

Action for Brain Injury Week 2024

A life re-written – for family, partners, friends, carers

This survey is being carried out by Headway – the brain injury association.

We are conducting this survey to find out how people feel their life stories have changed as a consequence of brain injury. Your responses will help us to campaign for greater awareness of the impact of brain injury.

Your responses will be kept confidential, although you will be given the opportunity to share your details at the end if you are interested in supporting us further with our campaign work.

This survey has been designed to be completed by family, partner, friends and carers of a brain injury survivor. Please complete this survey with your own personal experience of your life changes in mind, except where questions specifically ask about the brain injury survivor. A separate survey is available for completion by brain injury survivors.

Within this survey, we are referring to the person with the brain injury as 'survivor'.

Please note that this survey will take approximately 14 minutes to complete.

Please return all completed surveys to the following address no later than 26th February 2024.

Freepost RSGU–CSKS–CSJS
FAO Publications and Research Manager
Headway - the brain injury association
Bradbury House
190 Bagnall Road
Nottingham
NG6 8SF

Please tick the following two boxes before completing the survey:

I understand that this information is being used for Headway's campaign work to raise awareness of the impact of brain injury.

I understand that I have the right to withdraw my responses at any stage of this survey.

Section 1: About you

In this section we will ask you to tell us a bit about yourself.

1. What is your relationship to the survivor?

- Spouse/partner
 - Other relative
 - Friend
 - Professional carer
 - Other (please specify):
-

2. How old are you?

- Under 18 years old
- 18 – 24 years old
- 25 – 40 years old
- 41 – 60 years old
- 61 and above years old
- Prefer not to say

3. What is your gender?

- Male
- Female
- Non-binary
- Other
- Prefer not to say

4. Which country/region do you live in?

- Channel Islands
- East
- East Midlands
- London
- Northern Ireland
- North East
- North West
- Scotland
- South East
- South West
- Wales
- West Midlands
- Yorkshire
- Outside of the UK
- Prefer not to say

5. How long ago did the survivor sustain their brain injury?

- 0 – 6 months
- 6 – 12 months
- 1 – 2 years
- 2 – 5 years
- 5 – 10 years
- 10 – 20 years
- More than 20 years
- Prefer not to say

6. How long was the survivor unconscious/in a coma for?

- No loss of consciousness
- Less than 15 minutes
- 15 minutes – 6 hours
- 6 hours – 2 days
- More than 2 days
- Not sure
- Prefer not to say

7. What caused the survivor's injury? Please tick all that apply.

- Trauma (e.g. road traffic collision, assault, fall, sporting injury)
 - Stroke
 - Aneurysm
 - Haemorrhage
 - Brain tumour
 - Infection (e.g. encephalitis, meningitis)
 - Hypoxic/anoxic brain injury (i.e. lack of oxygen to the brain)
 - Hydrocephalus (i.e. excess fluid in the brain)
 - Prefer not to say
 - Other (please specify):
-

8. Which of the following physical effects of brain injury does the survivor regularly experience? Please tick all that apply.

- | | |
|--|--|
| <input type="checkbox"/> Balance and dizziness problems | <input type="checkbox"/> Epilepsy |
| <input type="checkbox"/> Headaches or migraines | <input type="checkbox"/> Fatigue |
| <input type="checkbox"/> One sided weakness or paralysis | <input type="checkbox"/> Hearing problems |
| <input type="checkbox"/> Hormonal imbalances | <input type="checkbox"/> Incontinence |
| <input type="checkbox"/> Loss of taste and/or smell | <input type="checkbox"/> Mobility problems |
| <input type="checkbox"/> Inability to recognise faces | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Sleep problems | <input type="checkbox"/> Swallowing problems |
| <input type="checkbox"/> Visual problems | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> Speech problems | |

9. Which of the following cognitive effects of brain injury does the survivor regularly experience? Please tick all that apply.

- Attention and concentration problems
- Communication problems
- Decision making difficulties
- Information processing difficulties
- Insight and awareness problems
- Memory problems
- Executive dysfunction
- None of the above

10. Which of the following emotional effects of brain injury does the survivor regularly experience? Please tick all that apply.

- Anger
- Anxiety
- Depression
- Emotional lability (rapidly changing or inappropriate emotions)
- Lack of confidence
- None of the above

11. Which of the following behavioural effects of brain injury does the survivor regularly experience? Please tick all that apply.

- Aggression
- Disinhibition
- Impulsivity
- Irritability or frustration
- Obsessive behaviour
- Social behaviour problems
- Use of inappropriate language
- None of the above

Section 2. Life changes

This section will ask you about changes in your life that have occurred as a consequence of the survivor's brain injury.

12. Do you feel that the survivor's brain injury has changed your life?

- Yes** – the survivor's injury has changed my life for the **better**
- Yes** – the survivor's injury has changed my life for the **worse**
- Yes** – the survivor's injury has changed my life for both the better and worse
- No** – the survivor's brain injury has not changed my life
- I am **not sure** if the survivor's brain injury has changed my life

Please tell us more:

13. Do you feel like you have the same amount of time to pursue your interests/hobbies since the survivor sustained their injury?

- Yes** – I have the same amount of time
- No** – I have **more** time
- No** – I have **less** time
- I am **not sure** if I have the same amount of time

Please tell us more:

14. Have you had to change your life goals because of the survivor's brain injury?

- Yes** – I have had to change my life goals
- No** – I have not had to change my life goals
- I am **not sure** if I have had to change my life goals

Please tell us more:

15. Have you set yourself new goals for the future since sustaining the survivor's brain injury?

- Yes** – I have set myself new goals
 No – I have not set myself new goals
 I am **not sure** if I have set myself new goals

Please tell us more:

16. Have you found ways to adapt to life after the survivor's brain injury?

- Yes** – I have found ways to adapt
 No – I have not found ways to adapt
 I am **not sure** if I have found ways to adapt

Please tell us more:

17. Have you developed new skills since the survivor sustained their brain injury?

- Yes** – I have developed new skills
 No – I have not developed new skills

I am **not sure** if I have developed new skills

Please tell us more:

Section 3: Aspects of life

This section will ask you about how different aspects of your life have been affected by the survivor's brain injury.

18. Do you feel that you have become more of a spiritual person since the survivor sustained their brain injury?

- Yes – much more** spiritual
 Yes – somewhat spiritual
 No
 Not sure/prefer not to say

Please tell us more:

19. Have your employment circumstances changed as a direct result of your caring duties for the survivor?

- Yes – I am no longer able to work, either now or in the future**

- Yes** – I am no **longer able to work, but hope to work in the future**
- Yes** – I am working in a **different job to the one held before the brain injury**
- Yes** – I am working in the **same job that I had before the brain injury but have had to change my role/hours**
- No**
- Not sure/prefer not to say
- Not applicable

Please tell us more:

20. How would you describe the state of your mental health since the survivor's brain injury?

- My mental health is **better** than it was before the brain injury
- My mental health is **worse** than it was before the brain injury
- My mental health is **the same** as it was before the brain injury
- Not sure/prefer not to say

Please tell us more:

21. Has your relationship with the survivor changed since they sustained their brain injury?

- Yes** – the relationship is **better**
- Yes** – the relationship is **worse or has broken down**
- Yes** – the relationship is **better in some ways and worse in others**
- No** – the relationship has not changed
- Not sure/prefer not to say
- Not applicable

Please tell us more:

22. Has your social life changed since the survivor sustained their brain injury?

- Yes** – my social life is **better**
- Yes** – my social life is **worse**
- Yes** – my social life is **better in some ways and worse in others**
- No** – my social life has not changed
- Not sure/prefer not to say
- Not applicable

Please tell us more:

Section 4: Open ended questions

This section will ask you open ended questions.

23. Please tell us about your greatest personal achievement since the survivor sustained their brain injury (i.e. what has made you proud of yourself?)

24. Please tell us about anything that has helped you to adjust to life after brain injury.

25. What message would you share with others about life after brain injury?

Section 5: Support from Headway

This section will ask you about the support you have received from Headway.

26. Have you previously been or are you currently being supported by Headway?

- Yes** – I have been supported **in the past**
- Yes** – I am **currently being supported**
- Yes** – I have been supported **in the past and currently supported**
- No** – I have not been supported by Headway
- Not sure/prefer not to say

27. Which of the following Headway services have helped you to adjust to life after brain injury? Please tick all that apply.

- Helpline
- Website information
- Social media pages
- Publications (booklets and factsheets)
- Emergency Fund
- Brain Injury Identity Card
- Your local Headway group/branch
- Training
- Approved Provider Scheme
- Headway HealthUnlocked community forum
- Headway's Justice Project
- I'm Calling About Chris* website

28. Are you connected to a local Headway group/branch?

- Yes
- No
- Not sure/prefer not to say

29. Which of the following benefits do you feel you gain from being connected to your local Headway group/branch?

- Peer support
- Regaining skills
- Improved confidence
- Improved well-being
- Feeling a sense of purpose
- Feeling connected
- Supporting others affected by brain injury
- Not applicable

Section 6: Consent

This section will ask you to share your details if you are happy to be contacted to further support our campaign work.

30. Would you like to be contacted by Headway to further support campaign work/external research in this area? Please tick all that apply.

- Yes** – I would like to be contacted by Headway to further support **campaign work** in this area
- Yes** – I would like to be contacted by Headway to further support **external research** in this area
- No** – I would not like to be contacted by Headway to further support campaign work/external research in this area

31. If you have answered 'yes' to the previous question, please share your contact details here. Please include your full name and the best contact to reach you on (i.e. your email address and mobile number).

Thank you for completing this survey.

We are very grateful for your time, and your responses will help to inform important campaign work in this area.

If you would like to receive the results of this survey when available, please subscribe to our mailing list. We will also publish the results on our website during Action for Brain Injury Week 2024.

If you have any queries or concerns about the way your data will be used or handled, or you wish to withdraw your responses, please contact publications@headway.org.uk. For any other queries regarding our campaign, please contact communicationsteam@headway.org.uk.

Our helpline is available to offer emotional support and a listening ear if you feel you need to talk to someone following completion of our survey. They are available on 0808 800 2244 or helpline@headway.org.uk.

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