We at The Brain Tumour Charity recognise that the previous Government health team had to leave the Department of Health and Social Care with short notice. The General Election being called was a bit of a surprise, so we imagine there was not much time for a proper hand-over note.

A month before the General Election was called, we sent an Open Letter to the then Minister, Andrew Stephenson, alongside 52,000 members of the brain tumour community highlighting why we need a National Brain Tumour Strategy. We’d love to hear your response to this letter and so we’ve created your own hand-over note to help you get up to speed on the issues affecting us as a community.

**Brain Tumours in Numbers**

In England, **47%** of patients were diagnosed with a cancerous brain tumour through emergency presentation (A&E, Emergency GP and other emergency routes), in comparison to **18.5%** for all cancers

**85%** of respondents to our Improving Brain Tumour Care surveys felt they had unmet needs

The Institute of Cancer Research reports that brain tumour clinical trials have the lowest recruitment levels of all cancers

**60%** of childhood survivors of brain cancer can’t live independently

**3.2% (£22.4m)** of the over £700 million invested in UK cancer research funding in 2019/20 was spent on brain tumours (this percent includes £6.6m of spending by The Brain Tumour Charity)
What are the difficulties with brain tumours?

For years, people diagnosed with a brain tumour have been falling through the cracks. This can range from multiple misdiagnoses and trips to GPs, to undergoing harsh treatments that largely haven’t changed in decades, or not having access to the support they are entitled to from an allocated Clinical Nurse Specialist (CNS).

Brain tumours often fall into the ‘too difficult’ pile due to the nature of the disease. But they are not just one disease; there are more than 120 different types of brain and central nervous system tumours. These can be high grade, or low grade (non-malignant), and as a result, this disease does not sit neatly in the cancer nor the rare disease world. Because of the differences in how brain cancers start, develop and are tracked, compared to other cancers, they are often missed by NHS cancer programmes. They are not staged like most other cancer types meaning they are not included in initiatives and targets to improve diagnosis at an earlier stage; they are not preventable, and so not included in initiatives around preventing cancer; and the only way to test for them is through MRI or CT scans, meaning there is no potential screening programme yet.

Separately, nearly half (49%) of the brain tumour population are neglected in NHS cancer programmes because they are not diagnosed with a cancerous tumour. Despite being called “low grade”, these tumours are still life changing, and the treatment and care of these, and subsequent long-lasting impacts, can be completely devastating.

There are issues along the entire pathway that we need to solve – including:

- **Diagnosis**
- **Support**
- **Treatment**
- **Research**

These can only be tackled through systematic change and a comprehensive National Brain Tumour Strategy that covers the whole pathway.
It’s a No Brainer – Open Letter signed by 52,000 people

March is Brain Tumour Awareness Month (BTAM) and this year we wanted to show the government the strength of feeling for a National Brain Tumour Strategy. We wrote an open letter to the then Minister, Andrew Stephenson, alongside the health ministers of the three other devolved nations, and invited our community to sign it. We have attached a copy of the text of that open letter.

We all read so many statistics and it’s hard to picture. To help, we have included a photograph of the 34 people who stood outside parliament in the rain, as a reminder of what a statistic can look like. How many people and families devastated by a diagnosis every single day.

We handed in our letter to the Minister, and to the health ministers in the devolved nations, on the 23 April with cross-party backing from 11 MPs, including the former Chair of the Health and Care Select Committe, Steve Brine MP. However, the election was called just a month later meaning we have not been able to have any meaningful engagement following our open letter.

Over 52,000 people signed our letter in just 6 weeks.

To launch the Open Letter, we brought 34 members of our community together to Parliament to represent the 34 people who, on average, are diagnosed with a brain tumour every single day in the UK. Each one held a portrait of themselves or their loved one in a powerful demonstration of the people and the families behind each and every diagnosis.

We need a National Brain Tumour Strategy

We need the Government to take action, alongside the devolved nations, to commit to a comprehensive National Brain Tumour Strategy that covers this whole pathway of care and research:

- Develop a new optimal diagnostic pathway across all four devolved nations, ensuring everyone receives a fast and efficient diagnosis of a brain tumour
- Ensure every brain tumour patient and their family has good access to wraparound support, meeting all of their collective needs
- Every brain tumour patient being offered the chance to participate in clinical trials
- Research into brain tumours recognised as a clinical priority alongside a strategic plan for adequately resourcing and funding for discovery, translational and clinical research