

# Position paper: End of life care

This document provides some information about end of life care for people with a terminal brain tumour diagnosis, the Brain Tumour Charity's views on what should be made available, and what we are doing to address the issues raised.

## Briefing

End of life care is support for people approaching death, as well as support for family and friends. The aim of end of life care is to provide people at this stage of care with the greatest amount of choice, and the best quality of life and dignity possible. The General Medical Council (GMC) considers patients to be approaching end of life when they are likely to die within the next 12 months (1).

End of life care can also cover legal issues, such as creating a Lasting Power of Attorney (LPA), so that the person or people of a dying person's choice can make decisions about their health care and financial circumstances if they are no longer able to do so.

End of life care includes palliative care, which aims to treat or manage pain and other physical symptoms, and also helps to cater for the psychological, social or spiritual needs of an individual.

## What we believe

We believe that there are three key areas where palliative care interventions could make a positive impact on the end of life experience of people affected by brain tumours:

### 1. Discussion of palliative care from the point of diagnosis if appropriate

Patients with a brain tumour should have the option of discussing palliative care with clinicians from the point of diagnosis, if appropriate for the stage and aggressiveness of their tumour.

If such conversations take place in the early stages of the patient pathway, it is more likely that a person with a terminal diagnosis will have the choice and control over important decisions such as the place of their death. For patients with high-grade brain tumours, introducing palliative care shortly after the time of diagnosis could provide the opportunity to deal with issues like symptom control, and ensure better planning for end of life care.

We recognise that not all patients will want to discuss palliative care options shortly after diagnosis, at a time of immense anxiety and uncertainty for them and their families, and this may not be appropriate for some patients with a longer prognosis.

However, it is important that patients are given the option to have these discussions at the appropriate time for them. Given that close to half of brain tumour patients (42%) with a terminal diagnosis say they are uncomfortable talking to those around them about dying, healthcare professionals should take the lead in initiating these conversations.

## 2. Advanced care planning

Within the NHS Constitution, it is stated that patients have the right “to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this” (2). However, our report [Losing Myself: The Reality of Life with a Brain Tumour](#) showed that 55% of patients with a brain tumour are not being provided with end of life care options, and that 49% had not been given appropriate information about end of life care (3).

Clinicians and health care professionals responsible for the care of people living with a brain tumour should promote the use of advanced care planning so that the needs and wishes of patients about their care management and treatment preferences are met adequately.

In addition, where appropriate patients should be made aware of the option to appoint and register one or several people to have Lasting Power of Attorney (LPA) for financial decisions. Patients can also setup a Health and Welfare LPA, where an attorney (usually a family member) is appointed to make decisions on their behalf in areas of day-to-day care.

Similarly, evidence from our [Losing My Place: The Reality of Childhood with a Brain Tumour](#) study of nearly 300 children and young people suggests that there is some variation in the level of information provision for children and families affected by a brain tumour at the end of life. (4)

It is crucial that local authorities initiate advance planning to identify the care needs children who will need palliative care needs as an adult before the young person is 16, as suggested by [Together for Short Lives](#).

We support the Health Select Committee’s recommendation that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advanced care planning (5). This training could be developed and delivered in partnerships with organisations that have the relevant expertise, such as the National Council on Palliative Care (NCPC).

## 3. Access to 24/7 hour advice and support

End of life care for people with a terminal diagnosis of a brain tumour could be improved by expanding access to specialist 24/7 hour advice and support services. To improve this situation, we believe that CCGs in England should specifically commission services that will provide 24/7 coordination – particularly for those receiving palliative care or dying at home.

Evidence from [Together for Short Lives](#) indicates this is not currently happening, with 4 in 5 local authorities in England failing to plan and fund care for seriously ill children and young people, including in the home. (6) Similarly, only 73% of CCGs commission a community children’s nursing service for children with life-shortening conditions out of hours and at weekends.

In Scotland and Wales and Northern Ireland, we call on local health boards (and trusts in Northern Ireland) to review out of hours palliative care services for patients in the last twelve months of their life.

## [What we are doing](#)

As of May 2017, we are participating in Marie Curie's Research Grants Scheme to address gaps in palliative and end of life care research. The Brain Tumour Charity are contributing £300,000 which will be allocated to successful applications looking at the palliative care needs of brain tumour patients. (7)

Our Patient Guide also includes a section on supportive and palliative care, setting out the standard of care that patients should expect at this stage of care. Recommendations in this section including the importance of patients being given advice around planning care if your symptoms worsen, and information about palliative care services in a local area. (8)

## References

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