

Identity after brain injury



This publication is part of Headway's *Effects of brain injury* series. To browse through our publications on a range of issues relating to brain injury and download these free-of-charge, visit www.headway.org.uk/information-library.

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Introduction

Sustaining a brain injury can be a life-changing and often devastating experience. Whether it is through an unexpected diagnosis, or a sudden illness or injury,

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many people feel like their lives have drastically changed in many ways after brain injury.

The long-term effects and impact of the injury can often make people feel like they are a 'new person'. This unfamiliar identity can be a very confusing and difficult thing to adjust to, both for the person themselves and others around them.

This publication has been written to explain what identity is, how it can be affected by brain injury and how to cope. Identity change in both brain injury survivors and partners/relatives is discussed.

The information in this publication does not replace clinical guidance.

What is identity?

Identity is **what makes you who you are**. It is your 'sense of self'. It means different things to different people, depending on what is most important to them about themselves. Our identities allow us to figure out where we fit in the world and what we want to work towards.

Identity can be made up of various things, such as...

- physical appearance
- personality
- role within a family and friendship network
- goals for the future
- culture or religion
- hobbies and skills
- sexual orientation
- ... among many others.

Personal memories and values can also shape how we identify ourselves.

***Take a moment to reflect on how you identify yourself.
What aspects of your identity are most important to you?***

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It is normal for our identity to change over time. Our sense of who we are today is probably very different to when we were children! It is also normal for identity to change following regular life changes such as taking on a new job or gaining new skills. These sorts of changes can often feel comfortable for us to adjust our identities to because they are within our control.

How can identity change after brain injury?

Unexpected life events such as sustaining a brain injury can cause some parts of a person's identity to change beyond their control.

Sense of identity can also change at different points of a brain injury survivor's journey, for example it might be different when they are in hospital, compared to when they are back at home, or 10 years on from the injury.

Some parts of identity, such as culture, values or religious/political beliefs might remain the same after brain injury. But the effects of brain injury might make it more difficult to stay involved in these things in the same way. For example, mobility problems might affect someone's ability to attend faith meetings, or memory problems might affect someone's ability to remember key dates for elections.

Identity change after brain injury might therefore be a mix of some things staying the same, some things changing a lot, and some things needing a bit of adjustment in order to find new ways to manage.

Interpretation of identity change

As mentioned in the previous section *What is identity?*, identity can mean different things to different people. Brain injury survivors will therefore interpret 'identity change' differently to one another, depending on what 'identity' personally means to them.

For example... *two brain injury survivors are unable to return to work following their injuries. One survivor feels they are no longer the breadwinner of the family and struggles with accepting this, as it was an important part of their identity. The other survivor does not feel this was important to their sense of self, and is more*

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concerned about no longer being confident enough to socialise with friends. In both cases there has been a change in employment status, but the survivors have different attitudes based on what is most important to their identity.

For some, a brain injury might not have changed their sense of identity at all, if their sense of identity relates to things that have remained the same since their injury, such as their values, culture, etc.

Effects of brain injury

There are many possible effects of brain injury. Our publication [The effects of brain injury](#) gives an overview of some of the most common effects, while other publications at www.headway.org.uk/information-library cover many of these in detail.

Living with the effects of brain injury can cause many changes, that can in turn affect someone's sense of identity. Some examples of how the effects of brain injury can change identity are given below...

Fatigue might make someone feel like a different person if they were used to be being busy and active before their injury but now struggle with outings.

Memory problems may cause someone to lose core memories that affect how they identify themselves, based on the life they had before their injury.

Someone might feel that they are no longer the 'decision maker' of their friendship group due to **executive dysfunction**, or no longer the 'funny one' because they cannot process information quickly enough to make jokes.

Take a moment to reflect on the effects of brain injury that impact you the most. Have they changed your identity?

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Changes in physical appearance

Our physical appearance can be a core aspect of our identity, for example how we dress, our physique, how we do our makeup or style our hair, how we carry ourselves and how we look.

Physical changes after brain injury such as limb weakness or loss of function, mobility issues, ataxia or sensory impairment might mean survivors have to use mobility aids and equipment, such as a wheelchair or special glasses. Using such aids can make it easier for others to recognise that the survivor has a disability, but can be difficult for the survivor to accept as part of their new self-image.

Some types of brain injury can cause physical changes, such as a stroke causing facial weakness, or weight gained cause by hormonal changes.

A survivor might also have difficulties with aspects of self-care such as washing, dressing, applying makeup or exercising, which can contribute to changes in physical appearance.

Changes in activities

Activities that a survivor enjoyed before their injury might no longer be safe or comfortable for them to do. This may change a survivor's sense of identity if they were previously part of a club, team, or even simply enjoyed partaking in an activity, for example considering oneself 'a painter', 'a footballer', 'a gardener', etc.

Changes in employment status

Someone's work status or role might form part of their identity, especially if it is a role they have spent considerable time training or studying for. If someone has been accustomed to working and suddenly finds they cannot work anymore (which is unfortunately very common after brain injury), this can affect their sense of identity.

Being unable to work can also change a survivor's financial independence or their financial status within the family (i.e. being a 'breadwinner' in the family).

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Changes within family or friendship network

Within our family network we can identify ourselves as someone's partner, spouse, child, sibling, niece, nephew, among other relationships. While these relationships do not change after brain injury, someone's feelings towards their role as parent/sibling/partner, etc, might change. Some examples of this are given below...

*A brain injured **parent** might find it difficult to help their child with their homework, which may affect how they view themselves as a helpful and involved parent.*

*A brain injured **partner or spouse** might no longer feel like an adequate romantic or sexual partner if they struggle with sexual dysfunction.*

*A brain injured **colleague** might not be able to contribute to group projects as they cannot meet deadlines and might therefore feel like they aren't a helpful member of their team.*

*A brain injury survivor might not feel like the 'fun **friend**' of their social group any more as they no longer drink alcohol and do not like to stay out late due to fatigue.*

Headway's series of relationships publications cover these in more detail, available at www.headway.org.uk/information-library.

Changes in aspirations

Aspirations are goals that we want to achieve in the future. Brain injury survivors may have had aspirations before their injury that they no longer feel they can achieve in the same way, and this might affect their sense of identity. Some examples of this are...

*A brain injury survivor who enjoyed **travelling** before their injury and aspired to visit every continent in the world may no longer feel they have the organisational skills to travel after their injury.*

*A brain injury survivor part way through completing their medical degree may no longer feel like they can achieve **becoming a doctor** due to their cognitive effects interfering with studying.*

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*A brain injury survivor who always dreamed of **opening their own business** might no longer feel like they have the skills to set this up due to executive dysfunction.*

Undergoing rehabilitation or therapy

Going through rehabilitation or therapy after brain injury is a very important step in the recovery journey, but it can cause a brain injury survivor to reflect on their identity, especially when there is a continued focus on functional impairment and how to improve this.

Rehabilitation will often be undertaken in the first few weeks or months of injury. It is important to remember that these are early days, and things can and do improve for many people over time. Sense of identity is likely to change from the time of being in rehabilitation or therapy to when the brain injury survivor returns home.

Feelings about identity change after brain injury

The sorts of changes described in the previous section might cause brain injury survivors or their partners/relatives to say or think things like...

“I don’t feel like myself anymore.”

“I feel like a new person.”

“When will I go back to how I was?”

“I miss the old me.”

There is no right or wrong way to feel about brain injury! People feel very differently about their experiences with brain injury. Many people feel sadness, but positive feelings can be experienced too. In fact, some people report preferring their ‘new self’ over time, or preferring the new life they have after brain injury once they have had a chance to adjust. More information on positive change after brain injury is available in our publication [Post-traumatic growth after brain injury](#).

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Sometimes people feel their identity has been completely lost. Getting stuck with this feeling can make it hard to move on. Over time however, people might realise that very important parts of their identity, such as their beliefs and values, are still there. Some people find new ways to be their 'old self'. This can feel very rewarding, for example finding new ways to help others or make a meaningful contribution to society.

Grief and 'loss' of self

People commonly feel a sense of grief over the loss of their 'old self'. We often associate the word 'grief' with the death of someone close to us, but grief can be felt over the loss of anything special to us, including our own selves.

It is important to consider that while it may feel like some aspects of your self are 'lost', there will be other important aspects that have not been lost and are still very much a part of you.

Identity change after brain injury can make people feel disconnected with their 'old self', but there is also potential for reconnecting with important aspects of oneself and rediscovering one's place in the world - even if this is a new place!

An example of this is...

A brain injury survivor is unable to return to work following their injury. Before their injury, they enjoyed being a hard worker, as it made them feel like they were contributing to society. After their injury, they decide to volunteer for a cause they have always cared about. Over time, they recognise that they are contributing to society again and feel a sense of re-connection with their 'old self', in a new way.

A changed sense of identity does not just impact on how a survivor feels about themselves. It can affect how the survivor interacts with the world around them, and affect social skills such as confidence.

How does the change in identity make you feel? Consider writing your feelings down or sharing them with someone you trust. Remember that you can call or email our confidential nurse-led helpline to talk your feelings through.

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Lack of awareness of identity change after brain injury

Some brain injury survivors may be unable to recognise the changes they go through after brain injury. It might be family, friends and others in the survivor's life that notice the changes. They might comment that the survivor is like a 'different person'.

It is a normal part of the psychology of identity/'the self' that it tries to protect itself. The changes after a brain injury can be huge, and it might simply be too emotionally overwhelming for our 'identity' to process, adapt or accept the changes.

Sometimes, when a brain injury survivor appears to 'lack insight' into the changes, a part of this might be them trying to hold onto a sense of continuity in their identity. They might therefore deny, downplay or ignore the changes pointed out by others. The survivor might also feel that others 'lack insight' into their own personal experience. This can lead to arguments and disagreements in families and services.

Cognitive effects of brain injury can affect some survivors' awareness of their changes. This can be challenging, or even dangerous if causes a survivor to be at risk of harm. It is important to be sensitive to identity change as well as cognitive factors when thinking about changes in self-awareness or 'lack of insight'.

In such cases, it can be helpful and sometimes necessary to get input and support from an appropriate professional. More information on this topic is available in our publication [Lack of insight after brain injury](#).

Changes in identity in partners/relatives

Partners, spouses and other relatives often take on caring roles following a brain injury. They might become responsible for managing the survivor's personal care, such as helping with washing and dressing, or helping to organise the survivor's day. These changes can make some people feel their roles have become blurred between being a 'partner', 'spouse', 'parent'; etc and a 'carer'.

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Another way in which partners/relatives can feel a changed sense of identity is if they have to give up working or reduce their working hours to manage the survivor's care. Employment status/roles can be a big part of our identity, and changes in this can be difficult for anyone to adjust to.

A brain injury can also cause partners/relatives to suddenly find themselves responsible for things they weren't previously responsible for, such as house chores, driving, helping children with homework, managing bills etc. These changed responsibilities can also contribute to identity change.

Tips for coping with identity change after brain injury

Identity change is a difficult thing to experience when it is beyond our own control. The process of coping with this change will take time, patience and kindness to yourself. For many, there comes a point when they stop trying to get their old identity back, and begin to reconstruct their new identity.

There is life after brain injury, even if it is a new one!

Here are some tips to help you to cope with this change...

The information in this section offers general tips and should never replace clinical guidance or therapy that you may be undergoing without first consulting your therapist.

Getting support from others

- Talk to your **friends and family** about how you are feeling. This can help them to understand how they can best support you, and might also help you to identify ways that you can help yourself.
- Get support **from a professional who specialises in brain injury**, such as a clinical neuropsychologist or a counsellor with experience in brain injury. Talking therapies can help with understanding your feelings, or assessments can be used to identify areas of difficulty that might be contributing to your identity change.

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Speak to your **GP** about getting a referral to a brain injury specialist, or contact our helpline for guidance on finding therapists in private practice. The helpline can also be a listening ear if you want to talk to someone about your feelings or experiences, or if you need any other information about life after brain injury.

- Remember that you can also talk to your GP if you feel that you would benefit from **rehabilitation**. Even if you have already undergone rehabilitation, or were discharged home without any, you can speak to your GP about providing a referral if you think it will be beneficial.
- Explore getting input from **external agencies** for aspects of life that are important for you. For example, if your physical appearance is changed and important to you, consider getting input from hairdressers/barbers and beauticians. Alternatively, there might be disability equipment that can help you with managing aspects of self-care such as dressing yourself or applying makeup. Or if you are a 'house proud' person but can no longer clean the house yourself, consider employing a cleaner, or a gardener to help with keeping things tidy. An occupational therapist might be able to help you with identifying ways you can get support for these aspects of life.
- Help your **friends and others in your life** to understand your brain injury so that they do not misinterpret situations. For example, if you used to have 'a good memory' and now no longer remember birthdays or events planned with friends, let them know about this so that they do not think you are being intentionally neglectful.
- Be honest with your **employer and colleagues** about any effects of brain injury that are affecting your ability to do your job. Your employer has a legal responsibility to discuss ways in which reasonable adjustments can be made to help you within the workplace. More guidance on this is available in our publication [*Returning to work after brain injury*](#).

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- Connect and share your feelings with **others affected by brain injury**, for instance through your local Headway charity/branch or our online communities – for more information on these, visit www.headway.org.uk/supporting-you or contact our helpline. Connecting with others that have a real understanding about brain injury can help with feeling ‘safe to explore’ life again and reconnecting with yourself.

Things to do

- **Understanding the effects of your injury and how to cope with them** is a good starting point, as it might help you to overcome difficulties you are having that are contributing to your change in identity. Visit our website to learn more about brain injury at www.headway.org.uk.
- **Find activities to keep you busy.** You could pick up a skill or hobby you enjoyed before your injury or learn something new. In fact, sometimes experimenting with new activities and opportunities without much of a plan or goal can help people to find themselves again. You could also consider volunteering – more guidance on this is available in our publication [Volunteering after brain injury](#).
- **Identify your values** – what is most important to you in life, and how can you continue to live by your values after brain injury to help with giving your life meaning? Our publication [Post-traumatic growth after brain injury](#) gives more information on a technique called values-based living that can help with this process.
- Use creative ways to **express how you feel**, such as art, music, dance or writing. (Remember that you can share these with us for possible feature on our website!)
- Find **new ways to do things** that were important to your identity before your brain injury – for example, if you enjoyed taking your children to the park on a Saturday morning but can no longer do this, consider finding a different

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activity that you can enjoy together so that you are still getting this quality time and feeling fulfilled in your role as a parent.

Keeping things in perspective

- Many survivors struggle with their changed identity because they feel like they have lost something. While this is perfectly normal, try to also **reflect on whether you have gained anything**, or whether there are important aspects of your life that have remained the same. Our publication [*Post-traumatic growth after brain injury*](#) can give some guidance on this.
- Remember that **no one's identity stays the same forever** – it is constantly changing over time depending on life circumstances, maturity, etc. This might help to keep things in perspective.
- Reflect on whether you want to acknowledge **the anniversary of your brain injury**. Some brain injury survivors say that they acknowledge this and treat it like another birthday, which can help them with the process of accepting their 'new' identity.
- **Think about your goals** and aspects of your identity that were important to you before your injury – is there any way you can continue to work on and fulfil these, with support or adaptations?

If it is more realistic to set new goals, think about what is important to you and what you want to achieve. For instance, do you want to undertake a college or university course, travel, publish a book or join a sports team? There are plenty of schemes and services to support people with disabilities with undertaking a range of activities and achieving goals, so it might be worth doing a bit of research first to explore your options.

- Remember that while things can be difficult in the early stages of injury, **things can and do improve for many people**. You might struggle with your identity in the early days, but over time you might discover new strengths.

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- Remember that being a 'brain injury survivor' is **only one aspect** of who you are as a person – do not forget about all of the other important aspects of your identity!
- In some ways, our sense of identity might be rooted in what we feel we 'should' be doing based on societal expectations. Remind yourself that there is **no set standard** for what you 'should' be doing in life, and everyone's circumstances are unique. You should also avoid comparing yourself to other brain injury survivors, as no two experiences are the same.

Acknowledgements

Thank you to the brain injury survivors, family members and carers who kindly contributed to this publication by sharing their experiences of identity change after brain injury.

Many thanks as well to Consultant Clinical Neuropsychologists Dr Fergus Gracey and Dr Peter Fleming for their very helpful comments and contributions to the development of this resource.

As a charity, we rely on donations from people like you to continue being able to provide free information to those affected by brain injury. To donate, or find out how else you can get involved with supporting our work, visit www.headway.org.uk/get-involved.

If you would like to leave feedback for this publication, please consider completing our short survey at www.surveymonkey.co.uk/r/hwpublications or contact us at publications@headway.org.uk.

First published 2023. Last reviewed 2024. Next review 2026.

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