

FASTER DIAGNOSIS: ITS IMPORTANCE AND HOW IT CAN BE ACHIEVED

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 know that many brain tumour patients have a slow and unsupported diagnosis experience with a large number of those affected having to attend repeat appointments, experiencing delays with getting appointments or are diagnosed with something else at first. This can mean that people wait an incredibly long time to be diagnosed and we regularly hear from our services that people are waiting over a year to get diagnosed. In some extreme cases, we've heard of people taking seven years and even eighteen years to get a firm diagnosis.

This must change. Faster diagnosis will make a difference to patient's wellbeing and provide them with more time to make personal decisions. That is why we are recommending that:

- The NHS ensure that all general practice clinicians can access readily available training on the signs and symptoms of a brain tumour and partner with The Brain Tumour Charity's *Better Safe Than Tumour* campaign to share among healthcare professionals.
- As per recent plans announced in England, the NHS ensure that universal direct access to MRI and/or CT scans for GP practices across all of the UK is achieved. This should always be available alongside sufficient training to interpret the results, appropriate staffing and systems resource, and a direct referral pathway to neurology.
- NHS England and Scotland widen the list of non-specific symptoms (NSS) that warrant referral to the NSS pathway so that they include more potential brain tumour symptoms.

The importance of a faster diagnosis

From feedback with our community we know that **brain tumour patient experiences often reference the importance of having symptoms recognised swiftly and for having access to faster pathways to diagnosis.** They talk of the relief and increased trust in healthcare professionals if they have a faster diagnosis where they do not feel dismissed or frustrated. This feedback led to our decision to focus on the importance of *faster diagnosis* rather than earlier diagnosis for brain tumour patients.

Faster diagnosis can **provide patients with the gift of time.** Patients within our focus groups often highlight how it would have helped if they had been diagnosed sooner. This would have helped them come to terms with their diagnosis earlier and to put personal affairs and arrangements into place as well as providing more time to explore their options for treatment and care.

Although it is not always possible, many brain tumour patients will undergo surgery as part of their treatment. **Faster diagnosis could potentially reduce the number of initial surgeries that are conducted as emergency procedures.** A later diagnosis can lead to the patient presenting more severe symptoms such as increased pressure around the brain (intracranial pressure) which does require emergency intervention. Having more severe symptoms, such as intracranial pressure, can increase the risk of morbidity or mortality during surgery which is why it is important we reduce the number of emergency surgeries.

There are other health benefits such as being able to better withstand treatment if symptoms have not progressed as much or that some permanent disabilities associated with low grade tumours could be prevented.

Improving Awareness of Signs and Symptoms

Data shows that just 17.9% of brain tumour patients receive a GP referral as their route to diagnosis but we know that a majority visit their GP with symptoms at some point before their diagnosis. This suggests

that there are missed opportunities for GPs to identify at risk patients who should be referred for urgent scans and must be improved.

How can this be resolved? We have found that many patients believe they could have had a faster diagnosis if they were able to better recognise signs and symptoms of a brain tumour. **The NHS should partner with The Brain Tumour Charity's *Better Safe Than Tumour* campaign and share symptoms cards and other tools amongst healthcare professionals so the campaign can reach a wider audience.**

For healthcare professionals, symptoms of brain tumours can undoubtedly be challenging as they can be vague, subtle and non-specific. Training is crucial and needs to be continually available for all GPs and healthcare professionals, including optometrists, with some brain tumours being diagnosed via a referral to an optician. **The NHS must ensure that all GPs have regular training on signs and symptoms as well as regular refreshment courses to help keep symptoms front of mind.**

Case Study

Better Safe Than Tumour

In July 2022, The Brain Tumour Charity launched a new campaign to raise awareness of the signs and symptoms of a brain tumour. It concentrates on highlighting the variety of symptoms and encouraging people to approach their GP, as soon as possible, if are they experiencing more than two symptoms. We have used billboards, bus posters, radio adverts and other digital marketing to try to ensure the signs and symptoms of a brain tumour are not missed by the public. To accompany, we have also created a website that provides support for those who are worried about symptoms including a guide for how to approach a GP appointment. We want people to feel supported and empowered to raise their concerns with their GP. In 2023, the campaign will aim to raise awareness among healthcare professionals and providing resources for those working in the sector.

Refining Brain Tumour Patient Pathways – GP Direct access and Non-Specific Symptoms Pathways

We welcomed the news in November 2022 that NHS England was committing to every GP team being able to directly order CT scans or MRIs for patients with concerning symptoms that would fall out of the threshold for an urgent cancer referral. However, for brain tumours this guidance has been available for some time through National Institute for Health and Care Excellence (NICE) with inconsistent results. Therefore, **it is vital to implement this with appropriate training to interpret results as well as ensuring that there is sufficient investment into the workforce and systems resource.**

We also believe that an expansion of symptoms on the non-specific symptoms (NSS) referral pathways in England and Scotland is required. Existing as a way for GPs to refer patients with vague or non-specific cancer symptoms to a rapid diagnostic centre (Community Diagnostic Centre (CDC) in England or Rapid Cancer Diagnostic Service (RCDS) in Scotland), these pathways have potential to help brain tumour patients. However, **the symptoms list is often not wide enough for people with potential brain tumours to be referred**, with the vague symptoms on the list not currently matching the non-specific symptoms of brain tumours.

NHS England and Scotland must expand the list of non-specific symptoms that warrant referral to NSS pathways so they include brain tumour symptoms.

How can you help us achieve faster diagnosis

- When our Faster Diagnosis report is out next week, please write to the Minister highlighting the main points
- Send our *Better Safe Than Tumour* signs and symptoms cards to local GP surgeries
- Write to your local Cancer Alliance to ask what diagnostic pathways there are for brain tumours
- Write to the Chair of your local Integrated Care Board or Integration Joint Boards to ask how widely direct access to MRIs is used among GPs

Contact Details

For more information about The Brain Tumour Charity or the Faster Diagnosis report please contact Steph and Liam in the Policy & Campaigns team at policy@thebraintumourcharity.org