang, S. and Page, M. 2014. *Transitions in Care for Patients with Brain Tumors: Palliative and Hospice Care*. [PDF] San Francisco: Neuro-Oncology Gordon Murray Caregiver Program, University of California. Available at: <https://www.ucsfhealth.org/pdf/transition_of_care_handbook.pdf> [Accessed 27 July 2021].

Dying Matters. n.d. *Talking about death and dying*. [online] Available at: <https://www.dyingmatters.org/page/TalkingAboutDeathDying> [Accessed 27 July 2021].

Koekkoek, J., Dirven, L., Reijneveld, J., Postma, T., Grant, R., Pace, A., Oberndorfer, S., Heimans, J. and Taphoorn, M. 2014. Epilepsy in the end of life phase of brain tumor patients: a systematic review. *Neuro-Oncology Practice*, 1(3), pp.134–140.

National Council for Palliative Care

Sizoo, E., Braam, L., Postma, T., Pasman, H., Heimans, J., Klein, M., Reijneveld, J. and Taphoorn, M. 2010. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Neuro-Oncology*, 12(11), pp.1162–1166.

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

Part 6

Hints and tips from those who have come through end-of-life care

Practical and emotional advice for caregivers

We've looked at the medical practicalities of end-of-life care, but what about the day-to-day living? To quote Cicely Saunders, 'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.' Saunders founded modern hospices, encouraging people, although dying, to live well. This can be a time to make memories and spend time together as a family.

Here we share some tips from a caregiver who looked after her husband.

Memory making

Important things to remember:

- Small things mean a lot.
- It's your journey, so do it your way.
- Do not pressure yourself to do too much.

These were activities that they all did as a family:

- Making cakes from kits.
- Doing craft activities – you can buy kits from hobby shops or online.
- Taking lots of photos – a local photographer can come to the house. Some ideas include black-and-white photos and photos of just hands or shadows.
- Making videos of you all reading out loud from a book or poems.
- Planting indoor seeds.
- Having a movie night – dim the lights, get the popcorn ready, and bring the duvets downstairs.

- Making footprints and handprints on paper or ceramics. Ask your local ceramic-painting place if they can come to your house to do this with you.
- Having fish and chips in bed.
- Buying small bottles of champagne as a special treat.
- Getting some expensive chocolates you wouldn't normally buy.
- Having fingerprint jewellery made.
- Finding a mobile therapist who will come to your home and give you treatments like massage or reflexology. You can ask your local hospice if they have a therapy team, as their therapists will be trained to work with cancer and end-of-life patients.
- Having a small break away with family. If you can't stretch to a few days, then a day out somewhere that is special to you.
- Making a special memory book containing old photos, new photos and anything special to you.

As you will see from the list shared, these are very simple activities, but most can be done even if the patient is housebound. You can probably think of a few of your own, but this list proves how it can be just simple things that create special moments and make memories.

Sources used in this section

Caregiver

What to do in the first 48 hours after someone has died

Advice on some of the practicalities of the first two days

This chapter is to help you with some of the practicalities after someone has died.

Your loved one is now at peace. There is no rush. Just take time to sit and be with them. If you are in a hospice, the staff will be there to support and guide you, but more importantly, they will allow you the space and time to sit with your loved one. They will issue the certificate that you need to register the death, and they will support you with the next steps that you have to take.

If you are at home, you will be required to inform the patient's GP.

When you have received your medical certificate and feel ready to do so, you can call a funeral director, who will move your loved one to a funeral home.

Most funeral directors will help you not only with the funeral arrangements but also with what you need to do legally in the next few days. They can provide information on registering the death, what documents you will need to take with you and what you need to provide them with for the funeral to take place.

All deaths have to be registered within five days in England, Wales and Northern Ireland, and eight days in Scotland.

There is a service available called Tell Us Once, which can be used to report a death to several government departments all in one go. This service is offered by most local authorities. You can arrange an appointment to do this when registering the death.

If you've had the conversation with your loved one and discussed wishes, such as funeral arrangements, the funeral director will be on hand to offer guidance for legal obligations you have to fulfil regarding registering the death. For the family, this post-death period is a time to draw close to one another to gain love and support.

The first things you will have to do:

1. Get a medical certificate from the patient's GP or hospital doctor.
2. Register the death. You can make an appointment with the registrar of births, deaths and marriages to do this.
3. Contact a funeral director.

Registering a death

To register the death, you will need to book an appointment with the registrar at the register office. You will need to give the registrar:

- the full name of the person who has died
- any other names they used (such as a maiden name or previous married name)
- their full address
- their date of birth
- details of where and when they died
- their occupation (if any)
- details of the person's husband, wife or civil partner.

Documents that you will need

You will need to give the registrar a certificate of the cause of death (signed by the doctor). You should also take along the following documents (where applicable):

- birth certificate
- NHS medical card
- proof of address (e.g. a utility bill)
- driving licence
- passport

- marriage or civil partnership certificate.

Don't worry if you don't have them all. You can still register the death.

Forms you will receive from the registrar

England and Wales

A certificate for burial or cremation (known as the 'green form'). This gives permission for the body to be buried or for an application for cremation to be made, and you should give this to the funeral director.

A certificate of registration of death. You'll need this to deal with your loved one's affairs if they were receiving a pension or benefits.

Scotland

A certificate of registration of death (form 14). You'll need this so that the funeral can take place.

A registration or notification of death (form 334/SI). You'll need this to deal with the person's affairs if they were receiving a pension or benefits.

Northern Ireland

A GRO form. This gives permission for the funeral to take place.

A certificate of registration of death (form 36/BD8). You will need this to deal with the person's affairs if they were receiving a pension or benefits.

Sources used in this section

GOV.UK. n.d. *Register a death*. [online] Available at: <https://www.gov.uk/register-a-death> [Accessed 27 July 2021].

mygov.scot. 2019. *Register a death*. [online] Available at: <https://www.mygov.scot/register-death> [Accessed 27 July 2021].

nidirect. n.d. *Registering a death with the district registrar*. [online] Available at: <https://www.nidirect.gov.uk/articles/registering-death-district-registrar> [Accessed 27 July 2021].

Self-care for those left behind

How to cope with grief

'How people die remains in the memory of those who live on.'
Dame Cicely Saunders (1918–2005),
founder of the modern hospice movement

This section will help you to understand a little more about:

- how to make sure you stay safe in a moment of extreme emotions
- what strategies can help to see you through the next few days
- how to identify who can help.

Death brings meaning to life. Without death, we would not understand what it means to be alive. There is no proper response to death. Grief hits deeply and in a hundred ways you would never expect. Grief is raw, awkward, visceral – even more so for an out-of-order death. We can accept with sadness that our grandparents will die before us, but we're not wired to lose someone before it is time, which so often happens with brain cancer. It's like nothing else, and unless you have been through it, you don't understand the feeling of being robbed and the confusion it brings. And your grief is a different shape from someone else's grief. You need people to hold you through this, not necessarily to understand it.

Life isn't linear. Neither is dying or the aftermath of death. Grief doesn't obey rules or follow a neat timeline until it's done and dusted. Your pain is sadness – it's the way you are meant to be. Your pain is part of the love that you have for the person you have lost, a meaningful reaction to the loss of life that you treasured and the future you should have had. It's not about moving on; it's about building the imprint of the loss into a new life shape. This road will be paved with grief and is best travelled with love, accepting life's unfairness and building those things that make your heart sing into every day. Love holds us hostage to fortune – at some point, one or other of you will lose the one you love. But not to love, a life without love, denies what it is to be human.

Each of us will react according to our own emotional baggage. For some, the loss will just seem too much to bear; for others, it will be a release. However you react, it is important to understand that the pain you feel is part of love. If you commit yourself to love, then unavoidably you are also committing yourself to pain. The alternative is never to love, and that is to shrink from the test of being human at all.

As a caregiver, you will feel your reserves are depleted. This is not a role for which you have had any training, nor is it a job you applied for. And just when you think it is all over, more is being asked of you. The signs of stress are well known: worry, anxiety, sadness and other negative emotions begin to colour each day. What used to feel like a walk in the park now feels like you have a mountain to climb. And this comes at a time when your concentration is non-existent. You are on a roller coaster of emotion, and nothing is making much sense. You may have trouble with sleep, and during the day, you may be tired or find it hard to concentrate, especially on tasks that seem irrelevant. Because of the effects of stress on the immune system, you may also experience more physical problems, including colds and flu and other upper respiratory illnesses. It is easy for caregivers to put their own needs and feelings second or aside, but it is crucial to take care of yourself.

When your loved one dies, first and foremost remember: you neither need to be inspirational to others nor conquer your grief. Also, keep in mind that what one person finds helpful may be quite different for another person. It may take some trial and error to figure out how best to take care of yourself. Some people may find it helpful to talk with others about their grief, particularly others who have been through a similar experience. Others might find solace in their church or religious community, a bereavement group or individual counselling. Although not for everyone, some people find meaning in public speaking, advocacy or volunteer work. Though your life will never be exactly the same, typically the emotions you experience as you grieve will get easier over time.

Self-care strategies

These coping strategies do not require extensive training. You simply need to think about them to make them happen. Find a good friend who will help you to stick to these strategies.

Caring for your body and staying active

Aim to get at least thirty minutes of moderate exercise per day. Pay attention to what you are eating, get enough sleep, rest regularly (deep breaths, meditation, gentle stretching), and keep up with your own check-ups, screenings and medications.

Making time for yourself

Develop and maintain planned episodes of pleasurable self-renewal. For example, go to the movies, be by yourself, read a book, watch TV, visit with friends or take a leisurely walk.

Joining a caregiver support group

In addition to providing information, support groups give you the opportunity to talk with others who are going through a similar situation, and they may help you feel less alone.

Finding what matters to you

Focusing on what matters can strengthen your sense of purpose and meaning in your life. It can help direct the choices you make and can help sustain you when the going gets tough. The most important thing is to be aware of what matters to you. Remind yourself of these things, especially when things are going badly. Some people find it helpful to create a ‘mattering’ list. What would be on your list? Why do these things matter to you?

Allowing yourself to laugh and have fun

Humour is one of the healthiest and most powerful methods of providing perspective on life's difficult experiences, and it is frequently shared during periods of crisis. To help find humour during a stressful time, think about what typically can make you laugh, and bring it into your day. Don't feel guilty about your laughter. Enjoy the moments of levity, and know that they will help restore your energy and perspective.

There is a body of research showing that humour and laughter can be very therapeutic and assist in psychological recovery from crisis. It's also good for defusing situations that have lots of emotion. Laughter and humour have been shown to provide relief and even facilitate survival. It may at first feel like a challenge to find humour during a hard time, but take comfort in knowing that if you cannot laugh today, you may be able to tomorrow.

Bottom line: positive moments and positive emotions are a part of the experience of stress. Take advantage of these moments. They can help keep you focused on what matters and sustain you when things are especially difficult. Know what creates positive moments for you, and use some of the strategies described above or others that work for you so that you can make the most of these often fleeting, but very important, moments.

When to seek professional help

If you find the intensity and frequency of grief has not improved by six months after the death of your loved one, you should seek further help from your GP or get in touch with *brainstrust* at hello@brainstrust.org.uk or call 01983 292 405.

Top tips

- Don’t be afraid to laugh.
- Know that grief is a process. It can’t be hurried or driven. It has its own time.
- Accept that it can be lonely, but it won’t be lonely all the time.
- Know that if you are in a dark place, you won’t stay in this place.
- Ask for help.
- Be tolerant of people who don’t know what to say or who are clumsy in what they say.
- Know where your sanctuary is. Visit it – often. It could be an hour with a good book, a piece of music or a walk in the sun.

Sources used in this section

Cohn, M., Calton, B., Chang, S. and Page, M. 2014. *Transitions in Care for Patients with Brain Tumors: Palliative and Hospice Care*. [PDF] San Francisco: Neuro-Oncology Gordon Murray Caregiver Program, University of California. Available at: <https://www.ucsfhealth.org/pdf/transition_of_care_handbook.pdf> [Accessed 24 June 2021].

National Council for Palliative Care

Sizoo, E., Braam, L., Postma, T., Pasman, H., Heimans, J., Klein, M., Reijneveld, J. and Taphoorn, M. 2010. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Neuro-Oncology*, 12(11), pp.1162–1166.

Sultanoff, S. 1995. Levity Defies Gravity: Using Humor in Crisis Situations. *Therapeutic Humor*, 9(3), pp.1–2.

Appendix 1: Identifying the support you are entitled to for end-of-life care

During the last days and hours of life, it is important to receive personalised, dignified care. The principles of good care include consideration of the patient's physical, social, spiritual and psychological needs. It requires senior clinical decision-making, communication, a management plan and regular assessment.

The table below will help you identify the support you are entitled to for end-of-life care. These recommendations reflect the adult pathway as outlined in the National Institute for Health and Care Excellence (NICE) guideline NG142, *End of life care for adults: service delivery*, (NICE) *End of life care for adults*, Quality standard [QS13] and guideline NG99, (NICE) *Brain tumours (primary) and brain metastases in adults: service delivery*.

Recommendations on end-of-life care service delivery	**Achieved ✓**
Advance care planning is discussed.	
Your caregiver and those important to you are identified.	
Your holistic needs assessment is completed, reviewed regularly, and the information is shared.	
Your caregiver is offered a carer's needs assessment.	
Practical and emotional support provided to your caregiver is considered.	
The amount and type of information you would prefer to receive is established, and arrangements to review this as circumstances change are made.	
The lead healthcare professional provides opportunities for you and your caregiver to discuss treatment plans.	
You receive a copy of your advance care plan.	

Recommendations on end-of-life care service delivery	Achieved ✓
Care is coordinated within and across services and organisations to ensure shared understanding of needs and cares.	
You are given access to highly skilled healthcare and social care practitioners who can provide support in the following areas: specific disease management, physical, psychological, social, activities of daily living, pastoral, cultural.	
You receive information on who is in your team, what their roles are and how to access them. There should be a healthcare professional available seven days a week who can access your advance care plan.	
You are given access to an out-of-hours pharmacy service that can dispense medicines for symptom management at end of life.	

Recommendations on end-of-life care service delivery **The last days of life**	**Achieved** ✓
If it is thought that you are entering the last days of life, the following information should be gathered and documented: • your psychological, social and spiritual needs • your current clinical signs and symptoms • your medical history and clinical context • your goals and wishes • the views of those important to you about your future care • an assessment for changes in signs and symptoms.	
Knowledge gained from the assessments and other information gathered from the multidisciplinary team, you and those important to you should be used to determine whether you are nearing death, deteriorating, stable or improving.	
Your prognosis should be discussed with you (unless you do not wish to be informed) as soon as it's recognised that you may be entering the last days of life, and those important to you should be included if you wish.	

Recommendations on end-of-life care service delivery **The last days of life**	**Achieved** ✓
You and those important to you should be provided with: ● accurate information on your prognosis (unless you do not wish to be informed), explaining any uncertainty and how this will be managed but avoiding false optimism ● an opportunity to talk about any fears or anxieties that you may have about your care in the last days of life ● information on how to contact members of your care team ● opportunities for further discussion with members of your care team.	
A healthcare professional should explore the following with you and those important to you: ● Whether you have an advance statement or statement preferences about your care in the last days of life. ● Whether you have understood and can retain information given about your prognosis. ● The fact that your prognosis should be discussed with other members of the care team and documented in your record of care. ● The level of involvement you wish to have and are able to have in shared decision-making. ● The resources you need (e.g. delivery of meals, equipment, care at night, volunteer support or assistance from an organisation and their availability as early as possible).	

Recommendations on end-of-life care service delivery **The last days of life**	**Achieved** ✓
A healthcare professional should explore the following with you and those important to you: ● The fact that while it is normally possible and desirable to meet your wishes, when it is not possible, the reason should be explained to you and those important to you. ● Your communication needs and expectations. ● Whether you would like a person important to you to be present when decisions are made about your care. ● Your current level of understanding that you may be nearing death. ● Your cognitive status and whether you have any specific speech, language or other communication needs. ● How much information you would like to have about your prognosis. ● Any cultural, religious, social or spiritual needs or preferences.	

Recommendations on end-of-life care service delivery **The last days of life**	**Achieved** ✓
In your final days, you can expect the following: ● Regular assessment and management of symptom control and comfort measures (including offering oral fluids and good mouth care). If in hospital, you should be assessed every four hours. If at home, you will be assessed each time a community team member visits. This could be the hospice-at-home team, a doctor or a nurse. ● Comprehensive and clear communication with you and your family, including answering questions about care and what to expect. ● The communication of all decisions in the change in care delivery, to you where appropriate and always to the person important to you, relative or caregiver. Views of all concerned must be listened to and documented. In particular, families need to be sensitively told if you are likely to die in the next few days or hours, so that they can be prepared. ● Provision of psychological, social and spiritual support.	
Your healthcare professional can help decide what medicines are clinically appropriate.	
Your healthcare professional should consider prescribing different routes of administering medicine if you are unable to take or tolerate oral medicines.	

Recommendations on end-of-life care service delivery **The last days of life**	**Achieved** ✓
Your healthcare professional should consider using a syringe pump to deliver medicines for continuous symptom control if more than two or three doses of any 'as required' medicine have to be given in 24 hours.	
Healthcare professionals should seek advice from colleagues with more end-of-life care experience when there is a high-level uncertainty about whether you are entering the last days of life, may be stabilising or there is any potential for even temporary recovery.	
Healthcare professionals caring for you should take into consideration your current mental capacity to communicate and actively participate in the end of life.	

Appendix 2: *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.

Bibliography

Ariadne Labs and The Conversation Project. 2020. *What Matters to Me: A Guide to Serious Illness Conversations*. [PDF] Boston: Ariadne Labs and The Conversation Project. Available at: <https://theconversationproject.org/wp-content/uploads/2020/12/WhatMattersToMeWorkbook.pdf> [Accessed 27 July 2021].

Batchelor, T. and Byrne, T. 2006. Supportive Care of Brain Tumor Patients. *Hematology/Oncology Clinics of North America*, 20(6), pp.1337-1361.

Behin, A., Hoang-Xuan, K., Carpentier, A. and Delattre, J. 2003. Primary brain tumours in adults. *The Lancet*, 361(9354), pp.323-331.

Black, P. 2013. *Living with a Brain Tumor*. New York: Henry Holt and Company.

Bostock, P. 2011. Useful questions when using GROW. High *Performance Coaching, Module 1*. Horsham: Zinnia Consulting.

brainstrust. 2014. How to hold a difficult conversation. Cowes: *brainstrust*.

Bulbeck, H. 2019. Communication Skills: The Patient as Co-pilot. In: I. Oberg, ed., *Management of Adult Glioma in Nursing Practice*, 1st ed. Cham: Springer, pp.177–193.

Bulbeck, H. 2020. Measuring What Matters to the Brain Cancer Community. In: W. Grisold, R. Soffietti, S. Oberndorfer and G. Cavaletti, ed., *Effects of Cancer Treatment on the Nervous System, Volume 1*, 1st ed. Newcastle upon Tyne: Cambridge Scholars Publishing, pp.329–356.

Bulbeck, H. 2020. Quality of Life in People Living with a Brain Tumour. In: W. Grisold, R. Soffietti, S. Oberndorfer and G. Cavaletti, ed., *Effects of Cancer Treatment on the Nervous System, Volume 1*, 1st ed. Newcastle upon Tyne: Cambridge Scholars Publishing, pp.300–328.

CaringBridge. n.d. *Personal Health Journals for Recovery, Cancer & More*. [online] Available at: <https://www.caringbridge.org> [Accessed 27 July 2021].

Cohn, M., Calton, B., Chang, S. and Page, M. 2014. *Transitions in Care for Patients with Brain Tumors: Palliative and Hospice Care*. [PDF] San Francisco: Neuro-Oncology Gordon Murray Caregiver Program, University of California. Available at: <https://www.ucsfhealth.org/pdf/transition_of_care_handbook.pdf> [Accessed 27 July 2021].

The Conversation Project. 2021. *Have You Had The Conversation?* – The Conversation Project. [online] Available at: <https://theconversationproject.org/> [Accessed 27 July 2021].

Correa, D. 2006. Cognitive Functions in Brain Tumor Patients. *Hematology/Oncology Clinics of North America*, 20(6), pp.1363-1376.

Da Silva, D. 2012. *Evidence: Helping people share decisions*. [ebook] London: The Health Foundation. Available at: <https://www.health.org.uk/publications/helping-people-share-decision-making> [Accessed 27 July 2021].

Dying Matters. n.d. *Talking about death and dying*. [online] Available at: <https://www.dyingmatters.org/page/TalkingAboutDeathDying> [Accessed 27 July 2021].

GOV.UK. n.d. *Register a death*. [online] Available at: <https://www.gov.uk/register-a-death> [Accessed 27 July 2021].

The Health Foundation. 2012. *A simple tool to facilitate shared decisions*. [online] Available at: <https://www.health.org.uk/newsletter-feature/a-simple-tool-to-facilitate-shared-decisions> [Accessed 27 July 2021].

Heimans, J. and Taphoorn, M. 2002. Impact of brain tumour treatment on quality of life. *Journal of Neurology*, 249(8), pp.955-960.

Hibbard, J. and Gilburt, H. 2014. *Supporting people to manage their health: An introduction to patient activation*. [PDF] London: The King's Fund. Available at: <https://www.kingsfund.org.uk/publications/supporting-people-manage-their-health> [Accessed 27 July 2021].

Janda, M., Steginga, S., Langbecker, D., Dunn, J., Walker, D. and Eakin, E. 2007. Quality of life among patients with a brain tumor and their carers. *Journal of Psychosomatic Research*, 63(6), pp.617-623.

Kissane, D. 2011. *Handbook of communication in oncology and palliative care*. Oxford: Oxford University Press.

Koekkoek, J., Dirven, L., Reijneveld, J., Postma, T., Grant, R., Pace, A., Oberndorfer, S., Heimans, J. and Taphoorn, M. 2014. Epilepsy in the end of life phase of brain tumor patients: a systematic review. *Neuro-Oncology Practice*, 1(3), pp.134–140.

Leidy, N., Elixhauser, A., Vickrey, B., Means, E. and Willian, M. 1999. Seizure frequency and the health-related quality of life of adults with epilepsy. *Neurology*, 53(1), pp.162-162.

mygov.scot. 2019. *Register a death*. [online] Available at: <https://www.mygov.scot/register-death> [Accessed 27 July 2021].

National Council for Palliative Care

NHS England. 2018. *Shared decision making*. [online] Available at: <https://www.england.nhs.uk/shared-decision-making> [Accessed 27 July 2021].

NICE. 2021. *Shared decision making: NICE guideline* [NG197]. [PDF] London: NICE. Available at: <https://www.nice.org.uk/guidance/ng197/resources/shared-decision-making-pdf-66142087186885> [Accessed 27 July 2021].

NICE. 2019 *End of life care for adults: NICE guideline* [NG142]. London: NICE. London: NICE. Available at: https://www.nice.org.uk/guidance/ng142 [Accessed 10 September 2021].

NICE. 2021 *End of life care for adults Quality standard* [QS13]. London: NICE. Available at: https://www.nice.org.uk/guidance/qs13 [Accessed 10 September 2021].

NICE. 2021 Brain tumours (primary) and brain metastases in adults: NICE guideline [NG99]. London: NICE Available at: https://www.nice.org.uk/guidance/ng99 [Accessed 10 September 2021].

nidirect. n.d. *Registering a death with the district registrar*. [online] Available at: <https://www.nidirect.gov.uk/articles/registering-death-district-registrar> [Accessed 27 July 2021].

Oliver, K. and Bulbeck, H. 2019. Surviving a Brain Tumour Diagnosis and Living Life Well: The Importance of Patient-Centred Care. *Neurorehabilitation in Neuro-Oncology*, pp.239-254.

Osoba, D. 2000. Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neuro-Oncology*, 2(4), pp.221-228.

Pelletier, G., Verhoef, M., Khatri, N. and Hagen, N. 2002. Quality of life in brain tumor patients: the relative contributions of depression, fatigue, emotional distress, and existential issues. *Journal of Neuro-Oncology*, 57(1), pp.41-49.

Seal, R., Kynaston, J., Elwyn, G. and Smith, P. 2013. Using an Option Grid in shared decision making. *Practical Neurology*, 14(1), pp.54-56.

Sizoo, E., Braam, L., Postma, T., Pasman, H., Heimans, J., Klein, M., Reijneveld, J. and Taphoorn, M. 2010. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Neuro-Oncology*, 12(11), pp.1162-1166.

Stacey, D., Légaré, F., Lewis, K., Barry, M., Bennett, C., Eden, K., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R. and Trevena, L. 2017. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 2017(4).

Sultanoff, S. 1995. Levity Defies Gravity: Using Humor in Crisis Situations. *Therapeutic Humor*, 9(3), pp.1–2.

Taillibert, S., Laigle–Donadey, F. and Sanson, M. 2004. Palliative care in patients with primary brain tumors. *Current Opinion in Oncology*, 16(6), pp.587-592.

Thomas, K., Lobo, B. and Detering, K. ed. 2017. *Advance Care Planning in End of Life Care*. 2nd ed. Oxford: Oxford University Press.

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

Notes

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