

# From Awareness to Action



the brain injury association

**Demanding better care for people affected by brain injury**



**Headway - the brain injury association Manifesto 2024**



# About brain injury and Headway – the brain injury association

An acquired brain injury (ABI) can strike anyone at any moment, instantly altering the course of life. An ABI is an injury sustained to the brain after birth that can profoundly impact vital functions like walking, talking, thinking, and feeling, often resulting in severe and permanent losses. It can mean saying goodbye to both the life you once knew and the person you once were.

Injuries to the brain can have various causes such as trauma, e.g. falls, assaults or road accidents, in addition to stroke, tumours, infections, or illnesses.

Countless survivors grapple with lifelong consequences, with approximately 2.6 million people in the UK alone affected by traumatic brain injury (TBI) and stroke-related disabilities – excluding those with other forms of ABI.

The physical ramifications of brain injury are vast and varied, encompassing mobility challenges, coordination issues, limb stiffness or weakness, hemiplegia, ataxia, sensory impairments, fatigue, speech difficulties, and epilepsy.

Moreover, many survivors contend with debilitating hidden effects – cognitive, psychological, emotional, and behavioural difficulties – leading to issues like lack of insight, impulsive behaviour, risk of misunderstanding, communication struggles, and social isolation. These hidden effects often fluctuate and are widely misunderstood.

A recent report from Economist Impact examined the economic impact of neurological disorders in the UK. The report found that **traumatic brain injury had a higher economic burden than any other neurological condition**, at £25.4bn, representing 1.13% of the UK Gross Domestic Product (GDP). The economic burden of stroke was 0.8% of GDP. Combined, the economic burden of just these two forms of brain injury represents nearly 2% of the UK GDP. There are many other forms of acquired brain injury not counted here, which will also carry an economic burden.

And we know that this economic burden will grow. The number of people living with neurological conditions such as stroke will increase with an ageing population, and the number of people surviving brain injuries is increasing.

In both human and economic terms, the need to both prevent brain injury and support those living with its effects, through high-quality, ongoing rehabilitation, has never been so urgent.

Headway is dedicated to supporting individuals across the UK as they navigate life after brain injury, offering crucial support and information services via our award-winning website and library of brain injury publications.

Our initiatives include an Emergency Fund that allows loved ones to stay by the bedside during critical care following an injury. Headway operates a free, confidential nurse-led helpline staffed by a knowledgeable team who truly understand ABI. Additionally, our innovative Brain Injury Identity Cards assist survivors in communicating the effects of their injury to ensure they receive appropriate compassion and support in society.

Headway actively advocates to increase understanding and awareness of ABI through lobbying and campaigning efforts. Headway also fosters and develops a network of volunteer-led branches which provide social engagement and support to survivors and their loved ones.

Furthermore, Headway proudly supports a network of volunteer-led branches and independent local Headway charities, which offer comprehensive rehabilitation and reablement services. These services empower individuals to regain lost skills and adapt to their new lives post-brain injury.

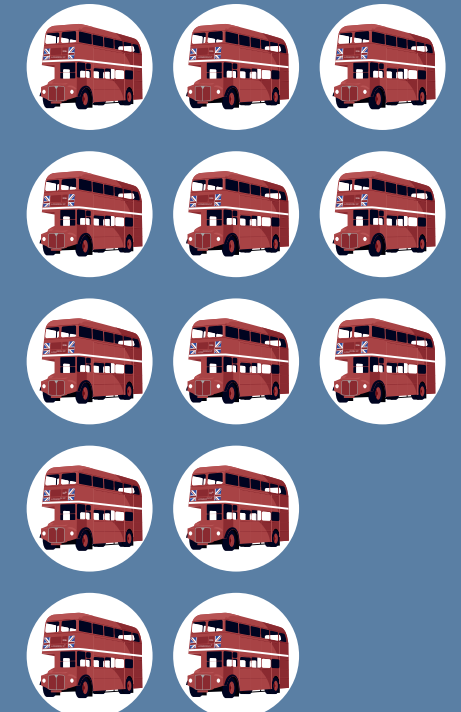
## Over the course of the next parliament around 1.8 million people will be admitted to hospital with an acquired brain injury.

**Urgent government action is needed to improve the lives of those currently affected by brain injuries, as well as those who will be affected in the future.**



**Every 90 seconds** someone is admitted to hospital with an acquired brain injury.

That's enough to fill 13 double decker buses every day.



**Every 90 seconds**

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# Headway's **FIVE ASKS** of government

Headway is calling on the next government to deliver meaningful change. We want the government to **understand** brain injury, to **prioritise** brain injury, and to **invest** in services to support brain injury survivors and their loved ones.

## ASK 1



### FAIR ACCESS

**end the neurorehabilitation  
postcode lottery**

Every brain injury survivor should have access to specialist neurorehabilitation services that will provide them with the best possible chance of living a fulfilling life after their injury. We know, however, that the chance of accessing services like this depends on where you live in the UK.

## ASK 2

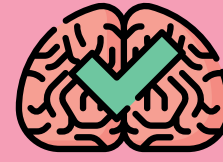


### COMMUNITY SUPPORT

**invest in local brain injury  
reablement services**

No two brain injuries are alike. While some individuals may recover well and regain independence, others face severe and lasting effects that require lifelong support. This ongoing need for support is where the network of Headway charities steps in, offering crucial and compassionate care to those affected by brain injury throughout their lives. However, some of these services are now at risk of closure.

## ASK 3

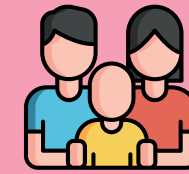


### INCREASE UNDERSTANDING

**raise awareness of  
brain injury**

Brain injury can happen to anyone at any time and, given its widespread impact, we must increase awareness of its profound effects, and encourage more understanding and compassion for survivors from society as well as from government. A brain injury can significantly disrupt every aspect of a survivor's life. Simple daily activities like using public transport, going shopping, or getting a haircut can become challenging or inaccessible for brain injury survivors. Importantly, many of these difficulties experienced by survivors in navigating daily life remain hidden or overlooked.

## ASK 4



### FAMILY CARE

**enhance support  
for brain injury survivors**

Brain injury affects the whole family. Enhanced support for caregivers is crucial. An holistic approach addressing the needs of both the family and the survivor leads to better outcomes for all.

## ASK 5



### REFORM SOCIAL CARE

**make social care equitable  
and sustainable**

Despite repeated government promises of reform, the social care system continues to fail brain injury survivors. The current system is underfunded, understaffed and undervalued. Good social care is essential to supporting brain injury survivors to maintain as much independence, choice, and control over their lives as possible. It is imperative that survivors are supported to live their lives by care professionals with specific understanding of brain injury.

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# ASK **Fair access:** end the neurorehabilitation postcode lottery

1

Every brain injury survivor should have access to specialist neurorehabilitation services that will provide them with the best possible chance of living a fulfilling life after their injury. We know, however, that the chance of accessing services like this depends on where you live in the UK.



## Background

The latest national clinical audit of neurorehabilitation services in 2019 revealed a stark reality: out of 1,381 individuals assessed in Major Trauma Centres needing specialist rehabilitation, only 40% actually received it. This glaring disparity is unacceptable, and the postcode lottery must come to an end.

The aim of post-acute neurorehabilitation is to provide timely and focused intervention to help brain injury survivors regain their independence. Effective neurorehabilitation can lead to shorter hospital stays, decreased reliance on expensive long-term care and, in some cases, facilitate a return to work.

**Importantly, neurorehabilitation is among the most cost-effective treatments offered by the NHS, making it a valuable investment in both patient outcomes and healthcare resources.**

Specialist neurorehabilitation is exceptionally cost-effective, offering potential savings of up to £1.13 million per individual who undergoes neurorehabilitation within a year of sustaining a brain injury, demonstrating significant cost benefits, including for individuals with severe disabilities.

## Recommendations

We want **everyone who sustains a brain injury** to have access to rehabilitation services that are delivered by specialists with expertise in ABI; are community-based; and are not time-limited. We are calling on the government to:

- Increase the number of neurorehabilitation professionals, in particular neuropsychologists.
- Ensure that commissioning of specialist neurorehabilitation services – acute, post-acute and community-based – is sufficient and consistent across the UK.
- Improve collaborative working between NHS, local authorities and VCSE organisations to ensure funding for in-patient and community neurorehabilitation and support services is sufficient and the transition between services for neurorehabilitation is seamless.
- Ensure there is a named neurorehabilitation lead in every health authority across the UK.

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# ASK

## 2

# Community support: invest in local brain injury reablement services

No two brain injuries are alike. While some individuals may recover well and regain independence, others face severe and lasting effects that require lifelong support. This ongoing need for support is where the network of Headway charities steps in, offering crucial and compassionate care to those affected by brain injury throughout their lives. However, some of these services are now at risk of closure.



## Background

The Headway network operates in communities throughout the UK, offering a range of fundamental rehabilitation and support services for brain injury survivors and caregivers. These services encompass brain injury rehabilitation programs, caregiver support, social reintegration initiatives, vocational rehabilitation, community outreach efforts, and respite care. Each charity offers services tailored to meet the needs of local people, so provision differs across the UK.

**These local Headway charities providing specialist community-based rehabilitation and reablement services are described as lifelines by those who benefit from them.**

However, these vital services are now at risk due to the escalating cost-of-living crisis, dwindling local authority funding, and decreased public donations. Many of our groups nationwide are being

forced to scale back services or are in danger of closure.

Being in a supportive environment where others share similar experiences and truly understand the impact of brain injury can significantly aid in recovery. Peer support is a cornerstone of what Headway offers. Research shows that participating in peer support groups after a brain injury is immensely beneficial. It fosters connections, meaningful interactions, and the exchange of support among individuals facing comparable challenges.

Moreover, peer support has been shown to positively influence activity and participation levels post-injury. It also helps combat loneliness by expanding social networks. However, it's important to combine this support with neuropsychological and psychological interventions for comprehensive care.

The potential closure of specialist charities like Headway could have significant implications for local public services. Our recent cost-of-living survey revealed that up to 70% of our service users might require more expensive

state-funded support if these vital services were no longer available.

Early and effective interventions after a brain injury are crucial for improving rehabilitation outcomes and recovery prospects. Community-based support services, including assistance for families and caregivers, play a key role in keeping brain-injured families together. Without these services, we could see an increase in family breakdowns and local authorities burdened with the cost of expensive residential care for survivors.

While we acknowledge the government's commitment to partnering with community-based rehabilitation organisations through its commitment to producing an Acquired Brain Injury Strategy, there is concern that some of these crucial groups may close before the strategy is published. These organisations will be essential partners in implementing the government's strategy once it is finalised, highlighting the urgent need to protect and support them now.

## Recommendations

Brain injury survivors should be able to transition seamlessly from acute to post-acute services, including those delivered by community-based services commissioned by local authorities. We are calling on the government to:

- Without delay, provide urgent financial support for local community-based rehabilitation and reablement services.
- Acknowledge the effectiveness of early interventions in rehabilitation and commit to securing long-term and consistent funding for these essential services nationwide.
- Provide a clear clinical and care pathway which includes ongoing rehabilitation for all brain injury survivors who need it.

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# ASK **Increase understanding:** raising awareness of brain injury

3

Brain injury can happen to anyone at any time and, given its widespread impact, we must increase awareness of its profound effects and encourage more understanding and compassion for survivors from society as well as from government. A brain injury can significantly disrupt every aspect of a survivor's life. Simple daily activities like using public transport, going shopping, or getting a haircut can become challenging or inaccessible for brain injury survivors. Importantly, many of these difficulties experienced by survivors in navigating daily life remain hidden or overlooked.



## Background

To gain a comprehensive understanding of the magnitude of this hidden epidemic, it is imperative that the government takes further action to collect statistics that accurately ascertain the numbers of those impacted by brain injury.

With reliable and extensive data, policymakers can allocate resources more effectively, implement targeted interventions and improve support services for those affected.

Understanding the scale of the problem is the first step towards addressing it comprehensively and minimising its impact on individuals and society as whole.

Research by Headway reveals that over three-quarters of brain injury survivors encounter daily challenges due to the hidden nature of their injury. Furthermore, 9 out of 10 individuals affected by brain

injury cite societal misunderstanding as a major obstacle to navigating life with a hidden disability.

Moreover, certain groups within society, such as victims of domestic abuse, individuals in the criminal justice system, homeless individuals, veterans, and participants in certain sports, are more prone to sustaining brain injuries that often go undetected. Enhancing awareness and identification of brain injury within these communities is vital to connecting survivors with the necessary support.

At Headway, we recognise the difficulties many brain injury survivors face in explaining their condition to others. That's why we developed the Brain Injury Identity Card, which aids the police and others working in the criminal justice service to quickly identify brain injury survivors and provide appropriate assistance and support. This card also boosts survivors' confidence in everyday social interactions.

Our initiative has already had a positive impact on numerous survivors. These cards are recognised by the Department for Work and Pensions (DWP), assisting survivors in navigating the complex benefits system and, for those able to, in their journey back to work post-injury.

The world of sports is undergoing a heightened awareness of the consequences of head injuries. Recent incidents have sparked greater attention to concussion awareness and management, yet there persists a culture in sports to persevere despite injury.

While Headway understands the benefits and encourages sports participation, there is a pressing need to increase awareness about the dangers of brain injury in sport as well as changing attitudes and culture, ensuring that appropriate assessment and return to play protocols are followed.

## Recommendations

We are calling on the government to:

- Compile precise statistics from all government departments to gain a comprehensive understanding of the widespread prevalence of brain injuries.
- Launch a public awareness campaign to educate the public about the impacts of brain injury, aiming to reduce stigma and enhance support for survivors.
- Recognise and promote Headway's Brain Injury Identity Card across all government departments and agencies to facilitate proper identification and support for brain injury survivors.
- Ensure that frontline public service staff interacting with ABI survivors receive specialised training on understanding brain injury and are equipped to utilise brain injury screening processes. This includes staff in social care, homelessness services, veterans' support, domestic abuse survivor services, and the criminal justice system.
- Promote awareness and understanding of ABI in non-government organisations where staff may encounter ABI survivors such as those working with homeless individuals, domestic abuse survivors, veterans, and offenders.
- Introduce mandatory training in concussion awareness throughout sport at all levels alongside or as part of safeguarding training to enhance awareness and safety measures in relation to head injuries in sport.

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# ASK **Family care:** enhance support for brain injury survivors' loved ones

4

Brain injury affects the whole family. Enhanced support for caregivers is crucial. An holistic approach addressing the needs of both the family and the survivor leads to better outcomes for all.



## Background

At Headway, we recognise that families who receive appropriate support to understand and manage the effects of brain injury are more likely to stay together in the long term. Preventing family breakdown is crucial for the well-being of all family members and can lead to significant long-term savings in public resources.

Involving families in the patient's rehabilitation from the acute phase and providing them with personalised, high-quality information throughout the care pathway is essential. Brain injury can lead to personality changes, difficulties with anger and emotion regulation, lack of empathy, and apathy, all of which can strain family relationships, particularly for the survivor's partner.

For many families, the cost and time involved in travelling long distances to specialist neurorehabilitation settings makes visiting prohibitive and sometimes impossible.

Headway understands this and provides grants to families in the immediate aftermath of brain injury.

Since its launch in 2011, our Emergency Fund has provided almost £650,000 to thousands of families to help them cope with the sudden practical implications of brain injury.

During the post-acute phase, carers of individuals with brain injury often struggle to obtain sufficient support from local authorities. This lack of support can lead to long-term mental and physical health issues for the carers and contribute to family breakdown. In some cases, this can result in brain injury survivors needing care in specialised facilities funded by the state.

Many carers of brain injury survivors are forced to leave their careers to take on full-time caregiving responsibilities, often without adequate support or understanding from statutory services. There is an urgent need for greater support to address these challenges and

prevent further strain on families and public resources.

Headway's recent survey demonstrated the impact of brain injury on those who care for survivors:

- **95% of carers feel that the brain injury has changed their life, with half feeling that brain injury has changed their life for the worse (50%).**
- **Almost 70% of carers (68%) report that their mental health is worse after brain injury, with anxiety and depression being highly reported.**
- **Almost a quarter of carers (24%) are unable to work following the injury, with 18% being unable to work either now or in the future. 30% have returned to work but have had to either take on a new job/role or change their hours due to the impact of the injury.**

- **70% of carers have less time to pursue their interests/hobbies since the injury.**
- **67% of carers have had to change their life goals because of the injury. Only 31% have set themselves new goals since the injury.**
- **Just over half (52%) of carers experience a worsened social life after brain injury.**

These figures demonstrate the need for improved support and awareness for carers of individuals with brain injury, including better access to assessments, mental health services, and financial assistance. Addressing these challenges is essential to safeguarding the well-being of carers and enhancing the overall quality of care for brain injury survivors.

## Recommendations

We are calling on the government to:

- Enhance acute-phase support for families and carers by:
- Providing facilities for families to stay close to brain injury survivors in specialised neurorehabilitation settings.
- Establishing an accessible grant scheme (modelled on Headway's Emergency Fund) to assist families in the immediate aftermath of an ABI. Recognising that family members need to be near their loved ones during this critical period, this support acknowledges the likelihood that they are unable to work.
- Improve long-term support for families and carers by:
- Ensuring improved and equitable access to community-based support and rehabilitation services for brain injury survivors.
- Enhancing access to counselling and other support services for family members affected by ABI.
- Facilitating the early identification of carers by clinical staff and hospital social workers. This allows for seamless connection to local authority services and ensures that every carer of a brain injury survivor undergoes a comprehensive carer's needs assessment.

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# ASK

## Reform social care: make social care equitable and sustainable

5

Despite repeated government promises of reform, the social care system continues to let down brain injury survivors. This persistent issue is characterised by chronic underfunding and inadequate staffing levels.



### Background

It is well-established that the social care system is under intense pressure. A recent King's Fund report demonstrated the following:

- **The social care workforce vacancy rate is at its second highest-ever level.**
- **There is a continued tightening of people's eligibility to receive care, as financial thresholds have not changed since 2010/11.**
- **The cost to local authorities of purchasing care is increasing faster than inflation.**
- **There are fewer unpaid carers receiving direct support and fewer people receiving respite care than in 2015/16.**

According to the Association of Directors of Adult Social Services 2023 Autumn Survey, 470,000 people are waiting for care, direct payments, or assessment of their care needs.

Effective social care for brain injury survivors can facilitate social connections, sustained employment, improved mental health, and overall life satisfaction despite significant challenges.

However, the current system falls short for the treatment of neurological conditions like brain injuries. A 2022 survey revealed that only 23% of adults with neurological conditions feel their social care meets their needs and over half reported feeling excluded from decisions about their care.

### Recommendations

We are calling on the government to:

- Commit to an ongoing increase in social care funding so that it is sufficient and sustainable, and brain injury survivors can access the care they need to lead fulfilling lives.
- Provide mandatory training for social care staff to understand and address the unique needs of brain injury survivors.
- Improve staffing levels by making social care careers more appealing through better pay, career prospects, and working conditions.
- Promote the closer collaboration of health and social services to ensure seamless transitions and continuity of care for individuals with complex needs living with acquired brain injuries.

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If you need help or support, or have a question  
about brain injury, contact our freephone nurse-led helpline:

**0808 800 2244**

**helpline@headway.org.uk**

0115 924 0800 | enquiries@headway.org.uk



HeadwayUK



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