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The All-Party Parliamentary Group  
on **Brain Tumours**

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# Brain Tumours

## A cost too much to bear?

Report of the All-Party Parliamentary Group on Brain Tumours  
Inquiry into the economic and social impacts of brain tumours

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## All-Party Parliamentary Group on Brain Tumours

The All-Party Parliamentary Group on Brain Tumours (APPGBT) was established in 2005 by the Right Honourable John Bercow MP, supported by Ali's Dream and The United Brain Tumour Campaign (founding members of Brain Tumour Research). The APPGBT aims to raise awareness of the issues facing the brain tumour community in order to improve research, diagnosis, information, support, treatment and care outcomes.

Since 2005, MPs and Peers from across the political spectrum have worked together in supporting the brain tumour community including researchers, clinicians and most importantly, patients and their families.

APPGBT Membership:

- **Derek Thomas MP**—Chair
- **Alistair Carmichael MP**—Vice Chair
- **Kevin Brennan MP**—Vice Chair
- **Jim Shannon MP**—Vice Chair
- **Pauline Latham MP**—Vice Chair
- **Lord Carlile of Berriew**—Vice Chair
- **Baroness Masham of Ilton**—Vice Chair



### Secretariat:

The Brain Tumour Research charity, supported by The Brain Tumour Charity and PB Consulting, provides the Secretariat for the APPGBT.

Brain Tumour Research exists to raise the awareness of and grow the funding for scientific research into brain tumours and improve outcomes for brain tumour patients. It is the only national charity in the UK dedicated to funding continuous and sustainable scientific research into brain tumours. It is a leading voice in this country calling for greater support and action for research into brain tumours.

Brain Tumour Research supports one of the UK's largest collaborative groups of laboratory-based scientists progressing world-class research into brain tumours, working tirelessly to glean new layers of understanding about this disease.

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*"Alexander was studying for his A levels when he was among a small group of students invited to take part in a Government focus group, speaking about their experience of policing in south London. He was vocal and charismatic and was invited to feedback directly to the then Home Secretary, Theresa May. Then came a dramatic invitation for my son to address the 2014 Conservative Party Conference. I almost burst with pride watching my son address the leaders of our country, an 18-year-old black boy who had yet to vote was contributing to a review of national policing policy.*

*"I know his friends have half-joked that he could have been the first black Prime Minister. It almost felt like it that day. Alexander's talk was of being a lawyer, a journalist, or a politician. He had the world at his feet.*

*"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.*

*"I was angry and full of what-ifs but we have his poetry, his humanity and his spirit as his legacy. We didn't discuss his mortality, he didn't leave us letters but he left us his prose and that comforts me. A book of his work was published a year on from his death and he would have been proud of that."*

**Joanna Brown**



# Foreword

from **Derek Thomas MP**

Chair of the APPG on Brain Tumours

I first became aware of the devastation caused by brain tumours after Sue Farrington Smith, Chief Executive of Brain Tumour Research, brought the issue to my attention when I was a prospective MP. Joining the All-Party Parliamentary Group on Brain Tumours (APPGBT) was one of the first things I did after being elected to Parliament in 2015. It was with great interest that I watched the Petitions Committee respond to a petition with 120,129 signatories, calling for an increase in national funding for research into brain tumours. The subsequent Westminster Hall debate took place and a Task & Finish Group was established.

Throughout all of these pivotal developments, I have been continually inspired by the campaigning of the brain tumour community and was delighted to take up the position of Chair of the APPGBT in 2017. Following the publication of the Task & Finish Group's report in early 2018, the Government announced it would allocate £20 million for research into brain tumours and this was boosted by a pledge of £25 million from Cancer Research UK. After the death of Dame Tessa Jowell from a brain tumour and the establishment of The Tessa Jowell Brain Cancer Mission, the Government allocated a further £20 million. The provision of £65 million heralds a massive shift in focus towards brain tumours.

Of course, the funding is extremely welcome, especially considering the historic underfunding of research into brain tumours, which has received just 1% of the national spend on cancer research since records began. However, this report details the very high ongoing costs of brain tumours so I would encourage the Government to find additional ways to minimise these costs—through a combination of further research funding, earlier diagnosis, additional benefits, and improved post-treatment support for brain tumour patients and their families.

Brain tumours kill more children and adults under the age of 40 than any other cancer. The brain is the most important part of our body, the organ which generates our memories and emotions, as well as containing our skills and expertise. Therefore, cancer of the brain is uniquely destructive. The changes a brain tumour can cause in cognition, behaviour and personality result in high costs, both economic and social, which are borne by individuals, the health system and the wider public purse.

My thanks to all my fellow Inquiry panellists, to the team at Brain Tumour Research for organising the Inquiry and collating evidence and to those professionals, experts and policy makers who gave written or oral evidence.

In particular, my most heartfelt thanks go to all of the brain tumour patients, their families and those who have lost someone to this devastating disease for submitting their story via the Inquiry's web forum, through oral evidence sessions or by completing surveys—your submissions guided this Inquiry. I imagine that recalling the details of what must have been an extremely difficult time in your lives, and for many continues to be a stressful time, was both mentally and emotionally draining. Please rest assured that your evidence has strengthened the findings of this Inquiry immeasurably. Over the coming months and years, we will use the results of this Inquiry to keep brain tumours on the political agenda and improve outcomes for brain tumour patients.

I do hope you find the report and the findings of this Inquiry as informative as I have.

Derek Thomas MP

# Executive Summary

Brain tumours are the biggest cancer killer of children across the UK<sup>1</sup>. This terrible disease continues to kill young adults and is also the biggest cancer killer of under 40s<sup>2</sup>. Around 3,800 people die from brain cancers across England and Wales each year<sup>3</sup>. The disease is responsible for 2.6% of all cancer deaths in England and Wales<sup>4</sup>, with an almost identical percentage in both Scotland<sup>5</sup> and Northern Ireland<sup>6</sup>.

The All-Party Parliamentary Group on Brain Tumours (APPGBT) and the brain tumour community know that having a brain tumour is a devastating and costly business for the patient and everyone around them.

As these costs are unfair and often invisible, the APPGBT wanted to take steps to highlight and address them.

Therefore, the APPGBT launched an Inquiry into the economic and social impacts of brain tumours to understand better the true cost of what it means to be living with a brain tumour in the UK for patients and their families as well as the wider society, from the appearance of symptoms right through to treatment and beyond.

This report concludes this Inquiry, the first-ever undertaken by the APPGBT. It details the costs of brain tumours, including those incurred by both patients and the wider society. It also makes recommendations as to how best to mitigate these costs.

The body of this report goes into detail about the Inquiry's findings. A broad summary of these are listed below:

- The costs of a brain tumour are borne by patients, their families, and the wider society. The incapacitating nature of a brain tumour, a cancer of the body's most important organ, 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 took evidence that the average household affected by a brain tumour will be financially worse

off by £14,783 per year versus £6,840 for all cancers<sup>7</sup>. 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 annum, ranking the third highest amongst more common cancers behind lung (£1.2 billion) and breast (£635 million)<sup>8</sup>.
- The experience of children, teenager and young adult (CTYA) patients is daunting. CTYA brain tumour patients suffer 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 report also makes some recommendations. Whilst some of these suggest immediate reforms to reduce costs, particularly for patients, many suggest changes required to facilitate a longer-term improvement in outcomes for patients. 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 this 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 recommendations.

# Recommendations

## ▶ Reduce the financial burden for brain tumour patients and their families

- Give back quality of life to brain tumour patients and their families, offsetting a loss in income by giving them and their carers additional benefits.
- Ensure full implementation of The Department of Health and Social Care's 2014 guidance on hospital car parking in England and make sure Trusts are clearly promoting concession schemes for cancer patients, as outlined in Recommendation Six of *Listen Up!*, the report of the All-Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer<sup>9</sup>.
- Develop a patient-friendly, non means-tested fund from which brain tumour patients can access the subsistence required to travel to and from hospital visits, for example reform the existing Healthcare Travel Costs Scheme along the lines of Scotland's Neonatal Costs Fund.
- Amend existing Personal Independence Payment (PIP) processes to include a tailored assessment with fit-for-purpose questions relevant to neurological disorders, and brain tumours in particular.
- Ensure that brain tumour patients are speedily signposted towards information and advice on how to access relevant benefits at point of diagnosis

## ▶ Ensure a swift return to independence for brain tumour patients

- Review level of resourcing within the Drivers Medical Group of the DVLA to ensure it is fit-for-purpose and serves the needs of those who are seeking the return of their driving licence after being given medical permission to drive again.
- Ensure implementation of the Recovery Package by 2020, which is currently being rolled out across England, and make it available to all children and young people living with and beyond a brain tumour diagnosis ensuring inclusion of specific services, for example neuro-rehabilitation.

## ▶ Facilitate increased investment for research into brain tumours and increase the number of patients involved in clinical trials

- Stimulate further investment for research into brain tumours, including for low-grade tumours which people may live with for a long time and for which there can be high ongoing societal costs.
- Bring together relevant parties to review and improve clinical trial design in order to create a sophisticated, efficient clinical trials network.
- Reduce 'red-tape barriers' and reform traditional clinical trial procedures including the liberalisation of rules around clinical trials for less survivable conditions, as has been done internationally, and the use of innovative clinical trials to test different treatments simultaneously.
- Implement a system of data collection for brain tumours which is affordable and longitudinal, allowing researchers to measure patients' outcomes from diagnosis through treatment and rehabilitation.
- Help embed a research culture into clinical practice so that cutting-edge research does not stop at the laboratory bench. Treating brain tumours via more research-orientated care models would ensure better integration of clinical trials and hospital care, which will ultimately improve outcomes for all brain tumour patients.

## ▶ Identify ways to improve patient experience

- Review and ensure implementation of advanced palliative care planning for brain tumour patients.
- Design a specialist pathway for younger brain tumour patients that ensures consistent care through the CTYA treatment pathway, including provision of neuro-rehabilitation, which is particularly beneficial to younger patients, and which incorporates a staged transition between the ages of 16 to 25 to adult services.
- Implement inclusion of under-16s in the National Cancer Patient Experience Survey in England and the devolved nations.



*"The impact of having a brain tumour has been enormous and has cost me tens of thousands in lost income over the 10 years since my diagnosis, aged 29. I went from having an exciting career as a journalist, to having to retrain as a self-employed tree surgeon because no one wants to employ someone with a brain tumour. I then had to pack in that job as my seizures made me unfit to work. After that I worked part-time in HMV and then relied on benefits. Of course, living on benefits doesn't bring in anything like the same money as I earned as a tree surgeon.*

*"It has been a huge struggle to provide for my family and I have had to totally give up my plans of buying a house.*

*"I have had more than 120 cycles of chemotherapy and continue to care for my two 'miracle children' who were born after I was told my chemotherapy treatment would make me infertile. However, I now have to rely on another member of the family being with me or pay to have additional support.*

*"My condition has deteriorated further lately and I haven't been able to work at all for more than a year, being currently reliant on a wheelchair and a mobility scooter to get around. For some months, I have been waiting for a bed*

*in a specialist hospital to give me neurological physiotherapy as part of my rehabilitation. In the meantime, because I was unable to access my home, I am having to live in sheltered housing alongside old-age pensioners as I couldn't find any suitable housing provision locally for people of my age who have disabilities. It can get quite lonely as I have had to move away from my home town and don't get to see my children or my friends as often as I would like."*

**Ben Lindon**



# Loss of Income

Loss of income due to a brain tumour diagnosis was one of the key themes that emerged from the Inquiry's evidence gathering. The vast majority of submissions from members of the public made mention of this topic, often stating that worries about reduced income were almost as distressing as the disease itself. Respondents also told us how brain tumour patients can miss the social, and less quantifiable, benefits of working, including how employment provides a sense of vocation, greater self-esteem, a sense of purpose and potential and an opportunity to form new social relationships.

Lost income has a severely negative impact on the lives and careers of patients; it also lessens the returns to the public purse in the form of lowered tax revenue and lower productivity (societal costs are explored on page 15). Indeed, it has been calculated that the annual economic cost of brain tumours in people of working age is £578 million, ranking the third highest amongst more common cancers behind lung (£1.2 billion) and breast (£635 million)<sup>10</sup>.

There have been recent surveys of the brain tumour community into the topic of loss of earnings. A survey by Brain Tumour Research revealed that an average household loses an average salary of £15,848 per year and receives benefits on average of £4,767. This results in an average net loss of income of £11,081 per household per year as a result of a brain tumour<sup>11</sup>. Once additional costs of £3,702 are factored in, an average household is £14,783 financially worse off per year.

The Brain Tumour Charity reported that, prior to diagnosis, 41% of households had an income of over £40,000 per annum. This dropped dramatically to only 17% after a brain tumour diagnosis. Its report also demonstrates that brain tumours force too many people into relative poverty – prior to diagnosis only 7% of households had an income of under £10,000, rising to 23% after diagnosis<sup>12</sup>.

## **Recommendation:**

Give back quality of life to brain tumour patients and their families, offsetting a loss in income by giving them and their carers additional benefits.

*"We lost Andy's income and I put my job in jeopardy by taking so much leave for hospital appointments. Now he's gone, I'm a single mum and no longer employed. I work for myself to support our sons and I have to scrimp and save.*

*"The financial burden is yet another devastating impact of Andy's brain tumour diagnosis and, even 10 months on from his death, it's a constant worry."*

**Gill Graham**

# Financial and Self-Funded Costs

We have already seen how brain tumours can significantly lower income, but this devastating disease also increases both the frequency and amount of other, less obvious, household outgoings.

For example, families of children affected by brain tumours reported spending an additional £606 per month whilst their child was being treated<sup>13</sup>. The most common additional expenses faced by patients and their families were extra food, new clothing, childcare costs, utilities/telecoms costs and spending on general consumer goods<sup>14</sup>. Studies have suggested that household expenditure will rise to 20% higher than weekly income<sup>15</sup>. A recent survey conducted by Brain Tumour Research found brain tumour patients face an average of £3,702 per year additional costs<sup>16</sup>.

This financial impact is often long term, with families using savings, selling their homes and becoming indebted<sup>17</sup>.

Patients have also reported increased travel insurance premiums, with an average £400 increase in the travel insurance premiums based on one foreign holiday each year<sup>18</sup>.

Similarly, brain tumour patients may face higher life insurance premiums, or difficulty in obtaining cover. Those with a low-grade tumour will normally struggle to get a life insurance policy for three years after treatment. For high-grade tumours, if life insurance premiums are even offered, then premiums are considerably raised for 10 years after the cessation of treatment<sup>19</sup>.



*"I hate being in tears a lot of the time as I can barely pay the bills, am in credit card debt, overdrawn on my account, and have to deal with the anxiety that the situation creates."*

**Heather Taylor Nicholson**

Brain tumour patient and constituent of  
Derek Thomas MP



*"My husband Guy had achieved such a lot with his career as a garden designer, medals at all the big shows including Chelsea and Tatton Park, and he had co-authored two books on horticulture with his father. He had just turned 60 when he was diagnosed. Nothing could have prepared us for what was to come, his steady deterioration over nine years and also the upheaval to our domestic arrangements and the financial as well as the practical challenges this brought with it.*

*"We incurred £50,000 in legal costs as we moved house to an area where there was better public transport and accessibility to hospitals. We spent around £10,000 on equipment to help Guy get around, £7,500 to make our home suitable and safe for him, lost £10,000 in deposits for holidays and so on. Fees for carers came to around £5,000 and in order to care for Guy in his last two-and-a-half years, I had to retire early from a well-paid job.*

*"Our social life was hugely curtailed as it became more and more difficult for my husband to get out, especially when he could no longer get in and out of the car. We tried to entertain at home in order to get round this but often found ourselves cancelling as Guy was frequently unwell or too tired for visitors.*

*"During the last couple of months, it became impossible for me to take any respite at all so I gave up my few hobbies to be with Guy as his mental capacity deteriorated and the world closed in around him. In the end it was too much for him to even understand the TV and, as his caregiver, I was making all the decisions in order to keep all the stress away from him as he simply couldn't cope."*

**Jenny Farthing**

# Home and Caregiving

Brain tumour patients also face a more expensive homelife, with the majority of patients reporting increased living costs such as higher utility bills, spending more on food and/or the costs of paying for help around the home. For cancer patients this averages an extra £63 per month of spending<sup>20</sup>, but for brain tumour patients this is between £80-£100 per month of spending<sup>21</sup>.

*"Living in the hospital is expensive, especially when you don't drive and can't leave your ill son to pop to the nearest supermarket, so you have to get expensive hospital food. When this goes on for a few months and you still have rent and bills to pay at home you feel lost. Totally."*—**Parent of child affected by a brain tumour**<sup>22</sup>

The severely debilitating nature of brain tumours means that many patients find it necessary to undertake significant renovations to their homes, such as relocating bedrooms and bathrooms and adding ramps to improve home accessibility, at an average cost of close to £7,000, although often much more<sup>23</sup>.

Within the home is also where some of the most negative social costs of brain tumours manifest themselves, including a strain on familial relationships. The Inquiry took evidence from experts who study carers and family members of brain tumour patients. Dr Alasdair Rooney, a psychiatrist specialising in the mental impacts of brain tumours, reported<sup>24</sup> that approximately 50% of brain tumour patients experience some degree of personality change and/or cognitive impairment.

## **Dr Rooney said:**

*"These difficulties may irreversibly alter the relationship between the patient and their primary carer (who is usually their spouse). Patients may show anger, apathy, disinhibition, emotional instability, difficulty planning, poor multi-tasking, and slowed thinking. Carers may report a sense of total responsibility for looking after their partner, who may no longer be an equal support within the relationship. Having a brain tumour can put a marriage under severe stress."*

Dr Florian Boele, an academic with expertise in family caregiving and quality of life in neuro-oncology, told the Inquiry<sup>25</sup> that family caregivers often struggle to cope more than patients. She stated that this was a result of a lack of support available for caregivers due to, for example, a lack of specialist nursing staff. Moreover, she noted that in those with high-grade brain tumours, palliative care is often started too late and advanced care planning by the health service is rarely done early in the disease trajectory. Both Dr Boele and Scott Sinclair of Marie Curie told the Inquiry that brain tumour patients are less likely to receive palliative care compared with other cancers.

## **Recommendation:**

Give back quality of life to brain tumour patients and their families, offsetting a loss in income by giving them and their carers additional benefits.

## **Recommendation:**

Review and ensure implementation of advanced palliative care planning for brain tumour patients.

# Transportation

Costs related to transport were frequently raised across all sources of evidence and comments focused on two distinct areas. The immediate problem for those facing a brain tumour diagnosis is the expense of travelling to and from hospital. In the longer term this is followed by difficulties in travel generally, especially as patients have had to relinquish their driving licence.

Brain tumour patients, in the main, have to attend numerous hospital appointments for diagnosis followed by initial treatment five times per week for at least six weeks for radiotherapy<sup>26</sup>. In addition, many patients will have to attend hospital for chemotherapy infusions and/or surgery. Treatment can continue, albeit at less intensity, for up to two years<sup>27</sup>. While costs vary across the UK, parking fees at NHS hospitals can reach £10 per day. Including transportation costs, meals and snacks, and accommodation where applicable, travel costs can stand at £1,582 per year<sup>28</sup>.

As new treatments, such as Proton Beam Therapy, become available for brain tumour patients, these will be delivered in centralised hubs, meaning that patients may have to travel even further<sup>29</sup>. Local access to post-treatment services can also be limited because of patients' proximity to regional or national centres. This can result in significant travel demands and costs to access rehabilitation services<sup>30</sup>.

The NHS does operate a 'Healthcare Travel Costs Scheme' to reimburse those receiving various forms of welfare benefits, but this is both underutilised<sup>31</sup> and prefers patients to use public transport, which is not always possible for patients whose immunity may be compromised as a result of their treatment. Furthermore, many brain tumour patients

can experience severe fatigue, memory problems and epileptic seizures. The Government has also published guidance on NHS parking<sup>32</sup>, which advises local NHS Trusts to offer concessions to those frequently attending outpatient appointments (such as brain tumour patients). However, the consensus is that these concessions are either not available or not promoted by many NHS Trusts<sup>33</sup>.

## **Recommendation:**

Ensure full implementation of The Department of Health and Social Care's 2014 guidance on hospital car parking in England and make sure Trusts are clearly promoting concession schemes for cancer patients, as outlined in Recommendation Six of *Listen Up!*, the report of the All-Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer.

## **Recommendation:**

Develop a patient-friendly, non means-tested fund from which brain tumour patients can access the subsistence required to travel to and from hospital visits, for example reform the existing Healthcare Travel Costs Scheme along the lines of Scotland's Neonatal Costs Fund.

# Transportation

Following a brain tumour diagnosis, many patients are required to surrender temporarily their driving licence whilst they undergo further diagnostics and treatment. The vast majority of patients understand the need to do this on the grounds of safety and so surrender their licence entirely willingly. Indeed, the Inquiry heard expert evidence<sup>34</sup> on this topic.

However, many submissions to the Inquiry complained that it took an unduly long time, sometimes more than three months, for driving licences to be returned after clinicians had declared patients fit to drive again. For those brain tumour patients who rely on a car for transport, these delays can result in unnecessary social isolation, reduced quality of life and financial loss.

On the basis of evidence<sup>35 36</sup>, the APPGBT believes that these delays in returning driving licences are due to a lack of resource in the Drivers' Medical Group (the part of the DVLA which considers whether drivers with a medical condition are safe to drive). The Inquiry heard that the DVLA has significantly improved the Drivers' Medical Group in recent years, by adding more specialist medical staff and improved computer systems<sup>37</sup>. Nevertheless, waiting times for those awaiting the return of their driving licence still seem unacceptably long.

## **Recommendation:**

Review level of resourcing within the Drivers Medical Group of the DVLA to ensure it is fit-for-purpose and serves the needs of those who are seeking the return of their driving licence after being given medical permission to drive again.

*"The process of applying for my driving licence to be reinstated was very traumatic. After the six-month period had expired, an MRI scan indicated all was well and my surgeon responded to DVLA confirming he was satisfied with the questions they asked. I contacted DVLA to ask how long it would take to hear back and for my licence to be returned and was told there was a 26-week backlog!*

*"I was totally distraught as getting my independence back was an important step in my recovery."*

**Tina Dufty**

# Public and Direct Medical Costs

Brain tumours are costly for individuals and also for the public purse. One reason for this is that the economic losses resulting from brain tumours are high. Of the cancers diagnosed among children and young adults, brain tumours are common. Deaths among these groups result in the loss of an individual for the entirety of their working life.

It has been calculated that the annual economic cost of brain tumours in people of working age is £578 million<sup>38</sup>. Costs like these are known as 'indirect costs' of a condition and, in addition to the loss of earnings already mentioned, also include things like 'social losses' which account for the lost value of informal care (for instance, looking after children), volunteering and domestic work (for example, household chores). It is estimated that the total 'social losses' associated with all cancer deaths in the UK are worth £473 million each year<sup>39</sup>. If we set a straight-line percentage against this, such that that brain tumours represent 3% of cancer deaths, this would give an approximate figure of £14 million annually, although this figure does not consider 'social losses' as a result of disability caused by a brain tumour. The figure for unpaid care of brain tumour patients, provided by family and friends, is unknown. Based on existing research, we can estimate this at £36.4 million a year<sup>40</sup>, although the true cost is likely much higher.

The Inquiry also took evidence on the psychological burden of living with a brain tumour and the related indirect costs. An approximate calculation is that the top four most distressing concerns of brain tumour patients, namely fatigue, worry, sleep difficulties and sadness, incur costs amounting to £20 million per year<sup>41</sup>.

Benefits are another major indirect cost. A survey by The Brain Tumour Charity found that, as a result of brain tumour patients losing their ability to work, 65% become at least partially dependent

on benefits. Half of this 65% reported relying on benefits for most or all of their household income<sup>42</sup>. Other brain tumour charities<sup>43</sup> reported that their patients had very poor experiences of dealing with Employment Support Allowance and Personal Independence Payment (PIP). The Christie Hospital also reported that:

*"PIP assessments do not truly measure the level of disability experienced as staff take a 'tick box' approach without understanding the implication of a person's long-term disability. A patient with a low-grade tumour who had severe cognitive changes affecting his memory was unable to do his job and had to leave work. He was rated as scoring zero on all areas of assessment so didn't meet the PIP criteria. People have been deemed 'fit for work' when they have severe disabilities and are clearly unable to work. A colleague who attended a PIP assessment with a patient saw how her disabilities were ignored."*<sup>44</sup>

The Inquiry also took oral evidence from a member of the public, Mrs Aleksandra Felix, who has suffered from a brain tumour. During her PIP Assessment, she had been asked entirely generic questions such as "Can you move your arm?" and "Can you read with prescription glasses on?"<sup>45</sup>. These questions are not appropriate for a condition such as brain tumours, which produce a range of different symptoms, not just basic physical impairment (although this can be an issue for many brain tumour patients).

Observations like these have prompted the brain injury charity Headway to ask for amendments to the PIP assessment process in particular – such as for these interviews to be recorded and for family members to be invited to join, as patients themselves can't always articulate the effects of their brain tumour. It called for evidence to be considered and for more training for the assessor to understand neurological disabilities<sup>46</sup>.

# Public and Direct Medical Costs

## **Recommendation:**

Amend existing Personal Independence Payment (PIP) processes to include a tailored assessment with fit-for-purpose questions relevant to neurological disorders, and brain tumours in particular.

Lack of information surrounding the availability of benefits was reported to be another issue for brain tumour patients. 46% of those diagnosed with a brain tumour did not receive any information about how to get financial help or any benefits they might be entitled to following their diagnosis. Similarly, 44% of respondents did not receive information regarding their eligibility for free prescriptions following their diagnosis. A worrying 76% of those looking after someone with a brain tumour did not receive any information regarding the financial assistance they may be eligible for as a carer<sup>47</sup>.

## **Recommendation:**

Ensure that brain tumour patients are speedily signposted towards information and advice on how to access relevant benefits at point of diagnosis.

## **Recommendation:**

Stimulate further investment for research into brain tumours, including for low-grade tumours which people may live with for a long time and for which there can be high ongoing societal costs.

Unlike most other nations, the UK has a state-funded health system and therefore the medical costs of people living with a brain tumour are borne more directly by the public purse than is the case in other countries. 'Direct medical costs' of brain tumours (including costs of hospital visits, drugs and staff time) are not the biggest drain on the public purse compared with providing patients with various social services and benefits ('direct non-medical costs') and the losses of tax revenue ('indirect costs').

However, as a complex disease with more than 120 different types of tumour, brain cancer has a relatively high direct medical cost. Average in-patient, post-diagnosis costs for brain tumours are £13,200, according to Macmillan Cancer Support. This is higher than breast, lung and prostate cancers<sup>48</sup>.

Of course, this varies dramatically depending on the patient. For those with a higher-grade malignant tumour an approximate direct medical cost for a year can be £180,000<sup>49</sup>.

On a per-patient basis, when looking at conditions of the brain, brain tumours have the highest direct medical costs and are the second most expensive condition overall (after neuromuscular disorders) and this is due to a lack of data on the true size of the indirect costs of brain tumours<sup>50</sup>.

The Inquiry also received evidence about the costs of treating the mental health aspects of brain tumours, which had direct medical costs of approximately £150<sup>51</sup> per patient. This assumes only one GP appointment and one psychological referral, which is most likely to be an underestimate—although the real expenses with regards to mental health and brain tumour patients are the 'indirect costs'.





*"Our daughter was just three years old when she started to experience the symptoms which would eventually lead to her brain tumour diagnosis, although she was 15 before we first heard those dreadful words.*

*"To say our lives have been turned upside down over the years would be an understatement. Charlotte, our only child, is now 18 and we have lost count of the number of hospital admissions and invasive procedures she has undergone.*

*"By rights she should be looking forward to an exciting future, perhaps looking at universities, starting work, or travelling with friends as she explores the world around her, finding her place in it and starting to achieve her potential.*

*"Sadly, none of these things are ever likely to be an option for Charlotte. In many ways, it is as if time has stood still. The happy-go-lucky teenager who loved fashion and make-up and enjoyed pop music slowly disappeared as the impact of six months of treatment, a necessary evil, began to reveal itself. Charlotte's life, and ours with it, has been turned upside down by the huge and life-changing side effects of her treatment.*

*"Hospital appointments and admissions have become such a huge part of our lives. In the early days she was in paediatrics whereas we now find ourselves in adult wards. Whilst the care we have had has always been exemplary, I sometimes do think that this transition has been particularly difficult for Charlotte who, because of her cognitive impairment and complex medical needs, is still very much a little girl.*

*"Although there is a comprehensive care package in place, so complex is Charlotte's case that on her frequent hospital admissions, one of us has to remain with her as her advocate."*

**Angela Reid**

# Children, Teenagers and Young Adults

Brain tumours kill more children and adults under the age of 40 than any other cancer<sup>52</sup>. Therefore, the Inquiry was keen to examine how the social and economic impacts of brain tumours are different for Children, Teenagers and Young Adults (CTYA)<sup>53</sup>.

The Inquiry found that younger brain tumour patients<sup>54</sup>, who comprise 15% of all young cancer patients, may suffer 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.

There are two key areas where the experiences of CTYA patients differ from adults – treatment and survivorship. As regards treatment experience, younger brain tumour patients lack a suitable service specification to meet their needs, with transition from paediatric to adult services being particularly problematic. The recent report from the All-Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer includes a quote from Dr Clare Rowntree (National Clinical Lead for Teenagers and Young Adults with Cancer – Wales) which outlines some of the issues children and young people face:

*"Once you hit 16 there seems to be this abyss... some of the cancers more common in the teenager and young adult age range, the brain tumours, the bone sarcomas, and lymphomas and you often hear very sad stories about very delayed diagnoses... health professionals just don't often think that young people get cancer, but also, young people aren't empowered to use the system and once they get to 16 or 17 they perhaps lose the advocacy of their parents and they don't advocate for themselves very well..."<sup>55</sup>*

This sentiment was backed by Headway, which has found that when a child patient transitions to adult services it always seems to be a danger point. Headway would like a staged transition from 16 to 25, to enable young adults to adjust to new clinics and health settings and new people. Dr Helen Spoudeas, an expert paediatric endocrinologist, took this concept even further saying that there needs to be a 13 – 30 service to match the reality of brain development<sup>56</sup>. The Inquiry was also told that once young patients are on an oncology treatment pathway in the NHS, it is very hard, if not impossible, to access paediatric and endocrine neuro-rehabilitation services – which can be particularly valuable to CTYA patients<sup>57</sup>.

## **Recommendation:**

Design a specialist pathway for younger brain tumour patients that ensures consistent care through the CTYA treatment pathway, including provision of neuro-rehabilitation, which is particularly beneficial to younger patients, and which incorporates a staged transition between the ages of 16 to 25 to adult services.

*"There are also all the children I have nursed over the years, because it is always those children with brain tumours who need end-of-life care, not for them the statistics of those diagnosed with leukaemia, and suffering significantly greater morbidity along the way."*

**Kaye Thomas**

# Children, Teenagers and Young Adults

Many of the researchers, clinicians and health policy experts who submitted evidence to the Inquiry felt that more CTYA patient experience data is an imperative to improve care for younger patients. Such data could then be used to create targets to incentivise change. The APPGBT understands that NHS England is making progress on developing processes to gather patient experience data for under-16s.

**Recommendation:**

Implement inclusion of under-16s in the National Cancer Patient Experience Survey in England and the devolved nations.

Survivorship, defined as a patient's quality of life (for example ability to enjoy normal life activities) after treatment, is another matter that differentiates CTYA brain tumour patients from adults. Taking a patient-centric view of quality of life is particularly important for paediatric patients, as younger patients may have to live with the burden of treatment for many years. Clinicians need to carefully discuss the side effects of treatments with patients—maximising survival time must be balanced against detriment to the quality of life. The patient's opinion on this balance must be considered.

Although far too many children and young people die from brain tumours (a family loses their child to a brain tumour every week<sup>58</sup>), those who do survive face challenges that can be very different from older survivors.

As Dr Clare Mills from the charity Headway told the Inquiry: *"The effects of a childhood brain tumour can be lifelong and must be considered when taking into account the social and economic impacts"*<sup>60</sup>. Other witnesses confirmed that more than 60% of young brain tumour patients will be left with a life-altering disability<sup>60 61</sup>.

Moreover, studies have revealed that childhood cancer survivors face higher rates of unemployment<sup>62</sup> and even those that do find employment often have a lower salary. One study also suggested that there were lower rates of marriage amongst survivors as well<sup>63</sup>.

The socio-economic benefits of improving these patients lives, through post-treatment provision such as neuro-rehabilitation or educational support, would be enormous. Unfortunately, 73% of patients and their families report these services to be insufficient or difficult to access<sup>64</sup>.

**Recommendation:**

Ensure implementation of the Recovery Package by 2020, which is currently being rolled out across England, and make it available to all children and young people living with and beyond a brain tumour diagnosis ensuring inclusion of specific services, for example neuro-rehabilitation.

*"I am a nurse working with 16 to 25 year-olds diagnosed with brain tumours. At this age they often have no health insurance to fall back on, their parents have to stop work to be carers and this impacts significantly on household income. They often travel a long way for treatment (up to 100 miles round trip). Social support for young people diagnosed as a child and now living with side effects is also lacking."*

**Kate Law**



*"In September 2015, I started experiencing strange feelings of nausea, hot flushes and partial seizures, but it wasn't until five months later when I had a tonic-clonic seizure that I was diagnosed with a low-grade brain tumour.*

*"The seizures kept increasing and the medication was not helping. The initial course of action was to 'watch and wait' but as the epilepsy was getting worse and daily life was becoming more and more difficult, so I decided to have surgery to remove the tumour.*

*"Although the surgery went well, it was the aftermath of the surgery that took its toll on me. I was always tired and suffered from post-operative depression. I would get upset for no obvious reason and cry all the time. Even when I returned to school, I would sit in class and suddenly become emotional, and there was a lack of understanding from my teachers and fellow pupils. I really wish there had been more support at school; I found that many people don't realise the full impact of brain surgery and it was difficult to communicate the complexity of issues I was dealing with.*

*"I often thought how unfair my situation was; I had always been very healthy and sporty, never ill, and I was only 16. The diagnosis and surgery had a huge impact on my studies too. I have*

*always had high expectations of myself and just want to do my best, so it was especially difficult that this was all happening while I was studying for my A-levels. Sometimes, I would get confused or lost for words. As a result of that and my tiredness, my grades dropped and my overall academic performance worsened, which was particularly traumatic for me as I was used to being an A\* student."*

**Flora Bouchier**

# Clinical Trials and Data

This Inquiry was tasked with examining what measures could reduce the social and financial impacts of this disease. Of course, the ultimate improvement would be to lessen the disease burden by researching improved treatments and therapies. Therefore, using research and data more effectively are key measures to reduce the impacts of brain tumours.

Professor Geoff Pilkington told the Inquiry that problems with research into brain tumours begin with poor pre-clinical models to test therapeutics. These models fail to capture the complex nature of brain tumours in the body, resulting in costly failed clinical trials for brain tumours<sup>65</sup>.

Indeed, Professor Pilkington advised that the transition from pre-clinical research to clinical trials is often very poor (both in the UK and globally) and therefore clinical trials can be badly designed. Cancer Research UK added that the UK is slow at setting up clinical trials – a debate is needed within the scientific community and between regulators, ethics committees and clinicians about alternate approaches to clinical trial design<sup>66</sup>. This was backed by public submissions to the Inquiry with one of the Inquiry's witnesses, Mr Glenn Karpel, who lost his wife Penny to a brain tumour, advocating for more responsive and collaborative research<sup>67</sup>.

## **Recommendation:**

Bring together relevant parties to review and improve clinical trial design in order to create a sophisticated, efficient clinical trials network.

Although it is vital that clinical trials are tightly regulated, for the protection of both patient safety and the scientific method, overly protracted clinical trial processes can stifle innovation. For example,

Professor David Walker told the Inquiry about an ongoing trial into 'Convection Enhanced Delivery', which seeks to improve outcomes for patients with a diffuse intrinsic pontine glioma (DIPG). Professor Walker reported that sometimes unnecessary regulatory processes were adding to the already high-costs of administering such a trial<sup>68</sup>. This was earlier highlighted by the Government's Petitions Committee in 2016 with a recommendation to address 'red-tape barriers' which may be reducing opportunities for clinical trials<sup>69</sup>.

In this more globalised era, clinical trials that are too slow to launch in the UK can result in patients, who are often desperate for hope, travelling abroad, often to countries where there are fewer protections in place, or where they may be sold futile treatments at significant cost.

Other nations have examined this problem and decided to streamline their clinical trials process. Japan was the first to do so, nearly five years ago, implementing conditional and time-limited pathways for regenerative medicines, which include certain types of cellular immune therapies for treating cancer<sup>70 71</sup>.

The Japanese system is careful to maintain patient safety, while greatly accelerating the clinical trials process and reducing the costs, enabling new treatments to reach patients much sooner and at lower cost. In brief, if an experimental treatment has been proven safe and is potentially effective after a small Phase 1 clinical trial (Phase 1 checks safety), patients should have the option to access that drug and the creators should have the ability to market and sell the product. This time-limited approval allows for full commercialisation, including marketing, for up to seven years, during which time drug developers must show additional efficacy and

# Clinical Trials and Data

safety and re-apply for full approval, or risk having their conditional approval revoked at the seven year mark in the absence of additional supporting evidence.

The USA has a similar concept with its 'Right-to-Try' legislation. This provides patients who are terminally ill the right to access experimental medicines that are in active drug development many years before those medicines would have completed the clinical trials process.

In addition to laboratory research and clinical trials, another useful source of data is public health data – often referred to as 'real-world data'. Although this is widely collected across both primary and secondary care, researchers and charities who want to access it have to pay the Government. The prohibitive cost, often tens of thousands of pounds, prevents researchers from accessing valuable data, for example the true effectiveness of the HeadSmart brain tumour early diagnosis campaign<sup>72</sup> cannot be easily ascertained as it is expensive to buy access to the relevant public health data. What's more, access to this data<sup>73</sup> continues to be important to enable ongoing evaluation of brain tumour treatments after they have become commercially available.

The need for relevant data cuts across all disciplines. Indeed, Sara Robson, a Specialist Allied Health Professional for brain tumour care, reported to the Inquiry there is no centralised source for rehabilitation data – meaning it is difficult for practitioners to learn best practice. Other conditions, especially for strokes with the Commissioning for Quality and Innovation National Goals, do have these data protocols established for rehabilitation. However, brain tumours aren't measured in the same way as strokes<sup>74</sup>.

## **Recommendation:**

Reduce 'red-tape barriers' and reform traditional clinical trial procedures including the liberalisation of rules around clinical trials for less survivable conditions, as has been done internationally, and the use of innovative clinical trials to test different treatments simultaneously.

## **Recommendation:**

Implement a system of data collection for brain tumours which is affordable and longitudinal, allowing researchers to measure patients' outcomes from diagnosis through treatment and rehabilitation.

## **Recommendation:**

Help embed a research culture into clinical practice so that cutting-edge research does not stop at the laboratory bench. Treating brain tumours via more research-orientated care models would ensure better integration of clinical trials and hospital care, which will ultimately improve outcomes for all brain tumour patients.





*"I was six-and-a-half when Ashley was born and I couldn't have been more proud to be the big sister of such a beautiful, happy little boy. My other brother, Shervin, arrived 17 months later and the three of us were extremely close. It was my saddest moment, yet my greatest privilege, to be at Ashley's side, holding his hand, when he died.*

*"When he was diagnosed with a grade two astrocytoma, Ashley was initially told he had one year to live, but surgery by the pre-eminent surgeon, Henry Marsh, meant that he lived for a further eight years and achieved his post-diagnosis life ambition of reaching his 30<sup>th</sup> birthday. Notwithstanding the treatment he received, there was nothing that Mr Marsh could do for Ashley at the end of his life. People don't talk about what loved ones go through during their final months of life, probably because it is so horrific that they try to block it out. To lose Ashley was devastating – to watch him suffer was unbearable.*

*"There were moments throughout Ashley's diagnosis and treatment when we really had to stand up and fight for him and threatening legal action was the only way to get people to take us seriously. In terms of palliative care, the system didn't seem able to properly cope with a terminally ill young man who wanted to live for as long as possible.*

*"He was moved to a hospice but only stayed for one night because he said he wanted to receive basic treatment for epilepsy should he suffer from a fit. This forced us to look after him at home.*

*"I gave up my work as a barrister and Shervin gave up his job as a solicitor and we moved home to help care for him. Although nursing support was provided (and many of the nurses were fantastic) there were times when the standard of nursing care provided fell far below the standard expected. At a time when we were going through so much emotionally, the responsibility to provide nursing care ourselves was overwhelming.*

*"The experience had such an impact on me that I changed my entire area of practice and am now a healthcare regulatory barrister."*

**Shardi Shameili**



# Appendix 1:

## Inquiry Terms of Reference and Methodology

### Terms of Reference

The Inquiry will seek to understand better the true cost of brain tumours in the UK, for patients, their families and the NHS, from the appearance of symptoms right through to treatment and beyond. The key questions are:

1. What are the social and financial impacts on families affected by a brain tumour diagnosis in both the short and long term, including the lead into diagnosis itself and any resultant brain injury? How is this different for younger people?
2. What is the typical relationship and interaction of families affected by a brain tumour diagnosis on NHS and social care services and can this be costed?
3. What pressures will the rising incidence of brain tumours have on the NHS, social care and other public services?
4. What measures could be implemented to reduce the social and financial impact of this disease, including the better use of data?

### Inquiry Panellists

The Inquiry Panel consisted of the following members:

- Derek Thomas MP
- Sarah Jones MP
- Alistair Carmichael MP
- Sue Farrington Smith MBE, *Brain Tumour Research*
- Clare Normand, *The Brain Tumour Charity*
- Dr Helen Bulbeck, *Braintrust*

### Methodology

The Inquiry was launched at the APPGBT meeting on 27th February 2018. With input from attending MPs and charity policy experts, the APPGBT agreed on the Terms of Reference and the timeline for the Inquiry, which ran throughout spring and summer, with the report being launched in November 2018.

The purpose of the Inquiry was to understand better the true cost of brain tumours in the UK, for patients, their families, and the NHS.

### Call for Evidence

The APPGBT, supported by Brain Tumour Research, launched its call for evidence in spring 2018 and gathered evidence via the following methods:

**Literature Review** – a review of published literature about the themes of the Inquiry was undertaken, (see Appendix 3). Comparisons were looked for within international publications. This helped both identify the calls for evidence and inform the Inquiry's report.

**Web Forum** – an online forum for brain tumour patients and community members was launched on 6th March 2018, hosted on Brain Tumour Research's website. The Inquiry 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 and support costs. These responses, along with subsequent case studies, helped the Inquiry Panel identify key themes experienced across the brain tumour community.

**Written Submissions from experts** – expert stakeholders from across academia, clinical practice, the third sector and industry were invited to submit written evidence. A list of those who submitted evidence can be found in Appendix 2.

**Oral Evidence Sessions** – from June to July 2018 the Inquiry held oral evidence sessions. During these sessions, the Inquiry panel heard from a variety of stakeholders, including both smaller and larger charities, young people with a brain tumour diagnosis, researchers, doctors, surgeons, academics, representatives of drug companies and, most importantly, brain tumour patients and their families. A list of those who gave oral evidence at these sessions is included in Appendix 2. Panel members also used these sessions to question witnesses and explore in greater depth issues that were raised by members of the public in web forum submissions.





# Appendix 2:

## List of Inquiry witnesses

The APPGBT heard oral evidence from the following witnesses:

### Session 1 – Tuesday 5th June 2018

- **Emma Greenwood**  
*Director of Policy and Public Affairs, Cancer Research UK*
- **Helen Gravestock**  
*Research and Policy Manager, CLIC Sargent*
- **Scott Sinclair**  
*Head of Policy and Public Affairs, Marie Curie*
- **Dr Clare Mills**  
*Public Affairs Manager, Headway*
- **Jo Plant**  
*Director of Fundraising, Headway*

### Session 2 – Tuesday 12th June 2018

- **Professor Garth Cruickshank**  
*Chair Transport Secretary's Medical Advisory Panel on driving and disorders of the nervous system*
- **Professor Geoff Pilkington**  
*Professor of Cellular and Molecular Neuro-Oncology and Head of the Brain Tumour Research Centre at the University of Portsmouth*
- **Dr Helen Spoudeas**  
*Paediatric Endocrinologist at Great Ormond Street Hospital and founder of SUCCESS Charity*

### Session 3 – Tuesday 26th June 2018

- **Professor David Walker**  
*Professor of Paediatric Oncology, University of Nottingham*
- **Dr Navid Malik**  
*Non-executive board director, Northwest Biotherapeutics Inc*
- **Erik Ramos**  
*Special Projects, Northwest Biotherapeutics Inc*
- **Dr Florian Boele**  
*YCR Academic Fellow, University of Leeds*
- **Dr Emanuela Molinari**  
*Consultant Neurologist and Honorary Clinical Senior Lecturer, The Queen Elizabeth University Hospital and University of Glasgow*
- **Sara Robson**  
*Specialist Allied Health Professional brain and central nervous system tumour rehabilitation, The Christie NHS Foundation Trust*

### Session 4 – Tuesday 3rd July 2018

*(for members of the public with a brain tumour connection)*

- **Dr Ingrid Wassenaar**
- **Aleksandra Felix**
- **Martin Felix**
- **Jenny Farthing**
- **Glenn Karpel**

The APPGBT received expert written evidence from the following:

- **Macmillan Cancer Support**
- **Cancer Research UK**
- **CLIC Sargent**
- **Teenage Cancer Trust**
- **Headway—the brain injury association**
- **Children's Brain Tumour Research Centre**  
*University of Nottingham*
- **The Christie Hospital NHS Foundation Trust and Salford Royal NHS Foundation Trust**
- **Brain Tumour North West**
- **Northwest Biotherapeutics Inc**
- **Dr Alasdair Rooney**  
*University of Edinburgh*
- **Tom's Trust**

# Appendix 3:

## Literature Review and References

The Secretariat of the APPGBT, Brain Tumour Research, completed a literature review to better understand the existing knowledge base regarding the costs of brain tumours. This was primarily focused on reports from the third sector, but did also include more academic literature, especially when this referred to the systemic costs of treating brain tumours.

Notable articles assessed during this literature review included:

**Fineberg et al (2013) The size, burden and cost of disorders of the brain in the UK, J Psychopharmacol.** 2013 Sep; 27(9): 761–770. - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3778981/>

**Raizer et al (2014) Economics of Malignant Gliomas: A Critical Review, Journal of Oncology Practice** 11, no. 1 (January 2015) - <http://ascopubs.org/doi/abs/10.1200/JOP.2012.000560>

**S Bradley (2007) I could lose everything: understanding the cost of a brain tumor, J Neurooncol** - <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.628.5913&rep=rep1&type=pdf>

**Future Proof Insurance (2014) Arranging Life Insurance with a Benign Brain Tumour** - <https://www.futureproofinsurance.co.uk/arranging-life-insurance-with-a-benign-brain-tumour>

**Nick McGowan, Life Insurance blog (2017) Life Insurance after a Brain Tumour** - <https://lion.ie/life-insurance-medical-issues/life-insurance-after-a-brain-tumour/>

**Macmillan – Cancer’s Hidden Price Tag** - [https://www.macmillan.org.uk/\\_images/Cancers-Hidden-Price-Tag-report-England\\_tcm9-270862.pdf](https://www.macmillan.org.uk/_images/Cancers-Hidden-Price-Tag-report-England_tcm9-270862.pdf)

**Marie Curie – The hidden costs of caring (2015)** - <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2015/hidden-costs-of-caring.pdf>

**Marie Curie – The hidden challenges of palliative cancer care (2016)** <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2016/hidden-challenges-palliative-cancer-care-report.pdf>

**CLIC Sargent – Counting the costs of cancer: The financial impact of cancer on children, young people and their families (2011)** - <http://www.clicsargent.org.uk/sites/files/clicsargent/Countingthecostsofcancerreport.pdf>

**MND Association – MND Costs: Exploring the Financial Impact of Motor Neurone Disease** - <https://www.mndassociation.org/wp-content/uploads/DEMOS-FULL-report.pdf>

**Stroke Association - Current, future and avoidable costs of stroke in the UK** - [https://www.stroke.org.uk/sites/default/files/costs\\_of\\_stroke\\_in\\_the\\_uk\\_report\\_-\\_executive\\_summary\\_part\\_1\\_v2.pdf](https://www.stroke.org.uk/sites/default/files/costs_of_stroke_in_the_uk_report_-_executive_summary_part_1_v2.pdf)

**Multiple Sclerosis International Federation (2010) Global Economic Impact of Multiple Sclerosis** - [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf)

**International Longevity Centre. Rethinking Cancer: The Big ‘C’: Quantifying the social and economic impact. 2015** - <https://ilcuk.org.uk/wp-content/uploads/2018/10/Rethinking-Cancer-The-big-C.pdf>

As part of their written evidence to the Inquiry, the Children’s Brain Tumour Research Centre (CBTRC) at the University of Nottingham very kindly undertook a literature review of published academic articles pertaining to the costs of childhood brain tumours etc. This literature review included 28 published academic articles.

The APPGBT would like to thank CBTRC for undertaking such an extensive literature review

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*"My son Stephen was training to be a pilot in the Royal Air Force, going solo after 10 hours tuition, before he'd even passed his driving test. Suddenly at the age of 19, following a five-month spell of having occasional "pins and needles" in his right arm, he was diagnosed with a "benign" Grade 2 Astrocytoma.*

*"Overnight he lost his authority to fly, drive a car, and with it his independence. He was signed off work for two years and had to return home. It soon became clear he would most likely lose the career he had worked so hard to achieve.*

*"After diagnosis things moved quickly, and the neurosurgeon removed an orange sized tumour in his left temporal lobe. Knowing nothing about brain tumours and the devastating impact they can have, we were very shocked when the neuro-surgeon announced "I'm afraid your tumour will re-grow, turn more aggressive, and will kill you" at a post-operative meeting. At the age of 19 our bright, funny, amazing young man was being told he had five to seven years to live.*

*"After less than two years, the 20% of Stephen's tumour impossible to remove during his neuro-surgery, started re-growing. Once again, the family was devastated and Stephen was left to dwell on his future – or lack of it.*

*"Six weeks of radiotherapy were scheduled, followed by weeks of chemotherapy, which his body couldn't tolerate. Each course of treatment had to be abandoned after three or four doses. Having lost his hair, and an interest in food, it was truly heart-breaking to see my young, previously fit son who could run 12 miles with a military Bergen on his back, now struggling to walk ten feet from our bathroom to his bedroom.*

*"Stephen passed away in August 2014, having just turned 26. He left behind a large circle of family and friends deeply affected by what they had witnessed happening to him.*

*"That is Stephen's story, but as you have read, sadly and unacceptably, our family's situation is far from unique, and survival rates for brain cancer patients remain largely unchanged during the last 30 years."*

### **Peter Realf**

The All-Party Parliamentary Group on Brain Tumours was established in 2005 to raise awareness of the issues facing the brain tumour community in order to improve research, diagnosis, information, support, treatment and care outcomes.

The APPGBT is grateful to the Inquiry panellists, to those professionals, experts and policy makers who gave written or oral evidence, and to everyone affected by a brain tumour who gave oral evidence, submitted their story, or completed surveys.

This report was produced by Brain Tumour Research.



**Brain Tumour  
Research**

Together we will find a cure

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