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End of life care

Patient Guide

What happens?

There is a point for many in the brain tumour journey when either the disease no longer responds to treatment, or you have had all treatment that is available and may no longer be able to tolerate more, and the disease grows. At this point priorities shift to what is called best supportive care to ensure that you are as comfortable as possible. End of life care is not the same as palliative care, but is an important part of palliative care for people who are nearing the end of life. End of life care is for people who are considered to be in the last year of life, but this timeframe can be difficult to predict.

End of life care aims to help you live as well as possible and to die with dignity. It also refers to treatment during this time and can include additional support, such as help with legal matters. End of life care continues for as long as it is needed.

It can be helpful to discuss with your family what is important to you before you reach this stage. It can also be helpful to have put your affairs in order. It's typically a very emotionally complex and difficult time, so it helps to take any support offered.

When end of life is reached, it may not be easy for wishes to be communicated by the person who has the brain tumour. It can be beneficial for everyone involved if there has been the opportunity to discuss where you would like to be cared for and what is important to you at this time, whilst you are still able to do so. This can be recorded as an Advance Care Plan (ACP). You may want to note preferences for a 'DNACPR' (do not attempt cardiopulmonary resuscitation). CPR rarely works with people who are dying of a brain tumour, and it can be distressing for everyone to see.

In the last stage of disease, people with brain tumours may get symptoms such as headaches and seizures, due to the pressure the growing tumour puts on the rest of the brain or due to treatment side effects. These are usually managed very well by the local palliative care team and GP.

What might you expect to happen? How do people with brain tumours die?

Our experience, which is based on talking with many carers, is that people with brain cancer at this point on the pathway can remain stable for a while, but when deterioration happens, it can happen quickly, sometimes over a matter of hours. Or there can be a slow deterioration over time that might not be noticeable on a day-to-day basis. The typical progression is that the person will spend more and more time in bed, will become withdrawn and sleep more; eventually, the person slips into a coma (a deep, unresponsive sleep). Symptoms during this time may vary depending on the area of the brain that is affected. Hearing is the last sense to go, so keep talking gently to the person/your loved one as much as you can.

During the last days and hours of life, it is important to receive personalised, dignified care and support. The principles of good care include consideration of the person's physical, social, spiritual and psychological needs. It requires senior clinical decision-making, communication, a management plan and regular reassessment if it is to work well. For more information on this phase, visit brainstrust.org.uk/end-of-life-care.

What is the optimum standard of care?

The optimum standard of care states the minimum level of care we should expect. Sometimes, for a variety of reasons, our health service may not be able to meet the standards.

- Regular assessment and management of symptom control and comfort measures (including offering oral fluids and good mouth care). If in hospital, the person with the brain tumour should be assessed every 4 hours. If at home, the person will be assessed each time a community team member visits you; this could be the hospice at home team, a doctor or nurse.
- Comprehensive and clear communication with the person and with their family, including answering questions about care and what to expect.
- All decisions in the change in care delivery should be communicated to the person with the brain tumour where appropriate and always to the person important to them, relative or carer. Views of all concerned must be listened to and documented. In particular, families need to be sensitively told if the person is likely to die in the next few days or hours so that they can be prepared.
- Provision of psychological, social and spiritual support.

What does *braintrust* think I should expect?

- You will be able to die where you have chosen to.
- Your wishes will be met.
- Sociological support/compassionate care to help come to terms with your life coming to an end.
- Everyone should be aware of your ACP, including doctors other than your regular carers who are contacted in emergency situations.

- That your close person will be regarded as a key part of your team and that they are informed about how things are likely to progress, that they are trained to carry out basic nursing tasks and that they know where to get help at any time.
- A named professional who will assist in accessing the services you need and coordinate your care.
- An assessment for your close person, which is followed by a written care plan for your carer.
- Bereavement support.

What questions could I ask?

- Who can help if I'm looked after at home?
- What equipment will I need? Where can I get it?
- Where else can I be looked after?
- Where can I get financial support?
- What emotional changes can I expect in the last few weeks of life?
- What physical changes can I expect in the last few weeks of life?
- What complementary therapies could I consider?
- What support is there for my family and close person?
- Carers are entitled to an assessment of their needs and a written care plan for them. How do I go about getting this?
- Who is the named contact that will assist in accessing health and social care services, equipment and support?

End of life care sources

Department of Health and Social Care. (2013). Review of Liverpool Care Pathway for dying patients. [online] Available at: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients> [Accessed 5 Jun 2018].

Dignity in Dying. (2011). Advance Decisions and Control at the End of Life. [online] Available at: <https://www.dignityindying.org.uk/blog-post/advance-decisions-control-end-life> [Accessed 5 Jun 2018].

Macmillan Cancer Support and Marie Curie Cancer Care. (2011). End of Life: The Facts. [online] Available at: <http://be.macmillan.org.uk/Downloads/CancerInformation/EndOfLife/MAC12149EndOfLife-E3.pdf> [Accessed 5 Jun 2018].

NHS. (2013). *Guidance for doctors and nurses: caring for people in the last days of life*. London: NHS.

NHS. (2014). National Cancer Peer Review Programme Manual for Cancer Services: Brain and CNS Measures, Version 1.2. [online] Available at: https://www.cquins.nhs.uk/download.php?d=resources/Measures/Brain_and_CNS_March2014.pdf [Accessed 5 Jun 2018].

NHS Choices. (2017). End of Life Care: Advance Decision. [online] Available at: <https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment> [Accessed 5 Jun 2018].

Social Care Institute of Excellence. (2013). *Phasing out of Liverpool Care Pathway: a briefing for social care providers*. London: Social Care Institute of Excellence.

Notes



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Mike, Tom, Rebecca, Charlie & Sophie

***brainstrust* patient guide**

This patient guide accurately reflects recommendations in the NICE guidance on [brain tumours \(primary\) and brain metastases in adults](#).

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