SEE THE HIDDEN ME

ACTION FOR
BRAIN INJURY WEEK 2022
16-22 MAY

Headway
the brain injury association

Brain injury: a hidden disability

Report for Headway – the brain injury association’s Action for Brain Injury Week campaign *See the hidden me*.

Contents

1. Introduction

An acquired brain injury (ABI) can be caused by an injury or illness and can take many different forms, including a traumatic brain injury, stroke, meningitis, brain tumour, among others. The effects can be varied, ranging from physical, emotional, cognitive (thinking and information processing) and behavioural. Many of these common effects are non-visible, leading to ABI being considered in many cases as a ‘hidden disability’. Frustratingly for many brain injury survivors and their carers, anecdotal evidence suggests that this ‘hidden’ nature of brain injury often leads to a lack of appropriate understanding and support being offered.

Our Action for Brain Injury Week 2022 campaign, *See the hidden me*, aims to explore this further in order to raise awareness of brain injury being a hidden disability. We hope that the findings from this report and other campaign activities in this area will help others to understand the non-visible, albeit life-changing impact of sustaining an ABI.

In February 2022, we launched a survey to explore the feelings and experiences of those affected by ABI around brain injury being a hidden disability. The survey was designed to be completed by brain injury survivors or anyone caring for someone with a brain injury (partners, family members, friends, etc).

We advertised the survey via our website, social media and Headway’s network of groups and branches across the UK. Electronic and paper copies of the survey were available.

The survey was completed by 2,682 respondents, providing a large sample to gain an accurate picture of the emotions and challenges of living with a hidden disability.

2. Key findings

- 76% of brain injury survivors experience daily problems as a direct consequence of their brain injury being hidden

- 55% of brain injury survivors feel they have been unfairly treated as a direct consequence of their brain injury being hidden

- 67% of brain injury survivors have at some point struggled with understanding the effects of their own brain injury

- 52% of brain injury survivors have gotten into a difficult situation as a direct consequence of their brain injury being hidden

- 71% of brain injury survivors have experienced issues in a shopping setting as a direct consequence of their brain injury being hidden

- 42% of brain injury survivors felt that their friends did not have a good understanding of the hidden effects of their brain injury

- 67% of brain injury survivors felt that their friendships had been negatively affected as a direct consequence of the effects of their brain injury being hidden

- 55% of brain injury survivors felt that their relationship with their spouse/partner had been negatively affected as a direct consequence of their brain injury being hidden

- 70% of carers felt that their relationships with others have been negatively affected as a direct consequence of the effects of brain injury being hidden

- 75% of carers of brain injury survivors have personally faced problems as a direct consequence of the effects of brain injury being hidden

- 86% of people affected by brain injury (survivors and carers) felt that a lack of understanding from society is one of the main challenges to living life with a hidden disability

3. Demographics

The survey was completed by 2,682 people, of whom 78% were brain injury survivors and 22% were carers (partners, spouses, other family members, professional carers, friends and others).

Respondents’ ages ranged from under 18 to over 65, with the most common age group being 55 – 64-year-olds. 85% of respondents were of working age, between the ages of 18 and 65.

The majority of respondents (91%) reported that the brain injury they were connected to was sustained over a year ago, with a third having been sustained a over a decade ago. Just under 10% of respondents reported that the brain injury they were connected to was sustained less than a year ago, allowing us to explore whether time is a factor in the attitudes towards and experiences of brain injury being a hidden disability.

The most common cause of brain injury was trauma (47%), followed by haemorrhage (19%), aneurysm (14%), brain tumour (9%), infection (7%), hypoxic/anoxic injury (6%) and hydrocephalus (5%). For this question we allowed respondents to select multiple answers, reflecting the fact that some people sustain more than one type of brain injury.

4. Survey results: See the hidden me

4.1. Types of hidden effects of brain injury

We asked respondents to tell us which hidden effects of brain injury they or the person they cared for experience on a regular basis – a checklist of predefined effects was provided, as well as an open text box for respondents to add any effects not already listed.

Over three quarters of the respondents marked memory problems and fatigue as being experienced following brain injury, while over half experienced problems with attention and concentration, thinking skills, communication, depression and/or anxiety and dizziness and balance on a regular basis.

Other hidden effects of brain injury experienced on a regular basis were headaches, mobility issues, problems controlling anger and visual impairments.

The table below shows the percentage of respondents who experienced the following hidden effects of brain injury.

Hidden effects of brain injury	% of respondents experiencing hidden effect regularly
Memory problems	84
Fatigue	82
Attention and concentration problems	73
Problems with thinking skills	72
Communication problems	62
Depression and/or anxiety	62
Dizziness and balance issues	51
Headaches	48
Mobility issues	38
Problems controlling anger	36
Visual impairments	29

The most common types of hidden effects of brain injury were cognitive (i.e. skills related to information processing). However, as all skills are ultimately processed in the brain, even effects that would be classified as ‘physical effects’ can be non-visible to others, such as visual impairments and headaches.

Free text responses highlighted the wider reaching impact of living with the hidden effects of a brain injury, such as the emotional consequences of no longer being able to work or relationships being affected.

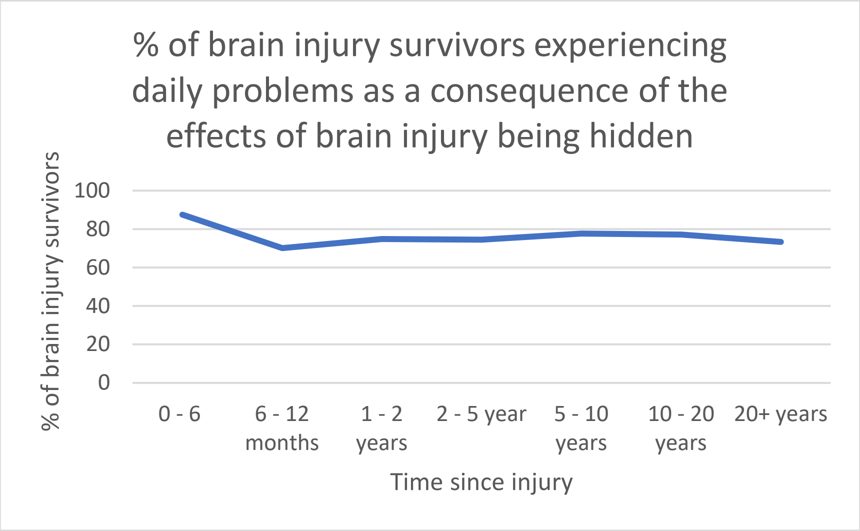
> *“Feeling guilt for not spending more time with people due to symptoms. Resentful towards work because of prolonged stress that contributed to illness.”* – Heather
>
> *“Heightened emotional states. Especially when I don't understand why someone is acting a different way to normal & won't tell me why, or what I have done. In response if I can't get an answer, I tend to turn nasty & have broken a few really good friendships because of this lack of emotional awareness, or lack of thought processing.”* - Jes

The hidden effects of brain injury are therefore varied and not limited to the direct impact of an injury itself; rather, there are a myriad of wide-reaching consequences on many different aspects of life that are often difficult for others to see or understand.

4.2 Difficult situations

We asked respondents how regularly they faced problems as a direct consequence of the hidden effects of brain injury. Alarmingly, just over three quarters (76%) reported experiencing problems on a daily basis. A further 15% experienced problems on a weekly basis.

Even as far as 20 years since a brain injury was experienced, around three quarters of survivors (73%) experienced daily problems as a direct consequence of the effects of brain injury being hidden.



Of the 2,682 respondents, less than 1% reported never having experienced problems as a direct consequence of their brain injury being hidden.

We asked respondents if they felt like they had ever been unfairly treated as a direct consequence of their brain injury being hidden. Over half (55%) of the brain injury survivors felt that they had, while only 19% felt that they had not. Situations in which respondents felt that they had been unfairly treated included personal relationships, employment, and even disability schemes/ services.

> *“Blue badge parking being approached and told to move as I don't belong.”* – Harry
>
> *“My partner expects me to be able to make big decisions quickly and has not really listened when I've tried to explain how hard it is for me. I've been told I've disrupted his plans.”* – Anonymous
>
> *“DWP and benefits can’t see my disability and assume through my job description what I can do.”*- Gail
>
> *“Within a work environment. Tell your boss and you become a problem.”* – Paul

Just over half of brain injury survivors (52%) reported having gotten into a difficult situation as a direct consequence of their brain injury being hidden. Examples of difficult situations ranged from the mundane (using public transport, shopping) to situations with serious consequences (such as within employment, relationships and the criminal justice system).

> *"Getting on the wrong bus and forgetting everything due to short term memory."* – James

> *"If left to her own devices in shops, Alison has difficulty understanding money, prices, payments etc."* - Anonymous

> *"I had to go to a wellbeing meeting at work. They said take your time. Then they go on to the next question. This made me really annoyed. Then the meeting was over. They left the meeting very quick."* – Shirl

> *"It has caused a breakdown in my marriage and I'm getting divorced because my husband finds it hard to cope and even understand my brain injury."* – Sharon

> *"I struggle to show the correct emotions, so people don't know how to react to me. I didn't cry at my mother's funeral last week. I was strangely cheerful while everyone around me thought I didn't care. I just have the wrong feeling at the wrong time and as I come from a very volatile family it can be dangerous."* - Anonymous

> *"Ended up in a cell for a night, detained under the Mental Health Act."* – Jacob

> *"Neighbour dispute had to call police."* - Isobel

We asked in which settings brain injury being hidden had been an issue; the most common setting by far was shopping, with 71% of brain injury survivors reporting having had issues in as a direct consequence of their brain injury being hidden.

> *"Retail - I can no longer read well. If I need to find an item and the shelves have been changed, I can't find it without help. At first retail was also really overwhelming - so many lights and signs."* - Anonymous

The second most common setting in which brain injury being hidden had caused issues was benefits assessments/appointments.

> *"I have had huge problems with the PIP assessors and my pip has been reduced because they don't understand and I can't explain in their environment when they are forcing words at you."* - Julie

The myriad of challenges facing brain injury survivors within the welfare benefits system is an area Headway continues to campaign on, with the charity's *Right First Time* campaign urging benefits assessors to recognise the impact of brain injury and to get assessments right first time. The 56% of brain injury survivors reporting this to still be a setting in which their brain injury being hidden is an issue calls for further awareness-raising work in this area, with Headway continuing to deliver training to benefits assessors. Indeed, 72% of brain injury survivors responding to the survey reported that they thought welfare benefits assessors could benefit from some training into the hidden impact of brain injury.

The table below shows the settings in which brain injury being hidden had been an issue for brain injury survivors.

Settings in which brain injury being hidden has been an issue	% of respondents who have experienced issues as a direct consequence of brain injury being hidden
Shopping	71
Benefits assessments/appointments	56
Employment	45
Hospital appointments	45
GP appointments	44
Public transport	41
Entertainment venues	37
Leisure venues	36
Education	27
Job interviews	17
Contact with the police	15

Headway Brain Injury Identity Card

62% of brain injury survivors either owned or were waiting to receive a Headway Brain Injury Identity Card. The ID card has been designed to assist brain injury survivors in everyday settings, as well as if they come into contact with the criminal justice system. It aims to make some of the hidden consequences of brain injury visible by listing effects of brain injury that the cardholder personally experiences, and can be used in the event of needing assistance.

Further information about the ID card and Headway's Justice Project is available at www.headway.org.uk/supporting-you/brain-injury-identity-card/.

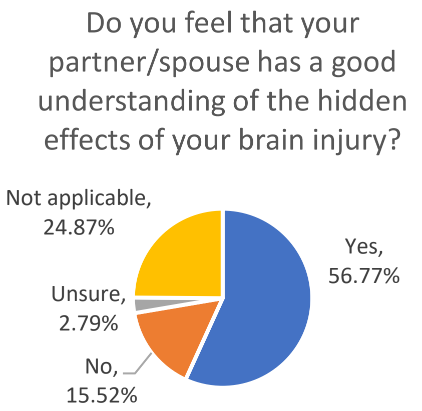
> *"If I have any problems, I find it helpful to show them my brain injury identity card, it seems to calm things down and people are helpful."* – Clifford

4.3. Relationships with others

We asked respondents to tell us whether they felt that the following people in their life had a good understanding of the hidden effects of their brain injury: partner/spouse, immediate family, wider family, friends, employers, colleagues, GPs and other professionals.

Personal relationships (partner/spouse, immediate family, wider family, friends)

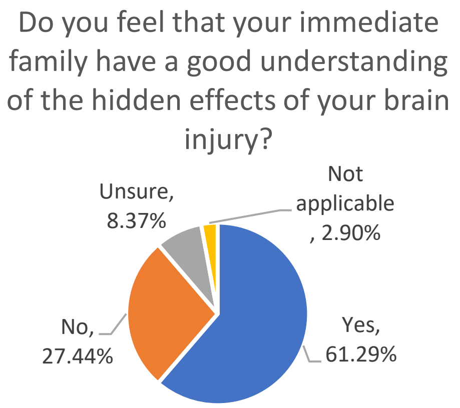
57% of brain injury survivors felt that their spouse/partner had a good understanding of the hidden effect of their brain injury; a quarter indicated that this was not applicable and only 16% felt that their spouse/partner did not have a good understanding.



61% also felt that immediate family had a good understanding of the hidden effects of their injury.

> *"Sometimes people don't know what to say to you, but my friends and family have all been very supportive."* - Kerry

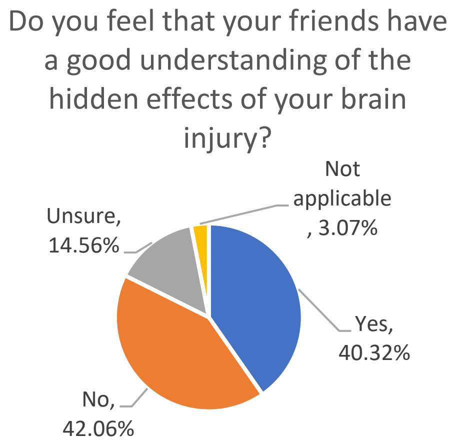
However, 27% of brain injury survivors felt that their immediate family did not have a good understanding of the hidden effects of their brain injury.



> *"My mum and big sister have always been in denial about my brain injury and have told people to stay away from me because I am fine. It is very hurtful for me."* - Anonymous

51% of brain injury survivors further felt their wider family did not have a good understanding of the hidden effects of their brain injury compared to 24% who felt that their wider family did.

Only 40% of brain injury survivors felt that their friends had a good understanding of the hidden effects of their brain injury, while 42% felt their friends did not have a good understanding, and 15% were unsure. This is in line with previous work conducted by Headway, in which it was found that 63% of brain injury survivors felt that their friends did not have a good understanding of brain injury (*Experiences of life after brain injury* – Headway – the brain injury association, 2017[1]).



An increasing elapse of time since the brain injury was sustained was not related to a better understanding of the hidden effects of brain injury among partners and friends. Assuming stability of these relationships, we could have hypothesised to have seen an increase in the understanding of the hidden effects over time; however, these findings suggest that the 'unseen' and therefore misunderstood effects of brain injury remain so. Even 20 years on from the

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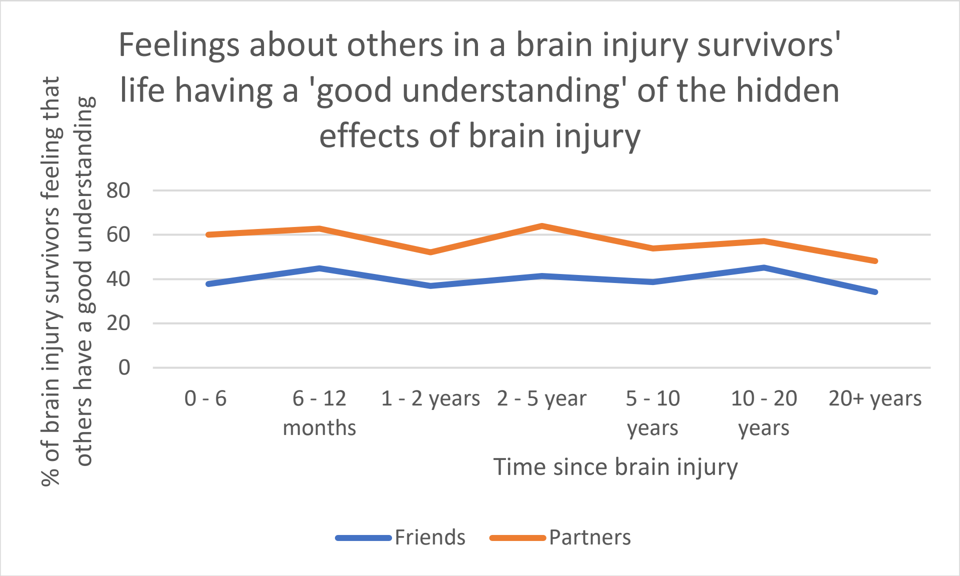
[1] *Experiences of life after brain injury* – Headway – the brain injury association (2017). Available at www.headway.org.uk/media/4655/a-new-me-experiences-of-life-after-brain-injury-report.pdf

event of a brain injury being sustained, only a third of brain injury survivors (34%) feel that their friends have a good understanding of the hidden effects of their injury, and less than half (48%) feel their partners do.

These conclusions are made under the assumption of these relationships being consistent in the survivor's life; however, previous work from Headway and others have reported that relationship breakdowns are common following brain injury, and this may be a consequence of the lack of improvement in understanding the hidden nature of brain injury, therefore causing ongoing frustration among survivors and their relations.



Indeed, over half of the brain injury survivors reported their relationships with a spouse/partner and wider family members had been negatively affected as a direct consequence of the effects of their brain injury being hidden (55% and 58%, respectively).

> *"My wife will say things to me and either I will forget, or I just won't understand what she is talking about. It leaves her frustrated and sometimes very annoyed and I DON'T UNDERSTAND WHY!"* - Philip

Two thirds (67%) of brain injury survivors reported that their friendships had been negatively affected, in keeping with previous work that Headway has done in which 69% of brain injury survivors reported breakdowns in their friendships (Headway – the brain injury association, 2018[2]).

> *"I lost all my friends because they couldn't understand why I couldn't do what I did before. It's very lonely."* – Donna

> *"Lost friends due to fatigue that hits they think it's an excuse not to go out not understanding I can't and how it will affect the following days."* – June

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[2] *You, me and brain injury* – Headway – the brain injury association (2018). Available from www.headway.org.uk/media/5734/relationship-changes-after-brain-injury.pdf

> *"I continuously have friendship losses, from school, up to now. People just don't understand me and think I'm being rude... I have become very timid and withdrawn, always apologising just to cover my back in case people still think I'm being rude or saying inappropriate things."* - Anonymous

It was not only brain injury survivors who felt that their friends did not have a good understanding of the hidden effects of their brain injury; 52% of carers also felt that friends in the survivor's life did not have a good understanding of these issues.

Friends are an important part of our lives, making us feel cared for, content and supported. To assist friends with understanding brain injury, Headway has created a bespoke publication for friends of brain injury survivors to offer guidance on how best to offer support, available at www.headway.org.uk/information-library, among other publications tailored towards various relationships in the survivor's life.

The 'ripple effect' of brain injury illustrates how far-reaching the consequences of a single brain injury can be, so that various relationships around the survivor's life can be affected. 70% of carers responding to our survey reported that relationships in their own lives had been negatively affected as a consequence of the effects of brain injury being hidden, with several carers remarking on the impact caring for a brain injury survivor has on their social life.

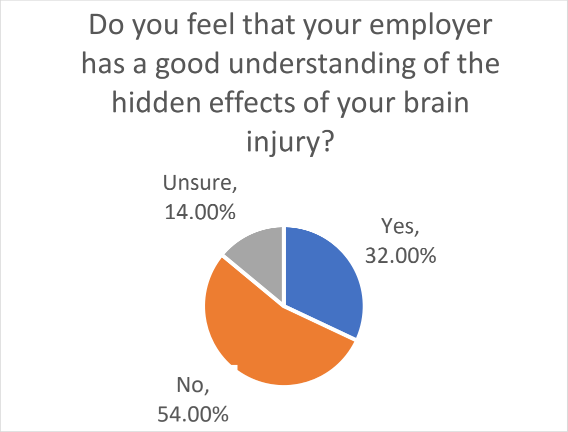
> *"It affects me having some form of social life. Time with family and so on. It restricts my movements and freedom."* – Giles
>
> *"I had to step back from socialising so I could focus 100% on my son's care."* – Katie
>
> *"Friends have given up on me because I can't do all the fun stuff they do."* – Rebecca

Carers also remarked on the lack of understanding from others about the hidden effects of brain injury.

> *"I'm the main (only) carer for my sister. A lot of people can't see why she needs care/ support and think I'm being over the top. She's a good mimic, and they don't see her daily confusion or inability to make rational decisions about everything, from how much breakfast cereal to eat, to giving friends money*." – Laura
>
> "*Some people find it hard to acknowledge that Andy has a cognitive disability. He presents well in 'small talk' situations so can't understand the significant cognitive difficulties he has with managing daily activities. I've pulled away from those previously very close friends as it hurts so much to have my grief for the impact of Andy's illness dismissed.*" - Robyn

Professional relationships

Fewer than half (43%) of the brain injury survivors responding to our survey were able to comment on colleagues and employers' understanding of the hidden effects of brain injury. Previous work by Van Velzen et al (2009)[3] found that only 40% of brain injury survivors who were in work prior to their injury returned to work within 2 years of the injury.



Of the survivors who were employed, around a third (32%) felt that their employer had a good understanding of the hidden effects of brain injury, while 54% felt their employer did not have a good understanding. Furthermore, 38% of brain injury survivors felt that their relationship with an employer had been negatively affected as a direct consequence of the effects of their brain injury being hidden.

> *"I had to give up work due to my illness and only one of my work colleagues kept in contact with me. I don't think they understood how hard it was for me to be able to get to them I couldn't get out, drive, be in busy places etc they saw me as just me still as I still looked the same."* – Julie

> *"When I tried to return to work folks would just see I looked fine & one even told me I'd "be fine, you look great" like that's some kind of good thing when there's a million symptoms kicking that no-one can see."* - Jodie

Headway's factsheets *Brain injury: a guide for employers* and *Brain injury: a guide for colleagues* have been written to explain how experiencing a brain injury may affect an employee within the workplace and how best to support them. These resources, among other publications tailored towards various relationships in the survivor's life, are available at www.headway.org.uk/information-library.

Brain injury survivors were mixed in their responses towards whether they felt GPs had a good understanding of the hidden effects of their brain injury, with 41% feeling that their GPs did have a good understanding, 35% feeling they did not, and 22% being unsure. As the first point of contact for accessing support for many medical issues, it is vital that GPs have a good understanding of the effects of brain injury, including those that cannot be seen. Headway has a dedicated webpage for GPs to assist with improving this understanding, including downloadable resources, available at www.headway.org.uk/news-and-campaigns/campaigns/supporting-gps/.

35% of brain injury survivors felt that other professionals did not understand the hidden effects of their brain injury.

> *"Some health professionals assumed I was better because my speech improved, and I had no contact with my stroke team for nearly 2 years. Once I remembered I had to contact them to get thing going to get help about cognitive problems and general health."* - Anna

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[3] Van Velzen, J.M., Bennekom, C.A.M., Edelaar, M.J.A., Sluiter, J.K., & Frings-Dresen, M.H.W. (2009). How many people return to work after acquired brain injury?: a systematic review. *Brain Injury, 23(6)*, 473-88.

> *“People supplying a service who do not believe I’m disabled.”* – Valerie

4.4 Hidden effects in one word

We asked brain injury survivors to tell us how their brain injury being hidden made them feel in one word.

The top three words given by respondents were frustrated, misunderstood and vulnerable.

These three powerful and emotive words offer an insight to the feelings that brain injury survivors live with.

Other words shared by brain injury survivors are shared in the word cloud below.

4.5 Challenges of living with a hidden disability

We provided respondents with a list of issues and asked them to select which ones they personally felt caused challenges to living with the hidden effects of brain injury.

The issue most rated by survivors as causing challenges was a lack of understanding from society, with 86% agreeing that this was a challenge. 82% of survivors also felt that a lack of belief from others about having a disability was a challenge to living life with a hidden disability. 62% felt that a lack of appropriate support was a challenge.

> *“People judge you as a normal person with no issues as that is how I look. They literally judge a book by its cover.”* – Stephen

> *“Social anxiety is so disabling and frustrating, I begin to feel like an old record player trying to explain how much it affects what I can do, knowing all the time people just don't understand as I would not have done before A.B.I; it's exhausting.”* – Neil

> *"Becoming frustrated having to constantly explain myself to others when I feel I shouldn't have to - that can be challenging on a daily basis. Sometimes though the balance can go the other way - people can become overprotective and not allow you to try and do things for yourself and that can be frustrating too."* - Diane

Some survivors remarked that these challenges were even experienced through contact with support and care services.

> *"Obtaining and retaining social and health care packages continues to be made increasingly difficult."* – Anonymous
>
> *"It's OK having a head injury but you're stuck in the big deep blue sea between employment and benefits."* – Anthony

The table below shows the percentage of brain injury survivors and carers who agreed with each listed item as being a challenge to living life with a hidden disability.

Challenges of living life with the hidden effects of brain injury	**% of brain injury survivors**	**% of carers**
Lack of understanding from society	86	89
Lack of appropriate support	62	74
Lack of belief from others that you have a disability	82	67
Having/maintaining a relationship	45	60
Applying to welfare benefits	55	58
Applying for and maintaining employment	39	34

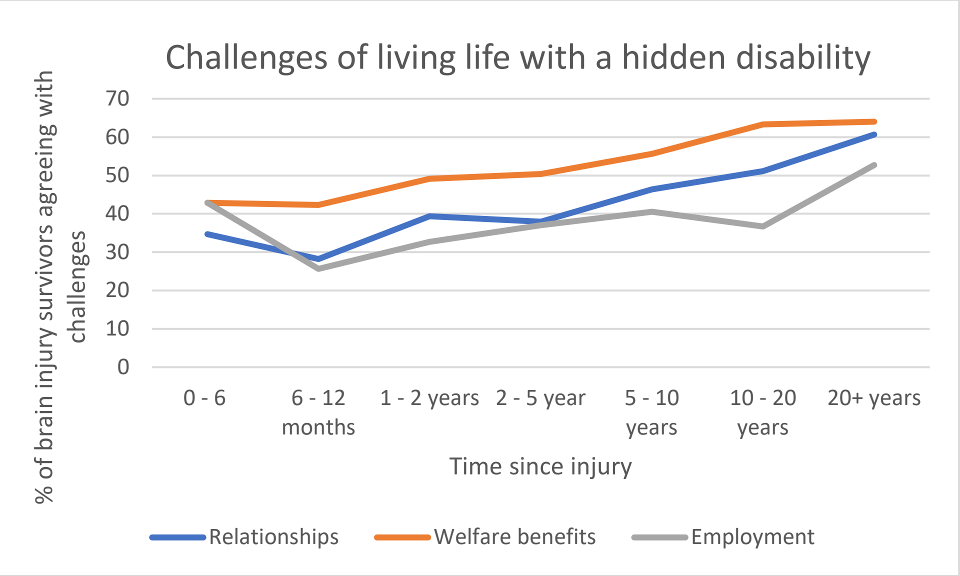
While a similar percentage of survivors and carers agreed that a lack of understanding from society, applying for welfare benefits and applying for and maintaining employment were challenges to living life with a hidden disability, a higher percentage of carers felt that lack of appropriate support and having/maintaining a relationship were challenges, highlighting the struggles that carers of brain injury survivors face when supporting someone with a hidden disability.

> *"Getting medical professionals to understand the ramifications of this disability."* – Laura
>
> *"Lack of support for parking, accessibility, appropriate changing facilities. Lack of time and courtesy from others to communicate, being treated as 2nd or 3rd class ...."* - Anonymous
>
> *"Having/maintaining close relationships with family and friends."* – Anonymous

> *“Your whole world falls apart & one minute you’re a loving wife and the next a life time carer with no life. My husband’s RTA destroyed both our lives.”* - Jacqueline

We examined whether time since the injury had any impact on feelings about the challenges of living life with a hidden disability.

A lack of understanding from society, lack of appropriate support and a lack of belief from others about having a disability were fairly consistently felt to be challenges across all time spans. However, following the elapse of 12 months, a steadily increasing number of survivors indicated that having and maintaining a relationship and employment were challenges, as well as applying for welfare benefits.



4.6 Understanding and insight

We asked brain injury survivors whether they had ever struggled with understanding the effects of their brain injury. Two-thirds of survivors confirmed that they had (67%), with many survivors explaining that the effects of their injury were especially difficult to understand in the early days of sustaining the injury.

> *“Taken years to accept the issues - try to play things down to please others.”* – Shand
>
> *“At first I did not understand. Very scared and depressed.”* – Anonymous
>
> *“In the beginning, I couldn't understand why the symptoms were taking so long to improve and why they were so severe.”* – Ann
>
> *“I didn't have the brain space to understand in the early days. Pain takes up so much of our emotional and logical processing.”* – Anonymous

Some survivors commented on the fact that it took them time to understand how the effects they were feeling were related to their injury, or to even recognise that they had sustained a brain injury at all.

> *"For first 3 – 4 years I couldn't understand or remember how it'd impacted me and my identity."* – Deb

For some survivors, the difficulties with understanding the effects of their brain injury were due to a lack of knowledge, information and support offered in the early days of medical care. However, some survivors described experiencing a lack of insight. Insight can be defined as the ability of a person to observe and reflect on their own thoughts and actions. Following a brain injury, especially an injury to the frontal lobes of the brain, insight may be impaired so that a survivor struggles or is unable to understand the impact of their injury, in some cases appearing as denial.

> *"I didn't even realise I'd had a stroke for 2 weeks because I was really ill. It took me a year to understand what had happened and accept it and notice things that were going wrong and not normal. 3 years on I'm still confused by some basic things and my cognitive functions are still up and down."* – Anna
>
> *"At the beginning it was hard to accept the changes as they were so small, I didn't believe they were real."* – Anonymous

We also asked carers of brain injury survivors whether they felt the brain injury survivor they were caring for had a good understanding of the effects of their own injury. While 61% of carers felt that the survivor did, a third felt that the survivor did not have a good understanding, which can possibly be attributed to a lack of insight. Indeed, a further 27% of carers reported the brain injury survivors they were supporting did not have a good understanding of their having a brain injury at all.

Other common effects of brain injury that the carers felt that survivors did not have a good understanding of included problems with thinking skills (65%), attention and concentration problems (51%), problems controlling anger (43%), depression and/or anxiety (42%) and memory problems (40%).

4.7 A message for others

We asked brain injury survivors what they would say to others to help them with understanding the hidden effects of their brain injury. Given the fact that a lack of understanding from society was the highest rated challenge of living with a hidden disability, the responses provided in this section are of particular importance and relevance in order to improve this widely reported lack of understanding about the challenges of living with a hidden disability.

Several key themes emerged from the responses, forming a number of suggested ways in which brain injury survivors can be best supported with their hidden effects.

1. **Be patient**

Cognitive skills are used to process information and respond accordingly, and we rely on them to be able to keep up with conversations, complete activities and tasks and navigate around the world.

A brain injury can commonly interfere with these skills and cause someone to take longer with processing information. Indeed, the most commonly reported hidden effects of brain injury were cognitive i.e. memory, fatigue, attention and concentration and problems with thinking skills. Many brain injury survivors stated that being patient and allowing more time to process and respond to information would be helpful for them.

> *"Please take a step back & take time to understand that an ABI can affect a person's ability to think logically and within normal time limits."* – Anonymous
>
> *"Give me some time to process my answer."* – Shirl
>
> *"Consideration and understanding we need space and time."* – Zarqa
>
> *"Give the person time to answer your questions and don't make them feel pressured into providing you with an answer as they get overwhelmed."* – Rebecca

2. Don't judge

Survivors were keen to remind others not to judge based on appearances.

> *"Just because I appear normal, does not mean I am. I struggle a lot with memory and concentration and processing information. But, I try and mask it, so I don't feel a burden on others."* – Anonymous
>
> *"Try walking in my shoes for a week before you judge me because if you went through half the things that myself and my family have been through in the past 7 years you might think twice before judging anyone again."* – Paul

In addition to remaining cautious about judging someone to not have a disability based on appearances, some survivors wanted to remind people not to judge them based on behaviours caused by the effects of their injury.

> *"I don't remember things. I will sometimes forget conversations ever took place - be patient with me, it's not intentional!"* – Ian
>
> *"I seem selfish or distant at times. But it's because I can't cope in the situation. Give me space and understanding."* – Anonymous

Headway's campaign video *Don't misread the signs* further illustrates this key message and is available to watch at www.headway.org.uk/news-and-campaigns/campaigns/see-the-hidden-me/.

3. Learn about brain injury

Underpinning many of the challenges faced by brain injury survivors and their carers is a lack of understanding about what a brain injury is and how it can affect someone. Brain injuries are complex and can lead to a myriad of issues, further complicated by the fact that no two experiences of brain injury are ever quite the same.

Survivors commented on the benefit of others learning about brain injury so that they can better understand how to offer support. Several survivors suggested utilising Headway's website (www.headway.org.uk) and publications to gain this knowledge.

> *"Take time out to understand my vision and memory problems."* – Anonymous
>
> *"Education is key to helping, including, assisting and wellbeing of all involved with person with any disabilities.... overall I think the more people are educated on disability the better they can understand and help."* – Tantra
>
> *"Go on the Headway Website every day to Read All of That Information Once a day every day as it's so Very Interesting And Educational."* – Jo
>
> *"Look at the Headway Website and regularly read all of their information, because reminders help information stick in all of our brains."*- Anonymous

4. **Just ask, and listen**

Simply asking a survivor how they are or if they need any assistance would be appreciated by some brain injury survivors.

> *"Please educate yourself about brain injury and don't be afraid to ask questions. Don't write me off, I'm still in there, it just a work I process. Finally, don't let someone recover from brain injury on their own. Make time for them."* – Anna
>
> *"Ask me what I think I might need support with / reassurance of in a given situation."* – Fiona
>
> *"If you are unsure then please ask, that way then you will be more aware and be able to help me with difficult day to day living."* – Sharon
>
> *"Just ask... are you okay how are you doing."* – Anonymous

5. **Don't undermine the effects of brain injury**

A cause of frustration for some brain injury survivors is when others attempt to undermine the impact of their injury. The phrase "I know what you mean.. I've got a terrible memory too!" was the number one statement listed on Headway's previously published 'top ten things of what not to say to someone with a brain injury', available at www.headway.org.uk/news-and-campaigns/news/but-you-don-t-look-disabled/.

Survivors raised this issue again by requesting that others not liken their regular day-to-day experiences to that of living with the consequences of a brain injury.

> *"It's not like a normal headache as everyone says 'I get them too and my memory is awful as well'."* – Michelle
>
> *"Fatigue is not like being tired. It's not something I can control, although I can put processes in place to try and mitigate it presenting."*– Michael
>
> *"Don't try and relate - you won't be able to. Understand every brain injury is completely different."*– Anonymous

6. **Recognise the fluctuating and unique nature of brain injury**

Adding further complexity to the impact of brain injury is that the effects can vary on a daily basis, and that no two experiences of living with a brain injury are ever quite the same. While certain types of brain injury often result in certain effects, the brain is complex and widely interconnected so that there can be any number of consequences following injury or illness.

Survivors wanted others to remember this varying nature of brain injury to caution against taking a ‘one size fits all’ approach.

> *“I say some days are good, some are bad and I never know what it will be until I wake up and even then can be hard to tell.”*– Clare

> *“No all disabilities are visible. Everyone brain injury is different. And it affects everyone in different ways. Be kind, caring , understanding, have board shoulders don't that things personal. Be willing to adapt to the person with a brain injury.*”– Elizabeth

> *“We don’t understand our own injury most of the time so expect others to struggle with it. It changes every day so sometimes we may be able to do things that other days we cannot.”* – Anonymous

> *“Just cos you cant see a disability doesn’t mean you can dismiss what someone is saying or maybe needing. Someone’s needs can really vary and completely change and its harder cos of the fluctuating, unpredictable and very individual nature of the disability.”* – Anonymous

4.8 Using analogies..

Brain injuries can be difficult to understand and process, due to their complicated nature and constellation of possible effects that are unique to each survivor. A brain injury can turn a survivor’s world upside down and lead to challenges and complications in multiple aspects of life and attempting to explain this can understandably be a tall task.

Several brain injury survivors used creative and relatable analogies to describe their unique experiences to make it simpler for others to understand the complexities of living life with a hidden disability.

> *“Try and put an analogy. E.g. like a permanent hangover without the expensive alcohol bill.”* – Elizabeth

> *“It's like when you've gone for a day out and then you think did, I lock the front door properly? I live with that feeling everywhere*.” -Russell

> *“A swan looks so graceful effortlessly floating along the surface of the water without a care in the world, but underneath its legs and feet are frantically paddling away at a million miles an hour just trying to keep up with everyone else”.* – Will

> *“My brain is like a computer that has crashed and is re-booting…sometimes things work ok, but other times they get stuck or just don’t make a connection.”* – Claire

> *“Imagine trying to walk in the fog every day even though you can't see so have no idea how you are walking - that is how it feels navigating life post my TBI.”* - Juthsana
>
> *“Most people understand the iceberg analogy, I've used this on occasion.”* – Kim
>
> *“It's like my motorway has closed roads, some are being diverted while repairs are on, and may reopen or may be reduced to single carriageway.”* – Martin
>
> *“I know it's very hard to think of someone, who seems well physically, to have a disability. Try and imagine someone has a bandage around their head, maybe a wound.”* - Julia
>
> *“I explained it by it's like dropping a smart phone the screen may be cracked but you can't see the damage inside to all the connections.”* – Anonymous
>
> *“Imagine going to your local city for work, for shopping, for socialising [sic] U take the same motorway/A road for every visit to the city, u do it automatically without planning or even noticing all the manoeuvres / junctions you pass.. Now that route is closed, you’ll never travel that motorway /A road again but u still need to get to the city. So now u take the B roads, there’s speed limit changes and there’s more junctions to pass. You’ll still get to the city but it’ll take u longer, you’ll use more fuel and you’ll feel tired.. Brain injury is the B Road. We’ll get there, we’ll manage our daily routines and commitments but they’ll take longer and the brain will get tired to the extent that it needs to rest.”* – Maddie
>
> *“My brain is like a jar of smarties, each different colour smartie represents a different section of my brain, they were once in identified and precise places as organised by colours representing functions, now the smartie jar has been all shook up, and everything is not where it should be.”* - Jacob

5. Conclusion

Our study shone a spotlight on the otherwise often hidden consequences of brain injury, which affect not only brain injury survivors themselves but the wider caring network around them, affecting opportunities, relationships and emotional wellbeing.

The concluding message from respondents is clear: be patient, kind and take the time to learn about brain injury. By following these maxims, we can all improve our understanding of what living with a hidden disability can be like, and therefore provide the right type of support. Survivors had creative and imaginative ways of suggesting ways of raising awareness of the hidden effects of brain injury, which can help to make the hidden and unseen easier to understand. Training and education can further assist in improving this understanding, and Headway will continue to work towards providing such opportunities and campaigning, to ultimately continue improving life after brain injury.

6. Acknowledgements

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