

Spring 2018

Headway News



The magazine of Headway - the brain injury association

*'No memory
of the day my
life changed
forever'*

*Get assessments
Right First Time!*

The fears
of ageing
carers

*'The ripple effect
of my brain injury'*



HATS FOR HEADWAY DAY



Friday 18 May 2018

headway.org.uk

#HatsForHeadway

ACTION FOR

BRAIN INJURY WEEK 2018



the brain injury association

Registered with the Charity Commission for England and Wales (Charity No 1025852) and the Office of the Scottish Charity Regulator (Charity No SC 039992).

Headway 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



Isn't it nice when someone says 'I'm listening'...

It feels that these days there's always so much 'noise'. So many opinions about so many issues that we're expected to care passionately about.

It can be easy to feel that our voices and the things we care deeply about don't matter in the grand scheme of things. After all, who's listening?

So when someone does listen it's uplifting to say the least.

The good news is that Parliament is listening! For example, 656 people contributed to our study into whether or not PIP and ESA assessments work well for brain injury claimants. They should feel proud that their evidence contributed to a Work and Pensions Committee report that stated the current system results in 'untenable human costs to claimants'.

Real change has been called for and we are using our new Right First Time campaign to see that it happens.

We're working really hard to make the voices of people directly affected by brain injury heard by politicians across the UK – and that effort is paying off.

Over the past few weeks and months, we have engaged with dozens of politicians to encourage them to support our work and get more involved with their local Headway groups or branches.

We've contributed to several debates and inquiries on issues including

disability benefits, carbon monoxide poisoning, Deprivation of Liberty Safeguards, and hospital parking charges.

We've even been mentioned in Prime Minister's Questions – the most high-profile debate in the House of Commons.

Noise is a funny thing. There will always be times when you want nothing more than a 'mute' button for life, but then there are the times when you want to increase the volume to maximum to make sure everyone is listening to what's being said.

One thing is for certain – we will keep listening to you and keep working to make sure others do likewise.

After all, only by working together can we continue to improve life after brain injury.

The Communications Team

While you're here, we have a little favour to ask. The way we interact with you, our supporters, is changing.

If you want to keep hearing from us in order to support our work and campaigns, or learn about our latest publications or services, you'll need to Tick YES!

Check out our website or page seven of this magazine for more information – and thank you in advance!



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 947 1912
information.manager@headway.org.uk

Website: www.headway.org.uk

Telephone: 0115 924 0800

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www.headway.org.uk/donate

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Your views...

The government has announced proposals to extend the blue badge parking scheme to include people with hidden disabilities. We asked our online communities what they thought of the news...

"Definitely agree with this as we forget where we park our cars. Find it really difficult to remember where I park my car, even which car park at times."

"I'm at the hospital now been sent here by my GP. I've been driving round and round looking for a space getting more and more anxious. This would help immensely."

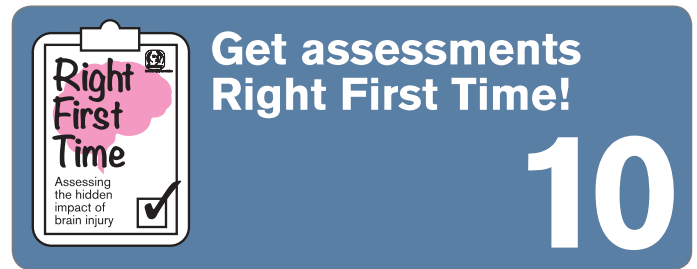
"My dad is only ambulant with a wheelchair, he has TBI and spinal cord injury,, but before that blue badge arrived we had a terrible time trying to park and get him into the wheelchair."

"Brilliant idea... I have TBI and this would be a great help."

"It's about time...TBI can cause so many conditions that individually at first don't seem worthy of a badge but then you put them together, they make life a struggle. TBI fatigue makes the brain work so hard that the body suffers so much."

"One problem with a TBI is remembering where you've put the car in the first place!"

"About time!
We questioned this nearly 10 years ago as it would have been a major help in the first couple of years of recovery."



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have missed...**

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Addressing the fears of
ageing carers

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My Story:
Shona Green

news you may have missed...

'Untenable human costs' of claiming PIP and ESA

Stark failings in disability assessments have been identified by a parliamentary inquiry, which found 'a pervasive lack of trust' that results in 'untenable human costs to claimants'.

Headway, which contributed to the inquiry, has urged the government to take immediate action by implementing the recommendations of the Work and Pensions Committee and the charity's own *Right First Time* campaign.

The inquiry, which looked at the processes for claiming Personal Independence Payment (PIP) and Employment Support Allowance (ESA), attracted an overwhelming response from claimants, their families, and professionals. In total, more than 3,500 individuals and almost 200 organisations contributed.

Headway's evidence comprised the views of more than 650 people affected by brain injury, with the parliamentary report referencing the charity's evidence 16 times.

Frank Field MP, who chairs the influential parliamentary committee, said of disability assessments: "A pervasive lack of trust is undermining its entire operation.

"In turn, this is translating into untenable human costs to claimants and financial costs to the public purse.

"The government cannot, must not, fail to recognise the unprecedented response the committee had to this inquiry, remarkable for the consistency and clarity of themes that emerged from thousands of individual accounts.

"No one should have any doubt (that) the process needs urgent change."

Peter McCabe, Chief Executive of Headway, said: "The voices of brain injury claimants who have been consistently failed by the system have been ignored or swept aside by the government for too long.

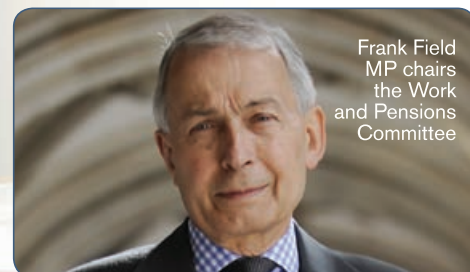
"The government can no longer fail to act, with this report yet another clear indication that disability benefits assessments are not fit for purpose – particularly for those with hidden, fluctuating or complex conditions."

Among the findings of the report was a recommendation that claimants' interviews be recorded in order to increase transparency, as previously recommended by Headway. The report also called for the introduction of a checklist system requiring assessors to record how they have used supporting evidence.

Peter added: "We welcome the findings of this inquiry, which not only echo the issues we have been raising for many years, but also the key calls-to-action outlined in our recently-published *Right First Time* report.

"The government simply must act immediately to implement the required improvements identified by the Work and Pensions Committee."

For more information on Headway's *Right First Time* campaign visit www.headway.org.uk.



Frank Field
MP chairs
the Work
and Pensions
Committee

Research highlights value of specialist care



Alyson Norman

New research has highlighted the ongoing need to review and improve community services provided to brain injury survivors.

The study was led by Dr Alyson Norman, a lecturer in clinical and health psychology at the University of Plymouth and a trustee of Headway Somerset, and case management company Head First.

The researchers asked 99 people affected by brain injury about

their experiences with community organisations. Key themes identified included a poor understanding of brain injury symptoms and poor availability of, and accessibility to, services.

Solicitors were ranked most positively in terms of being supportive of the needs of brain injury survivors. Social services were found to perform the most poorly.

A link to the full report can be found on the Headway website.

Ryan Mason retires from football

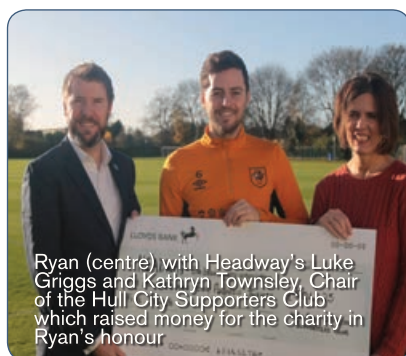
Headway has offered its ongoing support to former footballer Ryan Mason who has announced his retirement after fracturing his skull 13 months ago.

The talented 26-year-old suffered his life-threatening injury in a clash of heads with Chelsea defender Gary Cahill while playing for Hull City in a Premier League match in January 2017.

Headway Chief Executive Peter McCabe said: "We were sad to

hear the news that Ryan has been forced into retirement following his serious head injury.

"Although this difficult decision must be heartbreaking for Ryan, it is a sensible one."



Ryan (centre) with Headway's Luke Griggs and Kathryn Townsley, Chair of the Hull City Supporters Club which raised money for the charity in Ryan's honour

Tick YES! to improve life after brain injury

If you're reading this, the chances are that you share our passion for improving life after brain injury. We also hope it means you're interested in what we're doing to achieve that ongoing aim.

If so, read on!

New data protection laws will soon alter the way in which we can contact and interact with our supporters. We will no longer be able to contact you by phone, email or post without your express permission.

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

As always, we promise not to bombard you with excessive mailshots or messages, and you will always have control over how much information you receive from Headway.

We are passionate about improving life after brain injury. But we can only do this with your help.

We are proud of our fundraising principles. Charitable giving should always be about choice, trust, and respect, and knowing that your values and principles are reflected by the charity you choose to support.

Please visit our website at www.headway.org.uk/yes and tick YES! to help to improve life after brain injury.



news you may have missed...

Latest factsheets launched

Three new factsheets have been added to Headway's free-to-access information library.

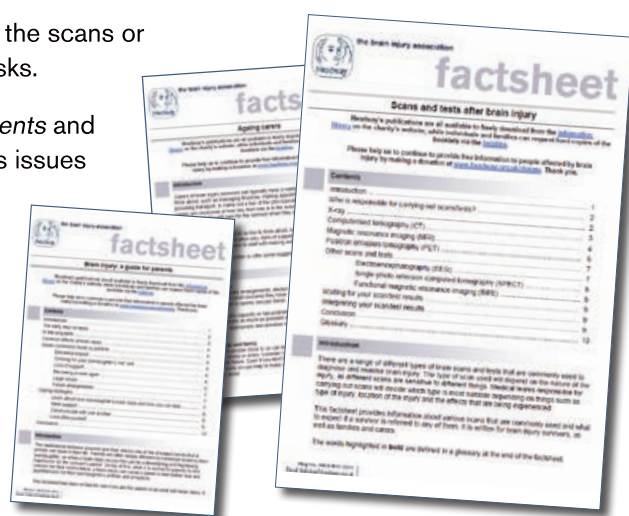
The latest additions are *Scans and tests after brain injury*, *Brain injury: a guide for parents and Ageing carers*.

Scans and tests after brain injury offers information about how commonly-used diagnostic and monitoring tools work, whether any preparations are required

beforehand, the process of the scans or tests and any associated risks.

Brain injury: a guide for parents and Ageing carers both address issues and concerns commonly experienced by many parents and carers.

To download Headway's range of free booklets and factsheets, visit www.headway.org.uk/information-library.



Hats for Headway Day is back!

It's almost time to dust-off your favourite hat or perhaps even create a new one for Hats for Headway Day, which will take place on Friday 18 May during Action for Brain Injury Week.

Hats for Headway Day is a simple and fun way to support our work to improve life after brain injury.

All we ask is that you – and your friends, colleagues or classmates – wear a wacky hat, make a donation to Headway and post a picture on Facebook, Twitter or Instagram using the hashtag #HatsForHeadway.

Last year's event was the most successful to date. We were inundated with fabulous photos, while more than 700 tweets used #HatsForHeadway and helped us to reach more than 800,000 people.

How do we beat that? We'd best start by putting on our thinking caps... quite literally!

To get involved, visit www.headway.org.uk/hats-for-headway.

HATS FOR
HEADWAY
DAY



Prime Minister questioned

Evidence from Headway has been cited during Prime Minister's Questions (PMQs) to support a call to scrap NHS hospital parking charges.

This is the first time the charity has featured in PMQs, which receives significant public and press attention.

Robert Halfon, MP for Harlow, quoted Headway while calling on the Prime Minister to abolish extortionate hospital car parking charges once and for all.

Mr Halfon said: "Headway, the brain injury charity, says that a family recently had to pay £1,500 over 15 weeks for hospital car parking charges.

"Despite government guidelines, 50 per cent of hospitals charge the disabled. Staff from nurses to hospital porters have to pay hospital car parking charges. Given the unanimous motion last week in the House of Commons, will my honourable friend address this social injustice and abolish hospital car parking charges once and for all?"

Theresa May PM acknowledged the issue and said the government had sent guidance to hospital trusts on how to approach the matter.



A helping hand...

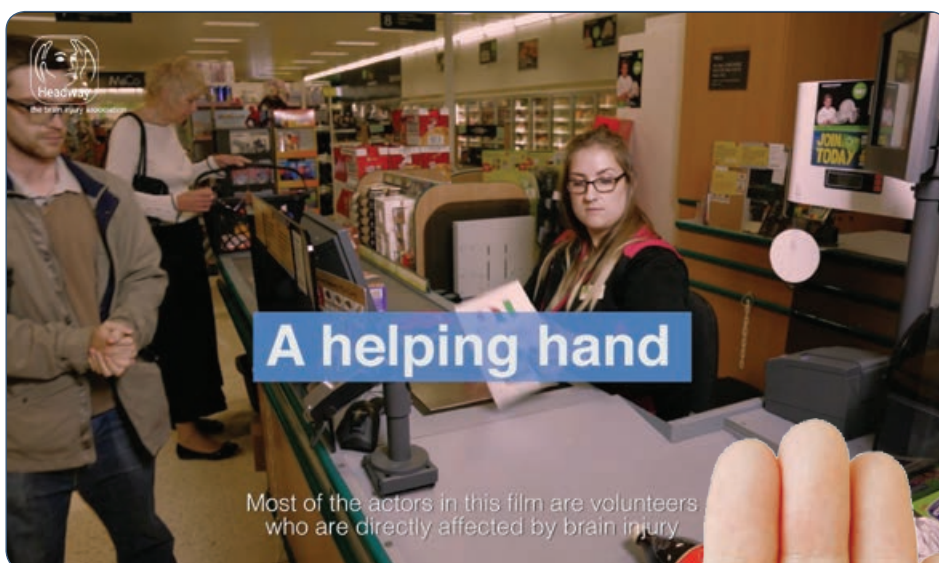
We've added to our series of short awareness-raising films depicting the often hidden effects of brain injury and how it can impact on daily life.

A helping hand is set in a supermarket and shows a brain injury survivor struggling to provide the cashier with the correct money, with an impatient and increasingly frustrated queue behind him.

The film calls for people to show more awareness, patience and understanding in such situations.

It features service users, staff and volunteers at Headway Essex, and was made with support from the East of England Co-op, which agreed for the film to be shot in its store in Stanway, Colchester.

Rob Smith, who plays the lead role in the film, said: "I sometimes have difficulties because of my slurred speech and poor



balance. But not everyone can see my disability.

"Every brain injury is different and there are no hard and fast rules about how it affects people. But it would certainly help if people were more educated about its hidden nature and some of the most common effects."

To view the full series of short films, visit www.braininjuryandme.org.uk.



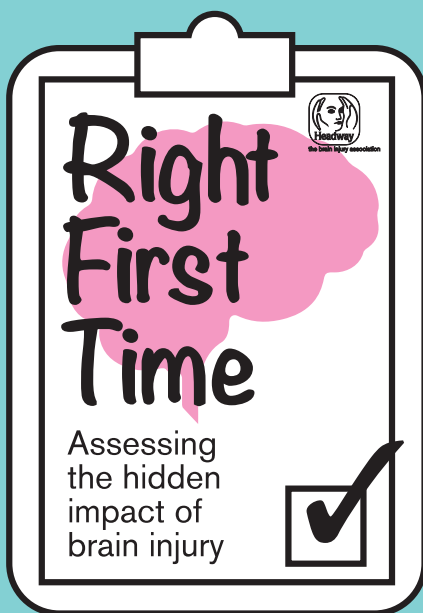
To keep up-to-date with all the latest news visit www.headway.org.uk or sign up to our *Bitesize* bulletin

09

BENEFITS ASSESSMENTS:

Get them *Right First Time!*

When it comes to conducting a person's disability benefits assessment, we at Headway have one simple request to assessors: Please, get it *Right First Time!*



Everyone at Headway knows the devastating and life-changing impact a brain injury can have.

It can transform lives and futures in an instant, putting immense pressure on families as people try to rebuild their lives.

But returning to the life you once had can be an impossible dream for many. As a result, brain injury survivors often find themselves reliant on disability benefits in order to lead lives that are as fulfilled and independent as possible.

Imagine then being faced with the practical and psychological challenge

of accepting you need to apply for Employment Support Allowance (ESA) or Personal Independence Payment (PIP) only to be denied help due to a lack of understanding of brain injury.

It can leave people without vital benefits, causing intolerable stress and financial problems that could, and should, be avoided.

Indeed, a significant number of survivors whose applications for ESA and PIP are refused subsequently have the refusal decision overturned on mandatory reconsideration or following an appeal.

To highlight this we recently launched our *Right First Time* campaign, which calls for the government to bring in changes to disability benefits assessments and make sure survivors and their families are treated fairly.

The campaign's report is based on a survey of more than 650 people directly affected by brain injury. It revealed that the experiences many survivors have when applying for these disability benefits is largely negative.

Findings included a perception that the system focuses too heavily on the physical impact of having a disability, at the neglect of more hidden issues; many assessors lack knowledge of ABI; and medical evidence is not routinely taken into account.

‘Hardship and distress’

Peter McCabe, Chief Executive of Headway, said: “You cannot underestimate the hardship and distress that can be caused to brain injury survivors and their families who are incorrectly assessed for disability benefits.

“Emotionally and financially they feel that their lives have been put on hold with many left feeling that their brain injury has just been ignored or completely misunderstood.

“Our *Right First Time* campaign highlights serious failings that the government must address in order to ensure brain injury survivors get the decision and support they deserve – without having to go through a challenging and stressful appeals process.

“Despite numerous calls, this issue has been ignored by successive governments, causing unnecessary and unacceptable suffering for vulnerable families across the UK.”

The campaign is being supported by a number of professionals including Consultant Clinical Psychologist Dr Stephen Weatherhead.

He said: “The benefits system has been getting progressively worse over recent years and people with a brain injury are suffering unnecessarily as a consequence.

“This campaign is a hugely important step forward in calling the government to account. We need a concerted and united effort from professionals, organisations, carers and people who have experienced a brain injury.

“Given the findings of the most recent survey conducted by Headway, it is clear that we all need to speak out.

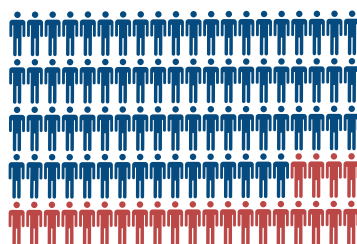
“It is a brave step to challenge policies and practice in this way, but there is a responsibility to do so. Hopefully this will help effect change in a system which is clearly failing people who have had a brain injury.”



STUDY FINDINGS

ESA

76% of respondents said it was difficult to explain the effects of their brain injury on the form



“I felt the assessment took my brain injury into account.”

■ Yes (31%) ■ No (69%)



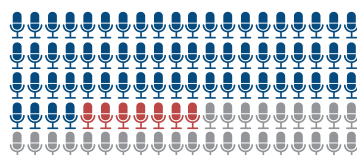
“Do you feel your assessor understood your brain injury?”

■ Yes (29%) ■ No (71%)



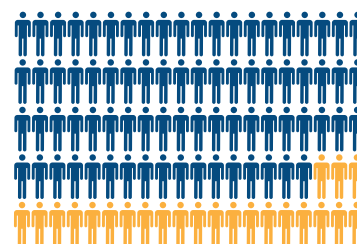
Should assessments be recorded?

■ Yes (64%) ■ No (7%) ■ Not sure (29%)



PIP

77% of respondents said it was difficult to explain the effects of their brain injury on the form



“I felt the assessment took my brain injury into account.”

■ Yes (40%) ■ No (60%)



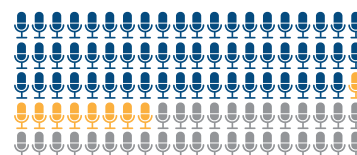
“Do you feel your assessor understood brain injury?”

■ Yes (40%) ■ No (60%)



Should assessments be recorded?

■ Yes (59%) ■ No (9%) ■ Not sure (32%)



WHAT WE'RE CALLING FOR:

- Specialist assessors with an expert knowledge of brain injury should conduct assessments for ABI claimants.
- To build more trust, a system for recording and confirming consideration of third-party evidence by assessors and decision makers should be introduced.
- Applicants should be offered the option for an audio or visual recording of the face-to-face assessment. They should not have to make special arrangements or provide their own recording equipment for this.



'Medical evidence was ignored'

Amanda Horton has been a full-time carer for her husband Alan since he suffered a subarachnoid brain haemorrhage in 2006.

Amanda, who lives in Lincoln, was left very frustrated by the process of helping Alan apply for PIP.

"The assessment was very stressful for me as a full-time carer and very negative for my husband," she said. "The emotional impact of going over and over the long list of things he cannot achieve, and needs help with, is quite harsh."

Since his brain injury, 63-year-old Alan struggles with a number of issues including memory problems, cognitive issues and a lack of motivation.

He also struggles to communicate when around groups of people or in noisy environments.

Although Amanda supplied numerous medical documents from health professionals, none of the information was taken into account and she was very unhappy with the assessor's level of understanding of brain injury.

She said: "We made sure to provide lots of information from Alan's consultant and physio but it was all ignored. It made me feel so cross. What a complete waste of time!"

"An acquired brain injury is very complex and uniquely personal. The person who conducts the assessment needs to be a specialist in that area so that the right decision can be made and the correct questions asked."

The assessors incorrectly judged that Alan could do complex reading.

Amanda said: "Just because he is able to read newspaper articles he was assessed as being able to do complex reading."

"He reads purely for his own pleasure and nobody ever tested him to find out if he understood or remembered any of it. For instance, he often reads something completely different to how it actually is."

The assessors also judged that Alan was able to make complex budgeting

decisions based on the fact he knows the value of money and change, a decision that amazed Amanda.

"He is totally unable to deal with household bills, look after his bank card or wallet, as he never knows where things are. In shops he often walks away without remembering to pick up his change."

"The assessment just doesn't work, it doesn't get to the truth."



Amanda and Alan Horton

MORE STUDY FINDINGS

The system largely focused on the physical impact of having a disability, neglecting other elements of disabilities.

76% and 77% of respondents felt that it was difficult to explain the effects of brain injury on the application form for ESA and PIP respectively.

Assessors were found to be lacking in this specialist knowledge. 71% and 60% of respondents felt that the assessor for ESA and PIP, respectively, did not have an understanding of brain injury.

Assessors were widely reported to lack empathy and patience.

A significant number of respondents commented on the fact that their medical evidence was not taken into consideration, and that the assessment environment was not suitable for them.

'No understanding of brain injury'

Brain injury survivor Jeff Clare and his wife Heather know first-hand the benefits of having a PIP assessor who understands brain injury.



Jeff, of Bishops Stortford in Hertfordshire, fell ill with encephalitis in 2010. He was left with memory, concentration and mobility problems, as well as fatigue.

After a distressing and disappointing PIP assessment in 2013, Heather was too stressed to appeal the decision on her husband's behalf.

"I didn't get the impression the assessor had read Jeff's reports or had an understanding of brain injury," said Heather.

"She did not appear confident and was trying to fit Jeff's abilities into boxes rather than assessing him as an individual, looking at his needs.

"The staff at Headway Hertfordshire said we deserved more financial help, but it was so stressful. I couldn't cope with going through it all again."

But after six months Jeff's health deteriorated and Heather requested a reassessment. Their second experience couldn't have been more different.

"I actually enjoyed the second assessment because it felt like talking to one of the professionals at the hospital," Heather recalled.

"He had read through all of my husband's reports and started the assessment by giving us a summary of what he thought the reports stated. He asked us if we agreed with his summary.

"We were very happy with the way he summarised things. It was reassuring that he had taken the time to read and understand the reports. Everything was clearly explained to us about the assessment process.

"It was clear to me that the person conducting the assessment had a good knowledge of the fluctuating nature of brain injury and how it could impact on everyday life.

"I felt confident throughout the assessment that my husband was being viewed as an individual and his needs were being assessed fairly.

"I would love it if everybody could have the experience we had. It was how it should be."

Visit www.headway.org.uk/get-involved to find out more about the Right First Time campaign.

“A fairytale I never want to forget!”

Headway
Annual
Awards
2017

Each year, the Headway Annual Awards provide memorable moments for guests, while giving finalists a once-in-a-lifetime experience that they will treasure forever. We asked one of our finalists to review December's event and share her experiences of the big day.

Natalie Parr had been nominated for The Alex Richardson Achiever of the Year Award, sponsored by Slater and Gordon Lawyers, after demonstrating an incredible determination to not let her disability prevent her from scaling the highest heights.

Natalie sustained her brain injury in 2002 after contracting Guillain-Barré Syndrome – a disorder in which the body's immune system attacks part of the peripheral nervous system and starves the brain of oxygen.

At the age of 25, she was left paralysed from the chest down, unable to return to work, confined to a motorised wheelchair, and needing to be tube fed.

But Natalie chose to challenge herself to see where she could go in her wheelchair, and has since scaled or descended iconic buildings including Blackpool Tower, the London Eye, and Tower Bridge.

“I felt like
Cinderella”

“Having wrapped up warm on a freezing December morning, my parents braved the snow and began our journey to The Dorchester Hotel in Mayfair, London,” said Natalie.

“Once we arrived at The Dorchester, I changed out of my winter layers and into my glitzy dress, sparkly shoes and jewellery. It felt really exciting to be all dressed up. I felt like Cinderella.

“Now feeling all glamorous, we joined the champagne reception where I met lots of other guests and Headway staff who came over and introduced themselves, before then getting my first glimpse of the stunning ballroom, which looked absolutely amazing!

“I couldn't believe the size of it. There were pink, blue and white lights shining on the ceiling, sparkly chandeliers, round tables set with flickering candles, shimmering glasses and shiny cutlery.

“I was shown to my seat near the stage along with the other finalists. I was chatting to my fellow nominees and we talked about what an unbelievable experience it was.

“A member of staff from Headway stood by us, so I didn't feel nervous because I knew if I needed to go onto the stage she would show me. I felt really calm.

“The awards ceremony started and Sky News presenter Tom Macleod introduced some more celebrities, including double Olympic gold medallist James Cracknell, who went up on stage.



Natalie receives her award from James Cracknell, alongside (r-l) Annie and Chris Richardson, and Deborah Johnson from Slater and Gordon Lawyers

"My award category was the first. When I was announced as the winner, I couldn't believe it! I'm just Nat but I suddenly felt a wave of pride.

"I was quite excited, emotional and proud. I got onto the stage where James Cracknell shook my hand before giving me my certificate and my award. I was speechless.

"I then turned to the screen and everyone watched a film that my friends at Headway Coventry and Warwickshire had made for me.

"At this point I felt really emotional – I had no idea they had made the film. It felt like they were there celebrating with me.

"It was a really special moment and I loved watching their video message. I went off the stage holding my award and couldn't believe this had all just happened!

"Once the awards ceremony had finished, I went back to my table with my mum and dad where we enjoyed the most amazing meal and chatted

to some other guests. Lots of people came over to congratulate me, I just felt so touched by it all.

"The atmosphere in the room was brilliant; full of laughter, lights, sparkle and hope.

"A young lady called Asher X then shared her story on stage before playing a video of a song she had written and recorded. It was about her partner, who had been very poorly in hospital after his brain injury.

"It just made everything feel so real and reminded me of where we have all come from to get to where we are now. It made me feel grateful and lucky and reminded me that I have lots to give and share from my experiences that might help other people on their journey, by showing them that there is hope.

"Back when I was poorly in hospital, I never would have pictured myself going up onto the stage in front of all of those people to collect an award all dressed up and in a glitzy sparkly room.

"I had the feeling that life was over and wondered what would happen now? But to sit there in that room full of life and fun felt a real honour and privilege.

"After Asher X's interview, pop star Marc Almond took to the stage and accepted donations from businesses that had fundraised for Headway throughout the year. They had raised an incredible amount of money and it was wonderful to see people doing so much to support Headway and brain injury survivors.

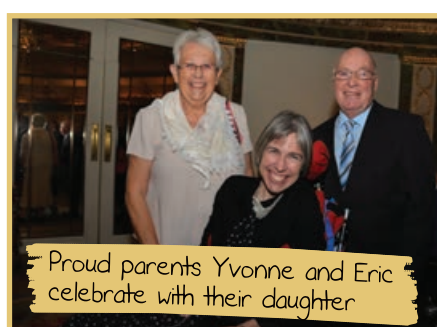
"I am so grateful to all of my family who have been there through every step, the medical professionals who looked after me, and all of my friends at Headway who nominated me for this award and made this wonderful day possible.

"The Annual Award ceremony was the most magical fairytale and I feel so privileged to have been there. I will treasure it and remember it forever."

Thank you to all the sponsors of the Headway Annual Awards 2017:



Natalie admires her award



Proud parents Yvonne and Eric celebrate with their daughter



Headway Annual Awards

A picture paints a thousand words...

For those of you unable to attend this year's ceremony, here's a taste of what you missed. And remember, you can watch a video of the ceremony on our website.



TV's Eric Knowles in full swing as guest auctioneer



Carer of the Year finalist Colleen Kelly (centre) shares a moment with Sonia de Blaquiére and Jane Weston from Headway Swindon



Tom Macleod once again hosted the ceremony in the stunning ballroom at The Dorchester



Carer of the Year Natasha Cassidy appeared on her local local ITV News



This year's 12 inspirational finalists, details of whom can be found on the Headway website



Headway Vice President James Cracknell is introduced to guests



Hip-hop artists Asher X gave a moving interview to host Tom Macleod

Sandy Johnson

It is with much sadness that we have to report that Sandy Johnson, winner of the Volunteer of the Year Award, passed away suddenly and unexpectedly on 17 February.

Sandy's family would like people to know that even being nominated for the Volunteer of the Year Award was an honour and to win was humbling. He had the most fantastic day at The Dorchester for which they will be forever grateful and express massive thanks to Headway for giving him such an accolade.



Watch the ceremony at www.headway.org.uk **17**

“NO MEMORY OF THE DAY THAT CHANGED MY LIFE”

How would you hope to come to terms with your brain injury if you can't recall how you sustained it? Here, Michelle Munt explains how she has coped with not remembering the day that changed her life.

Throughout our lives we all experience defining moments that change the course of our future.

This can range from something we are proud of, like graduating in your chosen subject, to something we're ashamed of, like being caught stealing. The former can be the opening to an exciting career; the latter could be the moment you seriously consider if a life of crime is what you want.

Personally I haven't experienced either of these moments, but I have had one such life-changing event. The difference is I have no memory of it, but I have to live with the consequences of it just the same.

I'm talking about the day I was involved in a road traffic collision in which I sustained a traumatic brain injury. It ended my career and I went through

the unenviable experience of having to learn how to walk, talk, read and write again.

I was driving to work on the dual carriageway I travelled on every day. Ahead the traffic was queuing, so I was slowing to join them. Behind me was a small lorry, but a low flying bird of prey smashed into the driver's windscreen.

He was unable to see anything and rammed into the company Smart Car I was driving. I was forced across the other lane and collided with the crash barrier on the central reservation.

Scans later revealed a bleed on my brain.

So if you can't remember the turning point in your life, how are you supposed to feel about it?

My feelings about it change minute by minute. I have the bad habit of over-analysing things and so I have lost many hours considering this subject.

As crazy as it sounds, the first thing I remember feeling was excitement mixed with disappointment. This was in response to being told I was airlifted to hospital.

I'd never been in a helicopter before, and you're a bit of a VIP if the air ambulance rather than the road ambulance is your chauffeur that day (albeit a seriously ill VIP!).

I thought it was such a shame that I couldn't remember this 'thrilling' experience. But at this stage I really didn't understand what had happened to me, so I was a bit delusional if I thought it was thrilling.

As I became more self aware, and recognised my limitations, I became apprehensive...wondering if I could have done anything to avoid the accident.

I wanted my life back, but needed someone to blame: me.

But then the rational realist in me finally started to wake up. Traumatic experiences can end in a phobia of the event happening again. And seeing as car accidents do happen every day, it wouldn't be an irrational fear for me to have.



Michelle Munt

However, as I remember nothing about it, I didn't have the memory to associate with driving a car. Thus, when I was physically able to, I returned to driving without fear.

Nevertheless, the not knowing gives me a sense of having no control over the event that changed my life. That has transpired into me being a very nervous passenger.

I can't bear the fact that not being a mind reader means I don't know if the driver is aware of the hazard I've just spotted. Often involuntary panicked noises escape me, when in fact the driver doesn't need any help from me, and has the situation under control.



HOW THIS EVENT HAS CHANGED THE FUTURE FOR ME....

I started to blog about brain injury as I felt there wasn't much awareness of what it means for the patient. It's such a confusing experience. I lost my communication skills and so struggled to help people understand what I needed.

Thankfully, I regained most of this, and therefore I try to say what others can't. My blog is called *No memory of the day that changed my life* and you can find it at www.jumbledbrain.com.

SUPPORT

It is not uncommon for people who have sustained a severe brain injury to have no memory of the moment it occurred, and often for a significant amount of time before or after the event.

A loss of consciousness is an obvious reason for this but, following this, many people go through a phase called post-traumatic amnesia (PTA) where they behave in a bizarre and uncharacteristic manner and will have no memory of day-to-day events.

Damage to the brain can also lead to a destruction of memories and/or the ability to recall them. Added to this, a severe trauma can in itself cause problems storing new memories.

Coming to terms with the loss of these memories can be deeply distressing. Professional support can help you to cope with the feelings this causes and your GP may be able to refer you to a neuropsychologist and/or trauma counselling.

Your local Headway group or branch may also be able to offer support, while you can contact the Headway helpline to talk things through and get further information.

There is more information on the stages of brain injury and memory loss on our website, www.headway.org.uk.

When I'm gone...

Addressing the fears of ageing carers

Carers of brain injury survivors can face countless practical challenges on a daily basis while supporting their loved ones to lead lives that are as fulfilled as they can be.

For many, the pressures and stresses that can result are compounded by a sombre question: who will care for my loved one when I'm gone?

It's a question none of us like to think about, but one that is unavoidable for ageing carers who have been the primary – and often only – form of support available to their loved one living with brain injury.

Here we offer some suggestions to help you plan for the future.

1. Talk to your loved one

When thinking about future arrangements, always start off by speaking with the brain injury survivor and finding out what concerns they have. They might have fears of their own, and it is important to be able to discuss these openly.

Even if the survivor lacks capacity or has problems with information

processing, involving them in these discussions as much as possible is very important. Naturally, this should be done in a way that is appropriate and sensitive to the individual so as to not instil a sense of fear.

2. Talk to close friends and family

Talking to people close to us can help with managing our thoughts and relieving emotional stress or worry. Consider talking to close friends and family about the survivor's care in the future.

Even if you don't have any plans in mind just yet, starting to have these discussions early on can help to make sense of what can otherwise be a difficult issue to even think about.

3. Take the discussions one step further...

If you are acting as a deputy for the survivor, meaning you are legally responsible for making decisions in their best interests, start thinking about who you would trust to act as a deputy for them in the future.

This is a big responsibility, but if there is someone who you feel would be able to take on such a role, start having this discussion with them and see how they feel about it.

Further advice can be found at www.gov.uk/become-deputy.

4. Find out what your local council can do

Your local council should offer a range of services for people who need support with living independently. This can include making adaptations to the home or giving advice on housing.

If the survivor will not be able to live independently when you are gone, start researching whether or not there are any supported living or sheltered housing facilities in your area that might provide a future option.

5. Make informal arrangements

Talk to family and friends about unofficial ways in which they can help out in the future.

Consider making informal arrangements. For instance, you could ask family members and close friends to each commit to ringing or taking the survivor out one day a month.

6. Make a will

Make sure you have a will in place. Writing a will ensures that your wishes are guaranteed to be fulfilled and provisions will be left for your loved one.



An ageing carer's view...

Allistair Renton, Headway UK trustee and Chair of Headway Suffolk

When our son Andrew fell while on a mountain in Scotland in 1994, my wife Maureen and I were catapulted into a world previously unknown to us.

In our mid-fifties, we were looking forward to making plans for our future retirement after bringing up two sons who were leading very active lives and were ambitious for their future.

Then everything changed overnight. We had to deal with the prospect

of an unknown future for our son and ourselves. In 1994, brain injury diagnosis and treatment was not as advanced as it is today.

Now, more than two decades later, we are acutely aware that as we get older, our ability to continue to give 24/7 support will become more challenging. We realise that things will eventually have to change and that our son will continue to need support when we are no longer able to give it.

Our advice would be to explore what options may be available in your area. This is likely to be difficult given the



Allistair and Maureen Renton with their son, Andrew

fast-changing circumstances of health and social care that are currently taking place.

Involve other members of the family and, most importantly, include the brain injury survivor in any discussions and decisions as they are the one that will be affected in the future.

Legal advice should always be sought when writing a will, particularly when leaving money to someone who is dependent.

Headway also offers a free will writing service via its Friends of Headway scheme. Visit www.headway.org.uk/friends for more information.

7. Inform other services

If the survivor is vulnerable, inform your local social services team and police. They may be able to make arrangements to ensure the safety of your loved one, for instance if they need assistance while out and about.

You should also consider applying for one of Headway's Brain Injury Identity Cards, which can provide invaluable help in these situations. For more information on the ID card visit www.headway.org.uk/idcard.

8. Other sources of support and advice

Your local Citizens Advice would be a good place to start when seeking general advice on making practical

arrangements. You could also contact the Headway helpline for information and support on 0808 800 2244 or helpline@headway.org.uk.

You can also download our new factsheets *Brain injury: A guide for parents* and *Ageing carers* from the information library on the Headway website.



THE RIPPLE EFFECT OF MY BRAIN INJURY

As anyone directly affected by brain injury will tell you, it's not just the individual that is impacted. Relationships can be changed in an instant, with a ripple effect of brain injury changing the lives and futures of partners, family members and friends.

Like many others, **Shona Green's** life was turned upside down after sustaining a brain injury, completely altering the way she saw herself and all of her relationships.

Here, Shona tells her story and gives her backing to Headway's forthcoming campaign **You, me, and brain injury**, which will be launched during Action for Brain Injury Week in May.

"My personality has changed massively. I used to be an outgoing party-lover who loved to go out. But now I don't like crowds at all and I often feel withdrawn or anxious," said Shona.

"The impact my brain injury had on all my relationships was massive and

without doubt I did see a ripple effect – with each person affected in some way."

In October 2015, Shona began feeling a throbbing in the back of her head and started suffering from severe headaches.

"I went to my GP every week and complained that the situation felt like it was getting worse," she recalls. "But each time I was told it was most likely a muscular problem and was prescribed ibuprofen and muscle gels.

"The situation came to a head six weeks later while I was working as a nurse at Victoria Hospital in Fife.

"I was on the ward so was able to check my blood pressure. It was really

high and my headache so incredibly painful.

"It felt like my head was crushing but at the same time like it was going to explode."

Her husband Kevin took her home and she was given an emergency GP appointment and then referred to Western General Hospital for a CT scan.



Shona has always been very active

*“Attending Headway
changed my life.”*



You, me and brain injury

ACTION FOR

BRAIN INJURY WEEK 2018

This year's Action for Brain Injury Week theme will build on the huge success of last year's *A New Me* campaign by once again putting people directly affected by brain injury at the heart of our awareness-raising work.

The aim of *You, me, and brain injury* is to highlight the fact that brain injury doesn't just affect the individual, but also their family, friends, colleagues, and many more relationships besides.

We will be highlighting the ripple effect brain injury can have on many different lives, in many different ways, while demonstrating the various ways in which people can help the person with the brain injury to adapt and regain a degree of confidence and independence.

Keep checking our website at www.headway.org.uk or sign-up to our monthly e-bulletin, Headway News – Bitesize, to make sure you don't miss any news about the forthcoming campaign!



24 Headway News

24 HOURS TO LIVE

The CT scan revealed a bulging aneurysm and Shona was rushed into emergency surgery.

She said: "It was the most terrifying moment of my life. The surgeon later told my husband if I had not been operated on there and then I would have been dead within 24 hours.

"The delicate surgery involved inserting a coil to seal the aneurysm.

"Before I went under the knife, I was advised that I should make the time to say what could have been a final goodbye to my three children, grandchildren and husband."

Thankfully, the surgery went well but Shona was left with numerous cognitive, emotional, and physical effects of brain injury, including fatigue. She also lost some of her long-term memory, including memories of her children growing up.

Shona also had to work through feelings of anger and resentment towards her GP, who she believes should not have dismissed her repeated concerns.

'My children said I'd changed'

Shona said not only had her brain injury completely altered her lifestyle, it also changed how she saw herself and all of her relationships.

Initially Shona and Kevin struggled to come to terms with the impact of the brain injury and the way it changed their relationship.

She said: "I really looked for Kevin to support me through everything and I wanted him around me all the time. I also would tell him how I was feeling a lot, so he could try and understand what was going through my head.

"This was really hard for him and put him under a lot of pressure."

Shona said other family members were affected too.

She said: "All my children have said that I have changed – and that can be hard to hear.

"Due to my fatigue, I can't be as involved with my grandchildren's lives as I would like. If I do want to see them, then I have to carefully plan the day.

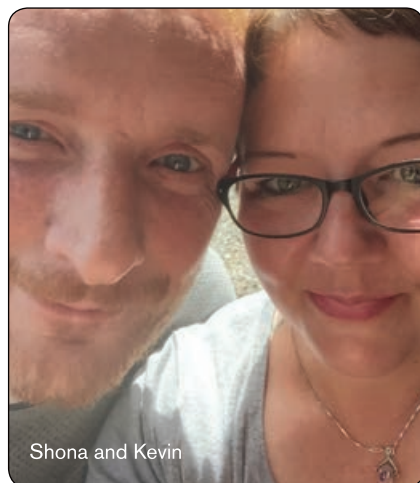
"This limitation does upset me sometimes."

The couple's fortunes changed when they began attending Headway Fife.

Shona said: "Kevin felt at a loss for what to do and was struggling to understand how to support me.

"Someone told him about Headway Fife and he eventually persuaded me to attend.

"Initially I was a bit sceptical and felt that it would leave me feeling stigmatised. But it was the total opposite, it changed my life. Being around people who understood my problems was a weight off my shoulders.



Shona and Kevin

"Kevin said he knew going to Headway was the right decision within five minutes of being there. Apparently he saw a happy expression on my face he hadn't seen for months."

Shona, with the help of Headway and her employers, has recovered to a level that has enabled her to return to work on a part-time basis.

She said: "I wanted to prove to myself that I could still do my job. My passion is caring for others and I was determined to get back to it. It's a big part of who I am.

"Since my brain injury, some friends have drifted away but others have become incredibly close."

"All of my relationships do take a lot of work to maintain but I know I'm very lucky to be here and I'm really trying to treasure every day and enjoy what I have.

"One thing I have learned is that it's not just the brain injury survivor that needs help to understand the changes that have occurred. My brain injury has affected so many lives, and my husband, children, grandchildren, friends and colleagues have all had to adapt.

"That's why I'm giving my backing to Headway's new *You, me, and brain injury* campaign, which I think is a brilliant idea.

"I know that the understanding of those closest to me has been so helpful in getting my life back on track, and anything that can help other families cope with brain injury has to be a good thing."



Shona is gradually regaining her social confidence

How brain injury affects relationships

Relationships are a very important and intimate part of life. They give us a sense of security and wellbeing, and contribute towards our sense of self-identity.

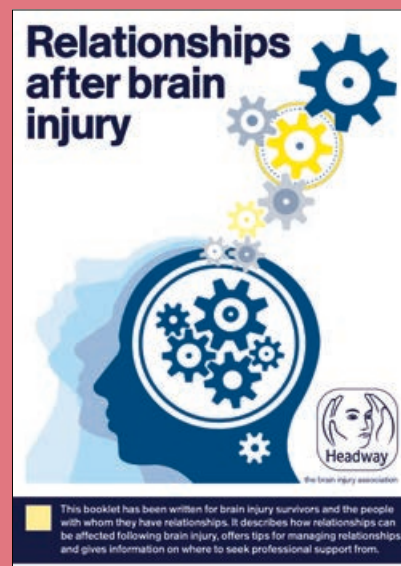
It is often our closest relationships that provide the vital emotional and practical support needed when hardships are faced, such as when a brain injury occurs.

For some people, the emotional, behavioural, physical and cognitive changes after brain injury can have

an impact on existing and future relationships.

There are a number of ways in which this can happen and a number of different outcomes. Some relationships may strengthen, whereas others may become strained over time or even completely break down.

For more information, download the Headway booklet *Relationships after brain injury* from www.headway.org.uk/information-library, where you'll also find a range of factsheets on specific relationships.



Not all law firms are the same



"You do great things and provide a fantastic service in terms of support and advice.

*You make a difference to peoples' lives and are very good at your job.
We thank you for everything."*

Anne Cahill

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The advertisement features a close-up photograph of an elderly woman with short white hair, wearing large, dark-rimmed sunglasses and a patterned brown jacket. She is looking slightly to the side with a thoughtful expression. The background is softly blurred, showing what appears to be a home interior with a lamp and some furniture. The text is overlaid on the right side of the image, with the agency name and phone number in large, bold, white letters. A pink banner at the bottom contains the tagline in white script.

#HeadwayHeroes

5K EVERY DAY!

Marc pauses to snap the beautiful snowy backdrop of his daily run



colleagues by posting regular updates on Facebook, LinkedIn and on his JustGiving page. The effort paid off as he more than doubled his original fundraising target of £500 by raising a fantastic £1,424 for Headway.

Marc's advice to anyone thinking of taking on a challenge? Don't spend too long mulling it over.

In December, when the weather is typically dark and dreary, most of us would look for an excuse to stay indoors and hibernate.

However, Marc Raybould had other ideas!

Braving the bitter chill and winds of winter, the intrepid fundraiser launched a series of outdoor physical challenges, which he aptly-named 'The Marcathon'.

His motivation was his friend, David, who underwent multiple operations to relieve the symptoms of a stage four cancer that had spread to his brain. Headway helped Marc and David's family and friends to understand his condition and its effects.

Sharing their experiences with other brain injury survivors also helped them to 'put things into perspective' and inspired Marc to raise money for Headway in order to ensure others are

able to receive the same help in the future.

So began 'The Marcathon', which involved running 5km every day during December – including Christmas Day!

"I ran every day in December and for once it actually snowed, which made it a bit trickier than usual!" said Marc.

"Normally it's just dismal and wet. The snow was fun though as it made early mornings quiet and peaceful."

Marc did the majority of his fundraising online and drummed up incredible support from friends, family and

"My biggest tip is, don't think about it, do it," he said. "Friends, family and colleagues are so supportive and we spend so much time thinking about ourselves in our own little worlds, it's good to step outside and do something for others."

GET INVOLVED

Planning on organising your own fundraising event? Our fundraising team would love to hear from you. You can get in touch by phone on 0115 924 0800 or email projects@headway.org.uk.

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

#HeadwayHeroes

Baton holders WE SALUTE YOU!

'Are you up for a challenge?' we queried. 'Do you fancy having some fundraising fun?' we asked. Well, the three firms that took on Headway Challenge Batons in 2017 answered both questions with a resounding YES!

Between them, EMG Solicitors, Burcher Jennings and Voyage Care danced, climbed and raced their way to raise an incredible amount to help support people living with consequences of brain injury. And they all had plenty of fun along the way!



Burcher Jennings



Staff from legal pricing and costs consultancy, Burcher Jennings, raised nearly £25,000.

Its staff put their fear of heights to the back of their minds to take part in the O2 Arena climb, held 'An Audience with...' dinner event with football chairman Peter Risdale, and one colleague, Claire Borradaile, even took on the gruelling London Marathon.

Victoria Morrison-Hughes, a costs consultant at the firm, said: "We were inspired to become baton holders after hearing inspirational speaker Kate Allatt talk about her stroke at a Headway event.

"It brought home to us how brain injury can happen to anyone at anytime. It's easy to see how Headway and its campaigns could have a relevant impact on the majority of us."

"It has been a wonderful year raising money for Headway and I'm so proud of everyone who has taken part in the fundraising events to raise the money which will undoubtedly help so many people coming to terms with brain injury."

EMG Solicitors



Durham-based firm EMG Solicitors got its fundraising off to a flying start with an office launch party in January.

They then took part in Headway's Pancake Party Day, where staff all donated to compete in the 'biggest pancake tosser' competition.

Staff members also competed in a River Rat Race in August, which saw them swim, crawl, climb, jump, splash and run their way around an urban obstacle course.

One of the highlights of the year for the firm was the glamorous Moulin Rouge-themed WonderLAN Ball, which helped the firm raise a brilliant £16,500 in total for the year.

Emma Gaudern, Managing Director at EMG Solicitors, said: "We really enjoyed being Baton Holders for Headway in 2017.

"Although it was hard work, we found that undertaking events for such a great cause brought the team together and we had some great team-building opportunities!

"From a quiz night, to a river rat race and a ball, we tried a variety of fundraising methods and thoroughly enjoyed ourselves in the process."

Voyage Care



Voyage Care enjoyed the year of fundraising so much it will be continuing as a Baton Holder to mark the firm's 30th birthday in 2018!

Staff from the firm, which provides specialist care to adults with brain injury, held cake sales, wore their Hats for Headway and ate plenty of mince pies!

One colleague took on the London Marathon, raising nearly £2,000, while teams from the firm's homes across the UK have even climbed mountains – with some of their clients joining in with their challenges.

The highlight of the year – although perhaps not for those taking part! – was seeing the senior management team take part in an 'I'm a Celebrity' Bush Tucker Trial.

The grim challenge involved a mouth-watering menu that included crickets, leafcutter ants, and silkworm pupae! Tasty.

After raising £12,000 last year, we are looking forward to hearing how they are progressing in achieving their £30,000 target as 2018 unfolds.

'A MASSIVE thank you'

Jo Plant, Director of Fundraising at Headway, said: "On behalf of the charity, I would like to say a massive thank you to everyone at Burcher Jennings, EMG Solicitors, and Voyage Care.

"We loved hearing about all the fun ways in which staff at the three firms raised vital funds for us.

"The money generated will ensure brain injury survivors and their families can access crucial support from the charity."

If you are interested in adopting Headway as your Charity of the Year, please contact partnerships@headway.org.uk.



#HeadwayHeroes

Over to the class of 2018...

Mark Stimpson and Simon Armstrong from Saltus Private Wealth Management accept their Challenge Baton from Headway Ambassador Marc Almond



Plans to abseil, hike and laugh, all while raising funds for Headway are in the pipeline for three companies in 2018.

Voyage Care, Saltus Private Wealth Management and Home Care Preferred are set for 12 months of fun after taking up the Headway Challenge Baton this year.

Saltus Private Wealth Management's Michael Stimpson will be donning his running shoes in April to tackle the famous London Marathon, while his colleagues will also get their pulses racing as they take part in a sponsored seven-hour hike up the Lake District's Scarfell Pike.

Not to be outdone, colleagues will also raise money for Headway by taking part in a daring group parachute jump.

Simon Armstrong, Managing Partner at Saltus, said: "We were so inspired by Headway and the work they do that we decided they should be our UK charity of the year for 2018."

The team at Home Care Preferred, which provides services to help people who are recuperating after a brain injury, are hoping for lots of laughs when they kick off their baton challenge year with a special comedy night.

They will also take part in a sponsored walk and an abseil event.

Ken Waterhouse, Managing Director at Home Care Preferred, said: "During our work we see first-hand how Headway changes the lives of people living with brain injury.

"We are all very excited about providing support to them during our baton year and beyond."

Provider of specialist care and support Voyage Care has taken up the Headway Challenge Baton for the second year running.

As this year marks Voyage Care's 30th birthday, the firm is aiming to more than double its previous total and raise an amazing £30,000.

Since 2002, Voyage Care has grown its specialist acquired brain injury provision to 17 services across the UK and has been a member of Headway's Approved Provider Scheme since 2006.

Voyage Care's ABI specialist Dave Barlow, who developed the partnership with Headway, said: "We are delighted to take up Headway's Challenge Baton for another year.

"Headway is a perfect fit for us as we support many people with brain injuries at our specialist services and know the real difference the charity makes."

Jo Plant, Director of Fundraising, said: "We are delighted that Voyage Care, Saltus Private Wealth Management and Home Care Preferred have signed up to take the baton challenge this year.

"I'm quite sure they'll smash their targets and we can't wait to hear how they're getting on."



Headway's Anna Kerr (left) with Ken Waterhouse and Farah Abdollahzadehnami from Home Care Preferred

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



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

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Craven House, 40-44 Uxbridge Road, Ealing, London, W5 2BS

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