



The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Northern Ireland Assembly Election Manifesto 2016

Northern Ireland Assembly Election Manifesto 2016

Ahead of the Northern Ireland Assembly election in May 2016, our manifesto outlines key measures that if implemented could transform outcomes for people affected by a brain tumour in Northern Ireland. Working in partnership with politicians and policy makers, together we can make the changes that will double survival and halve the harm caused by brain tumours by 2020.

1 Driving Early Diagnosis

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 access to diagnostic technology to reduce waiting times for MRI and CT scans (2) (3).

2 Ensuring Equal Access to Treatment and Care

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 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: Promote transparency and greater 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:

- The Public Health Agency and the DHSSPS should publish the Northern Ireland Cancer Patient Experience Survey (NICPES) on an annual basis, so that trusts can be held to account for the quality of care received by cancer patients.
- Future publications of the NICPES should measure the experience of cancer patients under the age of 16, and patients with a low-grade brain tumour.

3 Embedding Care Planning

Our Aim: Ensure that all people diagnosed with a brain tumour in Northern Ireland, low or high grade, are fully supported in their treatment decisions and signposted towards appropriate sources of information and support.

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

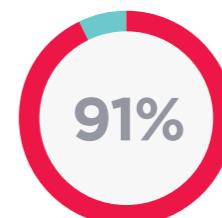
- Health and Social Care trusts should provide, or signpost towards, The Brain Tumour Charity's information and support services at the point of diagnosis and throughout treatment and care (4).
- Health and Social Care Trusts should ensure that all brain tumour patients (high grade and low grade) are provided with a written care plan before they are discharged from hospital.
- All healthcare staff who provide palliative and end of life care to people with life-limiting conditions should receive training in advance care planning (5).
- The DHSSPS should work with voluntary sector organisations to expand access to specialist 24/7 palliative care advice and support services across Northern Ireland.

References

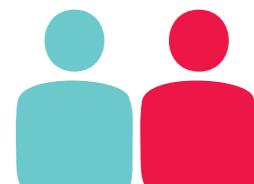
1. According to the Teenage Cancer Trust, their cancer education programme is currently delivered to 32 schools and over 8,000 pupils each year in Northern Ireland. These figures are from the Teenage Cancer Trust's response to Draft Northern Ireland Implementation Plan for Rare Diseases [Internet]. 2015. Available from: <https://www.teenagecancertrust.org/sites/default/files/11.%20Ireland%20Rare%20Disease%20Implementation%20Plan.pdf>
2. As recommended in the Royal College of General Practitioners (RCGP) Northern Ireland's report, Delivering change for general practice: A strategy for improving patient care in Northern Ireland [Internet]. Royal College of General Practitioners (RCGP); 2015 Sep. Available from: <http://www.rcgp.org.uk/rcgp-near-you/~/media/Files/Do-Not-Use-RCGP-near-you/Northern%20Ireland/NI%20Blueprint%20web%20Artwork%20Double%20S%20%201915.ashx>
3. This measure would help to reduce waiting times for CT and MRI scans, as identified in a report by the Information Analysis Directorate. Northern Ireland Waiting Time Statistics: Cancer Waiting Times (April - June 2015) [Internet]. Department of Health, Social Services and Public Safety (DHSSPS); 2015 Sep. Available from: <https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/hs-nivts-cancer-waiting-times-q1-15-16.pdf>
4. These measures would help to implement Standards 4 and 49 in the Department of Health, Social Services and Public Safety (DHSSPS)'s report, Service Framework for Cancer Prevention, Treatment and Care [Internet]. 2011 Feb. Available from: <https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/service-framework-for-cancer-prevention-treatment-and-care-full-document.pdf>
5. As recommended by the House of Commons Health Select Committee. End of Life Care [Internet]. 2015. Report No.: 5. Available from: <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf>

-20

Brain tumours reduce life expectancy by an average of 20 years, the highest of any cancer.



91% of adults report that their brain tumour affects their emotional and mental health.



1 in 2 experience memory problems.



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.'



Northern Ireland Assembly

Election Manifesto 2016



Registered office:
Hartshead House
61-65 Victoria Road
Farnborough
Hampshire GU14 7PA

01252 749990
enquiries@thebraintumourcharity.org
thebraintumourcharity.org