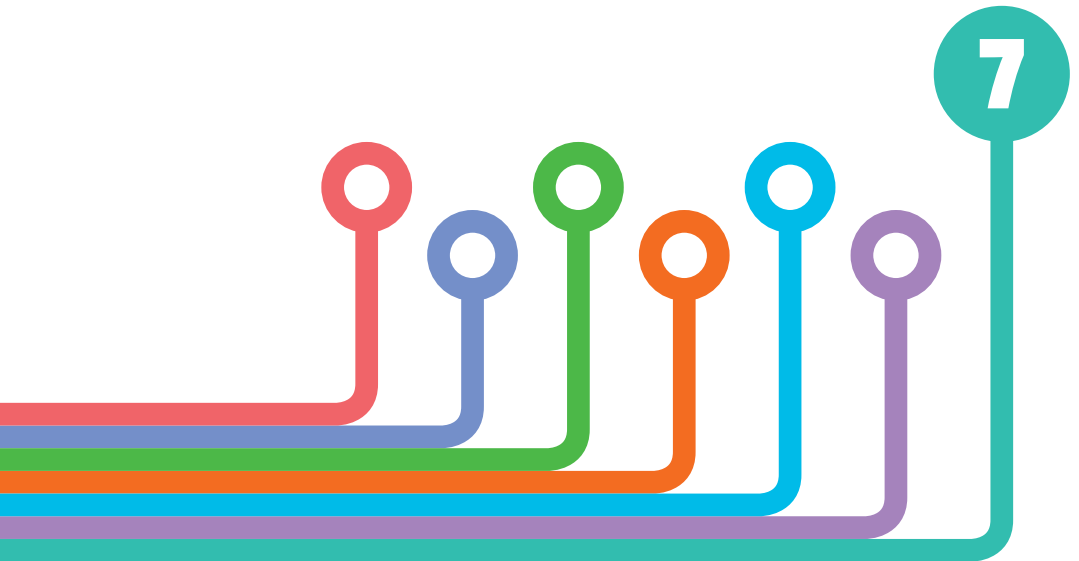


Patient Guide

End of life care



What happens?

Our experience, which is based on talking with many carers, is that a patient with brain cancer can remain stable for a while but then deterioration 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 The natural progression is that the patient will spend more and more time in bed, will become withdrawn and sleep more, so the patient slips into a coma. Symptoms 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 patient as much as you can. In the last stage of disease, brain tumour patients may get symptoms such as headaches and nausea, 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.

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 patient's physical, social, spiritual and psychological needs. It requires senior clinical decision-making, communication, a management plan and regular reassessment.

Patients may not have the capacity to communicate their wishes at this time. It can be beneficial to them and their family if they have had the opportunity to discuss with those caring for them where they would like to be cared for and what is important to them at this time, whilst they are still able to do so. This is called an advance care plan (ACP).

What is the optimum standard of care?

- Regular assessment and management of symptom control and comfort measures (including offering oral fluids and good mouth care). If in hospital, the patient should be assessed every 4 hours. If at home, the patient will be assessed each time the doctor or nurse visits.
- 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

patient where appropriate and always to the relative or carer. Views of all concerned must be listened to and documented. In particular, families need to be warned 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.
- Everyone should be aware of your ACP, including doctors other than your regular carers, 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 anytime.
- 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 are available?

- 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

Advance Decisions to Refuse Treatment, www.adrtnhs.co.uk/

Dignity in dying, *Advance Decisions*, available at www.dignityindying.org.uk/advance-decisions.html

Macmillan Cancer Support and Marie Curie Cancer Care, *End of Life: The Facts*, 2011

National Cancer Peer Review Programme Manual for Cancer Services: Brain and CNS Measures Version 1.2

NCAT, *Rehabilitation Care Pathway Brain CNS*, 2009, available at ncat.nhs.uk/sites/default/files/NCAT_Rehab_BrainCNS.pdf

NHS Choices, *End of Life Care: Advance Decision*, available at www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx

NHS England, *Guidance for doctors and nurses: caring for people in the last days of life*, 2013

Review of Liverpool Care Pathway for dying patients, 2013

Social Care Institute of Excellence: *Phasing out of Liverpool Care Pathway*, Briefing for social care providers 29 July 2013

