

DRIVING PROGRESS IN SCOTLAND

The Brain Tumour Charity's Manifesto

Scottish Parliamentary Elections 2021

Over the next term of the Scottish Parliament we want to see bold action taken to improve and extend the lives of people affected by a brain tumour in Scotland by:



ENSURING THE BEST CARE EVERYWHERE

Applying a 'Once for Scotland' approach to delivering brain tumour services – ensuring everyone diagnosed can access support from a Clinical Nurse Specialist or key worker regardless of their tumour type or location in Scotland.



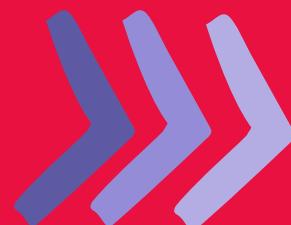
DRIVING EARLIER DIAGNOSIS OF BRAIN TUMOURS

By reducing the proportion of brain tumours diagnosed via emergency and piloting ClinSpec DX – a simple, low-cost blood test – across primary care in Scotland.



ADDRESSING THE IMPACT OF COVID-19 ON BRAIN TUMOUR SURGERIES AND SCANS

Establishing the extent of any emerging backlog of surgeries and scans, and setting out a clear plan to ensure everyone affected by a brain tumour gets the diagnosis, treatment and support they need.



ACCELERATING ACCESS TO DATA FOR PATIENTS AND CANCER RESEARCHERS

Accelerating access to real-world data for Scottish brain tumour patients, researchers and charities, including through our app BRIAN – to inform and empower those with a brain tumour diagnosis and accelerate research into finding a cure.

FOREWORD

As one of our founders, Neil Dickson MBE, says: "to have been affected by a brain tumour, is to be part of an exclusive club that no one wants to join". Over 1,000 people are diagnosed with a brain or CNS tumour in Scotland every year, and unfortunately of those who receive a malignant brain tumour diagnosis, more than half do not survive one year.



At The Brain Tumour Charity, we understand that when you, or a loved one is diagnosed with a brain tumour, a cure really can't wait. Our vision is a world where brain tumours are defeated and we have two very clear goals: to double survival and to halve the harm that brain tumours have on quality of life.

The next Scottish Parliament will convene in a changed world. A world in which we have been forced to recognise that every decision we take as individuals may have an impact on others and our collective wellbeing. A world where we are faced with a renewed sense of shared responsibility and what it means to act in the interest of the most vulnerable in our society. We have an opportunity to build on that greater sense of togetherness the COVID-19 pandemic has engendered, to transform outcomes and the quality of day-to-day life for those affected by a brain tumour in Scotland.

Brain tumours still kill more children and adults under 40 than any other cancer. Of those that do survive, quality of life for many is severely impaired.

This urgently needs to change.

We fight brain tumours on all fronts: through research, campaigning and support. But we need to work faster and go further, to beat brain tumours sooner. And we need the support and investment of the Scottish Government to do this. This is our opportunity to ask representatives from all political parties what their plans are for dealing with the issues that affect people with a brain tumour.

After speaking to our community in Scotland, including people living with a brain tumour, caring for those affected and those who have lost a loved one to this brutal disease, we've developed this brain tumour manifesto to lay out the action the next Scottish Government needs to take, to help deliver long-awaited progress towards a world where brain tumours are defeated.

We have identified four key areas, setting out what our community have told us urgently need confronting: a "Once for Scotland" approach to treatment and services, the need for earlier diagnosis, the need to address the impact of the pandemic on brain tumour services, and the need to recognise the power of data – and to share it.

We value everyone's contribution to addressing these challenges: patients, clinicians, nurses, politicians, fundraisers, researchers, and the Scottish Government. It is imperative we do this as part of a community of people affected by and working against this disease. Only by working as one, will we make these changes happen. Let's make that a lasting legacy of the parliamentary term ahead.

A handwritten signature in black ink, appearing to read "Dr David Jenkinson".

Dr David Jenkinson
Interim CEO, The Brain Tumour Charity

1. Public Health Scotland, Cancer Statistics [Online] <https://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Brain-and-Central-Nervous-System/#cns-tumours> [Accessed 18 Feb 2021]

ASKS OF THE NEXT SCOTTISH GOVERNMENT

Ensure the best care everywhere for those with a brain tumour

Everyone should have access to the best treatment and support, personalised to their needs as well as their tumour, everywhere in Scotland. Clinical teams and NHS staff have been doing their level best in exceptionally difficult circumstances to provide the best possible treatment and services over the last year. But we know the effects of the COVID-19 pandemic have been felt hugely by those living with a brain tumour in Scotland. 85% of users of our patient led app BRIAN reported effects of the first lockdown on their mental health.

However, fewer than 29% of patients with Brain/CNS cancer in Scotland have an identified key worker by their first multidisciplinary team meeting and access to a Clinical Nurse Specialist is inconsistent across the country. With the NHS on an emergency footing, and treatment plans changing or being delayed, those diagnosed with a brain tumour may have increasingly complex emotional needs and healthcare services to navigate.

We are calling on the next Scottish Government to apply a 'Once for Scotland' approach to delivering brain tumour services – ensuring everyone diagnosed can access support from a Clinical Nurse Specialist or key worker, regardless of their tumour type or where they live in Scotland.

Drive earlier diagnosis of brain tumours

The range and severity of possible symptoms of a brain tumour can make the journey to diagnosis a traumatic period for the patient and their loved ones. Minimising the time to diagnosis is crucial to ensuring people get the treatment and support they need at the earliest opportunity.

But brain tumours are a diagnostic problem. Patients often report subtle changes to their wellbeing and present with vague symptoms or those that are far more likely to be caused by less serious conditions. Moreover, GPs may see just four or five brain tumour patients in their working lifetime making it challenging to develop expertise. It's estimated that almost a third of brain tumour patients visit a healthcare professional five or more times before receiving their diagnosis , which can lead to significant emotional distress while they wait to understand what is causing their symptoms.

Currently, triage tools to support primary care professionals to identify those presenting with non-focal symptoms for an urgent scan are not effective. Fewer than 2% of patients referred from GPs for rapid access brain imaging to rule out more serious diseases, such as a brain tumour actually have one , yet, up to 64% of brain tumour patients are diagnosed via an Emergency Department . However, a new low-cost blood test developed in Scotland – ClinSpec DX – has shown promise in improving the diagnostic pathway, and was recently found to identify more than 90% of glioblastomas (the most common type of brain tumour) and more than 80% of all other brain tumours in a study in NHS Lothian. People affected by a brain tumour need earlier diagnosis.

We are calling on the next Scottish Government to:

- commit to reducing the proportion of brain tumours diagnosed via an emergency
- pilot a promising new blood test, ClinSpec DX, in primary care across Scotland as soon as possible and explore its potential to: triage those with possible symptoms and diagnose more brain tumours earlier, to improve patient experience and provide swift reassurance to those who do not have cancer

2. SANON Brain and Central Nervous System Cancers, QPI Audit Report [Online] https://www.sanon.scot.nhs.uk/wp-content/uploads/2020/12/BrainCNS_QPI_Audit_Report_2019_Final_V1.pdf.

3. Grant, R. Overview: brain tumour diagnosis and management/Royal College of Physicians guidelines. *Journal of Neurology, Neurosurgery & Psychiatry*; (2004) 75: ii18–ii23 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1765656/>.

4. The Brain Tumour Charity, *Finding myself in your hands – The reality of brain tumour treatment and care*. [Online] <https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/>.

Address the impact of the pandemic on brain tumour surgeries and scans

During the peaks of the pandemic, many patients faced disruption to their care, with clinics and appointments being cancelled or treatments such as surgery or chemotherapy being postponed. There has been great concern across the UK about a major drop in people presenting to GPs with potential cancer symptoms, and Public Health Scotland's rapid proxy indicators suggest there was a 24% drop in brain tumour diagnoses from January to November 2020, compared to the same period in the previous year.

While the NHS took extensive steps to keep cancer services running, we heard that in most areas, operations for those living with a low-grade brain tumour have been delayed. But the exact scale of these impacts is not yet known.

We are calling on the next Scottish Government to establish the extent of any emerging backlog of brain tumour surgeries and scans, and to set out a clear plan to ensure everyone affected by a brain tumour gets the diagnosis, treatment and support they need as soon as possible.

Accelerate access to data for patients and cancer researchers

Data can inform real change: it can accelerate research, tackle inequality and empower patient choices. Providing researchers with greater access to anonymised patient data could help answer the most difficult scientific questions and accelerate our ability to develop new treatments and improve outcomes. Equipping healthcare professionals with better data can help personalise treatment and care, and providing patients with data about others' experiences can empower them to ask questions about their own care and access the support they need at the time they need it.

Scotland's cancer charities have a key role to play at the interface of research, healthcare and patient support – and we must urgently harness the power of data to deliver progress and best serve our communities. That is why we believe BRIAN, our patient-led app, is central to progress. BRIAN has been designed for whether you are living with a brain tumour, caring for someone who is, or you work in healthcare or research. BRIAN generates insights intended to identify trends and help inform those affected by a brain tumour about their condition, the patient pathway and their treatment options.

Being able to pool data from across the whole of the UK is particularly important when looking at relatively rare diseases such as brain tumours, where there are over 130 different types, as it can be the only way to obtain statistically significant results. Thanks to collaborations with Public Health England, NHS Digital and the SAIL databank in Wales, anonymised data in England and Wales will soon be available to patients and researchers alike, maintaining the highest levels of privacy and confidentiality. But the current barriers to data access in Scotland – including high costs and significant length of time it can take for data to be released – could lead to preventable delays in research progress and in Scottish patients accessing relevant insights, limiting the information they have on treatment options and alternative patient pathways.

People affected by a brain tumour recognise the power of data and 97% of patients would choose to share their data – even if it only helps someone else. We know that when you or a loved one is diagnosed with a brain tumour, a cure can't wait. We must harness the power of data now.

We are calling on the next Scottish Government to commit to accelerating access to real-world data for Scottish brain tumour patients, researchers and charities, including through our app BRIAN – by addressing the current barriers to accessing the best data.

5. Zienius, K., Chak-Lam, I., Park, J. et al. Direct access CT for suspicion of brain tumour: an analysis of referral pathways in a population-based patient group. *BMC Family Practice*; (2019) 20: 118. <https://doi.org/10.1186/s12875-019-1003-y>.

6. Swann, R., McPhail, S., Witt, J., et al. Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit. *British Journal of General Practice*; (2018) 68: e63-e72. <https://doi.org/10.3399/bjgp17X694169>.

7. SAIL is the Secure Anonymised Information Linkage databank established by the Swansea University Medical School.

8. The Brain Tumour Charity: Data Sharing Survey. For more detail or to request a copy of the survey results please contact Alice. Russell@thebraintumourcharity.org.



For more detail, or if you'd like to join us in calling for change and driving progress for people affected by brain tumours in Scotland, please contact me
Alice.Russell@thebraintumourcharity.org

