Exposing the financial impact

Report on the financial impact of a brain tumour diagnosis
Brain tumours kill more children and adults under the age of 40 than any other cancer.

Less than 20% of those diagnosed with a brain tumour survive beyond five years.

“Being told I had a brain tumour wasn’t really the worst thing. I had to surrender my driving licence and that affected my ability to work… plus the huge rise in the cost of my travel insurance meant I couldn’t afford to go on a family holiday to get away from it all. The threat to my independence the diagnosis caused made my life so much more difficult at a time I really needed help and support.”

Ann Swadden
Brain tumour patients are more financially worse off than other cancer patients as a result of their diagnosis. What’s more, they often experience life-limiting physical and psychological symptoms, which can mean long visits to specialist hospitals, increased time at home, increased bills and costly home modifications. Added to this, patients are required to surrender their driving licence, leading to a loss of independence. This is all while facing a terrifying uncertainty about what the future holds.

The nation is letting brain tumour patients and their families down. We must urgently address this.

We are calling on the Government to:

• Speed up access to better treatments by stimulating further increases in the national investment for research into brain tumours to £30-35 million per year – to achieve parity with other cancers such as breast cancer and leukaemia
• 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
• Provide easily accessible financial support to brain tumour patients while they are receiving treatment

The sudden onset of severe financial pressure faced by brain tumour patients and their families after diagnosis can be truly overwhelming. Many patients say it is almost as distressing as the disease itself. In this report, we expose the financial impact on families affected by a brain tumour diagnosis.

As part of our submission to the All-Party Parliamentary Group on Brain Tumours Inquiry into the economic and social impact of brain tumours, we ran a survey to identify the financial impact on families affected by a brain tumour diagnosis. A total of 368 people responded highlighting an alarming burden of costs – 36% of respondents had been diagnosed with a brain tumour, while 33% had lost a loved one to this devastating disease. Carers represented 23%, with 8% being family or friends.

We thank each and every one of our respondents for sharing such highly personal and sensitive information in order to help us shine a spotlight on these issues.

We’re also indebted to the support of David Warne of Qlik for providing the independent expert analysis of the written submissions and subsequent data from our online survey.

• Brain tumour patients and their families face an £11k net loss of income per year
• Brain tumour patients face additional costs of nearly £4k per year
• Therefore, brain tumour patients are on average £15k worse off per year
• Whereas, reported by Macmillan, for all cancers the average cost is £7k per year

For the purposes of this report, the yearly figures have been grossed up to represent the whole brain tumour population – actual figures of those responding, and the variations between individuals were much higher.

**Financial Impact**

<table>
<thead>
<tr>
<th>Financial Impact</th>
<th>Avg. Cost per Year (£)</th>
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<tbody>
<tr>
<td>Loss of Salary</td>
<td>15,848</td>
</tr>
<tr>
<td>Benefits Received</td>
<td>(4,767)</td>
</tr>
<tr>
<td><strong>Net Loss of Income</strong></td>
<td><strong>11,081</strong></td>
</tr>
<tr>
<td>Travel Costs for Treatment</td>
<td>1,582</td>
</tr>
<tr>
<td>Household Items</td>
<td>881</td>
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<tr>
<td>Medicine not covered by benefits or insurance</td>
<td>544</td>
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<tr>
<td>Childcare Costs</td>
<td>226</td>
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<tr>
<td>Debt Interest</td>
<td>78</td>
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<tr>
<td>Holiday Travel Insurance</td>
<td>391</td>
</tr>
<tr>
<td><strong>Additional Costs</strong></td>
<td><strong>3,702</strong></td>
</tr>
<tr>
<td><strong>Total Impact (per household per year)</strong></td>
<td><strong>14,783</strong></td>
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**“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
The key findings of our survey reveal the true extent of the financial costs faced by brain tumour patients and their families after diagnosis. A high number of brain tumour patients report having to give up work, either permanently or temporarily, following their diagnosis. Within our survey, 66% of respondents reported having to substantially change the type of work they do, take a medical leave of absence or indefinite time off, or retire completely. This loss of economic contribution, vocational expertise, capacity and creativity, has a subsequent effect on the quality of the UK job market, and community as a whole. In the case of younger patients, many have to suspend or terminate their studies.

Financial Impact

Loss of income is often one of the first and most significant costs encountered after being diagnosed – 60% of those who responded to the question about loss of earnings, reported a debilitating average loss of household income of £26,413 (ranging from £5,000 to £150,000), almost equivalent to the average annual UK salary of £28,600. When averaged across the brain tumour population, the resulting loss of income is £15,848. After benefits and employer pay outs the net loss was £11,081. Some people were able to offset this financial impact with a lump sum pay out from their insurance company. However, only 8% of respondents declared receiving such a payment. The average amount received was £85,000 with pay outs ranging from £500 to £450,000.

Driving Licence

Further compounding this financial burden, 75% of respondents cited a loss of driving licence while undergoing further diagnosis and treatment, with 23% stating losing a job as a result. Those that had licences reinstated had to wait an average of seven months for it to be re-issued. While patients understand the need to give up their licence on the grounds of safety, this loss of independence can lead to feelings of isolation and despair.
Travel Costs for Treatment

A brain tumour diagnosis and treatment may require repeated visits to specialist hospitals over the course of months or for some patients, years. These specialist hospitals are often a considerable distance away from a patient’s home and the costs of travelling to these appointments can mount rapidly, irrespective of whether patients are using private vehicles, taxis, or public transport.

“My wife gave up work as a teacher to care for me. Now, two years on, I still need a lot of help. Additionally, we have huge travel costs to attend appointments 40 miles away. I calculate the financial cost of my brain tumour diagnosis to be around £50k net to date.”

Brian Rockell

“My farm was my brother’s livelihood but the disease and treatment ravaged him to the point that he had to sell up and move everything out. My parents had to pay for a specially adapted room at their house so Adam could live his final weeks in as much comfort as was possible.”

Kerry Robson

Household Items

The costs of running a household can dramatically increase after a brain tumour diagnosis. This is at a time when people can least afford it and when their focus should be on treatment and recovery. Other additional costs reported include having to pay for medicines not covered by insurance, home help, and childcare fees. Day-to-day living costs can range from higher household bills through to significant and expensive home modifications, such as installing stair lifts, adding ramps, or relocating bedrooms and/or bathrooms to a ground floor. Brain tumour patients are particularly affected with 30% having to modify their home compared to 4% for all cancers, as reported by Macmillan Cancer Support, whose analysis would include brain tumour patients.

Over and above this, 29 respondents reported having to endure the upheaval of moving home.

| Cost of attending hospital appointments | Respondents reported having to pay on average of nearly £200 on hospital car parking per year | Those who used public transport and/or taxis spent on average of nearly £1,000 per year on travel to and from hospital appointments |
|£1,582|£181|£989|

| Respondents paid nearly an extra £1,000 per year on household bills | Respondents spent £881 per year on other household items e.g. extra home help, clothing, entertainment | Dietary supplements, alternative therapies and private treatments totalled £544 per year additional cost |
|£991|£881|£544|

| 30% of respondents made significant home modifications vs 4% for all cancers | Average cost to those making modifications £6,813 | 29 respondents reported having to move home at an average additional cost of £70,734 in terms of fees and moving costs |
|30%|£6,813|£70,734|
Debt Interest

The sudden increased expenditure arising from additional living and transportation costs combined with a fall in income, can be the tip of the iceberg and can very quickly lead families into debt. Debts can spiral, leading to increased anxiety. It is one of the most tragic and enduring, non-physical effects of a brain tumour and can have a damaging impact on health and well-being. With an immune system already engaged in fighting off this dreadful disease, the psychological impact of mounting financial pressures further exacerbates a truly devastating life event.

Of those who chose to tell us about their experience with debt, 11% reported taking out additional loans or credit card debt averaging £4,762. The range of debt taken out was considerable with individual circumstances ranging from £500 to £30,000 over two years and an average estimated cost of interest of £714 per year of those responding. This was an average of £78 per year when grossed up across the brain tumour population.

Holiday Travel Insurance

In our survey, 80% of respondents said having a brain tumour affected their ability to go on holiday. Taking a holiday is a therapeutic way for people to take a break from the rigours of life, allowing them to enjoy some rest and relaxation and recharge their batteries. The opportunity to take a holiday abroad, even for a short break, is, however, restricted for brain tumour patients because of a dramatic increase in the cost of travel insurance and the limited range of companies that will offer such cover. Indeed, 60% of respondents reported incurring additional travel insurance premiums of an average of close to £400. This can deprive not only the patient but also their families the chance of respite from the impact of living with a brain tumour.

"Having a brain tumour has cost me tens of thousands in lost income over the years, 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. The impact has been enormous; having had an exciting career as a journalist I had to retrain as a tree surgeon and then had to pack that in as my seizures made me unfit to work. After that I worked part-time and then relied on benefits.

“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. I continue to care for my two children but I now have to rely on another member of the family being with me or pay to have additional support.”

Ben Lindon
(Also pictured on the front cover)
Brain tumours kill more children and adults under the age of 40 than any other cancer...yet historically just 1% of the national spend on cancer research has been allocated to this devastating disease.

Added to these shocking statistics:

**Brain tumour patients are financially worse off than other cancer patients.**

Not only have we discovered that brain tumour patients and their families lose £14,783 per year compared to £6,840 for all cancers, they also lose their driving licence, encounter additional costs as a result of their diagnosis, and face life-limiting physical and psychological challenges. Whole families are affected and life is never the same again.

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**This has got to stop**

We call on the Government to:

- **Speed up access to better treatments by stimulating further increases in the national investment for research into brain tumours to £30-35 million per year – to achieve parity with other cancers such as breast cancer and leukaemia**

Since launching in 2009, Brain Tumour Research and our Member Charities have been determined to address the historic underfunding for research into brain tumours, striving to achieve parity with research successes and the resulting improvements in treatments and patient outcomes for other cancers such as breast cancer and leukaemia. Through our representation on the Department of Health and Social Care Task and Finish Working Group on brain tumour research and the Tessa Jowell Brain Cancer Mission, we continue to work towards change. We want to reverse the shocking survivorship statistics. In the long term, we want to see a survival rate of 80% – the current rate for breast cancer is 87%. We urgently want to see the same five-year survival rate as all cancers – 54%. It is only through a committed and sustained focus on research into brain tumours that this will happen.

- **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**

For many brain tumour patients and their families, the loss of income can be marginally offset by receiving insurance pay-outs and benefits. Indeed, data from our survey indicates that households are, on average, receiving £4,767 in benefits from their employer and / or the Government. With so many families turning to benefits to supplement a measure of lost household income, it is vital this system is accessible and underpinned by timely processes. These findings support The Price You Pay report, published by The Brain Tumour Charity, which suggests that patients could be £5,000 better off if they seek specialist advice about accessing benefits.

- **Provide easily accessible financial support to brain tumour patients while they are receiving treatment**

It is simply unfair that brain tumour patients, with a standard treatment pathway requiring them to attend hospital for radiotherapy five times per week for at least six weeks, sometimes longer, bear the full brunt of those transportation costs. In addition, many patients will have to attend hospital for chemotherapy infusions and/or surgery. We believe the Government should develop a non-means tested fund from which brain tumour patients can easily access the subsistence required to travel to and from hospital visits.
“The journey we all went on following my sister’s diagnosis was harrowing, particularly for her husband and young daughter. Before she physically left us the Margot we loved had long since gone. She had so much more to give to those of us who loved her and to society in general.”

Danny Clarke
The Instant Gardener

**Member Charities**

**Fundraising Groups**

For more information, email us at: campaigning@braintumourresearch.org

For more information about accessing financial assistance, visit: www.finance.macmillan.org.uk

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