Our Aim: Reduce the number of people diagnosed with a high grade brain tumour following emergency admissions. Increasing the number of people diagnosed with a brain tumour at an earlier stage is likely to improve both outcomes and experience of diagnosis.

We are calling for the following measures to achieve this aim:

- All political parties should commit to maintaining the Be Cancer Aware campaign. In future rounds this should focus on cancers of unmet need such as brain tumours, using evidence from the HeadSmart campaign.
- The Public Health Agency should work in partnership with national charities to ensure that materials from the HeadSmart campaign are distributed to every school in Northern Ireland, so that every child, young person and parent can understand the signs and symptoms of brain tumours (1).
- The Department for Health, Social Services and Public Safety (DHSSPS) should invest in better data collection to reduce inequalities in care and improve outcomes for people with a brain tumour.

We are calling for the following measures to achieve these aims:

- Health and Social Care trusts should ensure that every person diagnosed with a brain tumour has their rehabilitation needs identified and addressed through a holistic needs assessment (4).
- The DHSSPS should review the capacity of the brain tumour clinical nurse specialist (CNS) workforce in Northern Ireland, and ensure that all patients with a brain tumour have access to a CNS.
- The DHSSPS should work with the Department of Health in the Republic of Ireland to improve co-ordination of radiotherapy services for people affected by brain tumours between Northern Ireland and the Republic of Ireland.

Our Aim: Improve the NHS experience of people with a brain tumour in Northern Ireland, helping them to recover from episodes of ill health.

We are calling for the following measures to achieve these aims:

- Health and Social Care trusts should provide, or signpost towards, The Brain Tumour Charity’s information and support services at the point of diagnosis and throughout treatment and care (4).

References
1. According to the Teenage Cancer Trust, their cancer education programme is currently delivered to 32 schools and over 8,000 pupils each year in Northern Ireland. These figures are from the Teenage Cancer Trust’s response to Draft Northern Ireland Implementation Plan for Rare Diseases [Internet]. 2015. Available from: https://www.teenagecancertrust.org/sites/default/files/11%20Teenage%20Cancer%20Trust%20%28response%20to%20Draft%20Northern%20Ireland%20Rare%20Disease%20Implementation%20Plan%20.pdf

Image (front): Neal Challice died in September 2015, 13 years after his brain tumour diagnosis. He initially underwent surgery and drug treatment but the tumour returned and he suffered a stroke that left him in need of round-the-clock nursing care. His wife Sara says: ‘We need a lot more research and awareness.’