

Headway – the brain injury association

Action for Brain Injury Week 2024: *A life re-written*

Short read summary

Introduction

For many people affected by brain injury, survivors and carers alike, life can change in an instant. The injury can throw plans into disarray, changes life goals, and even the sense of who we are. These events will often come out of nowhere and may spark a re-evaluation of life aims and objectives, requiring a recalibration of what is important to us. 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. We were overwhelmed with the response from the brain injury community, and have written this report to share the voices of those who contributed and are impacted by this often-hidden, life-changing disability.

This report is a short-read summary of the findings of our survey. For the long-read report, which includes quotes from brain injury survivors and carers along with additional information and statistics, visit our website at www.headway.org.uk/news-and-campaigns/campaigns/a-life-re-written.

We would like to thank all of the brain injury survivors, families, partners, friends 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 all professionals, who helped to circulate the survey to their service users, clients and patients. We would

like to extend particular thanks to the brain injury survivors and family, partners, friends and carers who granted permission 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.

Key statistics

- Our surveys were completed by 3,693 brain injury survivors and carers.
- 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.

Key messages

1. Brain injury as a life-changing experience

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.

2. Changed life goals

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 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.

3. Development of new skills

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.

4. *Relationships*

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.

5. *Social life*

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. *Employment*

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.

7. *Mental health*

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.

8. *Driving*

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.

9. Spirituality

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.

10. Personal achievements

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.

11. Adjusting to re-written life

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.

12. Message to others

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.

“Remember who you are. You are still you, you just have to sometimes go back to the start and re-build a better version of



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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."

For more information, visit 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.

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Headway – the brain injury association
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