

Action for Brain injury Week 2024

A life re-written

An exploration into the ways in which life can be re-written after acquired brain injury

This report contains the results of a survey launched for Headway – the brain injury association’s Action for Brain Injury Week 2024 campaign *A life re-written*.

A short-read version of this report is available from Headway’s website at www.headway.org.uk/news-and-campaigns/campaigns/a-life-re-written.



A life re-written

Contents

1. Introduction	3
2. Key findings	5
3. What did we do?	5
4. Who completed the survey?	6
4.1. Brain injury survivors	6
4.2. Carers	7
5. What did we find?	8
5.1. Attitudes towards life being re-written	8
5.1.1. Brain injury as a life-changing experience	8
5.1.2. Changed life goals	11
5.1.3. Development of new skills	18
5.2. Aspects of life	21
5.2.1. Relationships	21
5.2.2. Social life	25
5.2.3. Employment	31
5.2.4. Mental health	36
5.2.5. Driving	39
5.2.6. Spirituality	40
5.3. Inspiring stories and messages of hope	43
5.3.1. Personal achievements	43
5.3.2. Adjusting to a re-written life	54
5.3.3. Messages to others	55
6. Conclusion	58
7. About Headway	59
8. References	60

1. Introduction

Everyone has a story.

As we walk through life, we make plans for what we want our story to be, what chapters we want it to contain. We think about the job we want to do, where we want to go, what we want to achieve. We take steps towards our dreams. For many, life follows a script that they themselves have had a part in writing.

But for some, the script can go completely awry, and the story can change dramatically within the blink of an eye.

Nobody plans for a brain injury to happen. Nobody writes it in as part of their life story. But every year, around 350,000 people are admitted to a UK hospital with a brain injury.

For many people, survivors and carers alike, life can change in an instant. The injury can throw plans into disarray, it changes life goals, and even the sense of who we are. These events will often come out of nowhere and spark a re-evaluation of life aims and objectives, requiring a recalibration of what is important. For many, **it can feel as though life has been completely re-written.**

Our Action for Brain Injury Week 2024 campaign, *A life re-written*, has sought to explore these changes and illustrate life before and after brain injury.

As part of the campaign, we launched a set of surveys to explore what contributes to the experience of life feeling so changed after brain injury. The response from the brain injury community was overwhelming. We have written this report to share the voices of those who contributed and are impacted by this often-hidden, life-changing disability.



**ACTION FOR
BRAIN INJURY
WEEK 2024**

A LIFE RE-WRITTEN

We would like to thank all of the brain injury survivors and carers who completed our surveys to help us better understand how brain injury can re-write lives.

Thanks as well to all Headway groups and branches and professionals who helped to circulate the survey to their service users, clients and patients.

We would like to extend particular thanks to the survivors and carers who granted permission for us to use their quotes within this report.

For further information about *A life re-written*, visit our website at www.headway.org.uk/news-and-campaigns/campaigns/a-life-re-written.

For questions and enquiries about the survey and this report, please contact our Publications and Research Manager at publications@headway.org.uk.

For press enquiries, please contact media.office@headway.org.uk.

2. Key findings

- Over three quarters of brain injury survivors (78%) have had to change their life goals because of their brain injury.
- Around 70% of brain injury survivors and carers report that their mental health is worse after brain injury, with anxiety and depression being highly reported.
- 60% of brain injury survivors experience a worsened social life after their injury.
- 67% of carers have had to change their life goals because of the injury.
- Around a third of brain injury survivors (34%) have developed new skills since their injury.
- 50% of carers have developed new skills since the survivor sustained their injury.
- 52% of brain injury survivors have tried new activities since their brain injury that they had not considered before the injury.

3. What did we do?

We created and launched two surveys to be completed by brain injury survivors and their families, partners, friends and carers. The surveys contained both quantitative and qualitative questions to gather experiences from people with lived experience of brain injury on how their lives had been changed by the injury.

We asked questions relating to aspects of life commonly affected by brain injury (relationships, social life, employment, mental health,

driving and spirituality). We also asked broader questions on attitudes towards life changes.

Our surveys were promoted through our website and online communities. Our network of groups and branches and clinical contacts also helped with distributing the survey. Paper copies of the survey were made available for people who were unable to complete it online.

The survey was open between January – February 2024.

4. Who completed the survey?

The surveys were completed by a total of 3,693 people affected by brain injury. Of these, 2,406 were brain injury survivors and 1,287 were family, partners, friends and carers of survivors.

4.1. Brain injury survivors

Survivors' ages ranged from under 18 to over 61, with the most common age group being 41-60 years (59%).

41% of survivors were male, 58% were female and 1% were non-binary, other or preferred not to say.

Survivors came from all around the UK.

The length of time since the survivors' injury ranged from fewer than 6 months to over 20 years. A quarter of survivors had their injury between 2 – 5 years (25%), followed by between 5 – 10 years (22%). 16% of survivors had sustained their injury over 20 years ago.

Just over a third of survivors (36%) had sustained a mild brain injury, 9% had sustained a moderate brain injury and 40% had sustained a severe.

Causes of brain injury varied, with the most common causes being trauma (43%), brain haemorrhage (16%), brain aneurysm (14%) and stroke (13%).

4.2. Carers (family, partners, friends and professional carers)

Just under half of the family, partners, friends and professional carers were either a spouse or partner of a brain injury survivor (48%). Around a third were other relatives (32%), while 3% were friends and 1% were professional carers.

As all respondents in this group were providing regular care to the survivor, we will refer to this group as ‘carers’ for the remainder of this report.

A carer is defined as anyone who looks after a family member, partner or friend who needs help because of an illness or disability and is not paid for doing so.

Carers’ ages ranged from under 18 to over 61, with the most common age group being 41-60 years (49%).

79% of carers were female, 21% were male, and fewer than 1% were non-binary, other or preferred not to say.

Carers came from all around the UK other than the Channel Islands.

Carers reported that the length of time since the survivor’s injury ranged from fewer than 6 months to over 20 years. The most common length of time since injury reported was between 2 – 5 years (27%), followed by between 5 – 10 years (20%). 15% of carers reported that the survivor’s injury had been sustained over 20 years ago.

26% of carers reported that the survivor had sustained a mild brain injury, 7% had sustained a moderate brain injury and over half had sustained a severe brain injury (58%).

Causes of reported brain injury varied, with the most common causes being trauma (46%), stroke (14%), brain haemorrhage (12%) and brain aneurysm (11%).

5. What did we find?

5.1. Attitudes towards life being re-written

5.1.1. Brain injury as a life-changing experience

Our campaign [*A life re-written*](#) highlights how life can change after brain injury. To begin with, we asked survivors and carers to tell us whether they felt that the brain injury had indeed changed their life.

Brain injury survivors

The vast majority of brain injury survivors felt that their injury had changed their life (96%). Of these, just over half felt that their injury had changed their life for the worse (54%), while just over a third felt it had changed their life for both the worse and the better (39%). Only 4% felt it had changed their life solely for the better.

Ways in which life had **worsened** included:

- **Loss of employment** or change in employment circumstances, and the resulting financial impact;
- Weakening or **breaking down of relationships** (both personal and social), and the resulting social isolation;
- **Loss of skills**, affecting the ability to work, fulfil hobbies or

complete daily activities;

- **Loss of independence**, particularly following the loss of one's driving ability;
- Development of **mental health problems**, particularly depression and anxiety;
- Loss of **personal memories**.

Ways in which life had **improved** included:

- The development of a **changed life perspective** and priorities, including developing a renewed appreciation of life;
- The **improvement of personal relationships** for instance getting to spend more time with loved ones or the development of new relationships with peers;
- The development of **positive characteristics**, such as increased empathy and self-confidence;
- The emergence of **new opportunities**, such as a career change or a chance to pursue new hobbies;
- The development of a **healthier lifestyle**, such as stopping smoking, spending time in nature and having a healthier diet.

Carers

The vast majority of carers also felt that the brain injury had changed their life (95%). Of these, half felt that the injury had changed their life for the worse (50%) while 42% felt that it had changed their life for both the better and worse. Only 2% felt it had changed their life solely for the better.

Ways in which life had **worsened** included:

- The requirement of taking on **practical caregiving responsibilities**, such as assisting with washing and dressing, shopping, driving and paying bills;
- Needing to **give up activities** such as socialising, employment or going on holiday;
- **Navigating challenges** such as, undergoing legal proceedings, securing care packages and being responsible for making decisions;
- Experiencing **changed roles**, within the relationship with the survivor (feeling more like professional carer than partner), with others (feeling like a single parent to children) and with oneself (feeling second to the brain injury);
- Development of **mental health problems**, especially depression, anxiety and trauma;
- **Grieving the change** in circumstances, future prospects and the impact of injury on the survivor's life.

Ways in which life had **improved** included:

- A **changed life perspective** and priorities, including developing a renewed appreciation of life;
- The **improvement of personal relationships** for instance through getting to spend more time with loved ones or the development of new relationships with peers;

- The development of **positive characteristics**, such as increased empathy, resilience and patience;
- The development of a **healthier lifestyle**, such as having a better work-life balance and taking life at a slower pace.

Brain injury as a life-changing experience – summary

Brain injury is almost universally felt to be a life-changing experience by both brain injury survivors and carers alike. While around half of the survivors and carers felt that life is worse after brain injury, just over a third felt that while life is worse in some ways, it is also better in others. Less than 5% felt it had changed their life solely for the better.

Ways in which life was improved after brain injury were similar between survivors and carers and included the development of a changed life perspective, improvement of personal relationships, the development of positive characteristics and adopting healthier lifestyles.

Ways in which life was worse largely related to loss of skills and social or vocational opportunities for survivors, and living with new and additional responsibilities for carers.

5.1.2. Changed life goals

We asked survivors and carers whether they have had to change their life goals because of the brain injury.

Brain injury survivors

Over three quarters of survivors (78%) had to change their life goals as a result of their brain injury.

Types of goals that needed to be changed varied, but often related to career prospects.

“(I) planned to be headteacher but put it off because what if my tumour returned in the first 5 years.”

“I wanted to take my ballet company on tour and expand my school... since bacterial meningitis, I am unable to achieve this.”

“Academically qualified to train as a solicitor just before finding out about my brain tumour. I also wanted family but have spent a phenomenal amount of time in hospital.”

Long-term retirement plans had also been affected for many survivors. For some, the injury meant taking retirement sooner than expected, while for others, goals they had wanted to achieve during retirement had to be changed.

“I had planned to retire at 66 having completed and published all my major research projects. I had then intended to travel extensively with my wife and adult children. I had to retire early at 59 following my accident. We now holiday close to home when we can.”

“Goals of travelling in retirement no longer exist. Goals of cycling in France can no longer happen.”

Other types of goals that needed to be changed related to:

- Sports and hobbies;
- Undertaking further studies;
- Getting married, having children or becoming a grandparent;
- Travelling;
- Owning one’s own property.

“I had to relinquish my plan (which had been in place) to have children.”

“It saddens me that I cannot be the hands-on, active grandmother I had hoped to be.”

“My entire life and plans were changed. I had career goals, now I will never be back in that job. I wanted marriage, kids and a house...now it’s completely unknown..”

While for many, long-term goals needed to be changed or dropped, half of the survivors had formed new goals since their injury (50%). Many of the new goals formed related to advocating for others with disability.

“My life was changed nearly 20 years ago, and this has made me more determined to focus on getting things changed for disabled people and the criminal justice system.”

“I used to be at horse college, about to go to America, which I certainly can't do anymore. I've made it a goal to make people more aware of capability of disability.”

“I want to use my experience to help others in going through the same thing and I now prioritise my health and wellbeing.”

Other new goals related to:

- Learning to cope with the impact of the injury;
- Personal development;
- Getting one’s driving license back;
- Sporting/fitness;
- Acceptance of one’s injury;
- Returning to work/study;
- Living independently;
- Rebuilding social connections.

“My goals are all around trying to get fitter and healthier physically and mentally.”

“New goals tend to focus much more around emotional stability and regulation.”

“Pre-brain injury I enjoyed a fast paced, hectic lifestyle with lots of partying. Now I enjoy country walks and a slower, simpler life. My

goals are centred around happiness, as opposed to stereotypical success.”

“My new goals are to take care of myself more, spend more time with family and just enjoy life.”

39% of survivors had not formed new goals since the injury. Barriers to forming new goals included:

- loss of motivation;
- struggling to adjust and drawing comparisons with pre-injured life;
- living with the effects of brain injury;
- financial restrictions.

“I struggle constantly with living expenses, so the thought of setting goals is non-existent.”

“Unable to study, cognitive problems that increase anxiety levels. Lack of concentration and unable to cope with competing demands.”

“I don't have the motivation. I feel everything I try fails. I also feel about 20 years older than my age...”

Many survivors explained that they no longer focused on setting long-term goals, but rather on setting much shorter, more achievable goals, sometimes even focusing on simply getting through one day at a time.

“I set myself new goals every day. I don't aim too far into the future. 1 or 2 day goals are the furthest I set myself.”

“Be more present, appreciate the smaller things. Try to take day trips or weekend breaks instead of holidays in Greece.”

“I take each day at a time. I no longer have goals or plans.”

Some survivors described not setting themselves goals due to their low mood. If you are struggling with symptoms of depression, please consider contacting our nurse-led on 0808 800 2244 or helpline@headway.org.uk. The helpline is available to offer a listening ear and emotional support, as well as answering questions about life after brain injury. You can also contact Samaritans on 116 123.

Remember, help is available.

Carers

Just over two thirds (67%) of carers had to change their life goals as a result of the brain injury.

Types of goals that needed to be changed varied, but often related to travelling (either for work or leisure):

“Had hoped to travel when we retired but he is not up to that, yet.”

“Can no longer go travelling due to having to be nearby. Finances have suffered due to impulsive behaviours.”

“I planned to travel, progress my carer but now I need to be here for him while working 3 jobs to pay the annex we had to build him.”

Other types of changed goals related to:

- Plans for retirement;
- Employment and studying;
- Family plans such as relocating, starting a family or family activities.

“Unable to go on holiday or do any of the things we planned to do in our retirement.”

“We wanted to save and move to Devon with our dogs, but that isn't possible now.”

“I’ve had to let go of my desire to be a mum, to choose where we live or to pursue anything solely for me.”

“Initially I was studying when my dad got sick. So I gave that up. I also changed jobs and initially was working part-time; I now work full time due to the cost of living plus supporting my dad. It is hard, but with all of life’s experiences I have learnt to embrace this - my goals may have changed but that doesn’t mean there still aren’t goals I’m working towards achieving.”

Just under a third of carers reported having formed new goals since the injury (31%). As with brain injury survivors, many carers’ new goals related to developing a new appreciation of life and wanting to support others.

“It’s our aim to be thankful for what we have, and how he has recovered from such a devastating injury.”

“Two years post-injury, I set myself a goal of raising money for the hospitals who saved my nephew’s life and achieved that; I intend to continue to raise money to support the purchase of an MRI scanner for one of the hospitals. I prioritised family over work when I had a chance to retire early, even though I had not fully achieved my professional goals by that point. I have had to learn about being a trustee of a personal injury trust. I try to do more of what I enjoy now and recognise that life is precious.”

Many of the new goals described by carers centred around the survivor, including supporting and advocating for them, making future and financial arrangements, and identifying useful opportunities.

“My major objective is to get my son settled into a property fit for purpose. We have been ‘making do and mending’ for nearly 13 years now. Lord knows how long this will take, but when finished I have promised myself a lifetime’s goal of a cruise with my oldest and dearest friend from school.”

Goals also included prioritising health and wellbeing, for instance by attending support groups, taking time out for themselves and seeking

support for mental health. A few carers had goals of returning to employment or volunteering.

“To give myself some time even if only a few hours outside the home.”

“I want to improve my own health more by trying to fit in more exercise and also to encourage my husband to keep fit as well.”

“I’m thinking of returning to work part time to give myself some self-worth and escape from caring.”

54% of carers had not set themselves new goals since the injury. Barriers to forming goals included feelings of guilt, and caring duties leaving little time to pursue personal goals. Indeed, 70% of carers reported having less time to pursue their own interests since the injury.

“I don’t know what the future holds for myself or my sister. For the last 20 years, whenever I have made plans, they have had to be abandoned as my sister has consistently needed my help. This can be on a daily basis to help her attend to everyday tasks in the home, or everyday issues that have arisen regarding conflict she has caused. In addition, she also needs me to deal with solicitors, barristers, social services, police, etc and this happens very often.”

“I don’t set goals because I have to go on how my husband is feeling from day to day. He can be very stubborn and very selfish, so if he doesn’t want to do something it doesn’t get done, so I have to adapt constantly.”

Changed life goals – summary

Both brain injury survivors and carers often need to change long-term goals after injury, with many goals needing to be abandoned altogether. Survivors’ goals often relate to career prospects, while carers often have to change goals for travelling.

Setting new goals after brain injury can be difficult for both survivors...

Changed life goals - summary (continued)

... and carers for a variety of reasons. New goals formed after brain injury are often related to personal development and a desire to help others.

6.1.3. Development of new skills

Brain injury can cause a range of impairments and affect a wide number of skills. However, undergoing life changes can sometimes offer a chance to explore and discover new opportunities, through which new skills can be developed.

We asked survivors and carers whether they had developed new skills since the brain injury.

Brain injury survivors

Around a third of brain injury survivors felt they had developed new skills since their injury (34%). Various types of skills were reported, including:

- **coping skills** to manage the effects of brain injury, such as being able to monitor behaviour and using breathing exercises;

“I’ve worked hard to learn new skills to counter-balance my behaviours and impulses to control them and to be more socially acceptable.”

“I have learned well-being breathing and meditation exercises.”

- **positive personal traits** including perseverance, empathy, kindness, confidence and a greater appreciation of life;

“I have a glass half full outlook now, and I am more optimistic.”

“The injury has taught me new empathy and appreciation for others’ struggles.”

- **daily living skills**, with many survivors specifically describing new cooking skills;

“I find easier ways of doing things at times like chopping veggies a different way so it’s quicker.”

“New work skills and qualifications, knitting as I mentioned earlier, basic baking, I make a mean Victoria Sponge now!”

- **recreational skills**, with a wide range of hobbies described including art, sewing, gardening and sports;

“Learning to play piano. New gardening techniques.”

“My inability to return to work gave me time to develop my skills. Photography and dancing are my favourites.”

- **educational/vocational skills**, assisting with career prospects.

“I have attained a degree in photography, I have also completed a course in using Microsoft Office, I have also learned many useful lessons in ‘The University of life’. I have also become a mental health “peer-lead”. I am currently studying for a qualification in Mental Health First Aid, I have joined various societies, and clubs (after) my brain injury.”

“Since my brain injury and first-hand experience of feeling a complete loss of personal power (and losing my job) I have retrained as both a teaching and learning assistant in schools and am now a registered member of the British Association of Counselling and Psychotherapy having taken

a diploma in therapeutic counselling.”

Some survivors also described developing heightened sensitivities since their injury.

“Quicker reflexes. Weird one, I can hear a phone vibrate before people find it. My eyesight in the dark has gone so my hearing gets better, and I can sense where things are.”

“Yes, I've developed a remarkable skill since my brain injury, one that I didn't need to learn - it simply emerged. I possess an uncanny ability to sense and feel others' energy, often referred to as being an empath. I can intuitively read people, sometimes even foreseeing details about them without prior knowledge... while I've honed the skill of connecting with others quickly for camouflage purposes, it has also become a profound source of hope and purpose in my life. Thanks to my brain injury, I've developed an extraordinary capacity to create instant rapport and connect deeply with people on a level that defies explanation.”

Check out our article *Finding your superpower* for more stories on developing superpowers after brain injury, available at www.headway.org.uk/about-brain-injury/individuals/brain-injury-and-me/finding-your-superpower

Carers

Half of the carers felt they had developed new skills since the injury (50%). Many of these new skills were directly related to the caring role and becoming an expert by experience.

“I feel I very quickly became an 'expert' on brain injury during the 3 months my husband was in hospital. I realise I am far more patient than I knew and teach memory learning techniques.”

Some carers considered the development of positive personal traits to be newly acquired skills.

“I’ve found my voice and now will stand up and voice my opinion where usually I would sit back and let others do it.”

Development of new skills - summary

Both survivors and carers describe the development of a wide range of new skills after brain injury. For carers, new skills are often related to their caring role. Both survivors and carers described the development of positive personal strengths as newly acquired skills.

6.2. Aspects of life

6.2.1. Relationships

The many possible changes to relationships after brain injury is well documented throughout research and personal testimonies. We have also previously discussed this topic in detail through our campaign [*You, me and brain injury*](#).

We asked survivors and carers to tell us whether their relationships had been affected by the brain injury. For survivors, we asked about their role specifically with a partner or spouse. For carers, we asked about their relationship with the survivor dependent upon the nature of their relationship (i.e. parent, sibling, etc).

Brain injury survivors

61% of brain injury survivors reported that their relationship with a partner/spouse had been affected by the injury. Of these, a quarter felt that the relationship was worse or had broken down (25%).

Reasons for relationship breakdowns included:

- a **lack of understanding**, support or empathy from the partner/spouse;

“My ex-husband couldn’t handle my mood swings and lack of memory, we used to argue about conversations I had totally forgotten.”

“My wife does not understand the changes in me - she is broadly supportive, but I get frustrated when she doesn't recognise my behaviour had changed because of my brain injury.”

- difficulties with adjusting to **lifestyle changes** following the injury;

“I'm so grateful to my husband and appreciate him more than ever but our relationship has definitely changed, it's less intimate and a lot less exciting, no holidays, nights out etc.”

27% of survivors felt that the relationship was better in some ways and worse in others, while 9% felt that it was better. Reasons for the relationship being better included:

- going through challenging times together;
- spending more time together;
- greater understanding of one another's health issues;
- appreciating the spouse/partner as a source of support or advocate.

“We are closer, huge support given and has looked after me. He has learnt he needs to be more patient with me when making decisions and remembering words.”

“It's brought us closer. My husband had 2 strokes a year before my haemorrhage so understands a lot of what I'm experiencing.”

“My partner was instrumental in convincing the doctors at hospital that I really did need emergency brain surgery, without which I would have had a life-changing condition. As a result of her persistence, I am 100% recovered and our relationship is stronger.”

“We have time and do things more together.”

Carers

81% of carers reported that their relationship had been affected by the injury, with half feeling that the relationship had worsened or broken down (50%). Reasons for relationship breakdowns included:

- **changed personality** in the survivor, causing the non-injured partner to feel as though they were in a relationship with a different person;

“I feel I have lost a version of the person I once knew, while I have gotten the opportunity to know this new version all over again. It is a bittersweet grief.”

“He’s passive so less disagreements, no emotions, doesn’t hug the same or make me laugh like he used to.”

- coping with **anger outbursts**;

“All my son's anger is often directed at me. He can be really nasty, but he always wants my help.”

“We are closer in some ways but my wife is very irritable and that has put a strain on our relationship.”

“It is hard to see my daughter be so irritable and short tempered, it’s hard to remind myself that she is still recovering, she is also a teenager so she can be very angry or rude and I’m not sure how to handle her.”

Did you know...

Areas of the brain involved in emotional regulation may be affected through injury, therefore causing difficulties with managing anger and controlling behaviour. However, even in the absence of this, survivors may experience frustrations about their changed circumstances and abilities, and direct this towards those nearest to them.

For information and tips on anger after brain injury, see our publication [*Anger after brain injury*](#).

- changes in **intimacy**;

“There is no physical intimacy and communication can be extremely challenging.”

“He doesn't often show initiative even a cuddle needs a prompt and it's sad how that feels.”

- a sense of **role change** within the relationship due to needing to take on caregiving responsibilities;

“At times I feel more like a carer than a wife but would NEVER say that to my husband - it would break him.”

“I feel I have more say in what goes on, but perhaps the balance has shifted too far. I feel is more like a parent/child relationship than husband/wife.”

“We were a strong team, now I have to be the lead in everything. We are still a team but not equal. I carry the majority of the burden of our lives and living. We can no longer be intimate. I know he loves me, but he can't show me anymore. He lives in the moment.”

15% of carers felt their relationship with the survivor had improved. Similarly to brain injury survivors, this was often attributed to getting to spend more time with one another and growing closer through overcoming challenges.

“We are closer and have had to go through so much it has made us rely and trust each other more.”

“We cherish our time together more.”

We are now able to spend more time together and have learnt that you need to live life for today as you don't know what is around the corner. We have had deeper conversations and have a better understanding of each other.”

Relationships - summary

Living with the impact of brain injury and experiencing changes in roles can negatively impact both survivors' and carers' feelings towards the relationship. Going through challenging life events together can cause some relationships to strengthen.

6.2.2. Social life

Our social networks offer a sense of identity and belongingness as well as practical and emotional support. Brain injury survivors often report their social life being negatively impacted by the injury. We have previously discussed the themes underlying these experiences through our campaign [*You, me and brain injury*](#).

We asked survivors and carers to tell us whether their social life had been affected by the brain injury.

Brain injury survivors

60% of brain injury survivors felt that their social life was worse since the injury.

Reasons given for social life being worse included the following:

- Struggling with the **effects of brain injury** in social environments, such as anxiety, overstimulation and concentration difficulties.

“I struggle in social situations due to anxiety and sensory overload.”

“I find social occasions too difficult now, I struggle with the over-stimulation. I have adapted to meeting some of my closer friends in more suitable environments, but I’ve felt incredibly isolated and lonely since my accident, as everyone else’s life moves on and I’m no longer part of the things that I used to be part of.”

“Don't like going out as I struggle to communicate in noisy areas.”

- Fatigue affecting **energy levels** to socialise.

“I don't have the stamina that I once had and the fatigue really kicks in regularly, hence I don't do or go to half the things I used to.”

“I know that if I socialise in the wrong environment or with too many people it takes me a long time to get over the additional fatigue caused by it. So I have to choose wisely and more often than not say no to things.”

- **Friends failing to understand** or accommodate for the effects of brain injury.

“I struggle in public and have lost friends because they don't understand the new me.”

- **Friends no longer staying in touch** or including the survivor in social activities.

“I feel some friends don't invite me to do things because I would slow things down or not be able to make it because I can't get anywhere without transport or help.”

“I feel isolated. Friends don't invite me to coffee/lunch/dinner anymore.”

- Being **unable to remember** social events.

“I find any level of relationship impossible with people with whom I shared a friendship in the past but have no memory of that time. I do not want any new friendships but do make

an effort to mix and converse with other people through discussion groups etc.”

- **Socialising** being a different experience due to **no longer drinking alcohol**.

“Very different now I’m no longer drinking.”

- A **lack of interest** in socialising any longer.

“I don't like it noisy. I can't take the flashing lights. I'm not interested and tired I like to garden on my own.”

- **Practical issues** with socialising, such as being unable to drive, work taking priority, fear of stigma and having less money.

“Better in that I have more friends but worse in that I can't afford to do as much anymore.”

“I say no to social events more often. I've had to prioritise work so if I'm feeling my week is too busy I don't go out so much. I prefer to see friends individually rather than in groups as it's hard to follow and join in conversation.”

“Not being able to drive to visit my friends means it's all on them to get to me. I guess with them working full time it's hard on them. Plus they know I won't remember their visit in a day or so.”

“I am still a social person however anxiety and depression effect it as well as if alcohol is involved people see my wobble and assume I'm drunk when it's my disability it makes me wary or discourages me from going out.”

Around a quarter of survivors reported that their social life was better in some ways and worse in others (23%), while a further 5% of survivors felt that their social life was better.

Improved social life was attributed by many to forming more meaningful friendships since the injury, especially where new friends understood brain injury (for instance from personal experience), or more generally, living with a disability.

“I lost a lot of friends who didn’t understand or didn’t like the new me, but I meet a lot of great people at Headway Surrey that gave me hope.”

“In some ways it has hit worse because I have been moved - but in other ways it has got better because I have met other brain injury survivors like me.”

Research says...

Receiving peer support after brain injury is a largely a positive experience, with the benefits including being connected, interacting with others and providing and receiving support¹. Peer support after brain injury has also been found to have the potential to positively influence activity and participation².

To find details of your nearest Headway group or branch offering peer support, visit www.headway.org.uk/supporting-you/in-your-area.

Carers

Just over half of the carers (52%) felt that their social life was worse after the injury.

Reasons given for social life being worse after brain injury included the following:

- Being **unable to leave** the survivor unsupervised;

“OUR social life is better I think for J, but MY social life is worse – I don't want to leave J alone so rarely see my friends

now, maybe once every 3 months... not good for my wellbeing, but if I go out he gets very anxious and questions my conversations due to his loneliness I think!"

"We can only do things if he wants to so if he doesn't want to go out on a particular day because he's in pain, tired or got a headache then that's it we don't go. If I force him it just makes things 10 times worse and can be embarrassing at times so it's easier to stay home."

- Being unable to socialise due to the **survivor struggling in social environments**;

"Social life is virtually nil. Lack of confidence, noise issues, and not really understanding conversations can be a big no thank you. Of course you find different options for a social life, as limited as they may be, the main consideration must always be to the head injury survivor, so as not to add to any problems or discomfort."

"We rarely go out together and socialise as my wife finds it difficult. That is very sad and I really miss what we did before."

- **Logistical challenges**, such as needing to prepare outings more carefully;

"We rarely go out with others due to how hard it is for him to concentrate, hold attention, cope with conversations especially in busy environments. He also tends to go to bed early, so we end up declining invites regularly. He cannot manage work social events or big social gatherings. If we do go, we have to apply strategies and only stay for a while."

"We can't go to loud places. We can't go out at night because of his fatigue issues. We can't travel easy. Everything takes detailed planning on my part to help

mitigate any possible problem or issue that may arise.”

“I have to arrange things in advance, I can never do things spur of the moment.”

- Managing **survivors’ challenging behaviour** in public.

“Due to his outbursts, I personally don't go out as often and I have my own health issues.”

- **Friends no longer staying in touch** or including carers in social activities.

“I have struggled to regain a social life in the years since her injury. Some friends have fallen by the wayside as they’ve gotten bored with the ongoing challenges of caring for someone with an ABI. My energy reserves are still low and I need to spend more time alone to recuperate, making socialising more challenging than it was before.”

“Friends cannot understand, and are scared of knowing what is going on. Lost many relationships.”

“We just don't get invited to many things since. Daily life revolves around fatigue and there is a small window where any social activity is possible. People do not care or help with this. My husband held quite a high civic role and no one contacted him since. His family have also become very distant.”

- No longer having the **time or energy** to socialise.

“I don't have the time to be included in plans and have lost or more distant friendships / relationships.”

Just under a quarter of carers (24%) felt their social life was better in some ways and worse in others, while a further 2% felt that their social life was better.

As with survivors, improved social life was attributed by many to forming more meaningful friendships since the injury, especially where new friends understood brain injury (for instance from also being carers to survivors themselves).

“I also lost my freedom by choosing to support my partner, but I've met some incredible people through the journey so far.”

“I have met inspiring people through the experience- many are valuable friends - shared adversity is a bonding experience.”

“My daughter has got me involved in campaigns for disabilities, etc which has added to my social life.”

Social life - summary

Both survivors and carers report their social life being negatively affected by brain injury. Friends often drift apart or fail to offer the required level of understanding and support. Coping in social environments can be difficult for both survivors and carers. New, more meaningful friendships can form, often based on shared experiences of brain injury and disability.

6.2.3. Employment

Being employed (whether self-employed or employed by others) carries a number of benefits. For many, this is mainly financial security, but it also often grants a sense of purpose or contributing to society, a regular routine, an opportunity for personal development and progression, a sense of identity and social opportunities.

We asked survivors and carers to tell us whether their employment circumstances had changed since the brain injury.

Brain injury survivors

Just over half of the brain injury survivors had been unable to return to work following their brain injury (55%). Of these, 42% were unable to return to work either now or in the future, while 13% hoped to work in the future. 26% had returned to work, but either had to take on a new

role/job or change their working hours to accommodate for the impact of their injury.

For many survivors, returning to work was difficult because the effects of their injury interfering with workplace performance, especially fatigue, executive dysfunction, communication difficulties and memory problems.

“I don’t feel I could commit to a job as my moods change daily and my sleep patterns.”

“With the loss of executive function, I lost my sales and marketing job. My wife was told I would become a “man of lists.” Now I am a customer delivery driver for Tesco!”

“I no longer have the concentration, memory to undertake a part time or full-time role.”

“Fatigue, memory problems and head pain make this impossible. I was medically retired after a 22-year IT career. It hurt a lot losing a career I worked so hard for and loved. It took about two years to accept that decision and a long, long time trying to think of something I may be able to do. Now I accept if I manage to do a few bits round the house it’s an accomplishment.”

Research says...

Fewer than half of brain injury survivors are able to return to work after 2 years, with a substantial number being unable to return to a former role or return permanently³. Returning to work is challenging even among those with a mild brain injury⁴.

Many of the roles previously held by survivors would have required significant training to be completed beforehand. Despite this, many found themselves being unable to return to these former roles and turning instead to different vocations after the injury.

“I used to be a sports journalist for a regional daily newspaper, but now I work in a supermarket.”

“I was a recently qualified nursery teacher. I was unable to complete my NQT year and now I'm a craft tutor.”

“Whereas before I was a project manager in local government, I now work with my sister running a small local company making handmade cards, ornaments and gifts.”

“I was running a family-owned hotel with 5 storeys, 20 bedrooms, two bars, restaurant, function rooms. That all stopped when I had brain haemorrhage. 13 years I became a part time Latin dance instructor!”

“Previously I was a computer consultant, now peer support worker for stroke.”

Employer involvement, workplace accommodations and training can help with the process of returning to work after brain injury. Some survivors commented on the difference it made to have or not have these interventions.

“On a phased return to work schedule. I have recently reached full time employment but still have a degree of reasonable adjustments, for example remote working to avoid fatigue of travelling and information overload of face-to-face interactions. I work in a very challenging industry but in an incredibly supportive team which makes a tremendous amount of positive difference. This coupled with the enormous amount of help I'm getting from Headway which is positively impacting all areas of my life in and outside of work is a win-win formula to my wellbeing and recovery.”

“Changed roles at work as we got a new manager who wasn't very understanding of brain injury. In my new role my reasonable adjustment still not in place which makes it difficult.”

“I have found that if I am honest at work about how I'm feeling, i.e. fatigued etc, then initially people can sympathise because they have occasionally experienced those symptoms. But after the third or fourth time I mention it, they start to think I am just complaining

because their personal experience only lasted a day or so... When I started becoming more honest about my disability, I had a manager ask if I used it as an excuse not to do work.”

Being unable to return to paid work led some survivors to pursuing volunteering opportunities instead.

“I had to resign immediately from work, but I have taken on several volunteer jobs including becoming a Trustee of Headway East Lothian.”

“Initially, I wanted to do nursing, give back the care, but was advised by a nurse to do what I was good at, and I eventually made a vocation as an outsider artist, this has been much helped by the Outside In charity. And thanks to my return and volunteering at the Maudsley & Bethlem (Hospital's) Gallery input, I'm able to give back by enhancing the hospital / nursing environments.”

Carers

Almost a quarter of carers (24%) were unable to return to work after the survivor's injury, with 18% of these being unable to work either now or in the future. Around a third of carers had returned to work (30%) but needed to take on a new role or change their hours to accommodate for their new circumstances.

Feelings about continuing to work alongside caring duties were mixed. Many carers found the dual responsibility of caring and working difficult.

“I used to work freelance but now my wife needs to come first, it's too difficult to plan paid work.”

“Career progression stopped as I struggled to juggle my new-found responsibilities and it affected my work in a very negative way.”

“It's been hard to learn to be a full-time supporter for my son and hold down a job people do not understand or can even comprehend the situation and it's one you would not want them to as well because the only way you would is to have to live it.”

Some carers felt that working allowed them to take a break from their caring duties or maintain a connection with something they enjoy.

“I had to give up work after my husband’s injury and wasn’t sure I’d be able to work again. I now work part time, not necessarily out of need for money but more for my sanity - a bit of ‘me’ time.”

“I am a tutor rather than a classroom teacher, I only work one evening a week and do it because I love my subject.”

As reported by survivors, having flexible and accommodating employers helped many carers with managing their dual responsibilities of working and caring.

“I have had to become a lot more flexible at work to give me time to help with my son, taking him to appointments, spending time with him in the week to break his days up when his wife is working.”

Many carers described needing to reduce their working hours or changing their roles to accommodate for their caring needs.

“I was a broadcast director and producer. I now teach as this is more ‘possible’.”

“I have had to change to a nine-day fortnight to allow me every other Friday off in order to do things for my sister or just rest if I am tired.”

Some carers had to stop working altogether, either due to needing focus on the survivor’s care needs or as a result of their own ill health.

“At the time of the accident we had our own business so I could be flexible, but it was incredibly difficult running a business and providing care. I’m now retired.”

“I lost my job in part due to the stress and depression caused by my dad’s injury and the additional caring required and the worry about him.”

Employment – summary

Brain injury survivors and carers often face changes to their employment circumstances following the injury. Returning to work is facilitated by undertaking more suitable roles and being supported within the workplace environment. Many carers find it difficult to manage caregiver responsibilities alongside work, although flexibility and understanding from employers can help.

6.2.4. Mental health

The impact of brain injury on mental health has been well documented, with brain injury being linked to a range of mental health conditions such as depression, anxiety and post-traumatic stress disorder.

We asked survivors and carers to tell us whether their mental health was worse or better since the brain injury.

Brain injury survivors

Almost 70% of brain injury survivors reported that their mental health was worse since the injury (69%).

For many, mental health was worse due to living with the many and varied impacts of brain injury. Brain injury is a life-changing condition, and the emotional consequence of having life so changed in so many ways was poignantly described by one survivor.

“I was extremely confident, loved life, lots of friends never in always doing things going places. Now I have no friends, no job, no life, no wants, no memories, can't remember things I've done with my kids can't remember conversations one hour later, can't remember what I had for breakfast or if I've ever had one, can't remember when I shower last, can't cook, burn food, forget I've put in the oven, can't remember appointments the list goes on, and on can't remember people I meet things I say.”

Being unsure about the future also affected some survivors' mental health, especially where goals had to be changed.

“I lost my job, my social life, my passion and hobby in music. My life goals were affected.”

Several survivors described how being isolated from friends and having fewer social opportunities affected their mental health.

“I obsess about fitting in socially, which I struggle with since I cannot read people or body language like I used to and sometimes say inappropriate things, so I tend to think way too much before I interact and mostly, I just avoid it, which makes me lonely and depressed since I'm an extrovert.”

“Anxiety, depression, anger sadness - struggle sometimes on what to do with all the emotions- isolation is the biggest.”

A small number of survivors felt that their mental health was in fact better since the injury (7%) – this was attributed to preferring a slower pace of life, identifying new opportunities and keeping a positive perspective.

“My mental health is usually much better since my injury, though I experience greater dips and 'black spots' now since my injury.”

“My mental health was extremely poor before my injury, especially as I was working in a very stressful working environment. Now, I take the time to be more creative and calmer.”

“I have learnt to focus on ME doing things that I enjoy which helps me with my mental health.”

Mental health was reported to fluctuate on a regular basis by many survivors, with some survivors feeling particularly sensitive around the anniversary of their injury.

“Up and down. It's harder to be up when others are down. And the day/month it happened is always really difficult.”

“I have good days and bad days but try to not let the bad days win.”

“I have mostly good days where I am very grateful that I am alive and breathing and working. I do occasionally have bad days where I get annoyed that my body does not always respond how I want it

to.”

Carers

Almost 70% carers reported that their mental health was worse since the injury (68%).

For many, concerns for the survivor’s welfare and wellbeing were a primary cause of anxiety and depression.

“I am in a constant cycle of feeling desperately sorry for my sister, who has had this awful injury inflicted on her, to feeling resentful towards her for needing me all of the time and having to prioritise her.”

“I get depressed because of how upsetting it is to see my son have such a rubbish existence.”

Other causes of worsened mental health included:

- Feeling unsupported by health and care services;
- Missing life as it was before the survivor’s injury;
- Managing life with the effects of brain injury;
- Experiencing trauma or anxiety related to circumstances surrounding the injury, such as the memories of the injury incident;
- Difficulties within the relationship with the survivor, for instance managing challenging behaviour;
- Wider relationships being impacted;

“I am near to tears most days and feel permanently mentally exhausted as his moods change day by day.”

“I sometimes get very frustrated trying to understand conversations, which sometimes spills over into my life away from him.”

As with survivors, many carers described their mental health fluctuating on a regular basis, with this sometimes being dependent on the survivor’s mood. Many carers also described their mental health being worse in the earlier stages of injury compared to more recently. Several

carers described needing to access counselling to cope with the impact of the injury on their own mental health.

Mental health – summary

Brain injury survivors and carers commonly experience worsened mental health after brain injury, with depression and anxiety being especially common. Living with the consequences of brain injury caused worsened mental health in many survivors. Carers often attributed this with their concerns over the survivor's wellbeing as well as the changes experienced in their own lives. Anniversaries of injuries are particularly sensitive times. Carers as well as survivors can feel traumatised by circumstances surrounding the injury.

6.2.5. Driving

Driving is a skill that offers independence, convenience and pleasure for many. Being able to drive relies on many different skills including sustained concentration, attention, memory, multi-tasking and responding to situations quickly. Many of these skills can be impacted by brain injury.

We asked brain injury survivors if they had needed to stop driving since sustaining their injury.

21% of survivors had had their driving license revoked by licensing authorities. 14% had voluntarily given up driving, while 7% were waiting for a decision to be made by licensing authorities. 40% of survivors reported that they were still driving. The question did not apply to 14% of survivors.

Research says...

The loss of driving has been identified as one of the most important quality of life concerns for brain injury survivors, negatively impacting on functional re-integration, independence, and life satisfaction as well as increasing depression and a loss of identity⁵.

Several survivors described the practical difficulties they faced from no longer being able to drive, and the increased reliance this placed on others.

“Had a very tough time with losing my license twice in the last 6 years due to surgery 6 1/2 years ago and seizure 2 years ago. Took 8 months to get licence back. Challenging to travel to work in the Yorkshire Dales, as public transport limited.”

“My driving has reduced and I rely on others to take me places I need to be as I can only cope with short local journeys.”

Being unable to drive was reported to affect socialising opportunities, employment opportunities and the ability to complete daily activities such as shopping.

For many, being able to drive was an important part of their lifestyle prior to the injury, whether for vocational or leisure purposes. For these survivors, driving was described as being part of their identity, for instance belonging to a motorbiking group, or driving trucks for work.

Driving – summary

Many brain injury survivors experience both practical and emotional difficulties when their ability to drive is impaired by the injury. The loss of driving can form part of people’s experience of life being re-written after brain injury, especially where driving is perceived to be related to sense of identity. Being unable to drive can impair survivors’ independence and increase their reliance on others.

6.2.6. Spirituality

The term ‘spirituality’ describes the feeling or belief of life carrying greater purpose than everyday existence, involving the exploration of universal themes such as compassion, altruism, wisdom and truth. Spirituality has been found to be closely relating to positive outcomes after brain injury, in both survivors and carers.

We asked survivors and carers to tell us whether they had become more of a spiritual person since sustaining their injury.

Brain injury survivors

Just over a third of brain injury survivors felt more spiritual since the injury (36%). Some described their spirituality as aligning with religious faiths, while others discussed other forms of spirituality such as meditation, yoga, philosophy and feeling connected to nature.

Some survivors described how their new sense of spirituality helped with feeling more positive about their experiences, improved well-being and inspired opportunities to support others.

“I was always spiritual but being in bed for months helped me to know who I truly am.”

“I have reconnected with my religion since brain injury.”

“This journey has gifted me with heightened intuition, empathy, and awareness, enriching my spirituality and wisdom. However, it also comes with societal stigma and rejection. Nevertheless, I'm determined to use my experiences to advocate for brain injury research and acceptance. In my remaining years, I aspire to be a spokesperson, promoting compassion, understanding, and unity within our community, emphasizing that despite our differences, we're all in this together.”

Spiritual practises were described by some as helping to cope with specific effects of brain injury.

“I try to meditate daily to calm the tinnitus and balance the emotions. It's very hard with depression but you have to try. Meditation can help a lot if you put in the effort to try to get better.”

“My faith (and) prayer ... helped me recover physically from the surgery and some complications in the first year or 2 and helped me cope with having epilepsy, not driving, coping financially and coming to terms with the new me, although this is still a work in progress! It's easy to compare how you are with how you were and

look at what you've potentially lost but also you gain perhaps in a better perspective about what's important to you in life."

Some survivors expressed a spiritual sense of gratitude for having survived the injury. Others yet described feeling a sense of deeper meaning or purpose to their experiences but finding this difficult to describe or understand.

"There is something within me that provoked my survival- it's not easy to explain."

"Well I keep surviving near death experiences so I feel I'm here for a reason not sure what."

Expert comment

"Human spirituality involves psychological capacities such as the ability to transcend one's immediate concerns and see a bigger picture; to make meaning by weaving memories of events into a continuous story; and to regulate one's emotions through practices like meditation. It's therefore both surprising and encouraging that so many survivors of brain injury report increased spirituality or deepened religious faith. Traumatic life events can often lead survivors and their loved-ones engaging with big questions about why such things happen, why they happened to them, who they are now, and whether life is still worth living. Spiritual traditions can provide a framework for lamenting the disorientation and lack of control that so often accompany brain injury, and they can also offer new and unexpected insights into how to move forward and live life well in the context of loss. They therefore give hope, which is a crucial ingredient in recovery."

- Dr Joanna Collicutt McGrath CPsychol, FBPSS

58% of survivors did not feel more spiritual since the injury. Some survivors had never been spiritual, while others felt that they had lost a sense of spirituality or developed an altered sense of this following their injury. For some, this was due to feeling anger or disappointment about

their experiences, while for others the cognitive effects of brain injury interfered with their ability to process spiritual thoughts.

“I have lost all belief in anything Spiritual.”

Carers

Just under a third of carers (29%) felt more spiritual since the injury was sustained.

As with survivors, carers who felt more spiritual described using their spirituality as a coping mechanism for their experiences, with some carers feeling a sense of spiritual gratitude.

“Something definitely saw us through those darkest days.”

Some carers felt that their spirituality was the only source of support they had.

“We could not have gotten through this without prayer and faith.”

64% of carers did not feel more spiritual since the injury. Some carers reported to have never been spiritual at all, while others felt that they do not have time to consider spiritual matters.

Spirituality – summary

Spirituality is a personal and varied experience, carrying significance to people in many different ways. Spirituality can help some survivors and carers to cope with their circumstances and feel a sense of purpose to their experiences. Some survivors and carers may develop negative feelings or lose a sense of spirituality after brain injury.

6.3. Inspiring stories and messages of hope

6.3.1. Personal achievements

Many of the ways in which life has been changed by brain injury described throughout this report have described the loss, insecurities and challenges that a brain injury can introduce to life. However, positive

changes, new directions, accounts of strength and descriptions of fortitude have also been shared throughout. To further celebrate these positive changes, we asked survivors and carers to describe their greatest personal achievement since the injury was sustained.

The achievements described were varied, inspiring and deeply touching. At the heart of many of them was a sense of recovery, an overcoming of obstacles and recognition of new chapters beginning as life after brain injury is re-written.

We would like to take this opportunity to congratulate and thank each and every one of our survey respondents for sharing their personal achievements with us. The achievements shared are an incredible testament to the amazing successes that can be had after brain injury.

It is important to note that some survivors commented that they did not feel they had achieved anything since their brain injury. We hope that some of the below examples illustrate how all sorts of achievements are possible, and that living with a life that has been re-written after brain injury is in itself an achievement for many.

Brain injury survivors

Several themes emerged from the achievements shared. These were grouped into achievements that related directly to the injury itself, personal life achievements and the overall development of positive traits.

Achievements that related to the injury itself included:

- **Learning to cope** with the effects of brain injury;

“I’ve made a couple of social interventions to deal with situations that were awkward and managed to resolve them by myself. I used to do this as a matter of course but find it much more difficult with the lack of self-confidence that has

developed since the injury.”

“I completed a fatigue group through the neuro team. This helped me understand how I am impacted on a daily basis, emotionally and physically.”

“Learning to slow down, and manage stress better.”

“Reading and working on my speech. From October to Christmas 2022 I was unable to track text well enough to read. There has been no therapy available to me in my area. However, I told my osteopath about my concerns and he gave me some vestibular exercises to try. They made me feel really unwell when I did them but there was some improvement. I can now track text and have embraced reading as one of my bedtime rituals. (As long as there aren’t too many characters in the story, or I can’t follow it).”

- **Accepting the injury** and being resilient towards changed circumstances;

“The thing that I’m most proud of is that I’ve kept going every single day. I’ve implemented the advice that I’ve been given from all of the professionals involved in my recovery to the very best of my ability and I’ve continued to have hope that I’ll find a way of living/working that I’ll enjoy again even if it looks very different to the future I imagined for myself.”

“Learning to be the new me!! And accepting that I need to readapt.”

“My strength has made me proud of myself, life has been very difficult and different but I have fought hard to gain as much independence as I can, every day brings new challenges but I try to face every difficulty with as much strength as I can.”

“Battling to regain as much of my previous life as possible. Developing a mental strength in coming to terms with my brain injury and subsequent disability.”

- Seeking and **accessing help**;

“I have put myself first and have started counselling and CBT.”

- **Regaining lost skills** or returning to previously enjoyed activities;

“The seizures have stopped, I’m still alive, I can talk and walk and now eat from a fork! The smallest of details in life are treasured.”

“I have managed to go back to what I love most: motorcycle riding and I have returned to full time employment in the job I love.”

“Got myself out walking my dogs again, and made myself interact with people I met.”

“Getting back on a horse. A safe horse and cantered for the first time last year without losing peripheral vision and depth perception. I was so happy I cried. Felt a little bit of the old me.”

“My sewing achievements. I could sew before my brain injury but have had to learn all over again as I forgot a lot of how to do it but in a small group with the sewing teacher I am proud of the achievements I have made. I call sewing my therapy.”

“I have learnt to swim again as I enjoy snorkelling when on holiday. I used to scuba dive but that is still a goal.”

- **Learning new skills** or undertaking new activities;

“I’m happy that I was able to learn how to build dry stone walls as I really wasn’t sure if I’d be able to learn anything new again. I had a great teacher though - very kind and patient!”

“Two things. Firstly passing my driving test after a few attempts. People seemed to expect me to just give up. Secondly, achieving my qualifications to be a psychotherapist working with groups of clients I hadn’t in other jobs. My disabilities have a positive impact on who I can work with and having this speciality.”

- **Returning to work or education**, either to a former or new position;

“I gained a 2:1 in sports journalism, that I began after my injury. I am now an internationally published journalist/author.”

“Re-training to focus on a new career, having lost the career I loved dearly. The new career presented many challenges with my cognitive ability, but my resilience and determination helped me through.”

“After a few years of struggle, I managed to complete my degree in Veterinary Medicine. I became a very good vet.”

Personal life achievements included:

- **Family matters**, such as growing one’s family or being present for special family events;

“Knitting baby blanket and becoming grandmother.”



the brain injury association

**ACTION FOR
BRAIN INJURY
WEEK 2024**

A LIFE RE-WRITTEN

“I walked my daughter to school 6 weeks after waking up. Won my last hockey match after my ABI before retiring from the sport.”

“I became a dad to a girl & a boy AFTER my brain injury and am now a grandad to 3 girls.”

“After eight years of trying (normal attempts, NHS fertility, private fertility, 5 rounds, 1 miscarriage) I gave birth to a little baby boy who is now 7 years old. I can't put into words the joy that he brings to my life.”

- Securing desired **living arrangements** such as buying one's house or moving into independent living;

“Whilst working for the NHS I managed to buy a flat and moved in to live independently. This makes me very proud. I have now paid my mortgage completely. I am very proud of myself that I managed to do this last year. I am proud of myself that I am working and earning a living.”

- **Travelling** and sightseeing;

“I have travelled around the world twice. I have a beautiful wife and 2 wonderful children.”

“Traveling alone for 19 months to the other side of the world and buying a house and living independently.”

- Partaking in or organising **special events** or occasions;

“I organised a surprise weekend away (close by) for my son's 30th birthday and got the family together.”

“I planned and organised my wedding and hand made a lot of the decorations. It was a great achievement and I felt I

was finally achieving new things rather than trying to catch up to where I was before brain injury.”

“Getting a shower myself. Standing with support for my son's wedding photo.”

- Receiving **awards** or winning competitions;

“I won the most inspirational person award at the gym awards night.”

- **Volunteering** and fundraising successes.

“I volunteer for the NHS with patient champions, and I know I do it well because I’m a good people’s person and I love helping others.”

“I’m Chair of a large food bank/community kitchen in a big and diverse borough. I also am on the management committee of 2 other voluntary projects. These all take a lot of my time.”

“Volunteering. I’ve helped at a hospice cafe and a toddler’s group. Being unable to return to paid employment was difficult to accept. However, volunteering has given me a sense of purpose and social interactions.”

“I raised money for the Air Ambulance that airlifted me to hospital.”

Positive personal traits that had been developed and considered an achievement included:

- Greater appreciation of life;
- A desire to help others;
- Adopting a healthier lifestyle;

- Increased empathy;

“Helping my sister, it made me feel useful again, which has been missing since having a brain injury.”

“I retrained as a mental health nurse to put something back into the NHS after they saved my life.”

“It has made me think more about the people around me and not just family and friends. It has changed me into a more caring and understanding individual, such a small incident has changed my perspective of life for the better.”

Did you know...

The development of positive personal traits and increased personal strength after a traumatic period are part of a psychological experience called post-traumatic growth (PTG).

More information on PTG, including how to encourage this experience through an approach called values-based living, is available in our publication [*Post-traumatic growth after brain injury.*](#)

Carers

Achievements described by carers largely related directly to the brain injury and their caregiving role. Themes that emerged from carers' responses included:

- **Supporting the survivor** with coping with the effects of their injury and adjusting to their new life;

“Teaching him to live a life after being told he would be in a hospice for the rest of his life- helping to walk and talk again.”

“Using my skills as a teacher to help him to write again.”

“I’ve helped someone adjust to their new life and have supported them to be where they are today and for that I’m extremely proud and I’m glad to have been part of his journey.”

“Helping Mum with her emotional lability, as a stoic lady before the injury being able to be with her as she learns it’s ok to cry or share her feelings has been something I feel proud about.”

- Assisting the survivor with **navigating the care system**, or advocating for them;

“The way I supported him and fought for him to have the best treatment and rehab. We were not married at the time, and this was sometimes difficult.”

“I am proud that I have been able to advocate for my daughter and continue to encourage her on her recovery journey.”

“That I speak up for my son and my family.”

“Finding my voice and standing up to what I believe is right. Even if it is against medical teams (and then to be proven correct).”

- Coping with the **acute stage** of injury;

“Coping with all the hospital visiting.”

- **Family matters**, such as maintaining strength within the relationship and raising children alongside caring duties;

“The fact as a family we have grown and been so supportive of each other.”

“Growing and giving birth to our second child during the depths of the accident and subsequent hospital related admissions. Bringing up those two small children and supporting my husband to gain back his life skills and seek employment again.”

- **Adapting** to changed practical circumstances;

“I have taken over all the cooking and can now produce a bigger variety of meals that are cooked from scratch.”

- **Maintaining other aspects of life**, such as continuing to work or coping with personal health issues alongside caregiving;

“How strong I have been! I was 10 months postpartum when my husband sustained his brain injury and my hormones were all over the place at the time but I feel I held everything together when things were falling down around me. I am proud of how I handled everything and am handling everything as every day is so different even now he is at home and recovering!”

“Being able to change my career and succeed in what is a very stressful work environment whilst maintaining my caring role is a significant achievement.”

“I survived liver disease and a liver transplant as well as supporting him to achieve his personal development goals.”

- **Raising awareness** of brain injury with others, volunteering and fundraising.

“Telling her story. Fighting for the truth and sharing her journey as a patient after her TBI with health professionals for learning.”

As with survivors, many carers described the development of positive traits such as strength, resilience, assertiveness, and patience as an achievement.

“That even when I’ve felt hopeless I have never ever given up. I am RESILIENT.”

“My ability to deal with high levels of stress and pressure, decision making.”

“Getting my husband to understand the impact his actions have on others.... It took great patience and persistence to get through to him. But he has a better understanding now and is more aware. I am very proud that I could help him in this way.”

“Learning patience I did not know I had, to cope with what gets thrown at me.”

“Strength I didn't know I had. Learning to stand up for what we need although I hate being "demanding" as this is not my nature.”

Personal achievements – summary

Survivors and carers can achieve great things after brain injury, despite the re-writing of their lives. Achievements are varied and range from learning to cope with the impact of injury, to personal achievements to developing positive characteristics. Learning to live with a brain injury is in itself an achievement celebrated by many.

6.3.2. Adjusting to a re-written life

Many survivors and carers had described the ways in which their lives had been re-written by brain injury. We asked respondents to tell us about anything that had helped them with the process of adjusting to these changes.

Responses from survivors and carers were broadly similar and comprised the following themes:

- Attendance at brain injury support groups, such as their local Headway group or branch;
- Having an opportunity to help others to adjust to life after brain injury and learning about others' experiences;
- Support and understanding of the impact of brain injury from loved ones such as friends and family;
- Adaptations and adjustments made within the workplace;
- Access to specialist support such as through counselling, rehabilitation teams or a neuropsychologist;
- Owning supportive equipment and resources such as adaptive equipment, a Headway Brain Injury Identity Card or a Blue Badge parking permit;
- Acceptance of life having been re-written after the injury and changing life perspective;
- Learning about brain injury, coping mechanisms and relaxation techniques;
- Spirituality and faith;

- Support from pets;
- Ultimately relying on things to improve with time.

“My family and recognising that it's okay to fail sometimes.”

“Occupational health helped me to phase very slowly back to work. Talking therapy also helped.”

“Local brain injury support and psychologist to help me come to terms with my injury, and recommendation of aids such as, Google Nest, Dictaphone, Apple Watch for alarms.”

“Spending more time in nature/outside; using my lived experience to help stroke research; developing mutual support networks with other brain injury survivors.”

Adjusting to re-written life – summary

Factors that help both brain injury survivors and carers to adjust to a re-written life include the use of support groups, increased knowledge of brain injury and coping mechanisms, adaptive equipment and resources, social and professional support and spirituality.

6.3.3. Messages to others

Adjusting to a re-written life after brain injury can be incredibly difficult for many. As we have discussed throughout this report, accessing support and advice from peers can be beneficial, especially to those who may be new in their journey to re-writing their life after brain injury.

We asked survivors and carers to share a message with others about life after brain injury.

Brain injury survivors and carers shared very similar messages. These were powerful and inspiring, and encompassed the following themes:

- Being patient with recovery and trusting that time will make things better;
- Looking forwards, not backwards;
- Accepting the 'new you';
- Getting support from others;
- Celebrating achievements, no matter how small;
- Focusing on the positives;
- Setting smaller goals;
- Being proud of yourself;
- Allowing yourself to grieve and heal;
- Taking one day at a time.

“Mourn the person you were, embrace the person you have become.”

“Remember who you are. You are still you, you just have to sometimes go back to the start and rebuild a better version of yourself. Never let anyone dim your light because they no longer recognise the person you’ve become, be who you are, and change your world for the better so you can enjoy your new journey.”

“You’re not a failure, life just took us on a different route.”

“If you have a bad day please do not let it turn into a bad week. Have some relaxing time and start again tomorrow.”

“There is much enjoyment to be found in trying out new activities, especially outside in nature. Change is everywhere, outside us and inside us and nothing is forever - keep on pushing yourself when the time is right and rest when it isn't.”

“Don’t rush. There is no deadline for recovery. Your brain will be working hard on recovery and you will be tired. Don’t fight it and rest



the brain injury association

**ACTION FOR
BRAIN INJURY
WEEK 2024**

A LIFE RE-WRITTEN

when you need to. Don't feel guilty about saying no if you're not up to something. There'll be good days and bad days but accept that.

"Those bad days will be fewer and fewer. Take whatever professional is offered and if it's not offered, ask yourself. If you can, take whatever physical exercise you can, however small. The effects of exercise is psychologically huge. Don't be hard on yourself."

"It's ok to cry and it's ok to hurt. But remember that you are a warrior and a survivor. Early days of recovery will feel like a battle where you have fight to find some semblance of normal. You will find a strength you didn't know you had and you will win eventually."

"Please be patient with yourself. Love and care about yourself in the same way you would for a loved one."

"You ARE still 'you'. There will be hard days when you feel like giving up. Don't. Keep going, keep fighting. Keep a diary and try to write one "positive thing" in each day. Even if it's a bad day the positive thing will be you pushed through it. Have someone to confide in, someone to talk to and don't bottle things up. Take each day as it comes, good or bad. Things do get better, it just takes time."

"Do your best each day to try and stay kind and happy. Break the day into thirds if you have to. It's good to have some kind of dream occasion to look forward to helps. But looking ahead too far in future is frightening. Keep it simple."

Message to others – summary

Brain injury survivors and carers can offer invaluable advice to others on coping with the impact of brain injury through messages of resilience, strength, patience and positivity, as well as offering helpful suggestions on coping with the impact of brain injury.

6. Conclusion

The results from our survey for *A life re-written* have highlighted the heterogeneity of brain injury. No two experiences are ever exactly the same, with a huge array of possible consequences and challenges faced by both brain injury survivors and carers alike.

Various aspects of life are reported to worsen after injury, with life goals often needing to be abandoned and quality of life being impacted by the myriad of changes that sustaining a brain injury can introduce. But positive changes are often reported as well. Changed life perspectives, increased spirituality, the development of more meaningful relationships and new opportunities for exploring hobbies and vocations can all contribute to the experience of life being re-written in a positive way after brain injury.

For many, the development of positive personal characteristics following the injury are considered to be an achievement. This capacity for post-traumatic growth is hugely important for brain injury survivors and carers to help them with the process of adjusting to life after brain injury.

Support, understanding and messages of hope from peers can help to offer coping strategies and inspire resilience and strength for those impacted by brain injury. Through their powerful and moving testaments shared within this report, so many survivors and carers have shown that even though a life can be re-written, *there is still life after brain injury*.

And at Headway, we will continue to work tirelessly to raise awareness of, and help to improve life for those affected by brain injury.



**ACTION FOR
BRAIN INJURY
WEEK 2024**

A LIFE RE-WRITTEN

7. About Headway

Headway is the UK-wide charity that works to improve life after brain injury by providing vital support and information services, including:

- a freephone helpline (0808 800 2244, helpline@headway.org.uk);
- a comprehensive award-winning website containing information and factsheets on all aspects of brain injury (www.headway.org.uk);
- an award-winning range of publications designed to help people understand and cope with the effects of brain injury;
- an emergency fund to assist people dealing with the financial implications in the immediate aftermath of a brain injury;
- a Brain Injury Identity Card to help in everyday situations and if you come into contact with the criminal justice system;
- directory of approved residential homes, rehabilitation units and respite facilities specialising in ABI.

The charity also lobbies for better support and resources to be made available to people affected by brain injury and works to raise awareness of brain injury and the devastating effects it can have.

In addition to these services, a network of Headway groups and branches across the UK and Channel Islands provides a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care to survivors and families in their own communities.

8. References

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