

Action for Brain Injury Week 2024

A life re-written – for brain injury survivors

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.

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. 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

2. What is your gender?

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

3. 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

4. How long ago did you sustain your 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

5. How long were you 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

6. What caused your brain 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):
-

7. Which of the following physical effects of brain injury do you 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 | | |

8. Which of the following cognitive effects of brain injury do you 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

9. Which of the following emotional effects of brain injury do you regularly experience? Please tick all that apply.

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

10. Which of the following behavioural effects of brain injury do you 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 your brain injury.

11. Do you feel that your brain injury has changed your life?

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

Please tell us more:

12. Have you tried new activities since your brain injury that you had not considered before your injury?

- Yes** – I have tried new activities
- No** – I have not tried new activities
- I am **not sure** if I have tried new activities.

Please tell us more:

13. Have you had to change your life goals because of your 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:

14. Have you set yourself new goals for the future since sustaining your 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:

15. Have you found ways to adapt to life after 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:

16. Have you developed new skills since sustaining your 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:

17. Has your level of independence changed since sustaining your brain injury?

- Yes** – I am **less independent** and rely more on others
- Yes** – I am **more independent**
- No** – my independence has not changed
- I am **not sure** if my independence has changed

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 brain injury.

18. Do you feel that you have become more of a spiritual person since sustaining your 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 brain injury?

- 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 my brain injury**
- Yes – I am working in the same job that I had before my 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 your brain injury?

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

Please tell us more:

21. Have you had to stop driving since sustaining your brain injury?

- Yes** – because my **license has been revoked**
- Yes** – because I have **personally chosen to stop driving**
- Yes** – while I am **waiting for a decision from my GP/licensing body**
- No** – I am still driving
- Not sure/prefer not to say
- Not applicable

Please tell us more:

22. Has a relationship with a partner/spouse changed since sustaining your 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:

23. Has your social life changed since sustaining your 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:

24. Do you need support with completing activities of daily living (washing, dressing, cooking etc) since your brain injury?

- Yes** – I need **a lot** of support
- Yes** – I need **some** support
- No** – I do not need support
- Not sure/prefer not to say

Please tell us more:

Section 4: Open ended questions

This section will ask you open ended questions. Please feel free to use additional sheets of paper (clearly labelled) if you need more space to write your answer.

25. Please tell us about your greatest personal achievement since sustaining your brain injury (i.e. what has made you proud of yourself?)

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

27. 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.

28. 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

29. 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

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

- Yes
 No
 Not sure/prefer not to say

31. 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.

32. 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

33. 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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