

Spring 2021

Headway News



The magazine of Headway - the brain injury association

*“There’s
nothing minor
about any
head injury.”*

GB Hockey star
Alex Danson-Bennett
MBE



**Concussion
myth-busters**

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Adam, Thompsons' client



Welcome

Welcome to the spring edition of Headway News.

The pandemic has dominated our lives over the past year. Our regular activities have been hugely disrupted, altering our perspectives and re-shaping our plans. We all long for a return to something approaching normality.

The opportunity to meet with family and friends to enjoy the everyday social interactions that can play such an important role in our lives is something we are all desperately looking forward to.

For brain injury survivors and carers in particular, the easing of restrictions cannot come soon enough. Whether it is access to social interaction, rehabilitation, or carers' respite, there is no doubting the pressures and frustrations being endured.

However hard it has been for us, we should not lose sight of the fact that over 123,000 people have lost their lives to Covid-19 in the UK since the pandemic began. My thoughts are with the families who have lost loved ones to the virus, particularly those who are associated with Headway.

However, the development and impressive delivery of vaccines by the NHS has given us all a degree of optimism and it's important to remain positive about the future. But there is a long way to go and many challenges to overcome before all Headway groups and branches across the UK can fully reopen their services. I would like to thank all my colleagues throughout the Headway network for their extraordinary efforts to maintain these services and provide vital remote support to people with brain injury and their loved ones during the pandemic.

Every day that passes adds further financial pressure onto Headway UK and local Headway charities. Whether it's our shops remaining closed or the understandable reduction in all fundraising involving face to face activities, the challenge to survive the coming months remains very clear.

Thank you to everyone who has already donated to Headway. Your support means the world to us. If you haven't already made a donation and feel you can afford to help safeguard our future, please consider doing so at www.headway.org.uk/donate or to your local group or branch, details of which can be found on our website.

While much of society has been forced to shut down due to Covid-19, elite-level sport has continued. For many, this has provided a welcome relief and a means of channelling emotions. For others, it represents a lack of consistency in the way lockdown rules are applied in different sectors of the entertainment industry.

The continuation of sport has brought with it yet more concerning stories of sportspeople having to take early retirement as a result of sustaining repeated concussions. And it's not just footballers and rugby players.

In this edition of *Headway News*, Monica Petrosino, a Team GB ice hockey player, talks about a serious concussion ending her career at the age of just 24, while on our website you can read about Eleanor Furneaux who was also 24 when she was forced to quit the GB Skeleton team for the same reason.

Meanwhile, our cover star is Olympic gold medallist Alex Danson-Bennett MBE, who herself had to quit the sport she loved due to concussion. Alex, who has now become a patron of Headway, sustained her injury while on holiday. But while her injury is not due to sport, it is a stark reminder that even a minor head injury can have a major implication.

Concussion is an issue that affects all sports, at all levels. On a positive note, our *Concussion Aware* campaign continues to make a difference as, with the help of elite level athletes willing to share their experiences, we increase awareness and understanding.

Peter McCabe
Chief Executive



the brain injury association

Who we are

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.

Go digital!

If you'd prefer to receive Headway News as an email then let us know at headway.org.uk/tick-yes

Essential contacts

Headway office:

Bradbury House, 190 Bagnall Road, Old Basford, Nottingham NG6 8SF

Telephone:

0115 924 0800
enquiries@headway.org.uk

Nurse-led freephone helpline:

0808 800 2244 (9am - 5pm, Mon to Fri),
helpline@headway.org.uk

Website:

www.headway.org.uk

Advertising:

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Fundraising:

projects@headway.org.uk

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Your views

Never. I spend my time trying to forget the horrific incident although as fellow TBI survivors know, you get daily reminders.

Emma Louisa

The anniversary of a brain injury can be a particularly difficult time for survivors and their loved ones, but people have many different approaches to marking a day that shaped their lives like no other. For some it's a case of sadness and trying to forget, while others celebrate their new life and hopes for the future.

We asked our social media followers to tell us how they mark their brain injury anniversary...

Every year I recognise the date and I remember what happened, remember how hard I worked to become functional, and remember for whom I worked so hard - my child and my husband.

Sarah Gruen

I still grieve for the 'me' that I was on the anniversary, even though it is approaching 9 years.

Sue French

Has gradually become less difficult and last few we try to do something positive - a nice lunch or fundraising challenge. I now try to celebrate that my husband survived rather than the trauma of the event and aftermath. It's an adjustment.

Linzi Blair

Although I am frustrated by what I've lost, you can't turn back time, so I use the anniversary to think about the positive aspects and what I've learnt through the experience.

Philip Bush

I give thanks for my second chance at life with a few glasses of wine. It has definitely changed my outlook on life. I do live for today, don't worry about anything that I have no control over and tell my family regularly how much I love them.

Bal Tawana

I celebrate... and give thanks for being alive and to the wonderful NHS team that saved my life...my friends and family who still continue to give me the support I need.

Elizabeth Moxey

Visit our website at headway.org.uk/about-brain-injury for information on the effects of brain injury and practical guides to help you cope. You can also get in touch with our helpline to talk through your concerns and get information that is tailored to your circumstances. Contact the team on **0808 800 2244** or helpline@headway.org.uk

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Go green!

Did you know that the plastic wrap used for Headway News is recyclable? It’s made from polythene film and starts to break down after just three months. Recycle with carrier bags at larger supermarket stores, not at the kerbside. Do your bit to help save the environment and recycle today.



Latest news round-up

With news of your charity's ongoing work to improve life after brain injury

MP demands government takes action to increase access to rehabilitation for brain injury survivors

Chris Bryant MP, Chair of the All-Party Parliamentary Group (APPG) for Acquired Brain Injury, has called on the government to improve neurorehabilitation services for brain injury survivors.

Addressing the Minister of State for Care, Helen Whately MP, Mr Bryant laid out a series of 'demands' of government which included the creation of a national neurorehabilitation strategy. He also requested "a guarantee from the government that all those [neurorehabilitation] services and more will be reinstated" following the pandemic.

Chris also singled out Headway for praise, highlighting his appreciation for the work done by Headway and recognised the scale of the financial challenge we are facing as a result of the pandemic. He said: "Headway is also a wonderful organisation, although like many charities in this field, it is having a really difficult time this year."

In her response to Mr Bryant, Helen Whately MP, praised the contribution of Headway groups and branches

from across the country saying: "I recognise the vital work of charitable organisations such as Headway... Their work is invaluable not only in raising awareness but in providing hands-on help and support to patients, families and carers."

Commenting on the debate, Sarah Russell, Public Affairs Manager at Headway, said: "We are very grateful to Chris Bryant and his colleagues on the APPG for Acquired Brain Injury for their continued work in this area.

"The impact of this pandemic on brain injury survivors and their families cannot be underestimated. In a survey conducted with survivors we found that 57% of those who sustained their injury in the last two years said their rehabilitation had been negatively affected.

"We are pleased that the work done by Headway groups and branches across the country in supporting brain injury survivors has been recognised by the Minister. But we hope that more can be done by the government to support the continuation of these vital services in our communities."

Blue Badge disparity for hidden disabilities

According to research conducted by the BBC, eight out of 10 councils have higher approval ratings for the issuing of Blue Badges for people with physical disabilities than their non-visibly disabled counterparts.

Of those 109 councils who provided full responses to the BBC, 10 revealed that that the difference was greater than 50 percentage points.

Headway previously welcomed the decision to extend the Blue Badge scheme back in 2019 but is concerned that more work needs to be done in order to properly recognise the impact of hidden disabilities.

Sarah Russell, Headway's Public Affairs Manager, said: "It is worrying that there appears to be a lack of understanding about how debilitating the effects of hidden disabilities can be.

"Brain injury survivors can be faced with a whole range of challenges post-injury, including fatigue which makes walking long distances difficult. They should be able to access a Blue Badge where they are entitled to under the hidden disability rules, which would be hugely helpful for them in living an independent life."

The BBC also reports that the online process is overly long and complicated, meaning people have found it difficult to navigate.

Sarah added: "It is hoped that this will serve as a wakeup call to councils that they need additional training in recognising the effects of hidden disabilities, such as brain injury, and that the government takes the steps necessary to ensure the application process is consistent, accessible and fair."



Diop concussion shows new subs rule 'deeply flawed'

The first use of a concussion substitute in football in the UK has highlighted the 'deeply flawed' nature of the newly-introduced rule, according to leading brain injury charity Headway.

After 36 minutes of an FA Cup match between Manchester United and West Ham United on 9 February, Anthony Martial (Manchester United) and Issa Diop (West Ham United) clashed heads at a corner kick.

The players received on-pitch treatment for two minutes before they then both returned to the field of play, only for Diop to be removed at half time, becoming the

first player to be substituted via the new protocol.

"The decision to allow Issa Diop to return to the field of play after being assessed for concussion in just two minutes while still on the pitch shows just how deeply flawed this new protocol is," said Peter McCabe, Chief Executive of Headway – the brain injury association.

"When this rule was introduced to much fanfare, we warned that it would make very little difference in terms of protecting players from the risk of more serious injury.

"Had football's authorities followed the advice of Headway and other leading experts by introducing temporary substitutes, as successfully used in other sports, Diop would not have been at risk

of exacerbating the injury to his brain during the seven minutes he was allowed to play on before half time.

"Instead, he could have had a longer assessment, which would have included the 15-minutes of half time, in a quiet treatment room. This would have given the medical team more time to make their decision.

"The new protocol has failed its very first test. FIFA and IFAB must act now to alter the rule and introduce temporary concussion substitutes to avoid such unacceptable risk being taken in the future."



Latest news round-up

With news of your charity's ongoing work to improve life after brain injury



'Lawsuit should be a wake-up call', says Headway

Headway responded to news of a possible class action lawsuit on behalf of former rugby players, saying that all contact sports should be closely monitoring developments.

Media reports suggest that eight retired players, including England's World Cup winning hooker Steve Thompson, are taking action against World Rugby and their respective national governing bodies.

Thompson, 42, was diagnosed with early onset dementia and probable CTE in November. Speaking to the Daily Mail, he said: "I have no recollection of winning the World Cup in 2003, or of being in Australia for the tournament. It's like I'm watching the game with England playing and I can see me there, but I wasn't there, because it's not me.

"During training it was not uncommon for me to be left dazed, seeing white

spots and not knowing where I was for a few seconds, sometimes I would pass out completely. It was just an accepted part and parcel of training. I really wished that I had ended my career earlier, maybe my diagnosis might not be so bleak."

Peter McCabe, Headway's Chief Executive, said: "Reports of a possible class action lawsuit on behalf of former rugby players should be a wake-up call for all contact sports. It took similar action in the USA to force the NFL to recognise the seriousness of the issue and accept that it simply had to change in order to better protect the short and long-term health of players.

"But let's be clear: this is not an issue for rugby alone. All sports owe a duty of care to those who take part. Given what we now know about concussion and the cumulative, long-term effects of repeated blows to the head, no sport can afford to be complacent in the way it addresses head injuries."

Ryan reaches out to Raul

Former Premier League and England footballer Ryan Mason has offered his support to Raul Jimenez and his family after the Wolves player suffered a fractured skull in a game against Arsenal on 29 November. Jimenez required oxygen on the pitch before being taken to hospital for further treatment.

Ryan, who is now a Headway Ambassador, suffered a similar injury in 2017 while playing for Hull City against Chelsea. Despite a valiant attempt to regain fitness, Ryan was unable to play again and retired on medical advice at the age of 26.

"I was horrified to watch the incident in the game," said Ryan. "It has brought back a lot of negative memories for me and my family, who had the agony of not knowing whether I would pull through."



Raul is now making good progress towards a return to play, undergoing fitness work as part of his rehabilitation.

He has nominated Headway as one of two charities to benefit from a remarkable appeal set up by his devoted supporters who wished to fund a banner of support.

Thanking his fans, Raul said: "I am delighted that we have such a large amount of money left over to give to organisations that will make sure that the right people benefit from all the love and generosity I received."

TEST YOUR NERVES

by skydiving for Headway!

Ever wanted to jump out of a plane at 10,000ft, freefall for 45 seconds then take in the glorious view as you gently glide to the ground? Well this is your chance, and all for a good cause.

While many fundraising events have been cancelled or postponed over the last year, skydiving organisers

have devised extensive Covid-secure protocols to ensure your safety, putting this challenge of a lifetime firmly on your 2021 bucket list.

Jumps are available throughout the year at airfields across the UK, no training is required, and all we ask is that you raise at least £395 for Headway.

Tempted? Head over to headway.org.uk/skydive to find out more and book your experience!



Are you a Friend of Headway?

Becoming a Friend of Headway member is a great way to support the charity, accessing a range of benefits while helping us to continue improving life after brain injury.

Every member receives a Headway pin badge and wristband, a discount on our award-winning publications,

access to a free or discounted will writing service and a copy of this very magazine delivered four times a year.

There are annual and lifetime options available and a discount for brain injury survivors and their loved ones, and even ways to buy a membership as a gift.

Just complete the simple form at headway.org.uk/friend to become a Friend of Headway today.



“THERE’S NOTHING MINOR ABOUT ANY HEAD INJURY.”

Alex Danson-Bennett MBE is recognised as one of the finest hockey players Britain has ever produced. Having been vice-captain of the GB women’s hockey team for their historic gold medal performance at the 2016 Rio Olympics, she competed in multiple international championships amassing 306 caps for her country and a record-equalling 115 goals.

But everything changed in an instant when a seemingly mild head injury had a devastating impact that would force her to retire from the game.

Alex was on holiday in Kenya with her then boyfriend, now husband, who is also called Alex. The couple were enjoying a meal in a local restaurant when she threw her head back in laughter after he told a joke, hitting her head on the brick wall behind.

“At the time I thought ‘that was hard, that wasn’t great,’” said Alex. “But I just went back to the apartment, went to sleep and ignored it. When I got up the next morning things got progressively worse.



"Two weeks before my injury I was walking the GB women's hockey team out as captain. Two weeks after, I couldn't walk to the bathroom or hold a conversation."

"I returned home and had to lie in a dark room, I couldn't tolerate any noise or sound. I really wasn't very well. Six weeks after the injury I started being violently sick and having seizures, so I was rushed into hospital."

Alex received a wide range of tests, eventually being diagnosed with a mild traumatic brain injury. Having experienced concussion before during her hockey career, she was shocked to be told that it could take many months to recover from the injury.

Alex said: "In the beginning I literally couldn't do anything, but then you have to manage how much you take on as you start to get better. I'd get frustrated because I'd want to do something then very quickly feel terrible."

"I was very slowly building back up, and in the early days my husband had to do everything, like walking me to the bathroom, liaising with doctors, driving me to every appointment and cooking all the meals. He was a constant source of support while every day I felt like I wasn't the person I used to be."

"It's been about two and a half years now and I'm much, much better than I was. But I still get headaches every day, I still have to manage the cognitive 'load', and screens are a big problem for me."

In January 2020 Alex returned to hockey, but quickly realised that she would have to retire due to the ongoing effects of her brain injury. Since then, she has taken up coaching, runs her own hockey academy and works with Vitality to help people improve their health. Alex and her husband are also busy with the arrival of a new addition to their family, a daughter born in January 2021.

She said: "I manage my week now, spending time outdoors because that

suits how I respond to artificial light. I think there's a retraining your brain part of recovery, so it's important to work and positively challenge my brain."

"I would say life is very different to what it would have been if I hadn't hit my head. Two weeks before my injury I was walking the GB women's hockey team out as captain. Two weeks after, I couldn't walk to the bathroom or hold a conversation."

"I'm not the same as I was but I'm living a happy, fulfilled life, I just have to manage the symptoms which I believe, in time, will go. If I can get to the end of 2021 and be headache-free, I'll be absolutely delighted."

Alex recently found out that her mother regularly used the Headway helpline for support in the weeks and months following her injury.

She said: "For a family it's a horrendous time, to see your loved one suffering so badly with no one helping or understanding. But Mum used to call the helpline just to speak to someone, and they reassured her and gave her snippets of information about brain injury."

"She found it an incredible service that she accessed regularly. I was too unwell to call myself, but as a resource for the family, it was incredibly useful."

With a passion for raising awareness of brain injury, Alex has become a Headway Ambassador. She supports the charity's *Concussion Aware* campaign to help more people enjoy sport while having a greater understanding of the dangers of concussion.

"I know my injury wasn't in sport, but I don't want anyone to go through what I've gone through in the last two and a half years," said Alex. "If better concussion protocols, early management and early treatment can improve your recovery, which I believe it can, then I'd like to see that in place."

"My advice would be to not do anything until you're symptom-free. A few weeks seems like a long time, but two and a half years feels like an eternity so listen to your body, rest and don't rush back."



Monica's story:

"I want concussion awareness to become an absolute staple in sports."

Monica Petrosino dedicated almost 20 years to ice hockey and ascended to the elite level of playing for Team GB, but her dreams were tragically dropped when a serious concussion forced her to accept retirement at the age of 24.

"During a game in 2014, I was skating at full pelt when someone took my feet out from underneath and another came straight into me," said Monica. "My head slammed onto the ice. I don't think anyone realised the severity of what had happened."

Monica was sent home and had severe headaches and sickness, but no-one suspected a concussion.

"The next day I was brought into another game. About five minutes in, I completely blacked out. I was taken to A&E, which is where the injury was picked up.

"For the next three to six weeks I had sickness, nausea, headaches... I felt sleepy all the time, but the worst symptom was speech disturbance.

"I really struggled for a year to get back into hockey. My motivation and reaction times were drastically different."

Despite the challenges, Monica's love and tenacity for the sport saw her being reselected for the GB Women's Senior Team. But a series of minor knocks to the head along the way culminated when

she sustained another hit during the 2019 World Championships.

"I eventually decided that it was time to retire. I still get upset about the fact that I can't play."

Monica's retirement didn't end her career in ice hockey though, as she decided to start coaching instead. She is also now studying a degree in Psychology.

"There is a life after sport, and it isn't what completely defines you. If you have to step down because of a concussion, you will get that amazing buzz from something else."

Monica is now a keen advocate of raising concussion awareness. "I want concussion awareness to become an absolute staple in sports. I want there to be protocols, not just at GB level but at a club level as well. I don't care if I need to shout at the top of my lungs to tell everyone repeatedly, everyone needs to know."



Monica with her GB Ice Hockey teammates

Monica Petrosino



"I eventually decided that it was time to retire. I still get upset about the fact that I can't play."

Concussion

MYTH-BUSTERS

"I DIDN'T LOSE CONSCIOUSNESS, SO SURELY IT COULDN'T HAVE BEEN CONCUSSION?"

A person does not need to have lost consciousness to have experienced a concussion. In fact, less than 10% of concussions result in loss of consciousness.

"I DON'T WANT TO LET MY TEAM DOWN BY BEING REMOVED FROM PLAY IF I HAVE A CONCUSSION."

If there is any suspicion of concussion, it is important to take an 'if in doubt, sit it out' approach. Pushing on through a game can make the impact of a concussion worse. Paradoxically, doing so can jeopardise a team's chance of success even more because the concussed player may not perform as well as normal.

"MY FRIEND HAD A CONCUSSION AND THEY WERE FINE AFTER A WEEK. I'LL PROBABLY BE FINE IF I GET A CONCUSSION TOO."

It is important to remember that no two brain injuries are ever the same and experiences will vary from person to person depending on things such as the force of the impact, location of injury and personal differences. It is important to assess each case differently and listen to what your own body is telling you about how you feel.

"I HIT MY HEAD WHEN I GOT CONCUSSION. SURELY THAT DOESN'T MEAN I HAVE BRAIN INJURY?"

A concussion happens when a force to the head causes the brain inside to shake around the skull. Technically, this is considered a brain injury although it is classified as a mild brain injury.

"IF YOU DON'T HAVE ANY SYMPTOMS IMMEDIATELY, YOU DON'T HAVE A CONCUSSION."

Symptoms of concussion can often be delayed in their presentation and may not manifest for several hours or even days after the incident.

"YOU CAN RETURN TO PLAY AS SOON AS YOU FEEL BETTER."

If you have sustained a concussion or suspected concussion, it is vital that you do not return to play or training until cleared to do so by a medical professional – even if you feel fine. The advice is to leave it at least three weeks before returning to play, following your sport's return-to-play protocols in the process.



BACK BEHIND THE WHEEL

Driving might not be possible for everyone after brain injury, but for many people it's a realistic target that can greatly increase independence and quality of life. As a complex and potentially dangerous activity, it is important that everyone approaches driving carefully and follows the legal requirements.

Driving FAQs

Here we answer some of the helpline's most frequently asked questions on driving.

How can driving be affected by brain injury?

Driving is a complex activity requiring cognitive and physical skills, as well as the ability to co-ordinate these. Some of the key skills that driving relies on are commonly affected by brain injury, such as being able to react quickly to changing situations on the road, remembering routes, processing different things simultaneously and concentrating for sustained periods of time.

Dizziness and balance problems may cause difficulties with the motion of driving, while visual problems may affect

a driver's field of vision. The risk of experiencing a seizure while driving can also make it unsafe for survivors with epilepsy to drive.

Brain injury survivors who have difficulty managing their emotions may react worse to stressful situations that may arise when driving.

A survivor's ability to drive may change over time as the effects improve or worsen.

Who do I need to inform about my brain injury?

By law, you must tell the licensing authority (the DVLA in England, Scotland and Wales and the DVA in Northern Ireland) about your brain injury, as they are responsible for making the decision on whether you are safe to drive or not. You can notify the relevant

authority by using the government website (www.gov.uk).

You should also tell your vehicle insurance provider about your brain injury.

It can take over six weeks in some cases to hear back from the licensing authority. In the meantime, you should consult your doctor or neurologist as to whether you can continue driving while waiting for a decision.

Following the decision, you may be allowed to continue driving as normal or there may be conditions such as needing to take an expert driving assessment, having the vehicle adapted to make it more suitable or having a time-limited license after which you will be re-assessed. Your license may be withdrawn, but you may have the option to reapply later.

"I felt so elated and free again"



Brain injury survivor Paula Barlow shares her experience of returning to driving after brain injury.

"In April 2020 I had a sub-arachnoid brain haemorrhage. I had for many months suffered really bad headaches which had been misdiagnosed as migraines.

"I collapsed at home on a very ordinary Sunday afternoon and was lucky that my husband was home. I have no recollection of the events following but was taken to the local hospital and then transferred to Royal Preston Hospital for treatment. After having a few

complications following surgery I spent time on the neuro-rehab ward before finally returning home.

"It was fabulous to be home, but it soon became apparent how much I would rely on my husband and family for care. I was completely exhausted, confused and very emotional, but also determined to get better.

"I realised very quickly that driving would be out of the question for a number of months and was advised by the rehab team that six months was normal. I contacted the DVLA who were excellent in helping me with the necessary form that was very straightforward and notified my insurance company.

"I decided after five months that I wanted to drive again. I spoke at length to my doctor and had an up-to-date sight test to ensure my vision was

100% and was pleased all was ok. I then called the DVLA again who couldn't have been more helpful and advised that because my doctor had given me the green light, I could drive from that point and that written confirmation would be sorted in the background while my licence would be returned in due course.

"I went straight to my car and went for a very short drive. Yes, I was very nervous, but I felt so elated and free again. I made a promise to my family never to drive if I was having a particularly bad day with fatigue.

"If I can offer one piece of advice to others, allow yourself time to heal. I have a wonderful family and the most beautiful grandson, everything I need to get better for. Healing is a long process, be patient."



Get support

You can find out more about the legal requirements and support that is available to get you back to driving in the Headway booklet *Driving after brain injury*.

Contact the Headway helpline on **0808 800 2244** or **helpline@headway.org.uk** or download now from **headway.org.uk/information-library**.



A gift to mum

Debra Jones sustained a traumatic brain injury while on a night out with friends between Christmas and New Year in 2015.

Her story and experience of living with a brain injury will resonate with many – as will her frustration and anger about a general lack of understanding about the long-term and often hidden effects of brain injury.

It was a frustration also felt by her family. Until, that is, her son Kieran Nolan Jones decided to make a film documenting the effects of Debra's brain injury. The result, called *Jelly Brain*, is both powerful and emotive.



Abi, Debrah and Kieran

We spoke with Kieran to ask him about the challenges and rewards of making such a personal film.

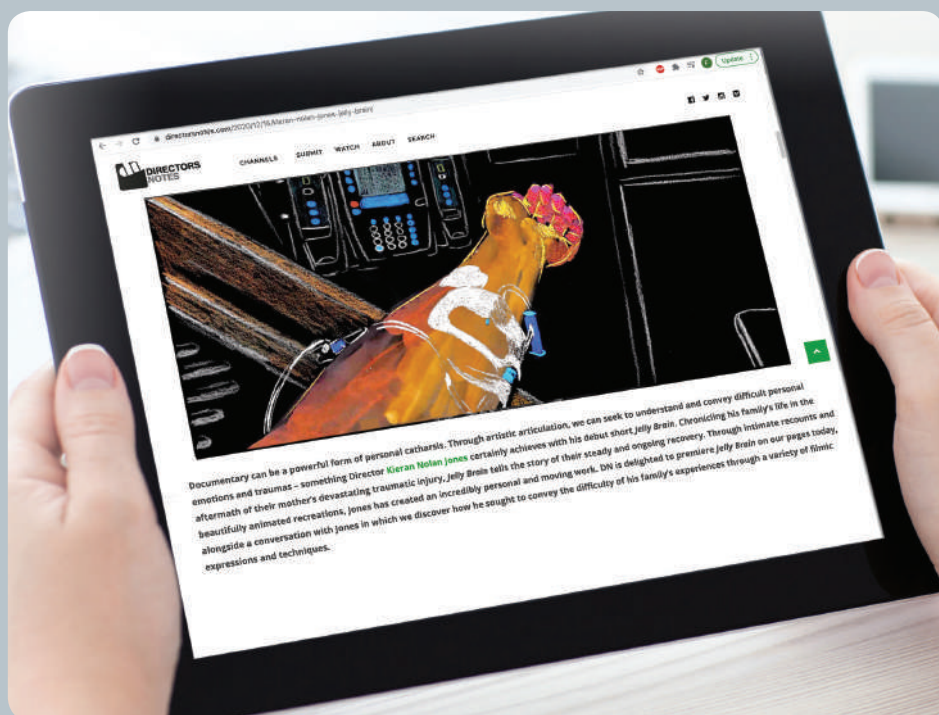
“Ever since I was 11, I have been interested in filmmaking,” said Kieran, now 29. “I had always harboured ambitions to have a career in television or film. Those hopes were enhanced when I was accepted onto a post-graduate course in production management at the National Film and Television School.

“I was 24 at the time and living at home with my mum and sister, Abi. In what now seems like a classic piece of role reversal, Abi and I stayed in one night just after Christmas while Mum went out with her friends.

“Abi then received ‘the call’ at 1am. Mum had fallen and hit her head. When we arrived at the hospital, she was conscious but glassy-eyed. At first, we were relieved, thinking it was just a concussion. But she then started retching and asking me to help her.

“She was immediately whisked off for further examination before being transferred to a neuro ward. It was a scary time as Abi and I gradually came to the realisation that something was seriously wrong – a feeling that was confirmed when we overheard a nurse saying Mum had fractured her skull and sustained a bleed on the brain.

“Despite this, Mum was discharged after just seven days and it was down to me and Abi to look after her. She struggled to walk unaided and needed help with basic tasks such as showering.



“She was always in pain. Her personality had changed and she was always angry.

“It was as if there was a toxic cocktail of emotional change, lack of empathy and constant pain.

“The anger was also fuelled by a lack of understanding among friends of what she was going through. She kept hearing ‘you look better’, or ‘glad to see you’ve recovered’, when in reality she was really struggling.

“I was desperate to help her raise awareness and to give her a voice, so I asked Mum and Abi to appear in a documentary film that would shed light on the hidden effects of brain injury and how it can impact the entire family.

“Thankfully, they agreed – largely because they thought it would never actually happen! But happen it did – and *Jelly Brain* is the result.

“It was incredibly challenging for all of us. Despite being around my friends and colleagues who agreed to help me with the filming, allowing me to be in the unusual position in front of the camera for a change, we all shared far more of our feelings than we had done previously.”

“It was a cathartic experience for us all. But most of all it’s helped to raise awareness.

“It’s my gift to Mum.”

You can watch the 15-minute-long *Jelly Brain* documentary on Headway’s *Brain injury and me* website at **braininjuryandme.org.uk**, or by searching online for ‘Jelly Brain Directors Notes’.





How to tame your anger

Damage to the brain can cause emotional and behavioural changes, so many survivors experience problems managing anger. This can lead to unpredictable, destructive, and sometimes aggressive behaviour that can put a strain on your relationships, work life and everyday activities.

Top tips for brain injury survivors

If you find that anger affects you after brain injury, try these tips to help keep it under control.

1. Learn to appreciate just how powerful your thoughts are. They are automatic and can cause you to become angry for no apparent reason.
2. It is only your interpretation of a situation that makes you angry. You may be right, but always think about other interpretations first.
3. Write down how you feel when you are angry. You can show this to someone you trust later and get another point of view.
4. Practise noticing how tense your body feels when you are angry, then relax and feel the difference. You will then be able to measure how angry you are, when compared to how you feel when relaxed.
5. Try to notice the warning signs of your anger, such as shoulders rising up, breathing faster, clenching fists etc. Remove yourself from situations when you feel those warning signs.
6. Practise relaxation and breathing exercises to calm down.
7. Distract yourself by doing something you like, for example listening to music.
8. Remember, everything becomes more difficult when you are angry. Remind yourself that you deserve to keep yourself calm in order to make good decisions or put your point across.
9. When you feel yourself getting angry think of someone who normally calms you down. What might they say to you if they were there? Or think of a special calming place, piece of music or picture. Try to make this part of a routine that you can use regularly to help you cope.
10. Record when these ideas have helped. This will make it more likely that you will use them again when you have angry feelings in the future.



Tips for family, friends and carers

Witnessing someone having an anger outburst or being on the receiving end of someone's anger can be very hard. It can be particularly hurtful if the anger is directed at family members, who are already upset and perhaps angry themselves.

Remember, however, that even if the anger is being directed at you, this is not personal so try not to get into an argument.

When you discover a trigger, help your loved one to find another way to look at the situation or try to direct their attention away from the cause. This may involve moving them to a quieter location.

Think about strategies to help yourself such as removing yourself from the area or having your own coping statements, for example "That felt very hurtful, but I know you didn't mean it that way."

What is anger?

Anger is one of many emotions that someone is likely to feel after brain injury. It can either be the result of damage to parts of the brain that control emotion, or because the brain injury survivor is frustrated with the effects of their injury.

Like all emotions, anger is normal and

healthy. However, when it gets out of control, it can become destructive and lead to problems.

Inevitably there are times when things are out of our control and it is natural to feel frustrated. However, if we start to shout and blame others, it is important to be able to identify that this type of anger is unhelpful, and we should try to make a

conscious effort to calm ourselves down.

Anger can be healthy if managed properly. This involves noticing that you are angry in the first place, keeping calm, and solving the problem in an assertive way. If you manage your anger in this way, other people may not even realise that you were angry at all.

It is important to seek professional support if anger becomes troublesome. For more information, tips and guidance, see the Headway booklet *Managing anger after brain injury*, available at www.headway.org.uk/information-library. You can also contact the Headway helpline on **0808 800 2244** or helpline@headway.org.uk for support and guidance.

FORTNITE



BORED AT HOME? GET FUN DRAISING!

There's no doubting that as with all aspects of life, Covid-19 has had a dramatic impact on the way people fundraise for charity. With numerous events cancelled or postponed, our army of budding Headway Heroes and their big fundraising plans have been left frustrated.

However, we've also seen a wealth of new, creative ways to raise money for Headway, with many people ramping up their everyday activities and exercise to support their favourite charity! The online fundraising website JustGiving has introduced a range of exciting new features which make it simple to set yourself a challenge or organise a digital event from home...

Fitness at home

Set yourself a physical challenge and track your progress with Strava.

Connect your JustGiving page with the Strava app on your smartphone, smartwatch or fitness tracker to keep track of your progress while helping your family and friends to stay updated.

It's a great way to make your daily exercise count, and research from JustGiving shows it can boost the amount you raise – a win-win!

Virtual gatherings

Stay connected with friends and family and raise money for a good cause!

While most people had never considered Zoom versions of quizzes, bake-offs and best hat competitions pre-pandemic, they're now an exciting part of our lives – and a great way to raise money!

Set up a virtual event on JustGiving to collect entrance fees and donations for your video call.

Gaming

Playing games for a good cause? What could be better!

This one's for the keen gamers out there! You can now link your Twitch account to a JustGiving page to live-stream your play, asking people to sponsor you to complete a challenge of your choice while they marvel at your gaming skills.

It could be taking on a FIFA marathon or tackling a tournament in Fortnite – just choose your game and make your playtime count!

GET STARTED

Head over to justgiving.com to set up your new page. After signing in and selecting Headway – the brain injury association or your local Headway group to raise money for, you can pick your options and get started. You can find guides and tips on using these fundraising tools at help.justgiving.com.

If you're stuck for ideas, need guidance on running and promoting events, or want to find out how Headway can support you, download our free fundraising guide at headway.org.uk/fundraising-guide.



Josh Rawson

INTRODUCING OUR VERY FIRST STRAVA FUNDRAISER...

Josh Rawson knows all too well the devastating impact a brain injury can have on entire families. In 2015, when Josh was 23, his mother Michelle died from a ruptured aneurysm.

"It came as a complete shock that someone who shined so brightly could be gone so quickly with no notice," said Josh.

"It was through researching what a brain aneurysm meant that I

found Headway, who undergo the wholesome endeavour of supporting those with similar injuries or trauma to mum. I have ever since kept them on my radar and would love to continue supporting people in similar circumstances."

With a keen admiration for outdoor walking and the continued Covid-19 lockdown having an impact on his mental health, Josh decided to take on a fundraising challenge for Headway, walking 100km over 30 days to support the charity. In the process, he became our first fundraiser to link his JustGiving page with the Strava app, a popular system that allows people to track their activity with a phone, smartwatch or fitness tracker.

Josh explained: "I loved the technology of this as I was able to have my totalled distance add up through my donation page instead of having to manually record it.

"It was rewarding to see analytics at the end of a walk such as your route, pace, and distance, along with the challenges the app offers you to join up with.

"The thought of being able to help people in a similar situation was also great for motivation, as it felt good being able to give back when options were limited in lockdown.

"I am extremely grateful and thankful for friends and family who have contributed to my donations page, as the final amount reached over double my original target!"

Asked what advice he would give to anyone thinking of starting a fundraising challenge, Josh said: "Definitely initiate a challenge which is obtainable and can be broken down to a daily routine if possible. This stops it from being overwhelming and means that 'catching up' can be done if you are unable to contribute on some days.

"Make sure it's something you can have fun with if you're doing it a lot - I caught up with a lot of music and podcasts, which I was very happy with!"



STARTED YOUR NEW FUNDRAISING PAGE?

TAKE TIME TO MAKE IT COUNT!

You've set up your fundraising page and maybe even linked it to your Strava account, so now it's time to start your challenge.

Not so fast! It's important at this stage to spend a little time improving your page and telling your loyal fans about your fundraising plans. There are many simple and fun ways to market your challenge that can make a big difference to the amount you raise.

Tell your story!

Record a short video, write a few paragraphs or share your favourite photos that sum up why you're fundraising for Headway. Many of us have had our lives touched by brain injury, so make it personal and your friends and family will get behind your cause.

Don't be afraid to share

Sharing your page is vital to tell people about the good work you're doing. Shout about your challenge on social media, WhatsApp, email or whatever platform your friends and family use to boost your fundraising total.

Update people on your progress

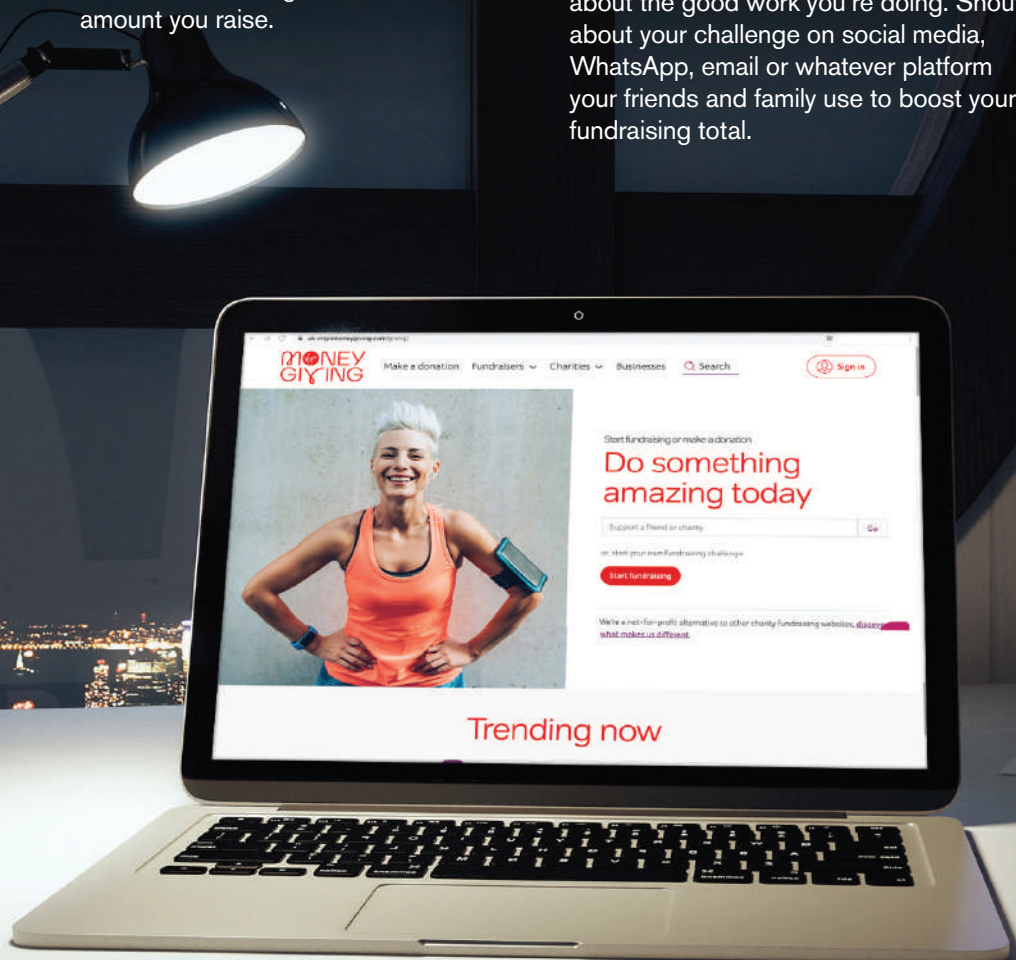
Whatever challenge you're taking on, post regular updates on your page to take your supporters on a journey with you. They're your friends, and they want to hear about the good things you're doing!

Be proud of your selfie!

According to JustGiving, each photo a fundraiser posts on their page increases the total raised by 14%. Whether it's running shots, preparation for a head shave or pictures of your virtual quiz, sharing photos makes your supporters more likely to donate.

How did you do?

Once the challenge is over, many fundraisers breathe a sigh of relief and move on. But it's really important to tell people how you did, which gives a great opportunity to make one final push for donations. People will celebrate your success and be keen to show their support.



DAILY NEWS

HOLD THE FRONT PAGE!

Local press are often looking for interesting stories about people doing extraordinary things, so why not send them a press release about your challenge and see if they want to share your story?

Remember to include information on:

- What is the fundraising event and who is doing it?
- When and where will it take place?
- Why are you doing this? What's your connection to brain injury and Headway?
- Send some good quality photographs with your press release.
- Remember to include details of how people can sponsor you!

Other ways you can get involved

- Set up a Facebook birthday fundraiser or simply ask for donations instead of gifts on a special day that's important to you.



- Make a regular donation by setting up a direct debit.
- Help us by donating to your local Headway charity shop.
- Donate via payroll giving.
- Nominate us as your workplace, school or community group Charity of the Year.
- Leave a gift in your will.

Visit [headway.org.uk/donate](https://www.headway.org.uk/donate) or contact your local Headway to find out more.



Keep in touch!

When you start planning for your fundraising challenge, don't forget to tell us about it! Our fundraising team are here to support you with any questions you may have. We love to hear the inspirational stories of our fabulous fundraisers, and often feature them on our website and social media.

However you decide to raise money for Headway, following these tips will help you to make a massive difference to the lives of those affected by brain injury. You're a true #HeadwayHero!

SEEKING JUSTICE

FOR BRAIN INJURY SURVIVORS

Since it began in 2015, the Headway Justice Project has focused on raising awareness of acquired brain injury (ABI) throughout the criminal justice system.

We spoke with Justice Project Manager, Holly Warner, to find out how it is changing lives.



The Justice Project seems to be going from strength to strength, Holly. What are the latest developments?

"We are delighted to have been awarded an NHS England contract to deliver acquired brain injury awareness training to prisons and probation services across the country", said Holly.

"The training forms part of our wider Justice Project and complements the training we have

provided to police forces across the UK, as well as prosecutors, appropriate adults, liaison and diversion services and other agencies within the criminal justice system.

"We are also looking at ways to increase the understanding of frontline staff within the DWP who regularly come into contact with brain injury survivors, many of whom may struggle to communicate or explain the hidden and fluctuating effects of their brain injury."

Why is this training so important?

"Research demonstrates a high prevalence of brain injury within the criminal justice system. But through Headway's Justice Project, we are working to improve understanding of brain injury to ensure survivors are identified and provided with appropriate support.

"As part of the contract we will be providing prisoners with brain injury access to the Headway Brain Injury Identity Card on their release. This will ensure that survivors will be easier to

identify should they have further contact with the criminal justice system."

How does the Brain Injury Identity Card work?

"Headway's Brain Injury Identity Card provides survivors with the support they need, when they need it, by highlighting the effects of their injury and providing access to 24-hour free criminal legal advice and representation should they come into contact with the police.

"Our card holders also tell us that they use their cards in everyday situations such as when shopping, enjoying a drink or meal out or on public transport. For many people, the use of their card has been transformative in promoting their confidence and independence.

"I would urge anyone who has a brain injury to apply for a card – they are useful in so many situations!"



"It's excellent to have something to show that explains your situation so succinctly."

Johnny Armstrong

"I find stations and trains truly overwhelming and having my card on display it actually provoked interesting discussions and offers of help. When I needed support in the station, they didn't look at me as if I was stupid and helped me. It gives me more confidence to travel alone."

Sue Cunliffe

A SURVEY ON USER EXPERIENCE

Headway has issued over 8,000 Brain Injury Identity Cards to survivors across the UK. We conducted a survey to ask about their experience of using the card, and the results were overwhelmingly positive. Here are some of the key survey results:

96%

of respondents thought their Brain Injury Identity Card was **'Excellent'** or **'Good'**

84%

said when they used their card it has been **'very helpful'** or **'helpful'**



The Brain Injury Identity Card can be used in a variety of everyday social situations

Where have people used their card?

31%

using public transport

12%

with the police

21%

to assist in applying for welfare benefits

11%

with other emergency services (e.g. ambulance service)

14%

during work-related assessments / appointments with Jobcentre Plus

34%

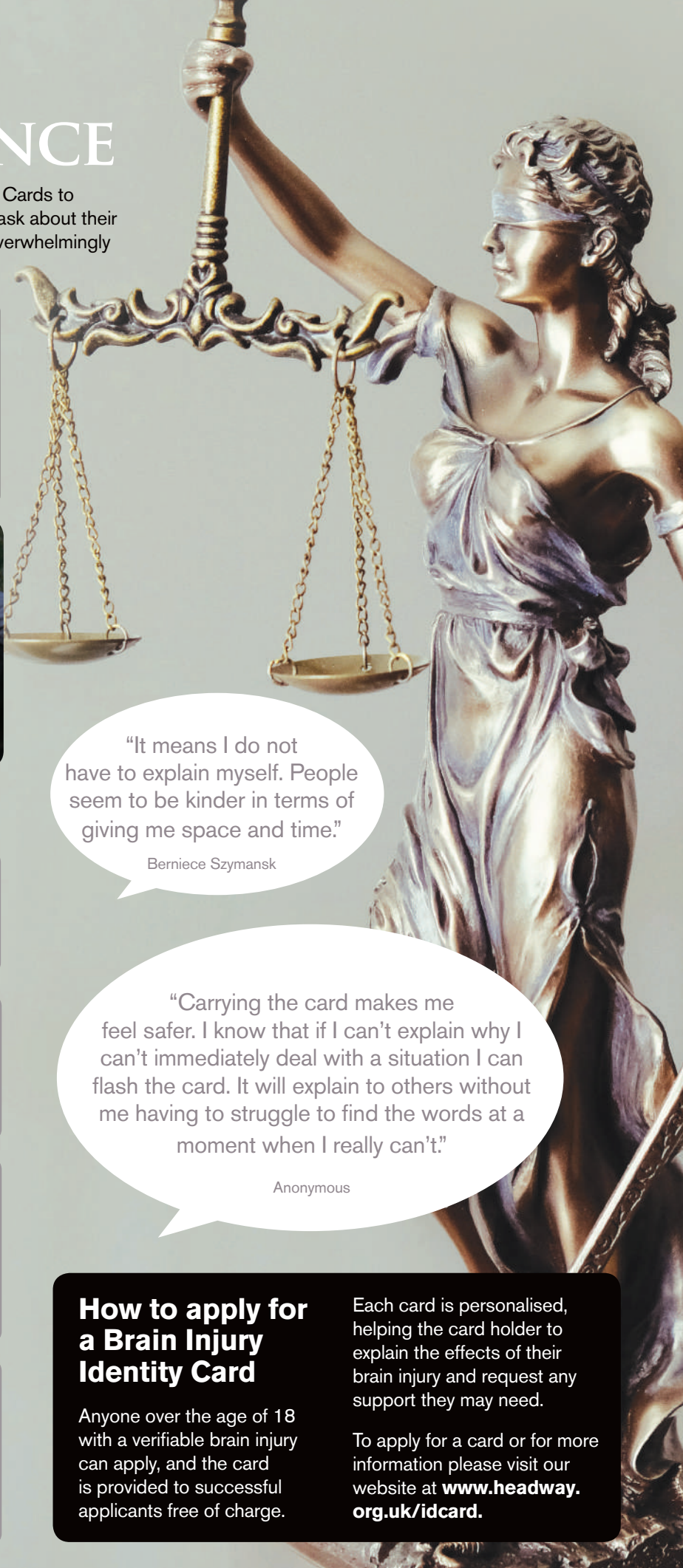
during a GP, hospital or other medical appointment

19%

with colleagues, employers or education providers

58%

in everyday social scenarios (e.g. in a shop, pub, bank, restaurant, supermarket)



"It means I do not have to explain myself. People seem to be kinder in terms of giving me space and time."

Berniece Szymansk

"Carrying the card makes me feel safer. I know that if I can't explain why I can't immediately deal with a situation I can flash the card. It will explain to others without me having to struggle to find the words at a moment when I really can't."

Anonymous

How to apply for a Brain Injury Identity Card

Anyone over the age of 18 with a verifiable brain injury can apply, and the card is provided to successful applicants free of charge.

Each card is personalised, helping the card holder to explain the effects of their brain injury and request any support they may need.

To apply for a card or for more information please visit our website at www.headway.org.uk/idcard.

"A hole in your head is a lot less fashionable than a cycle helmet"

When Haydn Garrod came off his bike in August 2018, he suffered devastating injuries after colliding with a car and an air ambulance was dispatched to treat him at the scene. However, such were the extent of the 15-year-old's wounds, that paramedics felt it was too risky to transport him by air.



Because he was in such a critical condition, Haydn had to be put into an induced coma before being transferred by land to Addenbrooke's Hospital.

At the time of the accident Haydn wasn't wearing a cycle helmet and following the collision his mum, Amanda Hymus, feared the worst. On arriving at the hospital, Haydn had a CT scan which showed considerable swelling of the brain. He had to undergo an emergency craniectomy to remove part of his skull in order to alleviate the pressure on his brain caused by the swelling.



Haydn in hospital following his brain injury



The damaged windshield of the car that collided with Haydn

Amanda was fearful about the operation, but knew it was the best chance Haydn had of survival. She said: "When they gave me the consent forms, I felt like I was signing his life away. It's a risky procedure but I was told without it, he had no chance."

Following the operation, Haydn's life hung in the balance as he remained in a coma for two weeks. But to the family's huge relief, doctors said he had made enough progress to be brought out of the coma, although the extent of his brain injury was still unknown. What followed was an arduous journey of recovery for Haydn, who had to relearn lost skills and abilities and learn to cope with the effects of his injury.

Initially, Haydn was completely paralysed on the right side of his body and had to be tube fed, but slowly he began to regain movement and show signs of improvement. His mum, Amanda, said: "Every tiny change was like a huge milestone, from his first sip of a drink, to his first steps."

After seven weeks in hospital, Haydn was transferred to a specialist residential rehabilitation facility for children, where he undertook intensive physiotherapy as well as speech and music therapies. Amanda

said: "His positivity and determination along with the experience and dedication of the team at The Children's Trust contributed to his astounding recovery." As a result, Haydn was able to return home to continue his rehabilitation in January 2019.

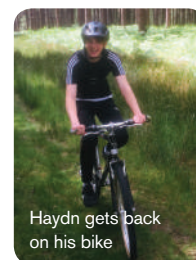
To thank them for their care and support, Haydn embarked on a fundraising mission for both The Children's Trust and the East Anglian Air Ambulance charity and partook in a Magical Music event, performing on his drumkit alongside Harry Judd of McFly. The event raised almost £100,000.

Alongside their fundraising efforts the family have also launched a petition to make cycle helmets mandatory for under 16s.

"Haydn knows how lucky he is. His team at Addenbrooke's Hospital said if he had been wearing a cycle helmet at the time of the accident his injuries would have been significantly less severe," said Amanda.

The campaign for a new cycle helmet law for children has been joined by other families from across the country who have suffered similar experiences to Haydn and his family. Amanda added: "The implementation of mandatory cycle helmet wearing has been successful in several other countries.

"A mandatory law for under 16s to wear helmets would keep our children safer on the roads, and we'll continue to do what we can to raise awareness and campaign for safer cycling."



Haydn gets back on his bike

Although Haydn is now registered as partially sighted and still has ongoing difficulties with his speech, physically he has made almost a complete recovery.

His partial sight means he won't be able to ride a vehicle on roads, but that hasn't deterred him from getting back on his bicycle off-road. Asked what it felt like to be riding again, Haydn said: "It felt amazing. I felt like 'me' again."

Haydn had one piece of advice he wanted to share with anyone considering not wearing a cycle helmet because of how it looks: **"Trust me, a hole in your head is a lot less fashionable than a cycle helmet."**

You can find the family's petition by searching 'Make the wearing of cycle helmets for children under 16 law' on the UK Parliament website. To follow the progress of their campaign search @HaydnsLaw on Facebook or @HaydnsL on Twitter.



PROTECT YOUR MELON

At Headway, we believe that all cyclists should wear helmets, particularly vulnerable road users such as children who do not possess the same level of competency or experience as adults.

We believe helmets should be compulsory for all child cyclists

while supporting calls for a range of additional measures to improve cyclists' safety, including more dedicated cycle lanes and educational campaigns aimed at both cyclists and motorists.

To find out more about our campaign, visit www.headway.org.uk/cycle-safety.

Inside your incredible brain

In this new series, we will be looking at some amazing facts about the greatest enigma and most fascinating object in the world – the human brain.

What makes it pink

Despite making up only 2% of our body, the brain is very energy consuming and uses 20% of the body's oxygen supply. It gets the oxygen from 15% of the heart's output of blood, which is why the brain is coloured pink.

What is its consistency?

The brain is very soft in consistency, a little like firm jelly. It's held in place and cushioned by three layers of membranes called the pia, arachnoid and dura mater, a layer of fluid called cerebrospinal fluid, and the skull.

Similar to a fingerprint

While brains may look alike, each one is unique. The overall structure is the same, but the finer details differ across people so that the surface pattern is almost like a fingerprint.





Einstein's brain

Albert Einstein's brain had several unusual features, such as having an extra ridge in the part of the brain responsible for working memory, which some scientists think accounted for his intelligence.

Three sections

The brain is generally divided into three sections. The cerebrum, which is the bulk of what we see of the brain in pictures, is where most of our conscious information processing takes place.

The wrinkly bits

The 'wrinkles' on the surface are comprised of bumps (gyri) and dips (sulci) which give it a greater surface area and allow it to do a lot more information processing than if our brains were smooth. By contrast, some animals who carry out very simple information processing such as frogs and mice, have relatively smooth brains.

Little brain

At the back of the brain is a structure that almost looks like a smaller brain – in fact the name of this structure, cerebellum, literally means 'little brain' in Latin.

The brainstem

The brainstem is at the base of the brain and is responsible for basic functions such as breathing, sleeping and heart rate.

Creative expression

Helen Wilson

A little bit about me

"Hello. On the 1st June 2013

I suffered a traumatic brain injury. It changed my life forever, in some ways for the better but the majority is for the worse.



"I am determined not to let this beat me, I have just managed to accept it now, I am learning who I am and building a new pathway. I have days where I'm stuck at the crossroads not knowing which way to turn, days where thoughts in my head cause confusion and also days that are a blur but hey ho, I'm here, right!

"I started my poetry when asked to write a thoughts diary. I felt pressure and could not cope but needed my thoughts to disappear and clear my brain. I find it helps me a lot.

"I hope this may provide encouragement for others to write, which will help them to clear and understand their thoughts and feelings but most importantly to know that they're not alone on this journey."

You can read more of Helen's poems on the Headway North Cumbria website at headwaynorthcumbria.org.uk/news.

Acceptance

by Helen Wilson

My life is now different, I hate all this change,
I've got so much stuff I need to rearrange.
It's hard to wake up knowing the day,
I won't talk to many people now as I don't know what to say.
It's easy to stay quiet and behind the closed door,
Apart from my walks where I can explore.
I like being alone, there's no hassle at all,
Being involved in drama and chaos, makes my recovery hit a brick wall.
I am blamed for everything but hang on why?
Sometimes individuals find it hard holding their hands high.
It's time to get rid of this paranoid soul,
Maybe accepting things now should be my new goal.
I should hold my head high, this is so I'm told,
Start venturing out, build confidence and leave all the old.
It takes a lot of courage to reach out and be brave,
This new me was failing, I need help to get me out of my cave.
List after list of writing the new me down,
Encouraged me to learn the way things will be, as I write with a frown!
I won't give up now and will continue to grow,
Acceptance is the key, once you are there then you'll know.

Leading Personal Injury and Medical Negligence Lawyers



Boyes Turner is proud to be an active supporter of Headway. Kim Smerdon, head of our Personal Injury team, is a Trustee of Headway Thames Valley.

Our specialist lawyers and brain injury support team have the knowledge, experience and commitment to ensure that you and your loved ones get the result you deserve and the support you need.

We are more than happy to visit you in hospital or at home at times that suit you. We provide national coverage.



Contact Kim Smerdon on
0118 952 7137
or claimsadvice@boyesturner.com

"A special thank you to my lawyer Kim. Her input has changed everything for me. She has given my life a level of security and stability that I never thought I was capable of achieving post-accident."

Jessica Stevens

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Legal 500 and
Chambers & Partners

**Top
Ranked**



Putting your life back on track

It's what we do



Prince Evans LLP is a specialist brain injury practice that focuses upon representing the interests of our clients and their families to the full.

We are understanding and knowledgeable of the multiple complexities that are experienced by all when a loved one is affected by brain injury.

We provide a free nationwide no obligation consultation to discuss respective claims and where our expertise can assist; including with potential interim payments, rehabilitation and case management and support. We offer no win, no fee funding.



For more information on how we can help, contact
Gary Smith, Head of Personal Injuries

Call free on 0800 019 0991

Email: gary.smith@prince-evans.co.uk

Gary Smith is a member of Headway – the brain injury association's Personal Injury Solicitors list



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