**Brain Tumour Awareness Month Debate**

**Key Messages**

The Brain Tumour Charity is the world’s leading brain tumour charity and the largest dedicated funder of research into brain tumours globally. We welcome this important debate in Scotland during Brain Tumour Awareness Month.

**Brain tumours remain the largest cancer killer of those under 40. Despite this, treatment options have been unchanged in decades.** With 12,000 people diagnosed with a brain tumour every year in the UK and over 1,000 people in Scotland, this has to be improved.

Research is undoubtedly important. Through research we will develop the tools and treatments we need to combat this devastating disease and improve outcomes for all of those affected. However, it is only one piece of the jigsaw.

For years, people being diagnosed and living with a brain tumour have been falling through the cracks. From multiple diagnoses and trips to the GPs, and then undergoing harsh treatments that haven’t changed in decades, to not having access to the support they are entitled to with an allocated Clinical Nurse Specialist (CNS). There are issues along the entire pathway that we need to solve. We believe these issues can only be tackled through a comprehensive National Brain Tumour Strategy that covers the whole pathway of care.

We recommend that:

- The Scottish Cabinet Secretary for Health and Social Care **commits to working with the Devolved Nations on developing a National Brain Tumour Strategy** that addresses the barriers across the whole brain tumour pathway. This includes diagnosis, care, treatment as well as research.

**Why do we need a National Brain Tumour Strategy?**

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 over 120 different types of brain and central nervous system tumours, and they can be high-grade (usually cancerous and aggressive) or low grade. **Neither sit neatly in the cancer nor the rare disease world.**

Because of the differences in how brain cancers start, develop and are tracked to other cancers, **they are often missed by NHS cancer programmes.** Prevention, screening and targets around catching cancers earlier are all examples of how brain tumours end up being left behind in work on cancers.

By solely concentrating on the NHS cancer programmes, **we also neglect nearly half (49%) of the brain tumour population. Low grade tumours are devastating** and the treatment and care of these, and subsequent long-lasting impacts, can be life altering. **They cannot continue to be ignored.**

**Increasing pioneering research**

Research into brain tumours is chronically underfunded and under resourced. **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).

We know that funding is not the only barrier to overcome. Current **government funding that has been allocated is not being adequately spent on high-quality research proposals.** There are significant delays in translating laboratory research to clinical trials and even further delays from clinical trials to medical regulatory approval. This means that brain tumour patients are missing out on promising new treatments. A National Brain Tumour Strategy can help support these advancements in research. We want to see:
• Research into brain tumours recognised as a clinical priority alongside a strategic plan for adequately resourcing and funding for discovery, translational and clinical research

Access to new and better treatments
Brain tumours can be complicated to treat, as depending on their specific location in the brain, interference can be dangerous. Additionally, some drugs cannot cross the blood brain barrier – the membrane that protects the brain from harmful substances in the blood - which means it is challenging to repurpose drugs used for other cancers.

Participating in potentially life prolonging research is vital to finding better treatments, improving people’s quality of life and finding a cure. However, the Institute of Cancer Research suggests that brain tumour clinical trials have the lowest recruitment levels.

Standard NHS treatment for brain tumours, in both adults and children, has not changed significantly in more than 20 years. And because they are still incredibly harsh, 60% of childhood survivors of brain cancer can’t live independently.

A National Brain Tumour Strategy is needed to get patients the treatment they need. To get to this point we need to see:

• Every brain tumour patient being offered the chance to participate in clinical trials.

Essential care for all
Over 1,000 people in Scotland are diagnosed with a brain tumour every day. But patients and their families tell us that more can be done to provide better care and support. Respondents to our Improving Brain Tumour Care survey told us that 85% felt they had unmet needs and 59% felt they needed more help understanding their brain tumour.

We know that access to a CNS is crucial and that’s why we were encouraged to see in the Scottish Cancer Action Plan that the launch of the final Improving the Cancer Journey service should ensure that everyone diagnosed with cancer has access to a key support worker. However, we were surprised to see that the target for this in the recent draft Quality Performance Indicators for brain & CNS cancers has been removed.

• This Scottish indicator should be restored and provide an evidence base as to whether those affected are getting the access they need.

Once diagnosed, people should have access to a Holistic Needs Assessment (HNA) and care plan as outlined in the Scottish Cancer Strategy.

Fast, efficient diagnosis
Current NHS targets focus on catching cancer in earlier stages to ensure an earlier diagnosis. However, brain tumours are not staged like other cancers as they do not spread around the body in the same way. We were pleased to see a recognition of this in the Scottish Cancer Strategy and that additional measurements, such as emergency presentations, would be considered to ensure non-stageable cancers, such as blood and neurological cancers, do not lose out on progress.

• We must ensure that brain tumours can be included in earlier diagnosis programmes and targets in Scotland by creating additional measurements that recognise non-stageable cancers

Ultimately, to ensure a fast and efficient diagnosis for all those impacted by brain tumours we want to see a National Brain Tumour Strategy commit to:

• Develop a new optimal diagnostic pathway to ensure everyone receives a fast and efficient diagnosis of a brain tumour.

Contact Details
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