Autumn 2018

Headway News

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

Right First Time

Assessing the hidden impact of brain injury

Campaign builds momentum

Real lives feature in new film

MPs debate ABI

The debilitating impact of social isolation

I'm calling about Chris

Helping you to connect, share, and update those who care’

Lanyon Bowdler SOLICITORS

BRAIN INJURY SPECIALISTS

Legal specialists in **Personal Injury**, **Clinical Negligence** and **Court of Protection**

OUR PEOPLE, YOUR TEAM

Brain injury, sustained during birth, other medical negligence, or as a direct result of an accident, can have life-changing consequences. Livelihoods can be lost and care needed.

At Lanyon Bowdler, we offer a holistic and personal approach and our clients often remark on our empathy and professionalism.

We use the best experts, therapists and case managers and with a multi-disciplinary approach, we are able to offer maximum support to a family at the time of crisis. In addition, we have a dedicated in-house Court of Protection team.

Our highly experienced lawyers take a forensic approach to obtain the best evidence possible, by thinking strategically about each case. We have a proven track record in taking over cases from other solicitors where we have been able to achieve a much better outcome.

The 2017 edition of The Legal 500 recognises the Clinical Negligence and Personal Injury teams in the Top-Tier for the West Midlands.

Lanyon Bowdler are Headway Corporate Supporters and appear in the Headway solicitors directory.

CLINICAL NEGLIGENCE TEAM

PERSONAL INJURY TEAM

“Very professional and approachable, you really cared and wanted the best possible outcome for our son. The personal touch makes you head and shoulders above the rest. Thank you!

Mr & Mrs Abernethy Cheshire

To speak with one of our birth injury or acquired brain injury specialists contact:

0800 652 3371 • info@lblaw.co.uk • www.lblaw.co.uk

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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.

Find us on facebook | Watch us on YouTube | Follow us on twitter | View us on Instagram

Headway
the brain injury association

Summertime and the livin' is easy...

As Ella Fitzgerald famously sang, summertime and the livin' is easy.

Whether you love or hate the heat, summer is typically a relaxing time for many. But here at Headway, we have been working as hard as ever to keep pushing for reform of the welfare benefits system and launching new projects.

Earlier this year we launched our *Right First Time* campaign. In simple terms, the aim was to improve the assessment processes for those applying for ESA or PIP.

That aim remains at the heart of the campaign and, as you'll see in our update on pages 12 and 13, momentum is growing.

We continue to hear so many reports of brain injury survivors being subjected to appalling treatment at the hands of assessors who do not understand the complexities of brain injury.

Stories such as Ian and Heather's, which you can read on pages 14 and 15, are all the motivation we need to continue fighting to make things better.

Our overriding aim is to improve life after brain injury through campaigning, supporting our network of groups and branches, and launching innovative projects and services to help those affected.

One such project is *I'm calling about Chris*. It's a simple-to-use free online resource to help people update friends and families on the condition of a loved one in the early stages post injury.

It can be emotionally and physically draining to make and return dozens of phone calls from people understandably eager for updates - particularly after spending all day at the hospital.

I'm calling about Chris can help people to not only keep loved ones updated, but also provide an effective way for others to offer their practical and emotional support.

You can read all about it on pages 10 and 11, or go straight to www.callingabout.org.uk to check it out for yourself.

And while you're online, why not take a look at the new short film on our website introducing the work we do to improve life after brain injury.

We hope it will lead to more people turning to us for help and support. And you can help by sharing it on social media (please!).

But we're not the only ones who have been busy this summer. Check out our special feature on gardening to see how Headway groups and branches have been enjoying the great outdoors (and weather!). And let's not forget our fabulous fundraisers whose exploits never fail to inspire us to do more!

The Communications Team

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www.headway.org.uk/donate

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Your views...

In the early stages after a brain injury, many people struggle to meet the challenge of keeping friends and family updated on the condition of a loved one.

To coincide with the launch of our new online resource, *I'm calling about Chris*, we asked people in our online communities about their experiences...

My daughter says that people always asked her how I was, but never how she and her brother were coping.

Lilian Morris

It was up to me to keep everyone updated, which meant I had to travel three hours every day so I could also see our three young children before school. Everybody wanted an update daily, while I was trying to come to terms with how and what had happened. At first, people wanted to visit and be on hand to help. Sadly we are 2.5 years in and all the friends have drifted.

Siobhon Phillips

Email mainly, and asked people not to telephone as to keep repeating was draining and I also wanted the line kept clear in case the hospital rang. I was working full time as was my partner and we suddenly had an 18-month-old to look after too on top of everything else.

Viv Gillespie

We set up a Facebook page, identified people who could let non-Facebook users know, and posted updates to there. Having one place for information also stopped the Chinese whisper effect.

A Facebook user

I was inundated with texts and emails asking how my husband was, which was lovely that people were showing their concern but also very draining because I was spending almost 12 hours each day at my husband's hospital bedside. All I wanted to do when I got home was to sort things and prepare for the following day. So I would email a group of friends at night when I got home and they would pass information onto all the other people.

Margaret Faulkner

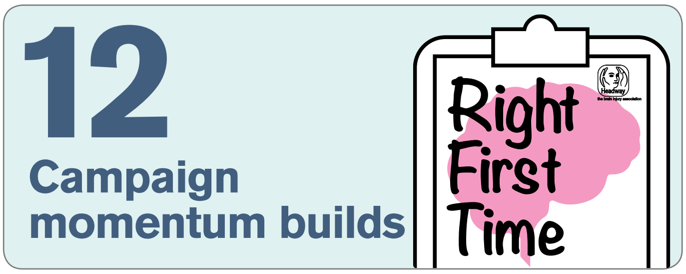
Sitting by the bedside for hours on end was hard, sometimes retelling it all at the end of the day helped put things in perspective. Sometimes updating it all was even more upsetting because it made it all more real. We used emailing and WhatsApp for day-to-day updates.

Emilia Jean

I used to telephone one sister with a daily update and she would ring everyone else. It is SO, SO important to conserve your own energy. Constantly answering calls, however well meaning the caller, can really zap your energy.

Jane Craig

...in this issue



Football fails on the biggest stage

Headway has criticised FIFA for failing to ensure its own concussion protocols were managed during the World Cup in Russia.

Specific criticism has focused on Morocco, which allowed Nordin Amrabat to play just days after his own medical team diagnosed him as having sustained a concussion.

Following the initial concussion, Amrabat spent a night in hospital before being discharged and allowed to return to the team base in Voronezh.

However, despite a statement from the Royal Moroccan Football Federation saying the player would be unavailable for a week, the player returned to the starting line-up just five days later.

FIFA's protocols state concussed footballers should not play for at least six days following concussion.

Peter McCabe, Chief Executive of Headway, said "This incident shows scant regard for FIFA's concussion protocols.

"FIFA's failure to act sends a very dangerous message to other teams – not to mention the millions of impressionable young players watching around the world – about the dangers of concussion.

> *"As the governing body of football, FIFA must stop sitting on the sidelines and strengthen its guidelines to ensure the safety of its players is not optional."*

RC GP Royal College of General Practitioners

RCGP praise

Headway's factsheet Hormonal imbalances after brain injury, has been endorsed by the Royal College of General Practitioners (RCGP).

The factsheet, which was reviewed earlier this year, contains information on how sustaining a brain injury can affect the balance of hormones in the body, and the effects this can cause.

The RCGP is the professional membership body of doctors in the UK, and provides ongoing support and training to GPs. With the endorsement of this factsheet, it is hoped that more GPs will recognise the impact of brain injury on hormonal imbalances, and that more survivors will receive access to the information and support they require.

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

ACTION FOR
BRAIN INJURY WEEK 2019
20-26 MAY

The date of next year's Action for Brain Injury Week has been announced.

The campaign week, which aims to raise awareness of brain injury and give a voice to those affected, will run from 20-26 May 2019.

Hats for Headway Day will take place on Friday 24 May and once again provide a fun way for people to get involved and raise money to support either national or local Headway services.

The theme for the week will be announced in due course, so keep an eye on our social media pages (@HeadwayUK) for further announcements.

Government responds to parking plea

Headway has accused the Government of not doing enough to protect vulnerable hospital visitors and users from excessive car parking charges following its disappointing response to a petition calling for change.

The petition, spearheaded by Robert Halfon MP and supported by Headway, has gained more than 22,000 signatures already, prompting the Government to respond.

Despite stating that hospitals' car parking policies 'must put patients first', the Government has refused to act, expressing concerns that removing charges would result in fewer spaces being available for genuine users.

Peter McCabe, Chief Executive of Headway, said: "When is the Government going to listen and take real action to help people when they need it most, for example when a loved one is in a life-or-death situation in hospital?

"By trying to pass the responsibility onto individual hospitals, the government is instead just passing the buck.

"The suggestion that the NHS, one of the most advanced organisations in the world, cannot find a technical solution to ensure hospital car parks are used solely for their intended purpose is simply not credible."

Blue Badges for hidden disabilities

The Government has announced that people living with hidden disabilities will soon be able to apply for Blue Badges, enabling them to park in designated disabled bays.

The news has been warmly welcomed by Headway, which presented the views of brain injury survivors, their families and carers in a consultation on this issue earlier this year.

Although some brain injury survivors have additional physical disabilities that mean they are already eligible for the scheme, others with hidden disabilities such as cognitive impairment, psychological effects and cognitive fatigue should also be able to obtain a Blue Badge in the near future.

Dr Clare Mills, Headway's Public Affairs Manager, said: "We are pleased that the Government has listened to Headway and others about the effect of hidden disabilities. Widening access to the Blue Badge Scheme will help many people living with the effects of brain injury which, because they are hidden, can make life extremely difficult.

"We hope the Government will move quickly to issue the revised criteria and push the necessary legislation through Parliament as soon as possible."

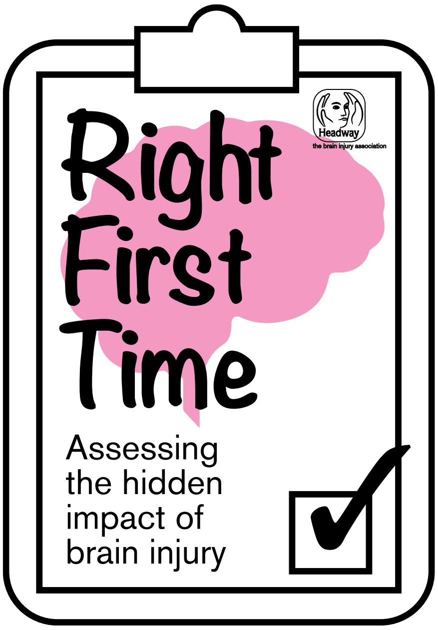
Headway delivers vital training to DWP

More than 300 staff at the Department for Work and Pensions (DWP) have received crucial training from Headway in order to help them better understand the hidden, complex and fluctuating nature of acquired brain injury.

Peter McCabe, Chief Executive of Headway, said: "This was an excellent opportunity to speak directly to DWP staff.

"We will continue to champion the voices of those we support as part of our ongoing commitment to increasing understanding of brain injury and improving the services available to those affected."

Turn to page 12 for an update on our *Right First Time* campaign and more details on the training provided to the DWP.



New film promotes life after brain injury

Headway has launched a new short film promoting the work of the charity in supporting people affected by brain injury.

The film, which features the personal experiences of two families affected by brain injury, is designed to raise awareness and ensure more people have access to the right help, at the right time.

"Over the past few years, awareness of brain injury and the support available from Headway has risen significantly, with record amounts of press coverage and social media interaction," said Luke Griggs, Director of Communications at Headway.

"This new film complements the additional short films we have created over the course of the past year, including *Things not to say to someone with a brain injury*, *Lost in a crowd*, and our moving personal testimony films.

"This is a hugely important area of our work as we want to make sure that everyone who needs us is aware that we're here to help.

"We are extremely grateful to Natasha and Paul, and Claire and Lauren for sharing so openly and honestly in the film.

"Their experiences of brain injury are unique to them yet they share many similarities, such as the impact a brain injury can have on the entire family.

"We hope that this film will be seen and shared by as many people as possible in order that others may access support from Headway."

View the film at www.headway.org.uk or find it and share it on Facebook and Twitter (@HeadwayUK).

Jo Plant (left) with Public Affairs Manager Dr Clare Mills at the Houses of Parliament

Headway gives evidence to Parliament

The All-Party Parliamentary Group on Brain Tumours has heard evidence from Headway as part of its inquiry into the social and economic impact caused by the condition.

Headway's Director of Fundraising, Jo Plant, provided a unique and personal insight by sharing her own experiences.

Speaking to the inquiry, Jo said: "It might seem unusual to have someone in my role speaking about brain tumour. But sadly I and my family have first-hand experience.

"In the spring of 2016, my dearly loved husband Carlton was diagnosed with a glioblastoma grade four brain tumour. He died just before Christmas that same year.

"That 256 day journey from diagnosis to death was a series of battles on so many fronts, and the fight for care and support took time away from Carlton that can never be replaced.

"I count myself lucky because working at Headway gave me insight and information that could have been much harder to find, and because my colleagues were incredibly supportive.

"But we know that this is not the case for so many people living with or after brain tumour. It is a privilege to be able to speak to the inquiry about my personal experience and on behalf of Headway."

The inquiry report is due to be published in the autumn.

MPs debate ABI

The impact of brain injury and the support requirements of those affected have been debated at length by MPs in the House of Commons.

The debate, which was supported from MPs from all parties, highlights the growing momentum within Parliament with regard to awareness of brain injury following numerous recent questions, inquiries, and positive mentions of Headway in the Commons.

Dr Clare Mills, Public Affairs Manager at Headway, said: "Survivors, their families and carers, as well as all of us working in the field of acquired brain injury, will be heartened to see members from all parties coming together to state their support and understanding of the many challenges those living with ABI face on a daily basis.

"Headway was mentioned dozens of times throughout the debate, and it is positive to see the excellent services being provided at both a national and local level being recognised.

"It was also telling that so many members spoke of their personal experience of ABI, drawing attention to its prevalence.

"It seems that everyone knows someone who has been affected by ABI. Working with Headway groups and branches, we now need to build on this momentum to see this genuine interest resulting in meaningful change."

I'm calling about Chris...

'Keeping loved ones updated was so draining'

New online resource to ease the burden of families dealing with sudden acute brain injury

Headway has launched an innovative new website called ***I'm calling about Chris*** in order to help people keep family and friends updated on the condition of a loved one following brain injury.

I'm calling about Chris is designed to make it easier to 'connect, share and update those who care' by providing regular updates without having to spend hours on the phone each night, exhausted after spending 15 hours at the hospital bedside.

The easy-to-use platform allows you to quickly and simply create a page dedicated to your loved one before drafting and posting updates on their condition using your smartphone or tablet. This can be done while you wait in the hospital, rather than on your return home from an emotionally exhausting day.

Importantly, the interactive set-up allows friends and family to post supportive comments in return.

"At Headway, we understand how difficult it can be to sit by the bedside of a loved one who is in critical care following a sudden acquired brain injury," said Luke Griggs, Director of Communications.

"For many families, the relief that their loved one has survived can quickly be replaced by uncertainty and fear about what the future may hold.

"Any remaining strength can then be sapped by making or receiving dozens of calls each evening from worried family and friends, each understandably eager for updates.

"We hope that by taking an innovative approach we can relieve just a little pressure."

Helping you to connect, share, and update those who care

I'm calling about Chris

How much does it cost to use?

I'm calling about Chris is entirely free to use, whether you're creating a page or commenting on one.

How do I set up a page?

Just go to www.callingabout.org.uk and follow the on-screen instructions. It's simple to do and will only take a few moments.

What information can I share?

What you choose to share is entirely up to you – providing it conforms to our house rules. You control what goes on your page, whether you choose to upload photos, videos or simple text updates.

Who can comment on my page?

Again, that's up to you as the page owner. You will have full control.

Can anyone see my page, or can it remain private?

You can choose to keep your profile private, only allowing people to access it via a unique link distributed by you, or you can keep the page open so that people can find your page using the search function.

What additional information is on the site?

Importantly, ***I'm calling about Chris*** also includes useful information about brain injury to help everyone connected with your loved one to better understand both the acute stage of care and how they might be affected in the long term.

There's also a section dedicated to friends and family members who are keen to provide you with practical support while you're at the hospital.

To find out more or to start using *I'm calling about Chris*, visit www.callingabout.org.uk.

‘My phone was ringing constantly... but I was too exhausted to talk’


Jane and Simon

Jane Hales, from Rutland, received the 2am knock on the door that every parent dreads.

She was greeted by the sight of two police officers who informed her that her 20-year-old son Simon was fighting for his life in a hospital 200 miles away.

Several years later, Simon is continuing to make progress and learning to adapt to life after brain injury.

But for Jane, the memory of those first few weeks and months when she had to cope with the fact she might lose her son, while keeping worried family and friends regularly updated, remain vivid.

“I wasn’t allowed to use my phone while in the intensive care unit,” said Jane. “But even if I had I wouldn’t have had the ability or emotional energy to speak to the dozens of people calling me all day to ask for updates.

“My phone rang constantly, but I couldn’t answer.”

Jane is fully supportive of the new ***I’m calling about Chris*** website.

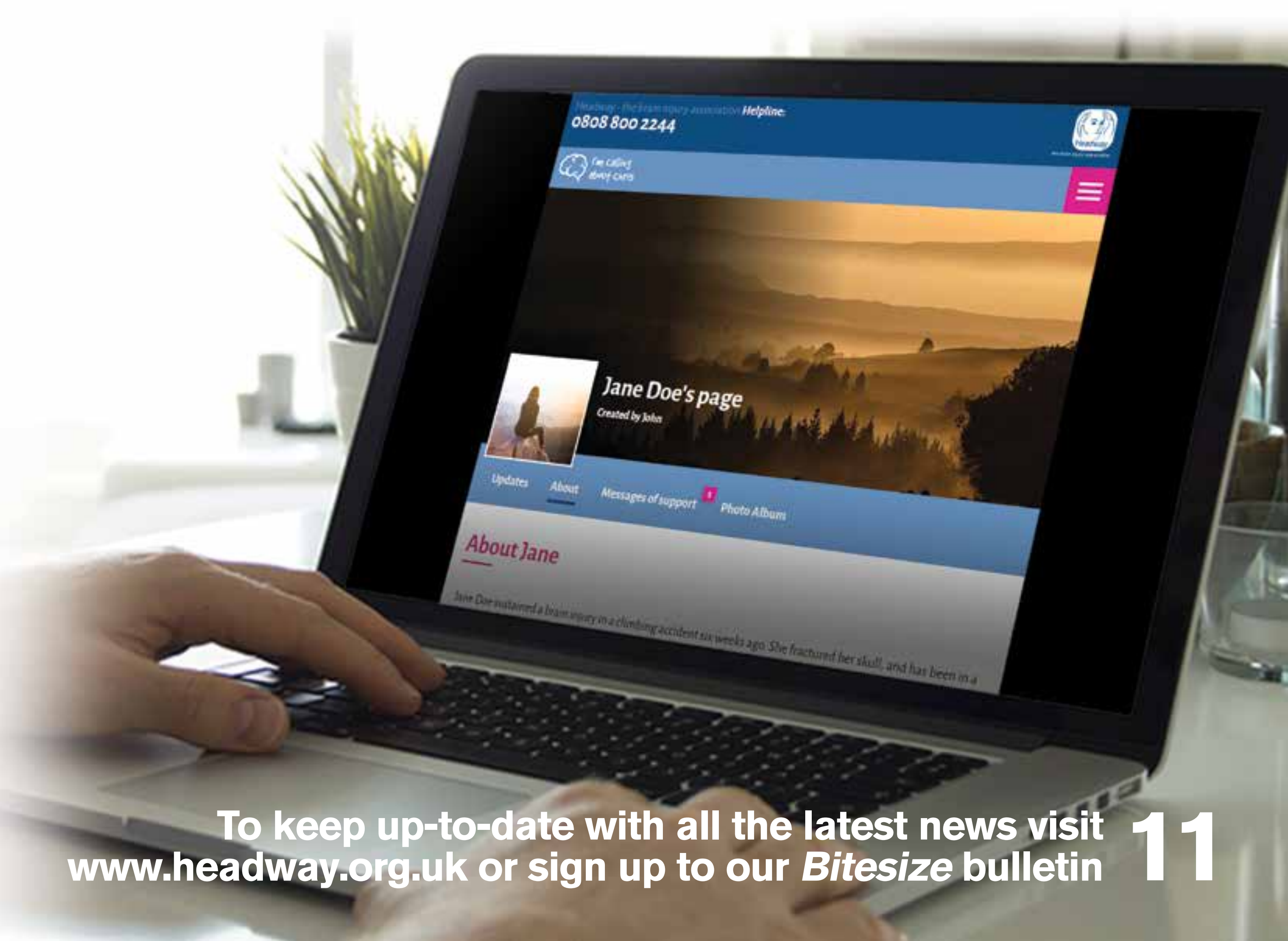
“You can’t imagine how hard it is to have a dozen phone calls to update worried relatives after spending 15 hours by the hospital bedside,” she said.

“***I’m calling about Chris*** is a great idea and I wish it had been around nine years ago when Simon sustained his brain injury.

“It would have been so easy to regularly post short updates throughout the day, knowing that friends and family would be updated.

“It would have also allowed them to ensure I knew that they were thinking of me, as well as Simon’s two brothers, George and Tim.

“It can’t alleviate the strain and turmoil, but if it relieves just some of the pressure, it has to be a good thing.”



Jane Doe sustained a brain injury in a climbing accident six weeks ago. She fractured her skull, and has been in a

Right First Time campaign builds momentum

Headway's campaign for urgent improvements to disability benefits assessments is continuing to attract support.

Earlier this year, we gathered the views of more than 650 people directly affected by brain injury who have experienced an assessment for either PIP or ESA.

The evidence is clear: disability assessments are failing people living with the often hidden, fluctuating and complex effects of brain injury.

We're trying to change that by challenging everyone involved in the process to better understand the effects of brain injury in order that all assessments are *Right First Time*.

Assessing the assessors

We are finding new ways in which to engage with Capita, IAS – formerly known as Atos – and the Centre for Health Disability Assessments (CHDA), run by Maximus.

These organisations carry out face-to-face assessments of people applying for PIP and ESA.

We believe that by working with them, while retaining our right to challenge poor services, we have a better chance of influencing change. Recent meetings with IAS, Capita and the CHDA have given us new opportunities to put forward proposals to improve the experiences of brain injury survivors across the UK.

Headway also provides expert advice and suggests improvements to the assessment companies' training documents covering ABI, as well as pushing for all assessors to complete the relevant modules.


Lisa Cameron MP

Right First Time in Parliament

Over the past few months we have met dozens of MPs and provided them with information about the *Right First Time* campaign, such as Dr Lisa Cameron MP from central Scotland.

Lisa previously worked as an NHS psychologist. She now chairs the All-Party Parliamentary Group on Disability. Her husband sustained an ABI some years ago while serving in the armed forces.

Lisa raised our *Right First Time* campaign in Parliament, calling for Ministers to give "a statement on the inadequacy of Personal Independent Payment assessments for people with acquired brain injury."

Speaking in Parliament, Lisa said: "Those with an acquired brain injury often feel that their difficulties are not understood and not well assessed under the current procedures, so we need not only further training for assessors, but possibly to review the assessment process itself.

"Assessment sometimes does not pick up the fine changes that can have such a crucial impact on the daily living skills of people with an acquired brain injury. Support will be necessary because it can be difficult for those with such injuries to complete forms, gather adequate evidence and so on."

A new system for Scotland

PIP is one of the benefits which will be transferred to the Scottish benefits agency as the Scottish government takes on more responsibility for welfare.

This may mean a change to the assessment regime. We are working with the Scottish Government to ensure that in the new system the needs of brain injury survivors are recognised and understood by assessors and decision-makers.

MUM-TO-BE ON THE MOMENT SHE KNEW INJURED BOYFRIEND WOULD PULL THROUGH AFTER ACCIDENT

We didn't know if our Andy would live.. he was in a coma, no spark in his eyes. But then he saw the baby scan and it was like he really understood

■ Jenny Morrison

As he lay in a coma, Cheryl Mainland stayed by her boyfriend's bedside, telling him over and over again about the baby growing inside her.

FAMILY GUY Doting dad Andy and wife Cheryl with their baby boy Miller

TOUCH AND GO Andy in coma in hospital

Dad's bond with baby who helped him beat death

BATTLE FOR LIFE Alfie

Toddler's parents in last-ditch court bid

Alfie Evans's parents will learn tomorrow whether the toddler will carry on receiving treatment to keep him alive.

Bomb girl's charity run

The lifelong effects of brain injury

Cheryl and Andy Mainland shared their story in the *Sunday Mail*, one of Scotland's leading national newspapers

DWP training

More than 300 DWP staff working in job centres across the UK recently received crucial training from Headway to help them understand the hidden, complex and fluctuating nature of ABI.

We also told them about support services provided by the charity on a national and local level, including Headway's Brain Injury Identity Card, the *Right First Time* campaign, and our network of groups and branches.

Paul Williams, Jobcentre Operations Director at the DWP, said: "We are extremely grateful to Headway for sharing its expertise and helping staff to better identify and understand the often hidden effects of brain injury.

"Partnerships with charities such as Headway are extremely beneficial to the DWP and demonstrate our commitment to improving our understanding of the conditions that impact on the day-to-day lives of people in need of support."

Peter McCabe, Chief Executive of Headway, said: "We will continue to champion the voices of those we support. We are committed to raising awareness and understanding of brain injury and pushing to improving services available to those affected."

How can I get involved in the *Right First Time* campaign?

We know that talking isn't always easy. But people like Andy and Cheryl Mainland from Scotland, who shared their ESA challenges in the national press, and Ian O'Connor and his partner Heather from Yorkshire, whose story you can read on the next page, are making a difference.

Together, we are making the voices of brain injury survivors heard.

Why not contact your MP and ask if you can discuss how ABI affects you and your family, and your experiences of disability benefits? MPs work directly on behalf of the people in the area they represent. Don't be put off approaching them because they are 'really important' or 'very busy' – you matter to them.

Please contact Dr Clare Mills, Public Affairs Manager at Headway, for more information about sharing your story or meeting your MP. Call 0115 855 0085 or email publicaffairs@headway.org.uk.

Headway
the brain injury association

Right
First
Time

Assessing
the hidden
impact of
brain injury

I WAS CLOSE TO A BREAKDOWN

Right First Time

Assessing the hidden impact of brain injury

When brain injury survivor Ian O'Connor was denied Personal Independence Payment (PIP), his partner Heather Pollard took up the fight on his behalf.


Ian sustained a TBI in 2000

She was determined to make the Department of Work and Pensions reconsider its judgement and provide him with the ability to maintain his independence.

But what followed was a year-long battle that put an incredible amount of stress and pressure on them both, driving Heather to breaking point and badly affecting their wider family and friends.

"It was a nightmare," recalled Heather. "It felt like my whole life was on hold and with little money coming in we were slowly eating into our savings.

"The injustice of what had happened to us at the assessment was always on my mind. I was going over it again and again. It wasn't healthy, and to be honest, I was close to a breakdown.

"It even affected my wider family and friends. I kept playing it over and talking about it. I think everyone got so tired of it and that made me feel even more desperate."

Ian, 68 and from Hornsea, fell while working at a bakery, resulting in a bleed on the brain and the lasting effects of a traumatic brain injury.

The accident, which happened in 2000, left him with a number of long-term problems including cognitive, memory and fatigue issues.

However, Heather said the healthcare professional that assessed Ian in 2017 not only showed a distinct lack of knowledge about brain injury, but also fired questions at Ian with little sign of compassion.

Heather said: "The assessment was a very unpleasant experience and we both found it very degrading.

"The assessor was rather aggressive and asked us to sit in the middle of the room, away from her. It was really off-putting and intimidating."

Heather said the assessor didn't take the time to understand the complex way that the Ian's brain injury affected him and when she tried to help she was told to stop.

She said: "Ian was unable to provide her with a full picture, partly because of the way she was wording questions and partly because he simply wasn't capable of it.

"I tried to interject but she told me to shut up and said if I continued answering on his behalf she would terminate the interview. It was awful and we left with little confidence that she understood Ian's condition."

The couple's fears were confirmed when the letter with the decision arrived weeks later.

Heather said: "Our application was rejected and we were astonished with the completely inaccurate assessment. It included things which simply didn't happen and only focused on points which played down the effects of Ian's brain injury.

"For instance, it said that Ian left the gas cooker on once. But that simply isn't true. He does it so frequently that he cannot be trusted in the kitchen.

> *"It would have been very useful to have the assessment recorded so we could easily challenge the report findings when it arrived. It's a simple thing to introduce and would protect both parties, save a lot of disputing of the truth and alleviate stress caused."*

The couple appealed the decision under mandatory reconsideration but again were rejected.

They had no choice but to pursue the decision at a tribunal – which was attended by a judge and an NHS consultant. Heather also invited Leslie Saunders from Headway Hull and East Riding to attend and offer her support. Ian has been going to the group for a few years.

"We didn't even get half way through the hearing before the judge called a recess, said Heather. "When we came back in, she apologised that we were put through this ordeal and awarded Ian PIP on an enhanced rate.

"I instantly burst out crying.

"I was so relieved. It was so nice to be treated in such an understanding and sympathetic way.

"It just felt like a pressure valve going off. I was completely overwhelmed."

Heather and Ian: "We fully support the *Right First Time* campaign."

Right First Time

Heather said she was happy to hear Headway was campaigning on the issue of disability assessments through its *Right First Time* campaign.

She said: "We fully support the campaign as we understand the pain it can cause when you are forced to go through the appeal process. Everyone should get involved and raise awareness of it."

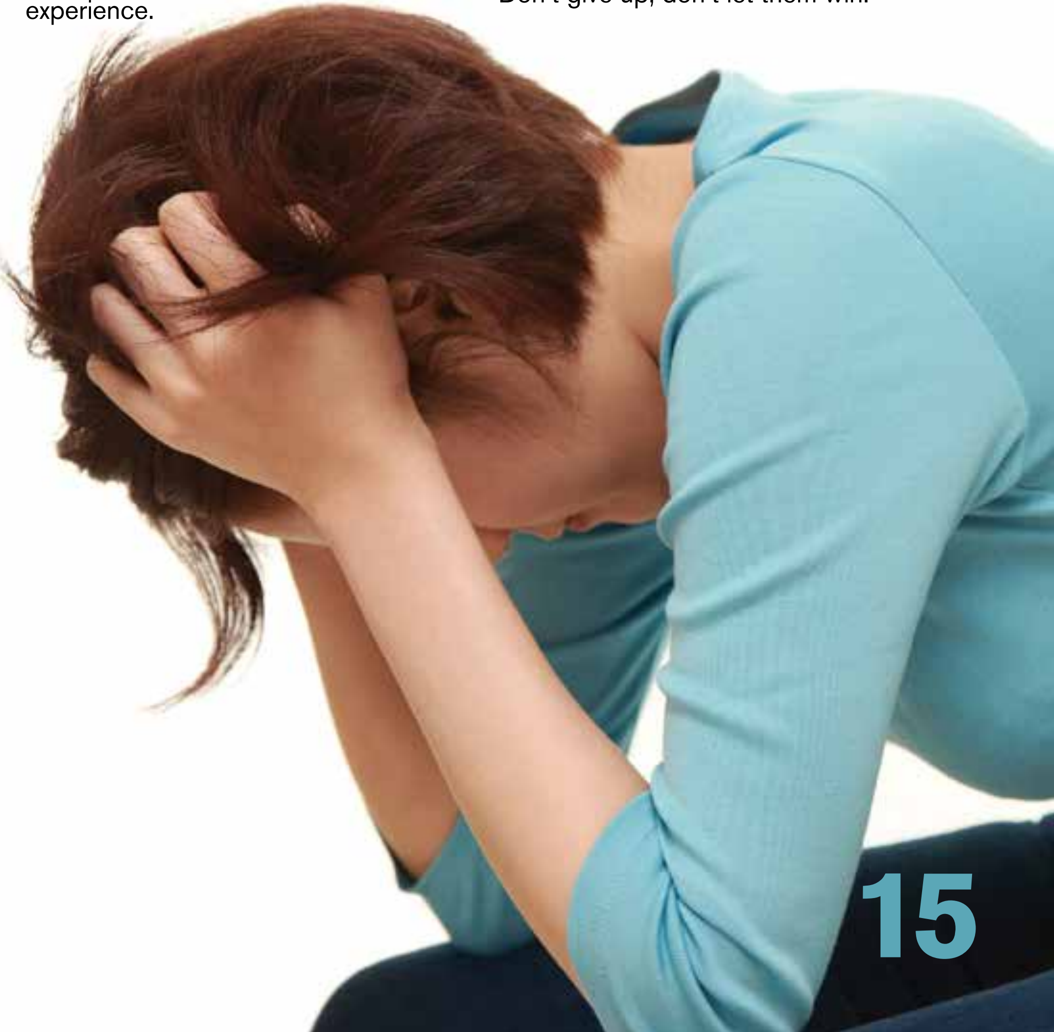
Heather said that although she is glad that the ordeal is over, it has left her feeling furious about the experience.

She said: "The whole thing put a massive strain on us, our relationships, our income, everything.

"These people need to understand the impact they are having when they make ill-informed and quick decisions. Brain injury is complex; it isn't a simple thing to assess.

"It makes me wonder how people cope if they haven't got someone fighting their corner.

"But if you are going through what I did, you have to fight and keep going. Don't give up, don't let them win."



NATURE'S WAY

(l-r) Richard, Joe and fellow gardener Dave Lister hard at work

Across the UK, Headway groups and branches run gardening projects that help to reduce depression, improve self-esteem and provide brain injury survivors with vital peer support and companionship.

Our press officer Charlotte Jones visited Headway Derby's allotment to find out how gardening is helping the group's members to rebuild their lives after brain injury.

When I arrive at the allotment it's a scorching 25 degrees and there's not a cloud in the sky. Despite being situated right next to a main road, the traffic is barely audible and my ears are filled with the sound of birdsong.

Baby sparrows peek their yellow beaks out of a nearby bird box, as mum and dad flit back and forth with tasty grubs.

Towering foxgloves sway in the breeze as busy bees buzz in and out of their tubular petals. The stress of my roadwork-riddled journey quickly fades from my mind and a wave of calm comes over me.

While the rest of the members have a drink, I take a stroll around the allotment with Joe Coleman, 72.

He tells me he has always been a keen gardener and started attending Headway Derby's allotment after sustaining a brain injury in 2007.

The father-of-two was in the driving seat of the family car, alongside his two teenage sons and their two friends when he suffered not one but two simultaneous ruptured aneurysms.

Thankfully the car was stationary and one of his sons was able to remove the keys from the ignition.

As a result of his injury, Joe had to give up his career as a carpenter and, like many brain injury survivors, his social circle also fell away.

"After my accident I met up with people less often," he said. "You get so used to chatting at work. It was a big part of my life, talking to people about day-to-day happenings. I lost all of that."

As he began to recover, one of Joe's support workers who had heard about Headway Derby's new allotment encouraged him to go along.

Joe never looked back and over the past 11 years, he has made some lifelong friends.

"I've met so many lovely people since I started coming here," he said. "I enjoy meeting other survivors and listening to the stories they tell.

"Sadly, some of them have now since passed away, but this place is full of memories. I look around and think back over days gone by and the people who came here. I've made some great friends."

When I rejoin the others, service user Richard Brooks, 67, is waiting eagerly with some photo albums.

After being hit by a car in 1989, Richard sustained a brain injury that resulted in severe memory loss.

"My memory has only started coming back to me in the past five years or so," said Richard. "That's 25 years without being able to remember any of my childhood.

> *"Many years after my accident, I started taking photographs around Repton in Derbyshire, which is where I grew up. I found it helped me to regain memories of my family and my childhood."*

These days Richard enjoys taking photos of Headway Derby's allotment and the wildlife it supports.

"I struggle with motivation and I need a project to work on," he said. "So I set myself a goal to take photos of the allotment each month, to show how it changes throughout the seasons.

"I suffer from bouts of depression where I am housebound. But when I do come to the allotment I feel helpful, I get to socialise and get some fresh air.

"Even though I have to rest for the next couple of days because of the fatigue, I leave the allotment feeling so much better because I've done something productive."

Joe and Richard have both come a long way since the allotment began, something volunteer Ruth Wright knows only too well.

Ruth joined Headway Derby as a paid member of staff in 2006, the year the allotment began. But in 2016, funding for the project ceased and Ruth took voluntary redundancy.

Ruth couldn't face abandoning the allotment and the next week she was back, this time as a volunteer. Her dedication led to her being named as a Volunteer of the Year finalist in the Headway Annual Awards in 2016.

Ruth has been instrumental in making sure both the allotment, and service users who attend it, continue to thrive.

"I couldn't just walk away," she said. "Here was a group of people who didn't want to lose their contact with Headway Derby.


(l-r) Richard, Joe and Ruth at Headway Derby's allotment

"For some, the draw is getting their hands dirty with the physical aspect of the gardening; for others the real benefit comes from socialising in a peaceful outdoor setting.

"It's a relaxing place, with a real sense of friendship and community. I love it here."

Brain injury rehabilitation is often seen in one-dimensional terms, often focusing on the early stages following injury.

But it's clear that gardening, in a similar way to other creative activities such as art and music, can provide very real benefits to those living with the long-term effects of brain injury, helping to reduce social isolation, improve confidence and develop skills.


Keen photographer Richard captures the changing seasons

Nature's Way

Many Headway groups and branches across the UK provide gardening projects as part of their service provision. Here's just a small selection of the green-fingered activities on offer...

Headway Cambridgeshire

Adam Bailey is a former service user at Headway Cambridgeshire who now volunteers at the group's gardening project called Growing Together.

"Before I took part in the gardening project I was finding it hard to contain my emotions and express myself properly," said Adam. "I was liable to blow a fuse if things got too much for me.

"Now I have much more confidence to approach people and talk to them. I am no longer so anxious about making a mistake or blundering in."

Headway Thames Valley

Thrive is a charity that uses gardening to bring about positive changes in the lives of people living with disabilities or ill health.

Having visited its Reading base with other service users at Headway Thames Valley, Rob Black said he was left motivated to do more gardening.


Adam Bailey volunteers at Headway Cambridgeshire's gardening project

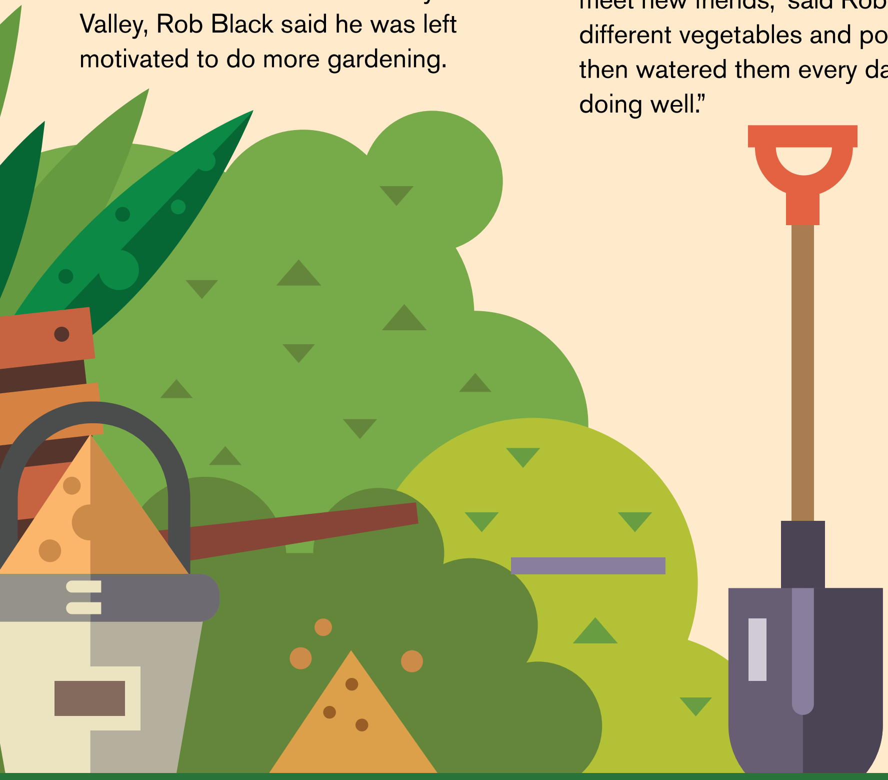
"The best part of the day was potting-up our own plants and taking them home," he said. "I've put mine in my garden and am watering them daily now.

> *"It was very inspiring and has made me want to get out in the garden more. The staff were very helpful and it was interesting to find out about the different plants."*

Headway North Lanarkshire

Getting active is one of the main benefits for brain injury survivor Robert Fraser, who regularly visits Headway North Lanarkshire's allotment.

"Being involved in the allotment has allowed me to get more active and meet new friends," said Robert. "I planted different vegetables and poppies, then watered them every day. They're doing well."




Robert Fraser enjoys a beautiful evening in the Headway North Lanarkshire allotment

Headway Cardiff and South East Wales

Headway Cardiff and South East Wales has a small garden plot at its Independence and Wellbeing Centre, which is based in Rookwood Hospital.

"We really enjoy the project because it gets us working as a team," said service user Christopher Jones.

"It makes us feel good about ourselves because it isn't just Headway members who can enjoy the garden; the rest of the hospital can come and look around the area and see our hard work."

Herefordshire Headway

Helen Mapp, Chief Executive of Herefordshire Headway, says its gardening project is the most popular of all the activities run by the charity.

"When we ask our members about what they've gained from the gardening group there are several themes that come up repeatedly.

"They tell us they have gained the confidence and skills to tend to their garden at home again. They like the fact it gets them out in the fresh air, it's good exercise, and it helps them to relax.

"They also say how much they enjoy working with others and making friends."

Headway Thames Valley's Bob Black comes fully prepared for a day in the sun!

(l-r) Alex Reading, Dave Hampson and Paul Rattle at Headway Cardiff and South East Wales

Les Wargen and Pauline Perry enjoy a gardening session at Herefordshire Headway

'Being out in my garden fills me with a warm glow'

Whether benefiting from the social aspects of communal gardening at a Headway allotment or being active in your garden at home, it's clear that there are many green-fingered gains on offer.

Sue Smith, 61, had always enjoyed being out in nature. But after she sustained a brain injury in a car accident in 1995, her love for the outdoors grew into something more.

"Since my accident, I struggle with my balance and I don't go out so much. Since I can't get out and about, it's great that I have a space at home where I can enjoy time outdoors.

"When I'm inside, it gets me down and it makes me feel low. But being out in my garden fills me with a warm glow. It makes me feel happier, more positive.

"There are a lot of things I can no longer do, but I can still do my gardening. I think it helps me to have a hobby, it keeps me busy.

"Gardening has a huge impact on my mood; it's what has kept me going since my brain injury.

> *"My neighbours like to come in my garden too. They say it has a lovely atmosphere, so there's a really important social aspect to my gardening.*

"I have so many dfferent plants in my garden I couldn't count them all. I love to see them grow and I take great care of them.

"The plants attract so much wildlife I could build an arc! There's a family of blackbirds, a thrush, a robin and two turtle doves, along with butterflies, bees and even squirrels."

THERE'S MORE TO ABI THAN MEETS THE EYE...

Sight is complex. Many people would assume that it is our eyes that do all the work, but actually their role is to merely take in information such as light.

It is our brains that then process and make sense of that information, helping us to identify familiar faces and find our way around, while also keeping us safe from danger.

After a brain injury, our ability to process the information captured by our eyes can be affected. In this feature, we introduce some of the common visual problems that affect people following brain injury, as well as offering some general tips on how to cope.

VISUAL ACUITY

Otherwise known as blurred vision, this can be a continuous issue for some people after brain injury.

DOUBLE VISION

Diplopia, or double vision, is where two images of a single object are seen at the same time.

NYSTAGMUS

Nystagmus is an involuntary rhythmic shaking of the eyes. It can cause issues such as nausea and problems with balance.

BLINDNESS

Complete blindness as a result of brain injury is rare but can occur if there has been significant damage to the visual pathway of the brain or the optic nerves.

VISUAL AGNOSIA

Difficulty with interpreting visual information and recognising objects is known as visual agnosia.

FACE BLINDNESS

Face blindness, or prosopagnosia, is another type of agnosia in which a survivor struggles with processing faces, including loved ones, famous faces or even, in extreme cases, their own.

Top Tips

1. Sometimes less complex visual problems can be corrected with the use of adjusted glasses or contact lenses, so an optician might be able to help.
2. For more complex visual problems, speak to your GP or optician about getting a referral to a neuro-opthalmologist. Ophthalmologists and orthoptists may also be able to diagnose and treat some visual problems.
3. Adapted technology can make it more comfortable for you to use computers and mobile phones. You could also use a screen reader, by which your computer or mobile can read text aloud.
4. Visual prompts can help with some types of visual problems. For example, focusing on non-facial features of a person, such as the person's voice or hairstyle, can help with prosopagnosia.
5. Contact your local authority's social services team for advice on how they can help, such as personal care at home or adaptations to be made to your home.
6. Consider getting a guide dog. You can get advice on whether this is a suitable option for you from organisations such as Guide Dogs.
7. Don't be afraid to ask for help! This can be from family, friends or even day-to-day encounters, such as someone standing at a bus stop with you, or someone working in a supermarket. You may find it helpful to show them your Headway Brain Injury Identity Card.

Headway's new factsheet on *Visual problems after brain injury* is available to download from **www.headway.org.uk/information-library**.

‘Integrating into society is difficult’

Katya

Katya Solyanko, 34, lives with left homonymous hemianopia as a result of a traumatic brain injury sustained in a motorbike accident.

The damage to the right hemisphere of Katya’s brain caused a loss of the left field of view in both eyes. She was also left with dry eyes and diplopia, more commonly known as double vision.

“I lived in denial,” she said. “Before my accident, I lived a very active life. I had built myself a career as a marine biologist, I could drive, I was independent.

“Because no-one really knew what had happened to me, they kept saying my vision would return to how it was before. That was the worst thing to say because I spent five years living in denial.

“I tried to be active and impress everyone with how well I was recovering, but I was lying.”

Once she accepted that her vision problems were permanent, she began to grieve for her eyesight, and the former life it allowed her to lead.

Katya finds it almost impossible to explain to other people how her visual problems affect her. She finds that even those who try to understand cannot comprehend what her life is like.

“Integrating into society is difficult,” said Katya. “People expect you to be completely blind. They don’t know what I can’t see and I can’t explain it to them. It’s so frustrating.

“I’m still learning how to tell people about my brain injury, so they can work with me and my visual problems.”

In November 2017, Katya started attending art sessions at Headway East Sussex. She found that by painting the world as she saw it, she could better express how her brain injury and visual problems affected her.

“People have to look at my paintings like I do, and it makes people realise how serious my condition is,” she said.

THE DEBILITATING IMPACT OF ISOLATION


Jodie: "I really felt the loneliness."

Isolation is a common problem after brain injury. In many cases it can stem from the changes in personality, cognition and behaviour that are so common for survivors.

Headway's own research shows that more than 70% of brain injury survivors have seen deterioration in their social life following brain injury, with a similar percentage feeling that people in their lives do not understand the effects of their condition.

There can be numerous reasons why isolation occurs. The 'new me' that many people experience after brain injury may be difficult for family and friends to accept, and many will slowly drop away over time.

Many survivors struggle with noisy environments, while fatigue can make socialising a challenge – as depicted in Headway's short film *Lost in a crowd* (see www.headway.org.uk/brain-injury-and-me).

Depression is also a common effect, making it hard to seek support and form a plan to address the problem.

Brain injury can have a hugely isolating effect on carers too, who can find that the demands of caring mean there is little time for socialising.

"I live alone and I worked full time as a nurse before I sustained a TBI," said Jodie Bacon.

"I was often busy arranging social events. I loved being out at coffee shops or going out for meals and catching up with my friends. I also looked after my mum who had problems with pain, so I'd take her out and do fun stuff.

"All of that stopped in an instant. My friends were still busy with their lives, which emphasised my lack of life. It felt like I no longer belonged anywhere. If I had the energy to get out chances were things would be too noisy so anything organised by someone else wasn't suitable.

"To begin with I thought the effects would soon be over. When it became clear it wasn't going to be that quick I really felt the loneliness.

"For me the change came when I stepped out of my comfort zone and wrote my friends a message explaining I was still poorly and isolated. I also spelled out to them specifically what I could and couldn't do, and what I needed help with.

"They had no idea and actually in the most part assumed I was back at work. Once they knew what I needed, some of them were there and have been amazing.

"Times like this always show the marks of a true friendship. But if you don't tell people you need help, they will assume you're fine. It's hard to do but well worth it. You'll be disappointed and also pleasantly surprised.

"My mum has really stepped out and grown in confidence and has come over often to take me out for a coffee or to the supermarket. She's been a real lifeline.

"I'd have been lost without my cat also. Her snuggles have filled a big gap in my life!"

AN EXPERT VIEW

Dr Simon Fleminger, Consultant Neuropsychiatrist, St Mary's Hospital, London

In my experience of seeing people with cognitive, emotional and behavioural problems months and years after a head injury, social isolation has a major adverse impact on outcome.

Social isolation is associated with depression, anxiety, low self-esteem and a sense that one has less control over one's life. Social isolation after a brain injury is common.

The emotional and behavioural problems that are regularly seen after head injury, such as lack of empathy and irritability, lend themselves to social isolation; social networks break up over time post injury.

Dr Simon Fleminger

At the best of times it is difficult trying to help people find the support they need, if they lack friends and family who can encourage them to seek help and attend appointments.

Things could improve if case managers were available to help, but this is rarely the case. Often the best hope lies in the voluntary sector.

Self-help groups can be invaluable helping the injured person understand that they are not alone, providing a safe place to talk about worries and some semblance of a social network, and pointing the way to further sources of help.

Getting support

In person: Headway groups and branches offer a range of services to people with a brain injury, their families and carers, and this includes a place to speak to other people who truly understand. You can find your nearest Headway at www.headway.org.uk.

People experiencing feelings of loneliness and isolation should always speak to their GP to discuss the options.

By phone: The freephone Headway helpline is available to anyone seeking support or guidance following brain injury. It's open Monday to Friday, 9am to 5pm, and you call contact the team by calling 0808 800 2244 or emailing helpline@headway.org.uk.

Online: *Our Relationships after brain injury* information is designed to help build and maintain personal relationships, addressing one of the major causes of isolation.

Information for family members, friends, colleagues and other relations will help them to understand how to help and stay involved.

You can read more at **www.headway.org.uk/about-brain-injury/individuals/relationships-after-brain-injury**.

Our website also includes information for carers on how to look after themselves after brain injury, including tips and strategies for balancing the demands of caring with an active social life.

Visit **www.headway.org.uk/caring** to find out more.

You can get support online from Headway's HealthUnlocked community, available at **www.healthunlocked.com/headway**.

Brain Injury Identity Card

WARM WELCOME for ID card in Northern Ireland

Noelle with Tim McGarry, who helped launch the card

Actor, comedian and broadcaster Tim McGarry has helped Headway officially launch its Brain Injury Identity Card scheme in Northern Ireland.

The star of numerous satirical BBC radio and television programmes teamed-up with senior members of the prosecution service and police to endorse the vital scheme.

In a room packed with brain injury survivors who are already benefiting from having ID cards, and dignitaries from a wide range of disciplines, Tim introduced a variety of notable speakers each keen to express their support of the project.

The card is endorsed by Police Service Northern Ireland (PSNI), the Public Prosecution Service and The Northern Ireland Appropriate Adult Scheme. It is designed to help the police to identify brain injury survivors at the earliest opportunity, ensuring they receive suitable support and are diverted away from the criminal justice system where appropriate.

It has the additional benefit of breaking down social exclusion, providing card holders with renewed confidence in the knowledge that they can easily explain their support needs should they require assistance in everyday situations.

Alan Todd, Assistant Chief Constable of the PSNI, warmly welcomed the initiative as a means of not only supporting vulnerable adults but also saving precious police resources.

“Headway’s Brain Injury Identity Card will be very useful to officers who might come into contact with brain injury survivors,” said Alan.

“The card will help to ensure that our police officers and custody sergeants can identify brain injury survivors at the earliest opportunity.

“This will not only save valuable and limited resources in many cases, but more importantly will ensure vulnerable adults are given the correct support for their often complex and fluctuating symptoms.”

The clinically-verified photo ID cards list some of the often hidden and misunderstood effects of brain injury that are experienced by the individual card holder.

Stephen Herron, Director of Public Prosecutions, said: “The ID card will undoubtedly help to improve identification and make sure brain injury survivors with complex or hidden effects are provided with the correct support when they come into contact with the criminal justice system.

“A greater understanding of brain injury will help our staff to ensure survivors’ difficulties are taken into account before deciding upon a course of action.

“For complainants this will involve conducting an individual needs assessment, and for those accused of criminality alternatives to prosecution will be considered in appropriate cases.”

Attendees at the launch also included brain injury survivors Noelle Robinson, Keeva Mullen, and Jacqui McNeil who each shared their experiences of how the ID card scheme is helping them.
Noelle sustained a brain injury in 2011 from a ruptured aneurysm.

The bleed left her with a number of problems including aphasia, fatigue and

Noelle Robinson proudly shows her ID card memory issues. These symptoms have brought many challenges.

"At times, people can be very impatient with me especially if I am trying to communicate with them and having one of my 'cloudy' moments," she said.

> *"I often struggle to get the right word out – particularly if I am being rushed or I'm struggling with fatigue, which is not uncommon after brain injury.*
>
> *"It is not helped by the fact that my injury is invisible and often people struggle to understand why I may appear a little 'woolly' at times. I may appear a little daft to them.*

"For this reason, I really love having my ID card with me at all times."

Noelle, who is a local councillor and chairs the disability forum on the Ards and North Down Borough Council, said she finds carrying the card reassures her.

She said: "Those who know me well don't need to have sight of my card, but for anyone new, or if I'm in a potentially stressful situation, the card is invaluable in helping them understand.

"Knowing it is there really gives me a lot more confidence. I keep it in my wallet and I know it's there if I need to show it. It gives me peace of mind. I used it at the City Airport recently to ask for assistance and the staff went out of their way to help me.

"The card means that if I go a little 'vague' I can produce it to help people understand why.

"Having an invisible injury can be difficult to convey to others, but this card gives me all the help I need."

Peter McCabe, Chief Executive of Headway, said: "We are delighted to be able to officially launch this vital project in Northern Ireland and we are very grateful for the support we have received.

"Special thanks must go to Noelle, Keeva and Jacqui. Sharing such personal information in front of an audience must be a daunting experience, but their passion to help improve life after brain injury came across perfectly."

Praise for ID card

To better understand the impact of the card we asked users to let us know if it was helping them and if anything could be improved with the application process.

The responses we have received have been overwhelmingly positive. They clearly show the important impact the card is having to help people cope not only explain their condition but also get the correct support or understanding.

The survey was sent out to more than 1,300 people who had indicated they were happy to be contacted and provide feedback.

Key findings...

Application Process

97% of respondents that used the online application form told us they thought it was excellent or good

92% of respondents that used the paper application form told us they thought the form was excellent or good

Brain Injury Identity Card

97% of respondents told us they thought their ID card was excellent or good

58% of respondents told us they had used their ID card

Brain Injury Identity Card

72% of respondents, told us they have used their ID card in a social scenario setting

97% of respondents told us that when they used their ID card it was very helpful or helpful

To apply for an ID card, visit www.headway.org.uk/idcard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What makes us unique... is you!

Keith takes a walk on the Welsh side

A determined pensioner from Lancashire has hiked an impressive 140 miles around Anglesey in just 12 days to raise nearly £6,000 for Headway in memory of his wife.

Keith Pilkington, 72, from the village of Helmshore in the Rossendale Valley, lost his wife Tricia after she sustained brain injuries following a fall at home in 2016. She was just 61.

While Tricia was a patient in the Critical Care Unit at Royal Preston Hospital, the family turned to Headway for advice, support and comfort.

Keith said he really enjoyed the walk, especially the beautiful scenery and wildlife that features on the island, although he did find the weather challenging.

"The extreme heat did make it tough going," said Keith. "It wasn't just the amount of miles I had to walk, but also the total height ascended – some 16,534 feet – which is more than four times the height of Mount Snowdon.

"But I was determined to complete it and it was very rewarding to have a chance to show Tricia's untimely death could lead to something very positive."

Friends and family joined Keith on different parts of the route with 15 people supporting him on the final day.


Keith Pilkington walked 140 miles around Anglesey in just 12 days.

Last year Keith's stepson Daniel Byrne ran the London Marathon for Headway, again in honour of his mum, raising more than £10,000.

Keith and Daniel recently visited Headway's main office in Nottingham to learn more about how their incredible efforts will support the charity's work to improve life after brain injury.

He said: "It was lovely to be able to visit the charity and better understand how they support people.

> *"What really came across was the fact that when someone sustains a brain injury it affects not just that person, but the whole family too."*

Jo Plant, Director of Fundraising at Headway, said: "What an inspirational family! Keith and Daniel's efforts to support others affected by brain injury are exceptional.

"Meeting our fabulous fundraisers – without whom we wouldn't be able to run our vital services – is always such a humbling yet motivating experience."

Get involved!

Planning on organising your own fundraising event? Our fundraising team would love to hear from you.

You can get in touch by phone on **0115 924 0800** or email **projects@headway.org.uk.**

#HeadwayHeroes

LEAP OF FAITH for daredevil fundraisers

Investment manager Michael Stimpson has been left in no doubt that he doesn't have a head for heights after he took part in a charity skydive for Headway.

Michael, who was joined by 15 other members of staff from Headway Baton Holders Saltus Private Wealth Management, plunged 15,000 feet over the skies of Salisbury.

The jumped helped to raise £7,340 towards the baton holder's target of £20,000 for the year.

Michael Stimpson, Partner at Saltus Private Wealth Management, said: "We had an amazing day skydiving for Headway.

> *"For most of us it was our first jump and while we were all very excited on arrival there were definitely quite a few nerves as our take-off time came closer.*

"I found it a particularly useful day as I now know for certain that I'm definitely scared of heights!

"We were delighted to be able to raise over £7,000 for such a worthy cause and have amazing memories that will stay with us for many years."

Did you know...

At Headway, we can help you take on a huge variety of fundraising challenges that will not only raise valuable funds to help improve life after brain injury, but also leave you with memories of completing a once-in-a-lifetime challenge.

In addition to a range of running and cycling events, from the London Marathon to a London to Paris bike ride, you can trek the Great Wall of China, climb Kilimanjaro, or even follow the Saltus team by jumping out of a plane.

Check out what's on offer at **www.headway.org.uk/get-involved.** Meanwhile, if you are interested in adopting Headway as your Charity of the Year, please contact **partnerships@headway.org.uk**.

SALTUS

PRIVATE WEALTH MANAGEMENT

All smiles: The Saltus team prepares to take the plunge!

Incredible views – if you're brave enough to open your eyes!

‘Marathon effort inspired by our guardian angel’


Denise proudly shows her medal for finishing the Blackpool Half Marathon

Sisters Denise Reynolds and Nicola Ellison have between them raised more than £1,300 for Headway – albeit using somewhat different means of doing so!

Denise raised more than £700 by bravely conquering the Blackpool Half Marathon. Nicola, however, chose a novel way to support the charity while at the same time marking the arrival of the latest member of the family, Sydney, by holding a guess the baby’s weight competition.

Nicola’s – or should we credit Sydney? – efforts raised an impressive £600. But while their methods may differ, their inspiration most certainly did not.

Their father, Andrew, sustained a traumatic brain injury after having a fall. When the sisters were sat by the bedside of their critically ill father they were racked with fear and uncertainty of what the future might hold.

Thankfully, while on the ward they were approached by a Headway Acute Trauma Nurse (HATS nurse).

“A wonderful lady came over,” recalled Denise. “She didn’t say much, but she just gave a caring squeeze of our hands, handed us a leaflet with a number on and said she was there for us.”

The nurse was Alex Power who works with hospitals in the North West of England to provide emotional and practical support for families and carers in the early stages following brain injury. Denise said: “From that day on, Alex was on the journey with us and as a family we could not have asked for more.

“We simply could not have got through those weeks, and months, without her constant support, guidance and care.

“She was and still is with us every step of the way. We really do not know what we would have done without her.

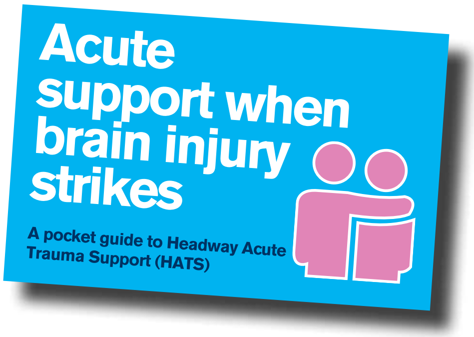
“We still have a long way to go but Dad is improving everyday and we are so thankful we got him home.”

Nicola added: “During the horrific time when Dad was in hospital, our family was sent a little miracle. We thought it would be nice to use Sydney’s arrival to raise money for Headway.

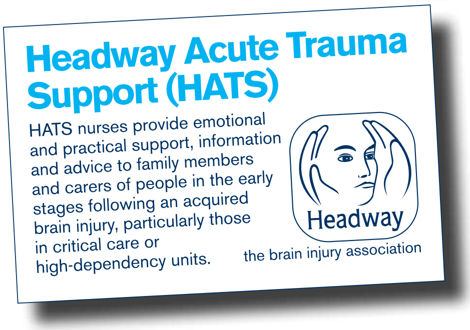
“It was such a nice feeling to be able to give something back.

“We really do not know what we would have done without Alex. She was our guardian angel and the charity has given me and my family incredible support over the past nine months.”

For more information about our HATS nurses, visit www.headway.org.uk/HATS.


Acute support when brain injury strikes

A pocket guide to Headway Acute Trauma Support (HATS)


Headway Acute Trauma Support (HATS)

HATS nurses provide emotional and practical support, information and advice to family members and carers of people in the early stages following an acquired brain injury, particularly those in critical care or high-dependency units.

#HeadwayHeroes

ANDY WALKS THE WORLD!

A brain injury surivivor from Lincolnshire has helped to raise more than a thousand pounds by co-ordinating a fundraising event that stretched across the globe.

Andy Nicholson, also known on online brain injury forums as the Brain Damaged Baron, sustained a brain injury in 1994 after falling 20-foot headfirst down an unguarded stairwell while working in Leipzig, Germany.

Since then, he has worked tirelessly to raise awareness of brain injury through his YouTube channel. Recently, he decided to take things one step – or rather many steps! – further by organising his own awareness raising event called Walk with the Baron.

Andy reached out to his online community and encouraged them to hold simultaneous fundraising walks – wherever they lived.

Andy explained: “Organising Walk with the Baron was largely an extension of what I have been doing online for two years now, making films and talking about living with a brain injury.

> *“I wanted people to do their own marathon. Depending on their individual ability, that might be 26 miles or 26 metres. That doesn’t matter.*

“Many of the contacts I have made online were very supportive of the event and when I wasn’t on the web, I was making endless phone calls to various organisations trying to drum up support.”

However raising awareness of brain injury, which is often widely misunderstood, did not come without its challenges for Andy.

Andy said: “The idea behind the walk was always to raise awareness of brain injury and therein lays the problem.

> *“That very same lack of awareness presented some obstacles. People struggled to understand that I had a severe brain injury but I wasn’t bedridden, wheelchair bound or struggling with communication.”*

Not to be put off, Andy persevered with organising the walk. He shared his plans widely on social media, contacted local businesses for support and featured in his local media.

Andy’s tenacity paid off and in July supporters around the world laced up their walking boots to ‘walk with the Baron’, with events taking place in the UK, Switzerland, Australia and the USA.

Andy said: “The day was enormously enjoyable. All sorts of people took part in their own ‘marathon walks’ from 12-year-old girls to a 65-year-old lady recovering from viral encephalitis.

> *“Although I have to say that to finally be able to stop walking after eight and half hours was also enjoyable.”*

As well as putting brain injury and its effects firmly on the radar of communities around the world, Andy managed to raise more than £1,000 for Headway and he’s not stopping there.

He plans to continue his awareness raising campaign in 2019 with another walk to improve understanding of brain injury.

Andy with his children Joshua and Hannah

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

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