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

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# 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 26 September 2024].

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# 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 26 September 2024].

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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.

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# 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**<br>**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:<br>● your psychological, social and spiritual needs<br>● your current clinical signs and symptoms<br>● your medical history and clinical context<br>● your goals and wishes<br>● the views of those important to you about your future care<br>● 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**<br>**The last days of life** | **Achieved** ✓ |
|---|---|
| You and those important to you should be provided with:<br>● 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<br>● an opportunity to talk about any fears or anxieties that you may have about your care in the last days of life<br>● information on how to contact members of your care team<br>● opportunities for further discussion with members of your care team. | |
| A healthcare professional should explore the following with you and those important to you:<br>● Whether you have an advance statement or statement preferences about your care in the last days of life.<br>● Whether you have understood and can retain information given about your prognosis.<br>● The fact that your prognosis should be discussed with other members of the care team and documented in your record of care.<br>● The level of involvement you wish to have and are able to have in shared decision-making.<br>● 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**<br>**The last days of life** | **Achieved**<br>✓ |
|---|---|
| A healthcare professional should explore the following with you and those important to you:<br>● 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.<br>● Your communication needs and expectations.<br>● Whether you would like a person important to you to be present when decisions are made about your care.<br>● Your current level of understanding that you may be nearing death.<br>● Your cognitive status and whether you have any specific speech, language or other communication needs.<br>● How much information you would like to have about your prognosis.<br>● Any cultural, religious, social or spiritual needs or preferences. | |

| **Recommendations on end-of-life care service delivery**<br>**The last days of life** | **Achieved ✓** |
|---|---|
| In your final days, you can expect the following:<br>● 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.<br>● Comprehensive and clear communication with you and your family, including answering questions about care and what to expect.<br>● 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.<br>● 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**<br>**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
𝕏 **x.com/brainstrust**, f **facebook.com/brainstrust** and ◎ **@brainstrustuk**.

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