Key Messages

The role of a Clinical Nurse Specialist (CNS) or key worker in providing support and Holistic Needs Assessments (HNA) is absolutely vital for brain tumour patients, particularly due to the challenges associated with coordinating specialised care and treatment for such a complex condition. Yet the NHS workforce is overstretched and under resourced.

This means that some brain tumour patients are unfortunately not getting the care and support they need to navigate such a devastating disease.

Nearly one in six respondents to The Brain Tumour Charity’s Improving Brain Tumour Care (IBTC) survey¹ were not given access to a Clinical Nurse Specialist (CNS) or key worker, which is critical for support and coordination of care. Not only that, but just 40% of respondents said they were offered a Holistic Needs Assessment (HNA) which are key for identifying patients’ unique needs and ensuring they are met.

Without sustained investment in these roles and a detailed plan for the future of the cancer workforce, the gap between staff available to carry out these roles and the need from patients for this support could continue to widen. The Lords’ amendment (29B in lieu) on workforce planning is an opportunity to put the NHS and social care workforce back on a sustainable footing, and ensure the system can bring down waiting lists and provide the care that people need.

We are urging MPs to support and vote for Lords’ amendment 29B in lieu

Lords’ Amendment 29B in lieu

We are part of a coalition of over 100 health and care organisations who are urging MPs to support and vote for Lords’ amendment 29B in lieu, which will require the Secretary of State for Health and Social Care to publish an assessment of current and future workforce numbers. The amendment has been revised from the last time MPs voted to address some of the government’s concerns. It requires the Secretary of State to publish independent workforce assessments every three years, rather than two, and revises down the maximum length of projections to 15 years to align with government’s own plans. The amendment in lieu also removes the requirement for assessments to be independently verified.

Projections are necessary because of the dynamic nature of workforce trends. Without projections, there is no way to assess how changes in workforce trends, such as retirements or working part-time, will affect the delivery of healthcare. Regularly published workforce projections will allow government policy and planning to capture and plan for these shifts in a way that the current approach of ad hoc and infrequent publications does not.

‘We need to have the ability to recruit and develop specialist neuro-oncology staff that will work towards going above and beyond for our patients and their loved ones. It is the reason that we, as a community do the job that we do, but we want to do more. We want to achieve more for our patients and we can only guarantee improvements through long-term workforce planning.’

Jill Sokratous, Neuro Oncology Clinical Nurse Specialist, Clatterbridge Cancer Centre NHS Foundation Trust

¹The Improving Brain Tumour Care (IBTC) survey is run by The Brain Tumour Charity in order to understand the experiences of brain tumour patients in six key areas across the patient pathway. The results included in this briefing were analysed in September 2021, and cover UK adults diagnosed or in treatment for a brain tumour since September 2018. There are 1,494 survey responses included in this analysis.
How the workforce shortage is impacting those diagnosed with a brain tumour - Access to a Clinical Nurse Specialist (CNS)

- **Nearly 1 in 6** respondents were not given access to a CNS or keyworker
- **Only 59%** of respondents were able to speak to their CNS or keyworker whenever they needed to
- **There is a 30 percentage point range** (61.1% to 91.1%) in respondents having access to a CNS or keyworker across Cancer Alliances in England

**Why is a CNS so important for brain tumour patients?**

CNSs play a vital role in providing high-quality cancer care and supporting people diagnosed with a brain tumour, including by requesting scans, accompanying patients to clinics, coordinating their care and signposting to available support services. For those diagnosed with a brain tumour, access to a CNS is crucial due to the challenges associated with coordinating specialised care and treatment for such a complex condition. There are often multiple clinical professionals involved in their care, making the role CNSs play in being an anchor and central point of call for the patient incredibly important.

**That’s why every brain tumour patient (whether living with a high- or low-grade brain tumour) should have access to a CNS or keyworker, as recommended by NICE clinical guidance (NG99) in England.**

However, the workforce is incredibly stretched, and despite doing everything possible to deliver high-quality care, there just aren’t enough staff to give every patient the support they need and deserve.

**Holistic Needs Assessment Provision**

- **Only 40%** of respondents said they were offered a HNA
- **Just over 1 in 5** respondents had a HNA and resulting care plan that they feel is working well
- **There is a 48 percentage point range** (11.8% to 56.8%) in respondents being offered a HNA and care plan across Cancer Alliances in England

**Why is a HNA so important for brain tumour patients?**

Holistic Needs Assessments (HNA) are crucial for good patient experience as the assessment is used to ensure patients’ needs are met and identify areas where extra support or signposting to other services is required. **This assessment is often carried out by a CNS, reiterating the importance of having access to a named CNS or keyworker.** HNAs are not just used after treatment has finished but also for those undergoing treatment. So it is very important they are conducted at the right time – which guidance suggests should be throughout the patient pathway, from diagnosis and at key changes in care or condition.

**How can access to a CNS and HNA provision for brain tumour patients be improved?**

Ultimately, this comes down to NHS workforce. In the 2021 Spending Review, the Government announced funding specifically for the NHS workforce for the coming financial years. This is incredibly welcome but we now need to see clarity on exactly how that funding will be used to boost the cancer workforce including nurse specialists, and a detailed plan for a sustainable workforce.

Without a sustainable long-term approach to workforce planning, granted a statutory footing, the gap between staff available to carry out these roles and the need from patients for this support could continue to widen. **This is why we are supporting Lords’ amendment 29B in lieu calling for assessments of current and future workforce numbers.**

**Contact Details**

For more information about The Brain Tumour Charity, or the Improving Brain Tumour Care survey, please contact Steph, Kate or Baron in the Policy & Campaigns team at policy@thebraintumourcharity.org