



THE PRICE YOU PAY

The financial impact
of a brain tumour

Improving Life Today

One of our missions is to halve the harm that brain tumours have on those affected by a diagnosis, and just one example of harm is to their financial stability.

This report highlights the experience of our community when accessing the benefits system and gives recommendations on how it could be improved to meet the financial needs of those affected by a brain tumour.

As an expert organisation in the field of brain tumours, The Brain Tumour Charity is offering support to relevant professionals, organisations and public bodies in the implementation of these recommendations.

Recommendations

- 1** Brain tumours should be added to the list of conditions requiring additional support in the PIP assessment guide.
- 2** The Department for Work and Pensions should ensure that PIP and ESA assessments for brain tumour patients are carried out by assessors who have received specific training on this condition, to enable effective assessment.
- 3** The Department for Work and Pensions should immediately introduce accessible claim forms that are readily available in a variety of formats from all places job seekers are likely to attend.
- 4** Healthcare professionals should inform those recently diagnosed with a brain tumour and their carers about benefits they may be eligible for, or organisations that provide advice on benefits.
- 5** Healthcare professionals should advise brain tumour patients on their prescription charge entitlements at diagnosis.

Background

A brain tumour has a devastating impact and can result in an inability to work for those affected. For the person diagnosed, 'invisible' symptoms such as fatigue, depression and cognitive difficulties, as well as 'visible symptoms' such as difficulties moving around and communication, may make continuing a career too hard.

For their loved ones, they may need to move into the role of carer, meaning they are no longer able to continue in their career or must cut down their hours.

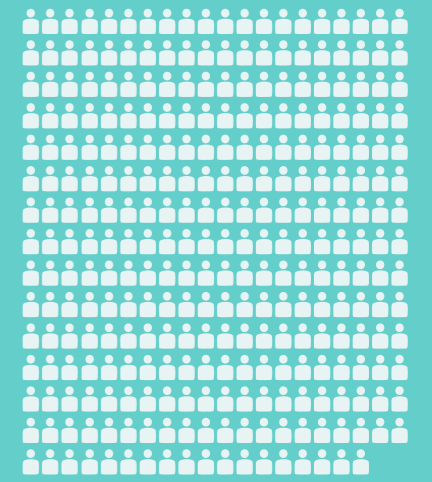
With the loss of both full-time incomes, it is not surprising that those affected by a brain tumour face serious financial difficulties. However, it appears they are being let down by the benefits system.

Patients and carers who receive specialist advice and support from our dedicated benefits clinic are, on average, nearly £5,000 better off as a result. This highlights that aspects of the benefits system, and a lack of relevant advice, may be preventing people with a brain tumour from claiming, and receiving, what they are rightfully entitled to.

To understand the full extent of how and why our community is being let down by the benefits system, The Brain Tumour Charity has conducted a UK-wide survey of those affected by a brain tumour.

298 patients and carers took part in the survey, which ran between September and October 2017. Some of the most important statistics from the survey are presented in this report, and have informed our recommendations to politicians, healthcare professionals and benefits assessors.

We would like to thank Farah Iqbal, Katarina Kentosova and Valentina Bordon from Royal Holloway University who contributed to the data analysis for this report.



298 people took part
in this survey

"Being self-employed and looking after my husband, my working hours have increased to cover his business also. The hours I work are all over the place to accommodate his condition, appointments etc. I am now working 60+ hours per week, including weekends and evenings."

A 56-year-old woman
caring for her husband



"I couldn't drive for four years until I got my seizures under control. I had to change job role to be less dependent on a computer screen as this impacted my fatigue and seizures. As a result my income is almost half what it was."

Simon, 46, living with a low grade brain tumour



1 in 3 respondents said that they depended on benefits



Over two thirds of those caring for people with a brain tumour have had to change the way they work

The financial impact of a brain tumour

Work and independence

The ability to work and undertake normal daily activities is often compromised following a brain tumour diagnosis.

- 81%** 8 in 10 (81%) of those diagnosed with a brain tumour had to stop work completely or reduce their hours due to their diagnosis.
- 69%** Over two thirds (69%) of those caring for people with a brain tumour have had to stop work completely or reduce their hours of work, while others have had to increase their hours to make ends meet.
- 56%** Over half (56%) of those diagnosed with a brain tumour have lost their driving licence as a result of their diagnosis.
- 36%** More than a third (36%) of those diagnosed with a brain tumour said they needed assistance with daily tasks, such as cleaning and shopping, following their diagnosis.

Household income

With any illness comes additional financial needs and yet those diagnosed with a brain tumour will see their income go down. This is exactly why the benefits system is so important.

- 41%** Prior to diagnosis, 41% of respondents had a household income of £40,000+ compared to only 17% after being diagnosed.
- 7%** Only 7% of respondents had a household income of under £10,000 prior to diagnosis, compared with 23% after being diagnosed.

Reliance on financial support

Because of the impact on people's ability to work and the loss of household income, those affected by a brain tumour are increasingly dependent on benefits.

- 65%** 2 in 3 (65%) respondents were at least partially dependent on the income they received through benefits. Half of that 65% said that they depended on benefits for most or all of their household income.

The experience of the benefits system

Almost everyone affected by a brain tumour depends on benefits, so it is important the system is easy for them to navigate and claim what they are entitled to, without unnecessary delays or difficulties.

This report recommends that the timely provision of information and improvement of the application process are two areas which, if addressed, can aid our community in accessing the benefits system more easily.

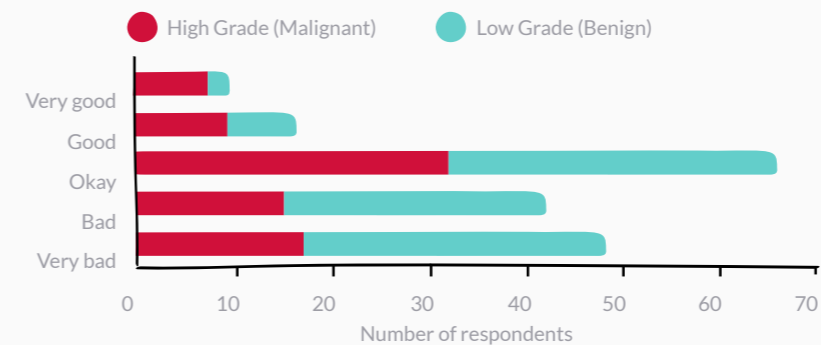
Information and support

Benefits advice can help those affected by a brain tumour deal with the impact of this disease. By providing relevant information at the point of diagnosis, healthcare professionals and other organisations can help ensure that those affected don't miss out on the financial support they need and are entitled to.

- 46%** Almost half (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.
- 44%** More than 4 in 10 (44%) respondents did not receive information regarding their eligibility for free prescriptions following their diagnosis.
- 76%** 3 in 4 (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.
- 13%** Of those who did receive information, 13% answered that their experience was 'good' compared to less than 2% of those who did not receive information.
- 64%** Overall, those with higher grade (malignant) tumours were more likely to have been offered information (64%) than those with low grade (benign) tumours (50%).

The level of information received may be having an impact on the experience of applying for benefits, with lower grade tumour patients more likely to have a bad or very bad experience. The majority of those who had a good or very good experience had high grade tumours.

Experience of the benefits system by tumour grade



"Not receiving information was appalling. I just never realised I could claim benefits, plus Carers Allowance, when I was allowed home after brain surgery. My husband reduced his hours. We lost about £30,000 in benefits over a number of years. When I realised, I wrote everywhere but they would not back pay more than three months. Even letters from consultants, used as evidence, were not accepted. If you claim too much they can take it back, but if you don't know you can claim, they will not repay you. It destroyed us financially just because we were not benefit minded."

Julie, 73, diagnosed with a low grade brain tumour

"The form for PIP is very long and requires a lot of information. I wouldn't be able to complete it in my current condition, and I am a solicitor used to complicated contracts. Fortunately, my family filled it in for me with my input. I thought the assessment result was about right, but the reasoning was ludicrous at times. For instance, I am a solicitor so clearly intelligent and able to understand things well, so therefore I can function in that regard, ignoring the fact that my brain tumour and treatment is causing extreme fatigue, seizures, concentration and memory issues!"

Rachel, 36, living with a high grade brain tumour



3 in 4 do not find the amount ESA offers enough to live on

Applying for benefits

- 48%** Of those who answered the question, almost half (48%) of brain tumour patients had a bad experience of the benefits system, with 1 in 4 stating their experience was very bad.
- 15%** Only 15% of respondents said they would rate their overall experience as good.

The Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) are the benefits our community depend on the most, with 87% of respondents receiving, or having applied for, ESA, PIP or both.

Employment and Support Allowance (ESA)

A benefit that provides financial support to those who are either not able to work because of an illness or disability, or who are limited in the work they are able to do.

- 76%** 3 in 4 (76%) do not find the amount ESA offers enough to live on. This impacts everything from their ability to socialise to being able to afford basic and necessary shopping.
- 8%** 8% of applicants had to wait over a year for an assessment, creating a significant loss of income.
- 85%** 85% of those who had a Work Capability Assessment found the process very stressful.

Employment and Support Allowance Case Study

A patient diagnosed with a grade 2 brain tumour in 2010 reported having to wait four to five months between submitting their Employment and Support Allowance application and having an assessment. Due to insufficient income during this wait, the patient lost their home and was forced to sleep at a local park before relocating with parents. The benefits received by the patient now make up most of their household income, but are not enough to live on. In addition, following an assessment for the Personal Independence Payment award to transition from Disability Living Allowance, the outcome was a complete loss of this element of benefits income.

Personal Independence Payment (PIP)

A benefit to help with the extra costs of a long-term health condition or disability.

- 45%** 45% found the PIP application form hard or very hard to complete, despite 60% receiving help to fill it out.
- 27%** Only 1 in 4 (27%) felt that those who assessed them for PIP understood their brain tumour during their most recent assessment.

Of those who responded to how the PIP assessment could be improved for brain tumour patients:

- 85%** 85% recommend that brain tumours be added to the list of conditions requiring additional support in the PIP assessment guide.
- 61%** 61% think that the assessment could be improved by adding additional criteria for invisible symptoms, such as pain or fatigue.
- 57%** 57% recommend improving the training of the assessors to make sure they understand complex conditions.

How The Brain Tumour Charity can help

Benefits clinic

Benefits are complex and ever changing, and we recommend that people affected by a brain tumour seek advice from a trained adviser.

The Brain Tumour Charity runs a telephone benefits clinic, with a highly experienced adviser from Citizens Advice, every Tuesday, 9.30am - 4.00pm.

If you know of a person affected by a brain tumour who needs advice on benefits, please ask them to contact our Information and Support Line (0808 800 0004) to make an appointment.

Policy Involvement Group (PING)

We put patients at the heart of everything we do; we're led by our supporters to address the issues that are important to them.

In October 2017, we set up the Policy Involvement Group to help us achieve this. The PING ensures the views of our community are represented in everything we do, keeping them at the heart of our work.

If you know of a person affected by a brain tumour who would be interested in contributing to the development of our policy work, please ask them to contact us.

For more information

We're here to help. If you would like more information on anything covered in this report, or if you would like to speak to someone in our Policy and Public Affairs team, contact us at policy@thebraintumourcharity.org



Patients and carers who receive specialist advice and support from our dedicated benefits clinic are, on average, nearly £5,000 better off as a result

Get in touch:

enquiries@thebraintumourcharity.org

01252 749990

thebraintumourcharity.org

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