

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 a life limiting illness. 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 situation and the extent of your symptoms. It may be given in conjunction with active treatment or when active treatment is no longer appropriate.

Palliative care forms part of best supportive care which is based on a person's needs and not their prognosis. It can involve:

- managing physical symptoms, such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing and eating support for your family and friends.

The aim of best supportive care is to help you to have a good quality of life so that you can have your best possible day. This includes being as well and active as possible through the brain tumour pathway.

What is the optimum standard of care according to the NICE guidance?

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

This is the optimum standard of care:

- 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 *braintrust* 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

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Notes

Notes

***braintrust* patient guide**

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

**National Institute for Health and Care Excellence
January 2021.**

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

Published September 2013.

Fourth edition printed October 2021.

Due for review October 2024.

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