

End-of-life care

a resource to help you
understand and manage
the end-of-life care
pathway for brain tumours

Part 3 How to talk about death and dying

Emotional and practical support

brainstrust resources that can help you

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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

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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.

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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](https://www.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].

braintrust
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.



To find out more about our work, call **01983 292 405**,
email **hello@brainstrust.org.uk**, visit **brainstrust.org.uk**
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and  **@brainstrustuk**.