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Prince Evans Solicitors LLP
Craven House, 40-44 Uxbridge Road, Ealing, London, W5 2BS

Tel: 0800 019 0991 **Fax:** 020 8579 0191

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

www.prince-evans.co.uk



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

Spring 2017

Headway News



The magazine of Headway - the brain injury association

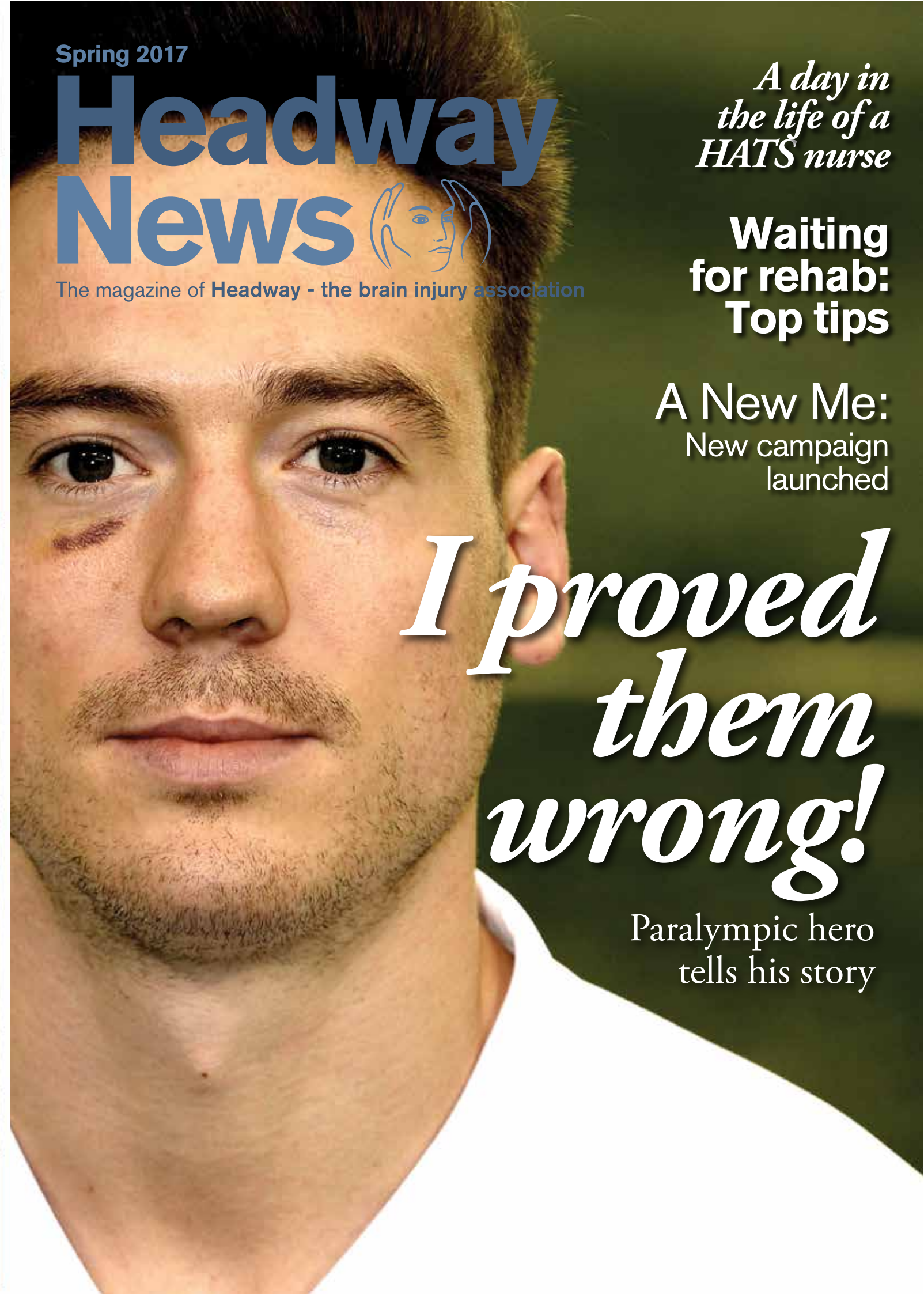
*A day in
the life of a
HATS nurse*

**Waiting
for rehab:
Top tips**

A New Me:
New campaign
launched

*I proved
them
wrong!*

Paralympic hero
tells his story



HATS FOR HEADWAY DAY



headway.org.uk
#HatsForHeadway

**ACTION FOR
BRAIN INJURY WEEK 2017**



the brain injury association

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

Headway is the leading UK-wide charity that supports people to rebuild their lives after brain injury through the provision of information and support services across the UK. To find out more, visit www.headway.org.uk or you can call the freephone helpline on 0808 800 2244 if you need support.



the brain injury association

A false positive or a positive negative?

We recently asked a question to our social media communities. We were curious to find out how – if at all – people acknowledged the anniversary of their brain injury.

While we expected a range of responses, we were surprised by the positivity of messages we received. Many of those who responded to us did so by telling us how they go out for dinner, or even celebrate it as a new birthday – a day that marked a new beginning, or 'a new me'.

Naturally, for many others the anniversary of their injury can be a difficult day that can cause unsettling feelings or negative emotions to resurface.

What is clear is that brain injury is an intensely personal journey and there is certainly no right or wrong way to acknowledge the anniversary of such a life-changing event.

Every brain injury is unique, as too is the way in which people are able to respond to the challenges it can bring – or the 'new me' it can create.

During Action for Brain Injury Week, which takes place from 8-14 May, we want to ensure the voices of people affected by brain injury are heard. Whatever your experience, whatever your outlook on life, your voice can help us to raise awareness of the impact of brain injury.

Your views, your frustrations, your successes – they can all start a conversation and get people thinking. And that's what we need, isn't it?

We need people talking and thinking about brain injury. We need people to realise that it can happen to anyone at any time, and we need people to understand that it can change the very fabric of who we are.

Find out how you can make your voice heard at www.ANewMe.org.uk and let's take action for brain injury this May!

The Communications Team

Published quarterly by:

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

Freephone helpline: 0808 800 2244

Advertising: Joe Leadley: 0115 947 1912
information.manager@headway.org.uk

Website: www.headway.org.uk

Telephone: 0115 924 0800

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

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Your views...

As we (slowly!) move away from the darkness of winter and head towards the sunshine of spring, which can help put a smile on our faces, we wanted to find out what else makes you happy. Here's what you said:

I like spending time with my wife, when I'm not being an awkward so and so, and having the energy/get up and go to get out and go and ride my bikes etc.

Roger Merriman

My children are my light, their energy, humour and love are such a tonic. My time with them is more important now than ever! Feeling emotional after writing this.

Graham Hunter

Things are so hard... hubby has sustained a hypoxic brain injury. I make sure he knows he is surrounded with love. However, It makes me happy that we wake up every morning. We can breathe, we are alive.

Maria-Louise Jenson Leech

What makes me happy is seeing my partner get better bit by bit every day after his brain injury a year ago and our three wonderful kids doing so well after a hard year.

Stef Tharme

Going for walks somewhere beautiful and peaceful, by the sea or in countryside nearby; or looking at photos of somewhere I've been where I was really relaxed, happy and panic-free; or spending time with my wife and little person!

Paul Matthews

Remembering something or figuring something out I struggled with before. Still pushing the glass ceiling of my disabilities. Always makes me happy. Also seeing others do the same... that's special.

Gary Kearney

Seeing my mum get stronger every day after her hypoxic brain injury in December.

Kirsty Clothier

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The different ways people acknowledge the anniversary of their brain injury

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'It meant I could breathe'
We look at how the Emergency Fund is making a difference

news you may have missed...

Record year for Headway help

More people than ever before accessed support from Headway in 2016, demonstrating increased awareness of the charity and the support it provides, while highlighting the ever-increasing prevalence of brain injury.

Enquiries answered by the charity's helpline rocketed to almost 10,000 in 2016, representing a 17% increase on the previous year.

In addition, there were almost 800,000 visits to the Headway website – an increase of 6% over the previous record total. For many of these people, their visit will have been the first time they have accessed help, with the website acting as a portal to vital information as well as an introduction to the their local Headway group or branch.

The impressive figures for the year also include 82,000 free downloads of the charity's award-winning publications, almost 1,500 families supported by our

HATS nurses, and around £50,000 distributed by the Emergency Fund.

Luke Griggs, Director of Communications, said: "We are pleased to see more people turning to Headway for help, but these figures demonstrate the increasing need for support.

"We are determined to continue to develop our services further in 2017 and beyond in order to meet this demand."

Charity praise for 'exemplary' care

Headway has praised the paramedics and doctors who treated Hull City footballer Ryan Mason after a clash of heads left the player with a fractured skull.

The shocking incident, which took place in a match between Chelsea and Hull City in January, led to doctors from both clubs treating the player on the pitch. Mason was then transferred to St Mary's Hospital in London and was in surgery within the hour.

"I was actually at the match and, while it was upsetting to witness the incident, it was encouraging to see the exemplary reaction of the medical teams," said Peter McCabe, Chief Executive of Headway.

"This is a tragic reminder of the serious implications that can result from a clash of heads, which can occur in any game of football or indeed any contact sport. Thankfully, in this instance, first-rate medical attention appears to have prevented a more serious outcome for this young man."

Headway has extended an offer of support to the player and his family and we continue to wish him well in his recovery.

Having accepted an offer of support from the charity, Ryan and his family - along with his former club Tottenham Hotspur - were keen to say thank you.

As a show of support to their former colleague, Spurs players wore t-shirts saying 'Get well soon Ryan' while warming up for their FA Cup match against Wycombe Wanderers on 28 January.

The t-shirts were then auctioned to fans, raising thousands of pounds for Headway.

"This means a lot to me, thank you @SpursOfficial," Mason wrote on Twitter.

"All funds raised are going to @HeadwayUK a fantastic charity who help those who have suffered brain injuries.

"I would also like to take this opportunity to thank everyone for all of your continued support it really does continue to help me. Thank you."

Calls to delay controversial cuts

Headway has welcomed calls to delay controversial cuts to Employment and Support Allowance (ESA) until the government clarifies how it will support all those affected.

The Work and Pensions Select Committee found there was little evidence that a lower payment would motivate disabled people to find work. The committee also said that evidence supporting the idea that introducing a lower rate of ESA would enhance incentives to work was 'ambiguous at best'.

Peter McCabe, Chief Executive of Headway, said: "Welfare support can provide brain injury survivors with the opportunity to increase their independence and confidence, play an active role in their communities and, where possible, seek a return to employment or education.

"These cuts will cause unnecessary hardship, increasing the risk of social isolation and anxiety, and potentially increasing brain injury survivors' long-term dependence on state support."



Ryan's teammates urgently call for assistance. Image courtesy of Hull City AFC.

news you may have missed...

Celebrating a decade of support



Two Headway groups have celebrated their tenth anniversaries in fine style.

In January, Headway Bradford welcomed 70 supporters including volunteers, members, MPs and city councillors to an evening of glamour at City Hall. The venue was symbolic as it was where the group held its first ever meeting a decade ago.

Deputy Lord Mayor, Councillor Alun Griffiths, opened proceedings with a speech, before presenting the Headway Bradford committee with a certificate to recognise their commitment to helping local people affected by brain injury.

"It is extraordinary to think about how quickly our support group has grown," said Pam Drake, Chair of Headway Bradford.

"From delivering a simple social meeting for just 15 people ten years ago, we are now supporting more than 100 members across Bradford and receiving floods of enquiries on a regular basis."

Meanwhile, Headway Guernsey marked 10 years of improving life after brain injury by kicking off 2017 with a move to a new home in the heart of the community. The move to the new centre has enabled the group to launch a host of new services, including gardening and independent lifestyle skills programmes, to sit alongside its highly-rated cognitive rehab programme.

"Our team of fabulous helpers worked tirelessly to prepare everything for the big opening," said Philippa Stahelin, Executive Director at Headway Guernsey.

"Thank you to all who have contributed to making this happen."



Party time at Headway Guernsey

news you may have missed...

ACTION FOR

BRAIN INJURY WEEK 2017

A New Me: ABI Week theme announced

The thoughts, feelings and experiences of brain injury survivors, carers and family members will be at the heart of this year's Action for Brain Injury Week campaign, which takes place from 8-14 May.

A New Me will provide a platform for people to creatively share their experiences in order to challenge

misperceptions of brain injury while demonstrating the value of having access to the right help, at the right time – such as the support provided by Headway groups and branches.

"We know that brain injury is generally misunderstood, while those whose effects are largely hidden can struggle to get the help and support they need," said Luke Griggs, Director of Communications.

"Through the power of social media, a targeted press campaign, and local events across the UK, we hope to increase the public's understanding of brain injury and ensure the voices of people living with brain injury are heard."

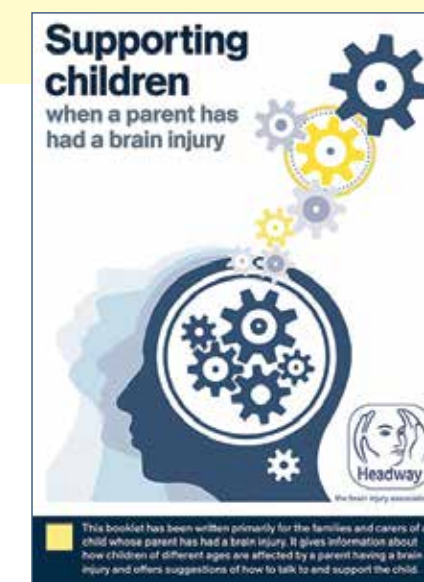
Keep an eye on our campaign website at www.ANewMe.org.uk and our social media sites for more information!

New publications added to information library

Headway has added to its library of publications by launching a new booklet, *Supporting children when a parent has had a brain injury*, and a new factsheet *Waiting for rehabilitation after brain injury*.

Supporting children offers information on how to give age-appropriate support to a child whose parent is in hospital or has returned home following a brain injury.

Waiting for rehabilitation addresses the concern that many families face when a brain injury survivor is discharged home and placed on a waiting list for rehabilitation.



Both publications have been written in conjunction with experts in the respective fields, and are available for free download from the Headway website.

Waiting for rehab

Specialist rehabilitation can play an important role in the recovery process following brain injury. Early access to key therapies, often in an in-patient setting, can help survivors on their potentially long journey.

It can also provide a timely boost to the morale of the patient and their family who can gain a sense of hope that they are beginning to move in the right direction.

While some survivors access rehabilitation services directly after being discharged from hospital, many are increasingly finding themselves being sent home to be either placed on a waiting list or with no referral to rehabilitation having been arranged at all.

Understandably, those who find themselves back at home are often confused and concerned at having to wait to receive appropriate therapy to maximise their potential of recovery.

"I fought for weeks to get a referral to a centre that was appropriate for my husband's needs and that he could actually get to," said Jenni Moorhouse.

"I also bought books from Headway and together we did training exercises.

"Four years on, he still has problems but has come a long way, which he wouldn't have done if I had not pushed for what he needed."

To address such concerns felt by many brain injury survivors and their families across the country, we've put together a list of top tips on what families and carers can do while their relative is waiting for rehabilitation after brain injury.

- Keep in touch with your relative's GP to ensure that the arrangement for rehabilitation is still on track.

- Let your relative rest and encourage them not to fight through fatigue.

- Minimise levels of stimulation in your relative's environment, such as loud noises or very bright lights.

- Encourage your relative to gradually increase their activities in the first few weeks rather than going straight back into the routine they had before their injury. This is especially important if your relative lacks insight into how their injury has affected them.

- Remember that problems with managing anger are a common effect of brain injury. If the anger is being directed at you, try to stay calm and remind yourself that it isn't personal.

- Explore the idea of a home activity programme. This involves creating a regular schedule for your relative that consists of activities around the home that they can enjoy and undertake safely.

- Take time to learn about the brain, and encourage your relative to do the same. This can help with devising coping strategies. You can download our booklet *The effects of brain injury and how to help* from the website.

- Consider making arrangements for other family members or friends to spend time with the brain injury survivor on a regular basis. Social services may also be able to arrange for some support with caring, or you could look into befriending schemes.

- Make contact with your local Headway group or branch or the Headway helpline for support and information. Visit our website to find your local Headway.

Why the wait?

In a study recently published by the Chartered Society of Physiotherapy, a fifth of health trusts were found to be making stroke survivors wait for at least 13 weeks before accessing physiotherapy.

Another source found that the average waiting time between assessment and



eventual admission to a rehabilitation unit was 31 days, despite standards published by the British Society of Rehabilitation Medicine suggesting that access to local specialist rehabilitation services should happen within two weeks of assessment.

So despite guidelines and the growing body of evidence highlighting the benefit of early access to rehabilitation, why are so many people finding themselves placed on a waiting list for rehabilitation?

"Lack of funding and services is a disaster," said Jem Swindell on Facebook. "We have also found it is a postcode lottery as to services and waiting lists. At the end of the day it should be classed as a long term condition and supported accordingly."

Lack of funding would certainly appear to be at the heart of the issue. Research published in the British Medical Journal shows that 63.5% of adult intensive care units feel that lack of funding is the main barrier to providing rehabilitation services. Insufficient resources and a lack of priority by clinical management teams were also seen as barriers.

Families have also reported to Headway concerns about flaws in the commissioning process and a lack of understanding of the needs of patients.

An expert view

Access to timely specialist rehabilitation following brain injury greatly enhances a person's chances of making a meaningful recovery.

Through a process called neuroplasticity, the brain can develop new connections as it attempts to heal itself. Intense therapy can aid this process, so early admission for patients who need rehab should always be a priority for healthcare services.

It's also important for people to understand that directly returning home from hospital will not necessarily have long-term implications. Every brain injury is unique and there is no singular route to recovery.

With rest and by using the top tips listed in this article, brain injury survivors and their families can aid the recovery process while waiting for rehabilitation.

Dr Daniel Friedland,
Consultant
Neuropsychologist



Find out more

For further information, including more top tips, download the free Headway factsheet *Waiting for rehabilitation after brain injury* from the information library on our website. Alternatively, contact the helpline on 0808 800 2244 or helpline@headway.org.uk.

A DAY IN THE life OF A

The acute stage of care following a catastrophic brain injury can be an incredibly challenging time for families. Fears over whether their loved one will survive can be replaced by apprehension over what sort of future they will have.

HATS nurses can:

- Be a 'listening ear'
- Link to hospital staff & community support
- Provide benefits information
- Visit you in the hospital
- Advise on the Headway Emergency Fund
- Continue supporting you for as long as you need
- Accompany you to meetings with hospital staff

Many families find themselves frightened, isolated and confounded by medical jargon. Headway Acute Trauma Support (HATS) nurses provide support to families during this unimaginably stressful time.

The HATS nurses can provide emotional and practical support, offer a listening ear, act as a link between the medical teams and the

family, and signpost people to other support services such as the Headway Emergency Fund.

Here, Alex Power, who has been a HATS nurse in the North West of England for the past five years, shares a typical day in her role in order to provide insight into the vital work of the team.

08.00

I check my messages before setting off to a meeting at one of my hospitals. I have an email from Hannah who lives abroad. Her mum is in hospital here following a fall, and she needs information and support. I email her back, reassuring her that I will phone later today.

09.30

I attend a neuro-team meeting at the hospital. We discuss current patients, planned care and other issues including how family members are coping. I inform the team that there is a patient's husband who is struggling to afford petrol to travel to the hospital,

and is very anxious. As a result, I have helped him successfully apply for the Emergency Fund; he now feels that 'one worry is off my shoulders'.

11.00

I meet with a neuropsychologist to discuss how we can work together to support patients and families. We talk through Headway services and I show him our literature and website. He seems impressed.

12.15

I catch up with Joyce and Tony over a cup of coffee. Tony, aged 70, had a brain injury three years ago. He is now living at home and attends his local Headway branch, but he needs a lot of support and Joyce is tired. She has told me before that while she was overjoyed when Tony returned home, she did not realise it would be so hard. Joyce is unable to speak about her feelings when Tony is there, so I make a note to call her tomorrow and talk things through.

HATS NURSE

13.30

I visit the critical care unit to speak with Derek. His daughter Emma was struck by a car two weeks ago and had a bleed on the brain.

He hoped she would be getting better by now, but although her condition is stable, it is not improving. I explain some of the clinical terminology to him, and we talk about the possible issues Emma may experience as time goes by. I give Derek some Headway factsheets regarding the early stages of brain injury.

He tells me Emma's mum passed away just six months ago, and he doesn't think he has the strength to get through this. I sit quietly and hold his hand while he cries. There are no guarantees for Emma's future, but I will try to support Derek for as long as he needs.

15.00

I head back to the office. I often use this time to think through the day. Derek's situation has left me feeling quite sad, so I contact a colleague for support.

15.45

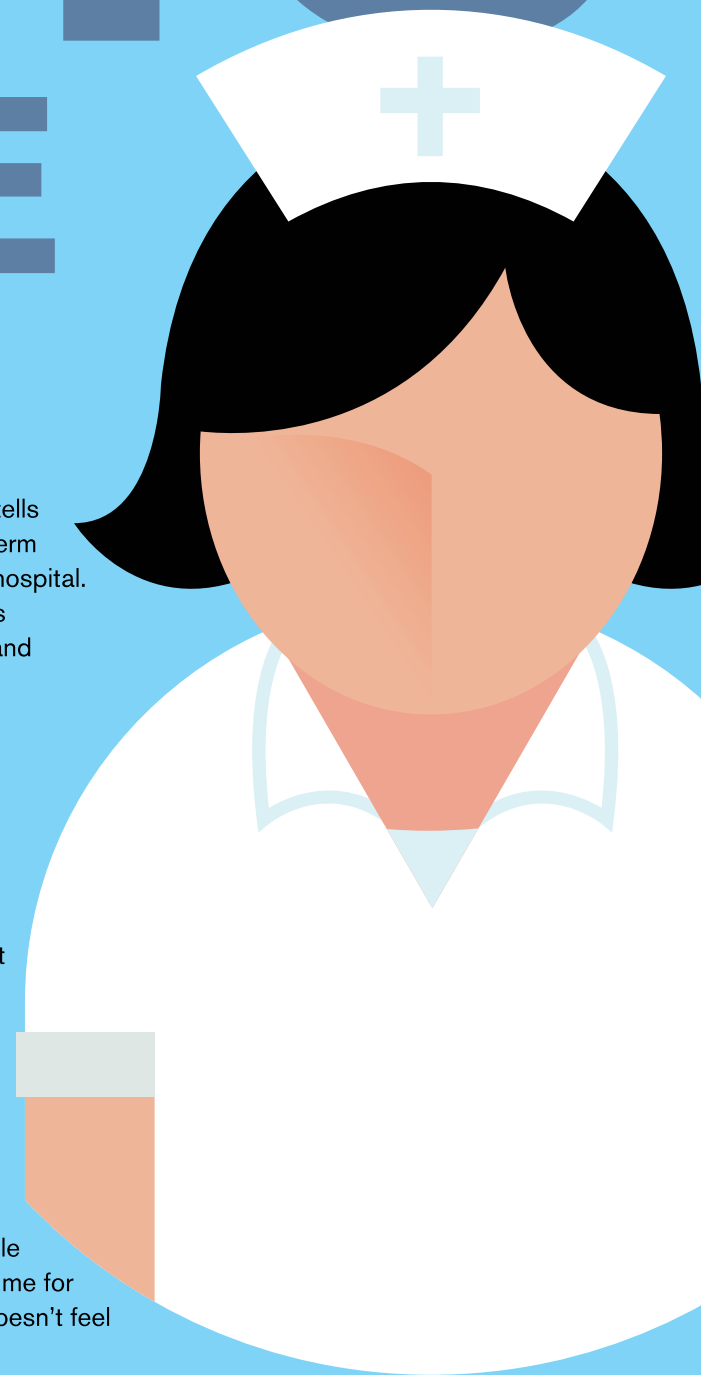
I call Hannah back, and she tells me her mum will need long-term care when discharged from hospital. I inform her about Headway's Approved Provider scheme and direct her to our website for units in the area.

As Hannah cannot access support where she lives, we discuss the Headway HealthUnlocked forum and I give her the number for the helpline. She can contact me or use these resources for help and information anytime she wants.

17.00

I write up my notes for the day and message Derek to say I will visit again in a couple of days. He replies, thanking me for being there and stating he doesn't feel quite so lost anymore.

Please note, names have been changed for confidentiality reasons.



TEARS, LAUGHTER & CELEBRATION at Annual Awards

Wonderful achievements, inspirational bravery and extraordinary commitment were recognised and celebrated as Headway supporters from across the UK attended this year's Annual Awards at The Dorchester Hotel.

The ceremony saw 12 exceptional people honoured in four categories of awards, all of which were presented by Headway's Vice President James Cracknell.

If you were not fortunate enough to be there, here's just a glimpse of what took place while you can also watch a video of the ceremony on our website.

Remember, the nomination process for this year's awards will open after Easter – so start thinking of someone special who deserves recognition and thanks.

Huge thanks must also go to our sponsors:



Tables set for a fabulous three-course lunch in the ballroom at The Dorchester Hotel.



Double Olympic gold medalist and Headway Vice President James Cracknell presents Janet Malcolm with her certificate for being a finalist in the Carer of the Year category.



Sue Hawkins, a finalist in the Stephen McAleese Outstanding Contribution to Headway Award category, gasps as she watches the surprise film made by her friends.



Sports journalist and Sky News presenter Tom Macleod did a masterful job hosting the event for the third successive year.



Jack Rutter, whose inspirational story you can read on pages 18-21, is interviewed live on stage by Tom.



TV antiques expert Eric Knowles once again acted as guest auctioneer on the day - and proved to be as entertaining as he was effective!



Guests were captivated by a number of powerful films depicting life after brain injury.



Jane Reams proudly shows her award and certificate after being honoured with The Stephen McAleese Outstanding Contribution to Headway Award.



Finalist Norma Williams receives her certificate from John and Susan McAleese.



Lucy Thurlow, a finalist for the Alex Richardson Achiever of the Year award, was supported by her family and friends.



Looking as impressive as ever, Headway Special Ambassador Lance Corporal Johnson Beharry VC accepted fundraising cheques on the charity's behalf, while handing out this year's Challenge Batons.

Raising awareness

As well as providing an opportunity to acknowledge and thank those who go to extraordinary lengths to support others affected by brain injury, the Headway Annual Awards also help us to raise awareness of brain injury and the wonderful work being done by groups and branches across the UK.

Thanks to the bravery and willingness of all 12 finalists who were prepared to share their experiences in the

press, this year's media coverage for the annual awards broke all records.

Around 130 pieces of powerful press coverage were secured, with each finalist and their respective Headway group or branch featured in either television news features, radio interviews, newspaper columns, or online articles.

The nomination process for the Headway Annual Awards 2017 will open in April.

The question is, who will you nominate?



Janet is honoured for her care

Pamela 'invaluable' to brain injury survivors

LIFE and TIMES Janet's in running for carer of the year

Heather's devotion wins top carer award

Mum's group helps support other patients

Brave Michael scoops top award

THE ROAD TO RIO

VIA INTENSIVE CARE!

When Birmingham City youth player Jack Rutter was attacked outside a Gloucester nightclub in 2009, the then 18 year old was left with a traumatic brain injury that brought his career goal of becoming a professional footballer to an abrupt end.

But while his dreams of being a professional footballer had been cruelly dashed, sporting glory would not elude him...

DARKEST DAYS FILLED WITH DEPRESSION AND ANXIETY

"I thought I'd be alright and could get back on the field. When it became clear that I'd never be the same again – that was when the reality of brain injury really hit me."

Many people who sustain brain injuries will resonate with Jack's thoughts and understand the challenge of having to accept the life they once led is gone. For Jack, this meant having to say goodbye to his hopes of becoming a professional footballer.

Jack had been on the verge of signing a professional contract with Birmingham City when, in the early hours of 22 March 2009, he fell victim to an unprovoked attack on a night out with friends.

Jack was punched in the head and fell to the ground, striking his head on the kerb. Just one punch – one moment of

senseless violence – changed Jack's life forever. His attacker was jailed for one year.

Jack spent two weeks in a coma in intensive care at Bristol's Frenchay Hospital before the terrible reality of his brain injury gradually began to sink in.

"Everything I'd worked towards had been wiped away," Jack recalled. "For the first 48 hours after the attack it was touch-and-go whether or not I survived.



10-year-old Jack was a star in the making

"My darkest days were filled with depression and anxiety. I just thought 'What are my options going to be?'"

"Even when I regained consciousness and was finally well enough to leave the hospital, I was exhausted and my balance and co-ordination were all over the place. For weeks, I would sleep for 20 hours each day and couldn't walk straight.

HEADWAY HELPED ME UNDERSTAND

A key moment for Jack was when Headway Gloucestershire's Hilary Osborne visited his house shortly after his discharge from hospital.

"Up until this point, no one had actually told me what 'brain injury' could really mean," Jack continued. "Once I was discharged back into the world, I had no idea what was going to happen.

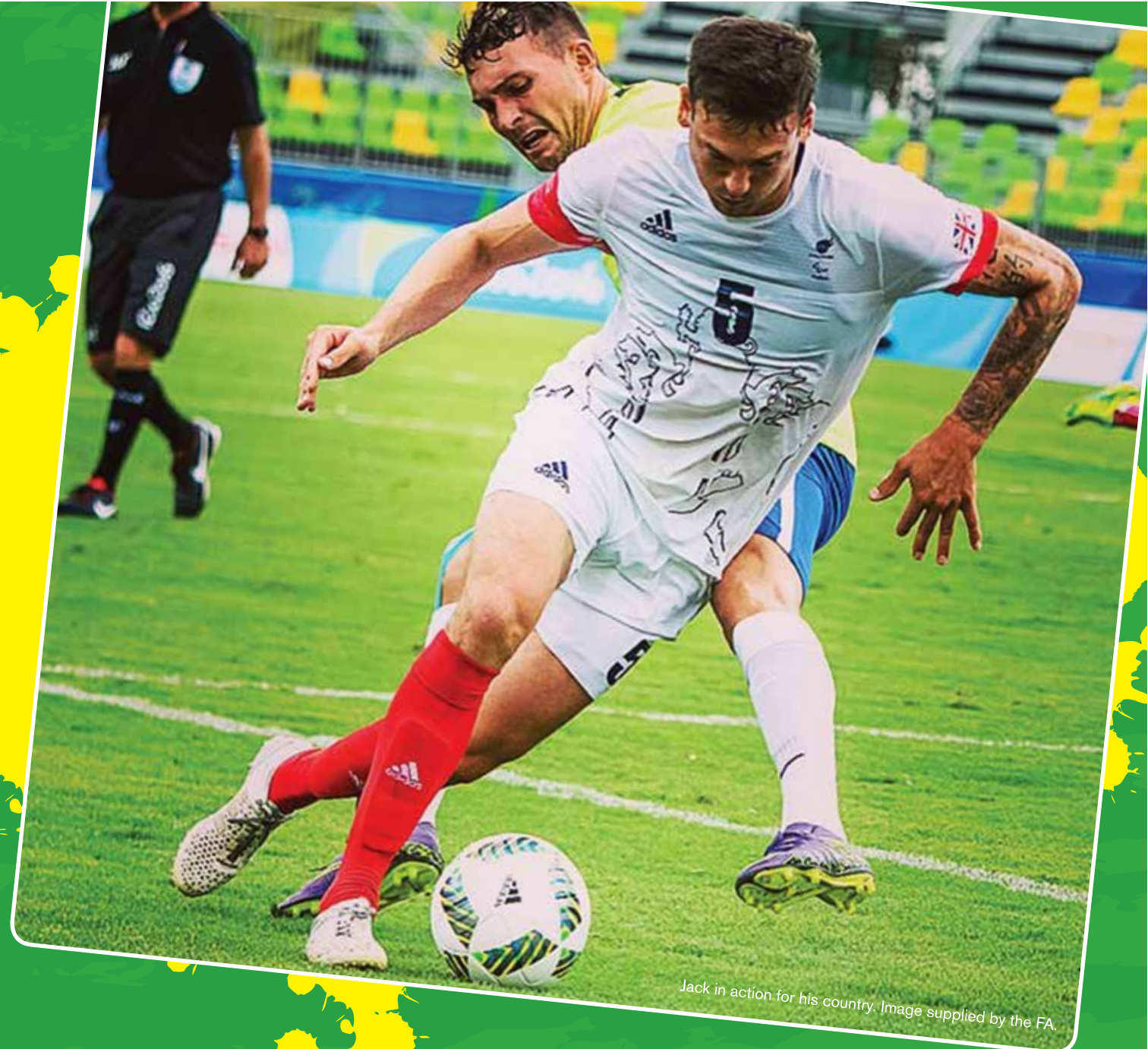
"Hilary spent time helping me understand my condition. Her whole manner and the way she spoke so

sensitively made me feel confident I was being supported after brain injury.

"This was my first interaction with Headway and my positive impression of the charity has continued the more I've gotten to see the work it does across the UK."

ANGER AND FATIGUE TOOK HOLD

"Managing the pressures of life after brain injury proved very hard. I quit university and began drinking too much. Anger and fatigue took over for a while.



Jack in action for his country. Image supplied by the FA.

My Story...

“When I was younger, my ‘Plan B’ if I didn’t make it as a footballer was to become a policeman. Even my ‘Plan B’ had gone. While my friends were doing well at football or university, I was paralysed by the anger inside of me.”

Jack had first been spotted by a football scout when he was just 10 years old and playing for Windsor Drive, a Gloucester boys’ team. After excelling with St Andrew’s Academy and later relocating to Kings Norton, near Birmingham, Jack joined Birmingham City as a youth team player.

“It was a brilliant time,” said Jack. “It’s a great, great club. I was definitely on course to become a professional footballer. It’s hard to say what level I might have managed if it hadn’t been for my brain injury – the Championship was probably my level. In many ways it was a real shame the way it turned out.”

PARALYMPICS FOOTBALL CAPTAIN

“I had moved to Nottingham and was still in a dark place when my mum decided to call the local Headway group for some advice and a supportive chat,” said Jack.

“Not only did Headway Nottingham’s team provide her with a confidential listening ear, but they also helped me learn to manage my anger problems and, for the next five years, gave us confidence that support was there when we needed it.”

Headway Nottingham also put Jack in touch with the East Midlands Cerebral Palsy football team, which accepts players with other neurological conditions. Jack’s passion and drive



returned and he soon learned to adapt to playing football with poor balance and deafness in one ear.

Jack was back. His football pedigree began to get noticed, along with his natural leadership skills, and he was soon invited for a trial with England.

Jack currently has 14 England caps to his name – nine of them as captain – and represented his country in the European Championships in Portugal, as well as the Cerebral Palsy World Championships, where the side finished fifth.

Through sheer guts and determination, Jack has established himself as one of the country’s top disability footballers. And in 2016, he was rewarded with the ultimate honour of captaining the Paralympics GB seven-a-side football team in the Paralympic Games in Rio.

“I was over the moon to be able to attend the Games as captain,” said Jack.

“The 14-strong squad is ranked eighth in the world and we have the best players from across the UK,” said Jack. “My mum and sister flew over to watch,

which was great for them to see what I’m now able to achieve following years of hard work after my brain injury.”

Jack even became a poster boy for Channel 4’s Paralympics film coverage, which showed his journey to the Paralympics following the assault.

He added: “Many people said that I ‘wouldn’t be able to do this and wouldn’t be able to do that’, but I was determined to prove people wrong. My co-ordination and energy levels after brain injury are still up and down, but I’m in a much better place.

“I hope my story can help other young people with rage inside of them to move through their difficulties. I also want to raise awareness of how, if you resort to violence, life-changing brain injury can be the result.”

I’M NOT FINISHED YET

In December, Jack was invited onto the stage at The Dorchester Hotel during Headway’s Annual Awards luncheon to share his long and arduous journey to Rio.

Interviewed by Sky News presenter and event host Tom Macleod, Jack moved the audience to tears while also providing a few laughs and impressing guests with footage from the Games.

“At the beginning of the interview, I was struggling to breathe from nerves and it took me back to the early days of recovery when I’d wonder ‘can I do this?’

“But I saw it as my test.

“Tom put me immediately at ease and the reaction of support from the audience was overwhelming. To share my story, thank the charity and see the phenomenal achievements and

journeys of others affected by brain injury was such an important moment for me – I’ve never been so emotional.”

With the World Cup season in Argentina just around the corner Jack is training hard, though he still finds time to squeeze in school visits to deliver talks and raise awareness of brain injury.

“My outlook now is that my brain injury happened for a reason,” said Jack.

“Before brain injury, I would never have dreamed I’d be on that stage or speaking in schools to help educate children about head injuries.

“Unlike so many people who are still struggling to function years after their brain injury, I’ve been lucky to be able to recapture my passion and sports

abilities. It’s my duty to make the most of all the new opportunities that are open to me now.”

And Jack has no plans of slowing down any time soon.

He concluded: “My journey has resulted in me believing that I can overcome life’s challenges. And I’m not finished yet.

“The plan is to keep going on this positive streak and enjoy every opportunity that comes along because I now know there can be a great life after brain injury. You’ve just got to believe in yourself.”



Jack at the Paralympics as England CP team’s football captain. Image supplied by the FA.

Happy anniversary?

It is often said that brain injury survivors and their loved ones pass through a number of stages as they adapt to a new life living with the long-term effects of their condition.

The initial shock of the injury is often followed by elation that the person has survived, which can then be replaced by frustration and denial as it becomes apparent that life has changed forever.

With the right support, many people will move on from this and reach a level of acceptance that allows them to live a fulfilling life as 'a new me', recognising that while the old person has gone, the new person can thrive.

With the launch of our Action for Brain Injury Week campaign exploring this theme, we asked our online community (using their real names or online profiles) to focus on a key event that can put the effects of brain injury into stark focus – the anniversary of their injury.

Is it a time of sadness and loss, or a time to reflect on the progress and achievements of life as a brain injury survivor?

The early stages

The first few years are, perhaps predictably, a difficult time as the effects of the injury are still new and developing.

"For a while I assumed that after 12 months I'd be fully recovered," said SideKickPete on the charity's HealthUnlocked forum. "I am doing well, but I now know that I probably won't ever be fixed fully. I am nearing my anniversary. I don't know if I will 'celebrate' as such. I'll probably give my parents a big hug."

Even a seemingly minor injury can have a lasting effect, as Liz Meddings explains: "I'm coming up to my one year anniversary of my concussion. I'm feeling frustrated at my lack of progress in getting back to working full-time hours."

Laura Fielding highlights the rollercoaster of emotions that an injury anniversary can bring: "I've had the second anniversary of my accident and it is always a tough day, full of tears and quiet moments. I try and keep myself

busy and acknowledge how far I've come rather than dwell on the negative long-term effects that I can't change."

Gaia_rising talks of the difficult stages of coming to terms with the effects of an injury: "I thought that the first anniversary last year signalled an 'acceptance' for me; that my life had changed beyond recognition, but I was getting on with it.

"I'm coming to realise now that it was probably more of the denial that I was different, rather than the acceptance. Two years next month, and I'm a 'walking, talking living doll', because I won't let other people see the 'sleeping, crying' bits.

"As far as everyone else is concerned, I'm 'better'. I am better than I was on that day, and on the neuro-critical-ward days that followed, but I'm not all-of-me anymore, and, after something of a relapse, I'm struggling with that emotionally."

Missing the old self

"I hate my anniversary. It just makes me remember what I was like before that date," said Sarah Field. "On that date I changed 100%, which really hurts. I just want to be my old self."

StrawberryCream recognises those feelings: "I am stuck and find it impossibly hard to move on with the 'new me'.

"Anniversaries are even more poignant with making me think lots about the life I had before, which was in a really good place. So I feel angry/devastated/upset that my life has been thrown back into everyday struggles with a brain-injured me!"

For Claire Louise Steen, the reactions of 'well-meaning' people just add to the difficulty. "I don't necessarily focus on the anniversary but I do find myself actually permanently attached to the event and everything that happened afterwards," she said.

"It was life changing for me in an unfortunate way...my worst issue is that I can't be open about my condition without someone belittling me and saying 'but look how far you've come', like it was easy!'"





A new me

We were struck by the importance many people place on celebrating their brain injury anniversary as a time of positive change. For many, this is something that is achieved over time, and the path to acceptance is rarely easy and never guaranteed.

"Mine (anniversary) was 12 years in January," said Lisa-Marie Russell. "I always celebrate it as a new birthday because if it wasn't for my accident I wouldn't be who I am now. I'm so grateful to still be here to celebrate it."

Leah Blake takes a similar approach: "I celebrate it as a new birthday and I remember how far I have come xx"

Similarly, Deb Grant talks of reaching a more positive mindset seemingly against the odds: "Anniversaries are a positive time for me despite my brain injury being life changing.

"Critical, typical frontal temporal damage, epilepsy diagnosis, career gone as a result, depression. My strategy for positive rehabilitation and recovery is hope, humour and positive thinking."

The 'new me' theme is echoed by a number of our members, including Gerald Mack who commented: "My personality has changed a lot since my accident.

"In my thoughts, I died on that day in May 2009 and a similar but different person now walks in place of my original self."

A number of people even make a permanent mark of the date. "My husband got a tattoo showing cards that say 'make your own luck,'" said Lauren Wright. "On his anniversary we tend to go out for tea and spend the day together. It isn't a day of sorrow as he is still here to tell his story."

Nicola Brown offers a similar perspective: "My tattoo says 'What does not kill me only makes me stronger 18/12/07'. A new me means my life was totally changed (in a good way!)"

Life after brain injury

As we often say, with the right support, at the right time, there can be life after brain injury. Judging by the wide range of ways people acknowledge the anniversary of a brain injury, it's clear that this is the case.

But while for many it is possible to see the injury in a positive light and move forward as 'a new me', for others it will always represent the start of a struggle to cope with the wide-ranging difficulties faced by brain injury survivors and their families.

We launch our A New Me campaign in May, and we'll be looking forward to seeing what a brain injury means to the diverse range of people we support. We'll leave it to Susan Wood to have the last word, with her inspirational quote showing how a negative struggle can be turned around.

"Devastated, life changing, relationship ruining or changing, loss of self. Early years was more about loss and anniversaries a little negative.

"15 years on a wife, mother and nana... I feel I'm the luckiest person I know.

"I like the 'me' I've become. I'm 62 and often have more energy than my peers. Bring it on!"

Support

We recognise that every brain injury is unique and there is no one-size-fits-all approach to coping with the long-term effects of brain injury.

If you would like support, you can contact the Headway helpline on 0808

800 2244 or helpline@headway.org.uk. Alternatively, you can find local support in your area by visiting www.headway.org.uk.

A New Me

We were struck by how often people referred to 'a new me' resulting from their brain injury.

This concept is at the heart of this year's Action for Brain Injury Week, which takes place from 8-14 May.

As announced on our website and page nine of this magazine, we're putting brain injury survivors at the heart of the campaign, asking them to share their voices and experiences in order to raise awareness of how brain injury can change lives and futures.

Over the course of the next few weeks, on our campaign website (www.ANewMe.org.uk) we'll be announcing various ways in which you can get involved with ABI Week 2017.

The first opportunity for you to play an integral role in the campaign is by completing a short survey for brain injury survivors.

This is your chance to make your voice heard and shape our campaign by telling us how brain injury has affected you.

The survey will remain open until 24 April 2017, with the results to be published in May as part of ABI Week.

To complete the survey, follow links on our website or www.ANewMe.org.uk. Paper copies are available upon request from Tamsin Ahmad, Publications and Research Manager, at publications@headway.org.uk or **0115 924 0800**.

Join the conversation at healthunlocked.com/headway **25**

Emergency Fund

It meant
I could
breathe

Imagine being unable to afford to travel to be by the hospital bedside of your partner as they lie in a coma having sustained a brain injury. For Eleanor Simcox, and hundreds of others across the UK, this nightmare became a reality.

"I was in bed when I heard a bang," said Eleanor, from Dawlish in Devon. "I quickly got up and found my husband Mark lying at the bottom of our stairs. He was unconscious and had blood coming out of his ear.

"It was at this point that adrenaline must have taken over and auto-pilot kicked in. I set about clearing his airway and putting him in the recovery position.

"It was a very long 25 minutes before the ambulance arrived and it was only when they turned up that the gravity

of the situation hit me. That is when my legs turned to jelly – I could barely stand up."

The ambulance took them to their local hospital in Torbay, but after a CT scan revealed a blood clot, he was transferred to the South West Neurosurgery Centre at Derriford Hospital – a full 55 miles away.

Surgeons performed a craniotomy, removing a piece of Mark's skull to relieve the pressure in his head.

He was in a coma for 10 days and remained in hospital for three weeks. During the first few weeks of his treatment, Mark suffered from post-traumatic amnesia and was left with a memory of only three minutes. It was at this point that Eleanor heard about the Headway Emergency Fund.

She said: "My sister was doing some research and told me about Headway. I rang the helpline, who were fantastic, and they told me I could apply for financial help through the fund.

"This was a massive help. Mark had just left his old employers and the day before the accident he had just finished his training to become a fireman but wasn't receiving any income. That meant that the only money the family had coming in was through my part-time job working at a pub.

Some of the family's funds were also in Mark's bank account, which Eleanor couldn't access at the time.

"It was a very stressful time," said Eleanor. "I was down to £107 a week. My boss was very kind to give me an advance on my wages, but this money was soon eaten up.

"I really struggled to support and visit Mark. It was a 110-mile round trip, which I would sometimes have to do twice a day as I had to come home to look after my boys and then go back to Mark in the evening.

Precious moments: Mark cuddles his two sons



"The fund was vital to me in those dark moments. It eased the financial pressure at a very stressful time. I could concentrate on being there for Mark but also making sure I could be a mummy to my boys, Joshua, who's seven, and three-year-old Lewis.

"The fund gave me the space to cope – it meant I could breathe."

Eleanor said she was also very thankful for the support other Headway services provided to her.

She said: "I got so much help from Headway's helpline and the charity's booklets. Not to mention the website, to which I refer daily. It has helped me learn so much about what Mark is going through and is a constant source of information and comfort."

Mark's accident has left him with a number of issues, including memory

problems, bouts of dizziness and headaches, but Eleanor remains hopeful about the future.

"His memory is not great," she said. "He will forget things a lot, even when it's something you've just told him five or ten minutes previously, but it's obviously a lot better than when he was in hospital.

"We are in touch with the neurosurgeons and consultants at the moment, trying to figure out what's going on with his headaches. We are hoping it gets better as time goes on, but more than anything, we are just glad he's still here."

About the Headway Emergency Fund

The Headway Emergency Fund exists to help families cope with the sudden practical implications of brain injury.

Since it was launched, the Emergency Fund has helped more than 1,150

families, and provided more than £240,000 in grants.

Anyone can apply for the Emergency Fund via a form on the charity's website. Many referrals to the fund come from the Headway helpline or the Headway Acute Trauma Support (HATS) nurses, while applications can also be submitted by support workers and qualified professionals on behalf of brain injury survivors.

The majority of the approved applications are to help people with the cost of travel to visit loved ones, with 76% of all grants falling into this category.

For more information about the Emergency Fund, please visit www.headway.org.uk/supporting-you/headway-emergency-fund, call 0208 640 8413, or email efcoordinator@headway.org.uk



Joshua and Lewis help Mum and Dad celebrate their wedding day

#HeadwayHeroes students get creative for valentine's day re-launch



Design students
Paige Johnson and
Emil Beacher
work on their window
display ideas

Tuneful youngsters from Hinckley showed some charity love on Valentine's Day by putting on a show to celebrate the relocation and re-opening of Headway's Hinckley shop.

Students from North Warwickshire and Hinckley College performed at the charity shop's event on Tuesday 14 February to mark the store's move to Station Road.

Performing arts and music students from the college sang a variety of pieces for customers, who admired love-themed window displays created by interior and graphic design students together with the shop's volunteers.

"It was a great show and fantastic effort from everyone involved," said Julie Chambers, Retail Area Manager at Headway.

"Several of our shop volunteers are brain injury survivors themselves, and engaging

with the students while at the shop has really helped to boost their social skills and confidence.

"We are proud to see young people stepping up to get involved and make a difference to the lives of people affected by brain injury. A big thank you to the college and its wonderful students!"

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Who cares Wins...

PEDAL POWER

marks decade of brain injury

For many survivors of brain injury, marking the anniversary of sustaining their injury can often be an important, even symbolic occasion.

Mick Smith, 54 and from Essex, chose to acknowledge the ten year anniversary of the assault that left him with a serious brain injury by taking on the iconic Lands End to John O'Groats cycle ride.

After several months of training and careful planning, it took Mick less than eight days to cover his extended 942-mile route. The challenge illustrated just how far Mick has come on his personal road to recovery, while raising more than £6,000 for Headway.

Perhaps unsurprisingly, the ride was not without its difficulties. The relentless climbs of the Devon and Cornwall hills were particularly challenging, with Mick cycling 110 miles and climbing almost 10,000 feet in one day.

An unexpected detour on day five didn't help, with Mick forced to ride 10 miles in the wrong direction before having to turn back!

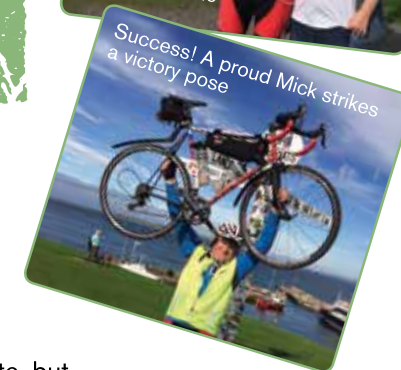
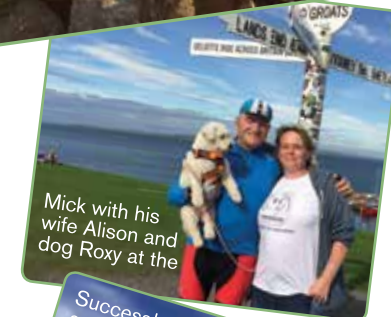
Encouraging Mick along the way was his wife Alison and the couple's dog, Roxy, who travelled alongside him in a campervan to act not only as lodgings at each stop, but also as a support vehicle to keep track of his progress.

"What an incredible sense of achievement," said Mick after the event.

"I couldn't have done any of it without the planning and ceaseless support of my wonderful wife. She certainly kept me well fed throughout the journey!

"Battling a seemingly continuous uphill journey with the occasional setback is not so dissimilar to life after brain injury. While there were some very long days and little sleep, it was worth it to raise funds and awareness of the work Headway does to support families like ours."

"We avoided main roads to enjoy as much of the UK's scenery as possible. This decision significantly lengthened



the route, but helping others served as excellent motivation to keep pedalling on through my mammoth challenge.

"I would like to thank my family, friends and church back home in Saffron Walden for their valued support. Most importantly, a huge thanks to my amazing wife and my best friend Glenn who joined me for a five-mile section of the journey on his wife's pink bike, complete with basket on the front!"

Mick's own top tips for other keen cyclists who are considering taking on their own challenge for the charity can be found on the Headway website.

If you've been inspired by Mick's incredible efforts and would like to help Headway improve life after brain injury, visit our website where you'll see a range of challenges to sign up for.

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

#HeadwayHeroes

Let the fundraising fun begin!

A trio of fundraising firms have been passed their Headway Challenge Batons and begun raising vital funds for the charity.

And while the three firms – EMG Solicitors, Burcher Jennings, and Voyage Care – all have exciting events lined up for 2017, they'll have to go some way to matching the efforts of last year's baton holders.

Between them, Majestic Wine Warehouses, St John's Buildings Chambers, and Sportscover raised a whopping £76,000 for Headway, with the firms presenting cheques to the charity at the Annual Awards in December.

"Brain injury is a cause very close to the hearts of everyone at EMG and we're very honoured to be able to give Headway our support," said Managing Director Emma Gaudern.

"We have already started our fundraising and have a number of events in the pipeline. So far, we have held two WonderLAN Balls, which have become hugely popular and we're now planning for the third to take place in November.

"We also hope to use our annual conference in April as an opportunity to raise more money for Headway and we're looking at other events throughout

the year. We're set for a busy 12 months, but hopefully it'll prove profitable for Headway."

Voyage Care, which provides specialist care and support to adults with a brain injury, will be involving its staff across the UK in the fundraising endeavours.

Chief Executive Andrew Cannon said: "Headway does such amazing and vital work and this feels like a natural charity partner choice for us. We work with so many people who have a brain injury and we know first-hand how Headway makes a difference.

"I have challenged our services across the UK to raise as much money as possible for Headway. I am looking forward to seeing what ideas people come up with. We already have one staff member who is running the London Marathon."



Legal pricing and costs consultancy Burcher Jennings has also taken on a baton. Its nationwide network of offices will be taking on a number of



fundraising challenges throughout the year from running the London Marathon, cycling the coast to coast route and even climbing the O2 Arena.

Michelle Barron, Head of Operations at the company, said: "Our objectives are to help raise money for a fantastic cause, raise awareness of the excellent work of Headway and throughout it all have a thoroughly enjoyable time!"

Could your firm help Headway improve life after brain injury? Visit www.headway.org.uk/get-involved/organisations or contact Anna Kerr on partnerships@headway.org.uk or 0115 924 0800.



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



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