

Written submission from:	Headway – the brain injury association
Date of submission:	30 April 2018
Contact details:	Dr Clare Mills Public Affairs Manager 0115 855 0085 public.affairs@headway.org.uk
Submission to:	All Party Parliamentary Group on Brain Tumour
Title of inquiry:	The social and economic costs of brain tumour

1.0 Executive summary

- 1.1 Headway is the UK-wide charity working to improve life after acquired brain injury (ABI), including brain tumour.
- 1.2 Around 350,000 people are admitted to hospital annually with an ABI, as a result of brain tumour, trauma, stroke or illness.¹ Of these approximately 16,000 are patients with brain tumour.² The majority will require some form of support or rehabilitation.
- 1.3 Brain tumours can be malignant or benign. Malignant brain tumours are cancerous growths in the brain. Benign tumours are non-cancerous and tend to grow more slowly. However all tumours cause brain injury. Treatment or management of the tumour causes injury to the brain, albeit with the effect of limiting further damage from an untreated tumour.
- 1.4 For those who survive this devastating illness, the effects of brain tumour can last a lifetime. Physical effects include: issues with mobility, balance and co-ordination; limb stiffness and/or weakness with reduced range of movement; hemiplegia; ataxia, with irregular, uncontrolled movement or tremor affecting the co-ordination of movements; sensory impairment; fatigue; difficulties with speech; epilepsy. Hidden effects can be cognitive, psychological, emotional and behavioural difficulties, contributing to issues around communication, social interaction, personal organisation and sensory overload. As an added complication these hidden effects are often fluctuating, and generally misunderstood.
- 1.5 Brain tumours kill more adults under the age of 40 than any other cancer. Brain tumours kill more men under 45 than prostate cancer and more women under 35 than breast cancer.³ Whether living a significantly shortened life or

¹ Headway, <https://www.headway.org.uk/about-brain-injury/further-information/statistics/>

² Brain Tumour Research, <https://www.braintumourresearch.org/campaigning/stark-facts>

³ Brain Tumour Research, <https://www.braintumourresearch.org/campaigning/stark-facts>

surviving for many years, brain tumour in adults can cause significant social and economic impact. Previously healthy, socially engaged and economically active adults who develop brain tumour undergo a range of treatments. As a result some are able to return to their former lives, but many face a radically different future: changes in their personal and social relationships; increasing reliance on family and friends; loss of independence; reliance on health and social care services; loss of employment and future earning ability (with long-term impact on pension provision); sometimes the loss of a driving licence and increased reliance on public transport; loss of self-esteem and mental wellbeing.

- 1.6 Brain tumour is the primary cause of cancer deaths in children and young people.⁴ For those who survive, the effects can continue into adulthood and have a lifelong impact on: relationships and social interaction; ability to live independently, including driving/using public transport; reliance on health and/or social care services; ability to study and work; opportunities to achieve and sustain financial independence; potential risk of developing subsequent health conditions including further cancers.

2.0 About Headway⁵

- 2.1 Headway works to improve life for people directly affected by brain tumour, their families and carers through providing services, support and information at every stage of the care pathway. Over 120 Headway groups and branches across the UK provide local services to brain tumour and other ABI survivors. UK services include a helpline, comprehensive website, Emergency Fund and award-winning publications.

3.0 About brain tumour

- 3.1 Brain tumour is classified as acquired brain injury (ABI). ABI is an injury to the brain which has occurred since birth. Other causes include: stroke, haemorrhage, encephalitis, carbon monoxide poisoning, hypoxic injury, and trauma.
- 3.2 Survivors of more severe brain injury, including brain tumour, are likely to have long-term problems affecting their personality, relationships and ability to live independently. Even with rehabilitation and support, survivors and their families are likely to face uncertain and challenging futures.

⁴ Brain Tumour Research, <https://www.braintumourresearch.org/campaigning/stark-facts>

⁵ Headway - the brain injury association is registered with the Charity Commission for England and Wales, charity no. 1025852, and the Office of the Scottish Regulator, charity no. SC 039992. Headway is a company limited by guarantee, registered in England no. 2346893.

- 3.3 This issue can be compounded as the effects of the person's ABI are often hidden. The cognitive, psychological, emotional and behavioural effects of brain injury can be difficult to detect by those who have not had specialist training.
- 3.4 Brain tumour causes brain injury in several ways. First, the development of tumour prior to diagnosis damages the brain. Second, diagnosis usually involves CT and/or MRI scanning and may also involve biopsy. Third, after diagnosis, treatment can include surgery, chemotherapy, radiotherapy and radiosurgery. Treatment will also require additional MRI and/or CT scanning. Although treatment or management limits further damage from an untreated tumour, treatment itself also causes some degree of damage to the brain. The presence of a benign tumour can also cause damage to the brain due to location and pressure on the brain as it grows.

4.0 The social and economic impact of brain tumour

4.1 A brain tumour can affect every aspect of life. Brain tumour can be notoriously difficult to diagnose, due to the diversity of symptoms which can overlap with other conditions. There may also be a lengthy asymptomatic period in which the tumour develops. It can take some time for patients to be referred on to a neurologist and receive a diagnosis.

4.2 Mike's story

In 2011, Mike began to suffer with persistent migraines which left him bedridden for 2-3 days at a time. He had just separated from his wife after 21 years together and was under a lot of stress. His GP diagnosed the pain as 'cluster headaches' and prescribed pain-relief.

Although his personal life changed – he met and eventually moved in with his new partner – by 2014 his migraines were recurring at least once every six or seven weeks. In August 2015, Mike was referred for surgery to remove a 6cm brain tumour. Although the operation was cancelled twice, the tumour was removed in November 2015.

Subsequently Mike has been left with numbness down the left side of his body. Fatigue has been a significant issue. Mike would become tired after completing basic everyday routines that he used to complete with ease. In addition, mood swings as a result of extreme fatigue caused problems in his relationships during the first nine or ten months following brain surgery. He found himself angry, frustrated, quick to burst into tears and depressed. Other cognitive challenges, including poor concentration, put additional strain on his ability to communicate and socialise, particularly when in a large group of

people. His ability to filter out noise in loud or busy environments has gone, particularly in noisy pubs and supermarkets.

Headway has worked with Mike to help him improve his memory and problem solving skills. He has learned how to recognise the signs of brain injury-related tiredness. Strategies and techniques to manage the symptoms of fatigue have helped him establish new routines and remember to take regular breaks and rests between activities.

Following his brain tumour diagnosis, Mike's driving licence was suspended by the Driver and Vehicle Licensing Agency (DVLA). After seven months he was assessed as fit to drive and was able to regain his licence. However he was unable to return to work as a bus driver for children with disabilities. The time without a driving licence put additional strain on his partner as she had to drive him everywhere. The loss of his job put the family under financial pressure.

4.3 Mike's story illustrates the many typical social and economic impacts of brain tumour, not just on Mike but also on his partner, family and friends. There are also impacts on his local community and economic impacts: Mike has been unable to return to his former role as a bus driver for children with disabilities.

4.4 A childhood brain tumour may be thought of as having far less social and economic impact: surely, the only people affected are the child's family? A child does not work and so is not considered as a contributor to the economy. However the effects of a childhood brain tumour can be lifelong and must be taken into account when considering the social and economic impacts.

4.5 Laura's story:

Laura was five years old when she was diagnosed with a non-malignant astrocytoma in her brain. Although not cancerous, the position of the tumour in the brain stem meant that it would eventually be fatal. Surgery and radiotherapy followed to remove all the affected cells.

The tumour had a significant impact upon Laura's balance, vision, learning and development, leading to struggles with everyday tasks and school projects. Academically Laura was able to catch up but bullying, both physical and psychological, became a problem at school. Eventually she had to leave school and was tutored privately at home, which also had an impact on her social development.

As she matured, other effects of Laura's brain injury became apparent. Aged 17, her hearing began to deteriorate markedly. On her 21st birthday, she suffered an epileptic fit caused by her brain injury. Fits became an almost daily occurrence.

Laura developed coping skills to deal with some of the effects of her brain injury and completed her degree at Liverpool University in 2010. It took her five years to complete the course. However, in 2013, Laura was diagnosed with nodular melanoma skin cancer, which resulted in her needing part of her right leg removed.

Laura found Headway's support helped her to live with the effects of brain tumour. She said:

"Having built-up my confidence, I began giving talks in front of other brain tumour survivors. I find that young adults living with brain injury tend to be less keen to seek support when they are struggling and we definitely need to find ways of reaching out to this age bracket.

"I would love to inspire people to overcome adversity to achieve their goals and I hope my story gives hope by showing others affected that there can be life after brain injury. Having said that, my own fight and recovery continues."

- 4.6 Laura's story clearly demonstrates that the successful removal and treatment for brain tumour in childhood is not the end of the story. The social and economic effects continue, into adulthood and often for life.