



Briefing to Parliamentarians

November 2018

“It is this sense of crushing loss, this waste of potential that haunts my days. He did so much but could have done so much more. When Alexander was diagnosed with a glioblastoma in March 2016, I did everything I could but I couldn’t save my son and he died in June 2017. Our tragedy is a wider tragedy also, as society needs men like my son, Alexander.”

Joanna Paul, bereaved mother.

Brain tumours – a cost too much to bear?

Report of the Inquiry into the economic and social impacts of brain tumours

Earlier this year, the All-Party Parliamentary Group on Brain Tumours (APPGT) launched its first-ever Inquiry. Launched on 27th February 2018, the Inquiry sought to learn more about the economic and social impacts of a brain tumour diagnosis in order to shine a light on these issues, many of which, although seemingly invisible, are felt deeply.

The Inquiry collected evidence from across the brain tumour community throughout spring and summer via the following platforms:

Web forum

An online forum for brain tumour patients and community members was officially launched on 6th March 2018, hosted on Brain Tumour Research’s website. The forum received more than 200 submissions, detailing numerous financial impacts including significant loss of income, early retirement, loss of driving licences, costly home modifications, and direct non-medical costs such as hospital parking. These responses, along with subsequent case studies, helped identify key themes experienced across the brain tumour community.

Written submissions

The Inquiry received written evidence from a range of expert stakeholders including Cancer Research UK, The Christie NHS Foundation Trust, CLIC Sargent, The Children’s Brain Tumour Research Centre at the University of Nottingham, Macmillan Cancer Support, Brain Tumour North West, Tom’s Trust, Headway and Brain Tumour Research. The APPGBT was delighted to receive such comprehensive submissions, which also included an academic literature review and results of brain tumour community surveys.

Oral evidence sessions

From June to July 2018, the Inquiry held oral evidence sessions, at which the Panel heard from a variety of stakeholders, including smaller and larger charities, researchers, doctors, surgeons, academics, representatives of drug companies and, most importantly, brain tumour patients of all ages and their families. Panel members also used these sessions to explore in greater depth some of the issues raised by patients and carers via web forum submissions.



Key findings

The evidence gathered was extensive and revealed that the costs of brain tumours are borne by patients, their families and the wider society. The Inquiry's key findings included:

- The incapacitating nature of a brain tumour can see patients faced with an immediate financial burden and the severity of this disease all too often means that people contribute less to the economy and society at large.
- The costs faced by brain tumour patients are varied, ranging from loss of income through to higher domestic bills and costly home modifications. The Inquiry received evidence that the average household affected by a brain tumour will lose £14,783 per year versus £6,840 for all cancers. Additionally, patients are required to surrender their driving licence, leading to a loss of independence.
- The costs of brain tumours to the wider economy manifest themselves as high costs for the NHS during treatment and rehabilitation, loss of tax revenue and the costs of supporting brain tumour patients and their families via the benefits system. The economic costs of brain tumours among working age people have been estimated at £578 million per year, ranking the third highest amongst more common cancers behind lung (£1.2 billion) and breast (£635 million).
- The experience of children, teenager and young adult (CTYA) patients is dismayingly. CTYA brain tumour patients experience less economic detriment because they are financially dependent

on their parents or guardians but will experience more social issues as this disease affects them at an important stage of their development and they will have to bear its burden for the rest of their lives.

- The root cause of these high costs is that no significant scientific breakthroughs have occurred in the brain tumour sphere for decades. The limited treatments that are available, at best, extend life and do little to ameliorate the debilitating effects of a brain tumour.

Based on these findings, the Inquiry's report makes key recommendations aimed at driving immediate reforms to reduce costs, particularly for patients, as well as facilitating longer-term improvement in outcomes. These include a need to stimulate further research funding and improve early diagnosis rates. If brain tumours continue to be diagnosed late, with few treatment options and no sign of a cure, then the economic and social costs of brain tumours will always be unnecessarily burdensome.

The topics raised in the report will be used to guide and inform the future work of the APPGBT. Working with key decision-makers, the APPGBT will continue to strive to improve outcomes for brain tumour patients and their families and facilitate the implementation of these and other recommendations.

Brain tumours – a cost too much to bear? is available on the Brain Tumour Research website.

For a hard copy, please contact us on campaigning@braintumourresearch.org

The Secretariat of the APPG on Brain Tumours is provided by:



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The Brain Tumour Research charity, supported by The Brain Tumour Charity and PB Consulting, provides the Secretariat for the All-Party Parliamentary Group on Brain Tumours.

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