

Winter 2019

Headway News

The magazine of Headway - the brain injury association

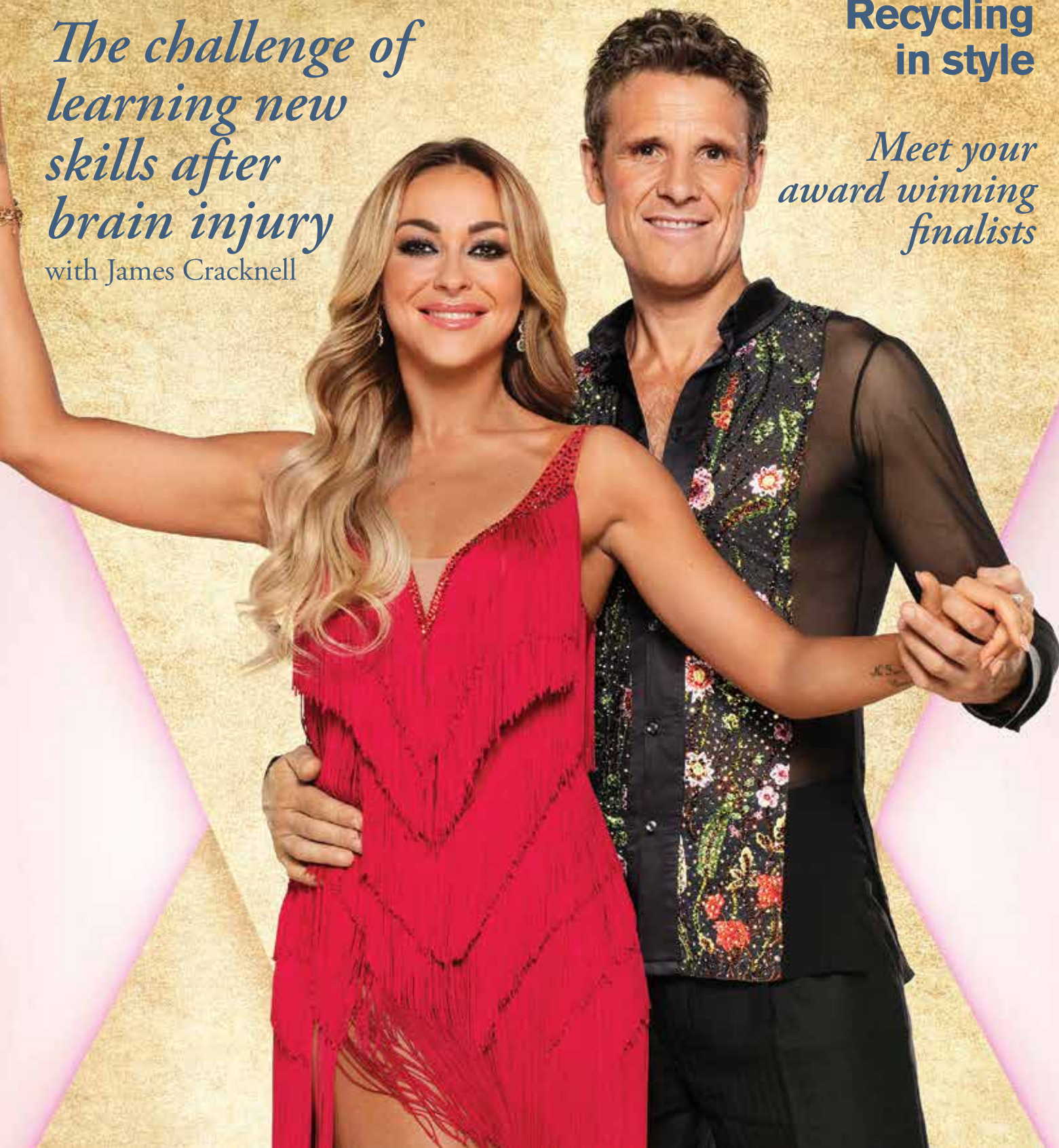
*The challenge of
learning new
skills after
brain injury*

with James Cracknell

Let's talk
continence
problems

**Recycling
in style**

*Meet your
award winning
finalists*





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Welcome



the brain injury association

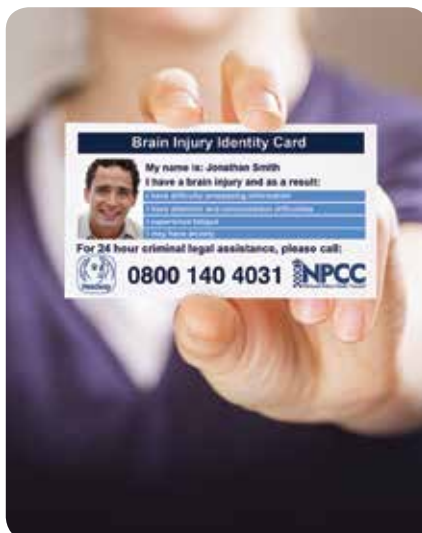
As the festive season approaches, I'd like to thank you for your contribution towards helping to improve life after brain injury in 2019.

This year, we've made significant progress in improving the understanding of brain injury among assessment staff working on Personal Independence Payments. Through specialist training, they can produce more accurate reports on the impact a brain injury can have on daily living. In turn, this ensures that survivors secure the financial support they deserve.

We've also raised awareness of the serious issue of brain injury-related fatigue, helping survivors to highlight their daily struggles and foster a community of understanding. This year, thousands of you connected with us through social media to share your stories and experiences.

Our passion for reducing the incidence of brain injury remains unwavering. As a charity we are proud to campaign for safer workplaces, better concussion protocols and improvements to road safety.

We are also proud to be able to offer practical support through our Emergency Fund, which provides grants in the immediate aftermath of brain injury, as well as the Headway Brain Injury Identity Card, which is designed to help police officers more easily recognise the effects of brain injury and provide appropriate support for survivors.



We will continue to position brain injury as a priority and campaign for better care and rehabilitation with MPs and ministers. This year has seen brain injury at the forefront of several parliamentary discussions and debates. In the most recent debate, Headway was mentioned 34 times!

Hundreds of you have emailed and written letters to your local MPs, and together, our voices are being heard. We're encouraged by how well they have responded to our calls for change but there is still so much more to be done.

Some of what we campaign for at Headway may take years to achieve, but together and with your support, you are helping to improve life after brain injury.

Thank you for standing with us.

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 0800 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 have a blue badge and my disabilities are not obvious, I had a stroke - I'm all for this. We also need more disabled spaces."

Tracy Hughes-Welsh

From 30 August 2019, people with hidden disabilities became eligible to access the Blue Badge parking scheme.

The updated eligibility criteria will now encompass some of the hidden effects of a brain injury - for example, when brain injury-related fatigue makes walking long distances difficult or when cognitive or psychological effects make seeking a parking space overwhelming.

We asked our social media followers for their views on the extension:

"I have had a badge for ages. I always get looks from others but I don't care!"

Karen Weatherley

"Massive help for me, I know it sounds daft but I can find my car because I know it will be in the disabled bays, before I had to photograph where I'd parked it to find it when I got back to the car park."

Darrell Meekcom

"Need to increase number of spaces for increase in demand."

Wonga Wong

"Hopefully the authorities will police disabled parking spaces with more rigor, some folks just take the mick. Supermarkets need to take some control and fine offenders, they are quick enough with shoplifters, how about space-stealers?"

Anon

We often hear that a Blue Badge is helpful – but that there simply aren't enough spaces. Headway has put together a guide on who and how to ask for more spaces in your area, complete with wording for emails or letters for you to send. You can find it at www.headway.org.uk/make-space-for-abi.

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Supporting Headway is as easy as pie...

MINCE PIE MORNING



the brain injury association

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Latest round-up

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

Headway evidence supports MP's demands on gambling

Gambling companies must do more to protect vulnerable gamblers, according to a report by the All-Party Parliamentary Group (APPG) on Gambling Related Harm.

Dr Clare Mills, Headway's Public Affairs Manager, said: "Giving evidence to the APPG's inquiry into harm from online gambling, and

supporting George* to do so, was a real opportunity to tell more people about some of the lesser-known risks after acquired brain injury. Any improvements in protection for vulnerable people are welcome."

If you have been affected by gambling after acquired brain injury, you may like to contact the Headway helpline on **0808 800 2244** or **helpline@headway.org.uk**.

*not his real name



More BMA Awards for Headway publications

Headway's information resources have been honoured for the eleventh year running at the British Medical Association (BMA) Patient Information Awards.

Headway's new resources, which help people to understand and manage the effects of alcohol consumption after brain injury, received the coveted awards.

Our factsheet *Alcohol after brain injury* was Highly Commended, with judges praising its evidenced-based approach, while our factsheet *Brain injury: A guide for parents*, which aims to help parents cope with the devastating and frightening experience of a child sustaining a brain injury, was Commended by the judges.



Patient information awards
Highly commended

Headway's Training for Solicitors course awarded accreditation by APIL

Headway's Solicitors Training for 2019 has been awarded accreditation by the Association of Personal Injury Lawyers (APIL).

The training course, which is specifically designed for solicitors involved with brain injury cases, is part of Headway's ongoing commitment to raise awareness

of the unique challenges faced by survivors and their families.

The course is now accredited by APIL Training at litigator and senior litigator level for 4.5 Continuous Professional Development (CPD) hours.

Headway's Director of Fundraising, Jo Plant, said: "It's a great achievement for Headway's Solicitors Training course to be awarded accreditation by APIL.

"It speaks volumes to the hard work and commitment from the charity's side to ensure solicitors fully understand the complex nature of brain injury and its life-long effects."

The programme for the course includes sessions on information gathering techniques and the hidden effects of brain injury, as well as a personal perspective session.

Headway welcomes findings of Tranexamic Acid study

Headway has welcomed the findings from a study which has shown a drug called Tranexamic Acid (TXA) can reduce the risk of death for those who suffer a mild or moderate traumatic brain injury.

TXA helps stop bleeding in and around the brain when blood vessels have been torn.

A large international study in The Lancet now suggests it improves

patient survival rates if given early enough. It cannot undo damage but can stop smaller bleeds becoming worse.

The study, led by the London School of Hygiene & Tropical Medicine, involves patients with isolated brain injury. It showed there was a small difference in outcome for those who had 'mild' and 'moderate' injury who were treated with TXA compared with those who weren't given the drug.

Using complex statistics, it showed that approximately 20 fewer deaths

if treated with TXA and recommends that ambulance/emergency treatment protocols should be changed to include administering the drug to isolated brain injuries not just patients with multiple injuries.

However, the study states that there is no noticeable benefit in providing TXA to those with severe brain injury and the method used to create the statistics doesn't take into account a number of variables.



Ministry of Justice deputyship fee refunds scheme launched

A scheme has launched to refund those who may have paid more than they should for some deputyship fees.

If you, or someone you are acting for, was a client of the Office of the Public Guardian (OPG) and paid fees relating to a deputyship between 1 April 2008 and 31 March 2015, then you could be due a refund.

The Ministry of Justice (MOJ) sets OPG's deputyship fees. An MOJ review found that fees did not always match how much it cost for the OPG

to supervise deputyships between April 2008 and March 2015.

The MoJ says it has improved support and supervision for deputyships and it continues to review the fees. Since 1 April 2015, clients have not been overcharged.

The MoJ has now set up a refund scheme for those who were charged fees that were higher than necessary, to enable people who have been affected to obtain a refund.

The scheme will be run by the OPG and does not apply to any fees paid to the

OPG Scotland, the Office of Care and Protection in Northern Ireland or the Court of Protection.

More information is available on our website.



Latest round-up

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

Headway shocked by Giggs concussion comments

Headway has appeared in the national media to express its shock after hearing recent comments from Wales manager Ryan Giggs.

He said Daniel James was never knocked out or concussed but was "acting" during a match against Croatia on 13 October.

The Manchester United winger appeared to be out cold after a heavy mid-air collision with Domagoj Vida. Players and the referee immediately rushed to James and motioned for medical staff to attend to him, with images showing the 21-year-old flat on his back, arms and legs splayed.

James received a couple of minutes of treatment on the pitch before he was taken off and then immediately brought back on.

Our comments appeared in all the national newspapers and we appeared on Sky Sports News to share our thoughts.

Peter McCabe, Chief Executive of Headway, said: "Like most people watching the footage of the incident, our immediate concern was for the player's health. As soon as the incident occurred, he was

attended to by the medics who then determined that he was fit to continue.

"Although it is argued that concussion protocols were followed, the rules state that if a concussion is suspected a player must be removed from the game. To all watching, it appeared that Daniel James lost consciousness. Regardless of his manager's comments after the game, this in itself must surely have given enough reason to take a cautious approach.

"However, Ryan Giggs' claim that the player was being 'streetwise' by staying down and appearing to have been knocked out is shocking.

"If that is the case and James was 'acting', it raises serious questions about the player's understanding of the seriousness of concussion. Not only has he put his own medical team under intense and unfair scrutiny, but he's also set a dangerous example for the millions watching at home.

"Similarly, we have serious concerns about terms like 'streetwise' or that the player was 'just using his nous'. It is simply not acceptable for teams to use concussion protocols for tactical gain."

Headway calls for further heading research

Headway has called for more research into the effects of heading modern footballs following a study which showed that former professional footballers were three-and-a-half times more likely to die of dementia than people of the same age range in the general population.

Experts at Glasgow University have been investigating fears that heading the ball could be linked to brain injuries. It compared deaths of 7,676 ex-players to 23,000 people from the general population.

The sample was taken from men who played professional football in Scotland between 1900 and 1976. However, despite the dementia risk, the study also found that playing the game increased average lifespan.

Now Headway is demanding further research be undertaken but this time focusing on modern lightweight footballs.

"For many years, families and campaigning charities such as Headway have been demanding research into the long-term effects of repeatedly heading footballs," said Peter McCabe, Chief Executive of Headway.

"We welcome the work done by Dr Stewart and his team, but this study was always going to leave a lot of questions unanswered.

"We have known for some time that there is a link between the cumulative effect of repeated blows to the head – such as those suffered by boxers – and degenerative neurological conditions such as dementia. The fact that this long-awaited study has now identified a link in former footballers will no doubt lead to questions about how this will impact the modern game.

"It is vital that this research is now built upon, with a particular focus on the relative risks of heading lightweight modern footballs."



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and practically address the impact
of traumatic brain injury on both
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In memory – Reginald Talbott 1936 – 2019



It is with a heavy heart that we announce the recent passing of Reginald James Talbott, one of the five founders of Headway and the charity's first Director.

Reg's first involvement with brain injury began during his time at the Queen's Medical Centre in Nottingham where he trained social workers. It was here where he met neurosurgeon Peter Weston, who asked for his help with brain injury survivors on the long-stay ward.

This involvement triggered Reg's lifelong interest in brain injury and his concern about not only the impact on the patient, but on their families too.

Reg later went on to join forces with Phillip Lockhart who was involved in similar work in Birmingham. Alongside Sir Neville Butterworth and Dinah and Barry Minton, the five called a meeting for all those involved in the care of brain injury survivors. A total of 23 carers and professionals attended a meeting on 23 October 1979 and Headway was born.

After the birth of the first Headway houses, in 1985, the charity moved to

new premises in Nottingham and Reg Talbott was appointed its first Director.

Without Reg's dedication and that of the other founders, the lives of brain injury survivors and their loved ones would be far more challenging. Thanks to their efforts, there is now a UK-wide network of support working to improve life after brain injury.

Reg passed away at home as he wanted, with his wife Gill by his side. His life ended in the same quiet and gentle manner in which he had lived.

He leaves behind his wife Gill, three children Sarah, Simon and Rebecca and his grandchildren Ieuan, Rhiannon, Tomos, Matthew and Daniel. Reg will be missed by all those who knew and loved him.

We thank the Talbott family for these words.

Meet your Finalists!

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. This year is no different and we are looking forward to celebrating their achievements at a glamorous party at the InterContinental Hotel in Mayfair, London on 6 December.

Let's meet this year's finalists:

Carer of the Year

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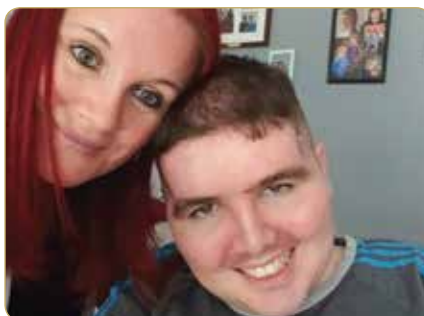
Tina Wescott

"Getting recognition like this helps to keep you smiling and if I'm able to raise awareness of brain injury and what being a carer can be like – then even better still."

Tina Wescott, 51, has been caring for her father Larry since 1993 after he sustained a traumatic brain injury in a car crash. The incident meant she had to give up her job as a supervisor at Bristol railway station.

Recently Larry, who is aged 77, suffered a fall in the night and broke his neck in two places. To make sure it didn't happen again, Tina slept on a sofa next to him for two years until she could afford to get the house altered.

During this time she rarely got a full night's sleep, as due to his brain injury, Larry needed help to use the toilet - which was often 15 times a night.



Janie Ferrier

"Janie will never give up her fight for Nick. She is one of our unsung heroes with the fight of a lioness."

Janie's son Nick sustained a traumatic brain injury after crashing his quad bike at the age of 22.

Following hospital treatment, Nick, who is now 27, was moved to a care home but was totally unsuitable and not geared up for a young disabled man.

Janie was tenacious in her attitude to bring Nick home, and after starting a local campaign, she managed to get care providers on board and fought red tape to achieve it.

To enable this all to happen Janie had to move from the family home to a property that could be adapted for Nick and his needs.

Janie, who is now Nick's full-time carer, never gives up her fight to improve her son's life.



Jackie Flavell

"I was really shocked and touched when I got told I was a finalist for such a prestigious award. It was a lovely moment."

Jackie's son Luke sustained a traumatic brain injury in July 2012 when his car skidded and crashed into a lamppost during a heavy rainstorm.

Against all odds, and with intense treatment, he pulled through, but when Luke finally returned home it was clear life would never be the same. It took a long time for him to come to terms with the cognitive and physical effects of brain injury.

His loved ones and family rallied around him, especially his mother Jackie who became his full-time carer.

Thanks to her care, and the support of Headway Black Country, Luke is now living independently and looking forward to the future.

Alex Richardson Achiever of the Year Award

Sponsored by Slater and Gordon Lawyers



Brooke Trotter

"It's a big honour to be recognised for an annual award. When I started my public speaking journey it was to help other survivors, not for the recognition, so it means a lot."

Brooke Trotter was just 24 when he sustained a brain injury. The university student was walking home from a night out when he was hit by a speeding car.

The car crashed into Brooke with such force that his head went through the windscreen – leaving him with a fractured skull and a life-threatening brain haemorrhage.

Despite only having a 30% chance of survival, Brooke has gone on to make a meaningful recovery, yet still battles with the ongoing effects of his injury.

Brooke decided to use his experiences to raise awareness of brain injury and the importance of being safe and careful on the roads.

Brooke has delivered motivational and informative speeches across the country to schools, hospitals, the emergency services and his local Headway group in Scarborough.



Peter Brown

"There are so many people doing amazing work to help improve the lives of brain injury survivors and to be appreciated as one of those people feels great!"

Peter Brown, 29 and from Orpington, was travelling home in February 2018 when he experienced a subarachnoid haemorrhage.

Before the brain injury it was a typical Saturday for Peter – he had spent the day playing football, followed by drinks in the local pub with his teammates. Having said goodbye to his friends, Peter headed home, unaware of what would happen next.

Shortly after setting off, Peter was found at the bottom of a train station staircase. He had broken his eye socket and almost bitten through his own tongue. However, it was the injury to his brain that would prove most life-changing.

In the early days, he struggled with short-term memory loss, communication problems, chronic fatigue and mobility issues.

Just over a year after the accident, Peter ran the London Marathon to show his support for the work of Headway.



Nicola Evans

"I work so hard every day to battle the fatigue, weakness and pain. To be nominated for this award makes it all worth it. I hope to inspire others and just keep going forwards."

When Nicola was just 13 years old, she was diagnosed with a cavernoma, a cluster of abnormal blood vessels on the brain, putting her at high risk of a haemorrhage or stroke.

Since then, Nicola, who is now 36, has gone on to suffer six bleeds on the brain, each one worse than the last.

Despite numerous challenges, such as undergoing a high-risk craniotomy, Nicola has gone on to start her own successful business as a nail technician.

Not only that, she has also started using her experiences to help other brain injury survivors at a local charity.

Nicola visited members at Headway Hertfordshire – where she has been a keen member for years – to deliver an inspirational talk about the possibilities of returning to work after a brain injury.

Volunteer of the Year

Sponsored by Anthony Gold Solicitors

AnthonyGold



Angela Caulfield

"John had incredible care and support while he was in hospital in Newcastle, but when we came home to Durham there was hardly any understanding of brain injury or access to ongoing rehab. That's why I set up Headway County Durham."

After a road traffic accident in 2004 left Angela's son with a traumatic brain injury, she decided to set up a steering group in Durham to provide support for brain injury survivors and their loved ones.

Two years on from the initial meeting, Headway Durham and Chester-Le-Street – later relaunched as Headway County Durham – was formed.

From small beginnings, the charity now delivers a wide range of services across multiple sites, ensuring those affected by brain injury have the opportunity to access proper support.

Angela's dedication to the charity over the years has been unwavering. She is now the Chair of the group, and her son John is able to make use of the services and support on offer.



Sharon Hargreaves

"Sharon describes herself as 'only a volunteer', but the reality is that she's an invaluable part of our branch. She'll go out of her way to help Headway."

After Sharon Hargreaves' husband sustained a brain injury three years ago, she started volunteering at Headway South Manchester and Stockport.

She began by helping at the weekly drop-in sessions, making teas and coffees and baking delicious cakes for all to eat. Since then, Sharon has gone on to support some of the group's most at-risk members, as well as setting up a hugely successful carers group.

To help set up the carers group, she sourced the venue, made plans to meet and help to co-ordinate its activities.

The number of people benefiting from this group has increased and she now regularly supports around 15 families at her sessions. All this, in less than a year.

Sharon goes out of her way to help Headway and her efforts are appreciated by members, staff and other volunteers alike.



Gillian Richards

"I've spent a lot of my life caring for and supporting those with an acquired brain injury and I wanted to use my knowledge and experience to help others going through the same thing as I did."

Gillian Richards' life has been dramatically affected by brain injury.

Her grandmother, mother and in-laws all suffered strokes and she too sustained a brain injury after hitting her head while swimming.

Gillian wanted to use her experiences of brain injury to help other survivors, so started volunteering at Headway East Sussex.

The professional counsellor has offered her support to members of the group on a voluntary basis for the past seven years, as well as supporting numerous fundraising events.

By her own admission, Gillian's voluntary role can be challenging due to her own need to manage fatigue, yet through careful pacing and organising her working environment, she has been able to combat the effects of her injury.

Stephen McAleese Outstanding Contribution to Headway Award

Sponsored by No5 Barristers' Chambers



Evelyn Menzies

"Finding Headway was a lifeline for me and my family. We were able to not only get support but also provide advice to other people going through what we did."

"It was a wonderful feeling to realise there were people who understood, who could lend a hand and listen."

Evelyn's life changed forever when in 1998 she received the phone call all parents dread.

Her son Neil was fighting for his life after being involved in a car accident while on holiday in South Africa.

Neil was left in a coma for 13 weeks and when he eventually returned home he had to relearn all of life's most basic skills – such as walking and talking.

As well as caring for her own son, she has been a volunteer and member at Headway Perth and Kinross for 16 years, helping to create new services which support people coming to terms with the effects of brain injury.



Rachel Rees

"Rachel is a lovable person to have around, is a hard worker and always tries to create a positive ambiance. She epitomizes all the right things in our group, Headway is like our family and if it was not for Rachel we would be lost."

Rachel has been a volunteer at Headway South Manchester and Stockport for more than 26 years.

She is a very active Chair and committed member of the groups committee and always goes above and beyond what is required from her.

The group are amazed at how she finds the time due to her having a busy work schedule and family commitments, but Rachel continues to be energetic and fully dedicated in supporting all the members.

She never hesitates to take on any challenge or difficult task to help the group grow and support families dealing with the consequences of brain injury.



Lesley McGuire

"I decided to nominate Lesley on behalf of everyone whose lives she has made a difference to, and on behalf of her late son Keith as a way of thanking her for all she did for us."

After Lesley McGuire's son, Keith, sustained a traumatic brain injury in 2010, she became his full-time carer and later went on to volunteer at Headway Hertfordshire.

In the early days of his recovery, Keith was able to access support from Headway and the group's Carers Education sessions helped Lesley to come to terms with the effects of her son's injury.

Sadly, Keith passed away earlier this year after a battle with cancer, but his legacy has lived on through Lesley and her determination to support others with a brain injury.

She now runs a number of the charity's peer support groups and has become an invaluable part of the team at Headway Hertfordshire.

Let's talk CONTINENCE PROBLEMS after brain injury

A brain injury can affect every aspect of a person's life. The resulting symptoms can be wide-ranging, from physical effects such as balance problems and dizziness, to cognitive, emotional and behavioural effects such as memory problems and anger.

However, there is an effect of brain injury that is rarely spoken about, even though it can have a major impact on people's everyday lives.

Continence problems, or in other words, struggling to control when you urinate or empty your bowels, is a common issue after brain injury, particularly in the first several weeks.

For many, this loss of toilet control is a sensitive issue, and people can feel as though they have lost their dignity. Guidance published by NHS England suggests that people "suffer in silence" because they are too embarrassed to talk about the issue.

Fortunately, with time and practice, many people regain control of their bladder and bowel functions. However, for others, continence problems can be an issue that they will need to learn to manage in the long-term.

Types of continence problems:

Neurogenic bladder

– bladder contraction and relaxation are uncoordinated

movement or activity, such as coughing, sneezing, laughing, lifting or passing wind

Functional – physical disabilities or problems with cognition and communication preventing a person from getting to the toilet on time

Reflex – no sensation that the bladder or bowel are full, therefore passing urine or faeces without realising it

Frequency – the need to pass urine or faeces more often than normal

Retention – straining or difficulty emptying the bladder or bowels (i.e. constipation)

Urgency – a sudden and uncontrollable need to pass urine or faeces at unexpected times

Overflow – the bladder or bowels over-fill and leak due to loss of feeling

Nocturnal enuresis – the need to go to the toilet several times during the night or wetting the bed while asleep

Faecal impaction – if somebody is constipated this can also press on the bladder, worsening any bladder problems that may be present

Stress – leaking urine or faeces during physical

Living with ongoing continence problems

For most people, these problems will resolve over time with appropriate treatment and professional support.

However, if problems do persist in the longer term, there is help available. With the right advice and preparation, continence problems can be managed.

Practical products available to help manage ongoing continence problems include:

- High absorbency pads and pants
- Washable or disposable seat pads to protect furniture
- Washable or disposable mattress protectors and bed pads
- Commodes (a chair with a removable potty under the seat)
- Alarms to sound at regular intervals throughout the day and night
- Catheters (a fine tube inserted into the bladder to drain urine) or other urine collection devices
- Anal plugs

Tips for living with ongoing continence problems include:

- **Following a daily routine with regular visits to the toilet.**
- **Plan access to toilets in advance.**

Disability Rights UK sell the RADAR National Key Scheme, which can give those struggling with continence problems access to locked public toilets across the country.

Bladder and Bowel Community also offer a 'Just Can't Wait' toilet card free of charge for those affected by continence problems. The debit-sized card explains that the card holder has a condition which requires urgent access to the toilet and provides a discreet and clear way to communicate with others. Headway Brain Injury Identity Card holders can also ask for continence

problems to be added to the front of their card. Find out more on our website at www.headway.org.uk/idcard.

- **Carry a 'survival kit' when out and about.**

It may include items such as a spare set of clothing, deodorising spray, disposable pads, scented disposal bags (for soiled items), anti bacterial wipes and hand gel.

- **Reduce the amount of liquid before bedtime.**

To avoid problems throughout the night.

- **Keep a clear pathway to the toilet at all times.**

- **Ensure good personal hygiene.**

To prevent skin irritation and general discomfort.

- **Wear clothes that are quick and easy to remove.**

- **Wash or dispose of soiled items safely and promptly.**

- **Talk to people, as continence problems can affect mood levels.**

Remember, the Headway helpline is available to talk Monday-Friday (9am-5pm) on **0808 800 2244** or helpline@headway.org.uk.

Case Study

"I'm very careful not to drink too late at night or I know I'll be up through the night. It's horrible to constantly feel like you need to pee when you don't, and that was the worst part of my brain injury."

Caring for someone with continence problems

Continence problems can be one of the most difficult aspects of caring for someone with a brain injury. It is often unpredictable and can be physically and emotionally demanding.

In addition, many brain injury survivors will find it difficult to accept that they need help, especially if the help is from someone close to them.

Tips for carers:

- **Watch discreetly for signs that the person needs the toilet.**

Especially if they cannot communicate this clearly. These signs may include fidgeting, pacing, getting up and down, or pulling at their clothes.

- **Make sure to give regular reminders to visit the toilet.**

- **Check the person has finished on the toilet and not become distracted or forgotten to use it.**

Case Study

"In the early stages after my husband's haemorrhage, he was doubly incontinent. I took him to the toilet regularly and verbalised for him when I noticed him fidgeting that he might need the loo so he could nod a response."

"As his language and mobility improved so did our success at getting to the toilet in time."

"Two years down the line and there has been a huge improvement. At night if he is restless, I put the light on and ask, usually once, maybe twice a night."

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

SATURDAY NIGHT FEVER

The difficulties of learning new skills after brain injury

Learning new skills can be a challenge for anyone, but even more so when living with the effects of a with the effects of a brain injury.

Many people find that their memory has been permanently affected and they struggle to learn new skills, retain information and have difficulties concentrating.

Headway's Vice President and double Olympic gold medallist, James Cracknell OBE, recently hot-footed his way onto prime-time TV to compete in *Strictly Come Dancing*.

Unfortunately, just two weeks in to the competition, James became the first celebrity to be voted off the show after struggling to get to grips with the dance routines.

James, 47, said: "One of the reasons why I did it is actually people's perceptions of what you can do after a pretty serious accident are limited.

"And if you listen to people putting limits on you, you're going to hit that ceiling. For me it was about proving them wrong, proving myself wrong and proving other people wrong."



Occupational Therapist, Meral Altılar, from the Second Chance Headway Centre in Wakefield, said:

“New learning requires a high level of task demand. Following a brain injury, cognitive impairment such as reduced concentration, attention and memory can prevent a person’s ability to retain new information long enough to recall later.

“New tasks demand a lot of our brain as we may have little to no previous knowledge or experience of how to initiate and put into action skills needed to achieve them.”

In July 2010, James Cracknell embarked on the challenge of cycling, rowing, running and swimming from Los Angeles to New York within 18 days. During the cycling leg of his adventure, James was hit from behind by a petrol tanker, resulting in a traumatic brain injury.

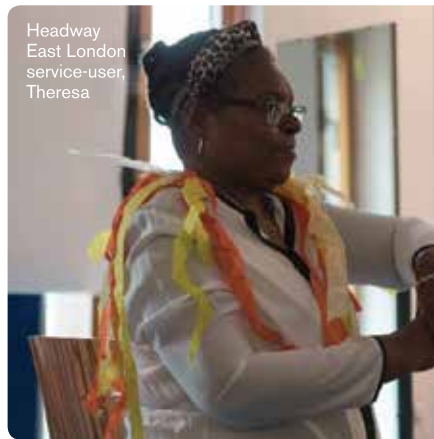
He said: “Following a brain injury, you can become more regimented, so you have to work within that. For me it’s a very structured way of learning. I needed to know the steps before progressing.

“Not only that, but a brain injury affects how you process information and your confidence, something you need by the bucketload for *Strictly*.

“Despite all the hurdles I faced when taking part in *Strictly*, I enjoyed challenging myself, putting myself out there and learning new skills.”

Top tips for learning new skills after a brain injury:

- ★ Set realistic goals based on your current abilities
- ★ Break sequences down into more achievable steps
- ★ Reduce the amount of verbal instructions given at one time
- ★ Practice and repetition
- ★ Reduce environment stimulus – find a quiet space with natural lighting
- ★ Incorporate regular rest breaks to manage fatigue



Headway East London

Headway East London is one group that has its service users throwing a few shapes.

We spoke to them about their adaptive dance groups and an ambitious new dance project.

“Here at Headway East London, we have been delivering two adaptive dance groups for our members each week, which are run by a physiotherapist and therapy assistant,” said Fiona Allen, physiotherapist.

“We have also recently received Postcode Lottery funding to embark on a year-long collaborative project with Studio Wayne McGregor. This will involve input from professional dance artists and choreographers as well as workshops at their dance space.

“The aim of our project is to develop dance and creative movement for brain injury survivors, and also create a digital resource pack which can be used to help guide the future delivery of dance groups at Headway and beyond.

“We have also introduced a couple of open workshops called ‘Wild Fusion’ which involved the collaboration of our art studio and musicians, along with improvised movement and dance. This promotes individual self-expression and exploration of movement, as well as creating a sense of teamwork and inclusion for all.

“Our groups go through a warm-up and general introduction activities, as well as a mix of partner work, use of props such as ribbons, improvisation, journeying or storytelling, gesture, voice and routines. The groups are enjoyable and provide a workout.

“They build confidence and tap into imagination and creativity away from impairments.”

Talking about being involved in the project, stroke survivor Theresa said: “It makes you feel good... I like to sing and dance, it gives you a rhythm.”

Headway Derby

We spoke to Sara Rose who is a Trainee Dance and Movement Psychotherapist at Headway Derby.

Sara told us: “I have a particular interest in working with people living with brain injury with a therapeutic approach based in movement. Often following a brain injury, people experience a loss of connection with their body and speak of feeling isolated or feeling misunderstood by their friends and family.

“Headway Derby has introduced Dance and Movement Psychotherapy (DMP). Members who joined the DMP sessions have had the opportunity to work in a safe space to explore the movement their body can make and to discuss issues that are important to them.

“Together we move and dance using props and themes, sometimes with music, sometimes without. The experience of moving together supports creativity and connectivity and brings about shared experience as each member is able to explore their breath, their senses, their movement and their connections between self and others.

“Dancing and moving together helps with memory as the movement builds a scaffolding of new movement narrative that can be built on each session.

Members have spoken of improved balance and co-ordination as they practice moving around the space with the support of myself and other members.

“The DMP sessions have proved to be successful and accessible and will be running for another year as we continue to capture and evidence the benefits of dancing and moving together after acquiring a brain injury.”



“*Dirty Dancing*” *is the perfect example of my memory failure”*

Ron Gains from Scarborough always loved watching musicals and it soon became one of his favourite hobbies. But following a ruptured brain aneurysm, he now forgets what he's seen after just a few days.

Ron is one of many brain injury survivors living with short-term memory loss. This means that he has difficulties remembering things that happened in the last few minutes, hours or days.

He says the only silver lining about his memory loss is that he gets to read books, watch TV shows and enjoy

musicals for the first time - over and over again.

In 2013, a few weeks prior to his brain injury, Ron was suffering from constant headaches. After visiting his doctor, and later his opticians, he was told he needed new prescription glasses.

Confident that he had found the cause of his ongoing headaches, Ron returned to work the following week, but he never prepared himself for what came next.

Whilst at work, he suddenly collapsed. Luckily a colleague was quick to notice and called for help.

Ron has no memory of collapsing or what came afterwards. According

to others, he was lying on the floor clutching his head and screaming in pain. He was taken to hospital and his wife Jayne was told to prepare for the worst.

A scan had revealed that a dissecting aneurysm had ruptured, meaning the wall of an entire artery in Ron's brain had ripped.

The severity of the aneurysm meant that Ron had to be transferred to a specialist neurological hospital in Sheffield. His chances of survival were slim.

Luckily, thanks to a revolutionary procedure called an Occipital Arterial Bypass, Ron survived.

But now he has to live with short-term memory loss, along with chronic fatigue, balance issues and daily headaches.

Prior to his injury, Ron had a strong memory and can still recall details of events that happened years before. However following the injury, he forgets almost everything within just five days.

Ron said: “*Dirty Dancing* is the perfect example of my memory failure. I watched the film many, many times pre-‘head pop’, so that remains very clear. Then I went to see the live musical show some months ago in Leeds and apparently I loved it, although I can’t remember.

“But more recently the musical was advertised on the TV and I said to my wife how much I’d love to go and see it one day. I had absolutely no recollection of watching it just a few months before.”

On a more practical level, Ron’s memory loss has had a huge impact not on only his life, but on his wife Jayne’s life too.

Jayne said: “Ron’s memory loss means that I have to constantly keep my eyes peeled for danger. Ron will regularly

forget to turn off the oven or the stove, and sometimes he’ll leave electrical items on.

“This means that before we leave the house, even if we’re just popping out for a few minutes, I’ll have to carefully check that everything’s safe and secure.”

Luckily, Ron has been able to access support from Headway. Along with more than 6,500 other brain injury survivors, he uses the Headway Brain Injury Identity Card to help explain his injury and its effects to those who may not fully understand.

The ID card is designed not only to help police officers and staff more easily identify brain injury survivors and ensure they receive an appropriate response and support, but to also provide survivors with added confidence in everyday social scenarios.

Ron, who has received a great response when showing his ID card, said: “For me, the card acts as confirmation of my brain injury. It helps

Ron and his wife, Jayne.



Ron forgets almost everything within just five days.



others to understand some of the challenges I face if I’m in a vulnerable situation.”

To find out more about the Headway Brain Injury Identity Card, visit [headway.org.uk/idcard](https://www.headway.org.uk/idcard)

SPORT STILL HAS A LOT TO DO TO GET ITS HEAD AROUND CONCUSSION

The issue of concussion in sport is rarely out of the headlines for long. Although rugby has made progress on concussion, other sports have shown they still have a long way to go to properly protect their players.



Steve Smith. Photo courtesy of Shutterstock.com.

During the Ashes, the Australian Captain Steve Smith put himself in an incredibly dangerous position at Lord's when he returned to the cricket field after being struck by a 92mph bouncer.

Smith was allowed to resume his innings less than an hour later having passed concussion testing.

Returning to play exposed him to the possibility of further blows to the head although, fortunately, he was not hit again. However, he was diagnosed with a delayed concussion the following morning, ruling him out for the remainder of the match.

In football, a reckless attitude to the condition was evident when the Wales' Manager Ryan Giggs told a packed press conference that player Daniel James was never knocked out or concussed, but was "acting" during a match against Croatia.

Headway regularly supports and hears from people whose lives have been drastically affected by concussion.

One such person is former York City footballer Daniel Parslow. He knows better than most the dangers of playing on after receiving a concussion.

Daniel sustained a traumatic brain injury when an opponent's shoulder collided with the side of his head during a match against Hereford FC in February 2019.

Immediately after the clash, Daniel was checked over by a physiotherapist, who asked a number of standardised questions in line with the team's concussion protocols.

Daniel was then deemed responsive enough to return to play.

But just one minute after he made his way on to the pitch and as the whistle blew to signal half-time,

Daniel had to stagger to the dressing room and forfeit his place as the team's centre back for the remainder of the match.

"I knew that I was in a bad way. I had a severe headache, double-vision and felt as though I was going to be sick at any moment," recalled Daniel.

The next few days were especially difficult for Daniel.

He said: "In the days following the injury, the headaches were chronic and relentless. Even opening my eyes felt like a real struggle.

"The only thing that would ease the pain was lying down with my eyes shut. For three or four days I went through similar cycles, only getting up to eat. I felt constantly exhausted."

Daniel recently retired from the sport he loves and his club held a benefit match on his behalf to celebrate his years with the team – as well as raise awareness of concussion.

Daniel supports Headway's calls to introduce more time to conduct assessments following a head injury and is also in favour of temporary substitutions.

He said: "With my incident, I shouldn't have returned to play - it's as simple as that. Concussion guidelines were followed but as it stands, this doesn't allow enough time for the delayed onset of symptoms. Medical professionals need more time to thoroughly assess players without pressure from match officials and fans to restart the game.

"Temporary substitutions are also a must in my opinion. They will help reduce the risk of an athlete receiving that second knock whilst the brain is in a state of trauma - and that could be fatal."

Daniel knows better than most the dangers of playing on after receiving a concussion.



Daniel has had to retire from the sport he loves following a concussion.



Former professional cyclist Matt Brammeier is determined to raise awareness of concussion in the sport that has given him so much.

In 2015, during stage six of the Tour of Utah, Matt crashed head-on into a car while travelling at high speed.

Matt only realised he was suffering with the long-term effects of concussion after his wife, a fellow cyclist, was diagnosed with it.



Husband and wife, Matt and Nikki, both sustained concussions.



Matt and Nikki out cycling together.

"Before Nikki's crash I had no idea about the lasting effects of a concussion," said Matt.

"All I knew were the immediate symptoms of a concussion and you should probably seek medical advice if you were having headaches, dizziness and nausea.

"I was never aware of the dangers of a second concussion or of returning to a mentally and physically demanding activity too early."

Matt hopes the UK's cycling bodies will sign up to Headway's *Concussion Aware* campaign, to raise awareness among athletes about the dangers of the condition.

Matt said: "Headway's campaign is leading the way to raising awareness of concussions.

"The simple explanations, videos and information on the website are amazingly effective.

"The links and associations with sports' governing bodies and teams are raising awareness among all sports."

PLEDGE YOUR SUPPORT

Are you involved in an amateur sports club, school, college or university? If so, help to raise awareness and encourage them to sign up to our *Concussion Aware* campaign and pledge to be more aware of the signs of concussion.

By pledging to take an *If in doubt, sit it out!* approach, you will be given a digital stamp to display on your website and social media pages in order to demonstrate your club or organisation's to demonstrate your club's responsible, no-risk approach to head injuries.

We've also developed a toolkit to help your sports club or organisation get involved and be concussion aware. The toolkit is full of useful information, including campaign materials, local support and more.

More information is available at headway.org.uk/concussion-aware

MANAGING CONCUSSION

It is important that relatives and employers are warned about the possible effects of a minor head injury, and for plans to be made accordingly. These might include not rushing to return to work or classes, keeping stress to a minimum in the short-term, and abstaining from alcohol.

One study showed that almost one third of people with a minor head injury were not working full-time three

months after receiving the injury, although other studies have been much more optimistic. Difficulties are certainly made much worse if the person has a mentally demanding job where there is a low margin for error.

Our booklet *Minor head injury and concussion* provides tips and strategies for coping with the effects of post-concussion syndrome and can be downloaded from www.headway.org.uk/information-library.



Recycling in style

Be the master of the bargain bin, the ruler of the £1 rail and the emperor of the bric-a-brac in your quest to be a fashion icon with a sustainable edge.

If charity shop outfits conjure up images of tatty t-shirts, buttonless blouses and saggy sweaters then think again! In the Headway charity shops we strive to provide good quality, stylish fashion at low prices. We're also helping the environment, by giving clothes, shoes and accessories a second chance, rather than being thrown away.

So, if you're looking for a fabulous frock or a stylish suit for a festive gathering, say 'no to new' and see what you can find at your local charity shop.

Not only can you pick up some bargain buys, but shopping with Headway also means you're helping to support the vital work we do to improve life after brain injury.

Headway's Director of Fundraising, Jo Plant, said: "The Headway charity shops

provide an invaluable source of income, helping us to raise awareness of brain injury and support survivors and their families.

"We are thankful to anyone who donates items to us - without the support of the generous public our shops would not exist. We are also grateful to the wonderful volunteers working in the shops, many of whom have a personal connection to brain injury."

To demonstrate just how easy it is to plan your Christmas wardrobe, a plucky team of Headway staff set themselves the challenge and raided the rails in search of festive fashion...



Fundraising Administrator, Zak Brown, looks dapper in a jacket (£8.99) and blue shirt (3.99)

Website and Social Media Manager, Andrew Taylor, and Services Department Co-ordinator, Sam Clarke.

"Love the jacket.
It really 'suits' you!!"

Fundraising Officer, Melanie Dickens, models a stylish black and white skirt (£3.99)



Andrew models a jacket (£4.99) and timeless blue shirt (£2.99)



Press Officer, Katie Morris, showcases a sophisticated black gown (£5.99)



Katie and Mel wrap up warm in some faux fur coats (£6.99 each), blue trousers (£3.99)





Our shops rely on generous donations – without them they wouldn't exist!

So why not make some space for your new Christmas presents by donating unwanted items to charity?! Find your nearest Headway charity shop on our website – **www.headway.org.uk**

Don't have a Headway shop near you? Don't worry! You can still donate your items and raise money for us by giving your items to Thrift+. Visit www.thriftplus.com, order your Thrift bag, fill it and then send it back for free.

Have you bought something from one of our shops?

We'd love to see it! Share a photo on social media using the hashtag #HeadwayFashion.



Headway Hinkley shop front

Lawyers have a ball raising thousands for Headway

National law firm Simpson Millar has raised more than £18,000 for Headway and the Child Brain Injury Trust after throwing an enchanting masquerade ball earlier this year.

The wonderful event, which took place at the Hilton Hotel in Liverpool,

included live music, drinks, a three-course meal and a raffle.

Caroline Fox, Senior Associate Solicitor, Personal Injury Claims, said: "It was a fabulous night and great to see so many turn out to support the brilliant work done by Headway and CBIT.

"Through my work as a solicitor, representing individuals who have



suffered head injuries, I see first-hand the vital support charities like Headway and CBIT offer to brain injury patients and their families."

Thank you to everyone who supported this amazing event.

CONSTRUCTION SAFETY PARTNERSHIP FOCUSES ON HEAD PROTECTION

We are proud to announce that Headway has partnered with leading safety equipment manufacturer Centurion to help raise awareness of brain injury in the construction industry.

The partnership centres around two shared goals: To raise funds to help Headway continue to develop its vital network of support for brain injury survivors and to reduce the incidence of brain injury through greater awareness and understanding within construction and industrial sectors.

Driven by its commitment to making safe safer, Centurion hopes the partnership will set a precedent for broader industry collaboration to understand and reduce instances of brain injury in the workplace.

The partnership kick starts a year of activity to promote head safety as Centurion celebrates its 140-year anniversary.

Centurion CEO Jeff Ward, comments: "We are proud to partner with an organisation that shares our goals of reducing brain injury in the workplace. Headway is a respected, forward-thinking charity making a real difference to the lives of those affected by brain injury. Working together we hope to drive the understanding and behaviours that will keep today's generation of workers safer than ever."

Headway Chief Executive, Peter McCabe, adds: "Even a minor head injury can have a major impact and this partnership with Centurion will help us to increase awareness and understanding within the construction industry of the importance of protecting our heads and brains from injury."



GEORGIA HITS THE GROUND RUNNING

When Georgia Banjo contracted encephalitis at just 16-years old, she feared her life would never be the same again.



Numerous relapses and lengthy periods in and out of hospital made it difficult for Georgia to imagine any kind of meaningful recovery.

She said: "When you're young you think you have your whole life ahead of you, and then everything changes in an instant. It can be hard to see any kind of positive in that situation."

Luckily, thanks to a strong support system made up of family and friends, as well as the help of local Headway groups, Georgia has gone on to achieve incredible things, including running a half marathon.

On 13 October, the 27-year old Headway Hero ran the Royal Parks Half Marathon to show her support for the work of the national charity.

Georgia said: "I felt so proud to raise awareness of something so close to my heart. During my training and the run itself I kept in mind all the amazing survivors and carers I have met along the way."

Georgia's journey with brain injury first started in 2009, when at just 16-years old she begun having violent seizures. She was admitted to hospital and diagnosed with a rare form of encephalitis.

Georgia was placed in a medically induced coma to stop the seizures and help stabilise her condition.

Despite being discharged just three months later, she relapsed and went on to have numerous stints in hospital over a five-year period.

Georgia, who was in her first year of sixth form at the time, had to take a year off from her studies to focus on recovery.

"For me, a lot of the recovery process was about learning to live with a brain injury," she said.

"The fatigue could be overwhelming at times, and in the early days I really struggled with memory loss and lack of concentration.

"Often the hardest part was explaining to people what had happened and how it had affected me. Because it's an invisible illness and the effects are often hidden, people assume nothing's wrong.

"I spent my teenage years not telling anyone about it – I know that wasn't the right decision – but at the time it was the easiest thing to do."

Georgia first learnt about Headway during her initial stay in hospital. For many years, she was a keen member of her local group in Cambridgeshire and took part in the group's Lets Get Going project.

After finishing her A-Levels, Georgia went on to study History at the University of Oxford.

She decided to transfer to Headway Oxfordshire, which is when she first met Emma Riley, the group's Community Support Worker.

"The team at Headway Oxfordshire were so supportive throughout my time at university," said Georgia. "Emma liaised with my professors to help them understand some of the difficulties I was facing as a result of my brain injury.

"But it wasn't just practical support that she provided – she was also a friendly face and someone to talk to when I felt exhausted. I'm really grateful for everything Emma and the rest of the staff at Headway Oxfordshire did for me."

To show her support for the work of Headway, and to help raise awareness of brain injury, Georgia decided to run the Royal Parks Half Marathon in October.

"It was so important for me to take on this fundraising challenge because Headway has helped me so much over the years," said Georgia.

"The thing I was most looking forward to was being a part of the Headway team and running alongside others all driven by a different purpose – and doing a spot of London sightseeing along the way!

"Running the Royal Parks was definitely a challenge, but knowing that I was supporting Headway and hopefully raising awareness of brain injury made it worthwhile."

If you are feeling inspired, contact the fundraising team on **0115 924 800** or email **fundraising.manager@headway.org.uk**

#HeadwayHeroes

Thank you!

We're constantly amazed by the kind generosity and support we receive from our local communities. With you, we can help to improve life after brain injury.



rehabilitate
therapy ltd

Charity of the Year partners, Rehabilitate Therapy, raised more £3,400 for Headway at its MDT Spotlight on Vocational Rehabilitation earlier this year.

Vocational rehabilitation, whether that be paid or voluntary work, or education, is a hugely important aspect of the rehabilitation journey – so the company chose to dedicate a whole day to the subject!

The event was attended by over 70 professionals, such as case managers and solicitors, who support survivors following a brain injury.

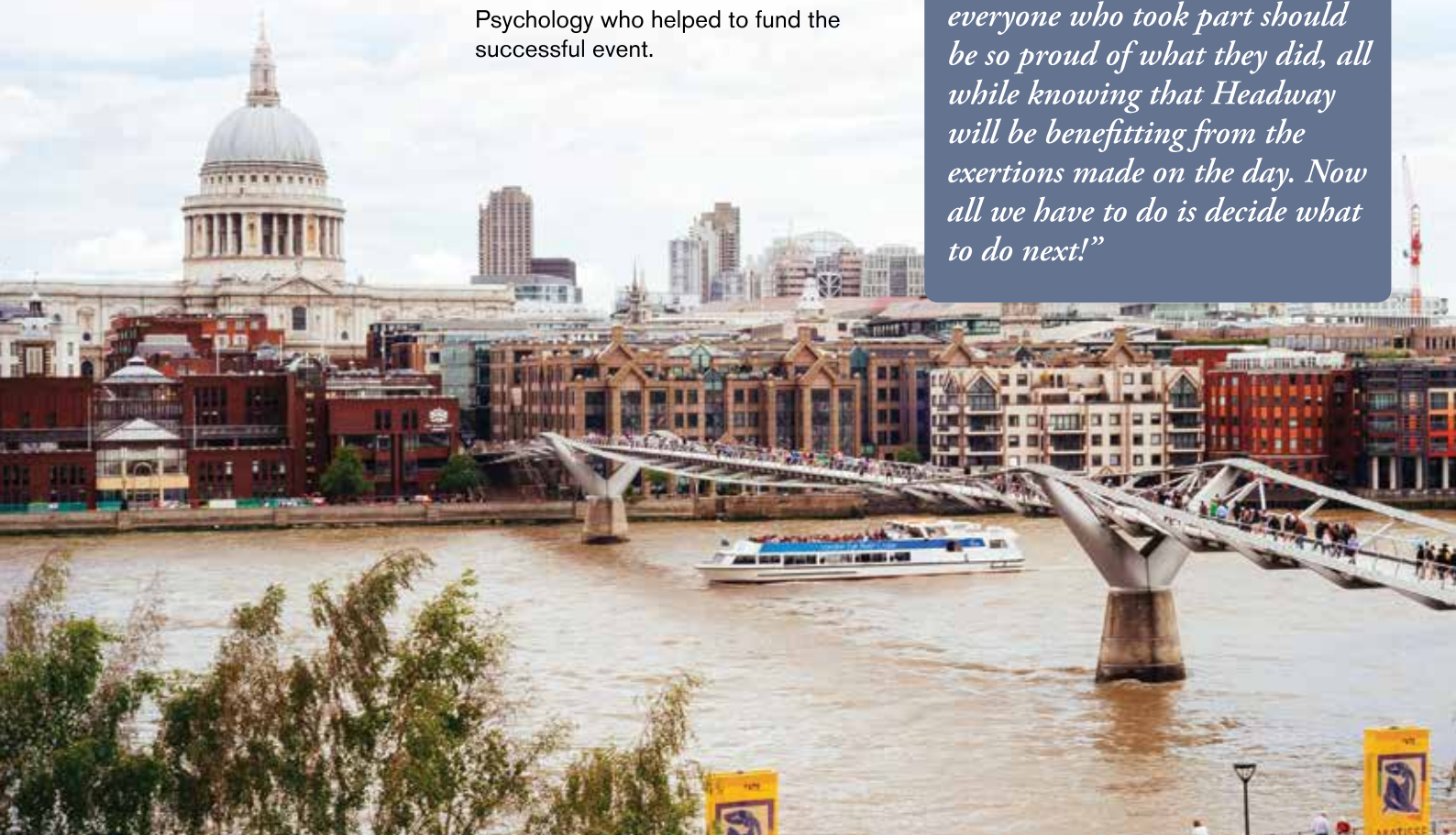
Thank you to all involved, including Steve Wiseman Associates and Reconnect Psychology who helped to fund the successful event.

We also want to say a big thank you to our supporters at IPRS Group who have raised an amazing £4,000 for us and Headway Suffolk in a grueling 27 mile walk round the capital.

The walk took in some of the great sights that London has to offer with the team passing Regents Canal, through Camden and Kings Cross, along Hyde Park from Kensington and then into Chelsea.

Ben Beckwith, Wellbeing & Workplace Services Lead and Physiotherapist at IPRS Group, said:

“It truly was a fantastic day and everyone who took part should be so proud of what they did, all while knowing that Headway will be benefitting from the exertions made on the day. Now all we have to do is decide what to do next!”



PUT YOUR WALKING BOOTS ON FOR HEADWAY

Become a Headway Hero and take on the ultimate charity challenge of a trek.

Taking part in a trek for Headway is the perfect opportunity to explore some of the world's most famous landscapes, all while raising money to support those living with the effects of a brain injury.

Whether you're seeking overseas adventure, or something a little closer to home, we've got the challenge for you!

You'll have the chance to witness breathtaking scenery as you trek along the twists, turns, steps and slopes of the Great Wall of China, climb to the top of the enormous

Chigaga Dunes and watch the sunset rise over the desert, or explore some of the UK's most-loved capitals, coastlines and countrysides.

Jackie Parker was one of the adventurers who took on this year's China Trek. She said: "Taking on a challenge which took me out of my comfort zone was an amazing personal experience.

"Fundraising for Headway was another amazing experience as so many friends and colleagues made generous donations. Combining these two amazing experiences together was just wonderful."

Prices, durations and minimum sponsorships vary from trek to

trek, so head over to our website – headway.org.uk – to find out more.

If you have any queries, or would like to register your interest, please contact Rachel Carman, Headway's Senior Fundraiser, on **0115 855 0491** or projects@headway.org.uk.



ESCAPE THE WILD FOR HEADWAY

Thursday 4 June – Friday 5 June
Ullswater, Lake District

Headway brings you a brand-new corporate adventure for 2020! Are you ready to put your teamwork to the test and take on exhilarating challenges for a great cause?

- Trekking & navigation
- Climbing & abseils
- Scrambling
- River crossing
- Rafting
- Tyrolean zip wire
- Gorges & ravines
- Camp under the stars

Individuals welcome

Registration £50 per person

Limited early-bird places available! £35 if you register before 31 January

Minimum sponsorship: £300 per person



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This is a corporate supporter only event, please contact us for all other fundraising opportunities.

Contact Anna Kerr for further details: partnerships@headway.org.uk | 0115 855 0084

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- ✓ Access realistic, affordable property adaptations and specialist vehicles
- ✓ Access and understand the medical equipment your loved one requires
- ✓ Implement and manage a care team

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, with no contract or minimum charge.



Toni Mousley
Owner of UCP



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

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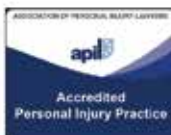
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Putting your life back on track

It's what we do



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

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

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



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

Call free on 0800 019 0991

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

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



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