

the brain injury association

# Headway UK Long-term strategy

2024 - 2029

Visibility + Connectivity = **IMPACT**

# Foreword

It is with great pride that I address you as Chair of this empowering charity, which for more than 40 years has played a leading role in improving life after brain injury.



In my previous role as Senior Judge of the England and Wales Court of Protection, I became acutely aware of the extent to which brain injury can change the lives of individuals and families in an instant.

I also witnessed the importance of individuals and families having access to high-quality, specialist support services, such as those provided by Headway UK and the network of local Headway charities and volunteer-led branches.

Whether it is acute support in the immediate aftermath of brain injury, via our helpline or Emergency Fund, or ongoing help to relearn lost skills and regain a degree of independence, everyone involved in Headway should be proud of the vital work we do.

But none of it would be possible without an incredible amount of hard work, passion and dedication from our incredible volunteers and staff across the UK.

**On behalf of my fellow trustees, I would like to thank everyone that supports Headway – either locally or nationally – by volunteering, fundraising, donating, or acting as a trustee or branch committee member.**

Denzil Lush, Chair

In developing this strategy, we wanted to ensure that we listened to as many voices as possible.



**We are hugely grateful to everyone that shared their experiences, ideas or feedback as part of this consultation exercise. Your voices have helped inform this strategy and will continue to shape our future.**

The context in which charities are operating, particularly those in the social care arena, has never been more challenging.

However, thanks to the prudent and stable stewardship of a highly experienced and dedicated board of trustees, and the exceptional hard work of a dedicated team of volunteers and staff, Headway UK is in a strong position from which to evolve in a new economic and social environment.

At the heart of this strategy is the desire to work more collaboratively to ensure all voices are heard. The short-term challenges are clear and growth will not be easy.

But we believe that by improving the visibility of Headway and awareness of brain injury, and by connecting and working with other organisations that share our vision, we can make an even greater impact.

We will be relentless in pursuing our aim of improving life after brain injury through the duration of this strategy and beyond. Thank you for your support!

Luke Griggs, Chief Executive

# Watch a brief outline of the strategy

To increase accessibility, we have created a brief video outlining the key aspects of this strategy document.

To view it, click on the play button below...



headway.org.uk



# What is a brain injury?

There are many possible causes of brain injury, including a fall, a road accident, tumour or stroke.

A brain injury can affect everything you do, think and feel. It can cause behavioural and emotional changes, hormonal imbalances, difficulties with cognition and memory, a range of communication problems, physical effects and, very commonly, fatigue.

A brain injury can affect anyone, at any time. Each brain injury is unique, with the often complex, hidden and fluctuating effects making it challenging to find the right help, at the right time.

At Headway, we believe there is life after brain injury and we are dedicated to supporting anyone affected by it.

This includes families, partners and friends, whose lives can be forever changed by a brain injury sustained by a loved one.

A brain injury can affect everything you do, think and feel.

For more information about the effects of brain injury and how Headway can help, visit [headway.org.uk](https://www.headway.org.uk) or contact our nurse-led helpline on **0808 800 2244** or [helpline@headway.org.uk](mailto:helpline@headway.org.uk).

# Why we exist

**EVERY 90 SECONDS**, someone in the UK is admitted to hospital with an acquired brain injury. That's around 350,000 people each year.



We all think 'it will never happen to me', but the reality is that a brain injury can affect anyone, at any time and can change the lives of individuals and families in an instant.

At Headway, we exist to help people to rebuild their lives, relearn lost skills and maximise their independence after brain injury. Equally, we support families and carers to adapt to life after brain injury.

In addition, we campaign to reduce the occurrence of preventable brain injury, while working to increase understanding of its effects and impact among the public and professionals alike.

By working with and supporting our network partners, we are able to support survivors and families from the moment brain injury strikes.

# What we do

## Support a network of independent local Headway charities and volunteer-led branches

operating across the UK that provide rehabilitation, reablement and peer support services to survivors, families and carers in their communities.



### Services in Northern Ireland

We facilitate weekly peer support, social and information sharing services for ABI survivors across 12 communities in Northern Ireland. We also provide information, support and signposting to families and carers.

## Our nurse-led freephone helpline

provides a vital listening and signposting service to brain injury survivors, families, carers and professionals.



## Our Emergency Fund

helps families cope with the sudden financial implications of brain injury, for example by providing small grants to assist with travel or accommodation to visit loved ones in critical care.



## The Approved Provider scheme and Solicitors Directory

are trusted directories, providing survivors and their families with lists of accredited residential care providers and personal injury lawyers with expertise in brain injury.



## The Headway website

is one of the most comprehensive sources of information available about brain injury and is often the first source of support for individuals and families affected.



Additional Headway websites, such as *I'm calling about Chris*, which is a free resource to help keep family and friends updated on a loved one's condition in the immediate aftermath of brain injury, the Headway HealthUnlocked community forum, and our dedicated in memory tribute site offer more tailored support.



## Award-winning booklets and factsheets

which are free to download from the Headway website, provide comprehensive and accessible information about all aspects of brain injury, with publications aimed at survivors, family and friends, carers and professionals.



## Campaigning and lobbying

in the national press and various parliaments across the UK to raise awareness of brain injury among the public and politicians alike. We aim to reduce the prevalence of brain injury and push for high-quality support services to be made available to anyone and everyone affected.



## Training courses

to help improve understanding and awareness of brain injury among professionals working directly with those affected. We also run courses for survivors and families to help them adapt to life after brain injury.



## Brain Injury Identity Cards

which help survivors to explain their support needs, whether in everyday scenarios, such as while shopping, or if they come into contact with the criminal justice system.



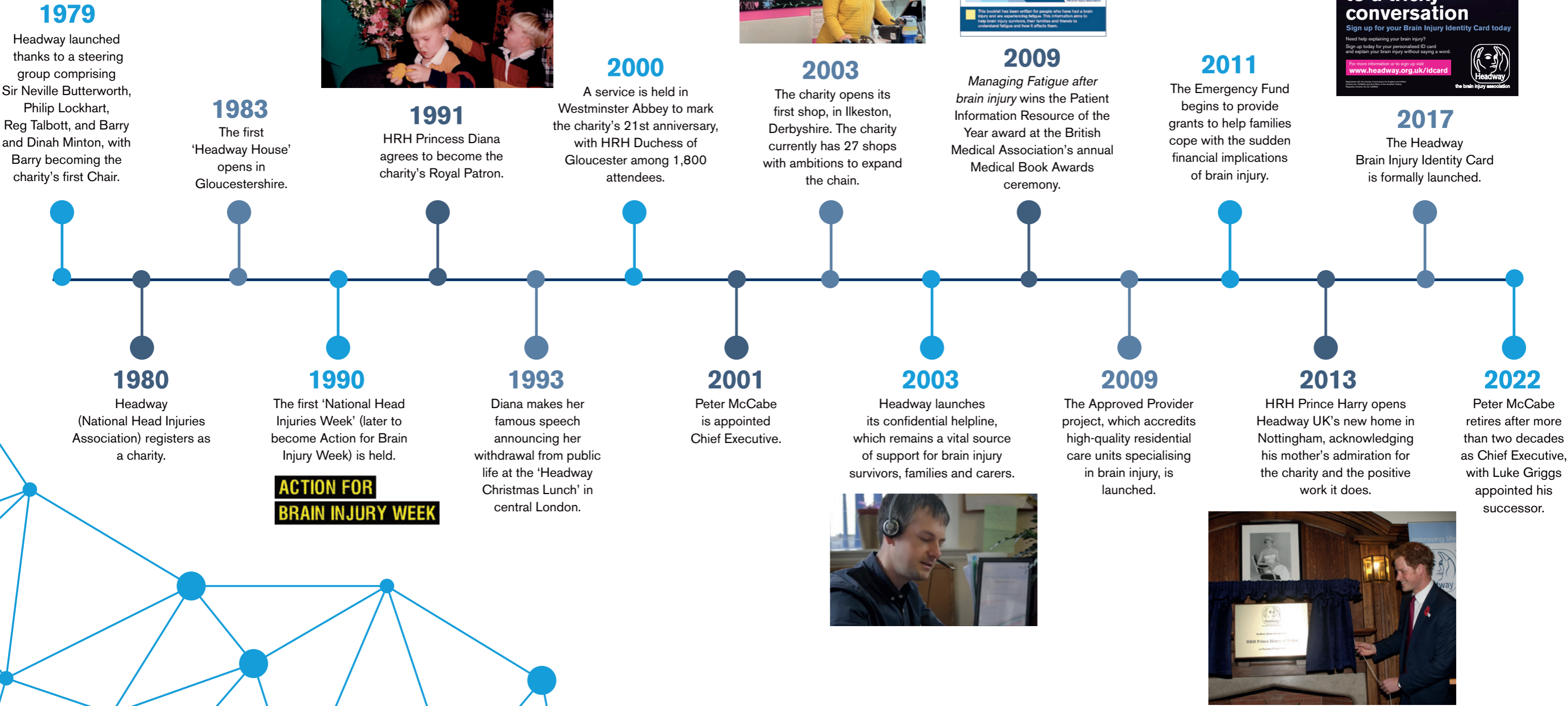
## Our Justice Programme

improves the support available to survivors who come into contact with the criminal justice system. We provide training to probation officers, the police and other related professionals to help them better understand the often hidden effects of brain injury.



# The history of Headway

We've come a long way since the charity was founded in 1979 by a small group of families and professionals in Nottingham. The charity's foundations are based on the concept that by working together, we can achieve more. That principle remains as fundamental to our work as it was back in 1979.



# How we developed our strategy

In developing this strategy, we wanted to learn what matters to brain injury survivors, carers and families, as well as the network of local Headway charities and volunteer-led branches. Where are the gaps in services? What are the unmet needs of brain injury survivors and families? How can Headway make the most impact?

More than 1,000 brain injury survivors or family members contributed to a series of surveys, with hundreds more responses from professionals and connected organisations.

In-person focus groups held with brain injury survivors, families and carers at several local Headways across the UK strengthened our understanding of the challenges of living with brain injury.

We also considered feedback from a detailed consultation exercise with the Headway network, and ideas gathered from trustee and staff awaydays held over the past 18 months to identify future opportunities for growth against a challenging financial backdrop.



# Our values

Devised in 2023 by staff and trustees, these values underpin everything we do and how we act – as individuals and as a charity:

## We collaborate.

We believe in the power of working together to amplify our impact.



## We are bold.

We are unafraid to challenge the status quo to drive innovation and improvement.



## We care.

Compassion and empathy are at the heart of everything we do and integral to the support we provide to those affected by brain injury.



## We celebrate diversity.

And we actively embrace inclusivity.



## We give you a voice.

We give a voice to those affected by brain injury by putting the lived experience at the heart of everything we do.





# Our vision

## Our vision is of a society in which:

- every individual and family affected by brain injury has fair and equitable access to all the support they need to lead a positive, fulfilling life;
- understanding and awareness of brain injury is prevalent in all walks of life; and
- there exists a shared commitment to eliminate avoidable brain injury or otherwise minimise its impact.

# Our mission

## We will drive change across society by:

- ensuring equitable access to high-quality brain injury services, support and information;
- increasing awareness and understanding of brain injury across society; and
- campaigning to reduce occurrence and the impact of brain injury.

# Strategic Aims



## 1 Strengthen the network of local Headway charities and volunteer-led branches

### What you told us:

"The positivity of other brain injury survivors is good; it makes me feel connected."

"Before coming to Headway, I was looking for something to blame. I had a lot of loneliness before. I get more support and friendship from Headway than I get from family."

"Finding Headway was a game changer."

### The challenge

Across England, Wales and Scotland, independent Headway charities, affiliated to Headway UK, provide rehabilitation and reablement services to brain injury survivors, families and carers.

Alongside this work, Headway UK is commissioned to run support groups in Northern Ireland.

Independent local Headway charities are under increasing financial strain as a result of the cost-of-living crisis and hugely varying approaches to adult social and health care commissioning practices.

In addition, Headway branches offer social engagement and support, enhancing wellbeing and confidence.

Headway branches are run by incredibly dedicated, passionate volunteers – many of whom are

directly affected by brain injury themselves.

But with volunteering levels having declined in recent years, there is pressure on existing volunteers to maintain Headway branch activities or introduce new activity or support programmes that will appeal to those not currently receiving support.

### What we will do

We want to help local Headway charities survive the current funding crisis in order to continue to provide high-quality services to brain injury survivors, families and carers in their communities. Throughout the course of this strategy, we will focus on strengthening the network by:

- Increasing the collaboration between local Headway charities through the use of digital technologies, building on the existing peer support platform to facilitate the sharing of best practice.

### How we will measure our progress

We will:

- Engage in regular and varied forms of consultation with the Headway network, including consultations, pulse surveys and network engagement events.
- Utilise data from tools to measure and evidence the effectiveness of the support provided at a local level to lobby for greater investment in specialist brain injury services.
- Monitor and report on the number of volunteers actively supporting local branches and the number of people accessing the services.
- Track the number of staff and volunteers from the Headway network engaging in Headway UK training or events.

- Investing in new forms of practical support for the network, such as tools to measure and evidence the effectiveness of the support provided, and the introduction of a Community of Headway Trustees to facilitate the provision of peer support and the sharing of best practice.
- Explore UK-wide partnership opportunities with a variety of sectors to increase fundraising opportunities and raise the profile of the charity and the national and local support available.
- Developing a new volunteer support programme to provide greater assistance to our existing supporters and encourage new volunteers to get involved, with the aim of increasing

and diversifying local engagement opportunities.

- Increasing our lobbying and campaigning activities, including in the devolved nations, to strengthen the business case for sustainable funding.
- Working with the network to identify means of increasing exposure of Headway in hospitals and other acute care settings to ensure those patients and families are aware of the support available in the immediate aftermath of brain injury.
- Invest in the support provided to the existing network of Headway branches and explore additional provision to try to launch new branches and community provision.



# Strategic Aims



## 2 Increase awareness and understanding of brain injury

### What you told us:

Only 4.5% of brain injury survivors that took part in our consultation feel that the general public has a good understanding of brain injury.

When asked about professionals' understanding of brain injury, 43% feel their GP does not have a good understanding. This increased to 66% in relation to welfare benefits assessors and 63% for employers.

As a result, 49.7% of brain injury survivors feel that raising awareness, understanding and knowledge of brain injury, and the profile of Headway, should be our main priority.

This was echoed by families and carers, 55.2% of whom agreed that this should be the main objective of this strategy.

"It is a massive problem with the NHS. My partner's main injury wasn't his brain injury, it was his spinal cord injury and physical injuries and because that was critical to keeping him alive, to support the spinal cord injury, his brain injury got forgotten about."

"Professionals don't seem to be aware of it and that's what is quite scary."

"Brain injury is a hidden disability. Unless we walk with a stick, I'm afraid people can't see. We are hidden."

### The challenge

The often hidden, fluctuating and complex effects of brain injury can make accessing the right help and support incredibly challenging for survivors and families.

While significant progress has been made in recent years relating to the public's understanding of brain injury, particularly sport-related trauma, there is far more work to

be done to make brain injury more widely understood.

This is also generally the case with professionals who come into contact with those affected, particularly in social and health care, welfare benefits advisors or those working within the criminal justice system.

### What we will do

- Empower more brain injury survivors, carers and family members to speak out, ensuring the lived experience is at the heart of all our awareness-raising and campaigning activities.
- Identify and engage with high-profile individuals with lived experience of brain injury to recruit their help in increasing the public's awareness and understanding.
- Develop tailored approaches to key audiences, such as politicians, researchers, and health and social care professionals that can influence the statutory support made available to those affected by brain injury.
- Review our existing promotional and informational materials, including the website and our branding, to ensure they have the maximum impact.
- Identify ways in which we can increase the accessibility of our information and support to reach individuals, families and communities that may otherwise be going without assistance.
- Strengthen our relationships with professional health and social care bodies to increase understanding of the often hidden, fluctuating and complex effects of brain injury.
- Better equip and empower Headway retail staff to champion local and national Headway services and raise the profile of the charity on the high street.
- Work closely with the network of Headway Approved Providers to increase visibility of the scheme and grow awareness of local and national Headway services within the units themselves.
- Continue to use our established platform as a voice of authority within the media to reduce the prevalence of brain injury via our established campaigns, such as Concussion Aware and safer cycling, while boldly speaking out at every opportunity to increase awareness.

### How we will measure our progress

We will:

- Run pulse surveys to capture and monitor the number of people seeing our messages or having access to our information.
- Use digital methods of data analysis, for example the use of QR codes, to identify which of our forms of messaging are most successful.
- Analyse visits to the website and calls to the helpline to identify timely trends, for example increases in visits or calls relating to specific campaigns.
- Record and monitor service user data to capture and analyse demographic information in order to monitor our progress with reaching communities that are currently underrepresented within our services.



BBC *The Traitors* star and brain injury survivor Andrew Jenkins is filmed as part of Headway's Action for Brain Injury Week 2024 campaign.

# Strategic Aims



## 3 Develop new support services to help people to live well after brain injury

### What you told us:

"We definitely need more groups for younger people."

"Anyone with an acquired brain injury should be given an information leaflet whilst in hospital so that support is available from the outset."

### The challenge

Brain injury can impact every aspect of life. At Headway, our aim is to help people to navigate life after brain injury through the provision of a range of services and support programmes.

In addition to supporting a network of local Headway charities and volunteer-run branches, we currently support and empower brain injury survivors, carers and families through frontline services such as the nurse-led helpline, the

Justice Programme, the Emergency Fund and a comprehensive library of free-to-access publications.

We are proud of the work we do. But we want to do more to increase the impact of our services, making them more accessible and visible. We also want to introduce additional programmes of work that are practically and financially supported by partners who share our vision.

We want to ensure that every adult, of every age, from all communities feels supported and able to engage with Headway.

"Help with the benefits minefield!"

Obtaining sustainable funding and the availability of volunteers will always be challenges to Headway developing new services, but our ambition is to diversify the support we offer and increase the number of people we help.

### What we will do

- Introduce a new welfare benefits advice line to help survivors and their families navigate the complex process of applying for PIP, Universal Credit, Carers Allowance and Housing Benefit.
- Identify means of utilising technology to improve the accessibility of our services and information, for example through the development of a Brain Injury

Identify Card app and the use of AI.

- Enhance our free online training courses for survivors, carers and families.
- Explore ways to better support employers to help brain injury survivors back into employment.
- Develop new branch services specifically for younger people,

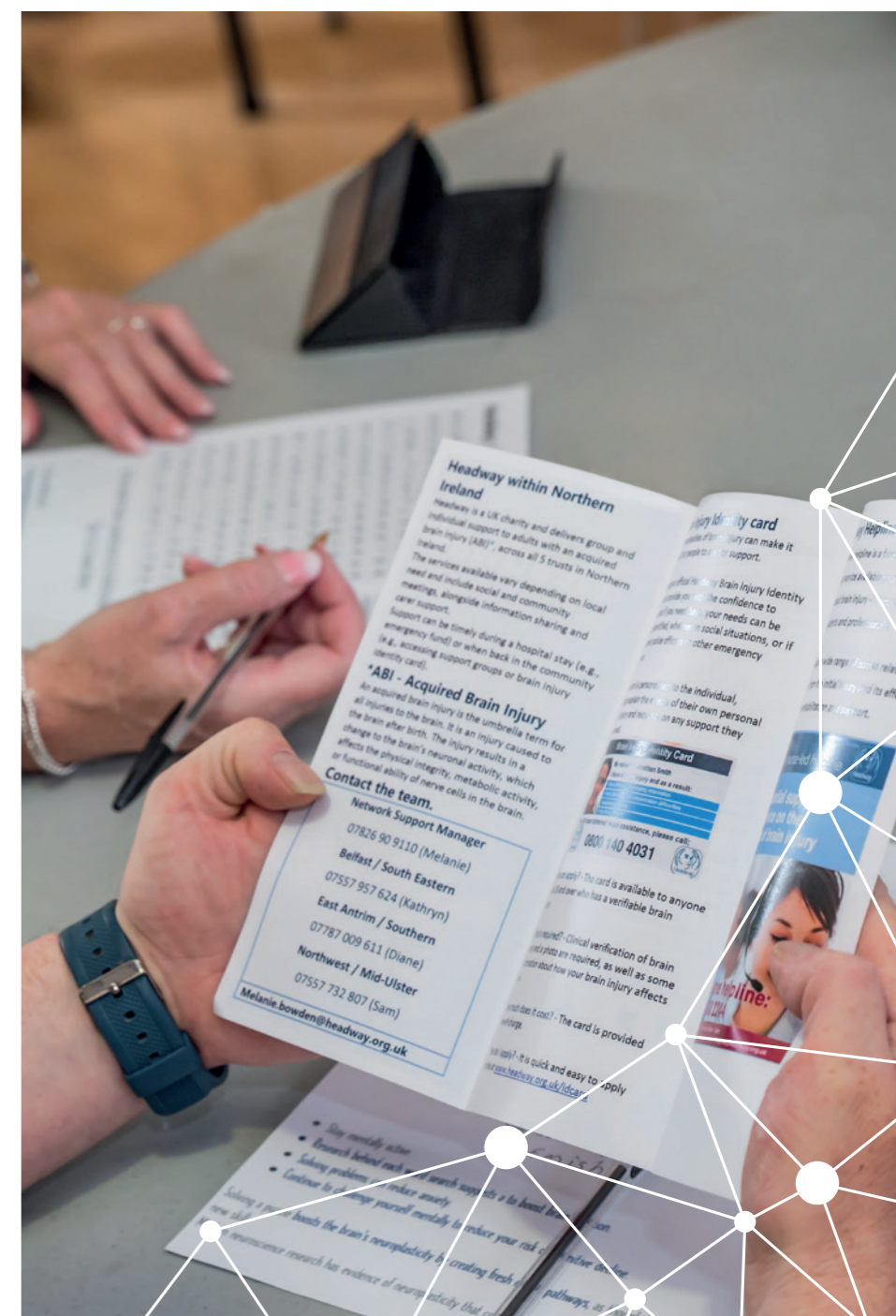
working in partnership with other organisations where appropriate.

- Develop partnerships with sporting bodies to increase access to sport and physical activity for brain injury survivors.
- Collaborate with other organisations to achieve shared aims.

### How we will measure our progress

We will:

- Analyse the number of people accessing any new services we launch, monitoring growth over the course of the strategy or programmes of activity.
- Improve our methods of measuring the impact of existing services, such as the helpline, Emergency Fund and Brain Injury Identity Cards in order to showcase the effectiveness of our work while driving continual improvement.
- Ensure robust evaluation methods are in place for all new services.



# Strategic Aims



## 4 Support research to evidence the need for better access to specialised services for people affected by brain injury

### What you told us:

"I would like to see research and training for all, but especially for those working with or caring for brain-injured people, in the longer-term effects of brain injury as those affected get older."

"The input of brain injury survivors is vital when it comes to developing new services."

"Headway could support transition in the community, while working with researchers to develop resources and tools that could benefit us."

### The challenge

Too often, the hidden, complex and fluctuating nature of brain injury means those affected struggle to get the help, support and understanding they need.

This issue is compounded by the fact that every brain injury is unique, with unpredictable outcomes.

We believe that everyone that sustains a brain injury should have access to high-quality specialist rehabilitation and support services. However, access to such services varies hugely across the UK.

We know that with the right help, at the right time, there can be life after brain injury. There is excellent research taking place to evidence the economic and social impact of

brain injury; we want to support and enhance this work in order to strengthen the case for brain injury rehabilitation and support services to be appropriately and sustainably funded.

### What we will do

- Continue to work with other charities, campaigners, medical and research organisations and Parliamentary supporters to lobby government to invest in statistical evidence.
- Establish more partnerships with researchers and institutions to support and contribute to research on a variety of brain injury issues, including homelessness, intimate partner violence, concussion, and mental health.
- Review and strengthen existing methods of demonstrating the impact of our work, for example through the development of the Brain Injury Outcomes Star to be used by local Headway partners.
- Continue to deliver our own non-clinical studies as part of and alongside the annual Action for Brain Injury Week campaign
- Continue to publish qualitative research by championing the voices

of brain injury survivors, families and carers.

- Work with the Headway network to establish an annual survey to understand the impact of brain injury on survivors, families and carers and to help us lobby for better statutory services while shaping our own.

### How we will measure our progress

We will:

- Record and report the number of research projects we are actively involved in, with data shared with our network and wider partners, including our Parliamentary Champions
- Report and share the findings of attitudinal surveys conducted throughout the year.
- Monitor the number of brain injury survivors, family members and carers contributing to internal and external surveys and consultations to ensure we are giving people a voice.



# The components for our success

In order to achieve the ambitions set out in this strategy, we will need:

## To continue to support the Headway network

The relationship between Headway UK and the network of local Headway charities and branches is crucial to our collective ability to improve life brain injury. We will continue to prioritise these relationships.

## Agility

The current political and financial environment remains volatile. Local health and social care commissioning remains inconsistent and underfunded, putting significant pressures on the local Headway network. We will need to ensure that we are able to respond to the continuing rapid political and socio-economic changes we are witnessing.

## To listen

It is vital that we continue to engage with all who support us or use our services, particularly those with lived experience of brain injury and our existing and future volunteers and staff, by developing continuous and accessible mechanisms for involvement and to help us shape the future of the charity.

## To be efficient and effective

We will continuously look for ways in which we can increase the effectiveness of our work, ensuring all donations we receive and income we generate has the maximum possible impact.

## To strengthen the support we provide to volunteers

Without volunteers, we simply could not do what we do. We are indebted to each and every person that gives their time to support and drive our work – but we do not take this help for granted.

## To be visible and connected

By establishing new relationships and forging partnerships, we can achieve far more and amplify the voices of all who share our aim of improving life after brain injury.

## To support, empower and invest in our staff

Our staff's expertise, compassion, and commitment underpin every aspect of our work. By prioritising their health and wellbeing, nurturing their talents, and investing in their development, we will ensure we continue to deliver impactful support and drive positive change for those we support.

## To embrace Equity, Diversity and Inclusion (EDI)

We recognise that EDI is fundamental to our mission and underpins everything we do. As we move forward with our strategy, we are committed to actively promoting EDI in all aspects of our work from service delivery, community engagement to recruitment and staff development.

## Support

We cannot do this alone. Whether you can help us generate the income we need to maintain and enhance our existing services, or develop new means of supporting those who need our help, your support will be crucial in the success of this strategy.

## A new fundraising strategy

We will develop a fundraising strategy that will facilitate continued growth and provide the financial resources to deliver our plans, diversify our income streams and offering flexibility to our donors to generate income to support our strategy.

## Regular governance reviews

To ensure we continue to be as effective and progressive as we can be, we will conduct regular governance reviews in line with Charity Commission best practice guidance.

# Investing in income generation

The socio-economic environment in which charities are operating has never been more challenging.

The economic downturn and cost-of-living crisis have put significant pressure on the charity's operational costs, impacting its ability to invest in new services.

However, Headway UK remains in a strong position to support this new long-term strategy, focusing on investment in new technologies and processes that will improve our efficiency, enable us to generate new income, evidence the importance and effectiveness of our work, and raise the profile of the charity.

We will look to strengthen our relationships with partners and

donors, exploring opportunities to work with a range of industries, including construction and sport where brain injury is prevalent.

We will also seek ambitious UK-wide partnerships that will allow us to work alongside the local Headway network to not only generate income but also increase the charity's profile.

# Retail

The development of the charity's retail portfolio has been pivotal to the charity's growth in recent years.

*None of this would have been possible without the huge array of volunteers who have given and continue to give their time freely to the cause. From the bottom of our hearts, THANK YOU!*

Headway shops generate significant funds to support the charity's frontline services. They also help us to raise awareness of brain injury and the local and national support available to those affected.

As part of this new long-term strategy, we will aim to expand our retail chain by at least 25%.



By increasing our high street presence, we can not only generate much needed and sustainable income, but also raise our profile. Our ambition is to make each of our shops an information hub for people to learn more about brain injury and local and national support available

We will also continue to work closely with our local Headway charity partners and volunteer-led branches to provide opportunities for brain injury survivors to learn new skills and gain confidence from volunteering in the shops, while promoting local support services.



“As soon as I came into Headway, I was made so welcome. The team at the shop are great, you cannot keep me away!”

Diane Noland, Headway Retail Volunteer

# How you can help

In order for Headway UK to achieve the aims and ambitions of this strategy, we need your help.

Our services make a remarkable difference in the lives of people affected by brain injury but this is only made possible thanks to our amazing supporters, whether individual donors, community fundraisers, trusts and foundations, or corporate partners.

There are so many ways in which individual fundraisers can get involved and make a difference – and there's something for everyone.

You don't have to run a marathon (but we can help you with that if you are keen!) or jump out of a plane (wearing a parachute, of course...). There's no limit to what you can do to help, whether its fundraising, volunteering or leaving a gift in your will.

If you want to help to improve life after brain injury, visit [headway.org.uk/get-involved](https://headway.org.uk/get-involved).

# Corporate support

Our corporate partners come in all shapes and sizes but what's common with all who work with Headway UK is a passion and commitment to transform life after brain injury.

At Headway, we are passionate about partnerships. Every partnership is unique, but each comes with a commitment from us that we will work with you to not only help you to raise money, but also to ensure your colleagues all feel involved in the process, valued for their efforts, and come away with a better understanding of brain injury.

To find out how your firm can become a charity partner of Headway, please call 0115 924 0800 or visit [headway.org.uk/get-involved/organisations/charity-partnerships](https://headway.org.uk/get-involved/organisations/charity-partnerships).



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



headway\_uk

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