

Summer 2022

Headway News



The magazine of Headway - the brain injury association

*See the
Hidden
Me*



**See the
Hidden Me**

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**Using your
gift for good**

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Adam McQuillan,
brain injury client

Welcome

Welcome to the summer edition of Headway News.



"But you don't look disabled..."

"Brain injury is like...a computer that's crashed and is rebooting; sometimes things work OK, other times they get stuck."

"It's like walking in fog every day."

"I picture dropping a smartphone. The screen may be cracked, but you can't see all the damage inside."

These powerful and emotive analogies are just a small selection of the contributions made by brain injury survivors to our new campaign, *See the Hidden Me*.

Approximately three quarters of brain injury survivors face challenges every day as a result of the effects of their injuries being hidden.

Problems with memory, concentration, or debilitating fatigue are routinely misunderstood by others, making it hard for survivors to get the help and support they need.

At Headway, we are determined to give a voice to survivors and their families by helping people to see what's hidden. To be kind and patient. To not misread the signs. To see the hidden me.

Those voices are coming through loud and clear! We could not do this without the courageous people – including the four stars of our campaign, who we introduce on page 12 – who choose to share the intimate and personal

challenges they face on a daily basis. To everyone who has contributed to this campaign, we offer a heartfelt thank you!

At present, the government is putting together a pan-departmental strategy that we hope will address the support needs of brain injury survivors and their families.

Importantly, the voices of those directly affected by brain injury are being heard as the strategy is formed. Those involved are seeing the hidden effects of brain injury.

The ABI Strategy presents a great opportunity to finally give brain injury the attention it deserves throughout all government departments.

We welcome it, we celebrate it, and we hope it will lead to meaningful change as we all work together to improve life after brain injury.

Luke Griggs
Headway's Deputy Chief Executive



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.

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Subscribe to our monthly Headway News Bitesize email at:
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Essential contacts

Headway office:

Bradbury House, 190 Bagnall Road, Old Basford, Nottingham NG6 8SF

Telephone:

0115 924 0800
enquiries@headway.org.uk

Nurse-led freephone helpline:

0808 800 2244 (9am - 5pm, Mon to Fri),
helpline@headway.org.uk

Website:

www.headway.org.uk

Advertising:

directorofcomms@headway.org.uk

Fundraising:

projects@headway.org.uk

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Your views

As part of our *See the Hidden Me* survey, we asked brain injury survivors and their loved ones what they would say to people to help them understand the hidden nature of brain injury...

"I can't control my feelings sometimes and I need help with my memory. I would like people to believe me as I hide my injuries well. I wish people would be patient with me and understanding."

Lisa

"It takes me longer to understand, so please be patient with me and I will try and answer the best I can."

Eddie

"Be kind to everyone, you never know what people have been through. Hidden or not."

Richard

"Don't keep telling me 'but I have that problem as well' or 'it's an age thing that we all get'. Listen and let me explain, and don't negate my explanation or stop me from speaking about it."

Caroline

"Just listen to us. If we can't do something or go somewhere, don't push us or make us feel bad, please comfort us and don't show any disappointment you might feel because we can guarantee we already feel guilty."

Jenny

"Please educate yourself about brain injury and don't be afraid to ask questions. Don't write me off, I'm still in there, it's just a work in progress."

Anna

"Looking 'OK' on the outside doesn't mean I am feeling 'OK' on the inside."

Anonymous

"Just ask: Are you okay? How are you doing?"

Anonymous

Visit our website at headway.org.uk/about-brain-injury for information on the effects of brain injury and practical guides to help you cope. You can also get in touch with our helpline to talk through your concerns and get information that is tailored to your circumstances. Contact the team on **0808 800 2244** or helpline@headway.org.uk

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Go green!

Did you know that the plastic wrap used for Headway News is recyclable? It's made from polythene film and starts to break down after just three months. It can be recycled alongside carrier bags at larger supermarket stores, not at the kerbside. Do your bit to help save the environment and recycle today.



Latest news round-up

With news of your charity's ongoing work to improve life after brain injury

What next for the ABI Strategy?

After launching in mid-March, the call for evidence on the new Acquired Brain Injury Strategy has now closed. All of the responses will now be reviewed by the government and used to develop a new strategy to improve services for people with brain injury.

Over twelve weeks, the consultation sought the views of brain injury survivors, carers and family members as well as charities and professionals supporting those living with ABI.

Headway put forward a response calling for action in the areas where you have told us it is most needed. This includes improved access to specialist neurological rehabilitation and support services, more support for families, disability benefits reform, greater awareness and understanding of brain injury in the criminal justice system, and better awareness and prevention of concussion in sport.

With the call for evidence now over and the strategy in development, we will endeavour to work alongside the

government to ensure that the views and needs of those affected by brain injury are heard. Keep an eye on our website and social media for the latest updates.



The Headway Awards are back!

Nominate someone special today

After two long years, we're delighted to announce that the Headway Awards are returning for 2022 and it's time to tell us who you think deserves recognition.

Always admired as one of the highlights of the Headway calendar, this glittering event will take place on 9th December at the Landmark Hotel in London. It's sure to be back with a bang as we recognise the inspirational achievements of people living with brain injury and the dedication of those working to support them.

Finalists will be considered for one of these four awards:

- Alex Richardson Achiever of the Year sponsored by Slater & Gordon
- Carer of the Year sponsored by Barr Ellison
- Volunteer of the Year sponsored by Anthony Gold
- Stephen McAleese Outstanding Contribution to Headway Award

Do you know someone who has defied their brain injury to achieve a great milestone this year? Or perhaps you know someone that often goes above and beyond when caring for someone with a brain injury? Or maybe you know of a long-standing Headway volunteer who is overdue public recognition and thanks?

Nominate someone special at **headway.org.uk/nominate**

The deadline for nominations is Sunday 24th July.



Headway welcomes new research into effects of heading the ball

Headway – the brain injury association has welcomed a new study investigating the long-term impact on the brain of heading a football, but believes there's still more to be done.

The four-year BrainHOPE study will work with 120 ex-professional footballers aged between 40-59 to look into ways of reducing the risk of repeated head trauma and subsequent disease.

The £1.3m project is being led by respected expert Dr Willie Stewart who is a consultant neuropathologist at the University of Glasgow, and is jointly funded by the FA and FIFA.

"It's positive to see football finally putting its hand in its pocket to pay for this excellent research, but it has taken far too long to get to this point," said Peter McCabe, Chief Executive of Headway.

"And whilst this is a helpful step forward, we hope that it will not be four years before the next funding announcement.

"More money needs to be pledged and more research undertaken, so that a wider body of evidence from a range of researchers can provide a real consensus as to what damage is being done to the brain every time someone heads the ball.

"At Headway, we know the benefits of sport and staying active, and it's very important to our wellbeing, but we also cannot wait for another four years to see the extent to

which players – from Sunday league to the global elite – may be putting themselves at risk.

"We look forward to seeing how the BrainHOPE study progresses but hope in the meantime more researchers, academics and funders come forward to make brain health in football a priority."



An iconic adventure on two wheels!

The London to Brighton cycle ride is one of our most popular two-wheeled challenges, taking riders on a 55-mile journey from the heart of London to the buzzing Brighton seafront.

It's just one of the cycling challenges we have on offer this year, with our keen cycling team choosing rides that span the length and breadth of Great Britain.

To find out more and secure your place, contact Juma on events@headway.org.uk or head to headway.org.uk/cycle-rides



Latest news round-up

With news of your charity's ongoing work to improve life after brain injury

Artist marks fifth anniversary of brain injury with new music supporting Headway

Producer Ross Wakefield, who writes under the alias Frankson, has spent much of his career composing for TV, documentaries and film.

Now, five years after suffering significant head injuries, the artist from East London is releasing new music and supporting Headway through his EP streaming and sales.

'The Retreat' was released in May and includes the opening track 'Burning Embers', which has attracted praise from world-renowned DJs including Rob Da Bank, whilst the EP's lead single, 'Mistaken' featuring Kathrin DeBoer, has had a number of plays on BBC Radio 6 Music.

You can buy 'The Retreat' at [franksonmusicuk.bandcamp.com/album/the-retreat](https://www.franksonmusicuk.bandcamp.com/album/the-retreat) or search on your favourite streaming service.



Head over to page 22 to read more about Ross' story.

Young volunteer 'overwhelmed' at surprise Child of Britain accolade

It wasn't the usual morning at the Headway shop in Winsford, after the Mayor and the town's media came in for a surprise visit.

They were there to see 15-year-old volunteer Callum Ellis and present him with a special certificate of merit from the Child of Britain Awards.

Callum, who has additional needs, has been volunteering at the Headway Winsford store for two years, and in that time has become a firm favourite with shoppers and staff alike.

After a nomination from Tina Cheswick, the manager at the charity shop, the judges at the Child of Britain Awards 2022 decided that Callum deserved special recognition. They stated: "Congratulations. Your spirit, determination and courage is an example to all."



Callum is a real Headway Hero!



Proud Callum receives his certificate outside Headway's Winsford shop

The award was presented to Callum by the Mayor of Winsford, Councillor Nathan Pardoe, who surprised the young volunteer at the shop where he spends so much of his time. The Mayor said: "It is a privilege to visit Headway and meet Callum to present him with a Child of Britain Award nomination certificate."

"Callum has volunteered tirelessly throughout the pandemic and brings so much joy to customers and staff."

Tina, who nominated Callum for all of his hard work, said: "Everybody compliments him. He's so outgoing and chats to everyone on the till. He's always offering to help people take their shopping out to their car and is a joy to have around."

Callum himself was overwhelmed with the award and delighted with the goodies the team at the Headway Winsford shop had got together for him.

Heather Imber (Jury)

1962-2022

Headway is mourning the loss of a charity champion who for many years helped to improve the lives of brain injury survivors across the south of England.

Heather Imber, known to many as Heather Jury, passed away in March after a long battle with cancer.

Heather was well known throughout the region, using her skills, knowledge and compassion in leading roles at Headway Portsmouth and Headway Basingstoke.

At Headway Portsmouth, she represented carers passionately and with great effect as a trustee before becoming Service Manager where she played a key role in stabilising and restructuring the group at a time of enormous financial pressure.

She later joined Headway Basingstoke as Service Manager, again at a time of great change, where she developed a bespoke brain injury service for people across North Hampshire.

Evelyn Vincent, Chair of Trustees at Headway Basingstoke and Deputy Chair at Headway – the brain injury association, said: “Heather was truly dedicated to making life better for people with brain injuries and their families.

“If you snapped her in half she would have Headway written through her like a stick of rock.”

“Anyone who met Heather would say how professional she was with a calm manner that inspired confidence in others. It was a working partnership that will be hard to replicate. Heather made many friends across the Headway network and will be sorely missed.



Heather

“We simply do not have enough words to express our deep gratitude for the years we were blessed to have her. She made strong friendships and was more than an employee. Her contribution to both Headway groups as well as the wider Headway network was invaluable.

“We will miss her forever and our sincere sympathies go out to her husband, Doc, and children Stuart and Christina.”



ACTION FOR

BRAIN INJURY WEEK 2022

16-22 MAY

SEE THE HIDDEN ME

The impact of a brain injury can be vast and varied, but for many survivors, it is the battle that they endure when their visible scars fade that makes life after brain injury a complicated path to tread.

For this year's ABI Week, the *See the Hidden Me* campaign explored the impact of what it feels like to live with a brain injury as a hidden, or misunderstood disability.

Frustrated. Lonely. Vulnerable. Different.

These are just some of the most common words that the 2,682 people who took part in this year's ABI Week Survey used to describe how it feels living with the hidden effects of their brain injury.

In many ways, the results of the survey gave a stark reflection of the realities of living with a hidden disability which was reflected in the figures and comments from brain injury survivors and their carers.

More than three quarters of brain injury survivors who responded to the survey said they experience issues because of their brain injury being hidden on a daily basis, and more than half say they believe it's meant they've been unfairly treated.

"People judge you as a normal person with no issues as that is how I look. They literally judge a book by its cover."

Stephen

"When I tried to return to work folks would just see I looked fine & one even told me I'd 'be fine, you look great' like that's some kind of good thing when there's a million symptoms kicking that no-one can see."

Jodie

Relationships appeared to be particularly hard to maintain, with more than two thirds of brain injury survivors saying friendships had been negatively affected and more than half of respondents saying their relationships with their partner or spouse had suffered.

"It has caused a breakdown in my marriage and I'm getting divorced because my husband finds it hard to cope and even understand my brain injury."

Sharon

"My wife will say things to me and either I will forget, or I just won't understand what she is talking about. It leaves her frustrated and sometimes very annoyed and I DON'T UNDERSTAND WHY!"

Philip

And the issues are not only felt by the survivor themselves; 75% of carers say they've faced problems as a direct consequence of their loved one's brain injury being hidden.

"Friends have given up on me because I can't do all the fun stuff they do."

Rebecca

"It affects me having some form of social life. Time with family and so on. It restricts my movements and freedom."

Giles

BRAIN INJURY: A HIDDEN DISABILITY

SURVEY RESULTS



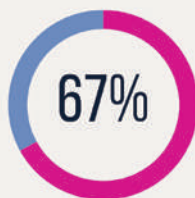
OVER THREE QUARTERS

of brain injury survivors experience problems on a daily basis as a direct consequence of their brain injury being hidden.

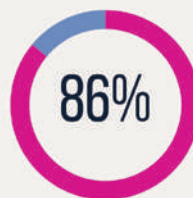
HOW DOES BRAIN INJURY BEING HIDDEN MAKE YOU FEEL?

"DIFFERENT" "ISOLATED" "ALONE" "FRUSTRATED" "MISUNDERSTOOD" "VULNERABLE" "LONELY" "ANXIOUS"

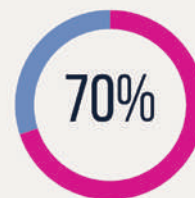
AS A RESULT OF HIDDEN DISABILITY...



of brain injury survivors felt their friendships were negatively affected



felt that a lack of understanding from society is one of the main challenges



of carers felt their relationships have been negatively affected

The message that spreads throughout the *See the Hidden Me* survey and testimonies of brain injury survivors over ABI Week is clear: Be kind, be patient, don't judge, and take time to learn what having a brain injury really means.

Across professional and personal relationships, by improving understanding of what living with a hidden disability is really like, people will be better placed to be a more valuable, more patient support.

You can find out more about the *See the Hidden Me* campaign at seethehiddenme.org.uk

Read on for more information on the campaign, including

the brain injury survivors that feature in this year's awareness film, and a look at how Action for Brain Injury Week was marked across the UK.

STARS OF THE SHOW 2022!

With this year's ABI Week shining a light on the hidden and often misunderstood effects of a brain injury, when it came to making the *See the Hidden Me* campaign video, we found four stars who wanted to share their experience of living with a hidden disability.

These are their words...



"I try and fit in. But fitting in is rather hard."

"My short-term memory has gone. It's been getting so much better over time, but to anyone else... it's terrible.

"It's awkward sometimes when you're having a conversation with someone, and they talk for ages and you're like... 'I don't know what you're talking about' because you can't remember the subject, or how it started, or you just can't concentrate and follow what's being said.

"And just talking to people causes me fatigue... When I get home my head doesn't want to work, and my brain doesn't know how to function. I won't be able to find the words, or I'll jumble them up and I'll have to go into my room, shut the curtains and just lie down.

"I don't think people understand the hidden effects of brain injury.

I've got friends who've read up on it and I really appreciate that and find it so helpful. My mum and uncle as well, before I got home from hospital, had done so much research and had learnt the things I might struggle with, so they understood the difficulties.

"That would be my advice to anyone who knows someone with a brain injury – go to the Headway website, which is brilliant, and read up.

"Without that understanding, friendships and relationships end."

Iona, 23



"I feel like my brain is like a start and stop button on a car, which breaks down for a few minutes and then takes longer to get going than it should."

"By the time it gets itself together, if I've been in the middle of a conversation and forgotten what I wanted to say, you and I are no longer together. We've moved on with our lives, or at least you have... then suddenly my brain re-engages, and I remember what I wanted to say. But it's too late, as you're no longer there.

"It makes me feel frustrated."

"At the beginning of my recovery, I couldn't walk or talk and needed constant help. But those obvious signs of disability are no longer there. Now, I am slower than I used to be and my thinking processes have slowed down, but then when I try to say that to people who have never had a brain injury, they say 'the same thing happens to me' and I say 'oh really, when was your brain operation?' and we laugh... but it's true."

Annette, 75



"I struggled to talk and struggled to walk for a few years. Then all of a sudden, I asked my son for a cup of coffee, and I thought someone must be in the room with me due to the shock. Since then, no-one's been able to shut me up!"

"It's like things flash into your brain and get pulled from triggers and it starts a conversation that ends up on ten or twenty roads to get to the point. So, for me, it's a nice feeling that I can speak now, but for the person listening, by the time I get back to the point, the point's gone. And I'm aware of that. And I'm trying my best to stop it."

"But also, sometimes when I'm talking to people, you see their eyes rolling when I talk, and it's off-putting. You can see them thinking 'what am I going to say' or 'how long's this going to take' and it's like they're assuming in that split second, you're 'ok'."

"You can't win. If you say what they want you to say, there's nothing wrong with you. But if you say something unexpected, they think, 'oh it's because of the brain injury'. It really is an invisible disability and total rollercoaster of emotions."

"It's just harder because when you feel that dip or that judgement from people, it's more difficult with a brain injury to get back up."

John, 50

"Whilst I came to the end of my brain tumour journey when I got discharged, it was the start of another journey dealing with the effects of the brain injury it left behind."

"It affects my memory, I get neuro fatigue, I do still slur and stutter occasionally - although it's not as bad as it was - and I also get very irate. I think that's the most frustrating side effect because I know it affects other people, and that's very hard."

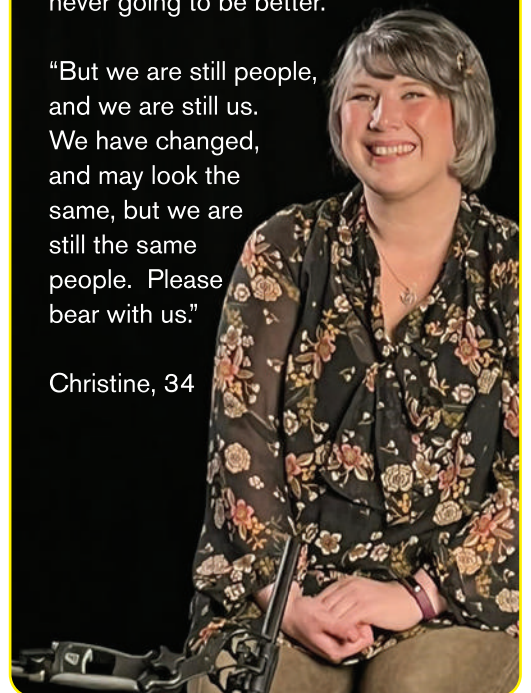
"It's also very difficult with the expectation that now my brain tumour has gone, I am now 'better'."

"It took a long time for me to realise that I will never be better. That's ok. I'm fine with that now. But you can see some people really struggle with that. They'll ask, 'well when will you be better?', 'Oh, are you really still going to Headway? Do you really still need that?'"

"Well, yes. In the politest of ways, I am never going to be better."

"But we are still people, and we are still us. We have changed, and may look the same, but we are still the same people. Please bear with us."

Christine, 34



14



BATH

Headway Bath created a series of videos including this one with Andy

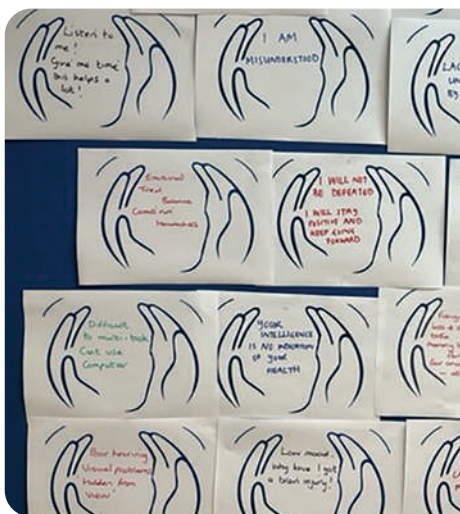
TELLING YOUR STORY

A series of personal testimonies of what living with a hidden disability feels like were created by the team at Headway Bath.

In Andy's video he said: "I don't think people can see how I'm feeling because they haven't had a brain injury, so they don't know what it's like."

To hear from Andy, Sal, Phil and so many of the brain injury survivors that attend their local Headway was incredibly powerful, and all of their words will help society to better understand.

"Getting up in the morning is the most difficult and surviving day by day."



LANCASHIRE



HAND IN HAND WITH THE BRAND

This excellent use of the Headway logo to surround the statements made by members of Headway Central Lancashire on how living with their hidden brain injury makes them feel, was really inspired. They worked together to complete the *See the Hidden Me* survey and held focus groups to share learning, overcome difficulties and help each other by

using this effective way to demonstrate their experiences.

Some of those difficulties that members wanted to highlight were:

"Your behaviour can be misunderstood."

"Listen to Me. Give me Time."

"Having a brain injury doesn't make you any less of a person."

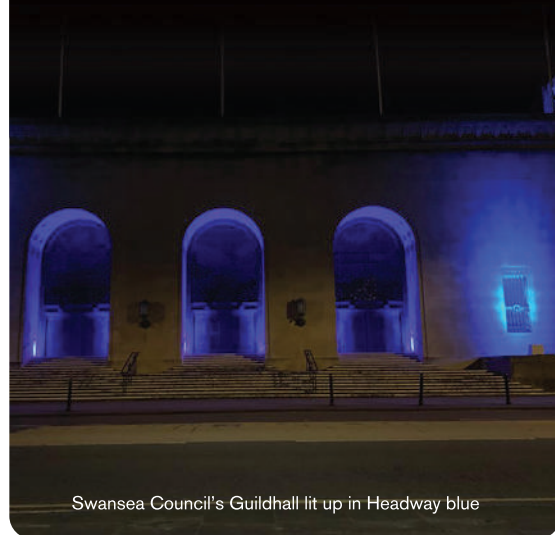
ILLUMINATING THE ISSUE

SWANSEA

A suggestion from a member of the public to Swansea Council, supported by Headway Swansea and Network Support Coordinator Ffion Jones, saw the city's Guildhall lit up in Headway blue on the final evening on ABI Week.

The council said: "We're lighting up Guildhall blue to raise awareness of brain injury which can be, for many of those affected, an invisible injury. If you're affected by brain injury or want to find out more go to headway.org.uk"

A simple, yet beautiful end to ABI Week, but not the end of the *See the Hidden Me* campaign as we all work to bring the effects of this hidden disability into the light.



Swansea Council's Guildhall lit up in Headway blue

These are just some of the ways *See the Hidden Me* was marked across the four nations.

Just search **#SeetheHiddenMe** and **#ABIWeek** on Twitter, Facebook and Instagram to see more excellent pieces of work, and once again a big thank you to everyone who got involved.



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'A JOURNEY OF A THOUSAND MILES STARTS WITH A SINGLE STEP'

THE HEADWAY TRAIL

In February, the team in Northern Ireland set a challenge for everyone to get out and get active. Whether it be walking, running, cycling or using a chair, each member of the network's thirteen groups was asked to cumulatively clock up a total of 250 miles – the distance it would take to travel between all of the country's 13 outreach meeting places.

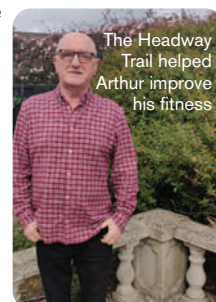
The ancient Chinese proverb used as the title to this article was used as motivation by the Headway team in Northern Ireland to convey the notion that however difficult the task is, it can only be completed if it's started in the first place.

From videos of a meander down the coast, to a stroll to the Derry Girls mural, brain injury survivors, their supporters and the Headway team shared their journeys on social media, and recorded distances travelled on record sheets, to happily reach their common goal.

Arthur Moore, who attends Headway sessions in Belfast, said he recorded his daily steps each day: "As the days went by, I wanted to set small targets to increase my steps. The next week, I felt I had to beat the previous week. I started going for walks around where I live, and the more I walked, the easier it was to increase my steps.

"The following week, I went shopping, and realised my step count increased to 4,000 per day. I began to enjoy going for walks and felt a lot healthier. I started to walk my dog Daisy along the sea front which increased my steps to 5,000 per day. Now I try to go out walking every day because it makes me feel better alongside improving my sleep pattern.

"Overall, I recommend walking for anyone that is physically able to



especially in a group walk and enjoy walking in the fresh air together. **KEEP ON WALKING!!**"

Also clocking up his steps was Mark Ewart, who is supported by the Lisburn base after he suffered a brain injury falling from a ladder at work.

He said:

"During the step challenge, I went out of the door every morning and evening, no matter the weather, rain and snow. I never missed a day. In total I did 250,604 steps!"



Mark said his physical and mental health improved



Brenda wrapping up for the South Down walks

Setting herself a goal of 3,000 steps a day was Brenda Degan, who attends sessions in Downpatrick.

"When I achieved my 3,000 steps, it gave me the incentive to go out and get more the next time," said Brenda. "I was trying to beat my own record each time – it was like I was competing with myself, it got a bit addictive!"

"I also felt a sense of achievement and felt much fitter for doing it."

"I would like to do the challenge again in the better weather and I would like to encourage others to come and join me – it is much better to have someone to walk and talk with you for a bit of craic!"



"YOU CAN DO ANYTHING YOU PUT YOUR MIND TO"

After falling down the stairs of her old Victorian house, Dee, a teacher and mum-of-two, suffered a fractured skull and two subdural haematomas.

When she was found at the bottom of the stairs by her husband and children, she was trying to talk but unable to form sentences.

After a stay in hospital, made more difficult by Covid restrictions, she returned home but felt sick all the time and had constant pain in her head, which meant she couldn't move for days.

Dee said: "All of my senses had altered. My sense of taste and smell were gone, but then everything else had become incredibly sensitive. It was like sensory overload."

"And as a busy working mum who was used to juggling twenty plates at a time, I struggled to focus on just one."

After lots of trial and error, Dee was able to get the right mix of medication for the pain and sickness, and things began to improve.

"The physical effects then seemed to be more of a challenge. I was so wobbly, but I wanted to get out walking as soon as possible."

With lots of work with her physio to improve her inner ear balance, step by step, she progressed.

"Improving my balance was just a game-changer," said Dee.

"Finally, I could shower by myself without needing help. I was starting to walk better without feeling dizzy. It took a while to build the strength in my legs, then the strength in my core, but I could feel I was getting stronger and so I decided I'd try the Couch to 5k app."

Whilst it took time and built slowly, the progress was heartening for Dee and remarkably, just eleven months after her accident, she was putting on her trainers to run a 10k.

"For my children to be standing there cheering me on, after an experience which has affected them far more than I think I realised, to see me running... I hope that helps them. I hope it helps them feel less anxious. I hope it means they'll stop worrying about me as much."

"I hope it helps them to feel that you can do anything you put your mind to."



Dee with her well-deserved medal

'I FELT A SPARK COMING BACK'

After moving to Gran Canaria to realise a life-long dream in 2016, months later, Clare Rutter collapsed onto a pavement and was unconscious for 30 minutes.

"I was dazed, confused and scared. I didn't recognise who I was anymore," said Clare.

"Fatigue, headaches, migraines, nausea, balance issues – only when I was asleep did I have any relief from my new normal and that's when I wasn't plagued by insomnia."

After months of trying to fit back into her 'normal life' Clare's mental health was suffering as she couldn't come to terms with being unable to do what she could so easily before, "It was soul destroying. I was crumbling. I was broken. I couldn't do it anymore."



Clare was named #ShePaddles Ambassador for Canoe Wales

Clare said the positivity, hope and knowledge she gained from the stories and information on the Headway website in the early days really helped, and after deciding to return to Wales, the help from her GP and the support she received from Headway Ceredigion was what she so desperately needed.

Having grown up on the coast, Clare loved being by the sea and after her occupational therapist suggested voluntary work, she eventually ended up helping at a contact's adventure business.

Despite her exhaustion, the canoeing and kayaking felt as if it was reviving her: "I felt a spark coming back. I was feeling more alive. More enthusiastic. More excited. Happier."

Then came stand-up paddleboarding – or SUP boarding as it's known – but Clare's balance issues, a part of her life since the brain injury, made it incredibly difficult.

Undeterred, the more she tried, the more determined she became, improving her confidence, self-belief and skill bit by bit.

After lots more training, Clare received her Paddlesport Instructor Award and was offered a full-time contract!

Despite lockdown threatening to take her beloved sport away from her, Clare invested in equipment and training.

Her faith was restored when British Canoeing selected Clare to be the #ShePaddles Ambassador for Canoe Wales in 2021/22.

"SUP is now the thing I love to do most. It saved me. It brings me new energy, so much joy and happiness and a determination to paddle many different locations and meet new people."

YOUR TURN!

If you'd like to start increasing your activity the first move is the hardest, but the benefits, as you can see here, are many. Make sure you check with your GP, physiotherapist or occupational therapist before taking on a new exercise programme.

Contact the Headway helpline on **0808 800 2244** or **helpline@headway.org.uk** if you'd like more information on the physical effects of brain injury such as balance problems, and details of where to find further support. You might also like to speak to your local Headway group for details of any services offered by them or other organisations in the local area.

"SUP is now the thing I love to do most. It saved me."



HATS^{FOR} HEADWAY DAY 2022

Well, it was another hat-tastic year for Hats for Headway with so many of you taking part.

Thank you so much to every human, dog and alpaca that shared their headgear with the world and made a donation to this special day. In fact, the calibre was so good, that we had to introduce a new category.

Ladies and Gentlemen... here are your winners:



BEST HAT 2022!

This year's top prize goes to Wayne who attends Headway Somerset. The panel loved that he had gone to lots of effort to make his incredibly tall top hat, and that he had created the headpiece out of old newspaper – epitomising Headway Somerset's reuse and recycle initiative.

"It's ace! I've always been a bit of an artist" said Wayne, explaining that both he and his family were delighted at the win and very excited about the prize.

And what a prize it is, as Wayne will now receive a luxury Fortnum and Mason hamper kindly donated by Anthony Gold solicitors.

The team told Headway: "From everyone here at Anthony Gold, we'd like to pass on our congratulations to the worthy winner of #HatsforHeadway for winning in style with this wonderful hat! Congratulations to everyone who took part and donated to this amazing cause!"





The team at Hugh James win best group category 2022!

BEST GROUP 2022!

There were feathers aplenty, fascinators for days and fluffy creations everywhere you looked when it came to the accolade of best group. It was incredibly hard to pick a winner, but one entry stood out for being so unique. The panel selected the team from Hugh James for the mammoth amount of effort they put into their clever hat-passing film.

"Every year, the Hugh James Neurolaw team loves taking part in Hats for Headway and this year was no exception.

"It's a chance for us to raise awareness of brain injury, shine a light on the incredible work that Headway does and raise money for a very worthwhile cause.

"This year we thought it would be fun to do a video which could be shared on social media to raise awareness of acquired brain injury and even managed to get some family members and pets involved!

"The hats were incredible, ranging from a fireman's helmet to a daffodil and we had great fun as a team making the videos and splicing them together to make one 'pass the hat along' video.

"We are delighted and surprised to have won the Best Group Entry!"

Well, it was much deserved and we at Headway are really pleased you had a great time too!



Brewster showing off his winning looks!

BEST PET 2022!

This year, we were totally blown away by the efforts of your four-legged companions (and their owners!), so much so we decided that it could not go unrewarded.

So, this year's inaugural Best Pet is Brewster the working cocker spaniel, who didn't just go for one hat... but four!

When Brewster found out he was "chuffed to bits" and his owner Michaela said he was "proud to support the wonderful work that Headway do."

And the question on everyone's lips... which hat did Brewster like wearing best?

The Highland Cow of course.

Michaela told Headway News that Brewster's choice was obvious as "he was very keen to play with it when he wasn't wearing it!"

Brewster will be getting a little canine treat through the post to celebrate.

Whether you wore a wig or doffed your cap, we at Headway are grateful for all of your help in 2022.

You can look through all the entries on social media by searching **#HatsforHeadway**.



Another dog gets involved at Headway Derby



Headway Shropshire put their best hats forward!



Ashleigh and her Alpaca Lyla



Hats even took centre stage at Rogers & Norton Solicitors bake sale

Using your gift for GOOD

Our Headway Heroes have been at it again!

From getting sponsored for active challenges, to supporting the charity using their creative genius – we are so grateful for all the incredible feats you put your body and mind to.

If you're thinking of setting yourself a fundraising challenge for Headway,

these wonderful supporters and survivors may just inspire you...

In this feature, we showcase some of the innovative ways that Headway groups and branches across the UK are supporting their members in their creative pursuits.



Liz before her stroke



Liz and Justina say disability is not a barrier to a fulfilling life

The Unplanned Paths

Justina and her mum Liz had long talked about writing a book together. A story that would mark their lives before and after Liz's stroke.

When the pandemic took hold in 2020 and the UK was plunged into lockdown, despite all the associated worries of Covid-19, the pair finally had the time to put pen to paper.

The mum and daughter from South London wanted to write about the journey they'd been on together, and Justina was convinced her mum's experience would "inspire others who had been hit by devastation to look at the opportunities that come with that."

Liz was 37 when she had her stroke, living abroad and raising two children single-handedly. But it wasn't just the life she knew that had changed, it was also the lives of her children.

Liz went on to spend five years living in a care home before Justina was able

to bring her mum home to live with her. With the help of carer Lorna, who Liz now sees as a 'sister', Liz and her family are able to travel together and enjoy the adventures and challenges they love.

"Life is for living!" Liz believes. "I was given two hours to live, and God has given me eighteen years. We don't take that for granted."

As well as the book guiding us through their lives pre and post-stroke, Liz and Justina want to raise awareness of the early warning signs of stroke, as well as raise money for other survivors of stroke and brain injury by donating all proceeds to Headway.

You can find out more about their book 'Unplanned Paths: A Stroke of Luck Life' which launches later this summer by following www.unplannedpaths.co.uk



Justina and Liz love their adventures together



When creativity is cathartic

On 28th April 2017, Ross was walking home from seeing a friend when he was knocked over by a moped while crossing a road. His face and head took the full impact of the driver's helmet.



48 hours later, the composer woke up in hospital with zero recollection of the event but with serious skull and facial fractures including his nose, eye-socket, jaw and cheekbones, as well as fractures to his shoulder and ribs.



Ross' recovery was then complicated when he contracted meningitis in hospital but thanks to his wife, who was a junior doctor at the time, the infection was caught.

Luckily Ross has been able to return to a career he loves, mostly composing for TV, film and documentaries, but as he approached the 5-year anniversary of the incident, Ross wanted to focus on a project much closer to home.

"The accident was a huge confidence knock, that I could be hurt so badly simply crossing a single carriageway road. How could I have been so stupid? It riddled me with self-doubt."

"So to put so much of myself into a project I care so much about, to lay yourself open to scrutiny... it wasn't

something I was ready to do and it's taken a long time to get here.

"But by deciding that the profits of sales and streaming should help Headway – a charity that is incredibly close to my heart and close to the journey that I've been on over the past 5 years - it meant that I had committed to something."

It gave Ross the motivation to finally work on his own music. So, writing under the alias 'Frankson', Ross used sounds he had collected on his phone during his recovery in hospital - from tapping on the night stand to using a pen against the water jug – and sampled them to create Frankson's debut EP 'The Retreat'.

With plays on BBC Radio 6 and receiving praise from globally-renowned DJs like Rob Da Bank, the EP, as well as singles 'Burning Embers' and 'Mistaken' is available on most music platforms, with profits from streaming and sales donated to Headway.



Giving Back

Nick Fletcher, a City shipbroker, was moving into a new flat on a snowy, windy day in March 2013.

In the awful weather, a telegraph pole fell and landed directly on the side and back of Nick's head, knocking him to the ground.

Whilst it was extremely unlucky timing, Nick had the good fortune that at that precise moment, an off-duty fireman was driving past and was able to help in the crucial minutes before the ambulance arrived.

In hospital, Nick was placed into an induced coma for a month and a third of his skull was removed. He also had to battle pneumonia due to the dust he inhaled from the fallen telegraph pole.

When he eventually awoke, his family, friends and girlfriend were by his bedside. Nick said they had been told about the work of Headway on day one - "They knew and subsequently I knew, that I would have their support if I needed it."

"So this year, I've decided to run the London Marathon... in order to give people who have suffered traumatic brain injuries the best chance possible.

"I hope that alongside my run, sharing my story of why I'm running, may help to raise funds for others to have hope too."

You can support Nick and the rest of Team Headway on our London Marathon fundraising page by searching for 'Headway – the brain injury association London Marathon Team 2022' on [Justgiving.com](https://www.justgiving.com).

COOKING WITH CONFIDENCE

The Headway Swindon Cookbook

For some, preparing a tasty and nutritious meal seems as easy as pie, but for others the very thought of it feels like pie in the sky. Our connection to food goes well beyond basic survival and nutritional needs, with the colours, textures, flavours and satisfaction of a well-cooked meal nourishing our souls as well as our bodies.

But making a meal can be complicated. Even after the ingredients have been purchased and prepared, following a recipe, timing things right and remembering to carry out key tasks uses the very abilities that are so often impacted by brain injury. This can lead to a range of difficulties and frustrations, making cooking seem impossible or even causing a hazard in the kitchen.

It was this challenge and seeing the enormous potential of incorporating cooking into clients' rehab programmes that inspired Sonia de Blaquiére, Service Development Manager at Headway Swindon, to set to work on an innovative cookbook that is designed by brain injury survivors, for brain injury survivors.

We spoke to Sonia and some of the clients who were involved in creating the Brain Injury Cookbook...

"I took inspiration from a client, Debi, who once told me of her frustrations when cooking and discovering she had missed out vital ingredients," said Sonia.

"We worked together to develop a strategy where she would prepare all the ingredients by placing them in order of use.

"Once they had been added to the dish, Debi would put them away in the cupboard. This strategy ensured she had remembered all the ingredients, avoided the frustration and kept her motivation to continue to cook.

"We realised that having a check list to mark off when each ingredient is used in the dish would reinforce the memory that it has been included, so we wanted to incorporate this into a new cookbook for people with brain injury."

"The cookbook has a variety of recipes for all abilities and encourages everyone to try something they can enjoy. I have also added Headway hints to each recipe to encourage people to experiment with the recipes and try something different."

For Debi, one of the biggest losses she felt after her brain injury was losing the ability to cook.

She said: "I loved cooking and was good at it. However, after my injury I blew up microwaves as I would not know what to avoid putting in them, for instance metal.





Joe proudly shows off this restaurant-style salmon dish!

"It makes me confident and braver to try new things."

I would get upset because I wouldn't remember the measure of ingredients and put too much in, or forget if they'd been added or not.

"Last week I made a curry at Headway using our own brain injury cookbook. It has clear instructions, large print and it was nice to participate and be involved. You can work out quick and easy meals for the week.

"Being able to cook again has made me feel confident and worth something, a bit like the old me. I can cook for my family and the book has helped that to happen."

Marco Gambi was no stranger to cooking before his injury, having worked in catering for 20 years before being hit by a mini-van while riding his motorbike in 2016. The resulting severe brain injury left him with a wide range of effects, from memory problems and fatigue, to reduced concentration span and difficulty with processing information.

"I wasn't able to cook for the first six months after leaving hospital," said Marco. "Then I could only cook one item at a time after months of practice.

"Now I'm able to help clients improve their skills and help them to cook dishes from the cookbook with confidence.

I have an understanding and empathy of their issues."

Since its launch, many Headway Swindon members have found the cookbook invaluable in boosting their confidence and helping them to feed themselves and family.

Joe, who was assaulted 11 years ago and still experiences memory issues, says cooking is "a little victory, which makes me feel proud and good about myself", while Don, who sustained a brain injury 35 years ago in a motorcycle accident and had never cooked before, says it "makes me confident and braver to try new things".

Finally, Marco offers some sage advice to those who are inspired to give cooking a try after brain injury: "If you're going to Headway, you're already a fighter. Have a look at the book and just take small steps, do the easiest one first and then go from there. Trust me, it will get better."



Sarah, Billy and Simon preparing their next meal from the cookbook



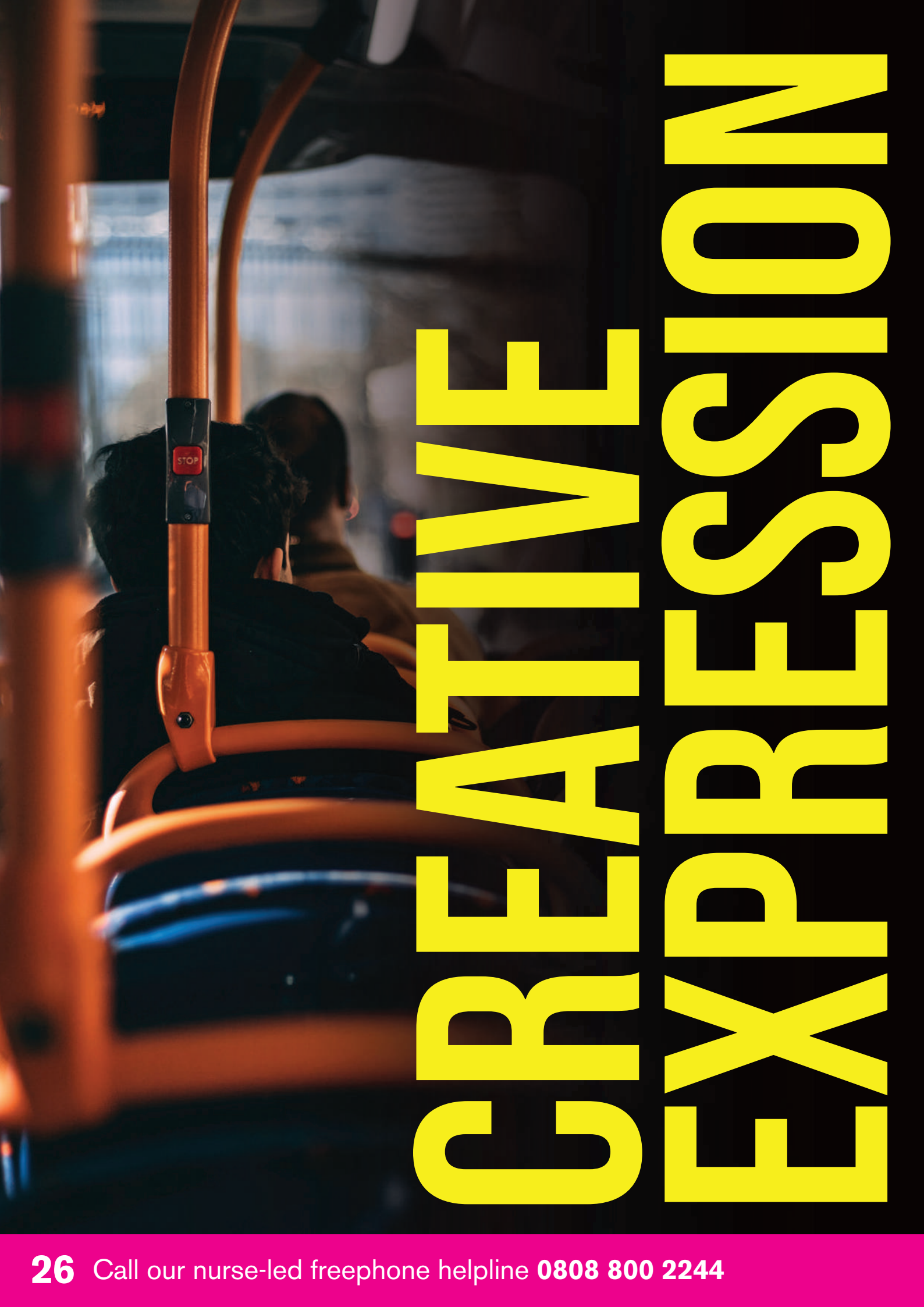
Darren and Debi P get stuck in at the hob in the Headway Swindon kitchen

To find out more and order the Brain Injury Cookbook for £22 + P&P, email info@headwayswindon.org.uk

If you're keen to get back to cooking but worry that the effects of your brain injury might make it difficult or put you at risk, always make sure you get support before you head to the kitchen. You might ask a family member or friend to help you, or for more complex issues an occupational therapist or social worker may be able to discuss your ability to prepare a meal and give you advice and aids to help.

Remember, as with any rehab it can take time and patience, so don't turn on the cooker unless you're confident (and safe!) to do so.

Contact the Headway helpline on **0808 800 2244** or helpline@headway.org.uk if you would like to talk things through.

A photograph of a person sitting on a bus, looking out the window. The person is seen from the back, with their head resting on an orange handrail. The handrail has a small red button with the word "STOP" on it. The background is blurred, showing the interior of the bus and the view through the window. Overlaid on the right side of the image is the text "CREATIVE EXPRESSION" in large, bold, yellow capital letters.

CREATIVE EXPRESSION

Brain injury survivor Stef Harvey, a client at Headway Hertfordshire, shares her powerful poem 'What did you not see?' to raise awareness of the hidden effects of brain injury.



"Six years ago, as a result of a whitewater kayaking accident, I acquired a brain injury," said Stef.

"My identity disappeared. I had amnesia, no language, no thoughts, no sense of time. My sensory input meter was jammed on overdrive, I became slow, I misjudged things physically and socially.

"Re-learning of such basic skills as the alphabet and counting, language and behaviour, left me with anxiety and depression.

"Life is still a challenge and sometimes a struggle, but with progress. I have a kind and patient husband, two very supportive daughters, a forgiving and loving dog; I have a phone full of apps to assist me, helpful neighbours, a support group, therapists, colleagues.

"From the outside, until I communicate or walk, you would have no idea my poor brain struggles.

"But here I am and, if you are lucky, you might get to know the hidden me :-)"

WHAT DID YOU NOT SEE?

By Stef Harvey

(Client of Headway Hertfordshire)

When you scowled at me on the bus, what did you see?
A person clearly undeserving of the seats for disability?
That I should stand? Or sit at the back? That others are more needing?
That I must come from arrogant stock, bad manners and bad breeding?

If I could, I would. You don't understand,
Being needing of accessibility wasn't in my life plan.
Was it a particular sort of disabled - how do you want me to look?
All my limbs amputated, a crash helmet, and eating my colouring book?

What you are failing to judge me on is the hidden me.
You won't be able to spot my symptoms of brain injury.
That you are challenging me now is why I prefer to stay home,
Than deal with the public as well as my brain injury syndrome.

When I awake to a new day with its challenges ahead,
I want to fall back asleep, delay waking, stay hidden in my bed.
Depression is the first thing I must conquer and be strong,
Paint on a face that shows the world nothing is wrong.

I must follow my lists of how each day should begin.
You can't tell but my brain has faulty executive processing.
Without my lists I have forgotten toileting, eating, even dressing,
When to leave the house and other actions equally pressing.

And things often go wrong with my deportment and balance,
My judgement of proximity is not one of my talents.
I am as likely to walk into a door frame as the gap in the middle,
Or not notice a trip hazard and go down like a skittle.

I see people I know, walk past and forget I need to acknowledge them,
I interrupt or walk away in the middle of conversations.
I get easily angry and impatient, I offend and confuse,
Cry or laugh at odd times and unintentionally amuse.

The attention I give is often a small fraction,
Because of my painfully high levels of distraction.
I used to hold an audience with my quick-witted repartee,
I used to present intellectual challenges with my academic degree.

But now in company when I open my mouth to speak,
People shuffle uncomfortably, fidget and their faces turn bleak.
They don't want to comment and I feel I need to explain,
The problem is not them, it is me and this stupid brain.

"Oh" they say, but I "look normal" or "gosh, we can't tell",
That they "had no idea" I had a brain injury and that I'm "doing so well".
This non-complement fails to acknowledge my struggle, my difficulties to survive,
And that most moments each day are a struggle to thrive.

I know that you can't tell the effort I'm making,
That I seem like everyone else, that you can't tell I am faking.
I use technology and gadgets and widgets to cope,
And the assistance of charities and support groups to give me hope.

I consider the day when it is over and mark myself out of ten,
And know in the morning I'll have to do it all again.
This exhausting treadmill feels like a criminal punishment assignment,
The isolation I experience is like solitary confinement.

I disembark with when the driver prompts me, and I say thank you and wave,
I breathe through anxiety: "I am ok, I will continue to be brave."
Fellow passenger please remember that it matters what you say and do,
And that one day, any day, this could happen to you.



Inside your incredible brain

In this edition, we will look at the second largest lobes of the brain, **the temporal lobes...**

Location

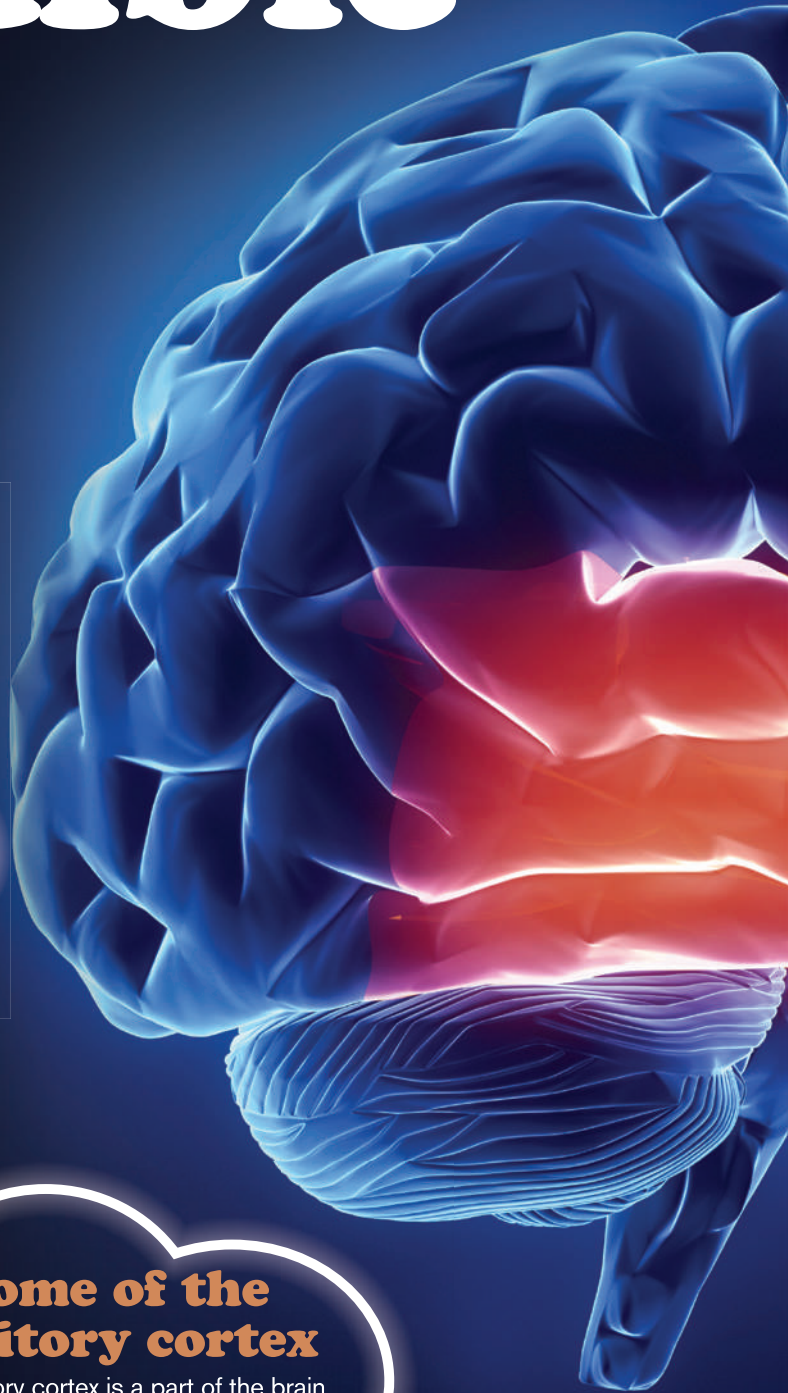
The temporal lobes (one on each side, 'hemisphere', of the brain) are located just behind the ears within the skull; they get their name from this location, as they are close to the temples of the head.

Functions

The temporal lobes are responsible for processing a number of skills, including speech and language, sound and vision, memory and hearing.

Home of the auditory cortex

The auditory cortex is a part of the brain located in the temporal lobes and is responsible for processing sound, for instance when we listen to music.





Home of the hippocampus

The hippocampus, so called because its shape resembles a sea horse, is an area of the brain largely responsible for memory and is located in the temporal lobe.

The famous case of H.M.

One of the most well-known patients in the field of neurology is H.M., a patient from the 1950s whose temporal lobes were operated on to relieve him of severe epilepsy. While H.M.'s seizures improved following his operation, he was left with severe memory problems and was no longer able to form new memories or keep hold of memories from a few minutes ago. The case of H.M. helped neurologists to better understand the role and importance of the temporal lobes.

Well connected

The temporal lobe has lots of connections with the rest of the brain. Skills such as memory, for instance, are not processed by just one single part of the brain – rather, lots of different parts of the brain are responsible for processing this complex skill, which is why the brain is so interconnected.

Responsible for processing language

Problems with language can occur following damage to two language specific parts of the brain, Wernicke's area and Broca's area, both of which are located in the temporal lobe.

Damage to Wernicke's area can affect understanding and processing speech, while damage to Broca's area can affect speech production.

Temporal lobe epilepsy

The most common type of focal epilepsy occurs in the temporal lobe, known as temporal lobe epilepsy.



CELEBRATING THE QUEEN'S PLATINUM JUBILEE 2022!

This June saw Her Majesty the Queen becoming the first British Monarch in history to celebrate 70 years on the throne.

Up and down the country, events took place to mark the occasion, with street parties and afternoon teas just some of the ways people got together to enjoy the long bank holiday weekend.

For Headway, marking the historic reign of Queen Elizabeth II came in many forms, from creating opportunity, to creating artwork.

The Sports Arena at the University of Worcester will host the Games



World's first Acquired Brain Injury Games

Earlier this year, Headway Worcestershire was awarded £50,000 from The National Lottery Community Fund to present the inaugural Acquired Brain

Injury Games in honour of Queen Elizabeth II's Platinum Jubilee.

In a world first, Headway Worcestershire will stage a series of physical, cognitive, creative and life skill competitions this summer accessible to all adults with an ABI.

The physical challenges will include boccia and walking tennis, whilst your pottery and woodwork skills will be amongst the creativity put to the test in the Creative Expression rounds! Dominoes and Memory games will form part of the cognitive element or if you fancy entering the Life Skills competition... it could be your wonky veg that captures the judge's eye!

Most importantly, Headway Worcestershire is working to ensure that everyone with a brain injury is able to participate in at least one of the events, and they are hoping that other groups and branches will get involved too.

The team are working with local schools and partnering with the University of Worcester Sports Arena to support the event which is scheduled for the August bank holiday. It's hoped that the Platinum Jubilee money will create a

long-lasting legacy for the Games, and this event will be the first of many.

If you'd like to know more, help or volunteer for the event, or have your group or branch involved, please email the team on ABIGames@hwtl.org.uk

The official portrait

And as is the case with all good celebrations, once again we have seen great creativity amongst the Headway network in preparing for the Queen's Platinum Jubilee.

Bobby, from Headway Black Country, drew this wonderful picture of the Queen in the lead up to the big day. We especially like the signature hat and pearls!



Bobby with his brilliant picture of the Queen



Leading Personal Injury and Medical Negligence Lawyers



Boyes Turner 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

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The Legal 500, 2022

"The team is practical, realistic and helpful, thoughtful and empathetic. Their practitioners are very intelligent and personable solicitors who really care."
Chambers & Partners, 2022

Legal 500 and
Chambers & Partners

**Top
Ranked**



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



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