



The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Welsh Assembly Election Manifesto 2016

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Ahead of the Welsh Assembly election in May 2016, our manifesto outlines key measures that if implemented could transform outcomes for people affected by a brain tumour in Wales. 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:

- Directors of Public Health should promote awareness of the key signs and symptoms of brain tumours through the distribution of HeadSmart cards in all schools under the remit of their local authority.
- Local health boards should ensure that GPs have timely access to diagnostic tests such as brain MRI scans, as recommended in *Together for health – cancer delivery plan* (1).
- Local health boards should conduct an audit of the diagnostic pathway and NHS Wales should publish data on routes to diagnosis including emergency admissions.

2 Ensuring Equal Access to Treatment and Care

Our Aim: Ensure that all people diagnosed with a brain tumour in Wales, 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:

- Future publications of the Welsh Cancer Patient Experience Survey should measure the experience of cancer patients under the age of 16 and patients with a low grade brain tumour.
- Public Health Wales should review the capacity of the brain tumour clinical nurse specialist (CNS) workforce in Wales and support local health boards to ensure that all patients with a brain tumour have access to a CNS as recommended in *Together for health – cancer delivery plan* (1).
- Multi-disciplinary teams (MDTs) should provide, or signpost towards, The Brain Tumour Charity's information and support services at the point of diagnosis and throughout treatment and care.
- Local Health Boards should ensure that all people with a brain tumour (low and high grade) are provided with a written care plan, with a package of follow up services, to ensure co-ordinated care between hospital and community.

3 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:

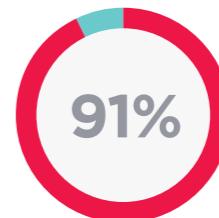
- People with a brain tumour should have access to information about relevant clinical research opportunities in Wales and England as specified in the Welsh Government's *Welsh Implementation Plan for Rare Diseases* (2).

References

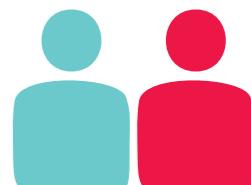
1. NHS Wales. Together For Health - Cancer Delivery Plan. A Delivery Plan up to 2016 for NHS Wales and its Partners [Internet]. 2012. Available from: <http://gov.wales/docs/dhss/publications/150427planen.pdf>
2. NHS Wales. Welsh Implementation Plan for Rare Diseases [Internet]. 2015. Available from: <http://gov.wales/docs/dhss/publications/150220rarediseaseplanen.pdf>

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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.'

Cynulliad Cymru Manifesto Etholiad 2016

Cyn yr etholiad fis Mai 2016, mae ein maniffesto yn amlinellu mesurau allweddol a allai, os y'u rhoddir ar waith, drawsnewid canlyniadau i bobl yng Nghymru y mae tiwmor ar yr ymennydd yn effeithio arnynt. Gan weithio mewn partneriaeth â gwleidyddion a llunwyr polisiau, gyda'n gilydd mi allwn ni wneud y newidiadau a fydd yn dyblu cyfraddau goroesi ac yn haneru'r niwed a achosir gan diwmor ar yr ymennydd erbyn 2020.

1 Ysgogi diagnosis cynnar

Ein nod: Lleihau nifer y bobl sy'n cael diagnosis o diwmor gradd uchel ar yr ymennydd yn dilyn derbyniadau brys. Mae cynyddu nifer y bobl sy'n cael diagnosis cynnar o diwmor ar yr ymennydd yn debygol o wella canlyniadau'r diagnosis a'r profiad o gael diagnosis.

Rydym yn galw am y mesurau canlynol i gyflawni'r nod hwn:

- Dylai Cyfarwyddwyr lechyd Cyhoeddus hyrwyddo ymwybyddiaeth o brif arwyddion a symptomau tiwmor ar yr ymennydd drwy ddosbarthu cardiau HeadSmart ym mhob ysgol o dan gylch gwaith eu hawdurdod lleol.
- Dylai byrddau iechyd lleol sicrhau bod gan Feddygon Teulu fynediad amserol at brofion diagnostig megis sganiau MRI ar yr ymennydd, fel yr argymhellir yn *Law yn Llaw at lechyd - Cynllun Cyflawni ar gyfer Canser* (1).
- Dylai byrddau iechyd lleol gynnwl archwiliad o'r llwybr diagnostig a dylai GIG Cymru gyhoeddi data ar lwybrau at ddiagnosis gan gynnwys derbyniadau brys.

2 Mynediad Cyfartal at Driniaeth a Gofal

Ein nod: Sicrhau bod pawb sy'n cael diagnosis o diwmor ar yr ymennydd yng Nghymru, gradd isel neu uchel, yn cael pob cymorth i wneud penderfyniadau ynglŷn â'u triniaeth ac yn cael eu cyfeirio at ffynonellau priodol o wybodaeth a chymorth.

Rydym yn galw am y mesurau canlynol i gyflawni'r nod hwn:

- Dylai cyhoeddiadau o'r Arolwg o Brofiad Cleifion Canser yng Nghymru yn y dyfodol fesur profiad cleifion cancer iau nag 16 mlwydd oed, a chleifion sydd â thiwmor gradd isel ar yr ymennydd.
- Dylai lechyd Cyhoeddus Cymru adolygu gallu gweithlu Nyrsys Clinigol Arbenigol mewn tiwmor ar yr ymennydd yng Nghymru a chefnogi byrddau iechyd lleol i sicrhau bod gan bob claf sydd â thiwmor ar yr ymennydd fynediad at Nyr Glinigol Arbenigol fel yr argymhellir yn *Law yn Llaw at lechyd - Cynllun Cyflawni ar gyfer Canser* (1).
- Dylai timau amlddisgyblaethol ddarparu gwasanaethau gwybodaeth a chymorth yr Elusen Tiwmor ar yr Ymennydd, neu gyfeirio atynt, ar adeg y diagnosis a thrwy gydol y driniaeth a'r gofal.
- Dylai Byrddau lechyd lleol sicrhau bod pawb sydd â thiwmor ar yr ymennydd (gradd isel ac uchel) yn cael cynllun gofal ysgrifenedig gyda phecyn o wasanaethau dilynol i sicrhau gofal cydgysylltiedig rhwng yr ysbyty a'r gymuned.

3 Ymchwil

Ein nod: Gwneud gwahaniaeth i bawb sy'n cael diagnosis o diwmor ar yr ymennydd drwy hyrwyddo a hwyluso ymchwil.

Rydym yn galw am y mesurau canlynol i gyflawni'r nod hwn:

- Dylai fod gan bobl sydd â thiwmor ar yr ymennydd fynediad at wybodaeth ynglŷn â chyfleoedd ymchwil glinigol perthnasol yng Nghymru a Lloegr fel y nodir yng nghynllun Llywodraeth Cymru Cynllun Gweithredu Cymru ar gyfer Clefydau Prin (2).

Cyfeiriadau

- GIG Cymru. Law yn Llaw at lechyd – Cynllun Cyflawni ar gyfer Canser. Cynllun Cyflawni hyd at 2016 ar gyfer GIG Cymru a'i Bartneriaid [Rhyngrywd]. 2012. Ar gael ar: <http://gov.wales/docs/dhss/publications/150427plancy.pdf>
- GIG Cymru. Cynllun Gweithredu Cymru ar gyfer Clefydau Prin [Rhyngrywd]. 2015. Ar gael ar: <http://gov.wales/docs/dhss/publications/150220rarediseaseplancy.pdf>

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