

7

# Palliative Care

**Patient Guide**

## What is it?

Palliative care is an approach that maximises the quality of life for people and their families who face problems associated with life-limiting illness. Palliative care may be offered at any time during your disease journey, depending on your situation and extent of symptoms. 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 is on managing symptoms so that you can lead as good a quality of life as is possible for as long as possible. 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.

Many people think that palliative care is end of life care, but it is more than that. Palliative care may be offered at any time during your disease journey, depending on your symptom burden, and is complementary to treatment. 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.

Prevention and relief of suffering is done through early identification, assessment and treatment of pain and other problems, which include physical, psychosocial and spiritual.

## What is the optimum standard of care according to the Improving Outcomes Guidance?

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.

- 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, and management of symptoms, and to contribute towards your management plan.
- Your neuro-oncology team should work closely with specialist palliative care services.
- You can expect to 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 services about further involvement as needed.
- You and your family can expect to 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 Advance Care Planning (ACP). Some patients may also wish to complete an Advance Decision to Refuse Treatment (ADRT). Your wishes should be observed, where possible. Sometimes this is not possible, but clinicians will always endeavour to observe your wishes. Things to consider are resuscitation and use of antibiotics. Talking about these early will help everyone.

## What does *brainstrust* think I should expect?

- A timely Advance Care Plan (ACP) 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 Advance Directive.
- Regular opportunities to discuss ongoing 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?

- 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?
- Are there any clinical trials available?

## Palliative care sources

Compassion in Dying. (2018). Planning Ahead: My treatment and care. [online] Available at: <https://compassionindying.org.uk/library/planning-ahead-treatment-care> [Accessed 5 Jun 2018].

Department of Health and Social Care. (2013). Living With and Beyond Cancer: Taking Action to Improve Outcomes. [online] Available at: <https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes> [Accessed 5 Jun 2018].

Dying Matters. (2018). What Palliative Care Is. [online] Available at: [www.dyingmatters.org/page/what-palliative-care](http://www.dyingmatters.org/page/what-palliative-care) [Accessed 5 Jun 2018].

Hospice UK. (2018). Find a Hospice. [online] Available at: [www.helpthehospices.org.uk/about-hospice-care/find-a-hospice](http://www.helpthehospices.org.uk/about-hospice-care/find-a-hospice) [Accessed 5 Jun 2018].

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](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].

National Institute of Health and Care Excellence. (2018). Brain tumours (primary) and brain metastases in adults. [online] Available at: <https://pathways.nice.org.uk/pathways/brain-cancers> [Accessed 5 Jun 2018].

**Notes**

**Notes**



Production of *brainstrust*'s information is supported by the Anna Horrell fund. Anna, wife and mum, tragically passed away in August 2017 after a valiant fight against a glioblastoma. Throughout her life and her illness, she was an inspiration to us all, fighting bravely and cheerfully in the face of adversity. She was the beating heart of our family, and her loss left a hole in our lives that can never be replaced. In her incredible memory, we are passionate about helping others diagnosed with a brain tumour to navigate this most difficult of journeys.

**Mike, Tom, Rebecca, Charlie & Sophie**



Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642).

Published September 2013.  
Third edition printed July 2018.  
Due for review July 2021.

© *brainstrust* 2018.