

Winter 2018

Headway News



The magazine of Headway - the brain injury association

**Meet
your fabulous
finalists!**

The long journey home

*Are you
banking
on local
support?*

**Let's talk
about sex...**





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the brain injury association

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.



the brain injury association



Talking benefits everyone

In early November, Headway met with 60 senior managers from the Personal Independence Payment (PIP) team at Capita, one of two firms contracted by the government to conduct assessments for this key disability benefit.

Our aims were simple: to increase understanding of the hidden, complex and fluctuating nature of acquired brain injury and to help Capita make urgent improvements to the process of applying for PIP.

Our *Right First Time* campaign lays bare the problems being faced by PIP claimants living with brain injury. The study, which has been cited in Parliament, shows that the hidden effects are routinely missed – or misunderstood – by assessors with no specialist knowledge of the condition.

It also shows that, too often, the evidence, experience or valid thoughts of companions – be they family or medical experts – are not listened to or fully acknowledged.

By speaking out in the national press and asking our Parliamentary Champions to raise this issue with government, we are pushing for the voices of brain injury survivors and their families to be heard by policy makers.

But while making clear our anger and frustrations with a system that is simply not fit for purpose, we know that by speaking directly with those involved in the process we can help to make clear and tangible improvements.

The presentation to Capita was the first of many training and engagement events scheduled to take place over the coming months. We're also talking with other assessment firms equally keen to engage with Headway UK and learn more about brain injury.

This has to be a positive. Through our campaigning and hard work, and by representing the experiences of brain injury survivors and families across the UK, we now have a chance to speak directly to those responsible for making crucial, life-changing decisions.

Your voices are crucial in this. As you'll see on page eight, the most powerful and influential voice at the recent meeting with Capita was that of Simone Mingle.

Simone bravely and eloquently shared her son Richard's distressing experience of trying to claim PIP. Her testimony will have been hard for Capita staff to hear, but to their credit they listened attentively.

The Communications Team

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

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Your views...

With Headway actively working to improve brain injury understanding among disability benefits assessors, we asked members of our online communities: If you could change one thing about disability benefits assessments, what would it be?

Decision makers being proactive in obtaining medical evidence from health care professionals that work with the claimants.

Catherine Thompson

There should be much more investigation and follow-up visits after being discharged from hospital, not only to help with the recovery and rehabilitation of a brain injury patient, but also for the assessment of their welfare and needs.

Margaret Faulkner

If the assessor could visit more than once and see the difference in each day...we go through so much confusion and each day is difficult and different. They need to see how we struggle with what used to be just everyday problems. They need to come to the home!

Dilly Hamilton

All of it. My son got 4 points in the assessment. When we finally got to the tribunal, the judge and the DWP rep had no idea why we were there. We walked out with 26 points about ten minutes later.

Michelle Whitby

The system discourages people from getting well. My husband was initially penalised for going to the gym. He was going on a doctor's referral to do rehab exercises and is always taken there and back and accompanied by his brother. He is not going there to bulk-up, but to try to get better.

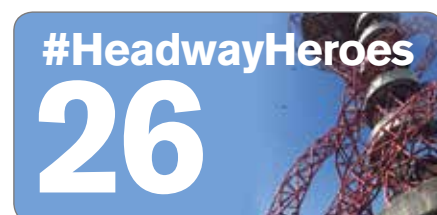
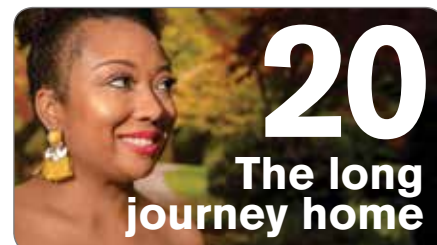
Mel Groom

Why all the assessments in the first place? If you have a head injury, which causes secondary illness with no room for improvement, why do you have to go for one/two year assessments?

Eleanor Harradine

Having someone with relevant qualifications to understand non-visual issues would be a start.

Dudley Garner



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#HeadwayHeroes

news you may have missed...

Craft beer tribute to Manchester man



One of the world's best craft breweries has created a special beer in memory of Manchester man John-Paul Cassidy, who was influential in developing the city's craft beer scene before he died of a brain injury in April.

John-Paul helped launch Port Street Beer House – rated one of the best craft beer pubs in the country. Now, the Cloudwater brewery company has created a special West Coast IPA in his honour.

Proceeds from sales of the beer, called JPA, will go to Headway as a thank you for the support provided

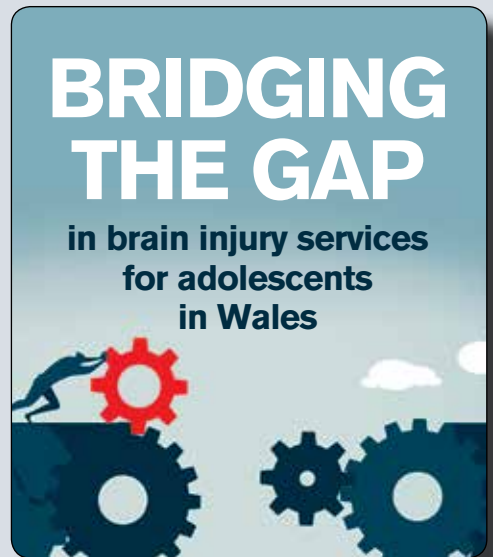
to John-Paul's family and his fiancée, Lucy Lovell.

Lucy said: "When John-Paul died, friends from the beer industry got in touch with me asking how they could help.

"Making a beer seemed like the perfect way for us to pay tribute to him, and thanks to Cloudwater's generosity, the beer will also raise money for Headway, which offered support to me and John-Paul's family while he was in intensive care."

"We decided on a classic West Coast IPA because it was a style that kicked off many people's journey into modern beer, and it was one of John-Paul's favourites."

JPA is available in all good craft beer shops as well as some online retailers.



Bridging the gap in Wales

Headway has joined forces with the Child Brain Injury Trust to host a special conference in Wales to explore some of the challenges of children with brain injury transitioning to adult services.

Speakers at the conference, called *Bridging the Gap in brain injury services for adolescents*, included Vaughan Gething AM, the Cabinet Secretary for Health and Social Services in the Welsh Assembly, and local MP Nick Thomas-Symonds, a long-standing supporter of Headway.

Moving presentations from Kyle Hitchings and Leanne Nicholas revealed the real-life impact on families.

Kyle spoke about how life for him and his family changed after he was hit by a car when he was 14, and how he spent seven months in hospital and rehabilitation, learning how to walk and talk again.

Meanwhile Leanne explained how her son Jack, who has an acquired brain injury, faces difficulties as he is 'too old for children's services, but too young for adult services'.

The two charities are now drafting a joint report to present to the Welsh Government, NHS Wales and local authorities to improve the support given to survivors like Kyle and families like Leanne's.



Anything but pointless

Headway's Vice President James Cracknell has teamed up with former World Cup skier Chemmy Alcott to win £500 for Headway on the ever-popular BBC One game show *Pointless*.

Contestants on the tea-time quiz are asked to try to score as few points as possible by plumbing the depths of their general knowledge to come up with the answers no-one else can think of.

The pair appeared on a celebrity edition of the show where they beat fellow sports stars Sally Gunnell, Greg Rutherford, Greg Rusedski and Neil Ruddock to get to the final.

Sadly the pair missed out on the £2,500 jackpot after failing to get a pointless answer for the category Fishy Sounding Films, but the money and awareness they did raise will be a great help.

Thank you James and Chemmy for your anything-but-pointless contribution!

James and Chemmy (Photography courtesy of Pointless Celebrities, Remarkable Television, part of Endemol Shine Group)



news you may have missed...

Parliament told it's 'Time For Change'

A new parliamentary report has called on the government to take urgent action in order to ensure brain injury support and rehabilitation services are fit for purpose.

The report, *Time for Change: Acquired Brain Injury and Neurorehabilitation*, has been published by the All-Party Parliamentary Group on Acquired Brain Injury.

Chris Bryant MP, Chair of the APPG on ABI, said: "Acquired Brain Injury is an invisible epidemic, and we need to ensure that the neurorehabilitation services required following a brain injury are 'fit for purpose' throughout the UK."

The report is backed by Headway, with the charity contributing to its findings. It includes a number of recommendations to government, including improving access to timely rehabilitation as well as improving the recognition of ABI.

By highlighting the impact of acquired brain injury on people in schools, the criminal justice system, disability benefits and other areas, the APPG is drawing attention to the need for government departments to work together on this issue.

Dr Clare Mills, Public Affairs Manager for Headway, said: "Alongside our ongoing work with many individual MPs and Peers, the launch of this report is another excellent opportunity to raise awareness of ABI across Westminster and Whitehall."

"We're calling on all MPs to look at the report and use their influence to bring about much needed change to availability of rehabilitation, disability benefits, and in so many other areas, for the benefit of their constituents and the country as a whole."

Dr Clare Mills, Public Affairs Manager
at Headway



Brain injury info given to PIP firm

Headway has met with senior leaders at Capita to increase their understanding of the hidden, complex and fluctuating nature of brain injury.

Capita is one of only two firms contracted by the government to conduct assessments for Personal Independent Payment (PIP) claimants, with the firm covering Wales, Northern Ireland, and the central belt of England.

Headway's Director of Communications, Luke Griggs, provided the 60 delegates with information about the often hidden and misunderstood effects of brain injury and how they can impact on a person's ability to access vital help and support.

Delegates were also provided with the findings of the charity's *Right First Time* study, with both statistical and anecdotal evidence shared.

Luke was joined by Simone Mingle, whose son Richard has been subjected to negative experiences of claiming PIP. Simone, who has received support from Headway Birmingham and Solihull, spoke passionately about the difficulties the family faced when trying to reapply for PIP.

"The process of applying for PIP simply does not work for people with brain injuries," said Simone. "The form focuses too heavily on the mechanisms of physical mobility and gives no opportunity to explain the cognitive challenges people face in completing basic everyday tasks."

"I was initially nervous about speaking at this event. But I was determined to do so

in order to help increase understanding of brain injury and, hopefully, prevent other claimants from having such a negative experience."

Luke Griggs said: "Simone's testimony was hugely powerful. As with everyone who contributed to our *Right First Time* study, we owe her a debt of gratitude for contributing to our ongoing campaign to improve benefits assessments."

"I would also like to thank Capita for inviting us to present and we are looking forward to providing additional training to the firm's assessors in due course."



Is Anna OK?

The BBC has produced a stunning new virtual reality (VR) project to help people better understand the often hidden effects of brain injury.

With support from Headway, the VR experience allows participants to assume the roles of 20-year-old twins Anna and Lauren to discover how their lives were changed in an instant by a single, terrible event.

In December 2015, Anna Khan was involved in a road traffic incident that left her with a devastating brain injury. Her story is told on the Headway website in a moving personal testimony film, but this new VR project from BBC Stories provides an innovative way of experiencing just some of the issues Anna and Lauren have been through.

Headway has supported Anna in her ongoing recovery and provided the BBC team with a better understanding of the unique nature of brain injury, as well on how it affects not just the survivor but also their wider relationships.

The VR experience is told in the twins' own words, based on months of interviews by BBC News reporter Camila Ruz. It explores how VR can be used to create a compelling and authentic piece of journalism from two unique perspectives.

Two participants can go through *Is Anna OK?* together, experiencing different perspectives of this powerful story at the same time, with one seeing events through Anna's eyes, and the other through Lauren's.

Anna and Lauren's story has been brought to life by BBC Stories in

collaboration with the teams at BBC Studios Digital and Aardman Animations, and published by BBC VR Hub.

"This is a truly innovative and imaginative way of giving people a hint of what life can be like for people living with brain injury," said Luke Griggs, Director of Communications at Headway.

"We recognise that most people won't own the equipment needed to experience this in full, but by showcasing it at festivals and events across the country, we hope more and more people will gain a better understanding of brain injury."

How to experience *Is Anna OK?*

To experience *Is Anna OK?* in full you will need to have an Oculus VR headset and download the file from the Oculus store.

We are currently working with the BBC to see if the experience can be showcased at Headway events across the UK.

BBC

Is Anna OK?

My story...

IT'S STILL POSSIBLE TO dream

Since he was a boy, David Greer dreamed of circumnavigating the globe. But when he sustained a brain injury in 2012, he thought his dream had died. And yet in 2017, David defied the odds by spending an entire year sailing the seven seas.

Post-traumatic amnesia. Poor balance. Cognitive difficulties. Emotional instability. These were just some of the issues David Greer was left struggling with after he sustained a brain injury in June 2012 after he fainted and hit his head on the ground.

Like many people in the early stages of life after brain injury, David lacked insight and struggled to appreciate the extent of his injuries. Put simply, David's brain was telling him that he had fully recovered, so he was shocked to learn that he was not allowed to drive or return to his role as a Chief Executive Officer.

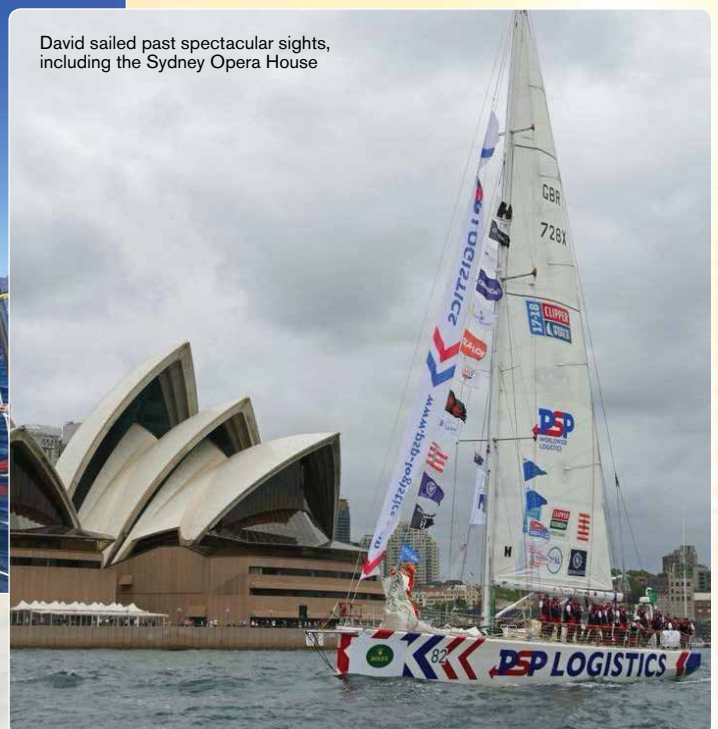
David felt he no longer had a purpose in life and sank into a deep depression.

For a few years, David found a new passion in cycling. But he began to yearn for a new challenge. A childhood love of sailing inspired him to research the Clipper 2017/2018 Round the World Yacht Race.

The event involves 12 identical 70-foot ocean yachts racing more than 40,000 nautical miles through the most extreme conditions, from the blistering heat of the equator to the 140-foot waves of a hurricane in the Pacific Ocean.



David stands proud at the helm of the boat



David sailed past spectacular sights, including the Sydney Opera House



Choppy waters for David and the crew

David believed that his brain injury had put an end to his chances of making his dreams a reality. But he applied nonetheless and, to his shock, in January 2017 he was selected to be a part of the event.

After five months of land and sea training, David left behind his beloved home, family and dogs and set sail.

On board the boat conditions were cramped with no luxuries. There was no privacy, just basic shared bunks lining corridors, nooks and crannies. There were no showers and there was nowhere to hide when the going got tough.

David was one of up to 22 sailors working on the boat at the same time. The two-foot space between the bunk and the toilet was often taken up by people repairing sails or trying to put on a dry suit whilst the boat attempted to roll them over.

Working and living in such close proximity with others was one of David's greatest challenges.

"Brain injury doesn't do much for your social or executive skills," he said. "Living cheek-by-jowl with more than 20 people can be quite wearing.

"Everyone has their little idiosyncrasies. In the first week they were quite

amusing, but by the end of the trip you could quite happily nudge them off the back of the boat!"

The boat performed at its optimum when heeling at a 45-degree angle – so David had to sail, sleep, cook, eat, and even go to the toilet at that angle. No easy feat for a brain injury survivor with balance issues.

The boat sailed continuously, so sailors worked shifts of up to six hours. On some days, David survived on no more than four hours of sleep. It would be a struggle for anyone, let alone a brain injury survivor susceptible to fatigue.

"The most punishing shift was 'dog watch', which was when the crew worked from 8pm until midnight and then 4am until 8am. But our reward was the magnificent sunsets and sunrises to calm our tired minds."

By the seventh leg of the race, the on-going impact of his brain injury, exacerbated by persistent lack of sleep, became too much and David took a break to recover. He knew how important it was to take care of himself and not become a liability to his fellow crew, as the likelihood of making major mistakes grew as his fatigue increased.

But David's persistence was eventually rewarded when the team completed its epic challenge.

"I was treated to the very best that nature delivers, including racing whales and dolphins in the company of wondrous birds such as the albatross. I was hit by flying fish and saw turtles circling the boat."

"I was never happier than when at the helm, steering the yacht through all conditions. The rougher the conditions were the more I enjoyed them. I never felt frightened; I trusted my crew mates and particularly the boat, designed and built for ocean racing."

As well as achieving more than he ever thought possible after his brain injury, David has to date raised more than £2,800 for Headway.

"If people with brain injuries look at what I've achieved and it gives them hope for the future and motivation to continue trying to improve themselves, then it was worth doing," he said.

"I have learned that it is still possible to dream and, if one is determined enough, to realise those dreams."

"Not all dreams have to be as big and as daring as mine, but whatever your dream my advice is to follow it."



LET'S TALK ABOUT SEX...

It's one of the most natural things in the world, yet intimacy and sex are still seen as taboo subjects that many of us don't feel comfortable talking about.

Throw disability into the mix and there seems to be a stony silence pervading the scene. There also appears to be an implicit reluctance, including among the professional world, to acknowledge and address the fact that having a disability does not stop feelings of wanting romance, intimacy and sex.

Brain injury, as we well know, affects people both physically and in 'hidden' ways such as cognitively, psychologically, emotionally and

behaviourally. All of these effects can have an impact on the brain injury survivor and their sexual partner's feelings towards sex.

Here, we discuss the challenges that having a brain injury can pose when it comes to having a healthy sex life, as well as how to address the issues head-on and work towards ending the myths around brain injury and sex.

What is sex?

Okay, so we all know that sex is the rumpy-pumpy hanky-panky business that typically takes place between the bed sheets. But sex isn't just about the physical act.

Sex has different elements that make it a much more intimate and psychologically fulfilling process,

while also having a basic reproductive purpose that comes down to pure biology. So all in all, what is sex?

Sex is sometimes divided into two aspects of sexual functioning: the physical aspect of sex (such as sexual arousal, intercourse and orgasm), and sexual well-being, which relates to the emotional and psychological aspect of sex such as sexual satisfaction. It also includes acts of intimacy such as touching and kissing.

But sex refers to more than just physicality. Complex emotional, psychological and social customs, such as forming romantic relationships in the first instance, are often involved in both initiating and having sex. The act of sexual intercourse itself is both physical and emotional.

Finally, there is no single definition of the word sex – it can mean different things to different people, depending on personal experience, values, personality and preferences.

Sex and the brain

So what does the brain have to do with sex? Actually, a lot! The brain is responsible for processing the feelings and sensations that are a core part of a sexual experience.

Different parts of the brain are involved in things such as the behaviour and social skills we use to meet and interact with a sexual partner, and our personality and overall interest in sex. These aspects can all be affected by a brain injury.

Sexual relationships after brain injury

Couples who already shared a sex life before the occurrence of a brain injury commonly find that the injury affects one or both party's interest or ability to have sex.

This in turn can cause difficulties in the relationship such as feelings of loss and a lack of fulfilment. But in some circumstances, can fear play a part?

Anna Smith-Higgs suffered a life changing stroke aged 24, just one month after her son was born. She was left partially paralysed down her right-hand side, has mobility issues and is partially sighted.

Anna, now 38, said following her stroke sex was the last thing on her mind.

"I couldn't accept what I'd become," said Anna. "I'd gone from being a fit 24 year old with everything to look forward to, to struggling to change my child's nappy."

"Before my stroke I had a very active sex life, but afterwards I spent months in bed and was scared to move, terrified that I'd have another stroke. At that point I was battling depression and I didn't want to know or partake in sex at all."

'Communication is the key'

Anna said sex after having a stroke can be extremely scary and fill you full of doubts.

"My stroke was due to hormones from child birth so I was scared of sex as getting pregnant again was my biggest fear."

"I would also worry in case an orgasm increased my blood pressure. I worried that with only half of my body working to its full capacity, the sex wouldn't be the same as it was before. I worried that I wouldn't be able to perform the way I once did."

"These fears got so bad that my partner and I just didn't do it. This left both of us frustrated. It just wasn't a very nice way to live."

"But with time I realised that all these worries were not worth thinking about. I realised that no, my blood pressure won't increase; no, I won't be able to perform like I did before. But that doesn't mean my sex life is over."

Anna said communicating with her partner about how she was feeling was the key.

"You have to try and not feel self conscious, you need to talk to your partner, no matter how uncomfortable you may be feeling," said Anna.

"It not only helps bring you closer as a couple but you will probably find your partner is feeling the same. A strong relationship can survive anything. It turned out my partner was just as scared as me the first time we had sex after my stroke."

Anna Smith-Higgs: 'Sex after a stroke is tricky'



Anna said sex after a brain injury can still be fulfilling.

"Sex after a stroke is tricky but you don't have to just do the missionary position."

"Why would I just lay there and get no pleasure at all. You need to experiment and find positions that work for the both of you."

Anna said taking up burlesque dancing was also a massive help to build up her confidence and feel sexy again.

She said: "I found my confidence through burlesque. I now perform as a disabled performer. I don't care that I am disabled and overweight – I embrace it."

Anna said her biggest advice about sex after brain injury is not to be put off.

"Talk to your partner and try to keep things relaxed. Things are going to fail but that shouldn't put you off, try again. Oh and most importantly, have fun."



TOP TIPS FOR MANAGING SEXUAL RELATIONSHIPS AFTER BRAIN INJURY

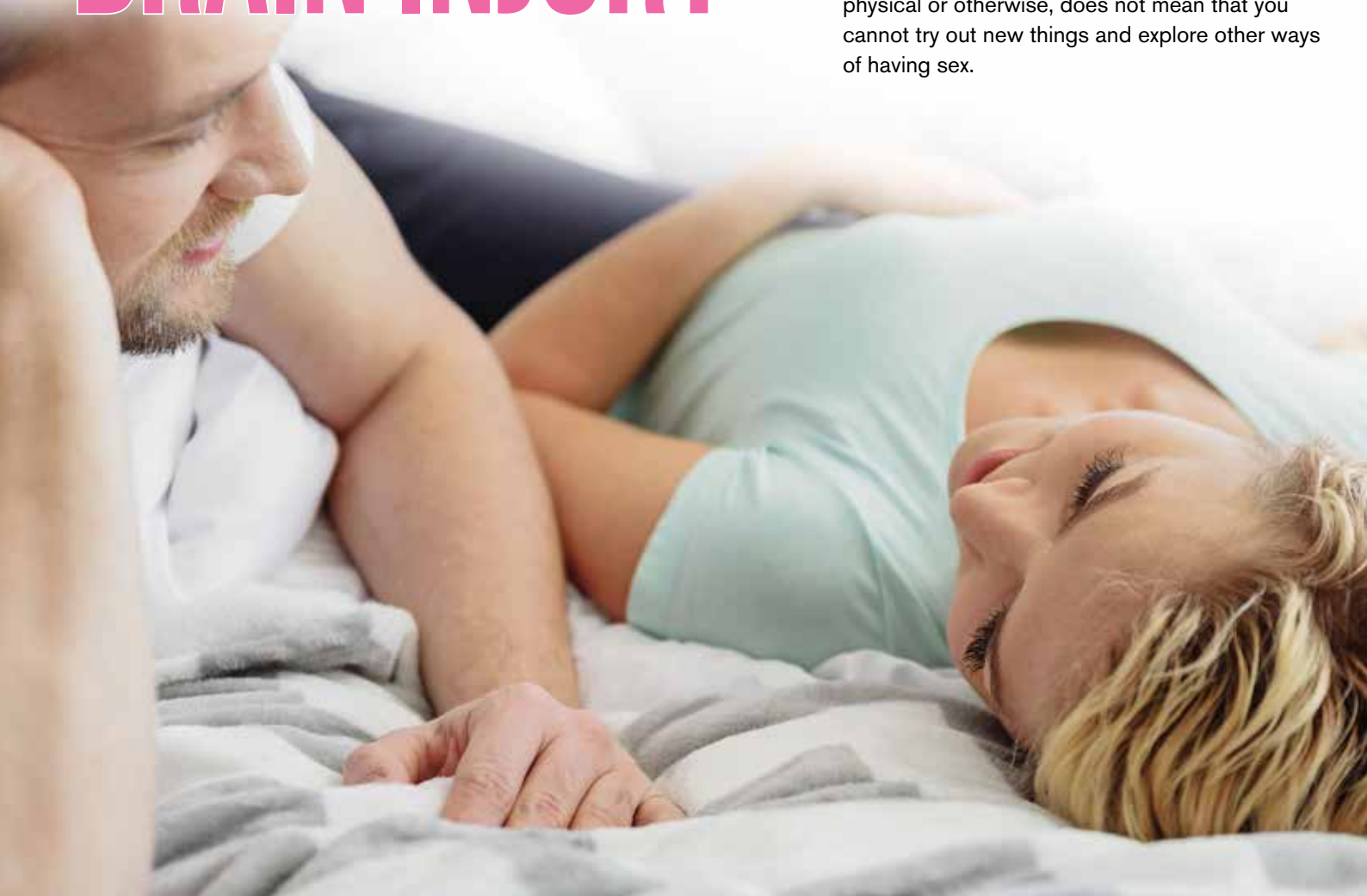
Try to identify if a particular effect of brain injury is causing the sexual issues, such as fatigue, pain or psychological effects. Read up on ways of coping with these effects and seeking professional support for them, for instance from Headway's booklets and factsheets at www.headway.org.uk/information-library.

Both your body and your brain need time to prepare for sexual activity, so don't rush into having sex. Instead, set time aside and make sure there are no distractions in the environment, and start off by engaging in activities such as touching and kissing to create a sense of intimacy.

Talk to one another about sex. If you aren't comfortable with any part of sexual activity, both physically and emotionally, it's very important to be honest and open about your thoughts, interests and needs with your sexual partner. Don't assume that your sexual partner will know this already!

Seek support from professionals, such as your GP, a sex and relationship therapist, a neuropsychologist or the Headway helpline.

Be adventurous! Having a disability, physical or otherwise, does not mean that you cannot try out new things and explore other ways of having sex.



BUSTING THE MYTHS AROUND BRAIN INJURY AND SEX

Alison Towner

Sex and relationships psychotherapist



MORE INFORMATION

Sexual relationships after brain injury can be complex. Brain injury can impact relationships, intimacy with long-term partners, and be a cause of depression and anxiety.

Issues such as disinhibition, impulsivity and general vulnerability may also be of natural concern, particularly for many carers and family members.

What is clear is that sex is something that we should all be comfortable talking about – regardless of disability.

This article introduces some of the main themes of the topic. More information is available in the award-winning Headway booklet *Sex and sexuality after brain injury*, which can be downloaded from www.headway.org.uk/information-library.

Brain injury survivors are not interested in having sex

Some of the effects of brain injury, or the experience of having a brain injury, can indeed make a brain injury survivor disinterested in sex, especially in the early days. But many brain injury survivors' sexual interests will not have changed and they will have the same desires for intimacy and physical contact as anyone else.

If you are a sexual partner of a brain injury survivor and you are not sure whether they are interested in sex, talk to them and give them the opportunity to be honest about how they feel. Having a brain injury does not automatically switch off someone's sex drive, but it is important to also recognise that it can affect their interest in sex for a number of reasons.

Brain injury survivors are not able to have sex

Again, this can be both true and false. Many brain injury survivors are still perfectly capable of having sex. However, some brain injury survivors might have hormonal imbalance issues that affect them on a physical level so that their body does not react in the same way to sexual activity as it did before the injury. This can impact ability and desire.

Others may experience issues such as pain, making sex uncomfortable. Emotional and psychological effects of brain injury can also prevent some survivors from being able to have sex.

However, there are things that can help to overcome these issues. Endocrinologists are specialists that can help people with hormonal imbalance issues. Medication can help with managing some of these issues, and exploring different positions can help to make sex more comfortable.

Brain injury makes people hyper-sexualised

There are some well-known cases of brain injury survivors developing hyperactive sexuality (drastically increased sexual interest) after their injury.

A brain injury can also commonly cause disinhibition, causing the survivor to behave or talk in a sexually inappropriate way. However, some survivors may also develop hypoactive sexuality, which is decreased interest in sex. This could be related to psychological issues such as depression, decreased confidence or post-traumatic stress disorder, or physical issues such as pain or hormonal imbalance.

Whether a survivor develops hyper or hypoactive sexual tendencies, support can be sought to help with managing this.

Annual
Awards
2018

Meet your finalists!

Carer of the Year

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It's that time of year again when Headway supporters, volunteers and staff come together at The Dorchester Hotel to celebrate the incredible achievements of people living with brain injury, and the inspirational support provided to them.

On 7 December, 11 fabulous finalists will be honoured at the Headway Annual Awards.

So let's meet this year's finalists:



Gwenda Gage

"I just do my best to keep going and stay positive. I have been a carer now for so long that it's just normal, it's just life."

Gwenda has devoted the last 24 years of her life to caring for her son, Stephen, after he sustained a life-changing brain injury in 1994.

With support from Headway Bristol, Gwenda provides emotional and practical care for her son, which is even more remarkable considering her own health issues that require her to carry with her an oxygen tank due to inflammation of the lung.



Trish Campini

"Trish's dedication to care for her family is inspirational."

Devoted pensioner Trish Campini, 81, has cared for her son, Stephen, for more than 40 years after he sustained a severe traumatic brain injury. She is also an invaluable volunteer at Headway Conwy and Denbighshire.

Trish and her husband Peter dedicated their lives to supporting their son through his prolonged disability until 2008, when Peter was diagnosed with cancer. Trish then became a carer for her husband and son. Peter passed away in 2011 and just three weeks after his funeral, Trish was taken into hospital for a triple by-pass operation.

But yet again, within days of returning home, she showed incredible strength and devotion to once again provide constant care for her son.

Stephen McAleese Outstanding Contribution to Headway Award

Sponsored by No5 Barristers' Chambers



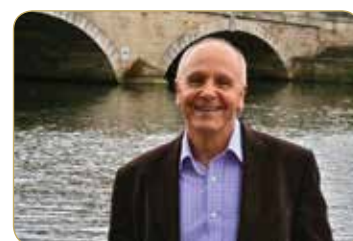
Udo Kischka

"I had been working in neurology for 20 years, but I knew nothing about brain injury until my own stroke."

Neurologist Udo Kischka spent his career advising medical professionals how best to care for brain injury survivors. In 2004, he joined the board of Headway Oxfordshire in order to help ensure patients received support when they left hospital.

But when he suffered a stroke in 2016, the tables had turned and his life lay in the hands of the colleagues he had trained.

Having made a good recovery, Udo uses his experiences as a doctor and a brain injury survivor to improve medical professionals' approaches to caring for survivors.



John Smith

"I'm very proud of being part of an organisation that has helped so many families to cope in some of the most drastic circumstances."

John Smith has been nominated after supporting Headway Basingstoke for more than 23 years as a volunteer and trustee.

John played a crucial role in helping the group survive a financial crisis as a result of a withdrawal of funding that threatened the very existence of the charity.

Put simply, without John's skills, support and dedication, Headway Basingstoke would not be as it is today – a successful rehabilitation centre for people living with the effects of brain injury.



John Dougan

"I had constant headaches, I forgot just about everything and I couldn't stay awake. But the doctor said I was fine and I started to wonder if it was all in my head."

When former army sergeant John Dougan was involved in a car crash, his broken leg was obvious. But doctors failed to identify his brain injury, and for years he struggled silently with his hidden disability.

Now, after re-training as a teacher, John runs a peer support group at Headway Rotherham, helping other survivors struggling to adjust to life after brain injury.



Volunteer of the Year

Sponsored by Anthony Gold Solicitors

AnthonyGold



Sally Palmer

“When I tell people I work with brain injury survivors they say ‘isn’t that depressing?’ Well no, it’s actually really heart-warming. We’re like a big family.”



Sally has been an indispensable volunteer at Headway Cardiff and South East Wales for more than 20 years.

Despite periods of ill health, including being diagnosed with breast cancer in 2004, she has provided invaluable support to the group, helping out in a variety of ways – including helping to raise more than £150,000 for the charity.



Arlette Foster

“It’s lovely to be nominated for the award but what makes me really happy is to be able to use what happened to me to help others going through a similar thing.”

23 years ago, Arlette’s 21-year-old son, Phillip, sustained a severe brain injury.

Arlette was determined to help other families going through similar ordeals, particularly in the early stages of care. Using her experience, she helped set up Headway East Sussex’s Hospital Liaison Service team.

She also delivers brain injury training and volunteers her time and expertise as an art therapist at the group.



Susan Kyle

“When they told me the cancer was incurable, I cried knowing I couldn’t help Headway Hull and East Riding anymore.”

Susan found Headway in 2009, two years after sustaining her brain injury. Since then, she dedicated herself to fundraising for the charity, raising thousands of pounds in the process.

Despite her life-long health problems and recent cancer diagnosis, Susan shows no signs of slowing down.

“I’ve told my husband John he has to carry on fundraising for Headway when I’m gone, or else I’ll haunt him!”

Alex Richardson Achiever of the Year Award

Sponsored by Slater and Gordon Solicitor



James Neal

"I'm qualified to dive to depths of 100 metres plus, carrying multiple cylinders, breathing gases that would be deadly if inhaled at the wrong depths. But I can't make a bacon and egg sandwich without ruining it."



James Neal's brain injury drastically altered his personality, ended his career and almost wrecked his marriage.

But his passion to scuba dive once again helped him to turn his fortunes around and he is now one of the most qualified divers in the UK, teaching others to do the same. He's also raised several thousands of pounds for Headway Gloucestershire.



Callum Maclean

"I was so proud of his involvement in helping to promote Headway's ID card. He had to fly to Edinburgh on his own, which was a big thing for him, and was so passionate about how useful it could be to people like him."

Callum, who was nominated by his proud wife Catriona, was diagnosed with a benign brain tumour in 2011. Following a complex operation he was left without speech and was unable to walk.

But with the support of close family and Headway Highland he is rebuilding his life and confidence. Earlier this year, he bravely shared his experiences on national television.



Andy Nicholson

"Andy won't let anything beat him and strives to help others 24/7."

These words from Andy Nicholson's wife Sharon go some way to explaining why he has been nominated for a Headway Annual Award.

Andy sustained a brain injury in 1994 after plunging 20-feet head-first down an unguarded stairwell on a building site.

He has since battled to rebuild his life and now dedicates his time to raising awareness of brain injury through his vibrant and ever-growing online community, as well as in the press.

Want to learn more?

To read more about our incredible finalists, visit www.headway.org.uk.

And don't forget to keep an eye on our social media channels on Friday 7 December as we keep you posted on what will be another very special Headway event!

My story...

The long journey home

'As I began the journey home I felt a huge sense of relief and thought that my battle was now over. Little did I know, it had only just started.'

Danielle Grant, 37, was delighted when she was told she was finally going home having spent six weeks in hospital following a ruptured brain aneurysm.

But at the time she had little understanding of the challenges she would face as she tried to rebuild her life.

Danielle, from Sheffield, sustained her brain injury while staying at her parents' house.

"I must have awoken from my sleep to use the bathroom," she recalls.

"I went to the toilet and that's when my aneurysm ruptured. I can only imagine the confusion and the unbearable amount of pain I must have experienced.

"It must have been the point of rupture that made me feel that I couldn't make it back to my bedroom and instead I crawled into the bath."

Thankfully she was found by her father, and his immediate intervention saved her life.

"Apparently I was breathing in a very loud and strange way and it was this that woke up my father," said Danielle.

"He said the noise was un-reconisable and decided to get out of bed to investigate. Thank God he did!

"I've thought about this over and over again. What if I had locked the bathroom door? They would have had to break the door down which would have added time that was critical to saving my life.

"What would have happened if I was alone? The list goes on."

Danielle was taken to her local hospital in Sheffield where she underwent life-saving surgery. She was transferred to the critical care unit before receiving specialist care courtesy of the Royal Hallamshire Hospital's neurology department.

When the time came to leave hospital Danielle was ecstatic. But the joy was short lived as even the short journey home was overwhelming.

She said: "As I began the journey home I felt a huge sense of relief and thought that my battle was now over. Little did I know it had only just started.

"In the car home all my senses were heightened and I noticed every tiny detail from the sounds to the smells, the fresh air and the movement of everything around me.

"It was only a short journey, around 15 minutes. But this is the first time I had experienced travel sickness. I literally held my head in my hands and had my eyes closed for most of the journey home."

"It was a sensory overload, too much for me to handle and incredibly overwhelming."

"I made it. I was home."

With the difficult journey home complete, Danielle began to come to terms with what lay ahead as she started her long road to physical, mental and emotional recovery.

She said: "Being back home forced me to realise how fragile I was. I soon became anxious about being left alone and constantly worried about having another aneurysm.

"I really struggled to manage all the medication I was on, as well as practical things such as taking a shower, walking up and down stairs, cooking, and managing my finances.

"As the days passed I started to feel incredibly isolated. I went from having round-the-clock care and many visitors, to people forgetting about me and getting on with their lives.

"The misconception was that I was now fine because I was home, so my support system from friends and family started to fade away."

"Luckily I had some core friends and family who stuck by me."

Listen to your body

Danielle said for the first month after returning home she managed to do very little other than sleep, a situation she tried to fight against.

"I was always exhausted and my medication just made that situation worse," said Danielle.

"But as time passed I learnt to listen to my body and knew when I needed to rest.



"I didn't always rest when I needed to and as a result I would literally shut down. I also found that my memory became worse when I was fatigued."

Since the aneurysm ruptured Danielle has received help from a physiotherapist, an occupational therapist and was also referred to a specialist brain injury unit.

Thanks to this support and help from her family she is now beginning the first steps back into employment.

"I felt so vulnerable when trying to make the decision about going back to work. There was so much conflicting advice... I just didn't know what to do.

"Because I don't have any real noticeable symptoms other than a few headaches, I was frightened to make such a huge decision without having the relevant advice and confidence that I was making my decision wisely.

"I was finally given the go ahead when my consultant told me that he was happy with my recovery and that I was able to return to work providing I followed his advice.

"I had to have a phased return, drastically reduce my hours, take regular breaks and correctly manage my fatigue.

"He actually said to me, 'Look at you, you are doing amazing! You are a miracle!' He had a huge Cheshire cat grin on his face when saying it. I'll never forget that."



Returning home after brain injury - Danielle's top tips

Devise a schedule, with reminders, to help you manage your medication.

"My short-term memory loss made it really easy to forget to take my pills."

Schedule visits from family members and friends, don't have too many people visit at one time, and spread the visits out across the week.

"It can be incredibly tiring to focus on the conversation and to keep up with multiple conversations and the various stimuli, especially as fatigue is a massive symptom at this stage."

Take regular naps when you need them.

"I was suffering from fatigue not only as a result of my brain injury but also due to initially being anaemic when I was discharged from hospital, not to mention from the lack of sleep due to the constant observations in hospital!"

Delegate and ask your family to help with things such as cooking as you just won't be able to manage this.

"It's imperative that you are eating healthy nutritious meals to help with your recovery."

Ask someone you trust to help you manage your bills, benefits applications, and other finances.

"You probably won't be able to manage this alone. Remember too that applying for benefits can be a long and tiresome process, so the sooner you start the better."

For friends and relatives:

Buy the person recovering some nice, useful and thoughtful gifts which they can use to occupy their time and are of interest to them.

"My friend bought me a Be your best self journal and some positive affirmation cards to help with dealing with any kind of trauma. I was also given adult mindfulness colouring books and art kits, which I loved."

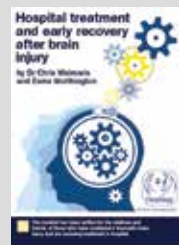
Oh, and don't forget the bright flowers. They helped to lift my spirits when I got home, particularly as you're not allowed to have them in the hospital these days."

Check in on your family member/friend regularly – even if it's just a short phone call. When they are feeling up to it, take them out of the house even if it's just for an hour or so.

"The recovery process and being back home can feel incredibly isolating. I would say that company is what I would have valued the most over anything! Giving your time and emotional support to someone in need is the most valuable random act of kindness you can do over anything and will be much appreciated – believe me!"

Further help and support

The Headway website contains plenty of information about discharge from hospital and the early stages of the recovery process. This



includes the booklet *Hospital treatment and early recovery after brain injury* and the *Waiting for rehabilitation after brain injury* factsheet, both of which can be downloaded free-of-charge from the information library on the site.

You can also find information on how to support a family in the immediate aftermath of a brain injury.

Alternatively, you can contact the freephone helpline on **0808 800 2244** or helpline@headway.org.uk.

It's open from 9am to 5pm, Monday to Friday, and is available to anyone with a question about brain injury.

Banking on local support

Rebuilding confidence and regaining a degree of independence are key aims for many people following acquired brain injury.

Managing one's finances and having the ability to withdraw cash can play a significant role in achieving these objectives. But with banks and building societies continuing to close branches, particularly in rural areas, is the era of online banking making it harder for brain injury survivors to manage their money?

Change can cast a shadow over daily life after brain injury, with anxiety about disruption to routine, difficulty adapting to change, problems learning new ways and even a threat to independent living. Here, we look at what help is available when your local branch closes.

Branch closures

Figures from the Office for National Statistics show nearly 6,000 local branches have shut since 2010, a fall of a third.

No longer just a place to send parcels and buy stamps, the Post Office – and its mobile service – is now the financial hub of many high streets.

You can operate accounts from nearly 30 banks and building societies at the Post Office, whether it's to withdraw cash, make a deposit or check your balance. If your local bank or building society branch closes, you may still be able to keep your existing accounts and access them by visiting the Post Office.

If you are told that your local bank or building society branch is going to close, try not to worry. There is help and support available.

The most important step is to make sure your bank or building society is aware

of your particular circumstances and needs, if they are not already.

Ask a family member or trusted friend to help you make an appointment at your local branch and perhaps also accompany you to meet the staff. Showing the staff your Headway Brain Injury Identity Card can be a useful way to begin the conversation.

Practical help from your bank or building society

Documents: Statements, letters and other documents can be requested in a range of formats, including large print, audio documents or printed on coloured paper to make them easier to read.

Payment cards: Many banks and building societies offer cards in high-contrast colours to make it easier to see and read the text. Others feature a bright stripe and arrow to show which edge of



the card you insert into a cash machine or card reader, while others have a notch to let you feel which end to use.

Cheques: Cheque templates fit over your cheque book pages and highlight the areas you need to fill in. Large print cheque books are also available from some banks.

Signing your name: Signature stamps are useful if you have difficulty signing your name, or have an inconsistent signature. If you can't provide a signature, your bank or building society could give you an ID verification letter. This allows you to use a debit or credit card without a PIN or signature.

Help when you visit your branch:

If you need to visit your branch, you can ask for a longer appointment time. Many branches will be able to arrange for your appointment to take place in a private and quiet meeting room. If you have a support worker, they are welcome to come to your appointment with you.

If you can't visit your branch:

In some cases, some banks and building societies may be able to offer appointments in your own home or in other settings such as hospital or residential care.

Adam and Janet's* story

Janet contacted Headway because she was worried about how her son Adam would manage his money safely when his local bank branch was listed for closure.

Adam has an acquired brain injury which has left him with communication and memory problems, although he is proud of his ability to live independently. Adam can be very trusting and lacks insight into how his brain injury affects him, which makes him vulnerable.

For several years, Adam has relied heavily on his local bank branch for help managing his money. To help keep him safe, Adam visits his bank branch almost every day and the members of staff issue him with small amounts of cash so he can do his shopping at the nearby supermarket.

The members of staff at the bank have Janet's phone number and call her if there are any problems on his account or if they do not see him for a few days. Their support really helps Adam to live independently.

When Janet and Adam heard that his bank branch was going to close, they were both very worried about how Adam would be able to manage his money in future and how he would stay safe.

The bank account Adam uses can be operated through the Post Office. Workers from the bank have accompanied Adam to the local post office, just down the road. They have introduced him to the staff there to help make sure he can continue to have access to cash safely.

Adam will now need to have a card to operate his account. This does concern Janet, but if having to use a card becomes a problem the bank's community team is on hand to provide additional support.

It will take time before Janet's fears are completely put to rest, as any change in Adam's routine is a cause for concern. It will also take time for Adam to feel as safe and comfortable with the Post Office staff as the staff at the bank, but the team has been very welcoming and so far, so good.

* Names have been changed.



#HeadwayHeroes

All aboard the

FUNDRAISING EXPRESS!

Ever had one of those train journeys that you feel has lasted for days on end? Well, for some rail enthusiasts, that prospect is an incredibly exciting one – particularly if they get to ride in special carriages pulled by rarely-seen locomotives.

Indeed, the GB Railfreight (GBRf) charity charter is one of the most important dates in a train enthusiast's diary. The event is so popular that tickets sold out within hours, with more than £100,000 already raised for the firm's two chosen charities – Headway and Macmillan Cancer Support.

GBRf 2018 – Out of the Ordinary saw more than 400 passengers tour up and down the UK over four days, from London Victoria to Blackpool, Fort William to Carlisle, with dozens of stops along the way.

Spotters had the chance to visit rail freight yards rarely open to the public,



A noteworthy sight for many a train enthusiast!

riding on trains that had never been across certain tracks before, and were unlikely ever to again.

Staff at GBRf named Headway one of its chosen charities as a thank you for the support the charity provided to one of their colleagues, Daniel Mole, after his brain injury.

On 22 January 2017, Daniel sustained a ruptured aneurysm, followed by a stroke that left him in a coma.

When he awoke he was unable to walk, talk or care for himself. His right side was paralysed and he also had significant cognitive and memory issues.

Thanks to the unwavering support of his fiancée Meg, Daniel started to make a good recovery, receiving support from Headway every step of the way.

Whenever the couple needed advice or support, Headway's helpline was on the end of the phone, while the information booklets helped them to understand what Daniel was going through and prepare for the future.

"During that period, Headway played a fantastic role in keeping Daniel supported," said John Smith, managing director of GBRf. "He got very frustrated with his rate of recovery, but it's great that he's now back on his two feet and I'm very grateful to Headway."

Daniel is now being supported by GBRf in a phased return to work, attending



Headway's Charlotte and Anna get ready for the off!

regular meetings to review his progress and working closely with his rehab team.

The colleagues who chose Headway because of their close connection with Daniel volunteered their time to man GBRf's charity charter train and raise money for charity.

Many worked for GBRf themselves, but some were simply family friends, happy to help out and do their bit for charity.

During the day, Headway staff were on hand to tell passengers about the work of the charity and explain how their donations would help to improve the lives of people affected by brain injury.

The passengers were interested to find out more, with some even sharing their own experiences of loved ones who had sustained brain injuries.

As the train made its way past rolling hills and city skylines, spotters noted which freight trains they had seen using voice recorders, and tracked their routes on interactive digital train maps.

Some had their cameras at the ready for the perfect photo, while others just sat back and enjoyed the view, even flicking through a copy of Headway News!

Finally it was time for the grand finale. As the locomotive pulled into Waterloo Station, crowds gathered to get a photo of this rare and special train that had been on an epic journey.

Jo Plant, Director of Fundraising, said: "We were honoured to be invited to join the GBRf team on the tour. We are extremely grateful to all of the volunteers and passengers who took the time to learn about the charity's work and made our staff feel so welcome.

"Returning to work can play a huge part in helping survivors to rebuild their lives and it's fantastic to see GBRf doing everything they can to support Daniel on his phased return."

"We can't thank them enough for everything they have done."



Passengers were given plenty of 'opportunities' to contribute to Headway's work on the four-day journey



John Smith, Managing Director of GBRf, with Charlotte and Anna



The incredible team of GBRf volunteers

#HeadwayHeroes



WHAT WILL YOU DO?

2019 marks Headway's **40th anniversary** and to celebrate we've set up **CHALLENGE 40**. We're encouraging all you fabulous fundraisers to do whatever you choose – as long as it involves the number **40**!

We know our fundraisers are a creative bunch. Whether it's sailing round the world, doing endurance go-karting events, or spending the night in a prison cell,

Headway Heroes are always taking on an array of weird and wonderful challenges.

Every penny raised allows us to help more and more people affected by brain injury. That support could be via our HATS nurses, who provide comfort and reassurance to families in early stages of care. Or our helpline team, which offers a reassuring voice and expert direction to anyone in need of a listening ear or a little guidance. Or our Emergency Fund, which enables families to be by the hospital bedsides of their loved ones.

None of these services would be possible without the unwavering support of our fundraisers, old and new. You have made Headway the charity it is today, and have helped to transform the lives of thousands of people affected by brain injury.

With your help, we've come a long way since the charity was formed back in 1979. But we know there's so much more to do.

So why not celebrate our big birthday by signing up to Challenge 40?

YOU COULD:

- 40** Give up **40p** for 40 days
- 40** Walk or run **40** miles
- 40** Hold a **40**-question quiz night
- 40** Swim **40** lengths of a pool

For those wanting to take on a bigger challenge or planning to fundraise as a group or company you could:

- 40** Hold **40** small events throughout the year
- 40** Host a **1940s**-inspired dinner
- 40** Play **40** holes of golf in a weekend
- 40** Have **40** people fundraise **£4000**, with each participant set a **£100** target

Anyone who completes their fundraising challenge will receive a special **CHALLENGE 40** certificate and limited edition pin badge.

If you would like any support such as a fundraising pack or help with ideas and events, we would love to hear from you.

Contact Headway's community fundraising team by emailing **projects@headway.org.uk** or calling **0115 924 0800**.

For more information about **CHALLENGE 40** and/or to register your challenge visit the **CHALLENGE 40** page on the Headway website at www.headway.org.uk/get-involved/support-us/challenge-40/



MOTTY AND ALDERMORE HIT THE BACK OF THE NET

Specialist bank Aldermore was joined by legendary football commentator John 'Motty' Motson to help raise more than £13,000 for Headway during the firm's annual charity football tournament.

The yearly event is held in memory of Adam Massen, a member of Aldermore's asset finance team who tragically died from a brain injury in 2014. Every year, the charity brings together teams from across the industry to support Headway. Over the past four years almost £40,000 has been raised.

This year's tournament was the biggest yet with a record 20 teams signed up. The teams battled it out for the Adam Massen cup and the eventual winners were the talented players from Henry Howard who beat White Oak Ltd 2-0 in the final.

Carl D'Ammassa, Group Managing Director, Business Finance at Aldermore, said: "The whole

tournament was a huge success and, more importantly, served as a fitting tribute to Adam Massen, our fondly remembered asset finance colleague who was a big football fan.

John Motson (left) and Patrick Jelly from Aldermore present the cheque to Headway's Anna Kerr



"On behalf of everyone at Aldermore, we want to express our thanks to all the teams that participated and congratulations to the winning team, Henry Howard. We're thrilled to have beaten last year's total of £12,000, making this year's tournament the best yet.

"The work Headway does is vital to support those with brain injuries and it is our absolute pleasure to help raise money for such a worthwhile cause, and one that is close to our hearts."

Unique Care Provider (UCP) Ltd offers a range of consultancy services to help you set up your own care team and manage your dependent's Trust Fund.



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- ✓ Calculate and understand the statutory benefits you're entitled to
- ✓ Provide access to local care facilities and support networks
- ✓ Advise on realistic, affordable property adaptations and specialist vehicles
- ✓ Access and understand the medical equipment your loved one requires – and provide training on how to use it
- ✓ Implement and manage a care team, including HR, payroll, pensions and employment law support.

We will never ask you to sign a contract with us and there is no minimum charge. We can work with you on an hourly rate, or on a project-by-project basis, so you only pay for the services you receive.



CONTACT UCP LTD TODAY!



Toni Mousley
Owner of UCP

#HeadwayHeroes

How did we get roped into this?



Geoff Carr prepares to do 'the lean'

What's the first thing that comes to your mind when you see an image of the ArcelorMittal Orbit in the Olympic Park in London? We're guessing it's probably not 'Ooh, I'd love to abseil down that!'

But that's exactly what dozens of brave souls chose to do in order to raise vital funds for Headway.

After the success of last year's Corporate Challenge, *Up The O2*, Headway managed to convince more than 60 willing corporate supporters to take on the UK's highest free-fall abseil.

Headway's Melanie Dickens and Anna Kerr led the way by being the first to descend the 262-foot structure.

Melanie said: "The most nerve-wracking part of the whole experience has to be 'the lean', where you have to force yourself to lean backwards from the structure and trust your ropes.

"Once we had made it over the ledge we had a chance to take in the incredible views over London and by the time our hearts had stopped racing, it was actually quite tranquil!"

After a morning of abseiling it was time for lunch and a celebratory glass of prosecco, which was kindly sponsored by No5 Barristers' Chambers.

Headway supporter and brain injury survivor Nic O'Leary then delivered a moving and

inspirational speech which brought home to everyone why their support is so important to our work and to people just like Nic.

Geoff Carr, Director of Clerking at No5 Chambers, said: "The support I had from the Headway staff was simply phenomenal. After their laughs and copious amounts of photographs of a palpable wreck, I decided to simply jump and trust the instructors.

"The fact you are reading this proves they clearly knew what they were doing.

"On a more serious note, the day was incredibly well organised and is a testament to Headway and all of the team running such a worthy charity."

Melanie added: "Everyone who took on the Corporate Challenge had a fantastic day. Although there were a few squeals and shaky legs, everyone showed true bravery and the event was a huge success.

"Thank you to everyone who took on the challenge or supported their fundraising."

We would like to say a huge **THANK YOU** to all of our corporate supporters who took on the challenge:

- Bolt Burdon Kemp
- Boyes Turner
- Clarkson Wright & Jakes
- Home Care Preferred
- Jefferies Solicitors
- Nic O'Leary
- No5 Barristers' Chambers
- Nockolds Solicitors
- Psychology Direct
- Osbornes Law
- Old Square Chambers
- Saltus
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- Wynne-Jones IP

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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.

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Anne Cahill

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Inspired? Get involved!
www.headway.org.uk/get-involved **31**

putting your life back on track



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Contact Partner **GARY SMITH**

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- We give you free advice on the merits of any claim
- We provide an expert, specialist service to victims of brain injuries
- We provide a national service to clients in all parts of England and Wales, including free home visits to discuss your needs and our service

Gary Smith is a member of Headway - the brain injury association's Personal Injury Solicitor's List

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