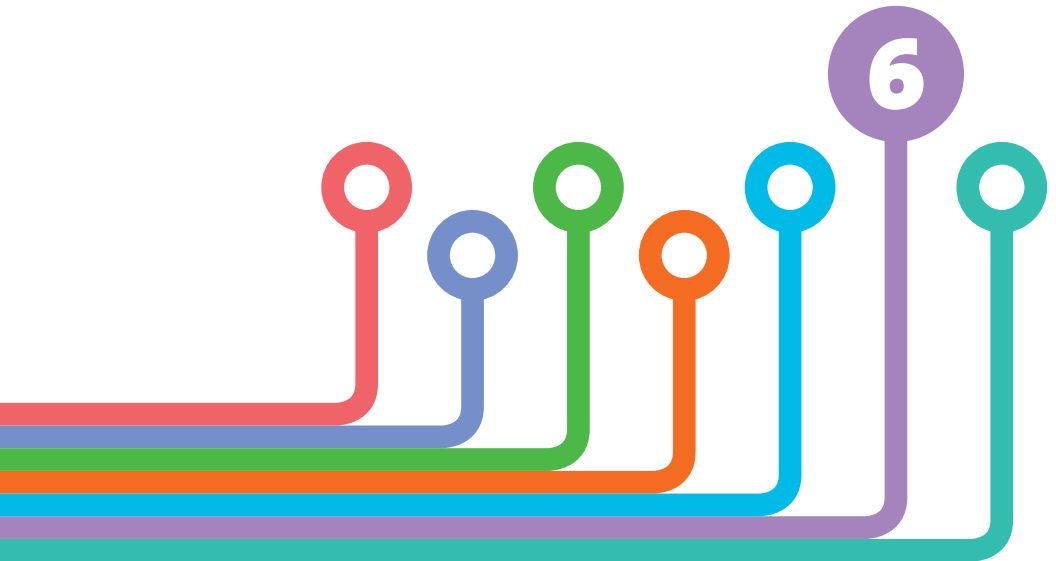


Patient Guide

Palliative care



What is it?

Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life-limiting illness. Prevention and relief of suffering is done through early identification, assessment and treatment of pain and other problems, which include physical, psychosocial and spiritual. Palliative care is not the same as end of life care. Palliative care may be offered at any time during your disease journey depending on your symptom burden. It may be in conjunction with active treatment or when active treatment is no longer appropriate. You will be living with your brain tumour, and may do so for a long time. The focus here is on managing symptoms so that you can lead a good quality of life.

What is the optimum standard of care according to the IOG?

- A holistic needs assessment.
- Palliative care specialists should be core members of the neuroscience MDT and of the cancer network MDT to provide advice on palliative and supportive care, management of symptoms and contribute towards your management plan.
- Your neuro-oncology team should work closely with specialist palliative care services.
- You should be given information on local specialist palliative care services.
- You should have the opportunity for regular systematic needs assessments and discussions with local specialist palliative care service about further involvement as needed.
- You and your family should have the chance to discuss your wishes for the future, which may include discussing where you wish to be cared for as your disease progresses. This is sometimes called AdvanceCare Planning (ACP). Some patients may also wish to complete an Advance Decision to Refuse Treatment (ADRT). Your wishes should be observed, where possible.

What does *braintrust* think I should expect?

- A timely Advance Care Plan for everyone who wishes to have a say in his or her management towards the end of life.
- All staff involved in your care to be aware of your wishes through the ACP and ADRT.
- Regular opportunity to discuss on-going palliative care needs, which include a management plan. This can make hospital admissions unnecessary.
- Your hospital to communicate with your GP and community palliative care team.

What questions could I ask?

- Are there any clinical trials available?
- What support is available to my family and me?
- How do I begin to have those difficult conversations?
- When the time arrives, where can I be looked after?
- What financial and physical support is available for me so that I can be cared for in my preferred place of care?
- How often will my needs be assessed?
- How can I ensure that my wishes will be met?
- Who is the named contact in the palliative care team?

Palliative care sources

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

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

Dying Matters, *What Palliative Care is*, available at www.dyingmatters.org/page/what-palliative-care

Improving Outcomes for people with brain and other CNS tumours, NICE, June 2006, available at <http://www.nice.org.uk/nicemedia/live/10905/28963/28963.pdf>

Living With and Beyond Cancer, DOH March 2013, available at <https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes>

Local hospice and palliative care services, www.helpthehospices.org.uk/about-hospice-care/find-a-hospice/

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

National Cancer Survivorship Initiative, www.ncsi.org.uk/communicating-the-ncsi-vision/

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

