



The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

**The Brain Tumour Charity
Manifesto**
UK general election 2015

Ahead of the general election, our manifesto outlines key measures that if implemented could make a big difference in transforming outcomes for all those affected by a brain tumour across the UK. 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.

Driving earlier diagnosis

Our aim

Reduce the numbers of people diagnosed with a malignant brain tumour following emergency admissions (62% compared to 23% for other cancers).¹

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

General practice

- NHS England should ensure continuity of care by providing a named clinician responsible for their care.
- NHS England should ensure that GPs have timely access to diagnostic tests such as brain MRI scans, as half of CCGs² currently do not allow GPs in England direct access to scans to detect brain tumours.

HeadSmart

- The next government should invest in GP training that includes the use of the HeadSmart early diagnosis campaign to equip GPs with knowledge about the signs and symptoms of brain tumours.
- All political parties should commit in their manifestos to roll out early diagnosis programmes in schools, promoting awareness of the key signs and symptoms of cancer through tools such as HeadSmart.
- The Department of Health should incorporate HeadSmart into the Be Clear on Cancer campaign, with the aim of reducing average diagnosis times for brain tumours in children to five weeks.

Ensuring equal access to treatments

Our aim

Promote transparency and greater data collection to reduce inequalities in care and improve outcomes for brain tumour patients.

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

Clinical nurse specialists

- The next government should ensure that 100% of brain tumour patients have access to clinical nurse specialists following diagnosis by 2020.

National Cancer Patient Experience Survey

- The NCPES must include children and young people's experience of being a cancer patient and reported outcome measures when evaluating the quality and success of commissioning.

NICE quality standard

- NICE must develop a quality standard to ensure that all brain tumour patients receive consistent, high-quality care across the NHS in England.



Enhancing quality of life

Our aim

Improve the NHS experience of brain tumour patients, helping them to recover from episodes of ill health and enhancing choice at the end of life.

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

Access to neuro-rehabilitation services

- NHS England should ensure that all children and young adults diagnosed with brain tumours have access to neuro-rehabilitation services.

End of life care

- The next government must introduce free social care for terminally ill patients at the end of life so that at least 75% of those dying from brain tumours are able to die in the location of their choice.

Accelerating research

Our aim

Make a difference for everyone diagnosed with a brain tumour through the promotion and facilitation of research.

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

Biobanking

- The next government should ensure proposed EU data protection law does not affect the ability of researchers to access tissue and the ability of patients to share data.

Repurposing drugs

- The next government should properly resource the Early Access to Medicines scheme to ensure that brain tumour patients have access to new drugs with the potential for efficacy.
- The next government should support adaptive pathways (the adaptive licensing of drugs) to improve the efficiency of the drug development process, following the pilot by the European Medicines Agency.

¹NCIN, *Routes to Diagnosis Report*, 2012

²GP magazine, report on responses from 182 Clinical Commissioning Groups to a GP freedom of information request, 21 November 2014



DRIVING EARLY DIAGNOSIS



62% of adults with malignant brain tumours are diagnosed as an emergency³



Despite halving diagnosis times in children, HeadSmart has still not been included in the Government's early diagnosis campaign

ENSURING EQUAL ACCESS TO TREATMENT

31%

Only 31% of brain tumour patients have a clinical nurse specialist as their single point of contact⁴



There is no data available of the NHS experience of children and young people with a brain tumour

ENHANCING QUALITY OF LIFE



81% of people who died in England in 2012 and expressed a preference said they wanted to die at home⁵

60%

60% of brain tumour patients have not received a neuropsychological assessment to help manage their symptoms⁶

ACCELERATING RESEARCH

76%

76% of patients who responded to a survey said they would be willing to undergo an operation to collect biopsy samples from their tumour⁷



Currently less than 3% of adult brain tumour patients take part in a clinical trial testing a new treatment in the UK⁸

³ NCIN, *Routes to Diagnosis Report*, 2012

⁴ The Brain Tumour Charity, *Finding a better way?*, 2014

⁵ Macmillan Cancer Support, *Can we live with how we're dying?*, 2014

⁶ The Brain Tumour Charity, *Finding a better way?*, 2014

⁷ Internal survey of 50 people (Unpublished), 2014

⁸ NIHR Clinical Research Network: Cancer, *Annual Report 2013-14*

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

01252 749990
policy@thebraintumourcharity.org
thebraintumourcharity.org