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

Part 4 Where should I die?

brainstrust resources that can help you

Contents

Part 4

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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 14 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].

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.	

brainstrust resources that can help you

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

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

Patient guide: End-of-life care

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

brainstrust.org.uk/patient-guide/eolc

How to hold a difficult conversation

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

brainstrust.org.uk/difficult-conversations

Walking a mile in our shoes

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

brainstrust.org.uk/walking-a-mile

Acceptance

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

brainstrust.org.uk/acceptance

Know Hows

Our Know Hows are published to help people living with a brain tumour to understand current topics. They are produced with input from relevant scientific and clinical experts and are written in a way that should help you to understand often complicated topics. Here are some that are relevant to managing end-of-life care.

Lasting power of attorney

brainstrust.org.uk/knowhows/lpa

How to make the best of the time I have left

brainstrust.org.uk/knowhows/time-left

Coping with bereavement

brainstrust.org.uk/knowhows/bereavement

Support and help for caregivers

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

brainstrust.org.uk/caring

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

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