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Summer 2017

Headway News



The magazine of Headway - the brain injury association

*What not to say
to someone with
a brain injury*

**The art of
expression**

A new
me

**Results of
A New Me
study revealed**

ACTION FOR BRAIN INJURY WEEK 2017

Fabulous fundraisers

At Headway, we love all our amazing fundraisers! Whether running a marathon or baking some cakes, we thank you all!



Suited and booted, Tom Batting and friends took on a Tough Mudder in style!



Dan Oscroft and friends completed the Three Peaks Challenge, raising more than £7,000



Joe Astbury and Ed Walker cycled from Liverpool to Chester-le-Street, County Durham



Mick Smith chose the iconic Lands End to John O'Groats route for his challenge of a lifetime



Lenny Martin (left) ran from London all the way to Brighton - an incredible 100km!



Warmer climes were preferred by Ross Dennison, who braved the heat of Borneo to run his marathon

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

Bad memory? You have no idea!

'I know what you mean...I've got a terribly memory too!' Just one of the phrases that brain injury survivors often hear when they attempt to explain the realities of living with a brain injury.

Sometimes these statements might be well meaning, if misguided. The intention behind saying something like 'Chin up - there's always someone worse off' may be to encourage someone to adopt a positive attitude to life, but it's hardly likely to win an award for Motivational Speech of the Year.

Furthermore, it highlights a lack of understanding among the general public about brain injury and the extent to which it can impact lives.

Filming the reactions of brain injury survivors to our top ten list of things not to say to someone with a brain injury was fascinating. There was immediate recognition of the sayings, which were greeted with a mix of frustration, anger, and humour.

There were also glimpses of empathy as some people accepted the challenges of trying to understand brain injury without having experienced it. A fair point indeed.

But in just under three minutes, our brilliant bunch of volunteers managed to say so much to help us bust the myths and misunderstandings that surround brain injury.

Our light-hearted short film, which was seen by more than 25,000 people on the first day it was published, was the perfect way to launch Action for Brain Injury Week.

A New Me can mean so much, in so many different ways, to so many people. This edition of Headway News is dedicated to the inspiring personal testimonies, incredible creative expressions, and passionate campaigning that helped us make this year's ABI Week campaign such a success.

Our thanks to everyone who took part - with a particular mention for the team at Headway Nottingham, which made such a valuable contribution to our film.

We'll leave the final word to Jeannette Worthington, who when asked to respond to the saying 'You should be back to normal by now...' said: 'I don't think I'd want to be 'normal' anymore...cos that were boring!'

The Communications Team

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www.headway.org.uk/donate

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The magazine of Headway - the brain injury association

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Your views...

In order to raise awareness of the misconceptions many people have about brain injury, we issued a list (and film!) of the top ten things not to say to someone with a brain injury. Here's how some of our supporters reacted to the list, which you can read in full on pages 18 and 19:

I had someone say to me the other day "But you look normal." So annoying!

Shona Stewart

I think all of us with a brain injury have developed the patient smile and nod when someone says these things to you. Missing your old brain function is the worst!

Amanda Wannell

All the time this is said ("You don't look disabled"). Well what are you supposed to look like?!

Susan Kyle

Apparently I don't look a) partially sighted, or b) brain damaged. We must have a specific 'look'!

Nicola Brown

I can so relate to all of these comments; I have heard them countless times but that is other people's ignorance, which is why we need to raise awareness.

Ellen Yates

I think most of us would of heard these comments. It is frustrating; quite often it's folks wanting to see the best - or they're in denial - about what has happened!

Roger Merriman

"I have a terrible memory too!" Or "It's an age thing." I just love those...

Gill Johnson

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#HeadwayHeroes

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0808 800 22 44

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news you may have missed...

Charity support for ‘long-overdue’ insurance change

Headway has welcomed a change to the discount rate used in calculating compensation payments in personal injury and fatal accident claims.

The rate, which is designed to discount a lump sum for future losses on the assumption that the money can be invested and earn interest for the future, was cut in March from 2.5% to -0.75%.

Peter McCabe, Chief Executive of Headway, said: “This change is long overdue.

“The previous rate was set in 2001 against the backdrop of an entirely different economic environment.

“We have to ensure that the most seriously injured members of society, whose lives are forever changed due to no fault of their own, are fairly compensated for their losses and able to access appropriate levels of support throughout their lives.”

Top tips...

Headway has issued the latest in its series of top tips for brain injury survivors, this time to provide ideas for designing home activity programmes to aid rehabilitation.

Often, there are times between periods of rehabilitation, or when formal hospital rehabilitation has

ceased, when someone who has a brain injury is at home for long periods of time.

If this time is used effectively, it can help towards continuing the process of recovery.

The eight top tips, aimed primarily at carers and family members of people with brain injury, can be accessed on the News section of the Headway website.

New depression factsheet launched

A new factsheet has been produced to support brain injury survivors experiencing depression.



Depression is a common psychological effect of brain injury, affecting almost half of all brain injury survivors in the first year of their injury. It can leave people with a profound sense of sadness, as well as changing sleeping and eating habits.

Participation in rehabilitation and social activities can be affected by depression, while relationships can also be negatively impacted.

Headway's new publication offers information on what depression is, tips on how to cope with it, and guidance on the professional help available. The factsheet has been guided by brain injury survivors and co-written with the support of two clinical psychologists with an expertise in brain injury.

To download the factsheet, visit www.headway.org.uk/information-library.

PIP REVIEW ‘another missed opportunity’

Headway has labelled the second independent review into the Personal Independence Payment (PIP) assessment ‘another missed opportunity’ after it failed to back calls for specialist assessors to be

used where a claimant has a complex condition such as an acquired brain injury.

Peter McCabe, Chief Executive of Headway, said: “While we welcome and support some of the recommendations in the review, we are disappointed at yet another missed

opportunity to ensure that brain injury survivors have access to the specialist medical assessors who understand the complex and often hidden nature of their injuries.”

You can read Headway's consultation response in full on the charity's website.

TIME TO NOMINATE YOUR #HEADWAYHERO!

It's time to tell us who you think is deserving of a Headway Annual Award.

Do you know someone who has defied their brain injury to achieve a great milestone this year? Or perhaps you know someone that often goes above and beyond when caring for someone with a brain injury? Or maybe you know of a long-standing Headway volunteer who is overdue public recognition and thanks?

The Headway Annual Awards celebrate the inspirational achievements of people living with brain injury and the dedication of those working to support them.

Each finalist, chosen by a selection panel, will be invited along with a guest to a glittering luncheon at The Dorchester Hotel in London on Friday 8 December.

The categories this year are:

- Carer of the Year, sponsored by SweetTree Home Care Services
- The Alex Richardson Achiever of the Year, sponsored by Slater & Gordon Lawyers
- Volunteer of the Year, sponsored by Anthony Gold
- The Stephen McAleese Outstanding Contribution to Headway Award sponsored by No5 Barristers Chambers

Visit www.headway.org.uk/nominate to complete an online application form, and to see a film of last year's fabulous celebration. Alternatively, you can call 0115 924 0800 to request a paper copy of the nomination form.

The closing date for applications is Friday 28 July. Good luck!

Jane Reams can't hide her delight after accepting the Stephen McAleese Outstanding Achievement to Headway Award



In loving memory

'Hearing others' tales and memories of Alex helped us to know more about our son through their eyes. Those messages mean as much to us today as they did when we first read them.'

At Headway, our aim is to improve life after brain injury. Sadly, for many people this isn't possible. Each year, around 80,000 people die in the UK as a result of a head injury, stroke, brain tumour or neurological illness.

Everyone copes with the loss of a loved one in their own way. For many, learning more about their loved one and how they

were regarded by others is an important part of both the grieving process and the celebration of the life they lived.

Others feel that taking positive action by either fundraising or donating to a meaningful cause in memory of the person they've lost can bring some comfort.

To support those who have lost loved ones to brain injury, Headway has launched a new website called *In Memory*.

The site provides families and friends with a private and secure online platform with which to share their memories and support one another in their grieving. It also makes it easy for people to set up fundraising events in memory.

All donations made via the tribute page or associated events pages will directly support our work across the UK – including our support of local Headway groups and branches, and other frontline projects such as the helpline, Emergency Fund, and HATS nurses.

Personalised and private tribute pages can be established, to which photos and videos can be uploaded, while family and friends can post their memories and messages of support.

'Messages of support still mean the world to us'

In 2009, Chris and Annie Richardson received the call all parents dread. Their son, Alex, had suffered a fall while at university – hundreds of miles from the family home.

Tragically, Alex sustained a brain injury that cost him his life two days later.

"Alex was very much loved and is greatly missed by all of his family and friends," said Annie. "His sudden death has left a huge hole in many lives.

"In the weeks and months that followed Alex's death, we were inundated with messages of support and love. Some of the most moving and memorable messages, that have come to mean the world to us, were from his friends who were willing to share with us stories about Alex's life away from his family.

"To us, Alex was a loving son. But to others, he was a friend; a teammate; a confidante. Hearing others' tales and memories of Alex helped us to know more about our son through their eyes. Those messages mean as much to us today as they did when we first read them.

"The Headway In Memory resource wasn't available when Alex died. If it had been, we are sure we would have benefited greatly from using it.

"It would have made it easier for people to share their memories of

Alex and leave a lasting tribute, whilst helping us to raise funds in his name to help others.

"After Alex died we became aware that he had been raising money for Headway and we wanted to carry on with this support of the charity. It is what he would have wished.

"In the years since Alex's death, raising funds in his memory and knowing that we are able to help the many brain injury survivors and their families that Headway supports has brought some comfort to us, his family and many friends.

"Our support continues to this day and ensures his light and memory remains bright in our lives."



About the Headway In Memory website

What is a tribute page?

Individual tribute pages, which are simple to set up, are private and secure online spaces for people to share memories and provide mutual support. The person setting up the personalised tribute page has full control over the content posted, and whether it is publically accessible for anyone to contribute to, or private so that only those with whom you share the unique page link can find it.

Is this a free service?

Yes, this is a free resource provided by Headway to those who have lost loved

ones to acquired brain injury. For those that wish to support the charity's work to improve life after brain injury, there are plenty of ways people can donate or support an event in memory of their loved one.

Will we get a running total of how much is raised in our loved one's name?

All donations made through the individual's tribute page or associated event pages will be collated and added to a running total. In addition, fundraising pages set up for Headway through JustGiving and Virgin Money Giving can also be linked to individual tribute pages and money raised through these sites will also be reflected in the tribute total.

What if I don't want to show how much money has been raised?

That's absolutely fine – you are in complete control of your tribute page. It is entirely your decision about whether or not to use this resource to raise money in your loved one's name, or purely use it as a way to share memories with friends and family.

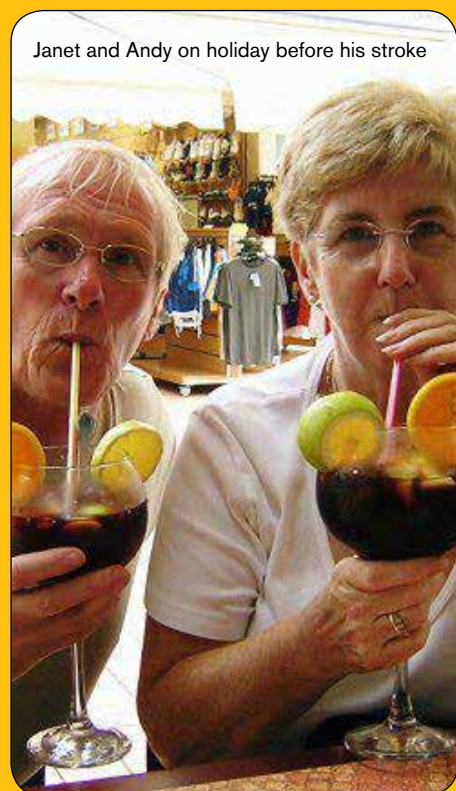
For more information or to set up a tribute page, visit www.headwayinmemory.org.uk.



A DAY IN THE life OF A CARER

Brain injuries can change many lives in an instant, often irreversibly altering family and relationship dynamics. Caring for someone with a brain injury can often be a lonely and frustrating experience, particularly if you do not have support networks in place.

To mark Carers Week (12-18 June), here we share a day in the life of a carer – with full recognition of the differing experiences of carers across the UK.



Janet and Andy on holiday before his stroke

When former fireman Andy Malcolm had a stroke in 2014, his life and the life of his wife Janet were changed forever.

After 49 years of marriage, Janet was suddenly no longer just Andy's wife, but also his full time carer.

Andy was left with paralysis of his left side and aphasia, which continues to make communication between the couple a challenge.

The couple attend Edinburgh Headway where they meet other carers, allowing Janet to benefit from friendships and mutual support, which goes some way to tackling the isolation carers often feel.

In 2016, Janet was a finalist in the Carer of the Year category of the Headway Annual Awards.

8am

I get myself and Andy up and ready. He has refused to get out of bed a couple of times recently, so today I'm pleased. He goes for his shower, holds out the shampoo bottle and I have to go and squeeze it for him because he forgets how to. He dries himself then I dry his back because he forgets to do that too. I dress him but he can do his own hair and clean his teeth.

10am

Andy has been poorly for the past fortnight and in that time I haven't spoken to a single soul. He doesn't have much speech so I feel very isolated. Before, I had the freedom

to put on a coat and go anywhere. But when you're a carer you've got somebody to look after, you don't have the freedom to have a life of your own. You don't have anyone to talk to because you don't go out of the house and see anybody. You go shopping and hold up the queue speaking to the person at the till just to have someone to talk to.

11.30am

Andy and I go out for a walk; he uses his mobility scooter. It took me three months to teach him to use it but now he can go out on it alone. I don't have to run after him to teach him how to cross the road anymore. He needs to be independent, but it's very difficult to allow him to make mistakes. I'm not happy about it but if something happens, it happens. In a way, it's like having a child again.

12pm

I've messaged my friend asking if she would like to go for coffee next week. Last time we arranged to meet we were getting ready and Andy decided he wasn't going. This happens all the time, but he won't tell me why. Sometimes our friends are sitting in the restaurant waiting. The more it happens, the less people invite us. We're at the stage now where people don't invite us.

2pm

Andy used to be a very active person and over the past three years I've tried to get him involved in lots of activities

that have all failed miserably. But at long last, he's started bowls! He was invited to join a bowls group with other disabled people and he's been going to indoor lessons over winter. It's not on the doorstep but I don't care! His coach just called to say he thinks Andy can hold his own with others. There's another chap in the same position as Andy and he's going to go with him. It's taken months to get to this stage but if you keep working at it and talking to people you find ways.

5pm

We go to the Edinburgh Headway supper club, which is held once a month. I didn't used to go to any clubs; I'm not one to join in. But I felt so isolated, so at sea, I didn't know where to turn. Getting it out of your system is the best thing. If you meet up with ordinary friends they say 'I feel so sorry for you'. That's not what you want; you want friends to support you and come up with ideas and make your life and your husband's life as good as possible. You learn things from other carers about how they cope. That's what I get at Headway.

9pm

Tomorrow we'll be going to the cinema with some friends so I call them to make arrangements. Every week there's a senior screen for pensioners. We go on the bus instead of driving because there may come a day when I can't drive so Andy needs to be used to travelling on the bus. We aim to arrive at about



Janet Malcolm receiving her Carer of the Year finalist award at Headway's Annual Awards 2016

10.15am and have a cup of tea and biscuits. I used to go before Andy's brain injury but now he comes with me and it's great. Everybody is so friendly, they always come up to say hello.

10pm

Once I have helped Andy get into bed, I go downstairs and use the last hour of the day to relax and recharge my batteries. I do this by watching some television or playing a game on my laptop. If I don't take this time for myself, I find I cannot get to sleep and thoughts just race through my mind. Once I feel relaxed enough, I go to bed, ready to start all over again.

If you are caring for someone with a brain injury and would like support, visit the carers section of the Headway website or contact the helpline on 0808 800 2244 or helpline@headway.org.uk.

‘MY SON LIVES ON through his gift to Headway’



Daniel Lingard was knocked down by a car when he was just nine years old while he was trying to cross the road near his home. He was left with a traumatic brain injury and spent most of his life battling epilepsy.

Although the fits were frequently severe, Daniel was resolute in his determination to never let them stop him doing what he wanted, when he wanted. He lived life to the full but was equally determined to help other brain injury survivors less fortunate than himself.

It was for this reason that Daniel chose to leave a gift to Headway in his will and, when he sadly passed away in July 2015 at the age of 36 while on holiday in Naples, Italy, Daniel left a lasting legacy to the charity and those it supports.

While devastated by his loss, his family has taken comfort in the fact that his gift will ensure more brain injury survivors and their families can access crucial support from the charity.

Daniel's mother Ruth said she wasn't surprised that he donated his legacy to the charity. She said: "Daniel was very positive about Headway and how it helped people like him.

"He said that money doesn't bring happiness, and he would rather do something good with it; that's why he gave it to Headway, so it could really help people.

"It's right and reassuring that his wishes were fulfilled. He would be happy to know that he lives on through the support that Headway will provide to people thanks to his legacy. I'm sure of that.

"Although he lived with severe epilepsy, he didn't let it diminish his aspirations. As he got older and became more independent, he moved into his first house in Sandbach, Cheshire.

"He became interested in computers, and enjoyed building websites, downloading music and watching movies. In his twenties, he moved into a flat in Manchester and enjoyed an active social

life living in the centre of a big city.

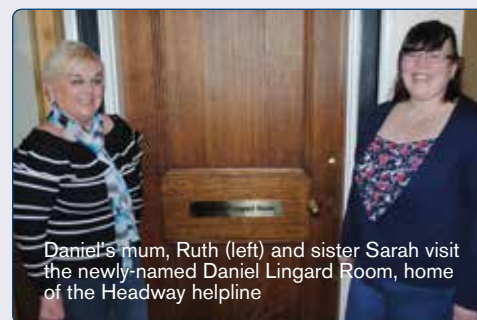
"He enjoyed going to Irish pubs and socialising with his friends. He had a fantastic sense of humour; in fact I think he should have been on stage!"

Throughout his adult life Daniel had a real passion for travel and would frequently embark on trips across the globe.

Ruth added: "He went all over the world and was always jetting off somewhere exotic or exciting.

"I remember him going to New York for five days, but instead of coming home when the trip was supposed to be finished, he ended up getting a job and stayed there for three months.

"But that is the way he was, he used to say 'Mum, I'm not letting the epilepsy control my life, if I do, I will never go anywhere'."



Daniel's mum, Ruth (left) and sister Sarah visit the newly-named Daniel Lingard Room, home of the Headway helpline

During the last few years of his life, his seizures became more frequent and aggressive in their nature. This took its toll on Daniel and meant he needed more time to recover.

"In my opinion, he was brave and very courageous," said Ruth. "It couldn't have been easy for him and I know on many of his holidays he would have seizures. But he would simply rest, recover, and then carry on.

"Losing Daniel has been really hard on all his family. But I will always remember him as a caring and kind person.

"His final gesture, to give his money to Headway, just shows that to be the case. I know that, like me, his father Ken is so proud of him. It was an honour to be his parents – we will miss him so much."

In memory of Daniel, Headway has named the helpline room after him.

Ruth said: "Seeing the helpline room named after Daniel has to be the proudest moment of my life. I never imagined his gift would be able to help so many people who have sustained a brain injury as well as their families.

"He was a truly amazing son, and to know he will be remembered in this way, well, I couldn't imagine anything better."

Leaving a gift to Headway

By leaving a gift in your Will – no matter how large or small – you can leave a lasting legacy by supporting our work to improve life after brain injury.

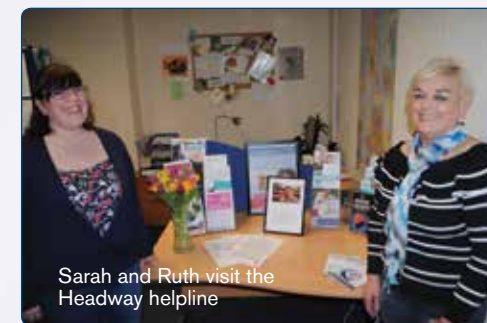
Whether a set sum, or a percentage of your residuary estate, your gift will help us to continue to provide services – such as the helpline, our HATS nurse project, or our Emergency Fund – for the increasing number of people affected by brain injury in the UK.

When the time is right for you to draft your will, and after you have taken care of family and friends, please consider Headway.

Leaving a gift in your will is easy. Simply give your solicitor our charity name and number: Headway – the brain injury association, registered charity number 1025852 (England and Wales) and SC039992 (Scotland).

Naturally, you may choose to support your local group or branch. If so, please ensure you provide the correct charity name and number.

For more help and information, including a free will planner and access to a will writing service through our Friends of Headway membership scheme, please contact Lisa Thompson on 0115 924 0800, email legacy@headway.org.uk or visit www.headway.org.uk.



Sarah and Ruth visit the Headway helpline

A new me

“I have changed. It did not matter if I wanted to, it happened. I had to start again and did. So I have a new me, a new life and I intend to live it as best I can.”

A new me. A new life. A new beginning. We have always known that brain injury can mean having to let go of the life you once led and the person you once were, but the extent to which it can change a person's very essence of self has been highlighted by the findings of our *A New Me* study.

A total of 862 people completed the survey, making this one of the best-supported studies undertaken by the charity, with three quarters of respondents stating they feel like a new person after sustaining their injury.

“We have always known that brain injury can affect personalities as well

as a person's cognitive and physical abilities,” said Peter McCabe, Chief Executive of Headway.

“People often associate brain injury with impacting cognitive or physical skills, such as memory, speech, or movement. But changes to personality and behaviour can have a dramatic impact on relationships and a person's ability to play an active role in their communities.

“What is clear, however, is that everyone's experience and feelings about brain injury is unique to themselves.”

‘An opportunity for a life review’

The first few months following Darren Wyn Jones' brain haemorrhage

included some very dark and challenging moments. His marriage broke down, he had to relinquish many aspects of the job he loved and was even forced to sell his home.

But now, just 15 months later, he feels remarkably upbeat about his future.

He said: “I have been blessed with an opportunity to ‘start over again’. To me, I genuinely feel the ‘new me’ is a reincarnation of the real me. I do feel like a new person.

“I feel a lot less stressed than ever before, and feel the injury has given me an opportunity for a life review.

“I take much better care of myself and I've slowed down my pace. I'm much more compassionate towards myself and I reflect on what's meaningful to me now.

“My brother thinks that my brain has re-wired itself differently, in a positive way, whereby I have developed more patience, more confidence and even more intelligence!”

‘One big, sick joke’

While some, like Darren, feel positive about their futures, many others understandably have entirely negative feelings about their brain injury. Indeed, 76% of respondents said that brain injury has had a negative impact on their life.

“I cry for the woman that I was, the children that I haven't been able to have and the loss of my career,” stated one respondent. “It's like one big, sick joke that isn't funny.”

Another said: “I'm grateful that I survived but I also mourn the loss of the person I was before it happened as I was at the best I'd ever been and that was taken away from me by my brain haemorrhage.”

The brain injured family

While the study only asked for brain injury survivors' views on the concept of ‘a new me’, many partners or family members have chosen to share their experiences of brain injury as part of the campaign.

“It's important to recognise that ‘a new me’ can refer to the husbands, wives, and children of those who sustain a brain injury,” said Peter.

“We often hear people tell us that their husband or wife is not the person they married, or that the person they knew didn't really return from the hospital.

“We hope that through the *A New Me* campaign, we can give a voice to those affected by brain injury in order to raise awareness of this often hidden and misunderstood disability and ensure no one suffers in silence.”

Lorraine Pratt's life was changed in an instant when she became a carer for her

husband Kevin after he contracted the neurological illness encephalitis in 2003.

Before his brain injury, Kevin was a confident, family-oriented sportsman. But after he contracted viral encephalitis he could no longer walk or talk.

Lorraine said: “I've had to learn to love a different man. There's an awful lot of Kevin still there but there are big chunks missing.

“He knows things aren't the same. But he also knows he's got me and he's got the children, so he knows he's very much loved and supported within the family unit and I think that's important.

“He had terrible depression in the beginning and very dark moods. It's changed him, it's changed me and it's changed us as a family unit. I'm mellow. I've had to be mum, dad, counsellor and stand up for Kevin, having to put myself and my needs to one side.

“It's not easy and it's not necessarily the life I would have chosen but I have Kevin in my life and that's what I want.”



“I've had to learn to love a different man.”

- Lorraine Pratt

A new me

Headway

ACTION FOR BRAIN INJURY WEEK 2017

“To me, I genuinely feel the ‘New Me’ is a reincarnation of the real me. I do feel like a new person.”

- Darren Wyn Jones

A new me

Headway

ACTION FOR BRAIN INJURY WEEK 2017

A New Me: Experiences of life after brain injury

Key findings:

74% of brain injury survivors feel like ‘a new person’ following their injury.

77% of brain injury survivors feel friends and family do not understand the effects of their injury.

56% of respondents reported their brain injury had negatively impacted their family life.

74% of people felt their social life was worse – with 60% of people feeling that their friends did not understand their injury.

69% of people felt their self esteem was worse.

62% of respondents acknowledge the anniversary of their injury; of those who positively commented on their anniversary, 1 in 10 explicitly mentioned acknowledging it as a new birthday.

A new me The ART of expression

Get creative! That was the request made to everyone directly affected by brain injury as we encouraged people to prepare creative expressions of what 'a new me' means to them.

We have been inundated with an incredible array of poems, photos, paintings, short films, podcasts, and letters. Not only that, but Headway groups and branches have been showcasing the creations in local exhibitions in order to increase the public's understanding of brain injury.

Our heartfelt thanks to all those who sent us their creative expression of 'a new me'. Here are just a few examples of the fabulous creations we received, whilst you can view the gallery at www.ANewMe.org.uk



'I see Headway as the pit stop', Matt Johns, Headway Portsmouth

"My creative piece is about me and a friend of mine. I picture us in two Formula One racing cars burning down the race track.

"We are racing at a similar speed until I am diagnosed with my first tumour, which sends my car out of control and smashes into a wall while his car carries on going. My friend's car is now way ahead of me; he has probably lapped my car a fair few times.

"That is how I see my life. It feels to me

like the first operations I had put my life on hold or it is going by very slowly while his life and other people's lives are way ahead of mine. I feel my friend has achieved much more than I have.

"I see Headway as the pit stop and they are rebuilding my car and adding aerodynamics to make me possibly catch up to my friend's car. I may not have done most of the things my friend has done but with the help of Headway I am leading my life, or F1 car, in a slightly different direction."

'A letter to my EX', Keeva Mullen, Headway Foyle

In September 2015, Keeva was struck by a hit-and-run driver after leaving a friend's house. She was left with a brain injury and is now being supported by Headway as she looks to rebuild her life.

As part of her recovery, Keeva wrote a letter to her former self. Here is an extract:

I hope you are well. People still ask about you after all these years. I tell them you are doing okay, that you have moved on in your life. Then I steer the conversation away from you so that the wound stays closed.

I used to think about you every day. I missed you so much that it hurt; I thought I could never go on without you...

The break up was painful...I cried for a year and then another, and then another. I never thought I'd be able to feel whole again with you gone. But I am healing now and have started my life over without you.

Writing to an EX may seem like a funny thing. Especially when I am the EX as well. Writing this letter to my past-self.

The one who died that September day. So long ago in another life in a twisted wreck of broken glass and steel.

I still see your face every day in the mirror you look back at me. The reflection of someone I once was. I hope you are well.



Will Perringwood, right, with Lee from Headway North West London, who features in episode four of the podcast

ACTION FOR BRAIN INJURY WEEK 2017



From reporter to supporter, Will and Amy Perringwood

As part of his contribution to the awareness-raising week, former journalist Will Perringwood decided to visit Headway groups and branches across the UK to speak with fellow brain injury survivors for a podcast, entitled *Life after brain injury*.

Accompanied by wife Amy, Will visited Headways in the south west of England, London, and the Midlands, meeting and interviewing numerous people along the way.

The couple's innovative idea also caught the attention of BBC Radio 4's influential *You and Yours* programme, which featured the couple on the show two weeks running in the build-up to the week.

Will said: "Everyone I met and interviewed was truly inspirational, displaying an attitude of 'this brain injury will not beat me', which sums up the determined spirit needed to get through such a potentially life-changing experience.

"Brain injuries have no prejudice – they do not care if you are black, white,

or green; short, tall, overweight, or underweight – it can affect anyone.

"We are all united in the feeling of making the most of our borrowed time – thriving, not just surviving.

"I feel honoured people were willing to sit, answer questions and share their own stories with me. I really hope anyone who has listened to the podcast has felt inspired, encouraged and motivated to see life after brain injury."

Please do visit www.ANewMe.org.uk to see our gallery of creative expressions of how brain injury can change lives and futures in an instant.



A new me 'But you don't look disabled...'

Ask most brain injury survivors if they feel people understand the hidden effects of their brain injury and you'll likely get a resounding 'No!' as a response.

Perhaps it should not be surprising that misunderstandings about brain injury are so common. Brain injury is, after all, highly complex.

But a lack of awareness can result in well-meaning comments causing great offence and frustration.

To help counter these false clichés, and with the help of members of the charity's social networks, we compiled a list of the top ten things not to say to someone living with the effects of brain injury.

In addition, a short film was created which shows brain injury survivors' natural and immediate reactions to some of the phrases they hear on a daily basis. The film has already proved a tremendous success, with in excess of 25,000 people viewing it on the day it was launched.

Luke Griggs, Director of Communications at Headway, said: "As soon as we started to look into this, it was immediately clear just how commonly brain injury survivors hear these statements.

"It must be incredibly frustrating to experience, but we hope that by sharing these examples we can go some way to challenging misperceptions of this often invisible disability.



"We had great fun making the film. While it is a very serious subject, we wanted to take a light-hearted approach to it in order to engage with the general public and encourage them to see brain injury in a different light.

"My thanks go to everyone who contributed to making the film, and for everyone that has shared it online and helped make it such a successful awareness-raising tool."

'I've heard them all!'

"I've heard all of them over the years and they can really be hurtful at times," said Andy Nicholson, from Lincolnshire, who sustained his brain injury after falling headfirst down a 20ft drop on a building site.

"For me fatigue is a big issue, so when people make passing comments making light of me being tired, I find it very frustrating. Being so fatigued that I'm tired the instant I wake is not just in

my mind. I wish it was.

"Having to concentrate more than non-brain-injured folk on everyday tasks as mundane as simply walking or talking is hard to explain and can be very hard going.

"Hopefully with more campaigns like A New Me, more people can talk about the issues that affect brain injury survivors and break down these misconceptions."

Huge thanks go to our film stars Jeremy Doyle, Jeanette Worthington, Chris Guy, Craig Willies, Deborah Blackmore, John Woodhall, John Parnham, Mike Bent, Craig Wilson, Isobel Andrews (all from Headway Nottingham), Anna Khan, Lauren Khan, and Fiona Grant-MacDonald (Headway East Lothian). Thanks also to Charlotte Leask (Headway Nottingham), and to Phil Knox at Purple Flame Media.

ACTION FOR BRAIN INJURY WEEK 2017

What NOT to say to someone with a brain injury

1. "I know what you mean...I've got a terrible memory too!"

Sure, we all forget things, but an injury to the brain can stop memories being stored and/or retrieved. Being forgetful and having memory problems as a result of brain injury are worlds apart!

2. "But you don't look disabled..."

The cognitive, emotional and behavioural effects of brain injury can still be present long after any physical injuries have healed. Sadly, too many people judge disability purely on what they can see.

3. "Move on and stop dwelling on what happened."

One to avoid at all costs! The effects of a brain injury can last a lifetime and a person can't simply decide to 'get better' and move on.

4. "You should be back to normal by now."

Where to start with this one! No two brain injuries are alike, and no two journeys to recovery should ever be compared. And what's normal, anyway?

5. "You're tired? At your age?!"

Fatigue is a very real and debilitating effect of a brain injury. Tasks that most of us take for granted can require much more effort after brain injury. Getting told you're lazy must be infuriating!

6. "It's all in your mind!"

Brain injury isn't something that can be controlled by simple conscious thought, so there's little more frustrating for a person with a brain injury than being told to 'snap out of it'!

7. "Chin up – there's always someone worse off."

When trying to adapt to an entirely new life after brain injury, it doesn't always help to know that others may be dealing with worse – as defined by someone who doesn't understand what you're going through.

8. "Are you sure you should be doing that?"

An essential part of the rehabilitation process is relearning lost skills by pushing yourself to

do challenging tasks. Although often said by people wanting to help, having your ability judged by someone else can be extremely frustrating.

9. "I know someone who had a brain injury and they're fine now."

No two brain injuries are the same! While it can be a motivation to hear of other people making good progress, it certainly isn't helpful to be judged for not recovering as quickly as them.

10. "But you were able to do that yesterday..."

People who say this don't realise the fluctuating nature of a brain injury, which is often down to fatigue. In some cases it can be because they did a task yesterday that they can't do it today.



Andy Nicholson with wife Sharon



Chris Guy and Jeanette Worthington from Headway Nottingham prepare to share their feelings about the misconceptions of brain injury

See the film at
www.ANewMe.org.uk

A new me An ACTION PACKED week

All across the UK, charity volunteers and staff were busy during ABI Week raising awareness of brain injury and letting more and more people know that Headway is here to help.

From A New Me art exhibitions to pop-up shops, there was plenty going on in local communities – not to mention in the world of social media!

HEADWAY SHARES ROCKET!

No, we've not listed ourselves on the stock market, but it's fair to say shares of Headway posts online broke all records during ABI Week.

Our short film, *What not to say to someone with a brain injury*, was viewed an incredible

43,000 times during the week, with hundreds of people sharing it on their own pages and adding their own positive comments and thoughts on the serious issue raised.

Overall, our ABI Week posts appeared on more than a quarter of a million Facebook pages!

Importantly, the social media campaign was hugely successful in encouraging people to visit the charity's website for further information or support. Almost 27,000 people did just that during ABI Week – an increase of

around 65% on last year's campaign, which reached out to a different audience.

Twitter was just as busy, with the #ANewMe reaching 625,000 people, who between them saw the hashtag and messages more than two million times during the week.

Traditional media was equally keen to help us spread the word, with the highlight being Headway Chief Executive Peter McCabe taking part in a 15-minute long Sky News interview alongside James Cracknell and Beverley Turner.



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The eye-catching window of Headway East London's pop-up shop

ACTION FOR BRAIN INJURY WEEK 2017



BBC Radio 5Live also supported the campaign, featuring an excellent interview with former Premier League assistant referee John Holbrook who sustained a brain injury following a haemorrhage.

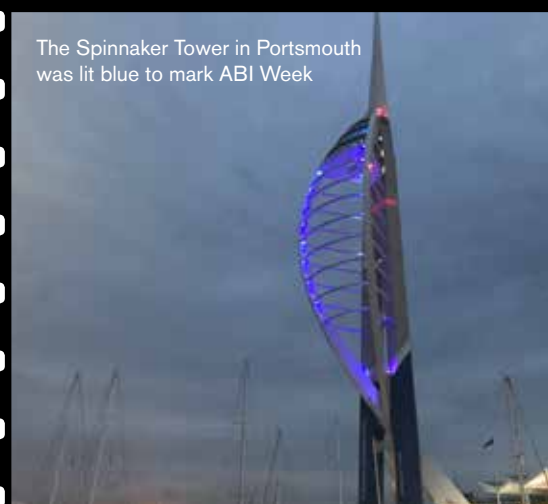
Not to be outdone by its sister station, Radio 4 also got in on the act by interviewing Will and Amy Perringwood on the *You and Yours* programme.

The BBC also supported Headway groups and branches, with numerous local television, radio and online features, including excellent coverage on the corporation's Ouch! disability channel.

Thank you to all those who clicked, shared and liked our posts during the week – you all helped to raise awareness and understanding of brain injury.



A fabulous display by Headway Norfolk and Waveney



The Spinnaker Tower in Portsmouth was lit blue to mark ABI Week

OUT AND ABOUT

As always, Headway groups and branches were busy during ABI Week, with creative expressions of 'a new me' at the heart of things.

Art exhibitions showcasing the incredible talents of brain injury survivors were held by the likes of Headway Southampton and Headway Rotherham, with the town's mayor in attendance to see the collection of poems, needlework, pottery, paintings, glass work and more.

Headway Norfolk and Waveney and Headway East London went a step further by opening pop-up shops to not only display the artwork but also sell it in order to generate funds.

Meanwhile, Headway Cardiff, Headway Glasgow, and Headway Blackpool, Wyre and Fylde all held information and awareness events giving brain injury survivors a platform to share their experiences and explore some of the issues that matter to them, or simply learn more about the support available.

Find out more at **21**
www.ANewMe.org.uk

HATS OFF TO YOU ALL

Wow! That's all we can say about this year's Hats for Headway Day, which proved to be the biggest and best to date.

Thousands of you took part across the country to raise awareness and funds for Headway, with more than 700 photos of you all wearing your wacky headgear posted to social media.

The event was even covered by regional BBC television news programme East Midlands Today. Great work everyone – and thank you!



Banksy looks less than impressed despite supporting Headway East Kent



Liz Meddings really used her brain to win the prize for best individual photo!

Best
hat
winner

HATS FOR HEADWAY DAY



Friday 12th May

headway.org.uk

#HatsForHeadway

ACTION FOR
BRAIN INJURY WEEK 2017



Best
group
winner



The team at Wolfertans Solicitors, led by mascot Wolfie, won the prize for best group shot

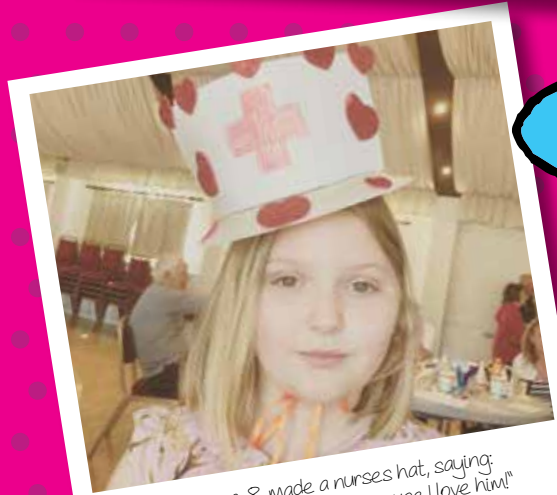
ACTION FOR BRAIN INJURY WEEK 2017



Where did you get that hat?! Police and fire officers swap hats at Darlington Fire Station



Having fun at The One Off design studio in Derbyshire



Jessica, 8, made a nurses hat, saying: "I'm now Daddy's nurse because I love him!"



Perhaps the day was beginning to dragon a bit for Melissa Lane...



BBC East Midlands Today's brilliant Hats for Headway Day feature



Pupils at Priestlands School in Hampshire get in on the act



QVC presenter Jackie Koller was certainly selling Headway with her hat!

The Headway UK team!

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News

See more photos at
www.headway.org.uk/hats-for-headway-day 23

COPING WITH GRIEF AFTER BRAIN INJURY

We're all familiar with the concept of grief – a feeling of intense sorrow usually caused by someone's death.

But after brain injury grief can occur in response to the loss of the previous self, as the cognitive, emotional, behavioural and physical effects of the condition change every aspect of a person, turning them into 'a new me'.

This form of grief is no less real and no easier to cope with, but brain injury survivors and their family members often find traditional approaches and support networks are unable to adequately address the problem.

"Even ten years on I struggle knowing my life isn't the same," said brain injury survivor CuriousConnie, a member on our HealthUnlocked forum.

"Grieving for loss of self and the person you were is very difficult and a very personal journey. Looking back, the rehabilitation teams have told me countless times I need to grieve for

who I was and accept she is gone, but no one offers guidance on how to do so."

A CARER'S PERSPECTIVE

Grief tends to follow five stages: denial, anger, bargaining (the feeling of 'if only...'), depression, and acceptance. Reaching the acceptance stage is difficult and by no means a certainty, but after brain injury things can be further complicated by the unfamiliar, complex and often unpredictable effects of the condition.

In the early stages after the injury, grief can be a particular shock for family members, especially when their loved one is discharged from hospital and the changes become apparent.

"People don't understand at all," said Laura Linton, whose father sustained a brain injury. "I am sick of people commenting 'at least you have him', or 'be grateful'. We have been handed back a totally different person and we are all struggling with this."

Family members can find it particularly difficult to cope with the absence of the person they once knew (the former self) while adapting to the presence of the new version.

Julie Heath explains the journey of grief following her husband's brain injury. "I have grieved for the changes in my marriage, for the father that the children no longer have, and for the future I thought I had," she said.

"I have coped through talking with friends, having counselling, and by just being prepared to acknowledge that it is grief I am experiencing."

A SURVIVOR'S PERSPECTIVE

For a survivor of a brain injury, the effects of the condition can create a different but equally difficult experience of grief.

In the early stages, particularly while in a rehabilitation setting, a person may receive more intensive support, with clear and measurable goals for

regaining lost skills. It can be further down the line, and especially when they are discharged home, that the reality of living with a brain injury becomes apparent and the long process of building 'a new me' begins.

"Once I realised that I was grieving and went through the steps, I was able to start moving forward," said Chrystal Thorburn. "I needed to grieve on my own, in my own time."

"Online support groups were a major help through the many stages of the grieving process, which was staggered as you think you're getting better and then next minute you're back down again. Grief was an unexpected thing to have to deal with."

Navigating through the maze of feelings and emotions to reach an acceptance stage after brain injury can require a great deal of support, trial and error, and motivation.

Gary Kearney explains his outlook on the issue: "An ABI is a massive change, almost instantly. Yes it is horrible, but acceptance of the reality is essential."

"You cannot force it but it will happen. Listen to the inner you, listen to Headway and other groups like them. They help. The last thing is this, listen to other survivors with an open mind and heart. They know."

A PROFESSIONAL PERSPECTIVE

"I would give almost anything for this never to have happened to me".

"As a clinician, this sentence in all its various guises, spoken by many of my patients over the years, captures some of the sorrow, loss and pain which colour the highly individual experience of grief after acquired brain injury."

"Because of each individual's personal experience of brain injury being different, grief does not always follow predictable or set stages of mourning after brain injury."

"From a more academic perspective, factors such as time since injury, awareness, family support, pre-injury personality traits, social networks, and severity of the injury can all influence the person's experience of grief."

"Furthermore, there is often a focus in the literature on the loss of 'how things were', but again, as a clinician, working psychotherapeutically I also often hear about the grief regarding the loss of 'what might have been', were it not for the injury."

"As clinicians, we can never say we really, really know what it must feel like to suffer a brain injury. But what we can do is offer the best evidence-based rehabilitation and give very generously of our time, with compassion, truthfulness, and loyalty."

Dr Rudi Coetzer
Consultant
Neuropsychologist



HELP & SUPPORT

It is vitally important that people experiencing feelings of grief seek support. Struggling through these feelings alone is sure to prolong the grieving process, and may cause ongoing feelings of loneliness and depression.

Speak to your GP or, if you have access to one, a brain injury specialist about your options.

Contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk **25**



#HeadwayHeroes

Volunteers: The lifeblood of the charity

Like most charities, Headway simply could not operate or achieve its objectives without the support of volunteers. Across the UK, thousands of people freely give their time and energy each week to support those living with the effects of brain injury.

To mark Volunteers' Week (1-7 June), we want to say a huge thank you to each and every one of our incredible volunteers.

Whether working behind the scenes in one of our offices, serving customers in one of our charity shops, or supporting your local Headway group – we salute you all!

Jackie Alton started volunteering at our shop in Eastwood, Nottingham, in 2015, working alongside her father, Michael, before he died of bowel cancer.

She said: "I first got involved with volunteering through the job centre. They said I should volunteer to get some retail experience.

"I came in one Saturday morning and got stuck in sorting donations. I was so into what I was doing, someone

had to tell me it was time to go home at the end of the day!"

Jackie does a variety of tasks from pricing items to sorting clothes and is currently learning how to cash-up at the end of the day.

"Every day is different," she said. "It's a really friendly environment, everyone is so lovely.



Jackie Alton serves another happy customer

"I've learned so much and gained a great deal from volunteering at Headway. It also feels really good to be able to support such a worthwhile cause."

'Why I love volunteering'

"Seeing our members enjoying themselves, seeing them blossom and gaining new skills is priceless. When a member calls us his family, well, what more can I say? I just think how lucky I am to know them all."

Lesley Stephenson, volunteer at Headway North Northumberland

"I love volunteering because it gives a structure to my life in retirement, and keeps me active and busy. I get a huge feeling of achievement from enabling our members to learn and partake in various tasks at our allotment."

Ruth Wright, volunteer at Headway Derby

"I love volunteering here because everyone's passionate and caring. They know people as individuals, not as clients, and it's all centred around having fun."

Deidre Kenney, volunteer at Headway Worcestershire

"I used to teach design and technology, so when I retired and saw they were looking to open a woodwork room I said 'I've got to do that!' You can see the delight in their faces when they do things themselves. They're laughing and joking and there's never a dull moment. It's amazing."

Les Hurwood, volunteer at Headway East Northants

Interested in volunteering? Visit the Headway website to find your nearest charity shop or Headway group or branch.

MATCH OF THE DAY!

As profile boosts go, taking over the match-day sponsorship of a Championship football match has to rank at the top of the league!

On Saturday 18 March, Headway's logo was splashed across St Andrew's, the home of Birmingham City Football Club as the team lined-up to play top-of-the-table Newcastle Utd.

The event was made possible by the generosity of the charity's corporate supporter No5 Barristers' Chambers, which chose to donate its match-day sponsorship of Birmingham City to Headway.

The result was the charity's logo proudly displayed on the home team's shirts, an article in the match-day programme, pitch-side digital banner adverts, and promotion of the charity to corporate ticket holders.



Headway's name adorned the shirts of the Birmingham City players

Volunteers from local group Headway Birmingham and Solihull were also on hand to meet supporters in order to raise awareness and accept much-needed donations.

What's more, the event saw Headway Ambassador Jack Rutter return to the club he played for before a brain injury put paid to his impending professional career.

The former Birmingham City youth team player led the teams out and was even interviewed live on the pitch at half-time in front of 20,000 fans in order to raise awareness of Headway and its work to improve life after brain injury.

"What an incredible day," said Luke Griggs, Director of Communications at Headway.

"This was a great opportunity to boost the profile of the charity, while bringing our Concussion Aware campaign to the attention of sports fans."

"We are immensely grateful to No5 Barristers' Chambers for this incredibly generous act. We'd also like to thank the club for the positive way it supported the initiative."

Tony McDaid, Chief Executive and Director of Clerking at No5 Barristers' Chambers, added: "We have been working with Headway over many years and continue to marvel at the level of

support they offer to individuals and their families post brain injury.

"The charity's Concussion Aware campaign is an initiative that both we at No5 and our friends at Birmingham City Football Club fully support."



Headway and No5's partnership is announced on the big screen



Jack Rutter, centre, with former Sky Sports journalist Chris Skudder and former Newcastle Utd legend Bobby Moncur before the half-time interview

#HeadwayHeroes TIGERS EARN THEIR STRIPES

A quartet of staff from a football club's charitable trust has completed a gruelling 200-mile cycle challenge to thank Headway for the support it has given to one of its players.

In January, Ryan Mason fractured his skull during a clash of heads with Chelsea player Gary Cahill while playing for Hull City, who are known as The Tigers.

The cyclists – Ed Griffiths, Adam Newton, Matt Conway, and Alex Lisney

– all work at The Tigers Trust, which aims to make a difference by involving people in sport and promoting sporting values.

They set off from Tottenham Hotspur's White Hart Lane ground, in north London, on 19 May and arrived back at the KCOM Stadium in Hull two (long!) days later.

A grateful Ryan said: "The support I have received has been overwhelming and Headway has played a significant part in that.

"I'm delighted that the Tigers Trust will be donating some of the funds it raises

from this cycle ride to Headway."

Matt Conway, Tigers Trust Programme Manager and Team Leader for the cycle challenge, said: "Headway is a great charity that does some exceptional work and it has been great to partner up with them for this challenge."



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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'Brilliant experience' thrills intrepid duo

Fundraisers Jennifer Cawthorne and Lynne Carrick-Leary proved they were made of stern stuff as they conquered the Great Wall of China to raise money for Headway as part of one of the charity's official challenge events.

The duo, who work in the Manchester office of Irwin Mitchell Solicitors, raised a fantastic £11,300 in support of the charity's work to improve life after brain injury.

"We have seen first-hand how Headway helps people with brain injuries and we wanted to raise funds for such a great charity," said Jennifer.

"We both had 'big' birthdays and decided that going to China and undertaking this huge challenge would be a great way to mark them.

"We spent months training, walking miles and climbing lots of hills and a few mountains along the way to prepare."

Jennifer said that all the training paid off and the stunning views along the route of the walk made all the effort worthwhile.

She said: "We were taken off the beaten track to remote areas where the scenery was absolutely spectacular.

"And although it was tough at times, we both loved the challenge.

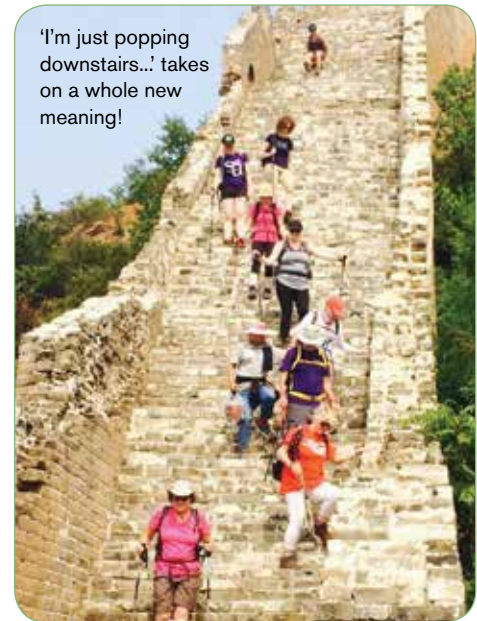
"It was very hot and some days we had to climb 1,400 steps just to get on to the wall. But undoubtedly it was a brilliant experience and we would highly recommend it to anyone."

"I've always wanted to take on a big challenge.."

At one point or another, many of us have contemplated taking on a charity challenge. Whether you're looking for a once-in-a-lifetime overseas trial, or would prefer to keep things closer to home, we can help you fulfil your ambitions.

Jennifer and Lynne were supported by Headway throughout their challenge, with the pair organising their trek through the charity's official partner, Skyline. The professional events organiser offers people a chance to take on guided treks ranging from

'I'm just popping downstairs...' takes on a whole new meaning!



Trek Kilimanjaro through to the more accessible Thames Path hike.

Visit the Get Involved section of the Headway website to see the full range of challenges you can take on. All we ask is that you raise a minimum amount of sponsorship and all your travel arrangements will be taken care of. Alternatively, you have the option to self-fund your trek.

If you're already planning to support Headway by organising your own sponsored trek or walk, please contact us first on 0115 924 0800 or projects@headway.org.uk and we'll be happy to offer support and guidance.



Jennifer and Lynne jump for joy on top of the Great Wall of China

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

#HeadwayHeroes

Headway Heroes go the distance

Yet again, Team Headway did us proud in this year's Virgin Money London Marathon, with a total of 51 runners donning Headway vests to tackle the gruelling 26.2-mile course.

The intrepid Headway Heroes, who have raised a phenomenal £90,000 for the charity so far, were part of the 55,000-strong mass of runners who descended on the capital for this year's event.

After loading-up on carbs at the Headway Pasta Party the evening before the big day, members of Team Headway – including the charity's Vice President James Cracknell – all completed the course in fine style.

James first tackled the marathon for Headway in 2011, less than a year after a cycling accident in the USA left him with a life-changing brain injury.

A veteran of endurance events, James was happy to share some top tips with other members of the team, including first-time runner Emma Garcia.

Emma took on the challenge in memory of her friend Amy Haskew, who died after a cycling accident during a trip around Australia with her boyfriend.

Emma spent every day with Amy as they studied their Masters degrees in Forensic Psychology at the University of Kent in Canterbury just a few years before the accident.

"Amy's parents came along on the day to cheer me on and that meant a lot to me. It was a very special moment when I recognised them in the crowd," recalled Emma.

"I had Amy in my mind as I ran, so to see them cheering me on as well was very touching. It helped to drive me forward – as did the wonderful crowd along the route."

Emma said she was delighted to have been able to raise more than £3,000 for the charity.

Another runner, Edinburgh nurse Elaine Murray, 50, managed to raise more than £2,200.

She was 28 when she got the devastating call to say her father Eddie had sustained a brain injury at work.

Eddie was left with double vision as well as problems with his balance, hearing and communication. But despite these challenges he lived a long and happy life before passing away in 2015 at the aged of 83.

Emma said it was this personal connection to brain injury that helped to keep her motivated as she ran the challenging marathon course.

She said: "When the pain kicks in, and you have to dig deep, it really helps to focus your mind on the reason why you're doing it."

"The crowds were wonderful too – they really helped you stay motivated. It was a lovely day all round."



Emma Garcia had friend Amy in her mind



Elaine Murray was running in memory of her father, Eddie

Have you been inspired to walk, run or cycle for Headway? Perhaps jumping out of a plane is more your thing? Find out how you can support Headway while having the experience of a lifetime by visiting www.headway.org.uk/get-involved

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Maisey, mother of Patrick, one of our brain injury clients

