

Summer 2018

Headway News



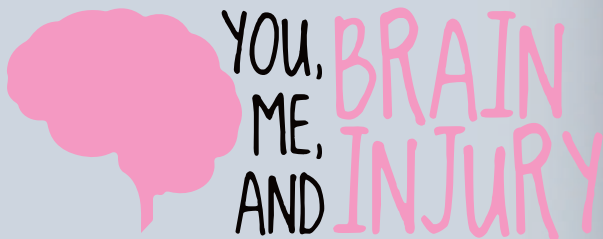
The magazine of Headway - the brain injury association

'Brain injury is a part of Rebecca now'

EMMERDALE star Emily Head

Drinking after ABI:

Is it worth the headache?



**ACTION FOR
BRAIN INJURY WEEK 2018**



WIN A VIP SOFT CELL EXPERIENCE!

Soft Cell have announced they will be reuniting for one final concert at The O2 Arena, London on Sunday 30 September 2018 to mark their 40th anniversary.

Thanks to the generosity of Headway patron and lead singer Marc Almond, we're offering you the chance to win two VIP tickets to 'Say Hello, Wave Goodbye', Soft Cell's last ever show!

This VIP experience includes:

- Two fantastic seated tickets for the concert
- An overnight stay for two in London courtesy of Old Square Chambers
- Meet and greet
- Access to soundcheck
- Aftershow party access
- Exclusive signed T-shirt
- Lanyard

For your chance to win go to headway.zaffo.com



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



Shock news: relationships are complicated!

During last year's Action for Brain Injury Week we launched our *A New Me* campaign, which highlighted the personality changes that can occur as a result of brain injury.

If a brain injury can alter the very essence of you, is it not perfectly natural to assume it will have an impact on your relationships with all those around you?

Relationships can be complex for all of us, but even more so if you are directly affected by brain injury – as so perfectly highlighted by this year's ABI Week campaign *You, me, and brain injury*.

More than 1,000 people took part in our relationships survey. Importantly, it was not just survivors who took part but also their partners, siblings, friends and colleagues.

What resulted was a fascinating insight into how relationships can be damaged or lost, but also strengthened and found after brain injury. Check out our findings on pages 16-23, where you'll also find a round-up of what else took place during ABI Week – including some fabulous Hats for Headway Day photos!

But it isn't just Headway tackling the topic of relationships after brain injury. *Emmerdale* fans among you will be well versed in the travails currently being endured by Rebecca White, played by actress Emily Head.

Rebecca sustained a brain injury in a road traffic collision on the popular ITV soap and is now battling to rebuild her life and relationships.

We have a proud tradition here at Headway of trying to help script writers, directors and actors portray brain injury on screen in as accurate a manner as possible.

Whether contributing to *Shaun the Sheep: The Movie*, Ben Price's portrayal of brain injury survivor Nick Tilsley on *Coronation Street*, or more recently Paddy Considine's film *Journeyman*, we aim to help creative works be based on reality and not fiction.

So when the *Emmerdale* team approached us for help, we were happy to assist.

And it's so far, so good with Emily's version of life after brain injury. As you'll see on pages 10-13, Emily and the *Emmerdale* team are determined to do all they can to tell it as it is.

It will never be perfectly accurate – after all, what in soap land is completely true to reality?

Perhaps the real question should be: how can we expect a soap to portray the effects of brain injury when the impact varies so widely from family to family? Ultimately, if *Emmerdale* can complement our campaign by raising awareness and getting the conversation going, surely it's a positive step forward.

The Communications Team

Published quarterly by:

Headway - the brain injury association,
Bradbury House, 190 Bagnall Road
Old Basford, Nottingham NG6 8SF

Freephone helpline: 0808 800 2244

Advertising: Joe Leadley: 0115 924 0800
information.manager@headway.org.uk

Website: www.headway.org.uk

Telephone: 0115 924 0800

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

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Your views...

We asked members of our online communities what they have learned since sustaining their brain injuries that they wish they'd known before...

I've learnt to learn and then pass it on. Also to be honest with people, because if you don't speak they can't help. Headway has been invaluable!

Jodie Bacon

To everyone who has yet to progress beyond the early stages of recovery, please don't rush it. Adjustments will take time and whilst you may never return to the person you once were you can open your heart and mind to the person you are becoming.

Matthew J. Pallett

BIGGEST lesson as a relative – the BI survivor receives care during critical and rehabilitation phase, the partner/family forget to care for themselves (the silent victims) and eventually it catches up. So carers – take care of you too x

Marie Greer

Some people just don't get it. Six years since I had a brain haemorrhage due to an AVM and I still have ups & downs. I have lack of insight (which I'm just learning about thanks to Headway).
It's hard.

Warren Heslop

As a parent of a TBI survivor, just accept them for who they now are as they will not be the same person. It could be big changes like disabilities or invisible ones like personality changes, which in my opinion are as difficult to deal with as you could be dealing with a whole new person.

Viv Gillespie

We can all make it helping each other. When I discovered Headway about five or six years ago it was a tremendous help to meet others with similar issues. Wouldn't have made it this far without my family, in particular my wife.
Love to all.

Anthony Hemy

My brother-in-law had a TBI 25 years ago. His accident changed the lives of everyone in the family and we have learnt to appreciate the little things, ignore the norm, and take each day as it comes.

Tracey Hynes



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news you may have missed...

Wetherspoon's fails to learn its lesson

Headway has reacted with anger and disappointment after a brain injury survivor was thrown out of a Wetherspoon's pub by bouncers who accused her of being drunk.

Brain injury survivor Gracie Currie had only had one drink at the beginning of a night out with friends when she was physically escorted out of the pub without even having the chance to grab her coat or bag, or tell her friends what was happening.

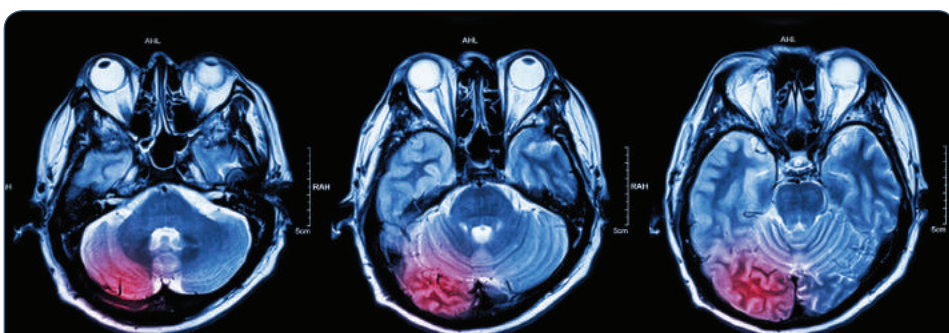
The incident follows a similar situation in 2015 when another young lady with

a brain injury was treated in the same way, leading Headway to offer training to Wetherspoon's staff – an offer that was not acted upon.

Luke Griggs, Director of Communications at Headway, said: "Brain injury survivors should not have to face this kind of blatant discrimination.

"This is entirely unacceptable behaviour from a pub chain that should know better."

Headway's Brain Injury Identity Card can help survivors to identify their needs in social scenarios. Visit www.headway.org.uk/idcard to apply.



TBI and dementia link further explored in new research

New research has found that the risk of developing dementia is higher following a traumatic brain injury (TBI).

The recent study, led by the Washington School of Medicine, reviewed almost three million cases in Denmark across almost four decades. The researchers found

that the risk of developing dementia was 24% higher in people who had sustained a TBI as compared to those who had no history of brain trauma.

While the recent results give further evidence of a link between TBI and dementia, the researchers emphasise that not everyone who sustains a TBI will develop dementia later on in life.

Government responds to ESA and PIP concerns

Headway has condemned the Government's response to the latest report on the failings of disability benefits assessments, labelling it as 'incomprehensible'.



Responding to the Work and Pensions Committee inquiry findings, which cited evidence from the 650 people who completed Headway's own survey, the Government insisted that 'for the majority of claimants, the assessment process works well'.

To read Headway's reaction in full, turn to page 24.



12-year-old Maisie in helmets plea

A brave 12-year-old girl from Hampshire who was told by doctors treating her that her cycle helmet saved her life has launched a campaign to make them compulsory for children.

Maisie Godden-Hall was cycling to school when she was knocked off her bike by a car – which subsequently ran her over.

She was left pinned under the vehicle with her head resting against its exhaust. She had also shattered her pelvis and collarbone, injured her face and lost a number of teeth.

Her skull had been protected by the helmet and it also stopped her from being burnt by the car's scorching exhaust. Whilst in hospital, her consultant told her loved ones that if she hadn't been wearing one she would have died.

She said: "I really want to use what happened to me to fight the cause for wearing cycle helmets.

"I think it should be law. It has been life changing for me and my family but I survived because of the helmet.

"I want other people to understand that it could happen to anyone. It happened to me!"

To find a link to Maisie's petition, visit www.headway.org.uk/news.



Maisie fights for her life in hospital



Maisie's life-saving helmet

To keep up-to-date with all the latest news visit www.headway.org.uk or sign up to our *Bitesize* bulletin **07**

news you may have missed...

Daily Express joins hospital parking campaign



The Daily Express has thrown its weight behind a campaign to abolish car parking fees for patients receiving treatment and their families.

The campaign is being spearheaded by Conservative MP Robert Halfon with support from numerous patient organisations, including Headway and the Patients Association, as well as MPs from across the political spectrum.

The newspaper's welcome intervention follows high-profile political pressure, with the MP for Harlow having already raised the issue with Theresa May during Prime Minister's Questions in the House of Commons.

Speaking to the paper, Luke Griggs, Director of Communications at Headway, said: "Every day our Emergency Fund hears from desperate families who are struggling to meet the costs of hospital parking.

The Express adds its weight to the campaign

"Understandably, families want to be by their loved one's bedside, particularly when in critical care or in a coma, for example. Following a brain injury, this can last many weeks or even months, meaning the daily costs of parking can reach into the hundreds or even thousands of pounds.

"Many people simply cannot afford to meet these costs.

"Charging people to use hospital car parks at a time when they are shocked, bewildered and vulnerable compounds their burden when they need support the most.

"We fully support this important campaign and we're delighted to have the support of the Express."

Robert Halfon MP commented: "Hospital car parking charges are a stealth tax on the NHS and the bane of people's lives.

"Despite the Government making it clear in 2014 that free car parking or concessions should be available, a postcode lottery on car parking charges still exists.

"The sick and the vulnerable are disproportionately hit by hospital parking fees. This injustice is backed up by several charities.

"Having campaigned since 2014, I know that there is clear public support for an end to this stealth tax.

"We all know being in hospital or visiting a poorly relative is stressful. Yet car parking charges mean that they are paying for the privilege to do so.

"It is time that this stealth tax on the sick was scrapped once and for all."





'Public transport wasn't an option'

Lisa Barnard has given her backing to the campaign calling for an end to car parking charges at hospitals.

In July last year, Lisa's 16-year-old son, Zak, was knocked down by a car while he tried to cross the road.

Zak sustained a severe brain injury as well as collapsed lungs and a broken leg. He had emergency surgery to relieve the pressure on his brain and was in an induced coma for two weeks.

In total, Zak was in hospital for six weeks before spending a further six weeks in a residential rehabilitation unit.

Understandably desperate to be by her son's side, Lisa racked up hundreds of pounds in parking expenses.

Initially, while Zak was in hospital, Lisa was allowed to purchase a £10 weekly permit, but this wasn't an option when he was transferred to the rehabilitation unit and Lisa was forced to pay £18 per day.

It was at this point that she turned to the Headway Emergency Fund for support

and was provided with £250 to help meet the spiralling costs.

"I'm self employed as a photographer so when this all happened I had to stop working, meaning no money was coming in," said Lisa. "It's only now, nearly 12 months later, that work is again starting coming in on a consistent basis.

"Having the financial strain on you when you are trying to cope and support the person you love can be huge. The Emergency Fund helped us massively, especially with the cost of travel.

"I was regularly bringing Zak home from the rehab unit and taking him back again, so I needed to park close by. Public transport just wasn't an option and I was trapped in this awful situation.

"I just feel that the parking situation in most hospitals is not clear. At different hospitals you pay differing amounts and, as we found out, if your loved one is in hospital for a long time then the charges can really start to build up.

"Hospital parking is a scandal. When people have got their next of kin in hospital, of course they need concessions."

"It seems appalling to me that the most vulnerable are charged like this.

"It really does affect those who are vulnerable. There needs to be a level playing field."



Doing it the Head way

Emmerdale actress Emily Head has spoken with Headway News about her experience of learning to play someone with a complex brain injury.

From pregnancies to punch-ups, Emily has experienced her fair share of dramatic storylines since she joined the soap in 2016.

But when her character Rebecca White sustained a brain injury in a car crash, Emily wasn't just taking on a new storyline. She was about to play a completely different character.

Headway spoke with Emily about the challenges of playing a person who is no longer the same after brain injury and why it's so important to her to get the portrayal just right.

"When I auditioned for the part of Rebecca I was given a character profile," said Emily. "It told me what she was like, how she would act in certain scenarios and how she would behave around certain people.

"After months of developing Rebecca's character on screen, they told me she was going to change following her brain injury. I immediately thought, 'oh right...change to what?'"



Rebecca wakes from her coma, to the relief of her friends



As a result of the crash, Rebecca was left with executive dysfunction and memory loss, and she struggles to remember that her sister and father were killed in the accident.

"I had to act the scenario of being told my father and sister had died four times, and be affected all four times, and find a way to do it as a performance worth watching four times," she said.

"It sounds ridiculous at first, but this is something people are having to live through, over and over."

In 2017, Headway ran its *A New Me* campaign highlighting the concept of feeling like a different person after brain injury. It was a notion that Emily has been keen to get across both on and off screen.

"The main question I keep getting from the other actors is 'when will Rebecca get back to normal?'" said Emily.

"I think it's really important to keep reminding people that there is no going back to the old Rebecca. Her memory could come back and she can improve. But this is how she is now.

"I have a friend who works with brain injury survivors and he told me the thing

he struggles with most is that brain injury survivors and their families expect things to just get better with time. The challenge is saying 'no, you might *improve* from here, but this is who you are now, and that's ok.'

Eager to find out more about life after brain injury, Emily paid a visit to Second Chance Headway in Wakefield. It proved to be an experience that shaped her portrayal of brain injury on screen.

"One of the soap's researchers and I sat in on a session with about 15 people. We asked what aspects of brain injury they would like to be portrayed and how would they like their stories to be depicted on screen.

"We listened to these extraordinary people. They were very honest and open in telling us how brain injury had affected them and their families."

"They told that us that Headway was a safe space they could go to every week and they wouldn't be judged for being different or doing something 'wrong'.

EMMERDALE

"There was a bit of dark humour surrounding the group, there were some very funny people there. That's what I took away the most; it isn't all doom and gloom. There are people facing difficulties and struggles but they're getting on with it.

"More than anything else, meeting brain injury survivors made me think I've really got to get this right and tell these people's stories sensitively and thoughtfully.

"I feel a duty to tell their stories as best as I can."

During our ABI Week 2018 campaign, *You, me, and brain injury*, we highlighted the ripple effect of brain injury on a survivor's friends and family. It's a subject Emily is keen to explore with her character's family.

"One thing that someone said to me when I visited Headway that really affected me was that brain injury doesn't just affect the survivors, it affects the families as well," said Emily. "I definitely came away wanting to explore that more.

"I spoke to Thomas Atkinson, who plays Rebecca's nephew Lachlan; Ryan Hawley, who plays Robert Sugden – the father of her baby; and Isabel Hodgins, who plays Victoria Sugden, Robert's sister and Rebecca's housemate.

"I told them what I had learnt at Headway that could help them shape their own performances."

In the world of soap operas storylines are often short-lived and life moves on at an incredible pace, and only time will tell whether Rebecca's brain injury will be a consistent part of the programme.

"It's really satisfying to be on a TV show that gives a true sense of brain injury."

But one thing is for sure: Emily is determined to show audiences the new Rebecca, and the lasting effects of brain injury.

“Brain injury is a part of Rebecca now,” she said. “It’s really satisfying to be on a TV show that gives a true sense of brain injury.”

“But I don’t always want it to be doom and gloom for her either. I have learnt there is a lot of laughter, love and kindness after brain injury. I want to portray the fact that there can be life after brain injury.”

Emily: “It’s really satisfying to be on a TV show that gives a true sense of brain injury.”



THE UNEASY RELATIONSHIP BETWEEN ALCOHOL AND BRAIN INJURY

The first sight of summer sun is normally enough to get most of us dusting off the barbeque, heading to the seaside, or arranging get-togethers in the beer garden of the local pub.

Whether we're on holiday abroad or simply relaxing on a deckchair in the garden, a cool alcoholic drink tends to not be too far from reach for many of us when the sun is shining.

But after a brain injury, the body's tolerance to alcohol is greatly reduced, and many survivors find that they are no longer able to enjoy alcohol in the same way as they did before their injury.

The reduced tolerance to alcohol means that many effects of brain injury are exacerbated after drinking, such as memory problems, mobility issues, speech and fatigue.

It is clear that there is an uneasy relationship between alcohol and brain injury. Survivors are often faced with the challenge of balancing a desire to enjoy the social life they had before they sustained their injury with the acceptance that alcohol now affects them in a different way.

We asked brain injury survivors to tell us about how their relationship with alcohol has changed.

'I don't drink anymore'

For some, the enjoyment of drinking is simply outweighed by the effects caused.

"I don't drink anymore," said Louise Fry on the Headway Facebook page. "I couldn't drink to start with because of meds, but now? It just hits me too hard."

Janet Creamer agreed: "Drinking is now a no-no. Just one alcoholic drink does awful things to my brain. It feels like I've drunk way too much and I get that spaced out feeling."

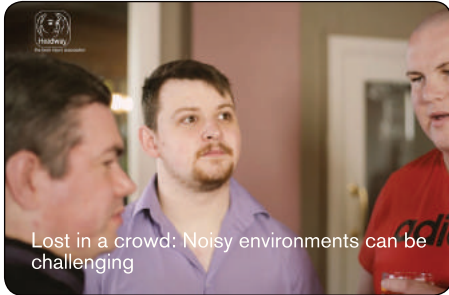
Others, like Giles Philip Hudson, have found that being advised by doctors to no longer drink has actually been a blessing in disguise.

"After sustaining my brain injury and spending over four months in hospital, doctors advised me not to drink alcohol," said Giles. "During this time I found I no longer needed to drink alcohol to make me feel good or enjoy myself. I certainly don't need the headaches it causes."



ENJOY A DRINK AT HOME WITH FAMILY AND FRIENDS

Naturally, many people want to continue to be able to enjoy a drink every now and then, particularly at social gatherings. But what if going to the pub is too daunting a prospect?



Home drinking is increasingly popular as supermarket prices tumble, a trend the Scottish Government has tried to address through minimum pricing.

For some, staying in allows them to enjoy a drink without some of the challenges of being in a busy, crowded and noisy pub or bar, as depicted in Headway's short film *Lost in a crowd*.

"Since my disability I do not feel comfortable going into a bar as I may find it hard to use the restrooms," said one member of Headway's HealthUnlocked online community, "so my drinking is done in my home."

Patricia Nugent on Facebook agreed: "We tend to drink at home so it is easier and less stressful to moderate intake," she said.

If you are choosing to drink at home, it's important you monitor your intake carefully. The charity Drinkaware (drinkaware.co.uk) has some useful advice for home drinkers, including:

1. Keep track of how many units you're consuming
2. Use smaller glasses
3. Use proper spirit measures to avoid inadvertently pouring yourself a double or triple measure
4. Eat as you drink
5. Invest in a good bottle stop to make that bottle of wine last longer

OUT AND ABOUT

For others, however, a good night out is still a must! If that's the case, then planning ahead can be the key to the success of the evening.

"I don't go out much, once every two months," said Michelle Richardson. "But it's lovely to have some drinks and let my hair down and forget how challenging recovery is for a while."

"I do have to prepare for a night out by having an afternoon snooze."

If you do want to enjoy a night out on the town with friends, here are some more top tips:

1. Don't drink on an empty stomach
2. Check your medication allows you to drink
3. Make sure your friends know about your brain injury, lowered alcohol tolerance levels, and any other issues such as an intolerance to noise
4. Drink water between alcoholic drinks and avoid getting into rounds
5. Don't forget to take your Brain Injury Identity Card with you!

ALCOHOL-FREE ALTERNATIVES

Of course, not drinking alcohol doesn't mean you can't still go out to pubs and bars.

"My husband has been told he can't drink alcohol," said Amanda Hopkins. "So, as he is a real ale drinker, we made a pact to still go to country pubs but to just check out 'alcohol-free' ales and to become connoisseurs of the growing 'alcohol-free' ranges that are now appearing from many microbreweries."

"It won't be quite the same but we hope it will be a bit of fun tasting them."

Kathy M agreed: "I sometimes have a non-alcoholic beer shandy so I feel like I am having a pint and I've discovered things like elderflower cordial with soda. There's nothing wrong with ordering a fancy coffee or mocktail either."

Headway's new factsheets on alcohol after brain injury are available to download from www.headway.org.uk



The power of positive relationships

Ask anyone affected by brain injury and they'll tell you that it's not just the individual whose life is changed.

If you dig a little deeper and ask the right questions, it's likely you'll begin to get a good picture of how many people can be impacted by just one brain injury.

Relationships can be altered in an instant. You might think it obvious that a partner or immediate family member would be affected, but what about wider relationships? What about relationships with friends or colleagues?

You, me, and brain injury examines the ripple effect of brain injury, exploring the extent to which different lives are affected in different ways, while highlighting the ways in which everyone can play a role in helping people to rebuild their lives after brain injury.

Study

At the heart of our awareness-raising campaign is our latest survey, which was completed by more than 1,000 people directly affected by brain injury.

The survey, entitled *Relationship changes after brain injury*, sought to explore whether the relationships of survivors,

friends, family members, partners and colleagues improve or break down after the injury, as well as the reasons for this.

Here, we look at the key findings of the study, along with some of the experiences shared with us.

After an ABI, relationships with spouses:

Ended
28%



Improved
34%



Partners

Despite many studies suggesting that the divorce rate increases following brain injury, less than a third of people responding to our survey said that their relationship with their spouse or partner had ended. In fact, just over a third of survivors and partners felt that the relationship had actually strengthened.

Nevertheless, many survivors and partners did talk about the challenges that they faced. Issues such as personality change after the injury, changes in the role from partner to carer and lack of understanding were seen to negatively impact relationships and cause breakdowns.

69% of brain injury survivors experienced loss of friendships



Friendships

Many respondents to our survey, including carers and family members, reported breakdowns in their own friendships after the injury.


Indeed, almost 70% of brain injury survivors reported breakdowns in their relationships with friends, whilst 65% of partners and just over half of the family members responding to the survey had also experienced friendship loss.

Of all relationship types, it seems that friendships are most commonly impacted by brain injury.

This may be attributed to friends lacking an understanding of brain injury – an issue highlighted by last year's ABI Week campaign, *A New Me*.

However, it is clear friendships can be strengthened after brain injury, particularly if friends are willing to learn about ABI and provide practical and emotional support.

Having understanding friends who were willing to make allowances for the effects of the injury was also a major factor in strengthening friendships.



YOU, ME, AND BRAIN INJURY

'I'm not a carer'

In 2012, Paula Stanford and Richard Symes' relationship was going from strength to strength. The couple were about to move in together and were talking about marriage.

But on New Year's Day 2012, Richard suffered a stroke.

"It was horrible," said Paula. "I thought he was going to die. Then, as he recovered, we believed he would be in a wheelchair for the rest of his life."

Richard spent the next eight months recovering in hospital and was left with left-sided weakness.

Paula believes the distinction between partner and carer is really important for their relationship.

"It does make me laugh when people refer to me as his carer. That's not how we see it. I do have to do stuff for him sometimes but I'm not a carer."

"In the first year or so after the stroke people would say 'you're so good for staying with him!' But I'm not doing it out of charity! We both get benefits out of the relationship. We love spending time together.

"Things are different, but they're not necessarily worse. They're just different from how we imagined. It's still a really good loving relationship."

Family members

Perhaps the most complex area to examine was family relationships after brain injury. Let's face it, families can be complex at the best of times, regardless of whether or not brain injury is involved.

Just under half of the survivors responding to our survey felt that relationships with family members had broken down, whilst the remaining respondents felt that these had strengthened.

Interestingly, 40% of those identifying themselves as partners of brain injury survivors also felt that the relationships they had with their family strengthened after the injury due to the support they received from family members through their difficult time.

Around a third of the family members who filled in our survey felt that their relationship with the survivor had improved since the injury.

"My relationships with friends have broken down due to a lack of understanding and labelling and stigma attached to brain injury."

David McManus

"My brain injury has brought me and my partner closer together. He has been my rock and I wouldn't have gotten through the last nine months without him."

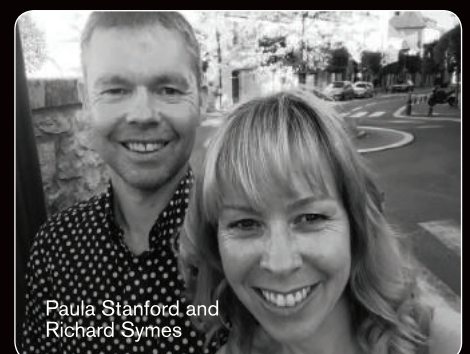
Lynsay Railton

"I am a different person since the removal of my brain tumour and my relationship has broken down, partly due to the lack of knowledge my husband has of what to expect."

Catherine Hooks

40%

said relationships with other family members had strengthened



Paula Stanford and Richard Symes

So what makes or breaks a relationship?

As well as finding out *how* relationships changed, we asked respondents to tell us some of the underlying reasons.

A consistent theme in successful relationships was a good level of understanding of the effects of brain injury. This extended beyond friends and families to employers, with partners reporting the difference having an understanding boss can make.

Receiving practical support from others, such as help with daily living tasks, travelling or financial support, also strengthened relationships.

Many respondents also commented on the fact that the injury had given them a renewed appreciation of life and the people they loved.

Conversely, relationship breakdowns were mainly attributed to a lack of understanding about brain injury, with survivors, partners and family members all reporting this to be an issue, particularly where their friendships were concerned.

Having less time to see one another, for instance survivors with their colleagues if they were unable to return to work, and partners with their friends if they had caring duties, also caused relationships to break down.

Across all of the categories of respondents, the challenges of dealing with the effects of the injury were a cause for relationship breakdowns. Survivors, friends, family members, partners and colleagues all remarked on the fact that effects such as fatigue and personality change were difficult for them to deal with.

Life after brain injury

What is clear from the research is that a little understanding goes a long way. Everyone who knows someone living with a brain injury is a ripple in the pond and can be impacted to varying degrees.

But rather than being negatively affected by brain injury, we all have an opportunity to play a positive role in helping brain injury survivors rebuild their lives and confidence and once again enjoy healthy relationships with all those around them.

To download our relationships information pack, including the booklet *Relationships after brain injury*, visit www.headway.org.uk/information-library.

'My friends stopped contacting me'

In January 2017, Keely McGhee sustained a subarachnoid haemorrhage in a skiing accident.

Although her friends came to visit her in hospital, many stopped keeping in contact once she left.

"When I message my friends it feels awkward," said Keeley. "I'm quickly cut off with 'I'm good, I will come and see you soon.'"

"Maybe a lot of people don't want to talk to me about what they are up to but I still want to chat about our interests and what's going on in their lives.

"A lot of people only want to talk to me about the accident, and while I'm happy to answer any questions, I don't want it to be the only thing we talk about."

But several of Keely's friends did provide her with the support and normality she needed.

"They check in to see how I am doing and what progress I have made," she said. "They chat with me about silly stuff and take me out for a coffee and a catch up."



Keely McGhee, right, and her best friend

"It's not always easy for me to notice the progress I am making so it's always nice to have friends and family tell me the improvements they can see in me."

"My husband and I could not have done as much... without the close support of my sister. She has been my rock through everything, from watching our children when my husband was in hospital for a year to helping out caring so I could return to work."

Diana Mcleod

"Certain friends have been very supportive and helpful for both of us. Inviting us round for meals more frequently and regularly, keeping in contact, offering to help with tasks and events...asking how we are and listening when we respond."

Fiona Maxwell-Stewart

YOUR SONG

Launching Headway's very own Spotify playlist!

ACTION FOR BRAIN INJURY WEEK 2018

We asked our supporters to tell us the one song that means the most to them in the context of life after brain injury – and why – in order to create our very own Headway playlist on Spotify.

You can now listen to the playlist by going to www.headway.org.uk/playlist where you'll also find a link to download it to your own Spotify account if you have one.

Life after brain injury

MOUNTAIN Only Girl

Chosen by Headway

Ellen McKechnie, who performs as Only Girl, wrote Mountain for her husband Jamie who sustained a brain injury in 2011. "When I perform this song, it usually brings me close to tears," Ellen said.

TRUE ROMANCE Asher X

Chosen by Headway

Asher Bourke's track is based on her initial feelings as she raced to her partner Peter's hospital bedside.

THIS IS ME (from *The Greatest Showman*) Kesha

Chosen by Joanne Wood

Joanne said: "This track is very relevant when accepting the new me. No apology, this is me!"

BAT OUT OF HELL Meatloaf

Chosen by Lilian Morris

Lilian chose *Bat out of Hell* because it "...rouses me up and reminds me of good times to be repeated!"

YOU BETTER RUN Liam Gallagher

Chosen by Corey Hegarty

Why did Corey choose this song? Simple: "...just because it's a banging rock-and-roll tune that motivates me on a bad day."

ALBATROSS Fleetwood Mac

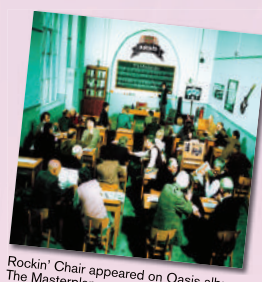
Chosen by Shirley Ireland-Jones

"This song helped me focus on my breathing at a time when processing language was difficult," said Shirley.

I GIORNI Ludovico Einaudi

Chosen by Eileen Poole

This track was chosen by Eileen, who said: "Its simplicity is the perfect 'medicine' for my brain as there are no demanding lyrics... just beautiful, melodic piano music."



Rockin' Chair appeared on Oasis album *The Masterplan*



QFX album cover, complete with mention of David Bogie's story

FREEDOM QFX

Chosen by David Bogie

While 12-year-old David was in a coma, his parents regularly played his favourite song, repeatedly asking him to identify it. When he started to regain consciousness his first words were 'Freedom, Freedom', a story that's printed on the back of the proud band's album!

ROCKIN' CHAIR Oasis

Chosen by Natasha Cassidy

"This was one I listened to on repeat on the journey to and from the hospital," said Natasha. "I always focused on these lyrics...It's hard enough being alone, sitting here by the phone. Waiting for your memories to come and play..."

RISE UP Andra Day

Chosen by Hayley Nye

"This song helped me discover my strength to battle through the really hard times and reminded me to never give up," said Hayley.

TUBTHUMPING Chumbawamba

Chosen by Sean Dolan

"I think that chorus sums up what I had to do over and over throughout the recovery," said Sean.

BEST DAY OF MY LIFE American Authors

Chosen by Julia Robertson

Julia: "This song has been a major theme in my recovery from brain surgery. I even created a piece of art based on it."

ACTION FOR

BRAIN INJURY WEEK 2018

PRESSING HOME THE MESSAGE



Action for Brain Injury Week provides the perfect opportunity to generate some much-needed awareness of the wonderful work of Headway's network of groups and branches across the UK in order to ensure no one feels they have to suffer in silence.

And what a week it was! Open days, project launches and celebrity visits all helped to generate plenty of noise in the regional press and on social media.

At the heart of any successful awareness-raising campaign are the voices of those affected. Sharing your deeply personal experiences of life after brain injury in public requires strength and courage but can give so much hope and encouragement to others.

Headway Norfolk and Waveney led the way by creating a series of short emotive films featuring service users talking about how their lives and relationships have been impacted by brain injury.

Craig Jennings was one of those who chose to share his emotional journey. In July 2010, Craig sustained a traumatic brain injury as a result of a motorcycle accident just three months after his wedding.

In the incredibly touching 90-second film, Craig, who has limited speech and mobility, uses a series of hand-written cards to explain how his brain injury has brought him and his wife, Rebecca, closer as they together weathered the storm.

The film also contains a beautiful moment where Craig makes a big announcement – but you'll have to watch the film at www.headway-nw.org.uk to see for yourself!

The films, along with a collection of artwork created by service users, were showcased in a gallery in Norwich during ABI Week and featured as the top news item on BBC Look East. The piece even included a live studio interview with brain injury survivor Emily Millican, who is a volunteer at Headway Suffolk.

Headway Sefton also featured in its local press, with the Liverpool Echo covering





Delegates at Headway South Cumbria's conference take time out to pose for Hats for Headway Day

the story of service user and dad-of-two David Jenkins.

David was a happy-go-lucky man in his early 30s, with an active social life and a career in wealth management.

But in 2014, a car accident changed everything and the Sefton man suddenly found he was experiencing poor memory, a short temper, constant fatigue and difficulties processing information.

David, who now leads a social group at Headway Sefton, shared his story to help raise awareness and give hope to others, telling the paper: "The social group is a huge part of my new life and seeing the improvements it makes to peoples' lives on a weekly basis gives me huge satisfaction."

THE RIPPLE EFFECT

Headway South Cumbria chose ABI Week to hold a special conference based on this year's theme.

Entitled The Ripple Effect of Brain Injury: Count the Ripples, Count the Cost, the conference was attended by around 200 delegates, including health professionals, service users and academics.

It also featured one of the largest Hats for Headway Day group shots ever seen!

Over in Yorkshire, another group was also holding a special event.

Having already hosted Emmerdale star Emily Head as part of her research for the soap (see page 10), Second Chance Headway in Wakefield invited the actress to return to open the group's new centre.

The facility includes a specially designed accessible kitchen, a multi-

purpose physiotherapy room, and a music suite.

The event was covered by local media including the Yorkshire Post and the Wakefield Express.

Emily certainly had a busy ABI Week as she also attended a fundraising event held at Headway Blackpool, where she talked to a reporter from the Blackpool Gazette about what it was like to portray someone living with the consequences of a brain injury.



Headway's Lizzie Winkfield welcomes Emmerdale star Emily Head to Blackpool

OUT AND ABOUT

In Wales, Ben Lake MP helped Headway Ceredigion to raise awareness by manning a stall in Aberystwyth, while of course wearing a hat.



Ben Lake MP (left)

Headway Portsmouth and South East Hampshire teamed-up with its local hospital.

As well as getting medical staff at Queen Alexandra Hospital involved in Hats for Headway Day, a team – aptly named Neu-Row Mermaids – then hit the water to take part in the Portsmouth Rotary Dragon Boat Festival to raise money for the group.

Headway Tyneside also partnered with its local hospital, with volunteers hosting an information stand at Newcastle Upon Tyne Hospital Trust, while Headway Rotherham chose their local Co-op store to spread the important messages of this year's campaign.

Likewise, visitors at Tamworth library also had the opportunity to learn more about brain injury thanks to Headway Tamworth and Lichfield.

Headway Bristol took advantage of the week's wonderful weather by holding an ABI Week Volunteer Day in its garden, with green-fingered volunteers working throughout the day to spruce up the garden and turn it into a sensory sanctuary for its service users.

HATS

ALL FOR NOW FOLKS

Hundreds of you donned your wackiest hats to make this year's Hats for Headway Day our most successful ever.

From traffic cones to party hats, there was a huge range of fantastic headgear on show. Several of you got crafty and created your own weird and wonderful inventions, while others went for a fancy hat to celebrate the royal wedding. There were tiaras, crowns and even a castle!

Thank you to every one of you who made Hats for Headway Day 2018 such a success. Until next year, hats all for now!



WINNER! Natalie Corrigan from Headway East Sussex wins the Best Hat competition



Be cool, dawg... Ziggy the Airedale Terrier is looking good!



The Neuro Service Outreach Team at Rotherham, Doncaster & South Humber NHS Foundation Trust



Best group winner

Harry and Meghan pop by the Lanyon Bowdler offices for a wedding rehearsal.



Justine Wright from Stephenson's LLP provides afternoon tea to go!



Er, five hats are better than one? We hope David Richardson from Ashtons Legal donated five times...



Headway Blackpool service user Keith Whigham shows he's a real record breaker!



Gaye Griffith's children donned their hats to support their brother Bobi (left) after his head injury.

GOVERNMENT AGAIN FAILS TO ACT ON DISABILITY BENEFITS



The Government has issued a ‘deeply disappointing’ response to Parliament’s strong demands for a major overhaul to disability benefits assessments.

Headway’s *Right First Time* evidence was referred to in a report from Parliament’s Work and Pensions Committee, which made numerous recommendations to the Government.

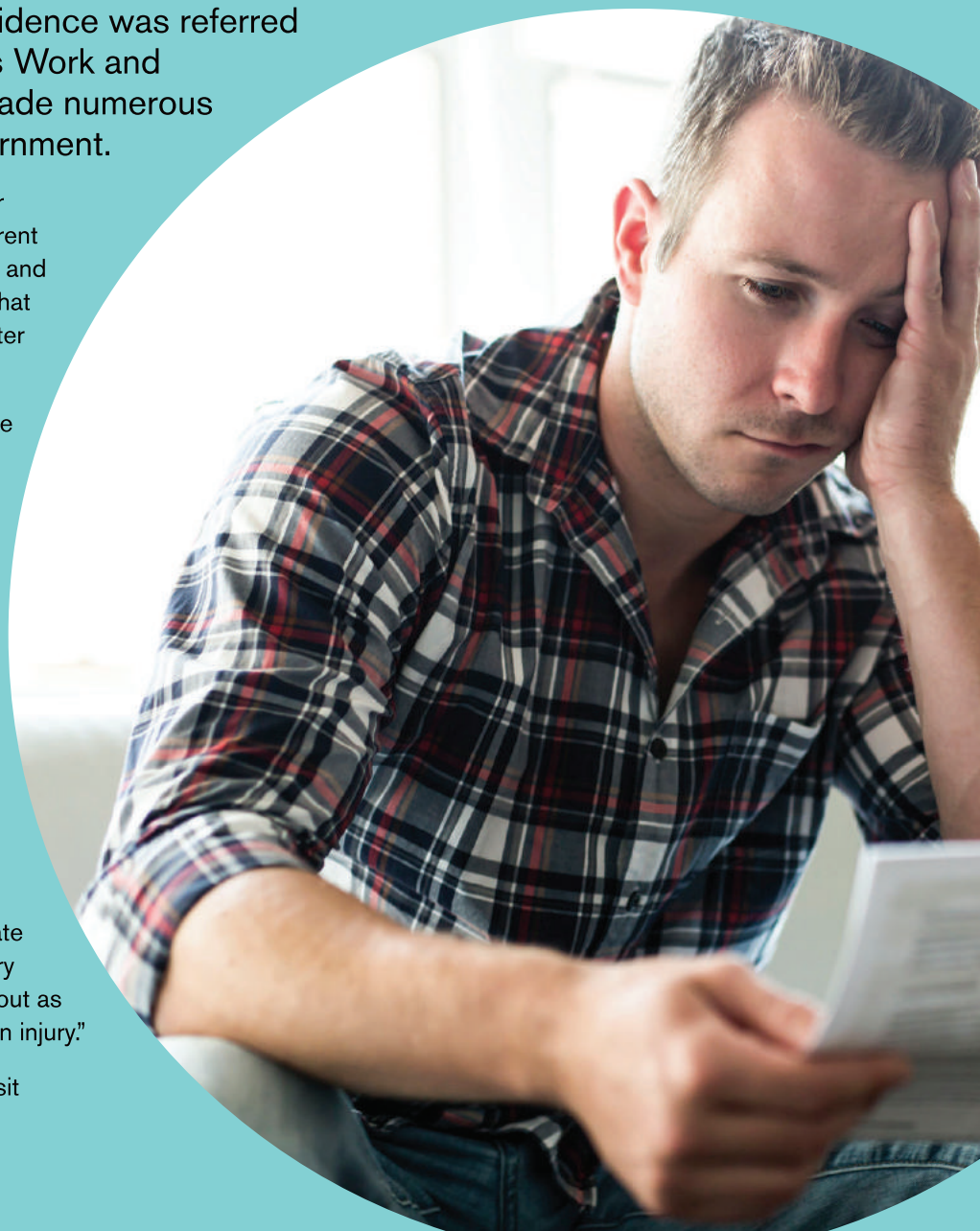
The committee echoed Headway’s calls for assessments to be recorded, for a transparent system to reassure applicants that medical and other evidence is taken into account, and that assessors and decision makers have a better understanding of hidden conditions.

Headway’s Public Affairs Manager, Dr Clare Mills, said: “We are deeply disappointed that the Government has chosen to ignore the disturbing evidence from brain injury survivors, their families and carers about their experiences of disability benefits assessments.

“The Government has a golden opportunity here to overhaul the system and make sure decisions are, as we demand, right first time. Yet despite overwhelming evidence and calls for change, the Government is prepared to make only minor tweaks and adjustments.

“There is no excuse for continuing to operate a system that lets down so many brain injury survivors. Headway will continue to speak out as the leading voice for those affected by brain injury.”

For a link to the Government’s response visit www.headway.org.uk/news.



'We were lucky...we had support'

Aberdeen couple Cheryl Mainland and Andy Irvine had just found out they were expecting their first baby. But what should have been the most joyous moment of their lives turned to tragedy when Andy was hit by a car just four days later.

Andy, 36, had a slim chance of survival. He suffered swelling and bleeding on his brain, bruised lungs, a broken pelvis, broken ribs and a severe leg wound. He spent three weeks in a coma and was left unable to walk, talk or feed himself.

Thankfully, following weeks of intensive rehabilitation and care, Andy was able to leave hospital.

It was a tough time for Cheryl, 35, who had to adjust to becoming a carer and prepare for motherhood.

Although very stressful, she thought that getting Employment Support Allowance (ESA) for Andy would be simple enough. Sadly this wasn't the case.

"I began to fill in the assessment form but it was a huge document and I quickly felt completely overwhelmed," recalled Cheryl.

"I was struggling to answer the questions, and I wasn't the one living with a brain injury.

"The assessment itself was also completely inadequate. We were asked whether Andy can cook a meal. Yes he can. But he might leave the gas on, or he might burn himself because he isn't



Andy, Cheryl and their son Miller (Photo by Newsline)

concentrating. And although he can make one meal, that doesn't mean he can make three meals a day, seven days a week.

"The assessment quizzed Andy on his ability to get around. Andy can easily become disorientated and confused, which affects his confidence.

"He would rely on me or a family member to help him get to a certain place, otherwise he risked getting lost, particularly in unfamiliar locations.

"I felt like the assessment was saying that because he could get to the corner shop and back, there wasn't a problem."

Cheryl said that the assessment simply wasn't designed to judge brain injury correctly.

She said: "I think the assessment should be tailored to suit disabilities such as brain injury. I felt like I wasn't asked about brain injury at all during the assessment process, I was just ticking boxes.

"Andy was asked to fold a piece of paper in half and stand on one leg. These were not suitable tests and really showed a lack of understanding about the complex nature of brain injury."

Andy's ESA application was rejected and Cheryl was forced to go back to work full time to make ends meet,

rather than spending more time with her newborn.

Thankfully the couple received support from Andy's employer who was keen to help him on a phased return to work and was very flexible in accommodating his needs – support that sadly is not offered to all.

"He was able to go back as an administrative assistant to his previous manager," said Cheryl.

"He made mistakes and there were problems but they have been so very supportive of him. It was good for him to have that routine."

Cheryl's experience of how important welfare benefits are to survivors has been reinforced after they began attending their local Headway group, Brain Injury Grampian.

She said: "I've seen firsthand how much a change in benefits can affect people's lives and how upsetting it can be.

"People with brain injuries have good days and bad days, good moments and bad moments. You've got no idea how the brain injury will affect them from one day to the next, and it's very difficult to convey that through the assessment process."

FREETHS



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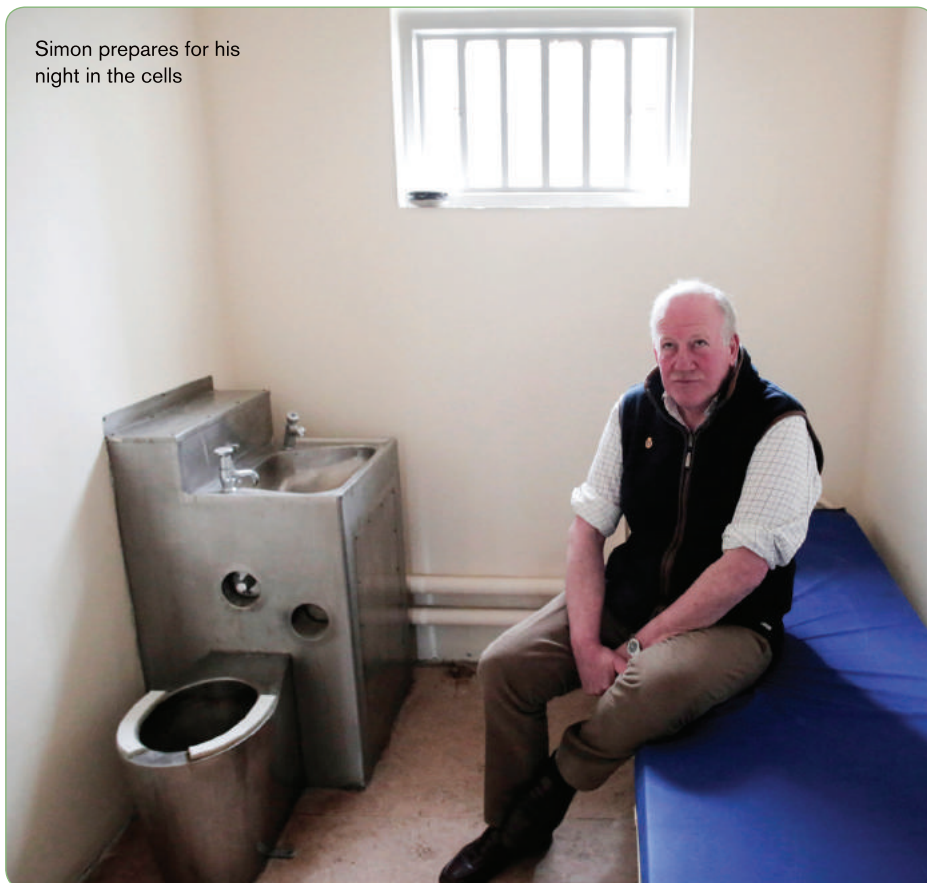
If you'd like to continue to hear about our news, campaigns, and fundraising activities, all you have to do is tick YES!

Visit www.headway.org.uk/yes and help us to improve life after brain injury.

#HeadwayHeroes

HIGH SHERIFF - BYE FREEDOM!

Simon prepares for his night in the cells



It was the ultimate case of role reversal for one Headway supporter who chose a novel way to raise awareness of brain injury.

Indeed, staff and inmates at HMP Kirklevington were shocked when the High Sheriff of North Yorkshire arrived in handcuffs!

Simon Wrightson's usual duties were suspended as he voluntarily spent a night in a cell to raise money for Headway and ABF The Soldiers' Charity.

Headway is a charity close to Simon's heart as he sustained a brain injury 25 years ago while holidaying in the French Alps.

"I slipped on some ice in a car park at the bottom of Mont Blanc," said Simon. "My injuries left me on a life support machine and in a coma for several weeks. It took me more than nine months to fully recover."

The wine merchant was brought to the category D open prison in handcuffs before being checked in like any other prisoner.

Mixing with regular inmates, Mr Wrightson ate in the dining hall and chatted with several 'fellow prisoners' as they shared stories of their convictions and hopes for the future.

Simon said: "It was an amazing experience – really eye-opening but also very uplifting.

"While I was in the dining room I was sitting with a man who was serving time for murder and had been in a category A prison but was now being prepared for release. It was incredibly interesting to listen to how the process works."

Whilst Simon was doing his time, his family, friends, and members of the community were frantically donating to his Virgin Money Giving page in an attempt to raise enough money to bail him out.

To date, Simon's supporters have donated over £10,000 in 'bail money' and the total continues to rise with the final figure expected to be in excess of £15,000.

More than enough was raised to see the High Sheriff of North Yorkshire walk free and provide a very generous donation to ABF The Soldiers' Charity and Headway.

Simon has supported Headway for many years. In 2002, he took part in the Great North Run and raised an incredible £26,000. At the time, it was the largest single donation Headway had ever received. In 2012, he opened his gardens to the public and raised a further £6,205.

Jo Plant, Director of Fundraising for Headway, said: "This has to be one of the most innovative ways of raising money that we've come across!

"It just shows how a bit of creativity can really help generate sponsorship."

"Simon is a superstar and we are extremely fortunate to have his ongoing support."

If you are taking on a challenge or organising a fundraising event in support of Headway - the brain injury association we'd love to hear from you! Get in touch on **projects@headway.org.uk** or **0115 924 0800**.

Inspired? Get involved! **27**
www.headway.org.uk/get-involved



#HeadwayHeroes

For Daniel Mole and his fiancée Meg Parsons, the support of his employers GB Railfreight (GBRf) has been invaluable and has enabled him to make a graduated return to work following a devastating brain injury.

When Daniel and Meg found out they could not have children naturally, it was heartbreaking news. Starting a family was all they ever wanted.

Determined to try every option, they began the long wait for fertility treatment and wedding plans were put on hold.

After 11 agonising months they received notification that their treatment would finally start on 23 January. But hours before the appointment, Daniel was fighting for his life.

Daniel had collapsed at home following a ruptured aneurysm. He was rushed to hospital for emergency surgery but following complications he suffered a stroke and was left in a coma.

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

"I struggled to remember my loved ones when I woke from the coma," recalled Daniel. "It really was hit and miss."

"Meg used to show me pictures of family and friends. She said that I used to look at some people that would visit like they were strangers when they would go to hug me.

"I couldn't remember most of the previous two years. I also didn't remember that I lived with Meg. I thought I still lived with my mum and dad."

Relearning how to live

After making good progress, Daniel was able to return home in May but adjusting to his new life was very hard.

He said: "I found everything difficult at first. I struggled a lot with my mobility and

LIGHT at the end of the tunnel

There are many reasons why firms choose to fundraise for Headway, but none more touching than to offer support to a member of their team.

needed help to do very simple things.

"I couldn't cook because I was unable to multitask and I would forget to turn the oven off.

"I would regularly forget to take my tablets too.

"It was very tough on both of us. Meg was unable to go back to work as she had to care for me full-time and it placed a lot of pressure on our relationship. Suddenly, she wasn't just my fiancée but my carer too."

Throughout Daniel's recovery he has received support from Headway.

He said: "They have always been there if we needed some advice or help. We called the helpline to help prepare for what issues we might encounter as my recovery progressed.

"We also found its booklets very useful."

'GBRf so supportive'

With intensive support and four months on a rehabilitation programme, 28-year-old Daniel has now been able to return to work with GBRf.

Before the injury he worked as Yard Shift Leader. The role meant that he had to work 12-hour shifts on a roster which consisted of swapping between days and nights.

He said: "My previous role was very mentally tiring and it required a lot of thinking. I had a lot of responsibility and had to be very organised.

"I couldn't return on a full-time basis straight away but GBRf has been so supportive by putting things in place to help me, such as working closely alongside my rehab team in order to support me in a phased return to work."

"They've also allowed me to start back on reduced hours, with regular meetings to review my progress, and shadow someone until I get my confidence back.

"Their remarkable support throughout has been what has allowed me to get my life back to some form of normality.

"I'm so thankful."

Daniel's colleagues were so affected by what happened to him that they nominated Headway to be the firm's charity of the year.

Daniel said: "I was over the moon when I heard they had picked Headway because it has provided me and Meg with so much advice and support.

"It is also great because it is helping to raise awareness of the effects of brain injury and that is really important to me."

Happy ending or new beginning?

Daniel and Meg are now looking forward to the next phase of their lives and are positive about the future.

Daniel said: "It was only six months ago that I couldn't do anything for myself, including work, drive or have any kind of social life.

"I have learnt to just keep pushing and pushing yourself, even on the darkest days where you feel like your life has all been ripped away and turned upside down, because anything is possible with a positive attitude and a good support network of family and friends.

"You have to push yourself out of your comfort zone, push yourself to socialise and do things you used to and aim to be not the person you used to but an even better version of yourself.

"Having a brain injury has taught me how valuable life is!"

But if Daniel and Meg had hoped the next period in their lives together would be a little calmer, they can think again!

"After trying for two years we fell pregnant naturally in September. Like they say, everything happens for a reason!

"Our baby is due in May and I hope to be the best dad I can be. I want to continue enjoying life and not letting the brain injury define who I am.

"I am really looking forward to family days and holidays. With help I'm moving on from the darkest days of my life. I'm so grateful for what I have now."



GB Railfreight

Inspired? Get involved! **29**
www.headway.org.uk/get-involved

#HeadwayHeroes

Headway Heroes beat the heat

As if tackling the gruelling 26-mile London Marathon course wasn't enough of a challenge, this year our dedicated runners had to contend with record-breaking temperatures as they pounded the streets of the capital.

Around 50 brave souls were adorned with the Headway logo as they ran in temperatures reaching more than 24°C to raise money to support either UK-wide services or their local group or branch.

But as always, Team Headway was looked after from start to finish. Proceedings got underway with a pasta party to help our runners stock up on carbohydrates in preparation for the many miles that lay ahead.

One of the runners who put those carbs to good use was 21-year-old Sam Tall.

Sam was raising money in memory of his girlfriend Amy Haskew who sustained fatal brain injuries in a bike accident in Australia in 2016.

"Amy was the most beautiful, warm and thoughtful person I've ever known," said Sam.

"She was so fearless in how she lived and had the most refreshing 'never give up' attitude in the face of adversity. She was always determined to live her life to the full in any moment.

"Her energy, enthusiasm, and fearless attitude to life was what I loved and will always love so much about her."



Team Headway member Joanna Rhydderch proudly shows her medal

Sam said running the marathon was a fantastic and really positive and uplifting experience.

He said: "The support from the public was really amazing and helped massively to push me on and keep trying my best to the end.



Sam Tall ran with a smile on his face

"You definitely feel like you are part of something special, where so many people come together to support each other. Many of the runners have stories and suffered some heartbreaking experiences – but everyone pulls together."

Brain injury survivor Faye Hetherington, 30, completed the marathon in an impressive four hours and 38 minutes.

Four years ago she sustained a brain injury after falling and smashing her head on the pavement outside her home.

The injury left her with many problems including headaches and fatigue.

Faye said taking part helped her realise how far she had come since her accident.

She said: "Before I'd even got off the train, six different runners had asked me about Headway, and when I explained my story they all said how proud I should be to even get to the starting line, let alone the finish!

"I had got so wrapped up in my training to make everyone proud that I'd forgotten to look back and acknowledge the achievement for myself.

"Crossing the finish line was the proudest moment of my life!"



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Boyes Turner is proud to be an active supporter of Headway.
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"Thompson's helped us to settle a legal case for a substantial sum and we now have the financial security we need to access the best possible care and support for Adam."

Anita, mother of Adam, one of Thompsons' brain injury clients



To speak to our serious injury team and find out how we can help you call **0800 0 224 224** or visit www.thompsons.law. An initial consultation is entirely free of charge.



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

Prince Evans Solicitors LLP
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Tel: 0800 019 0991 **Fax:** 020 8579 0191

E-mail: gsmith@prince-evans.co.uk

www.prince-evans.co.uk



Contact Gary Smith Head of Personal Injuries
CALL FREE ON 0800 019 0991