

Summer 2024

Headway News



The magazine of Headway - the brain injury association

ACTION FOR

BRAIN INJURY WEEK 2024

**Telling the stories of those who have had
their lives re-written by brain injury.**

Pages 7-13



**Holidays and
brain injury**

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**Services spotlight:
The helpline**

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**Peter's
3D model**

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HEADWAY WEBINARS



We're delighted to be continuing our series of free Headway webinars across 2024, covering a range of topics delivered by experts, in support of rebuilding the lives of brain injury survivors.

Our webinars run for approximately 45 minutes and are suitable for anyone with an interest in brain injury unless otherwise specified.

Scan the QR code below or visit our website at www.headway.org.uk/webinars to find out more about these sessions and to book your place.



Recordings of past webinars are available to watch on our YouTube channel and include the following titles:

Brain injury in the criminal justice system
Managing memory problems after brain injury
Identity change after brain injury
Disability discrimination in the workplace
Understanding and responding to behaviours that challenge following ABI
... among many others.

Visit www.youtube.com/user/headwayuk to find out more.

UPCOMING TOPICS FOR THE REMAINDER OF THE YEAR INCLUDE:

30th May

NATURE'S BENEFIT AFTER BRAIN INJURY

Delivered by Dr Claire McDonald,
Principal Clinical Psychologist and
Dr Mary Delaney, Consultant Clinical
Neuropsychologist

27th June

MANAGING SLEEP AND FATIGUE AFTER BRAIN INJURY

Delivered by Dr David Lee,
Clinical Director,
Sleep Unlimited Ltd

29th August

SMELL AND TASTE DISORDERS AFTER BRAIN INJURY

Delivered by Helen Rhodes,
Education and Engagement Officer at
Fifth Sense

24th October

LIFE AFTER ACQUIRED BRAIN INJURY: COPING WITH ANXIETY AND DEPRESSION

Delivered by Dr Ben Marram, Consultant
Clinical Neuropsychologist at Leeds
NHS Community Healthcare Trust and
Clarity Psychology

28th November

RETURNING TO WORK AFTER BRAIN INJURY

Delivered by Paul Morris, Occupational
Therapist specialising in neurological
rehabilitation

5th December

DIET AND NUTRITION AFTER BRAIN INJURY

Delivered by Sheri Taylor,
Dietician and Director at Specialist
Nutrition Rehab

For more information and to register interest, visit our website or scan the QR code.



Welcome

Welcome to the summer edition of Headway News! As the days grow longer and warmer, we're excited to bring you a jam-packed issue filled with inspiring stories, essential advice, and vibrant highlights from our community.

Starting on page 7, we dive into the recent ABI Week campaign, showcasing the incredible awareness-raising activities from around the UK. We also have our favourite snapshots from Hats for Headway Day with some amazing handmade creations on show.

If you are planning a getaway this summer, then turn to page 19 for our special travel feature, designed to provide invaluable advice for those planning a holiday after a brain injury. Whether you're dreaming of a tranquil retreat or an adventurous escape, our tips will help ensure your trip is as smooth and enjoyable as possible.

On page 22 we explore the benefits of lasting power of attorney. This useful guide highlights why it's an essential consideration, providing peace of mind for you and your loved ones.

The Look Ahead in the North residential weekend has been a beloved event for our groups and branches in the North-East and Cumbria since 2011.



Colin Morris

Flip to our feature on page 25 to relive this year's highlights and see why it remains a cherished tradition.

We also take a moment to celebrate our incredible Headway Heroes on page 26. These marathon runners have shown extraordinary dedication and we're proud to share their inspiring journeys with you.

Carer's Week 2024 kicked off on Monday 10th June. We asked brain injury survivors, "What does your carer mean to you?" and the heartfelt responses can be found on page 5 with many moving messages of love and gratitude.

Finally, in this edition on pages 16 and 17, we highlight the launch of the Headway Election Manifesto. Aimed at influencing policy decisions by the next government, our manifesto outlines crucial changes needed to better support brain injury survivors.

Additionally, read about Alison and Jason, two inspiring brain injury survivors who spoke to MPs at the All-Party Parliamentary Group for Acquired Brain Injury, advocating for greater awareness and improved resources.

I hope you enjoy the summer edition of Headway News and thank you for being part of our community.

Colin Morris
Director of Communications



the brain injury association

Who we are

Headway is the leading UK-wide charity that supports people to rebuild their lives after brain injury through the provision of information and support services across the UK. To find out more, visit www.headway.org.uk or you can call the freephone helpline on 0808 800 2244 if you need support.

Go digital!

Subscribe to our monthly Headway News Bitesize email at:
headway.org.uk/join-our-mailing-list

Essential contacts

Headway office:

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helpline@headway.org.uk

Website:

www.headway.org.uk

Advertising:

CommunicationsTeam@headway.org.uk

Fundraising:

community@headway.org.uk

Volunteer!

Would you like to help us improve lives after brain injury? You can join us today in our shops or at our events as a Headway Volunteer. Read more about volunteering on our website: www.headway.org.uk/donate/volunteer

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Volunteer at a Headway shop!

We're on the lookout for some amazing volunteers to join our team and have fun while making a difference!

A few hours a week at Headway can truly be life-changing. You'll be helping us raise vital funds for our services to support people with brain injuries, all while getting stuck into the fun world of charity retail. Volunteering at Headway is a fantastic way to develop new skills that look great on any resume. From mastering the art of customer service to becoming a whiz at creating eye-catching displays, you'll gain valuable retail experience you can use anywhere.

Plus, the best part: our shops are full with friendly faces from our communities! You'll meet new people, make lasting friendships, and have fun along the way. It's the perfect way to add some excitement and purpose to your week.

So, if you're looking for a rewarding experience where you can learn new things, be part of a fantastic team, and help a worthy cause, then Headway wants you! Head over to your local shop and apply to volunteer today. Visit [headway.org.uk/volunteer](https://www.headway.org.uk/volunteer) to find out more.

Your views

What my carer means to me

This year, Carer's Week 2024 took place
Monday 10th – Sunday 16th June.

This year's theme is 'putting carers on the map'. It's an opportunity for people to celebrate carers – people who mean the world to those they support. We asked brain injury survivors from Headway groups and branches across the UK: "what does your carer mean to you?" You can read some of the heartfelt responses below.

"Mum and Dad are there for me a lot and my sons keep me company and that's all I need."

John

"Wife and my sons, I wouldn't have got where I am today without their support."

Daniel

"My family have supported me through all I have gone through and I could not have done it without their support."

Robin

"My family and friends have been with me every step in my recovery and give me a focus and meaning to my life."

Kenneth

"Without the support of my family I am sure I would not have made it to today. They have supported me through the unknown and we have changed and adapted together. A never-ending challenge I'm glad I'm not facing alone."

Helen

"Without my wife and family's support I'd be lost. My wife deals with all financial and official business and let's me concentrate on things that I can still do. I need my wife and other family members to tell me to slow down and rest when it is needed. So their support is vital."

Quincy

"Past 4 years my family have supported me and I feel I wouldn't be here without them."

Cameron

"My husband of 1 year is my rock, the reason to face my everyday challenges. Sometimes he finds it difficult to understand my mood swings, but we both just get on with it. God knows what would have happened if we didn't have Headway. Dennis has had to learn new skills as well as myself. He is always there for me. I couldn't be without him."

Lesley

"My family, especially my amazing sisters have been such a support to me and given me strength and encouragement to keep pushing on through to everything I have been through over the past couple of years."

Les

News in brief

News of Headway's ongoing work to improve life after brain injury

The Headway Annual Awards 2024

The Headway Annual Awards are back and this year we're heading to the elegant 5-star JW Marriott Grosvenor House, London.

The Headway Annual Awards celebrate the inspirational achievements of people living with brain injury and the dedication of those working to support them.

Each finalist, chosen by a selection panel, will be invited along with a guest to a glittering luncheon at The Grosvenor Hotel on Thursday 5th December 2024.

Do you know someone who deserves to be nominated?

This year's Headway Awards categories are:

- Alex Richardson Achiever of the Year sponsored by Slater & Gordon
- Carer of the Year sponsored by Hugh James
- Volunteer of the Year sponsored by Anthony Gold Solicitors LLP
- Stephen McAleese Outstanding Contribution to Headway Award sponsored by No5 Barristers Chambers
- *NEW The Headway Extra Mile Award sponsored by Irwin Mitchell

Now is the time to get your nominations in! Nominating someone is easy. Visit headway.org.uk/nominate and follow the instructions. The deadline for nominations is **Monday 8th July 2024**.

Special award for Headway South Cumbria

Huge congratulations to Headway South Cumbria, which has received a special award from the High Sheriff of Cumbria.

The local branch, based in Kendal, was started around 12 years ago and has helped hundreds of people in the South Lakes and Furness Peninsula area – an area that historically has had little support for those with brain injuries.

The High Sheriff is appointed personally by the Sovereign for one year and is his representative in the county in all matters relating to the judiciary. Samantha Scott, who was the first

High Sheriff of Cumbria to be appointed under King Charles III in April 2023, awarded Headway South Cumbria in recognition of its 'great and valuable services to the community.'

Headway South Cumbria Chair, Glenys Marriott, said: "We were so thrilled and excited to be acknowledged by the High Sheriff for our contribution to the community. For us to get this acknowledgment, it was very, very special."

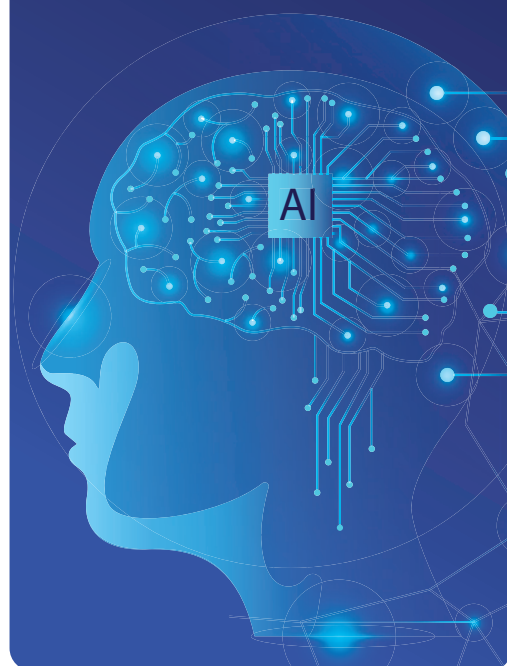


Headway delivers talk on AI and brain injury for AbilityNet

We were delighted to be invited earlier this year by adaptive technology charity AbilityNet to deliver a webinar talk on how AI could support people affected by acquired brain injury.

Led by input from brain injury survivors through social media, Headway's Publications and Research Manager, Tamsin Keyes, delivered a 10-minute talk on how AI technology is already being used by survivors and within research, as well as the wider concerns in the world of neuroethics.

Visit AbilityNet's website to watch the webinar, which also includes talks from AbilityNet's Head of Digital Inclusion Robin Christopherson, and Microsoft's Accessibility Go to Market Manager, Michael Vermeersch.



ACTION FOR

BRAIN INJURY WEEK 2024

A LIFE RE-WITTEN

In May, we were thrilled to launch this year's Action for Brain Injury Week (ABI Week) campaign, *A life re-written*.

A life re-written explored how brain injury can affect anyone at any time, focussing on how it throws plans into disarray, changes life goals, and can even alter people's sense of identity.

This campaign told the stories of brain injury survivors and their loved ones who have successfully rebuilt their lives but

also showed the realities of life post-brain injury and that positive outcomes aren't always the norm.

Telling stories of re-written lives

We were delighted to welcome Andrew Jenkins to be a part of this year's campaign. Andrew is a familiar face to many after appearing in series 2 of the BBC TV reality show *The Traitors*, where he was a popular finalist and shared his personal experiences of being a brain injury survivor following a catastrophic car crash in 1999.

As well as sharing his own story as part of *A life re-written*, Andrew spoke to brain injury survivors Alison, Liz, and Liz's daughter Justina about how all their lives were re-written after brain injury.

He also spoke to brain injury survivor and professional photographer David Baker, who was the official photographer for the campaign.

"Headway – the brain injury association is an amazing charity doing amazing things to help people rebuild their lives after brain injury. I'm delighted to support this year's Action for Brain Injury Week and help tell the story of others who have had their lives re-written by brain injury."

Andrew Jenkins

Behind the scenes

Filming for this year's campaign videos took place at the offices of Bolt, Burden Kemp in London.

ACTION FOR

BRAIN INJURY WEEK 2024

ANDREW'S STORY

Andrew Jenkins shares his personal experiences of being a brain injury survivor following a catastrophic car crash.

Andrew was driving home from a wedding when his wheel hit a curb and the car flipped onto its side.

He was thrown out of the driver's window, knocked unconscious and dragged along the floor. When the emergency services arrived, they initially thought Andrew was dead: "My mother says she recalls that night every single

day since it happened 24 years ago," he said.

"On August 28, 1999, I was involved in a very serious road traffic accident where my dream of playing rugby for Wales was taken from me, and my life was re-written."

"The first operation I had was to remove the bone from my brain," said Andrew. "I spent nearly four weeks in a coma in intensive care fighting for my life in hospital."

Andrew's loved ones were warned he may never wake up and if he did, he may not recognise anyone, walk, talk, or use his arms or legs again. But when Andrew finally woke up, he was determined to defy the odds and learned to walk again.

"The physical injuries I had were horrendous but the worst thing for me was the psychological and the mental illness," said Andrew. "I want to show people that when you have a trauma in life, you can maybe look a different way with scarring, lose your dream, lose something in life, struggle with your mental health, but you can still turn your life around and achieve great things."

"I keep re-writing my life every single day. I'm on a mission to break the stigma that surrounds mental health and wellbeing."



Andrew Jenkins



Justina and Liz

JUSTINA AND LIZ'S STORY

When Liz Ekeledo had a life-changing stroke at the age of 37, she and her family's world was turned upside down.

Liz's daughter, Justina, was just 17 when it happened: "My mum was rushed to hospital, and they discovered that she had a bleed in the brain, an aneurysm, and it had burst. We were told to prepare for the worst," she said.

Liz underwent 10 hours of emergency surgery overnight as her family anxiously awaited any news. "When I visited again in the morning, I remember thinking, 'oh my goodness, this is the end,'" Justina said. "I'm already from a single-parent household, I only have one parent, and now the parent that I have is vanishing before my eyes."

Following the stroke, it was suggested to the pair that Liz join her local Headway to meet people, build relationships, and to do things in the community.

"While this is a different version of Mum there are parts of her life and her personality that she enjoyed that we're still able to do, Justina added. "She is full of energy and wants to get out into the community."

Justina has also lived a re-written life to the fullest: "I've gone on to have a fulfilling career, I can leave my mum in the company of people who support her to live an amazing life and that's due to our strong community and included in that community is Headway," she said.

Liz is now hoping to get a job. "I have a positive attitude about life," she said. My key thing is while you've got life you've got hope."

"I used to be a very good fitness person; I was passionate about it. I used to run over 20 miles three times a week. But on December 12, 2004, my life was re-written because I had a stroke."

DAVID'S STORY

David Baker, from Dorset, survived a life-changing accident in 2016, when he collided with a van whilst riding his bike home from work.

Now 49, David has no memory of his accident but has pieced the events together with the help of onlookers and photographs taken at the scene.

He said: "As I was cycling along, a transit van overtook me and turned onto its driveway. I had no time to react, apparently, and I went head-first into the side of the van." Despite wearing a cycling helmet that David said '100 percent' saved his life, he sustained a traumatic brain injury, and his life was forever changed.



David Baker

At the time of his bike crash, David worked as a detective with Dorset police, but his injuries were so severe that he never returned to the force. As a result of his brain injury, David has severe visual problems, including double vision, meaning he needs to wear an eye patch to help with his balance.

"For me now, my identity isn't as a police officer, it's as a photographer. I think without it, I'd probably dwell too much on the past and what could've been and what should've been, as opposed to what life can be now."

A few months after his crash, David's family welcomed a new puppy into their home - something that would prove to be transformative for David. Rapha, a Border Collie named after David's favourite cycling clothing brand, became David's constant companion and they would walk miles together each day while David took countless photos.

He said: "A friend of mine gave me a camera, so I started taking pictures of Rapha and I started to really enjoy photography. I decided to enrol on a photography course - just to see how I'd cope. It went really well." Now a professional photographer, David has also provided the photography for Headway's *A life re-written* campaign.

ALISON'S STORY

Alison Goodrum, 49, had her life re-written when she was diagnosed with a brain tumour in December 2018, having suffered from headaches all her adult life.

"Unlike a lot of brain tumours, mine was not a sudden crisis in that I had an attack or an episode. I didn't feel myself and gradually declined," Alison said. "The headaches I was having got worse and worse and there was a moment where I was sitting on the edge of the bed with a splitting headache and thought 'this is not normal'. Originally putting symptoms down to stress or working too hard, Alison was finally diagnosed with a slow-growing brain tumour, she couldn't believe it.

"I think I probably went into denial," she said. "I was 44 years old with an established career as a university professor. It was a big bombshell to drop on my family. It's not just your diagnosis, it's your loved ones' diagnosis."

Initially Alison mostly kept her diagnosis to herself, however she did reach out to Headway for support: "I found Headway's helpline number and almost immediately phoned them up because I just wanted to speak to people," she said. "The person on the helpline was just so lovely and with that the floodgates opened, and I sobbed down the phone. And it was one of the few times that everything came out. They were just so helpful and welcoming."

Following her brain tumour surgery, Alison had a hard road ahead. However, she also found a new pathway of living her life post-surgery.

"My illness forced me to switch from a full-time to a part-time role at my university and, with that, fresh opportunities knocked," she said. "For the first time ever, I had space in my working week to spend away from my academic pursuits," she said.

This scenario gave rise to 'Goodrum & Merryweather', Alison's handmade millinery studio.

Alison explained: "The craft of millinery, and my development as a milliner, has been an exceptionally important part of my convalescence. A meditative practice. A creative act. A silver lining."

"My hat-making was never intended to be this big! I'd had a lot taken away from me by my tumour, and I felt this was something I was actively making rather than having taken away."





A LIFE RE-WITTEN

THE EXHIBITION

Headway in Northern Ireland once again partnered with other brain injury charities to play their part in this year's campaign.

In Northern Ireland, roughly 10,000 people experience brain injury every year. Headway Northern Ireland created a video alongside The Cedar Foundation, Brain Injury Matters and Child Brain Injury Trust to let people in Northern Ireland know that help is out there.

In support of the *A life re-written*, Headway Northern Ireland also organised an art exhibition at Lisburn City Library.

Over 80 brain injury survivors from Headway groups across Northern Ireland decorated small wooden feet to reflect their thoughts, feelings and personal journeys.

The exhibition also featured contributions from patients currently in the Regional Acquired Brain Injury unit in Musgrave Park Hospital. They decorated foot shapes with words to show us how they're feeling as they begin the journey of their 're-written lives'.

The individual art pieces highlight the many stages and aspects of living with an acquired brain injury. Some feet highlight overcoming struggles, or a particular difficulty, others showcase an important task or achievement e.g. making a cup of tea for the first time. No matter how insignificant the achievement may feel, or where they are on the path they are important steps.

"An acquired brain injury is not something anyone would choose, but the stories in the art illustrate how everyone is moving forward down their new life path. The exhibition showed a shared journey from the beginning of an acquired brain injury, making strides along the way, to a point where they are looking towards the future. Be sure to take the time to walk in their footsteps."

Melanie Bowden, Network Support Manager, Headway Northern Ireland

THE SURVEY

Throughout our ABI Week activity, we have shared some incredible testimonies, quotes and facts about the many ways in which life can be re-written after brain injury. The campaign messages have resonated far and wide, helping to amplify the voices of those whose lives have been so completely changed within the blink of an eye.

We couldn't have done this without the input received through our surveys, which were launched before ABI Week and completed by just over 3,000 people directly impacted by brain injury, including both brain injury survivors and carers.

In this feature, we take a look at some of the powerful statistics and key messages that emerged from the surveys.

We would like to thank all of the brain injury survivors, families, partners, friends and carers who completed our surveys to help us better understand how brain injury can re-write lives. Thank you also to all Headway groups and branches, and all professionals, who helped to circulate the survey to their service users, clients and patients. We would like to extend particular thanks to the brain injury survivors and family, partners, friends and carers who granted permission to use their quotes within the report.

An exploration into the ways in which life can be re-written after acquired brain injury, of which short and long read copies can be found on Headway's campaign page.

WHAT DID WE DO?

We created and launched two surveys to be completed by brain injury survivors and their families, partners, friends, and carers. The surveys contained both quantitative and qualitative questions to gather experiences from people with lived experience of brain injury on how their lives had been changed by the injury.

We asked questions relating to aspects of life commonly affected by brain injury (relationships, social life, employment, mental health, driving and spirituality). We also asked broader questions on attitudes towards life changes.

Our surveys were promoted through our website and online communities. Our network of groups and branches and clinical contacts also helped with distributing the survey. Paper copies of the survey were made available for people who were unable to complete it online.

DID YOU KNOW? Our A life re-written survey was Headway's most-responded to survey ever?

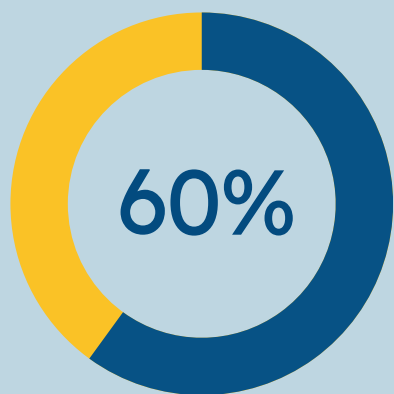


WHAT DID WE FIND?

Around 70% of brain injury survivors and carers report that their mental health is worse after brain injury, with anxiety and depression being highly reported.

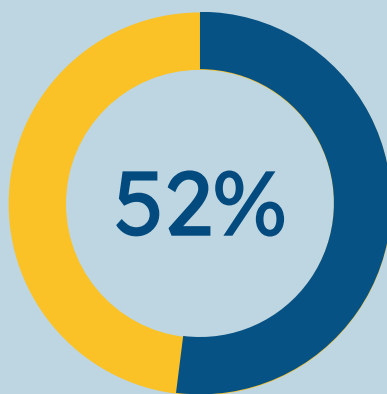
For survivors, living with the impact of the injury, being unsure about the future and feeling socially isolated contributed to worsened mental health. For carers, feeling concerned about the survivor's welfare and wellbeing, feeling unsupported, missing life as it was before the injury and managing life with the effects of brain injury contributed to worsened mental health. Mental health was reported to fluctuate regularly by both survivors and carers.

BRAIN INJURY SURVIVORS SAID



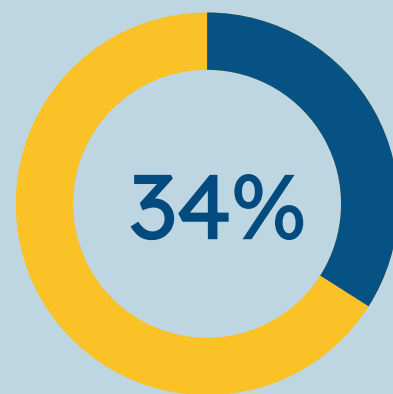
of brain injury survivors experience a worsened social life after their injury.

Survivors reported difficulties with coping in social environments, friends not accommodating for the impact of brain injury, fatigue affecting energy levels and practical issues with socialising, such as no longer being able to drive.



of carers also reported a worsened social life after the injury.

This was often due to needing to adjust their own social life to support the survivor.

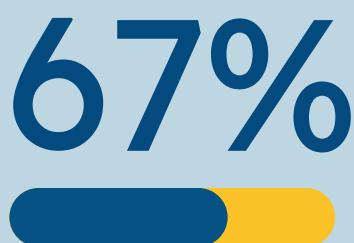


of brain injury survivors have developed new skills since their injury.

This included coping skills, positive personal traits, daily living skills, educational/vocational skills and even some 'superpowers'! 50% carers also felt they had developed new skills, often relating to their caring role and the development of positive personal traits.



of brain injury survivors have had to change their life goals because of their brain injury.



of carers have also had to change their life goals.

Types of goals that needed to be changed varied, but often related to career prospects, travelling plans, retirement plans, sports and hobbies, undertaking further studies, family matters (such as getting married or having children), travelling and owning one's own property.

Visit our campaign page to find out more about the results of our surveys.

[headway.org.uk/a-life-rewritten](https://www.headway.org.uk/a-life-rewritten)

We also asked people to tell us about anything that had helped them with the process of adjusting to these changes. Responses included:

Attendance at brain injury support groups, such as their local Headway group or branch

Having an opportunity to help others to adjust to life after brain injury and learning about others' experiences

Support and understanding of the impact of brain injury from loved ones such as friends and family

Adaptations and adjustments made within the workplace

Access to specialist support such as through counselling, rehabilitation teams or a neuropsychologist

Owning supportive equipment and resources such as adaptive equipment, a Headway Brain Injury Identity Card or a Blue Badge parking permit.

HATS FOR HEADWAY DAY

This year's photo competition brought us some of the best hats we have seen to date! A big thank you to everyone who took part across our social media channels. We've picked out some of our favourites from Headway groups, branches, and shops across the UK – and we're excited to announce the winners below.





**BEST CORPORATE PHOTO WINNER
COLES MILLER**



**BEST HAT WINNER
MALCOLM FROM
HEADWAY SOMERSET**



**Three questions for
this year's winner.**

**What inspired you to create
this hat?**

My daughter helped me, my grandchildren call me Mr. Bump because I am accident prone.

**How do you feel about
winning the best hat in this
year's Hats for Headway Day?**

It's very exciting to be able to raise awareness for Headway Somerset and ABI.

**What does Headway
Somerset mean to you?**

Support.

Brain injury survivors share powerful testimonies in parliament



Two brain injury survivors recently delivered moving testimonies to the All-Party Parliamentary Group (APPG) on Acquired Brain Injury.

These cross-party groups allow charities and non-governmental organisations to engage in discussions that influence politicians. The meeting, chaired by Baroness Morris of Yardley, saw MPs and other stakeholders listen intently to the experiences of Jason Clark and Alison Clarke, two brain injury survivors who are members at Headway East London.

Jason, who experienced a brain injury due to hydrocephalus early in life, spoke candidly about his struggles to find suitable employment. He highlighted the reluctance of many employers to make reasonable adjustments, a common barrier for individuals with brain injury. Despite these challenges, Jason has found fulfilment through volunteering at Headway East London who have been invaluable in assisting him navigate the complexities of claiming benefits and improving his housing.

Alison Clarke, who sustained her brain injury from a fall at home seven years ago, shared an equally impactful story. While she too faced an unsympathetic employer, she also experienced the positive side of the employment spectrum with a supportive and understanding employer. Alison's testimony underscored a critical message: there is no such thing as a "mild" brain injury. Her symptoms continue to affect her daily life years after her injury, illustrating the long-term impact of brain injuries.

Both Jason and Alison expressed profound gratitude for the support they received from Headway East London. Jason emphasised the advocacy and practical support provided, while Alison highlighted the crucial role of occupational therapy in her return to work. However, the most resonant theme was the solidarity and friendship they found within the Headway community. The shared experiences with other brain injury survivors fostered a sense of belonging and mutual support that has been indispensable in their journeys.

Their testimonies gave a clear reminder of the ongoing challenges faced by brain injury survivors and the critical importance of supportive networks and understanding employers. The APPG on Acquired Brain Injury were given a clear and compelling call to action: to improve policies and support systems for those living with the long-term effects of brain injuries – a message that has been built on by the Headway general election campaign and the launch of its manifesto.



Headway launches General Election manifesto calling for urgent action for brain injury

Following the general election announcement, Headway – the brain injury association has launched a General Election manifesto ahead of the 4 July vote.

Headway says 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.

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

The charity's manifesto, *From awareness to action, demanding better care for*

people affected by brain injury, focuses on five key asks of the government. Headway wants to see an end to the neurorehabilitation postcode lottery, investment in local brain injury reablement services, increased awareness and understanding of brain injury, enhanced support for brain injury survivors' loved ones, and a reform of social care making it equitable and sustainable.

Launching the Headway manifesto, Headway Chief Executive Luke Griggs said:

"Ahead of the General Election, we are calling on all political parties and candidates to commit to delivering meaningful change for brain injury survivors, their families and carers.

"It is crucial that the new government understands brain injury, prioritises it, and invests in services to support survivors and their loved ones.

"Brain injury survivors and their families deserve better. They deserve improved access to neurorehabilitation and local reablement services, reliable and sustainable social care, and comprehensive support to help them lived fulfilling lives.

"By adopting our five calls for change, we believe that the next government can transform the lives of those affected by brain injury."

How you can get involved:

There are many ways that you can try to influence prospective members of the next parliament to create change for brain injury survivors.






- You can write to or email your prospective parliamentary candidates, telling them about brain injury and Headway's five key asks.
- You can ask your prospective parliamentary candidates to sign the Headway pledge card.
- When canvassers from political parties knock on your door, you can talk to them about brain injury and the impact it has on survivors and their loved ones.

Templates and more information on these items can be found on the Headway General Election campaign page [headway.org.uk/ge24](https://www.headway.org.uk/ge24) or by scanning the QR code.



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	ASK 2  COMMUNITY SUPPORT invest in local brain injury reablement services	ASK 3  INCREASE UNDERSTANDING raise awareness of brain injury	ASK 4  FAMILY CARE enhance support for brain injury survivors' loved ones	ASK 5  REFORM SOCIAL CARE make social care equitable
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Let's go on holiday

With the brighter, warmer weather upon us, it's the season for packing up travel cases and heading out for a summer break.

Whether it's a chance to relax or a chance to explore, for many, being on holiday is an exciting and fun-filled activity. But the preparation and planning that goes hand in hand with travelling can often be stressful and quickly become overwhelming, especially after brain injury.

In this series, we look at everyday activities that brain injury survivors may need to adapt. For this feature, we discuss planning for a holiday after brain injury. Don't forget to check out our publication *Holidays and travel after brain injury* for more useful information, by scanning the QR code at the end.

The search is on...

A holiday begins with deciding on where to go! After a brain injury, it may feel as though there are fewer options available. However, with a little exploration, there are plenty of good options available to suit a range of needs.

- Ask friends, family or other brain injury survivors for recommendations if they have been on holidays. They might be able to suggest places that they think would be enjoyable and suitable for you.
 - If you have difficulties with making decisions, narrow your options to make it easier to choose a destination, for instance choosing somewhere within Europe, within the UK, within a certain region, or somewhere with a beach, or historical sites, or natural landscapes.
 - Explore accessible holiday providers. These can often cater for a range of disability needs, including both physical and non-physical accessibility requirements.
- Carefully consider what kind of destination or accommodation would be suitable for you:
 - Do you need a ground floor room, adapted toilets, or somewhere with clear enough floorspace for a wheelchair to be moved around?
 - Would somewhere in a quieter location be more suitable, or a room with dimmer lights if you struggle with bright lights?
 - Is there a restaurant on site, or are you within close enough distance of the sights you want to see, if fatigue may affect your energy levels?
 - Do you need to check weather conditions if you have difficulties with regulating temperature, or if hot conditions trigger headaches or anger?
 - Once you have a destination in mind, search online for what they can offer in the way of accessibility. For example, try searching 'Tenerife accessibility' on Google to see what comes up. Places which recognise accessibility issues might have more accommodation and travel providers who are more willing to work with you to adapt. Similarly, you can search online for major attractions in an area and tick off which you can and can't visit.



Check your insurance policy

Travel insurance offers a level of reassurance that you will be covered if things go awry with your holiday, for example if your luggage gets damaged or stolen, or if there are transport delays or cancellations. Travel insurance is a must if you are travelling abroad, but it is also advisable to check for policies if you are travelling within the UK.

Things to remember include:

- Try to find a policy that covers pre-existing medical conditions such as brain injury but be aware that the cost of insurance may be higher.
- Always get a few quotes before buying travel insurance, as prices and cover can vary depending on your circumstances.
- You can also apply for a European Health Insurance (EHIC) card, which covers the cost of emergency treatment in many European countries. Be aware that this doesn't replace travel insurance though, and won't cover the cost of many things such as medical repatriation back to the UK if an emergency occurs.
- When taking out travel insurance, make sure to check that your policy will cover any aids or equipment that you may need to take with you.

Booking your trip

Once you have chosen a destination, whether domestic or abroad, you will probably need to make advance bookings such as for transport, accommodation or activities and attractions. Some things to consider when making your booking are:

- Dates and times that may be busier, such as rush hour times on roads or summer holiday break times. You may be able to ask travel companies or attractions in advance about quieter times to travel or visit.
- Make lists or use an app to help you with making bookings and staying organised.
- Consider booking through a travel agent who has knowledge of your chosen destination and can offer advice, face-to-face meetings and arrange bookings for you.
- If you need assistance with funding your holiday, consider looking into grants. You may also be able to get discounts for either yourself or a carer on accommodation, attractions, or travel.

Planning your journey

Before you arrive at your holiday destination, you may need to travel significant distances. Whether travelling by land, sea or air, here are some suggestions for the journey:

- Have a plan or strategy in place for managing anxiety or anger if things don't go to plan, for example if there are complications or delays with your travel. This could include forming a backup plan in advance or learning breathing techniques to remain calm.
- Include breaks along the way so that you can rest if you struggle with fatigue. You should also try to keep days before and after your travel free from plans.
- Research any support and accessible facilities in advance, such as assistance with boarding, accessible rooms in hotels, quiet rooms at airports or train stations, or toilets along your route. Remember that you may need to make advance arrangements to access these, such as notifying travel companies in advance for assistance with boarding or having a Radar Key in the UK - or equivalent in other countries - to access Changing Places toilets.
- Be sure to contact travel companies (such as airlines and train companies) well in advance to arrange any assistance you might need. Don't be afraid to email or call accommodation or activity providers to ask if they can cater to your needs; most are only too happy to help.

Your packing list

So, you've chosen your destination and booked your trip... what will you be taking with you? What goes into your travel case will depend on your destination, your plans and the impact of your brain injury, but some general suggestions of things to consider taking include the following:

- **Lists** – keep a note of the things you pack and write these down in a list as you put them into your cases. This can help you to stay organised with packing again when you return from your holiday.
- **Camera/camera phone** – most people like to take photos while on holiday, and this might be particularly helpful if you struggle with your memory.
- **Medication** – make sure you take enough supplies of any medication, aids or equipment that you may need. Ask your GP if you need any extra supplies. Keep medication in their original packaging which shows your prescription label. Be aware that certain medications may be restricted in some countries, so ensure you check local regulations before departure.
- **Emergency contact details** – have some emergency contact details written down and keep this with you at all times. Many smartphones allow you to set your 'In case of emergency' (ICE) contact details, which can be accessed by others if needed even if you're incapacitated.
- **Brain Injury ID Card** – if you have a Headway Brain Injury Identity Card, keep this with you while travelling so that you can access the right help and understanding if you need it.



In your words

We asked our online community to give us their tips for travelling. Here's what they suggested:



Scan for more advice on travel after brain injury

"I don't fly any more as I don't want to push my luck after two subarachnoid haemorrhages. I cruise. I travel alone for the most part but always check the hospitals wherever I'm going. Just in case! Take meds plus a couple more days in case I'm delayed, or some other event occurs. Take my time driving. Regular breaks. Always keep it simple too and always ask for assisted boarding. I get so overwhelmed and I can't handle that part. Awful. My best bit of advice is: take your time!"

"I don't do early flights; always get later ones, get a lanyard so you can fast track, always wear a hat and sunglasses and try not to be in the sun too long. Most of all don't do too much, I get headaches all the time, so I sleep when my body tells me, don't fight it."

"Check your holiday insurance and if in doubt call them to make sure your cover is adequate. We booked our holiday a year ago and since then I've suffered a ruptured brain aneurysm and had to notify the travel insurance company of this. Yes, the premium went up a little, but for peace of mind it's worth it, knowing it's all declared properly."



LASTING POWER OF ATTORNEY

By Christine Thornley
- expert Will, Trust and Estates
Solicitor at Irwin Mitchell.



Losing the mental capacity to make sound decisions about aspects of our own lives is not something any of us like to think about happening. But it is important for everyone to plan for the future as, if this scenario occurs without any guidance, it can be difficult for loved ones to help.

A Lasting Power of Attorney (LPA) is the best way to ensure that those people you would want to make decisions for you have the authority to do so. This is even more important where there is a brain injury, as that person may require more support than others.

It is not correct to assume that a parent, spouse, partner or sibling has any automatic right to make decisions for their loved one.

What is a Lasting Power of Attorney (LPA) and why would somebody need one?

An LPA is a legal document that gives an individual (a “donor”) an opportunity to choose a person or people they trust (“attorneys”) to make decisions on the donor’s behalf if they lose mental capacity. There are two types of LPA – one for Property and Financial Affairs and one for Health and Welfare. Anyone over 18 who has mental capacity can make an LPA.

What does ‘mental capacity’ mean in this context?

Mental capacity means somebody is able to understand and make decisions for themselves. In this context, capacity means the donor must understand the

process of making an LPA, why they are making it and the likely outcome.

Having a brain injury does not automatically mean that that person lacks mental capacity and, if someone does have a brain injury, making LPAs should be considered as a priority.

What powers does it grant an attorney?

Each LPA ‘does what it says on the tin’.

A Property and Financial Affairs LPA means an attorney can deal with any decisions regarding the donor’s property and finances, including things such as managing buying and selling the donor’s property, paying household bills and managing the donor’s bank account. It is possible for a donor to restrict the types of decisions an attorney can make, or the donor can give the attorney authority to make all financial decisions on the donor’s behalf.

A Health and Welfare LPA means an attorney can make health and care decisions, such as whether a particular medical procedure is performed, what medication is administered and what level of care the donor requires (including, where relevant, what residential care setting the donor lives in). As with the financial LPA, it is possible for a donor to restrict the types of decisions an attorney can make or give the attorney authority to make all decisions on the donor’s behalf. In particular with the Health and Welfare LPA, it is possible for a donor to give



the attorneys special permission to make decisions about life-sustaining treatment.

What can't an attorney do?

- An attorney can only act in accordance with the power they have been granted by the LPA. Therefore, if the donor has limited the attorney's power in any way, it follows that the attorney can only act within the constraints of those limitations.
- A health and welfare attorney can never make decisions on behalf of the donor where the donor has the capacity to make those decisions themselves.
- An attorney must always act in the best interests of the donor. To help the attorney with this, the donor can include instructions and guidance within the LPA documents, setting out their views and wishes. This can be very helpful for the attorneys.

Can I appoint substitute attorneys?

Within the LPA there is the ability to appoint attorneys who will act for you initially and replacement attorneys, who will act as a permanent replacement when the first named attorney can no longer act.

The appointment of multiple layers of attorneys can be very useful and

ensure there is someone to act on an ongoing basis.

How should I choose my attorneys/replacement attorneys?

It is essential that you trust your attorneys and that they would be able to fulfil the role. There is no point appointing someone who does not have the skills/time to do the job or would not be able to deal with the additional responsibility.

If you are appointing more than one attorney, it is a good idea to appoint people who will be able to work together. There is no rule that your attorneys should get on, but experience shows that it can be very difficult if they do not.

Can you make changes to an LPA once it has been registered with the Office of the Public Guardian (OPG)?

The changes a donor can make to an LPA once it is registered are limited and any amendments need to be communicated to the OPG.

If a donor simply wants to remove one of their attorneys (e.g. their spouse) but wishes for their other attorneys' appointments to remain valid they would need to partially revoke their LPA.

If a donor wanted to remove all attorneys or "cancel" the LPA (to either make a new one or leave themselves without a valid LPA) they would need to revoke the LPA in its entirety. The OPG requires particular wording to be used for any revocation. They would then need to make a new LPA.

It is not possible for a donor to add further attorneys to an LPA once it is registered so it is important for clients to think carefully about who they would wish to appoint in the first instance and as replacements. In order to appoint new attorneys, the donor would need to revoke the existing LPA and register a new one.

How long does it last?

In general, an LPA lasts from registration until any of the following occurs:

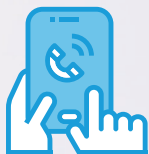
- the donor revokes the LPA in its entirety;
- all the attorneys and replacement attorneys have died, lost capacity or do not wish to act; or
- the donor dies.

It is therefore important for clients to choose attorneys who will hopefully survive their lifetime as, if there are no living attorneys or replacement attorneys, the LPA can no longer be used.

Services spotlight:

The helpline

The Headway helpline is a free, confidential service available to anyone with a question about brain injury - from survivors and carers to students and professionals.



Run by a team of trained nurses and non-clinical staff with expertise in supporting people with brain injury, the helpline aims to provide information on all aspects of acquired brain injury, including symptoms, rehabilitation, and practical problems.

In 2023 alone, the Headway helpline answered a staggering **11,019 enquiries**.

People contact the Headway helpline with a variety of support needs and questions. Headway's helpline team offer advice on many practical and social issues, such as: *rehabilitation, isolation, welfare benefits, counselling, carers, relationships, legal, employment and advocacy.*

The helpline: in numbers

Some of the most common effects of brain injury discussed in 2023 were:

- Fatigue **939**
- Memory **915**
- Cognitive **724**
- Psychological **671**
- Anxiety **538**
- Anger **510**
- Depression **426**
- Headaches **455**
- Behaviour **428**
- Executive dysfunction **416**

The helpline: in your words

"I feel blessed and very grateful for you being there each and every call with kindness, reassurance, and information."

"You helped me to feel empowered to take a step forward."

"I had lost hope... but this is the most I have been able to speak about my brain injury to anyone since my diagnosis."

"You are so very kind and compassionate, and now we have a place to start, because of you."

LOOK AHEAD IN THE NORTH 2024

The Look Ahead in the North residential weekend has been a highlight for groups and branches in the North East and Cumbria since 2011.

In March 2024, the weekend was held for the 12th time at the Calvert Trust in Kielder Water & Forest Park, Northumberland. 90 brain injury survivors, family members, carers and volunteers from nine local groups and branches attended for a fun filled weekend.

Tim has been a member of Headway North Cumbria for 8 years after sustaining his brain injury in June 2012. He first attended LAN in 2019 and attended in March 2024 as a photographer for the event.



Tim explains: "I have been a gig photographer for over 10 years, I have a lot of friends in bands, some even touring the world, so I have free tickets to snap them in action. I want to start my own photography business and so I volunteered to photograph the LAN weekend to add to my portfolio and meet others with a brain injury from the region."

Tim is an experienced photographer, but the weekend kept him on his toes. He said: "Photographing the owl show was really fun and challenging, picking the right settings and finding a 'safe' spot but

I still got a few owl wings clipping me on the way past...!"

Although Tim was there photographing the action, it didn't stop him from getting involved: "I did a couple of new things; the zip coaster was something I'd normally be scared of, but my room mates talked me into it," he added. "I screamed around it a couple of times but I'm glad I did, it was a nice thrill which isn't something I feel often. I also tried archery for the first time, and I really enjoyed that."

Tim was the only one from his Headway branch to attend LAN this year but he quickly made friends: "I felt really safe and welcomed by everyone from the North East Headway groups," he explained.

"After the weekend, I will definitely try new things that I haven't done before and won't be so scared of trying. Hopefully I can open my eyes to different types of photography styles."

A huge thank you to the sponsors of the weekend, EMG Solicitors and Burnetts Solicitors along with support from The Scott Eredine Charitable Trust, Irwin Mitchell, The Proven Family Trust and The Catherine Cookson Charitable Trust.



HONOURING OUR LONDON MARATHON

HEROES

What a day it was!

Here we celebrate our Marathon heroes, flying the flag for Headway in one of the UK's most famous events. A huge well done and thank you to each and every one of them.

Here are just a few of our heroes and what they've raised to support life after brain injury.*

Rolf Zartner

£17,402

Emily Watts

£7,353.99

Katie Oliver

£6,160.88

Matt Elliman

£5,199.71

Kelly Holzherr

£2,564.73

*Totals correct at time of writing...
and still rising!





“Once again, our Marathon Team surpassed our expectations. It was wonderful to be there to cheer them all on. Their fundraising efforts, training dedication and pure determination to complete the course, raising money and awareness for those living with brain injury is staggering. We are incredibly grateful to each of them and to their families, friends, and supporters who encouraged them along the way. It really does make a difference and supports us in our mission.”

(Jen Murgatroyd, Director of Fundraising)



Peter's 3D model

We are delighted to share the latest artwork from Headway Sussex member, Peter Ross, who has an incredible background in engineering.

Peter was born in Southern India and came to England as a child. He went to school in Sussex, where he still lives and has three grown-up children. He was an Aircraft Technician in the Royal Air Force, during which time he obtained a BA, BSc and a masters.

For three years after that, he was a maintenance manager at Worth Engineering before joining British Airways as an aircraft engineer in 1987. He remained there until 1995 when he became the engineering manager responsible for the Supersonic Land Speed Record Project known as 'Thrust'. This was the first car to beat the land speed record on 15 October 1997 in the Black Rock Desert, Nevada. The vehicle was jet-propelled, weighed nearly ten tonnes and was driven by a Royal Air Force fighter pilot. The car is now displayed in the Coventry Transport Museum.

Peter was also the Technical Superintendent at the School of Engineering at Surrey University and later became the Safety Advisor at the University of Brighton.

Peter suffered a devastating stroke in November of 2012, which left him paralysed on his right side, and his speech was badly impaired. Peter was in hospital for nearly a year and was unconscious for many weeks.

Peter now attends Headway in Newick East Sussex one day a week, where he participates in several activities. He is a talented artist and produces pencil sketches from imagination.

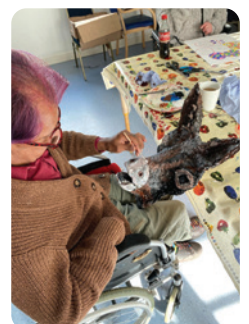
He recently finished creating a 3D donkey model, which took six months



and began life as a flat piece of card. Peter finds artwork helps him with mobility in his upper body and encourages relaxation. He also draws and paints at home and is a member of Brighton Art Club.

At Headway, Peter also takes part in group cognitive exercises, which he says enable him to gather his thoughts and transfer them into words – something which has proved an enormous challenge since his stroke.

Peter finds meeting up at Headway with others who have suffered brain injury beneficial, as he can chat with them as well as the carers and volunteers. When he wishes to have some quiet time, he also enjoys tending the raised beds of herbs and vegetables and maintaining the house plants and seedlings.



Photography with Headway Northampton



Photography workshops taking place at Headway Northampton allow service users to be creative, unlock forgotten skills and develop new ones. Together, the Headway Northampton photography class, wrote:



"Whilst this is the first of the photography workshops taught at Headway Northampton in recent times, we hope that it will encourage other venues to create their own. Through our weekly classes with our teacher, we have not only improved our photographic knowledge but also see the personal impact it has had on us directly.



"Photography unlocks so much more than simply taking a pretty photo. We have to work together to set the lighting, alter the camera settings, work as a team to achieve a photograph to be proud of."



"Our current project is based on the feelings we have around our brain injuries. We are creating portraits that attempt to convey the feelings we have experienced individually. The aim is to show more authentically how we feel, something that is not always comfortably shared.



"As a group our confidence has soared. At the start of the year, we began to learn how to set up our own lighting to create different effects, how the camera settings work in unison to achieve desired results and even came together to do a peer review of our work.

"So now when we see our work on display, it is us that created it. It gives us such pride."





HEADWAY TRAINING

More information



0115 924 0800



training.admin@headway.org.uk

INTRODUCING OUR EXCITING NEW TRAINING PROGRAMME FOR 2024!

Headway delivers a range of online training courses focussing on a range of issues and effects of brain injury. Our 2024 training programme has expanded this year to include **three new courses**.

We have courses available for those living with a brain injury, their families and professionals working within the brain injury field. Find the right course for you or your team, from tried-and-tested courses to brand-new sessions.

**SCAN
HERE
TO BOOK
YOUR
COURSE**



HEADWAY TRAINING PROGRAMME 2024

Understanding MY brain injury

A 40-minute session about the hidden effects of brain injury and the rehabilitation journey: delivered by and created for brain injury survivors.

Navigating life after brain injury

New for 2024! If you are caring for someone with a brain injury or have a relative being treated in hospital, then this session will help you to understand more about brain injury.

An introduction to brain injury

This session has been designed to provide awareness of the hidden effects of brain injury. It is aimed at professionals new to the world of brain injury.

Understanding acquired brain injury (CPD Accredited)

Designed for care professionals and those working with brain injury survivors, this session will aim to give delegates a better understanding of brain injury and its effects on survivors.

Effective communication strategies

New for 2024! This session aims to provide frontline staff and other professionals with effective communication strategies when interacting with individuals who have experienced a brain injury.

Behaviours that challenge

This session will examine the main models explaining challenging behaviour and explore proactive and reactive strategies to manage those behaviours.

Goals training

New for 2024! This session has been created to assist professionals and care staff in establishing SMART goals while working with individuals who have experienced brain injuries.

Solicitors training (CPD Accredited)

This course has been designed for solicitors and their colleagues who are involved in brain injury cases.

Understanding brain injury training for criminal justice professionals

The training combines specialist brain injury knowledge and understanding to provide participants with an understanding of the often-hidden consequences of brain injury.

Intimate partner violence (IPV) and brain injury

Survivors of intimate partner violence (IPV) suffer from traumatic brain injuries (TBIs) at a high rate. This condition can be misunderstood and difficult to spot due to the hidden consequences. This course further explores IPV.



Leading Personal Injury and Medical Negligence Lawyers



Boyesturner is proud to be an active supporter of Headway. Kim Milan, head of our Personal Injury team, is a Trustee of Headway Thames Valley.

Our specialist lawyers and brain injury support team have the knowledge, experience and commitment to ensure that you and your loved ones get the result you deserve and the support you need. We are more than happy to visit you in hospital or at home at times that suit you. We provide national coverage.

A special thank you to my lawyer Kim. Her input has changed everything for me. She has given my life a level of security and stability that I never thought I was capable of achieving post-accident.

Jessica Stevens

Contact Kim Milan on
0118 952 7137 or
claimsadvice@boyesturner.com
boyesturnerclaims.com

Personal yet professional legal advice.

Freeths vastly experienced Personal Injury team, led by the highly respected Jane Goulding has an unrivalled reputation for handling brain injury claims, helping our clients receive the life-changing rehabilitation and compensation they deserve.

Please call Jane today for a free introductory chat on **0345 050 3296**
or email jane.goulding@freeths.co.uk



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FREETHS

Putting your life back on track

It's what we do



Prince Evans LLP is a specialist brain injury practice that focuses upon representing the interests of our clients and their families to the full.

We are understanding and knowledgeable of the multiple complexities that are experienced by all when a loved one is affected by brain injury.

We provide a free nationwide no obligation consultation to discuss respective claims and where our expertise can assist; including with potential interim payments, rehabilitation and case management and support. We offer no win, no fee funding.



For more information on how we can help, contact
Gary Smith, Head of Personal Injuries

Call free on 0800 019 0991

Email: gary.smith@prince-evans.co.uk

Gary Smith is a member of Headway – the brain injury association's Personal Injury Solicitors list



PRINCE EVANS
S O L I C I T O R S L L P

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