**Winter 2017** 

# Headway News

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

Are you fit for purpose?

Scottish government praise for ID card

My Story: No laughing matter

True Romance

Grime star's touching tribute



Host a mince pie coffee morning and raise money for Headway!

www.headway.org.uk #mincepiemorning



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.











# 'Are benefits assessments working?' Er...no!

Sometimes, you're asked what appears to be a simple question and yet you're unable to provide a simple answer.

If you ask brain injury survivors whether they feel welfare benefits assessments are working (and we do), most will provide you with a resounding one-word response: NO!

Many others will garnish their answer with justifiable (but unprintable) embellishments!

For years we have been talking about failings in the processes for assessing people for welfare benefits such as ESA and PIP. Numerous consultations have come and gone; multiple reports have been published and reviews conducted; and repeatedly Headway has called for changes that would put a stop to the unfair practices that seem to discriminate against those with hidden or fluctuating conditions.

Despite all this, people living with the long-term effects of brain injury are still telling us that they are being unfairly denied access to the vital benefits that they need in order to live independent lives.

More than 550 people have completed our most recent survey, which remains open in order that we can continue to collate evidence. They told us all about the problems they are facing, saying things like: '...it is difficult to explain brain injury on the application forms', '...assessors do not understand the complexities of brain injury', and '...medical evidence is not taken into account'.

These survey responses have been used to form the basis of Headway's evidence to the latest review of ESA and PIP assessments.

Some might feel a sense of déjà vu at yet another review. But we're optimistic as this is an inquiry being conducted by the Work and Pensions Committee – a cross-party body that oversees and scrutinises the work of the Department for Work and Pensions. Its recommendations carry weight and can influence change.

We have presented strong evidence to the committee, clearly demonstrating the need for urgent improvements to be made.

Perhaps not every question has a simple answer. In this case, a powerful and hopefully persuasive one will have to do!

**The Communications Team** 

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# Your Views...

"Not geared to brain injury.

Cognitive tests were
over-simplified, short and could
not take into account the onset of
fatigue often experienced
by survivors."

Anonymous

With parliament once again looking at whether or not the assessment processes for ESA and PIP are working, we asked our online communities to share their views...

"The assessor doesn't take into account what I find difficult because my brain injury is mostly hidden. I may look fine on the outside but it's not taken into account my hidden problems that someone medically would know about like doctors etc

"ESA has been an absolute nightmare.

My son receives highest rate PIP and yet is currently having to apply for Job Seeker's Allowance while waiting for an ESA reconsideration. He is missing vital rehab appointments while he is signing on at the job centre."

Lyndsay

Michael

"You cannot make any form that will cover every type of illness. does not consider brain injury in

"We did eventually get to talk with a compassionate decision maker but this was after involvement decision maker but this was after involvement from MP and medical specialists, and support from from MP and medical specialists, and support from Headway. It was a very long process which was Headway. It was a very long process which was almost too much for my son – and certainly was too almost too much for him on his own."

Alan

John

"Form very long and complicated. Decision makers need to be experienced in the condition they are assessing."

"My son has an acquired brain injury through various surgeries. He has various problems and can't read or write due to an operation. Trouble is, he seems OK at first to people."

**Jules Cartwright** 

Joanna

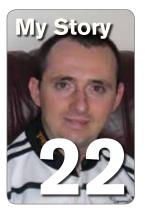
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ACTION FOR BRAIN INJURY WEEK 2018

**ABI** Week theme revealed











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#### news you may have missed...

# You, me, and brain injury

# ACTION FOR BRAIN INJURY WEEK 2018

14-20 MAY

Relationships after brain injury will be the focus of next year's Action for Brain Injury Week, which takes place from 14-20 May.

You, me, and brain injury will build on the huge success of this year's A New Me campaign by once again putting people directly affected by brain injury at the heart of our awareness-raising work.

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

The campaign will provide an opportunity for people to share their experiences – positive and negative – about how their relationships have changed following brain injury.

More details will follow in due course, so sign up to our *Headway News Bitesize* email newsletter via the homepage of our website if you'd like to keep up-to-date with this and other news from Headway!







# **Rita Rees MBE** 1930-2017

It is with great sadness that Headway announces that Rita Rees MBE, founder of Headway Bristol and a trustee of Headway UK for more than a decade, has passed away at the age of 86.

Rita was a tireless advocate for people affected by brain injury, using her personal experience to improve the lives of others.

Rita was driven to support those affected by brain injury after her own daughter, Jane, sustained a traumatic brain injury. Determined to ensure other families received more help in adapting to life after brain injury, Rita became a founding member of Headway Bristol in 1977. Today, Headway Bristol is a thriving charity supporting hundreds of people each year.

Rita finally stepped down from the board of Headway Bristol in 2011 aged 80, but continued to be actively involved, taking on the role of President of the charity.

In addition to caring for Jane and helping to develop Headway Bristol, Rita served on the board of Headway UK for more than a decade, acting as Deputy Chair for several years.

Rita's dedication and commitment led her to be awarded an MBE, while she was presented with a Lifetime Achievement Award in the 2004 Headway Annual Awards.

Rita left a lasting legacy and will be missed by all those who knew and loved her, particularly her daughter Jane.

# More publications 'highly commended'

Headway is celebrating once again after scooping two more accolades at the British Medical Association's annual Patient Information Awards ceremony.

Lack of insight after brain injury and Supporting children when a parent has had a brain injury both received Highly Commended status at this year's ceremony.

The latest awards bring the total number of BMA accolades claimed by the charity to 24 in just nine years.

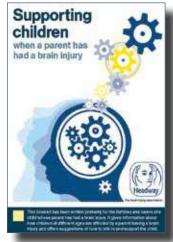
Lack of insight after brain injury addresses the complex issue affecting some survivors who lack awareness of how their brain injury affects them. The factsheet offers a range of tips to help partners, family, friends, and carers manage this.

Supporting children when a parent has had a brain injury was co-written by Dr Jo Johnson, Consultant Neuropsychologist and sponsored by Michael Jefferies Injury Lawyers.

It provides information about how children of different ages typically respond to a parent sustaining a brain injury, and how to offer age-appropriate support to them.

You can download these and our other award-winning brain injury resources from the information library on the

Headway website.



# Headway responds to ESA and PIP inquiry

Are assessments for Employment and Support Allowance (ESA) and Personal Independence Payments (PIP) working? That's the question being posed by the Work and Pensions Committee in the House of Commons.

Headway has taken the opportunity to champion the cause of people living with brain injury by submitting a comprehensive response to the inquiry, once again making clear the charity's long-standing and serious concerns.

The charity's evidence draws on the findings of our survey, completed by more than 550 people with brain injury who have undergone assessments for either ESA or PIP (or both) in the past two years.

"We are pleased that the Work and Pensions Committee is looking into this issue as part of its scrutiny of the Department for Work and Pensions," said Luke Griggs, Director of Communications at Headway.

"We have expressed repeatedly the views and feelings of the charity and those we support with regard to the way assessments are carried out. Despite numerous reviews and tweaks, the system is still failing those with complex, fluctuating, and often hidden conditions.

"Too many people are being denied the vital support that they need, as evidenced by the high number of brain injury claimants being rejected and having to appeal.

"More must be done to reform a system that is simply not fit for purpose."

The survey, which can be completed via the Headway website, will remain open in order to underpin the charity's *Right First Time* campaign.

We will share the results of our survey once the Work and Pensions Committee has published its findings.

#### news you may have missed...

# Cabinet Secretary for Justice launches ID card in Scotland

The Cabinet Secretary for Justice in the Scottish Government has officially launched the Headway Justice Project in Scotland.

Speaking at an event in Falkirk on 26 October, Michael Matheson MSP warmly welcomed the project, at the heart of which is the Brain Injury Identity Card.

A former patron of Headway Falkirk, which hosted the event, the Cabinet Secretary also spoke highly of Headway's work to improve the lives of people living with brain injury across Scotland.

He said: "Scotland's health and justice systems need to work closely together if we are to successfully tackle health inequalities, reduce reoffending and improve the lives of the individuals that use these services.

"The new brain injury ID card will help police identify brain injury survivors and ensure they get the support they need when they come into contact with our justice system.

"I'm grateful to Headway for its work on this project and hope that it will lead to a wider understanding of the needs of brain injury survivors."

The project is endorsed by the Scottish Police Federation and the Scottish Appropriate Adult Network. The card is also supported by Police Scotland, with cards issued in









Scotland carrying the organisation's logo, adding authority to the card and ensuring it is recognised by officers.

Superintendent David Pettigrew represented Police Scotland at the launch, saying: "Brain injury survivors can find themselves coming into contact with the criminal justice system as victims or when they have been arrested.

"When we were first approached about this project, the benefits were immediately obvious – both to those holding the cards and indeed to Police Scotland.

"By working together with Headway, we can provide better support to brain injury survivors, and save precious police resources."

#### **Changing lives**

Attendees at the launch also included brain injury survivors who have encountered difficulties in common day-to-day scenarios and are now benefiting from carrying a Headway Brain Injury Identity Card.

Callum Maclean, from Wick, Nell Gregory and Stephen McNulty, both from Glasgow, shared their experiences during an on-stage question and answer session.

Callum was a commercial fisherman for more than 20 years and a qualified welding inspector before a brain tumour changed his life in 2011.

The tumour left him with a number of problems such as impaired balance, affected temperament and limited

#### **Brain Injury Identity Card**



My name is: Jonathan Smith I have a brain injury and as a result:

I have difficulty processing information

I have attention and concentration difficulties

I experience fatigue

I may have anxiety

For 24 hour criminal legal assistance, please call:



0800 140 4031



#### Andrea MacDonald, Chair of the Scottish Police Federation

"This is a very worthy project which will undoubtedly make life easier and more importantly safer for members of the public who are brain injury survivors.

"It will also be a valuable tool for our members to help them identify brain injury survivors who are in custody or whom they otherwise encounter during their duties and thereafter ensure that these individuals receive the necessary support and medical assistance."

## Karen Donoghue, Chair of the Scottish Appropriate Adult Network

"The Scottish Appropriate Adult Network welcomes the introduction of the Brain Injury Identity Card. Any measure that can assist the right people getting the right help at the right time can only be a good thing."

mobility. These symptoms have brought many challenges, including dealing with the often inappropriate ways people react to his disabilities.

He said: "I suffer from impaired balance which can cause me to stagger and it can look as if I am drunk or under the influence of drugs.

"This has drawn attention from the police and they have watched me closely as I have crossed the road or when I'm at football matches.

"I have also been treated differently by staff in shops and restaurants including a comment being made by an assistant suggesting that I had been drinking."

Callum, who was also interviewed for an excellent feature on STV News, said carrying the card has brought him confidence, especially when he is feeling tired.

He said: "When I am tired I struggle

to communicate and this can be very stressful when I'm out on my own.

"But now with the card, I don't have to explain myself to strangers, the information is all there. It's like having back up plus there is a phone number for legal assistance too just in case anything was to happen."

Accusations of being drunk have also been levelled at Stephen McNulty.

"I often get strange looks and people sometimes mistake me for being drunk," he told guests, "but I know if I need to, I can show the card and clear things up."

Stephen also explained that he often has difficulty controlling what he says, which can lead to inappropriate use of language that some find offensive.

"I've had stewards at football matches try to throw me out of grounds because of inappropriate language," he said. "But when I've presented my card to nearby police officers, they have always been very understanding."

Nell explained that her brain injury has left her with a number of problems that affect her memory, sight and balance problems. She also suffers from bouts of severe fatigue.

She said the card has provided her with a boost in confidence, especially tackling those everyday tasks that people often take for granted.

"The card has helped in many ways. Bus drivers in particular have been very supportive. They lower the step for me, and wait until I'm seated before moving away.

"I do feel more confident carrying my card. It reassures me that I can prove I have brain injury if I need to – especially if people think you're drunk, for example, when you just have balance problems."

#### My Story...



# ROMANGE

#### "It was 7am when I found out... I felt sick to my stomach."

Too many families reading those words will be able to empathise with the experience of Asher Bourke.

The knock on the door or the phone call at an unexpected time, signifying that life would never be the same again.

Asher received a call from a police a ja officer informing her that her boyfriend, Peter, had been viciously assaulted.

"I was told to get to the Queen's Medical Centre in Nottingham as soon as possible," said Asher. "They said Peter was fighting for his life on an operating table.

"I felt sick to my stomach."

The beginnings of True Romance

Asher faced an agonising two-hour train journey to reach Peter's bedside; a journey where every mile and every passing minute felt like an eternity.

To help her remain calm, the emerging poet and rapper began scribbling down her thoughts and feelings about Peter.

"On the train to the hospital I couldn't stop thinking about all the times we shared and special memories," she said.

"I just started to jot them down. I suppose it was a way to channel my worries and cling onto Peter at a time when I thought I might lose him."

Those thoughts and raw feelings have now been transformed into a new single, entitled *True Romance*, profits from which will be going to Headway as a thank you for the support the charity has provided to the couple.



#### LIFE CHANGED IN AN INSTANT

In 2015, childhood sweethearts
Asher and Peter had just started their second year at university. Both were enjoying success; Peter had been offered a placement at The Southbank Photography Collective, while Asher was a campus radio manager at University of Arts in London and had just been named Media Student of the Year.

In October, Peter went home to Leicester to mark the one year anniversary of his mother's passing. That night his life changed in an instant after being assaulted by a total stranger while on a night out with his friends.

He was rushed to intensive care at the Queen's Medical Centre (QMC) in Nottingham where he underwent surgery to have a part of his skull removed in order to relieve the swelling to his brain.

Peter remained in a coma for two weeks, leaving Asher increasingly concerned. It was at this point that she called Headway's helpline for support. She said: "Understandably, the nurses in the intensive care unit were really busy and couldn't always answer my questions; they were keeping Peter alive.

"So I rang the Headway helpline. Right from that first phone call they were so supportive. They have been vital, helping me to understand what was happening with Peter's care.

"I wanted to know why the nurses kept checking his pupils. The nurses said it was to see if he was brain dead – which really panicked me.

"I again called Headway and they reassured me that this was a necessary part of the process. They always kept me calm whilst telling me the truth.

"They offered emotional support, but also really important practical tips that enabled me and his family to concentrate on Peter."

#### 'I KEPT ASKING FOR MY MUM'

When Peter awoke from the coma he had severe memory problems. He would forget where he was, became confused, and suffered from hallucinations.

One of the hardest things for Peter was when he remembered that his mum had passed away.

"I kept asking for my mum," said Peter.
"I asked my auntie for her number
and was telling the nurses to call her,
because my mum always made stuff
better.



"I forgot she had died. My sister sat me down and told me 'Mum's gone'. I had to re-live it over and over again as I kept forgetting."

After a few weeks Peter was transferred to a brain injury unit in Leicester where he began the long process of rehabilitation. To begin with, he could not feel the right-hand side of his body. He was often delirious and severely confused, but gradually learned how to walk again.

On his eventual return home, Asher became his full-time carer, but the couple struggled to adapt to their new life.

Asher said: "Peter could not be left alone as he had a giant hole in his skull, would pass out, struggled to walk and he had issues controlling his anger. One episode was particularly scary as he tried to get out of a moving car.

## "He had moments where he was very low, too, and had a hard time accepting things."

Again, Asher turned to Headway, this time in the form of her local group Headway Leicestershire, Leicester and Rutland.

She said: "I spoke again to the helpline who told me about Headway Leicester's day centre.

"I would drop Peter off there, so I could go and do some shopping and get some respite, and Peter could regain some social skills and confidence through being out of the house.

"Although it wasn't for long, it was so important."

Peter underwent a cranioplasty operation and his recovery continued over the course of the year.

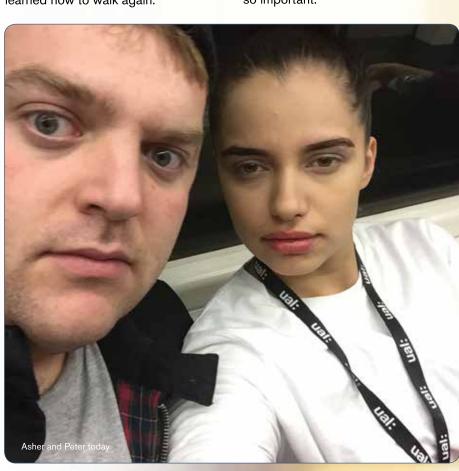
Asher said: "He had the same brilliant surgeon he had for his initial life saving operation, Maria Cartmill from the QMC.

"I had every trust in her and the team at the QMC. She truly is an angel, but still the thought that Peter was going to have another operation made us so nervous.

"I picked up the phone and gave Headway a call. Looking back, they were there with us for every step of the way.

"I remember calling them when I was very upset whilst Peter was in surgery. I was freaking out but they just listened, reassured me and helped to calm me down. They were great."

Now the couple are about to embark on the next chapter of their lives.





"We are both going back to university to complete what we started. We are living in London and feel good about life again," said Asher.

"There is lasting damage. Peter has epilepsy now and he still has problems associated with the injury. We have a long way to go, but we consider this to be a huge success story.

"I remember a point when I just wanted him to be alive. The moment he woke up was a success, but to be back at university, finally being able to move on, is more than we'd ever dare hoped for."

#### CHARITY TRACK

Asher performs under the name
Asher X. She recently released her first
song for the record label HQ FAMILIA.
It got 125,000 views and was played
on BBC Radio though Dean Jackson's
BBC Introducing show.

Her latest track, True Romance, is based on her initial thoughts and feelings jotted down during her difficult train journey, along with her experiences of supporting Peter and her feelings about those who assaulted him.

It also reflects on the impact a brain injury can have on families.

Asher said although creating the song was at times difficult, she said it was worth it to be able to raise awareness of brain injury and say thank you to those who helped.

She said: "Performing the song back for the recording was very hard and it stirred up a lot of emotions. I broke down a number of times and struggled to get the words out.

"I hope that people will relate to my lyrics and I think no matter what you are going through and how awful it is, just to connect and know you are not alone and that your feelings and experience match those of others, will help.

"I also want to raise awareness about brain injuries, the assaults that can cause them, and about the families and people who go through them.

"But mainly I want to shout about Headway and all the amazing work they do."

True Romance is available on Apple Music, iTunes and Spotify, or simply visit headway.org.uk/true-romance.

All proceeds will be donated to Headway to support its work to improve life after brain injury.





# MEETOUR FABULOUS FINALISTS...

## The Alex Richardson Achiever of the Year Award



Sponsored by Slater & Gordon Lawyers





#### ARTHUR MOORE

Just a few days after his 18th birthday, Arthur crashed his new motorbike. The accident resulted in four factures to his skull and left him with a traumatic brain injury.

Almost four decades later, Arthur's brain injury still affects him in a number of ways including intolerance to noise and severe mood swings.

Since joining his local Headway group in Larne, Arthur has been a passionate and determined campaigner. He has used his personal experiences to raise awareness of brain injury and generate vital funding for Headway services in Northern Ireland, including playing a key role in securing a £10,000 grant by speaking to audiences of up to 200 people.

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#### **NATALIE PARR**

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.

Natalie spent 11 months in hospital and needed another five years of neurological rehabilitation. At the age of just 25, Natalie was left paralysed from the chest down, unable to return to work, confined to a motorised wheelchair and tube fed.

Earlier this year, Natalie undertook her Duke of Edinburgh Diamond Award, using special ropes and hoists to climb a number of iconic buildings including Blackpool Tower and Tower Bridge.

As if her physical achievements weren't enough, Natalie has also raised £10,000 for Headway Coventry and Warwickshire since the start of the year.

#### DANIEL REEVES

Daniel contracted encephalitis after a bout of chickenpox in September 2009. His cognition and mobility were severely affected and he became reliant on using a wheelchair. He also suffered regular bouts of severe anxiety, depression, and debilitating pain.

By the time Daniel and his wife Ruth found their local group, Headway Gloucestershire, they were at crisis point. But with the support of the charity, Daniel and Ruth gradually began to rebuild their lives.

Showing incredible determination, Daniel began training in his wheelchair and in 2016 managed to complete a local 'parkrun' event.

He began to exercise regularly and really pushed himself, going to training every week, culminating in him completing a 10km event. Even more impressively, in October this year, he completed the Cheltenham Half Marathon.

Event brochure sponsored by

#### On 8 December, 12 inspirational people will take to the stage at The Dorchester Hotel for the Headway Annual Awards 2017.

#### **Leigh Day**

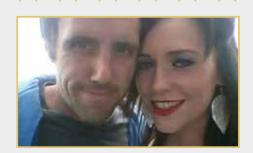
Drinks reception sponsored by

barr ellison

## Carer of the Year



#### Sponsored by SweetTree Home Care Services





#### NATASHA CASSIDY

Natasha's partner, Paul, was the subject Imagine having to spoon-feed your of a vicious assault that left him with a traumatic brain injury as a result of a fractured skull and bleeding and bruising on the brain.

The assault meant Natasha becoming his full-time carer while looking after their two young children.

Natasha received support from the Headway helpline, as well as a grant from the charity's Emergency Fund to pay for her daily bus trips to and from the hospital. She now volunteers at Headway's charity shop in Cheadle as a means of saying thank you.

Meeting other people affected by brain injury has inspired Natasha to go to college and train to become a counsellor, supporting other people affected by brain injury.

#### **COLLEEN KELLY**

husband at the same time as your ninemonth-old baby.

Colleen had just qualified as a carer when her fiancé Andrew sustained a severe brain injury in a motorbike crash. Andrew remained in a coma for around eight weeks and spent a year in hospital, where Colleen visited him daily.

Rather than starting a new career, Colleen found herself caring for the love of her life while looking after their two young children and her mother who, just a month after Andrew's accident, was diagnosed with throat cancer.

Colleen was also forced to give up her dreams of marrying Andrew due to his severe memory loss.

Colleen puts everyone else before herself for several years and is described by Headway Swindon as 'a wonderful woman'.

#### **DANIEL WOOD**

In 2015, Daniel and his partner Dawn were involved in a car crash that left Dawn with a traumatic brain injury after suffering a bleed on the brain.

Daniel refused to leave her side, and when Dawn eventually returned home, he adapted his whole life to help her cope with the effects of her injury, which include serious mobility problems, fatigue, and dyspraxia.

As well as caring for Dawn, Daniel also somehow finds the time to work parttime as an electrician.

The couple are supported by their local Headway group Headway East Northants.

"Everything he does means more than I can ever show him and it's because of him that I get up every day and I fight a new day," said Dawn.

## Volunteer of the Year AnthonyGold

#### Sponsored by Anthony Gold Solicitors









#### PAUL DIAPER

After suffering optical nerve damage at the age of the 19, Paul's eyesight steadily deteriorated and he has been registered blind for the past 15 years.

He was diagnosed with intracranial hypertension, a build up of pressure on the brain caused by excess fluid.

As a result of being treated with steroids, Paul also developed avascular necrosis - the death of bone tissue due to a lack of blood cells which caused his bones to deteriorate.

He had his first hip replacement at the age of 29, and has had seven hip replacements and two shoulder replacements in the past 30 years.

In spite of these health problems, the father-of-three has dedicated the past six years of his life to supporting brain injury survivors and the work of Headway Southampton.

Whether he is accompanying service users to live music gigs, helping them cook, or hosting an afternoon tea with scones in his garden, Paul is always doing what he can to support brain injury survivors and raise awareness of the condition.

#### SANDY JOHNSTON

Twenty years ago, Sandy's son Daniel sustained a traumatic brain injury when he was left for dead in a hit-and-run incident.

When Daniel started to attend Headway Basingstoke, Sandy was asked whether he would like to volunteer - and he's not looked back since.

Over the past two decades, Sandy has donated thousands of hours to the charity and has taken on every job going.

He motivates clients to engage in their rehab activities, mediates when an individual's behaviour becomes challenging and supports men who have lost their network of friends and struggle to talk to female staff.

He takes people on trips to the garden centre and the swimming pool, activities they would not be able to enjoy if it wasn't for his generosity.

He's also been known to put on a silly outfit or two to help the charity raise funds, from a maid's pinafore to a Christmas elf costume.

Heather Jury, Service Manager at Headway Basingstoke, said: "Without volunteers like Sandy, the voluntary sector would be a quieter, smaller and less effective place."

#### **COLIN ROBERTSON**

Colin was enjoying a quiet night out in Livingston when he was brutally assaulted by three men who repeatedly stamped on his head.

The attack had ongoing repercussions for Colin including dizziness, blackouts and persistent headaches. Almost a year later, he suffered a subarachnoid haemorrhage and a variety of other complications, including epilepsy.

At first, Colin struggled to complete basic everyday tasks that he once took for granted, such as eating and speaking. He even struggled to remember his children's names or where he lived.

Colin began volunteering at Edinburgh Headway in 2009. Today, he is involved with a number of Headway groups and branches across Scotland, helping to arrange events, volunteering on committees, and educating children about cycle helmets and road safety.

Joyce Cattanach, from Headway East Lothian, nominated Colin for the award. She said: "Colin has a down-to-earth friendliness, cheekiness and ability to communicate with others on many levels which makes him a friend to many. Once you meet him you never forget him!"







# Stephen McAleese Outstanding Contribution to Headway Award



Sponsored by No 5 Barrister Chambers



 $\star\star\star\star\star\star$ 





A founder member of Headway Sheffield, Barbara has provided invaluable support to the charity for nearly 30 years.

BARBARA HARRIS

She has been an ever-present support for many families across Sheffield and South Yorkshire who are coming to terms with the devastating consequences of a brain injury.

Barbara supports all social events put on by the group, providing not only organisational skills but also sharing her clinical expertise as an occupational therapist to support and advise people as appropriate.

Cath Waterhouse, Chair of Headway Sheffied, said: "Barbara is the heart and soul of the charity. Her sense of duty to help people with brain injuries is unwavering and her enthusiasm and motivation to support individuals and their families has been huge.

"Without all of Barbara's hard work Headway Sheffield just couldn't support those people who rely on us." Geoffrey has volunteered at Headway Suffolk for more than two decades, selflessly devoting his time, energy and expertise to helping the charity and those it supports.

He has been a trustee and treasurer of Headway Suffolk since 2000, overseeing its accounts and offering a constant source of support.

In addition to overseeing the finances, Geoffrey has always been keen to offer support in any way he can. This has included helping to teach swimming, driving the charity's minibus, helping with an array of fundraising events, and offering a listening ear to service members and their families.

Helen Fairweather, Chief Executive of Headway Suffolk, said: "Geoff is a very special man."

#### PAULINE WATSON

From the moment she joined Headway Cardiff as a volunteer almost 20 years ago, Pauline's commitment and passion for helping was obvious.

Her skills and attributes were instantly apparent as she immediately began building a rapport with service users, whatever their background.

Within one year, despite her own serious health problems, she became a trustee and a key member of the group's fundraising committee.

She has been extremely influential in many key developments of the charity helping to support a number of services including community social groups and outreach services.

Although she has now retired from her trustee and fundraising duties, Pauline continues to volunteer at the group's Independence and Wellbeing Centre twice a week.

Headway Cardiff's Chief Executive Rebecca Pearce said: "Pauline's commitment to our charity is remarkable. 18 years of service – and all for free!"



# FITFOR FURPOSE: THE BENEFITS OF BEING ACTIVE

# Make sure you eat your five-a-day. Get plenty of exercise. Don't drink too much.

Messages encouraging us to live healthier lifestyles are everywhere these days – and understandably so. The benefits are clear and obvious, but while we can control what we eat and drink, is it always that easy to get regular exercise if you're living with a brain injury?

In this feature, we explore some of the innovative ways in which Headway groups and branches are making exercise accessible.



ONE SMALL STEP

The physical challenges after brain injury will be different for every brain injury survivor, and will vary depending on each stage of a person's recovery.

For Lucy Thurlow, who was told she would be paralysed for the rest of her life, walking again was a distant dream – let alone doing any form of exercise.

In 2011, Lucy suffered a series of epileptic seizures that left her blind and unable to walk. She was also unable to swallow, while her ability to communicate was significantly impaired.

But with support from Headway Hertfordshire, and through pure determination, Lucy worked tirelessly to regain movement in her legs.

Now she goes for assisted walks around three times a day, and also takes part in keep fit classes.

"The best part about my recovery has been re-learning how to walk," she said. "I love to walk everyday now, and will never again take such things for granted."

In 2016, Lucy created her own 2.6 mile version of the famous 26.2 mile-long London Marathon, which she dubbed the 'Lucy Marathon'. Displaying incredible will-power, Lucy completed the course over seven days, raising thousands of pounds for Headway Hertfordshire in the process.

Earlier this year she decided to challenge herself once again, this time walking three miles in 10 days.

Lucy said: "The whole thing gave me a buzz because it was so rewarding, especially knowing I had raised money to help other brain injury survivors along the way.

"To anyone else who is thinking about exercising I would say accept the challenge. If you are offered help, you should accept it.

"Also, you must not lose your temper and get frustrated when it's difficult. Keep smiling."

Lucy's story is a strong reminder that each brain injury survivor has their own marathon to face, but through determination and with support it's possible to achieve incredible feats.



## MAKE A SPLASH

Sarah Whitchurch, from Guernsey, also credits a passion for sport for helping her rehabilitation.

In 1997, when just 10 years old, Sarah fell ill with meningitis. As a result, she sustained a brain injury that left her wheelchair-bound with long-term partial paralysis in her limbs.

"I suffered short-term partial paralysis and for a long time I could only communicate through blinking," said Sarah. "Even today, I still suffer from weakness in my limbs."



"When I was finally discharged from hospital, I began a lengthy and very tiring process of rehabilitation. Eventually, I re-discovered my love of swimming and used my passion for the sport as an incentive to improve my movement.

"A daily challenge I faced – and still face today – is that I was unable to kick my legs and I suffered with limited dexterity in my hands."

In 2005, Sarah started attending cognitive development sessions with Headway Guernsey, where she made great progress. And, having rekindled her passion for sport as part of her rehabilitation, she went on to win national swimming and cycling competitions.

Her incredible achievements also include completing marathons in her wheelchair, and becoming the first disabled swimmer to battle the intense cold to complete the Guernsey to Herm race, which involves swimming 6 km against strong tides in open water.



# I WAS MUCH MORE CONFIDENT PHYSICALLY AND MENTALLY."

For many brain injury survivors, getting back on their feet can be tough.

But Pippa Bateman found that becoming steady on her feet helped with every aspect of her recovery.

"I had mobility and balance problems," she said. "I couldn't read, I was massively fatigued. I lost my sense of taste and smell and couldn't eat. I was depressed."

Before her accident Pippa ran her own alternative therapies company called Holistic Health Team. One of the exercises she taught was Nordic Walking – cross country walks using walking poles.

When she was confident enough to once again leave the house, Pippa took her Nordic Walking poles with her to help her balance. She never looked back.

"My husband commented on how I was a different person when I came back from my first walk with my poles. I was much more confident physically and mentally."

Over time Pippa found Nordic Walking improved her gait, her co-ordination and sense of wellbeing.

"When I go Nordic Walking I come back buzzing. The exercise releases natural endorphins which boost your mood. But I think there's something special about the co-ordination of it. It gives me confidence."

Pippa now teaches Nordic Walking to others and recently ran sessions at Headway's annual conference, The Way Ahead.



### ACCESS FOR ALL

The incredible achievements of others can be inspirational. But you don't have to be a record-breaker to reap the benefits of being active.

Many of Headway's 130 groups and branches across the UK provide a range of accessible exercise activities and sports for people of all ages and abilities.

#### SEATED ZUMBA

Zumba is an increasingly popular form of exercise that involves moving to the sound of energetic carnival music.

Sounds fun – but perhaps daunting for those with limited mobility. Not so at Headway South Staffs, where all service users are able to enjoy the high energy activity thanks to the introduction of a new seated version of Zumba.

"The good thing about the class is it's really inclusive," said Mitchell Wakeman, the group's support worker.

"There are moves for people who can stand and walk, and moves for those who need to use a chair." Mitchell has seen a real improvement in the people who have been attending the classes for the past six months.

"We have brain injury survivors who had problems with co-ordination and struggled with their balance or those who could stand but leaned to one side.

"After taking the classes for around six months they improved dramatically."

Paul Rowley, who developed a brain abscess in 2014, said: "It's good exercise for a Monday morning, it blows the cobwebs out.

"I get a chance to chat to the instructor Victoria about fitness. I also do Pilates in the week and it's great for my coordination and balance."

Mitchell has found holding sessions on a Monday morning helps set everybody up for a good week ahead. "When people arrive on Monday morning they might have had a bad week or be feeling stressed.

"The Zumba sessions tends to improve the mood in the room. Those who take part are more relaxed and ready to engage."

#### **BOCCIA**

Despite the 'Strictly factor', for some people dancing may not appeal. The Headway team in Northern Ireland was looking to run fun activity sessions that were more inclusive for all of their users – and stumbled across boccia.

Similar to bowls, the sport is specifically designed for people with disabilities.

Players work as a team to throw balls as close to the 'jack' as possible, working together to strategically plan their shots. They must take their shot from a seated position, so wheelchair users are immediately on a level playing field with able-bodied players.

Around 12 players attend the Belfast sessions each fortnight and players take it in turns to play in teams of six.

Steve Derby, Headway's outreach support co-ordinator for Northern Ireland, says playing a team sport has been really beneficial for those taking part.

"It encourages teamwork and communication," he said. "The idea is you work with the team to figure out who has the best shot.

"Talking can be hard for some, but it



gives them something to focus on and they have to communicate with one another."

"It also helps with co-ordination and balance; having to throw from a seated position has meant the guys have had to develop their own ways of throwing."

Service user Mark Rooney said: "I like coming to boccia because it's amazing craic. We're all playing a sport where we're sitting down. But we're competitive and we shout just like you would in any other sport.

"I love the social side of it, I get to spend time with everyone and have a laugh while I play a sport."

Fellow service user Chris Mooney, said: "What makes boccia great is that it's such a simple game that anyone can pick up and it's easy to take part in.

"We have guys in our boccia group who are in wheelchairs and guys who aren't; everyone has just as much chance of winning because the game is about strategy and teamwork. I've been playing for about three years and I'm still improving."

#### DISABILITY CYCLING

Spending a sunny Sunday gently pedalling around the park is commonplace for members of Headway Hull and East Riding.

The group has a selection of specially adapted cycles for a range of



disabilities, ensuring everyone has the opportunity to get involved, even people like Neil whose wheelchair can be locked onto the front of a bike, with another member providing the pedal power. Side-by-side bicycles provide another alternative for those who are unable to propel a standard bike.

For others like Shaun, who cannot ride an ordinary bike because of his balance problems and one-sided weakness, tricycles provide an opportunity to once again enjoy cycling.

Lesley Saunders, of Headway Hull and East Riding, said: "We thoroughly enjoy the fresh air and exercise together.

"Afterwards we find time for a chat and a coffee in the café, so it's very much a social activity as well as a healthy one."

#### DISABILITY FOOTBALL

Headway Wearside offers service users the chance to play walking football at the University of Sunderland, where they play among other members of the community with differing disabilities.

Not only have the sessions helped improve the players' mobility and balance, but by meeting other members of the local community they have broken down the barriers of social isolation.

Kim Hunter, Business and Community Development Officer at the Headway group, said: "We're football mad up here in the North East. A lot of our guys are Sunderland fans and have season tickets. They have football in common and playing it brings them together.

"They have made some really close friendships. As well as playing football, they go out themselves on a Wednesday afternoon and play ten pin bowling."

For Jimmy Dowell, the benefits of being active are abundantly clear.

"It's been 15 years since my brain injury and I've just sat about," he said. "Now I'm doing exercises and meeting lovely people.

"Playing football has given me my life back."



# PATHOLOGICAL LAUGHTER - DO FORE

Laughing and sharing a joke with loved ones and friends is a massive part of relationships and feeling close to them.

But imagine if you couldn't control when you laughed, even in the most inappropriate situations.

Worse still, although you were laughing, you actually thought you were crying.

Paul Pugh faces this problem every single day.

Paul was a victim of an unprovoked assault in his home town of



Ammanford, Carmarthenshire, while on a night out in January 2007.

A gang of four men, who were unknown to Paul, repeatedly punched and kicked him so hard that they fractured his skull, causing a blood clot that would leave him in a coma for more than two months.

Thanks to the support from his local branch Headway Carmarthenshire, Paul, now 37, has made a gradual recovery, but the attack has left him with a number of problems including pathological laughter.

"It can start at pretty much anytime, I feel a laugh coming a few seconds before it happens. Sometimes I can control it but a blip can happen," said Paul

"The laugh doesn't last long, a minute at the most, but it can cause a lot of problems if people don't understand what is happening or why I'm doing it."

Paul's laughter is caused by something known as the Pseudobulbar Affect (PBA).

Someone with PBA can be subject to involuntary bouts of crying, laughter or episodic anger. The outburst may be out of proportion and the effects are uncontrollable and can occur without any emotional trigger.

The frontal lobe of our brain normally keeps emotions under control. The cerebellum and brain stem are where our reflexes are mediated. With PBA, there is a disconnect between the frontal lobe of the brain and the cerebellum and brain stem.

Paul has been struck with hundreds of episodes of pathological laughter – many of these masking his actual tears.

He said the first time it happened was during an appointment four months into his 13-month hospital stay.

He said: "It was a serious meeting with my consultant, rehabilitation therapists and my family to discuss what my life and future was going to be like.

"When they started talking about me, I was frightened and it triggered something off in my brain and I laughed right through the meeting. Little did I know at the time, I was actually crying my eyes out, but it came out on the surface as laughter. It's heartbreaking.

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"It wasn't a until a few years later that I got a diagnosis and that hit me hard because I didn't know what to do with myself.

"I was lost and felt that the world was caving in on me. But it has improved and now it all makes sense to me."

Paul said the laughter has led to many awkward situations and reactions particularly from people who are not aware of his injury.

He said: "People can feel uncomfortable, hurt and confused. Some have been upset and have reacted by being sarcastic with me or even aggressive.

"It's amazing how important laughing is. You take it for granted but it has a really powerful effect; if you share a joke with someone it's special."

Paul is very keen to raise awareness around pathological laughter and the effect it has on the people trying to live with it.

He said: "People most definitely need to be aware of pathological laughter,

because it can have a serious impact on the person who is trying to cope with it.

"Even some people that know I have sustained a brain injury can be insensitive towards me at times because of the laugher. They don't realise the impact it can have on someone's life.

"At times, it does make you feel like you are incapable of moving on.

"I just want people to fully understand the issue and have the ability to recognise it and treat people with some compassion. We aren't laughing out of spite - something more could be going on and we could even be very sad.

"We cannot always control it, but people can control how they react."







#### **Andy Tyerman, Consultant Clinical Neuropsychologist** and Trustee of Headway, said:

"The term Pseudobulbar Affect refers to uncontrolled expression of emotion that is disproportionate or inappropriate to the social context in which it is expressed and may be inconsistent with what the person is actually feeling.

"For example, a person might appear very distressed about something that would previously have been only slightly upsetting or respond to situations with inappropriate emotions such as laughing at bad news.

"Having control of our emotions is incredibly important and losing that ability can be deeply upsetting and lead to challenges when trying to form and maintain relationships.

"The impact of PBA should not be underestimated. Anyone affected by this or other behavioural or emotional problems after brain injury needs access to specialist support to help them cope with the significant challenges that brain injury can bring."

# ADOGISFOR LIFE...

It's often said that dogs are man's best friend. But for some people, their pets provide a listening ear that never complains and companionship they may not receive elsewhere.

Owning a pet can have huge benefits for our health and wellbeing. Indeed, for some brain injury survivors having a furry friend to love and care for has completely changed the course of their recovery.

Here, brain injury survivors tell us why their pets have meant so much to them after brain injury.

## Karen, Ross and Benjie

Karen Hampson's team of furry friends comprises of Ross the Shetland Sheepdog, Benjie the Yorkshire Terrier/ Jack Russell cross, and two albino rabbits called Terry and Pixie.

After she was assaulted in her own home, Karen was left with a number of longterm problems with planning, memory, concentration, mobility and vision.

"When humans let me down my animals put me back together," she said. "Ross helps me stick to a routine by getting me up in the morning, while Benjie plays his part by singing as a prompt when the washing machine finishes.

"My support network has paws. What can I say...I'm so blessed."



### Lydia, Dusty, Lancelot, and Pablo

Lydia Galvin's two Beagles and a Staffordshire Bull Terrier have played a vital role in rebuilding her life after she suffered a stroke in November 2016.

"It may sound sad to some but my dogs have become my friends," she said. "I need peace and quiet to rest my brain and my dogs are so therapeutic. They know when I'm suffering from fatigue and they'll just cuddle up on the couch with me."

Feeding her dogs, playing with them, and walking them gives Lydia a sense of routine. But it also provides her with a reason to get out of the house.

"My dogs have saved me from the loneliness a brain injury can cause." Alice and Digby

Alice Ashton, 61, owes her life after brain injury to her Boxer/Labrador Cross, called Digby.

On a cold, wet January day, Alice was walking Digby when she collapsed behind parked cars having suffered a brain haemorrhage.

A passenger in a passing car noticed Digby jumping up and down and went over to investigate, and found Alice on the floor.

"He is quite literally my lifesaver," said Alice. "When I first came home after my brain injury I was quite weepy. Digby would get on the sofa, rest his head on my shoulder and look at me as if to say 'It's alright, Mum'.

"He gives me reassurance. I wouldn't be without him."











## Tom and Stanley

Tom Wright found it hard to accept how his brain injury had changed him after he was involved in a motorbike accident in 2012.

But, like others have reported, his Sprocker Spaniel Stanley gives him a reason to get up in the morning.

"I had a difficult time after my brain injury," said Tom. "Stanley helped to motivate me because I needed to get up to feed him, walk him, and let him out to go to the toilet.

"A spaniel isn't a breed everyone could cope with. I often say he's on Duracell Plus batteries because he doesn't get tired no matter what I get him to do.

"Without Stanley, I wouldn't be the person I am today. He has become my best friend.

"He loves a fuss. He is so loyal, gentle and just a soft, soppy dog."

### Azra and Jazz

Azra Harte, 39, has owned her four-yearold Cavalier King Charles Spaniel Jazz since he was a puppy.

Two years ago, Azra fell ill with meningitis and then encephalitis. Afterwards she was left feeling extremely low and developed severe anxiety.

"The unconditional love of a pet is like nothing else," she said.

"I truly believe Jazz is the reason I'm still here. He gave me purpose, consistency and a reason to keep going when I was at my lowest points.

"But Jazz gives me a purpose to get up, because I needed to feed him and walk him.

"We go everywhere together and he's very special because he's so in-tune with me. I don't have any family so he really is my everything.

"When I go out I feel like people are looking at me but when I'm with him that feeling fades away. People come over to stroke him, which helps me to interact



# Things to consider before getting a dog

Having a dog can be extremely rewarding. But it is also a very big commitment that demands time, money, and care. Every dog is different, so if you are considering getting one, you should research which kind of dog is best suited to you.

## What dogs need:

- A safe and suitable environment
- Toilet breaks throughout the day
- A daily routine including regular exercise and play time
- · A balanced diet
- Grooming
- Training
- Vaccinations, flea, tick and worm treatment
- Pet insurance
- A microchip and a collar and tag when out in public – this is a legal requirement

(Information supplied by Dogs Trust. For further information on owning a dog, visit www.dogstrust.org.uk)









# #HeadwayHeroes Artists find a STRIKING way to raise awareness

How do you make a cycle helmet 'cool'? That was the challenge set to a group of prominent artists, fashion designers, jewellers, milliners and illustrators... and boy did they deliver!

Strike: The Helmet Project was a unique charity exhibition of bike helmets that had been transformed into decorative works of art.

The project was created by friends Alice Snape, Mark Holloway, and Alex Binnie after Alex's wife, Zoe, sustained a serious brain injury when cycling in Brighton in June 2015. Sadly, she wasn't wearing a helmet.



26 Headway News The exact cause of the accident is unknown but after being found alone, convulsing in the street Zoe was in hospital for 15 days, including time in intensive care.

Although she has made a good recovery, it was a long and frightening experience involving almost a year of debilitating anti-convulsive drugs.

Alex explained: "The idea was to raise awareness about brain injury and the importance of bike helmets and provide essential financial support to the charity Headway.

"We also wanted to have a bit of fun by turning a rather functional piece of kit into a piece of art. Why can't bike helmets be the new skateboard?"

The creative superstars, including artist Grayson Perry, were each sent a helmet as a canvas on which to put their own artistic touch – to stunning effect.

The artwork was on display at Look Mum No Hands, a cycle cafe in London, before being auctioned to raise money for Headway.

And thanks to some very generous bids – including one from music legend











Boy George, who successfully bid for Grayson Perry's creation – more than £13,000 was raised to improve life after brain injury.

"What a fabulously creative event!" said Jo Plant, Director of Fundraising at Headway.

"A big thank you must go to Alex, Mark and Alice for organising it, and indeed to Majestic Wine Warehouse for providing auction guests with a glass of bubbly.

"Naturally, we also have to say thank you to our fabulous artists for giving their time and expertise so generously."



# Aldermore Bank scores record amount

A football tournament held at the FA's national training centre, in memory of a bank employee who died of a brain injury, has raised more than £12,000 for Headway.

Now in its third year, the annual fivea-side match was hosted by national finance broker Aldermore Bank to honour the firm's former employee Adam Massen.

This year's tournament, held at St George's Park in Staffordshire, saw a record of 20 teams sign up, including 13 broker teams and a number of other financial services providers.

Co-hosting the event was exprofessional footballer, Ray Parlour, who made more than 300 appearances for Arsenal and was capped 10 times for England during a glittering 20-year career.

The teams battled it out for the Adam Massen Cup, with the mighty LDF Operations Limited taking the honours

by beating Kennet Leasing 1-0 in the final.

Carl D'Ammassa, Group Managing Director, Business Finance, at Aldermore, said: "The whole day was a huge success and a fitting tribute to Adam, our fondly remembered asset finance colleague and a big football fan.

"A huge thank you to all the teams that participated and congratulations to LDF Operations Limited. It was great to see other funders participate this year, making this a true industry-wide charity event.

"Aside from the football, the biggest result of the day was beating our original target of raising £10,000, making this year's tournament the best yet.

"Headway is a great charity to be involved with and it is our pleasure raising money for such a worthwhile cause, and one that is close to our hearts."



Jo Plant, Director of Fundraising at Headway, said: "We are extremely grateful to Aldermore's staff and all the other participants who took part.

"The tournament always has a wonderful atmosphere and is such a fitting memorial to Adam.

"The funds raised will help ensure more brain injury survivors and their families access crucial support from the charity."

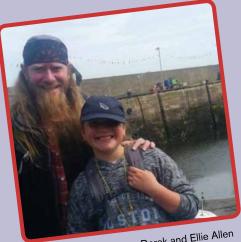


### #HeadwayHeroes

# THANK 10U

## to our #HeadwayHeroes!

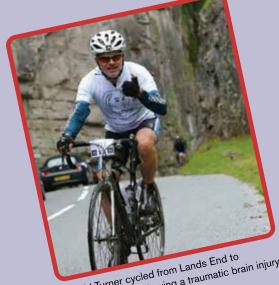




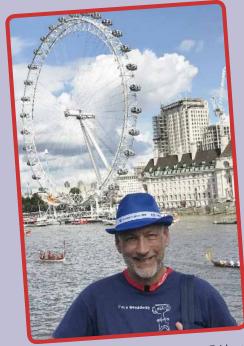
Father and daughter duo Derek and Ellie Allen who this time completed a 100-mile walk over five days raising more than £1,500



Siobhan Sharp was one of many to conquer marathons in 2017!



David Turner cycled from Lands End to John O'Groats following a traumatic brain injury in 2014



Peter Spillman completed the Thames Bridges Trek and continues to fundraise for Headway after he sustained a brain injury in 2007



The Channel Ladies swim team who together swam the channel three times over, completing the



Giles Johnson tackled rough terrain and open waters raising thousands of pounds in the process



Thanks to everyone who took part in this year's Hats for Headway Day!

Have you been inspired to help Headway? Find out how you can help improve life after brain injury in 2018 by visiting www.headway.org.uk/get-involved

# Charlie shows plenty of get up &

When it comes to fundraising challenges, sitting down for 24 hours seems a doddle.

But for motorsports fan Charlie Rickett, his day in the seat involved tackling a 24-hour endurance go-karting event to help raise awareness of brain injury and support others affected.

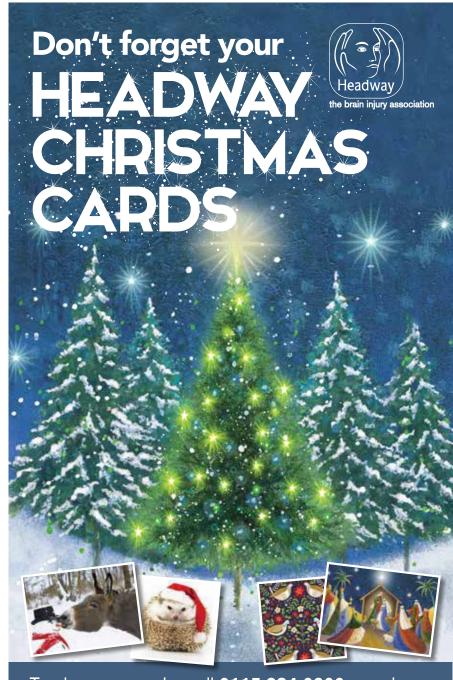
In March 2010 Charlie sustained a brain injury following a fall. He had hit the back of his head so hard that he had a six inch crack in his skull, resulting in a hematoma between the brain and skull itself.

Seven years on, having made a good recovery, Charlie wanted to help others similarly affected.

After a strict diet and training programme, Charlie completed the gruelling endurance race - raising more than £14,000 in the process!

What a guy!





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Anne Cahill

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

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