# Headway News

Holidays after brain injury

The magazine of **Headway - the brain injury association** 



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# Welcome

## Welcome to the spring edition of Headway News.

It has been an exciting few months here at Headway. We celebrated the achievements of the finalists at our Annual Awards in London. It was truly humbling to hear so many inspiring stories from brain injury survivors, their families and carers from across the UK.

Last month, there was a further debate in Parliament to discuss the impact brain injury can have on individuals and families, as well as the work that needs to be done to make changes to areas such as the disability benefits system and access to timely and appropriate rehabilitation.

It was heartening to hear MPs from all sides of the House speak with such passion and determination.



During the debate, the work of Headway's groups and branches was mentioned numerous times, as was the work of Headway - the brain injury association.

We were delighted to hear Siobhain McDonagh MP, one of our Parliamentary Champions, raise concerns about hospital car parking charges. This is an issue we had raised with the Secretary of State for Health and Social Care and we are pleased to have Siobhain McDonagh's backing on the injustice suffered by families spending enormous sums of money on hospital car parking fees so that they can be by the bedside of family members who have suffered an acquired brain injury.

In this edition, there is a moving interview about bereavement after brain injury with Lauren Gilligan, page 24, the harrowing story of comic book author Leah Moore's brain injury while at a festival, page 12, and details of how you can make a difference by volunteering in one of our charity shops, page 22.

You will also find out many other ways Headway is helping brain injury survivors. Indeed, this is an exciting time to get involved with Headway. By working together, we can ensure that our services are available to those who really need them.

**Peter McCabe** Chief Executive



# 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!

If you'd prefer to receive Headway News as an email then let us know at headway.org.uk/tick-yes

# **Essential contacts**

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# Your views...

"I can't help it, by the time I've thought about the comment I've already said it and the damage is done."

Daniel MacEachern

## Following a brain injury a person may be left with issues of impulsivity and disinhibition.

For example, they may speak without thinking through the consequences of their words, laugh at inappropriate moments or engage in dangerous or costly activities without considering the negative impact of their actions.

We asked our followers on social media whether they, or their loved one, experience impulsivity following brain injury.

"I swear a lot now, even in front of my parents which I would never have done before my brain injury. I also say some very insensitive things to people because I'm so direct and I don't often know until it's pointed out to me."

**AJ Johnston** 

"I'd blurt out things that I thought were really funny in the spur of the moment and then realised it was inappropriate as I saw everyone's face drop to

**Anthony Potter** 

"I definitely bought too much online and was very impulsive and spent far too much money on clothes and shoes. My husband imposed a rule that all purchases had to be checked with him in advance and this worked

**Emily Draper** 

"My husband was affected in this way with impulsiveness but has calmed down a bit as time has gone on. Now we talk about the practicalities of things first, things that he may not have

thought about, I have to be the realist which isn't

**Claire Freeman** 

# In this issue...

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# Latest round-up

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

# Headway delivers vital brain injury training to Surrey Police

Headway has delivered training to Surrey Police's custody staff to help them identify and support brain injury survivors when they come into contact with the criminal justice system.

The training included an overview of the effects of brain injury and the impact it can have. It also featured a section on Headway's Brain Injury Identity Card.

Nev Kemp, Deputy Chief Constable for Surrey Police and the National Police Chiefs' Council's Lead for Custody, said: "We were delighted to have Headway

- the brain injury association deliver training in understanding brain injury to our custody staff in Surrey Police.

"This will help custody staff identify and support brain injury survivors when they come into contact with them. As the National Police Chiefs' Council lead for custody, I would encourage other police services around the country to participate in this training."

Peter McCabe, Chief Executive of Headway, said: "We would like to thank Surrey Police and the National Police Chiefs' Council for the opportunity to raise awareness of brain injury, and our Brain Injury Identity Card, directly with

the staff that may come into contact with brain injury survivors.

"Brain injury is widely misunderstood in all facets of society and those working in the criminal justice system are certainly not alone in struggling to identify and appropriately support those affected.

"It is vital, however, that vulnerable adults living with the long-term effects of brain injury are identified at the earliest possible opportunity.

"Training such as this is a great way to help increase the chances of brain injury survivors receiving the correct support and we hope to deliver more training of this type to other forces across the UK."

# Headway calls for football to answer key questions on heading

Headway - the brain injury association has welcomed the joint announcement from football associations in England, Scotland and Northern Ireland regarding new heading guidance for age groups between undersix and under-18.

The main elements of the guidance are:

- No heading in training in the foundation phase (primary school children)
- · Graduated approach to heading for children in the development phase U12-U16
- U18 heading drills should be reduced, to take into consideration the heading exposure in matches
- Don't over inflate the footballs: use the lowest pressure authorised by the Laws of the Game

However, key questions remain.

"In light of the robust research conducted by the University of Glasgow linking football to degenerative neurological conditions, it seems entirely sensible to limit the number of times children are allowed to head footballs," said Peter McCabe, Chief Executive of Headway the brain injury association.

"The question is, is this enough? Should it be limited to children?

"We cannot allow for key questions to remain unanswered, such as at what age is it safe to head a modern football - if at all? Neither can we afford to wait 30 years for the results of a longitudinal study to reveal the answers or hesitate to introduce other common-sense measures that protect players - such as concussion substitutes.

"More and more research is now emerging showing differences in brain functioning immediately

following football matches or heading practice.

"Football has to be willing to react to this growing body of evidence and not solely rely on dementia diagnoses when assessing the relative risks of heading footballs compared to the wider health benefits we know playing sports brings."



# Free or discounted will writing service for Headway supporters

# Did you know that 60% of UK adults don't have a will?

A will is the only way to ensure your money, property, possessions and investments (known as your estate) go to the people and charities you care about. For example, if you and your partner aren't married or in a civil partnership, your partner won't have a right to inherit if you don't have a will.

Headway has a list of solicitors who offer free or discounted wills to Headway supporters. We also offer a home visit solicitor will writing service through The Goodwill Partnership at a cost of £125 + VAT for a simple will.

You don't have to leave Headway a gift in your will to use this scheme, however all gifts, whatever the size, are very welcome.

For more information contact Rachel Broughton, on 0115 924 0800 or by emailing legacy@headway.org.uk.

# Do you work on a building site and are passionate about safety? Share your views through our survey!

We want to find out your views on the use of hard hats and other issues around head injury while at work.

The results of the survey will be shared during Hard Hat Awareness Week in June, as part of our partnership with leading safety manufacturer Centurion, which aims to raise awareness of using and maintaining hard hats while on site.

If you complete the survey, which will be open until 30th April and can be found on our website, you'll also stand the chance of winning a £50 Amazon voucher.

For more information visit our website.



# **Headway welcomes** credit card gambling ban

Headway has welcomed the news that gambling using a credit card will be banned but has reiterated its calls for more to be done to protect brain injury survivors.

The ban, which starts on 14 April, comes after reviews of the industry by the Gambling Commission and the government. Last year Headway gave evidence to the All-Party Parliamentary Group (APPG) on Gambling Related Harm to explore the links between brain injury and gambling addiction.

Behavioural effects of brain injury, such as disinhibition, impulsiveness and obsessive behaviour, and cognitive effects, including memory loss and impaired reasoning, can make brain injury survivors more vulnerable to the addictive nature of gambling.

Luke Griggs, Deputy Chief Executive at Headway, said: "We've heard harrowing accounts of brain injury survivors losing huge amounts of money as a result of insufficient protections being put in place by online casinos. For example, one brain injury survivor lost £67,000 in just 40 minutes despite registering himself as being a vulnerable adult.

"The credit card ban is a helpful first step in protecting vulnerable people from gambling related harm. However, the government needs to do far more to force the gambling industry to better protect vulnerable people who have significant amounts of cash at their disposal. This includes brain injury survivors who may have access to large compensation payments that were supposed to support them for the rest of their lives.

"This multi-billion pound industry can, and must, do so much more to protect vulnerable people like brain injury survivors from the often-devastating consequences that problem gambling can inflict on people and their families."









# **MPs** debate acquired brain injury

MPs from across the political spectrum took part in a debate in Parliament about acquired brain injury early this year.

The debate was called by Chris Bryant MP, who chairs the All-Party Parliamentary Group (APPG) on Acquired Brain Injury and has championed the cause of brain injury on numerous occasions, including speaking at our The Way Ahead conference in 2019.

MPs raised concerns about several issues including funding for Headway

groups and branches, the provision of neurorehabilitation, how changes to

welfare benefits are impacting on brain injury survivors, the criminal justice system, hospital car parking and sports related injuries.

We would like to thank all the MPs who spoke so passionately about the issues that affect brain injury survivors and their families every day.

Below are some of the key points raised.



Sharon Hodgson, MP Washington and Sunderland West (Labour), said: "I give special thanks to Headway Wearside, which goes above and beyond for people in my region in the north-east, especially for people in my constituency. Headway Wearside has given me a lot of help over the years with constituents."



The Minister for Care, Caroline Dinenage (Conservative), said: "I have had quite a long-standing involvement with Headway in my region of Portsmouth and Gosport. They are remarkable and offer the most fantastic support to people in my area. They certainly make a difference to people's lives and they are so inspiring."



Chris Bryant, MP for Rhondda (Labour), said: "I remember one woman said to me, 'I know I have to use all the energy in my head to make my head better, but I am using all the energy in my head to try to work out this DWP form.' That is not what the state should be doing."



Siobhain McDonagh, MP for Mitcham and Morden (Labour), said: "The help provided by Headway is seen as a lifeline to those who receive it.

"Headway groups and branches are under severe financial pressure as a result of cuts to local authority budgets. The fact that they continue to provide such vital support, through rehabilitative therapies and social interaction programmes, is a testament to their determination to support this vulnerable community.

"Let us be clear: the pressure under which Headway groups operate must be eased, and they must be afforded the funding they need to continue to support people who may otherwise be cut adrift from society."



Sir John Hayes, MP for South Holland and The Deepings (Conservative), said: "When the storm of head injury happens, the skies darken for individuals. Our job as parliamentarians is to bring change to those individuals, through brightening their prospects in all that we do."



## Headway to take part in e-scooter consultation use roads and cycle lanes. We know Headway will take part that many e-scooters are already in a consultation into the being used illegally on our roads and possible introduction pavements. of the battery-powered "We will participate in the scooters to British roads consultation and take a keen interest something that has in the results of the trial. Reports until now been resisted from other countries indicate that there have been a significant number despite their popularity of injuries where e-scooters have in more than 100 cities been introduced to busy city roads. globally including Paris, It is reported that in 2018, 1,500 Copenhagen and San people were injured in accidents involving e-scooters in the USA. Francisco. "We expect the government Currently, e-scooters in Britain exist in a limbo – available for purchase on to show consistency by the high street but illegal to ride on informing e-scooter users that both pavements and roads. But even they should wear a helmet as with small numbers of people riding indicated in rule 59 of the them, doctors are beginning to see Highway Code, which relates serious injuries. to cyclists. Headway will be urging the government to advise e-scooter "It is surely common sense for users that they should wear helmets. all e-scooter users to protect themselves by wearing helmets, Peter McCabe, Chief Executive which evidence shows can save lives of Headway - the brain injury and prevent lifelong disability. association, said: "We understand that the government is undertaking "Our message to all is simple: a consultation and trial which may use your head - use a helmet." result in allowing e-scooter users to





# Thousands of families helped as **Emergency Fund** hits £400,000

When someone you love sustains a brain injury everything changes. Your daily routine is suddenly blown apart and your life can quickly become unrecognisable.

For many people the normal commute is replaced by long trips to the hospital and the impact this can have on finances can be stark at a time when they are already under immense strain.

But the world outside the hospital doors continues, the same daily pressures exist, and the bills still need to be paid.

To help people in these circumstances we created the Emergency Fund, which provides grants of up to £500 in the immediate aftermath of brain injury.

We are proud to announce that our fund has just surpassed a new milestone.

Since its launch in June 2011, the fund, which is supported by The Stewarts Foundation, has provided more than £400,000 in grants to help more than 1,900 families dealing with the sudden financial implications of an often life-changing brain injury - such as unexpected travel costs and emergency accommodation.

Also, every applicant is given extensive signposting to other organisations that can provide further support, advice or financial assistance. This is regardless of whether the application is successful signposting is tailored specifically to them and is linked to their profession or where they live.

Eleanor Simcox applied to the Emergency Fund for help with the accumulating costs of the 110-mile trip to visit her partner in hospital, after he sustained a brain injury from a fall.

She said: "My sister was doing some research and told me about Headway. I rang the helpline, who were fantastic, and they told me I could apply for financial help through the fund.

"This was a massive help. Mark had just left his old employers and the day before the accident he had just finished his training to become a fireman but wasn't receiving any income. That meant that the only money the family had coming in was through my part-time job working at a pub."

Some of the family's funds were also in Mark's bank account, which Eleanor couldn't access at the time.

"It was a very stressful time," said Eleanor. "I was down to £107 a week. My boss was very kind and gave me an advance on my wages, but this money was soon eaten up.

"I really struggled to support and visit Mark. It was a 110-mile round trip, which I would sometimes have to do twice a day as I had to come home to look after my boys and then go back to Mark in the evening. The fund was vital to me in those dark moments. It eased the financial pressure at a very stressful time."



"My son was in a very bad way and in a different city. So we were a little lost but Headway approached us and helped by paying for our room which was one less thing to worry about, thank you, thank you, thank you.'

"Thank you so much for your help toward my travel costs. They helped me to take the pressure off worrying about money. Very quick service and application."

"Having a wife in hospital over the last year has been incredibly stressful, with extra costs such as travel, car parking etc. Your compassion and the extra help you have provided has been most welcome."

> "I am so very grateful to you for arranging the emergency funding so I could visit my husband almost every day in Birmingham. Without this help my visits would have been limited to once or twice a week. Thank you!"

"I was so grateful for the help towards my travelling costs at this very stressful time. It was dealt with so professionally and hassle free which was very much appreciated. Thanks again for your help."

# Who can apply?

Anyone may apply to the Headway Emergency Fund. However, we are unable to support applicants who do not reside in the United Kingdom.

Only one application per survivor of a brain injury can be considered.

The purpose of the Headway Emergency Fund is to support families facing an increased financial burden following a brain injury.

Our resources are limited, and Headway will assess the financial circumstances of each applicant when allocating funds and prioritise those in greatest need. We cannot consider applications for families with savings of more than £1,000.

# What support can we provide?

- Travel costs for families visiting relatives in hospital or rehabilitation
- Emergency accommodation costs
- Clothing needs (related to the brain injury, such as significant weight loss)
- Travel costs to ongoing outpatient appointments relating to the brain
- Essential white goods, where a survivor has been made homeless and re-housed in accommodation lacking basic equipment such as a cooker or fridge
- A one-week self-catered carer's break at a cottage in Pickering, Yorkshire

# How to apply

Applications to the fund can be done via a form on our website.

If you have any questions about the Emergency Fund please feel free to get in contact.

E-mail:

emergencyfund@headway.org.uk

Telephone:

0208 640 8413

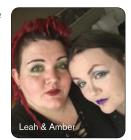
All applications will be treated in the strictest confidence.





# "I think the staff assumed I had taken drugs."

Leah Moore had a busy life. Her career as a comic book author was relentless



and to keep the money coming in, she and her husband often worked long hours. Add three young sons into the mix and it's fair to say Leah had little spare time away from her work or family commitments. So when the chance to attend a music festival arrived in 2018, she grabbed it with both hands.

Leah loved attending festivals and the freedom of a few days not having to worry about anything. In 2018, the night before the festival bands started, she partied the night away in one of the event's large tents - dancing to her favourite metal tracks.

It was while dancing that she believes the bleed on her brain started. The bleed would set in motion several worrying events which could have cost Leah her life

"It was Thursday, the day before the bands started, and I was in one of the tents dancing and drinking cider, enjoying a night away from any responsibilities," recalls Leah.

"As I left the tent at the end of the night, I remember falling down. Not tripping over, not hitting my head, but just falling, like a sack of spuds, to the floor."

Leah not only collapsed but also vomited violently and bit her tongue extremely hard. Unknown to her she was taken to the festival's recovery tent and assessed by a medical team.

Medical notes from the time described her as 'confused, struggling to mobilise and mostly asleep'.

It was during this point that her family claim that Leah was left unattended while unconscious, and without regular fluids or food. Throughout Friday she was in the care of a constantly changing rota of volunteers who kept asking what bands she had seen and didn't realise that she had been unconscious since the day before the music had started.

Leah said: "I was asleep for virtually all of Friday. Only awoken at intervals by friends or the volunteer staff, but the staff would changeover their shifts, and I don't think they realised how long I had been asleep for.

"I found I could hardly see through my right eye and I found it hard to walk without help. I felt incredibly sleepy. I think the staff assumed I had taken drugs, as they were polite and cheerful at all times, but not concerned about my confused condition."

During Friday, and despite her confusion, Leah managed to briefly speak to her husband who broke the heartbreaking news that his sister had died of cancer.

Leah said: "I can remember the phone call and him asking me to come home as soon as I could. I told him I would try and get a train home the following day but wasn't sure how I was going to."

Leah woke on the Saturday morning just before seven and found a text from her sister, Amber, saying she and her partner were driving down to get her.

Amber had heard Leah was unwell on Friday night, and had been trying to contact her to arrange some form of extraction for ten hours.

That morning Leah managed to get herself to the site's gates on foot, an unbelievable challenge in hindsight.







She said: "I asked a security guard to help me get to the main gate, and then walked there slowly with her.

"When I arrived, I messaged my sister to tell her whereabouts I was. I have the whole WhatsApp conversation on my phone. My messages are all garbled and I clearly couldn't type the words properly. I stood on a traffic island, and by pure chance my sister pulled up next to me."

Amber said that nobody from the festival's formal organisational or medical structures had responded to any of her contacts or assisted in any way to help Leah meet up with her family.

She said: "If Leah hadn't regained some functional level of consciousness we would have really struggled to find her.

"The frightening thing was that if her sister-in-law hadn't died, we wouldn't have even contacted her. Nobody from the festival attempted to reach out to us to let us know what had happened."

On the journey back to their local hospital, Leah couldn't see correctly, had no interest in food and was incapable of staying awake for more than a few minutes at a time.

She struggled to talk, and while fairly coherent, was clearly confused.

Amber said that even when they got to their local hospital it took a while for her sister to get the correct treatment.

She said: "She was assessed through a Plexiglas screen. Someone came and took her blood pressure and then she was left in the waiting room for nearly four hours.

"There were no staff to ask and when I did get to speak to someone, I was told to get her water, which I believe was indicative of their diagnosis of hangover.

"However, from the moment the doctor actually saw her, and listened to my potted history of what happened, she went from hello to diagnosis in about 20 minutes. From then on, the care she received was faultless, but to know she had sat there with a bleed on the brain for all that time is horrifying."

Leah underwent surgery to treat the swelling on her brain, and although she suffered from chronic fatigue in the early days following the treatment, she has made a good recovery.

She is now working hard to rebuild her life and is thankful for still being alive.

She said: "Everything has been thrown into sharp focus by my injury. I strive to make the most of every day, and make sure to hold my loved ones tight. I take each little victory as it comes. I'm alive, and everything else is extra now. Every day is extra. Every cup of tea. Every hug. Every second."







A comic Leah created about her brain injury experience







# COPING WITH FISHER BRAIN INJURY!

The festival environment can present many challenges for brain injury survivors, however having a brain injury doesn't have to be a barrier to attending a festival. Following these top tips may help you get the most out of your festival experience:

# 1. Accessible camping

Most festivals will provide an accessible wheelchair-friendly camping area with easy access to the main festival site.

Often, a quiet camping area is also provided. This is usually away from the main stage and campers are discouraged from playing music or making noise in the evenings. Therefore, if you do not require accessible camping but experience some of the hidden effects of a brain injury, such as fatigue or noise sensitivity, you may want to consider applying for a space in the quiet camping area.

Accessible camping normally needs to be applied for in advance and fields may fill up quickly, so enquire about availability prior to purchasing your ticket.

# 2. Accessible viewing platforms

Most major festivals will provide accessible viewing platforms at main stages. This is a raised wheelchair-accessible area in the crowd where disabled festival-goers can enjoy performances, usually accompanied by another person.

Accessible toilets will be close to the platform and stewards should be available to assist festival-goers on and off the platform. People are likely to need a pass permitting them access to the viewing platforms.

# 3. Personal assistant tickets

If you have a carer or personal assistant it may be possible to apply for an extra ticket, free of charge, to enable them to attend.





# 4. Managing noise sensitivity

If you experience noise sensitivity following your brain injury, there are some steps you can take to make this more manageable, including: quiet camping, earplugs, noisecancelling headphones and taking timeout from the music.

# 5. Managing fatigue

Festivals can be tiring places and it's important to remember not to push yourself too much. Sticking to a routine, planning ahead and knowing your limits may help you to manage your fatigue. Maybe even take a folding chair to use when watching performances.

# 6. Alcohol and brain injury

After a brain injury the body's tolerance to alcohol might be reduced. Many effects of brain injury are also exacerbated after drinking. You should consider your own relationship with alcohol and, if you are going to drink, be mindful of the amount of alcohol you consume during the festival.

# 7. Headway Brain **Injury Identity Card**

The Headway Brain Injury Identity Card is designed to let other people know about your brain injury and ensure you receive an appropriate response. Consider using your card to explain the effects of your brain injury and request any support you may need.



# 8. Consider alternatives to a camping festival

Unfortunately, the nature of many festivals - camping, muddy fields, crowds and loud music - is always going to present challenges for many brain injury survivors. But that doesn't mean you have to miss out and there are lots of alternative options that don't involve tents and/ or mud, including: a city centre festival, day tickets and gigs and concerts.













doing incredible things to improve life after brain injury

# Inspirational achievements honoured

# at the Headway Annual Awards

Volunteer of the Year sponsored by Anthony Gold Angela Caulfield with Headway Vice President James Cracknell

Every year Headway's Annual Awards attract nominees with incredible and inspirational stories of dedication, love and sacrifice, as people come to terms with the effects of brain injury.

In a glittering ceremony at the InterContinental Hotel in Mayfair, London, we honoured their special achievements.

The nominations open for this year's awards on 6th April.



Tina Wescott is presented with her Carer of the Year Award, pictured with ex-England footballer Ryan Mason and Emma Truin sponsored by



Ex-footballer and brain injury survivor Ryan Mason, Paraolympian Jack Rutter, Olympian James Cracknell and Sky News presenter Tom Macleod



Eric Knowles, star of many antiques television programmes, for hosting the live auction



The ceremony concluded with a series of special awards, presented to organisations who have gone the extra mile to support the work of Headway. Pictured above are representatives from Thompsons Solicitors, National Police Chiefs Council and the Police Federation with Ryan Mason



Rachel Rees collects the Stephen McAleese Outstanding Contribution to Headway Award, sponsored by No5 Barristers Chambers



The Headway Annual Awards 2019 was kindly sponsored by:

 ${\sf AnthonyGold}$ 











# We're all going on an assisted holiday

Whether you like relaxing on a tropical beach, getting away to a cottage in the countryside or want to satisfy your sense of adventure, holidays are a perfect way to escape from the stresses of everyday life.

However, the effects of a brain injury can make finding and planning a holiday hugely difficult.

An increasing number of hotels and attractions are accessible to people with physical disabilities, but what about people who need high levels of care, or are living with the hidden effects of brain injury such as memory problems, difficulties in crowded places or fatigue? In these cases, a more specialist supported holiday may be the best option.

In this article we focus on some of the supported holiday options that are available, and give some top tips to help you plan your perfect getaway...

# Meg's story

Meg Elliot feared she'd never be able to return to the active lifestyle she once led, after a fall while rock climbing in Snowdonia left her battling the physical effects of a brain injury.

But she found that while on a holiday to the Calvert Trust in the Lake District, she was given the opportunity to experience things she never thought possible.

From horse riding to accessible cycling, the Calvert Trust offers a host of exciting activities.

Meg said: "I chose the Calvert Trust because I really like outdoor activities and they have a very good reputation."

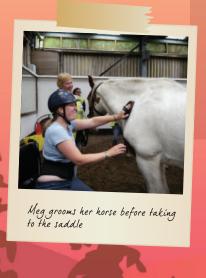
Fatigue, a reduced concentration span and physical weakness meant that Meg needed special measures to be put in place to help her during her stay.

"I was given extra time at lunch so I could go and rest in my bed," said Meg. "I was asked how I wanted to do things. The team were all very encouraging.

"Overall it was a very relaxing atmosphere and there was no stress at all."

Meg now visits the Calvert Trust every year.

She said: "It's an amazing holiday with friends, family or carers. When I'm there, I can be independent which is such a great feeling."







# Samantha's

Samantha\* was on holiday in Lanzarote when she fell and sustained a traumatic brain injury, leaving her with mobility and balance problems.

She found that after her injury, she required specialist accommodation while on holiday.

"I really struggle with my balance and I find it difficult to get around so I needed somewhere with wheelchair access," said Samantha. "I also struggle with steps so this was an important factor when finding somewhere."

Luckily, Samantha found the perfect resort which catered for her needs in Matagorda, Lanzarote.

She said: "The facilities were perfect. Without things in place such as wheelchair access and walk-in showers, I would have really struggled.

"Going on holiday also gives me and my family the opportunity to relax and step away from our daily routine."

Samantha now visits the resort three times a year.

She said: "I'm so glad I found somewhere abroad that is fully accessible for everyone. I really enjoy my time there and it's so beneficial for me."

\*name changed for anonymity



Enable Holidays customers take to the water

# Finding a holiday

Assisted holidays come in many different forms, and there are a huge range of providers to choose from.

Try to think first about the type of holiday you prefer, and take your time to put together a list of requirements - things like step-free access to your room, quiet spaces to relax or carers on hand to assist. Then, speak to the provider to make sure they can meet your needs, and don't be afraid to ask lots of questions!

We've put together a short list of holiday options to get you started:

### Calvert Trust

Provides centres in Exmoor, Kielder Forest and the Lake District, providing accessible adventure breaks for everyone. They enable people with cognitive, sensory, behavioural and physical disabilities to achieve their potential through exciting activities.

www.calvert-trust.org.uk

# **Enable Holidays**

Choose from over 600 disabledfriendly holidays in more than 50 destinations, including overseas beach holidays, adapted villas, group holidays for wheelchairusers, city breaks, luxury holidays,



Accessible cycling at Calvert Trust Exmoor

accessible tours & safaris - and much more. The 'Enablers' arrange everything from airport assistance and adapted transfers to guaranteed adapted rooms in accessible hotels, apartments and villas.

www.enableholidays.com

# **Houghton Haus**

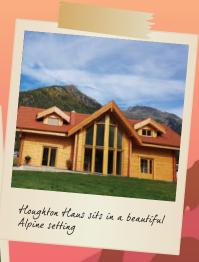
Houghton Haus is a beautiful villa for up to eight people, set high in the Austrian Alps. The owners have over 10 years of experience in disability tourism including supporting people with acquired brain injury, and can support you to find a range of accessible activities nearby such as rafting, kayaking and walking routes.

www.haughtonhaus.com

### Revitalise

Revitalise provide everything you'd expect from a proper holiday, combined with the reassurance of excellent nurse-led care and an army of brilliant volunteers. Revitalise has three fully accessible holiday centres situated in Chigwell in Essex, Southampton and Southport. With plenty of support, live entertainment and a host of accessible excursions, there's something for everyone.

www.revitalise.org.uk



More information on this topic is available in the Headway factsheet Holidays and travel after brain injury, which can be downloaded from www.headway.org.uk/ information-library.









# Memory set to be the focus for Action for Brain Injury Week

One of the most common concerns among brain injury survivors contacting our helpline or posting on social media is the profound impact that memory problems can have on their lives and relationships.

Memory loss: A campaign to remember aims to raise awareness of the ways in which memory problems can affect brain injury survivors and their families. It will explore the impact of memory on relationships, recovery and returning to work.

Keep an eye on our website and social media channels for more details of how you can get involved, or sign up to our email newsletter *Headway News – Bitesize* at **www.headway.org.uk/your-contact-preferences/** for more news on this campaign and all the other work we're doing to improve life after brain injury.

## Take part in our survey

As part of the campaign we have launched a new survey asking brain injury survivors to share their experiences of memory problems. Visit our website for more details.





BRAIN INJURY WEEK 2020



Taking on a fundraising run for charity is a huge achievement, and it'll be a day you'll remember for the rest of your life.

Whether you are a seasoned runner or someone who wants to achieve a personal goal, taking part in a running event for Headway is a great way to challenge yourself, get fit and have fun - all while raising money for an important cause.

From the major high-profile races such as the Virgin Money London Marathon to the more suburban atmosphere

of the Richmond 10K, there are a number of ways to get involved.

From the initial sign up to crossing the finishing line, our fundraising team will be on hand to support you every step of the way.

You'll get a fundraising pack which includes everything you'll need to ensure the best experience possible, as well as a Headway running vest and access to a community of online support.

To find out more or register you interest, contact the Community Fundraising team on 0115 924 0800 or projects@headway.org.uk.

# Chris' top tips

Headway Hero Chris Erridae shares his top tips after running the 2019 London Marathon for Headway.



Keep in touch with your charity - If you're in a slump or feeling down, they're a friendly voice at the end of the phone. They can help connect you with others in your team to share stories, tips and motivation as you work towards the same goal.

Track your progress - There are a host of apps and websites that allow you to track your progress. I found it helpful to look at my first run and then compare it to where I was at the time. The miles you've run, and the improvements in your speed and distance will be staring you in the face, and should give you some perspective on what you're already achieved.

Vary your routes - The mind craves novelty, so make sure you vary your running routes - fields, forests, parks and footpaths...whenever you can blaze a new trail, you should - it's more interesting and it will seem to go much more quickly.

Run with others - This is a big one. Running with other people keeps you accountable, as you don't want to let others down. Having someone to talk to and share the experience with as well is a massive help, as you can carry each other through the tough times.

## Keep the 'why' in mind -

Finally, when it gets tough - and some days it really will - it helps to keep in mind the 'why'. You signed up to this challenge and this goal for a reason; to help a cause that really needs it. It's not about 'letting the side down,' it's about knowing that what you're doing is bigger than you; you're doing something that's really going to make a difference.







# "Volunteering has helped to get my life back on track."

Whether your life has been affected by brain injury or you're looking for opportunities to make a difference, volunteering at a Headway shop is a great choice.

If we were to replace our volunteers with paid staff it would cost us £1.4 million per year, wiping away any profits which we could have otherwise spent on helping brain injury survivors across the UK.

# We need you!

Whether it's staffing the till, greeting customers or sorting stock, there are a range of ways to get involved with our charity shops.

# The benefits of volunteering

There are a number of benefits that go hand-in-hand with volunteering, from improving existing skills and learning new ones, to feeling part of the community.

For some, volunteering may be a way to build confidence and self-esteem, while for others it may help with employment prospects in the future. Meeting new people, improving physical and mental wellbeing and spending time away from a busy work or home life may be just some of the reasons to take up a volunteering role.

Whatever the incentive, volunteering can be hugely rewarding and enjoyable.

# Why choose Headway?

As a Volunteer Shop Assistant you get the chance to try a variety of tasks, from serving customers to sorting stock and dressing windows. You choose what hours and what days you want to work and you'll get plenty of training and support – as well as working in a team of great people.



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

- Diane Noland, Headway Retail Volunteer

# Stewart's story

When football fan Stewart Gray was viciously attacked by thugs with an iron bar, his life changed in an instant.

He sustained a traumatic brain injury and now struggles with chronic fatigue, memory loss and weakness on the right-hand side of his body.

Like many other brain injury survivors, Stewart found that in the months following his brain injury he became very isolated and, without his job to keep him socially and cognitively engaged, he quickly entered into a depressive state.

But things improved when he began volunteering at the Headway Hinckley

He said: "Volunteering has been instrumental in my recovery. It has helped me to develop a routine and regain a sense of normality.

"My life completely changed after my brain injury. I know that I'll never be the 'old' Stewart again, and that's okay. But for my own sake, I want to try and regain some elements of my old life.

"Normality for me before my injury was a full-time job and I think volunteering is the closest thing I'll ever get to working again, so I'll continue to do it for as long as I can."

Stewart said he is also passionate about working in the shop because he understands the impact brain injuries can have on a survivor's life.

He said: "I know what it's like to live with a brain injury and I want to do anything in my power to help others like me.

"I help to sift through donations, organise stock and contribute to the general upkeep of the shop. I find the work both physically and mentally stimulating which I think is really important for my recovery.

"I especially struggle with my memory but volunteering has helped with this. I know that if it's a Tuesday or a Thursday, I'll need to make my way to the shop. It's become such a routine for me now."

Since joining the team of 15 other volunteers at the shop, Stewart has never looked back.

He said: "Volunteering here at Headway gets me out the house. It gives me something to do and look forward to, even if it is just for a few hours a day.

"Volunteering has helped to get my life back on track.

"I know that I'm doing something worthwhile for myself and my recovery, and knowing that I'm helping to support other brain injury survivors across the UK at the same time makes it even more rewarding."

Sarah, Manager of the Headway Hinckley shop, said: "Volunteers are a really important part of our dynamic and the way we work here at the Headway Hinckley shop. Volunteers like Stewart are crucial to the success of the Headway shops and it's always nice to know that volunteering is helping them throughout their recovery

"Stewart's progress since he first joined as a volunteer has been incredible and really inspiring to watch and be a part of. He's grown in confidence and his social skills have really improved."



Stewart organising stock at the Hinckley shop



Stewart proudly standing outside the Hinckley shop



The Headway Loughborough shop front

To find out more about other volunteering opportunities at Headway, please visit our website **headway.org.uk** – or call 0115 927 0800.







# "It tore our lives apart, yet brought us closer together."

Every year around 350,000 people are admitted to hospital with an acquired brain injury. The majority of these go on to make a good recovery. However, sadly not everyone gets to leave hospital, with some families being left to deal with the devastating impact of bereavement after brain injury.

Lauren Gilligan experienced just this. When she was 18, her muchloved father, Steve, suddenly passed away at the age of 52 from a brain haemorrhage, leaving the family in a

state of shock and desperately trying to cope with their grief.

She said: "My mom and my dad got together when they were teenagers. They were soulmates. It's sickly I know to think about it, but they really were. The love between them was undeniable. My dad cared so much for my mom. He treated her like a queen.

"The grief never goes away. You still sob. You still ache. You still feel like you want to be with your loved one rather than here. But you learn to live with it. You learn to manage it, most days."

At the time, Lauren (now aged 31) had just started her first year at the University of Plymouth.

"I had a call from my older brother," explains Lauren. "He told me that our dad had gone to hospital but that it was nothing to worry about.

"However, half an hour later I received a call from my mom who told me I needed to get home quick as my dad was really poorly and would probably

Lauren rushed back and learned that earlier in the day her father had developed a severe headache and, a short while later, was found by her mother drifting in and out of consciousness in the family bathroom.

Steve was rushed to hospital and placed into an induced coma. Immediate tests showed that he had experienced a very severe category



"A coil was placed in the aneurysm that caused the bleed. A few days after this, they gradually woke him up. He remembered us. The damage from the bleed had had a minimal effect on him and it looked like he was going to be okay."

However, in a terrible twist of fate all was not okay and two weeks later Steve took an unexpected turn for the worst.

Lauren said: "We had a call from intensive care to say that my dad was going to die and that we needed to get to the hospital as soon as possible. Family and friends came to visit him that day. They all said goodbye.

"Dad was back in a coma and was being kept alive by a life support machine. At 5pm it was just me, my mom and my brother at his bedside. They switched off the life support and we held his hands, sobbing, telling him how much we loved him.

"During his final hours, we made the decision to donate his organs. We found some comfort in knowing that others would benefit from my dad's death. His liver went to gentleman of a similar age, and his heart valves went to a number of babies.

"My dad has saved several people's lives. He is not just my hero, but other people's hero. It was his last gift to the world, and wow, what an amazing one!"

# Coping with the grief...

In the days, weeks and years following Steve's death, Lauren's family began to process the pain his death had caused and develop coping strategies for their grief.

Lauren said: "We were brutally honest with one another. We helped each other where possible. We tried to continue with life, but there was a massive hole that couldn't be filled.

"I felt numb. It's an impossible situation to comprehend and it's difficult to understand how that can settle in your brain, particularly at the age of 18.

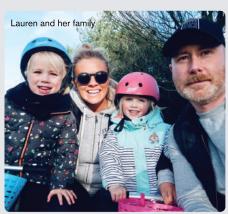
"I remember feeling awkward about telling people, like my work and friends. I felt too shy to be honest, mostly

because I didn't know how others would react and it'd make me upset or feel awkward how they reacted.

"I felt like I didn't care about life. I didn't mind if I died. I would be with my dad, and that felt ok. I wasn't suicidal, I just behaved like I was invincible because I had no fear.









"As time goes on, what changed for me was experiencing things and doing things when I know my dad should be here. Like at graduation, or my wedding, and my children being born. Knowing he should be here for those milestones.

"I made a memory box. I kept all the precious things in it. I still have it beside my bed now. Some of it is newspaper clippings, his socks, and probably what most people would call junk, but to me, it's priceless."

Lauren has gone on to marry and start her own family with husband Matt. The couple have three-year-old twins - Sid and Elsie - and she documents their life on her popular Instagram account @Twinmamatales.

She said: "My son Sid is named after my dad. When my mom and dad were dating, his nickname was Sid. Sid is so very kind, he's practically minded, funny and he loves telling jokes. He's gentle and extremely loving. All traits that my dad had."

Lauren and her family were supported by Headway in the months following Steve's death.

She said: "When dad died, we asked for donations at his funeral for Headway. We also went to our local Headway group - Birmingham and Solihull - a few times. I know that my mom had good support from them, and for me living a few hundred miles away, this was a big comfort."

# **Headway In Memory**

This site offers those who have lost loved ones to brain injury a way in which to share precious memories with family and friends in a safe, secure and private space. Visit the site - headwayinmemory.org.uk

If you would like support following a bereavement please contact the Headway helpline on **0808 800 2244** or helpline@headway.org.uk.









# Help us improve life after brain injury

# **Become a Headway Corporate** Member in 2020

Headway Corporate Members are invaluable to us and ensure we can support as many brain injury survivors as possible across the UK.

They become a part of our network, committed to improving life after brain injury and receive a range of benefits, such as:

- A Headway Corporate Supporter logo for website and email signatures
- Membership certificate to display in your workplace
- · Quarterly mailing of five copies of Headway News

- Invitation to exclusive members events such as the Headway Annual Awards Luncheon and Corporate Challenge
- Being the first to hear about news, events and sponsorship opportunities through our Corporate Member's e-bulletin
- 20% discount on exhibiting at The Way Ahead conference
- 10% discount on advertising
- 10% discount on all hard copy orders of Headway publications
- 5% discount for members on Headway training
- Free brain injury prevention campaign literature and posters

Being a member can also boost staff morale and give a positive impression to your customers, suppliers and the communities in which you operate.

the brain injury association

CORPORATE SUPPORTER 2020

### Is your business interested?

There are three rates of membership ranging from £305 - £790 per annum.

Please contact

partnerships@headway.org.uk or visit the Headway website for further information.







Each year, we are amazed by the support of organisations who become a Headway 'Baton Holder', or Charity of the Year partner.

These organisations are truly inspiring and show a clear commitment to help people living with the effects of brain injury in the UK. Their staff go above and beyond to raise funds and awareness for Headway, so we would like to take a moment to appreciate their support.

Thank you to Simpson Millar who raised over £32,000 and Rehabilitate Therapy who raised over £9,500 during 2019! Their efforts will ensure we can continue to provide support through frontline services such as the Headway helpline, Brain Injury Identity Card scheme and vital information services.



Thanks also go to GB Railfreight who reached the end of a two-year partnership with Headway last year. The rail freight company raised a whopping £92,258 over two years! The company presented a cheque to Headway representatives, Anna Kerr and Melanie Dickens, at their charity presentation event on 25 January 2020.

Thank you to all at GB Railfreight! We are very grateful for your commitment to improving life after brain injury.

If you would like to work in partnership with Headway, contact Anna for an informal discussion on 0115 9240800 or email partnerships@headway.org.uk











# Raise funds to improve life after brain injury during Action for Brain Injury Week!

During this week we are focusing on the devastating impacts of memory loss. Please donate and wear a hat that brings back special memories, is from your favourite era or belonged to someone special!

#HatsForHeadway
#ABIWeek #MemoryLoss





Headway - the brain injury association is registered with the Charity Commission for England and Wales (Charity No 1025852) and the Office of the Scottish Charity Regulator (Charity No SC 039992). Headway - the brain injury association is a company limited by guarantee. Registered in England No. 2346893.

# **Brain Injury Identity Card**



My name is: Jonathan Smith I have a brain injury and as a result:

I have difficulty processing information

I have attention and concentration difficulties

I experience fatigue

I may have anxiety

For 24 hour criminal legal assistance, please call:



0800 140 4031



# Brain Injury Identity Card

The Headway Brain Injury Identity Card is designed to give brain injury survivors added confidence in everyday social situations by providing a tool to explain the effects of their injury and request any support they may need. It provides a simple solution to what can sometimes be a tricky conversation.

Following a brain injury, effects such as memory loss, confusion and impulsive behaviour can lead to difficulties when out and about. Furthermore, changes in personality and physical effects, such as anger, irritability, balance difficulties and slurring of words, can cause incorrect assumptions to be made about a survivor's behaviour and may lead to confrontation or conflict.

The Identity Card was developed as part of Headway's Justice Project. The project aims to raise awareness of brain injury throughout the UK criminal justice system (CJS) and to ensure that brain injury survivors are provided with the appropriate response and support should they come into contact with the police.

Since the launch of the scheme, over 7,500 brain injury survivors have been issued with an Identity Card, personalised with individual effects of their brain injury they choose. Many card holders have gone on to use their card in a wide range of scenarios, both within the CJS and when out and about in public.







We spoke with a selection of these Identity Card holders to hear how they have benefited from using the card...

# Joe Devlin

61-year-old brain injury survivor, and Headway Borders committee member, Joe Devlin credits his Brain Injury Identity Card with giving him renewed confidence. Joe has used his ID Card multiple times to explain the effects of his



brain injury, which he sustained in a quad biking accident in 1987.

One of these times was during a trip to Tesco. Recalling this experience, Joe said: "It was really busy and I absolutely flipped and needed to get out of there ASAP. I hurried towards the exit but forgot I had my trolley and hadn't paid for my shopping. I was called back and I shoved my wallet at the guy to pay and get out quickly, but he had called for the manager."

Thankfully, the store manager spotted Joe's ID Card in his wallet and was very understanding.

"She calmed me down and even helped pack my shopping and escorted me to the car," said Joe.

"I would have been in so much trouble emotionally, and no doubt police would have been called, if I hadn't had my ID

Joe also recalls a time when he became confused at the train station. He said: "I showed my card and they couldn't have been more helpful, even sitting me in the first-class waiting room with coffee."

# Jacqui Fowler

Jacqui Fowler, from Surrey, has used her Brain Injury Identity Card when starting a new job to explain her effects to her employer. 37-year-old Jacqui was hit by a motor vehicle in 1994, sustaining a brain injury which left



her with memory loss, fatigue and headaches.

"Since starting work, I've never previously declared my head injury but have struggled silently," said Jacqui. "I decided that it was time to accept the new me and tell a new employer about my head injury and ask for reasonable adjustments.

"I used the card to give details to my new manager of the support I need to succeed, which is mainly clear instructions and additional time to learn complex tasks. The card made this easy to explain and gives me the confidence to ask for help if needed."

# Deborah **Johnston**

54-year-old Deborah from Hertfordshire experienced a brain aneurysm in 2015. This left her with short-term memory loss, noise and light sensitivity, as well as confusion when handling money.



"When I count money out, I can't always work it out," said Deborah. "One time at the shop the server got a little impatient because I couldn't work out my change and there was a queue. I handed her my card and she soon changed her attitude."

Deborah has also found her ID Card useful when at the airport, saying: "As I have photophobia, I can't use the eye-scanner. Luckily this is listed as one of my effects so I can show my card if I need to explain something to an official. I get words mixed up so it's easier to show them than explain."

# Helen **Graham**

Stroke survivor Helen Graham from Northern Ireland finds her ID Card useful for explaining the effects of her brain injury, particularly as all her disabilities are invisible, including memory loss and fatigue.



Recalling one time when she used it, Helen said: "I had crashed both physically and mentally when travelling through Charles de Gaulle airport. I was able to use my card to seek assisted check in, access to a waiting area and help with boarding."

Helen has also used her card while at the bank when she became overloaded with information. "I showed them my card and was given extra support and processing time," she said.

### APPLY FOR YOUR CARD

The Headway Brain Injury Identity Card is available to anyone in the UK aged 18 and over with a clinically verifiable brain injury.

To apply for your card visit headway.org.uk/idcard.

If you would like to find out further information about the card, or need assistance with your application, please email justiceproject@headway.org.uk

# Leading personal injury solicitors



Boyes Turner is proud to be an active supporter of Headway. Kim Smerdon, 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 results

you deserve and the support you need.

We are more than happy to visit you in hospital or at home at times to suit you.

We provide national coverage.

Contact Kim Smerdon 0118 952 7137 claimsadvice@boyesturner.com

"You do great things and provide a fantastic service in terms of support and advice. You make a difference to peoples' lives and are very good at your job. We thank you for everything."

Anne Cahill

www.boyesturnerclaims.com Ranked #1 for personal injury claims











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

