Autumn 2021

Headway News

The magazine of Headway - the brain injury association

"She sees me for what I can do, not what I can't"

Thomas Leeds



10 years of the Emergency Fund

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Headaches after brain injury

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Covid-19 and long Covid

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Welcome

Welcome to the autumn edition of Headway News.

Uncertainty. It's a feeling that we're all too familiar with after the last 18 months of unprecedented changes and challenges in the world. Covid-19 has left many of us uncertain about what the future may hold, and although the lifting of restrictions allows us to return to something closer to normality, we're still pondering how things will change for ourselves, our loved ones and wider society as we head towards the winter.

Those whose lives have been touched by brain injury are no strangers to uncertainty of course, with hopes and dreams for the future changed in an instant. That's where Headway can step in to help, and it's through frontline services like our local groups and branches, national helpline and Emergency Fund that we can support people through some of the most difficult and unpredictable of times.

In this issue of Headway News we're delighted to be celebrating the 10th anniversary of our Emergency Fund, which gives grants of up to £500 to support families in the immediate aftermath of brain injury. Since its launch all those years ago in 2011, we're proud to have distributed almost half a million pounds to help thousands of people, thanks to the hugely generous support of the Stewarts Foundation.

We take a look at the real-life impact of this support from page 10, sharing the stories of Tracy Dickson and Julie Mueller, two mums who applied for assistance after their sons sustained catastrophic brain injuries which left them in hospital, miles from home. Taking away at least some of the financial concerns in those early stages made a tremendous difference to both families and helped them to be there by the bedside when they were needed the most. We also share the hugely inspirational story of our cover star, Thomas Leeds, who has battled adversity to become a true brain injury ambassador after he was hit by a car in 2003 at the age of 19. Despite the ongoing memory problems and fatigue that continue to affect his day-to-day life, Thomas is now happily married and a proud father, working hard to raise his two daughters while sharing his experience of brain injury in the media to raise awareness.

Stories like these remind us that positive changes can often arise from the most uncertain of times. For people with brain injury and their loved ones, learning to cope with the ongoing effects of brain injury and the multitude of related issues can help to move forward with more confidence.

To that end, we provide a comprehensive guide to headaches after brain injury (page 15), a Covid-19 and brain injury Q&A with Dr Aravinthan Varatharaj (page 24), and tips on completing benefits application forms (page 26) to help you access the right support.

Finally, we'll end with something that's always certain here at Headway – the change of season means it's time to launch our range of Christmas cards, and those of you with an early festive spirit can find full details on pages 22 - 23. But to everyone, including those who'd prefer to overlook the fact that Christmas is peeking around the corner, we hope you enjoy this magazine and wish you a safe and happy autumn.

The Communications Team



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

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Website:

www.headway.org.uk

Advertising:

directorofcomms@headway.org.uk

Fundraising: projects@headway.org.uk

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Your views

Since the Headway Emergency Fund began in 2011, it has helped thousands of families to cope in the early stages after a catastrophic brain injury.

In this issue of Headway News we celebrate the 10th anniversary of this vital service, so we wanted to start by sharing some of the moving feedback we have received from those who have benefited.

This fund was such a huge help to me whilst my husband was in hospital 25 miles away. Parking was expensive and I had to pay a toll each way, every day. He is now recovering at home, but appointments are still at the

I was struggling to raise the funds required for a washing machine and was relying on others to help wash mine and my baby's clothes. The Emergency Fund has helped so much to ease the pressure and has helped me to become more independent.

My condition led to the breakdown of my relationship, and I ended up homeless, then sofa surfing for what felt like an eternity. Then with the help of my local Headway, I was re-homed. In my own house I had a sofa to sleep on, a microwave to cook in and a radio to listen to. Thanks to the Headway Emergency Fund, I am now able to wash and dry my own clothes.

We were very grateful to receive the £150 towards accommodation costs whilst our son was recovering from a very rare brain injury. Our total costs for time spent supporting our son ran into the thousands but the fact that the charity was able to contribute towards these costs was very helpful.

I am most grateful for all the help I have received for my travel to and from the hospital because without your help I would not have been able to support my husband in his hours

I cannot express enough thanks. We have a long road ahead of us but it's nice to know people care.

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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 plothene film and starts to break down after

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 recycle today.

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Latest news round-up

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

New legislation proposes biggest shake-up of health system in a decade

The Government claims that the new Health and Care Bill, which was introduced to Parliament in the summer, will reduce bureaucracy and create better partnershipworking in the health system.

The Bill aims to create local collaboration in the health system with the introduction of 42 Integrated Care Systems (ICSs) across England, which will replace over 100 Clinical Commissioning Groups (CCGs).

Each ICS will be designed to deliver health priorities across local areas. and membership will be made up of Integrated Care Partnerships (ICPs), Integrated Care Boards (ICBs), local authorities, charities and other sectors.

There is some concern that the geography of the systems will be confusing for local people and some may cover areas which are too big and unwieldly, potentially leading to problems with service delivery.

The Bill will also amalgamate NHS

England and NHS Improvement into a single body which will be known as NHS England (NHSE). It will also remove the requirement that was previously placed on CCGs to put all health contracts out to tender.

But some critics are concerned about the "Whilst we can broadly welcome the direct powers which would be conferred on the Secretary of State for Health, making them the sole decision-maker on some aspects of health services and NHS England.

Jonathan Ashworth, the Shadow Secretary of State for Health, described the Bill as a "Trojan horse to hide a power grab by the Secretary of State", and the British Medical Association (BMA) cautioned: "What should also have been ruled out is extending the powers of the Health Secretary."

There is also concern about the provision of seats for private sector providers to sit on local boards. The BMA warned: "The threat of private health providers having a formal seat on new decision-making boards, and wielding influence over commissioning decisions, must be ruled out."

What is clear is that there will be widespread change, however the Bill does not include proposals on how to fix the crisis in our social care system.

Commenting on the Bill, Sarah Russell, Public Affairs Manager at Headway, said: proposals for better local collaboration in the provision of healthcare, what is desperately needed is a long-term solution for the crisis in social care.

"The services that are provided" to brain injury survivors by Headway groups are largely funded by local authorities and wider reforms on social care should include assurances that no brain injury survivor will be left without the support they rely on."

The Bill will now progress through the Houses of Parliament and is on track to pass into law in April 2022. However, there are opportunities for the Bill to be amended and Headway will monitor any developments closely.



Study reinforces link between dementia in professional footballers and heading the ball

A landmark scientific study has revealed that those who play football professionally for longer periods or play in positions where heading the ball is more frequent, are more likely to develop neurodegenerative disease than their counterparts.

It found that for goalkeepers, neurodegenerative disease risk was similar to general population levels. In contrast, the risk for outfield players was almost four times higher than expected and varied by player position, with the risk being highest

among defenders, at around five-times higher than expected.

These new findings also show that neurodegenerative disease diagnoses increased with increasing career length, ranging from an approximately doubling of risk in those with the shortest careers, to around a five-fold increase in those with the longest careers.

Commenting on the results, Professor Willie Stewart said: "We have already established that former professional footballers are at a much greater risk of death from dementia and other neurodegenerative disorders than expected. "Taking these new results together with our and others' post-mortem findings and data from our previous FIELD studies, the evidence is clear that the standout risk factor for neurodegenerative disease in football is exposure to head injury and head impacts."

Headway has repeatedly called for additional research into the impact of heading footballs. Commenting on these latest findings, Peter McCabe, Headway Chief Executive, said: "This study demonstrates what we have been saying for a long time – repeated blows to the head, whether from heading the ball or other factors, such as blows to the head suffered by boxers, increase the risk of having a degenerative neurological condition such as dementia.

"All sports – including football – must take urgent action to review their own protocols and identify ways in which they can immediately reduce the risk of head trauma."

Sport accused of 'marking own homework'

Headway has welcomed the findings of a parliamentary inquiry that has accused sport of failing to reduce the risks of concussion.

The Digital, Communications, Media and Sport Select Committee (DCMS) heard from sporting bodies, sportspeople and campaigners, including Headway, as part of its inquiry.

DCMS Committee Chair Julian Knight MP said: "We've been shocked by evidence from athletes who suffered head trauma, putting their future health on the line in the interests of achieving sporting success for the UK.

"What is astounding is that when it comes to reducing the risks of brain injury, sport has been allowed to mark its own homework."

Reacting to the report, Peter McCabe, Chief Executive of Headway, said: "This is an important step forward in the campaign to better protect people from the short and long-term risks of concussion.

"We are grateful to the committee for inviting us to contribute to this important inquiry. The report makes a number of clear recommendations, all of which we broadly support, although some questions remain.

"For too long it has been left to charities such as Headway to hold sport to account and we agree with Julian Knight that this has to change. Sport has had long enough to get its house in order and the time has come for the government to intervene."

Among the recommendations made by the committee was for UK Sport to pay for a medical officer to be present at every major sporting event and take sole responsibility for preventing athletes from competing if concussion is suspected.

The report also recommends the establishment of a UK-wide minimum standard definition for concussion that all sports must use.

Peter concluded: "The ball has been repeatedly dropped by sports authorities when it comes to concussion. It has now been passed to the Government by means of the recommendations of the DCMS Committee and we will be watching carefully to see how seriously this report will be taken by government."



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Headway champion pushes for legislative change in Parliament

Chris Bryant MP, one of Headway's valued Parliamentary



Champions, has been a long-time advocate of all things brain injury. He has recently been successful in tabling a Private Members' Bill on Acquired Brain Injury.

The MP, who is also the chair of the All-Party Parliamentary Group on Acquired Brain Injury, is seeking to bring legislation that would require the continuing to speak up Government to consult on and publish an Acquired Brain Injury Strategy.

Sarah Russell, Headway's Public Affairs Manager, said: "Despite it being notoriously difficult to get Private Members' Bills progressed through the House, they can stimulate wider debate and potentially affect legislation indirectly.

"As always, we are hugely grateful to Chris for for brain injury survivors and their loved ones."

Step into Christmas with Headway

It may sound outrageous to some, but the start of September marks the beginning of the Christmas season here at Headway. It's time to proudly (and unapologetically) launch our range of festive Christmas cards...Ho Ho Ho!

As always, we're offering eight wonderful designs, from the bright Christmas cheer of 'Santa's Friends' to the traditional 'Nativity at Night' and everything in between.

Each pack of 10 cards is priced at £3.50, and thanks to our generous sponsor Bolt Burdon Kemp, every penny will go directly to supporting brain injury survivors, their families and carers.

Our Christmas cards always sell out fast, so don't delay - head to page 24 to see the full range and find out how to get your hands on them, or visit shop.headway.org.uk to dive straight in and buy your cards now.

But before you go, let us be the first to say it - Merry Christmas!



LIAM'S LEGACY CELEBR ATED AT SPECIAL RACE DAY

The legacy left by former Grand National winner Liam Treadwell was celebrated at a special race day held at Worcester Racecourse on the anniversary of his death.

Liam, who rode 100-1 shot Mon Mome to victory in the 2009 Grand National, sadly passed away in June 2020. Over the course of his career, Liam - like many Cheltenham Festival win as well as his jockeys - suffered some falls resulting in concussions, including one serious head injury that kept him out of the saddle for six months.

Determined to challenge a culture in the sport where jockeys were reluctant to talk about the impact of concussion - particularly on mental health - Liam became a passionate campaigner.



Following his passing, Liam's family and friends have taken up his mantle, ensuring his memory lives on and inspires change.

The event at Worcester Racecourse celebrated some of Liam's many successes, including his 2013 most famous victory on the back of Mon Mome, who was paraded to racegoers on the day.

An online auction was also held, with more than £3.000 shared between Headway and the Injured Jockeys Fund.

The event was organised by Liam's friend Bundle Pickard at the suggestion of racehorse owner Bill Hawkins. Bundle said: "Liam was truly loved and respected in the racing world. So many people came together to make this event be a single race in Liam's memory soon turned into an entire race day - such was the esteem in which he was held.

"We wanted to celebrate his life while raising awareness of concussion and the depression and mental health issues it can cause.



"It has been an emotional roller-coaster that I could not have done without the support of Abbie Hawkins, Nancy Von Short at Macchina Media and Racing Welfare, who have helped at every step of the way.

"Tragically, nothing will bring Liam back but I, amongst others, would love to keep his legacy alive and for us all to learn and be more conscious of those around us."

Peter McCabe. Chief Executive of Headway, said: "It is inspiring to see the lengths people are going to in order to cement Liam's legacy.

"It is crucial that we continue to a reality and what was initially intended to raise awareness and understanding of concussion in sport. Too many people are afraid to admit that they are struggling – either physically or emotionally – resulting in them suffering in silence.

> "Liam sought to change that and get people in the sport talking openly and honestly about how they are feeling. We are honoured to have the chance to work with his family and friends to carry on this important work."





OF THE HEADWAY EMERGENCY FUND

Headway is celebrating ten years of its **Emergency** Fund, which provides grants to families facing the immediate aftermath of brain injury.

Since its launch in 2011, almost half a million pounds has been distributed to thousands of families to help them cope with the sudden practical implications of acquired brain injury.

"It is incredibly humbling to think about how many lives have been touched by the Emergency Fund over the past decade," said Holly Warner, who manages the project.

"When your loved one is fighting for their life in hospital, all you want to do is be by their bedside. People who sustain severe brain injuries are often sent to specialist trauma centres, which can be located hundreds of miles from where their relatives live.

"This means relatives are faced with long and expensive journeys to and from hospital or rehabilitation centres every day. The impact on finances can be extreme, at a time when lives have already been turned upside down.

"Our role is to take a little pressure off families at such a difficult time. Relatively small grants can make a significant difference to the strain families are under.

"We are delighted to be celebrating the tenth anniversary of this hugely important project."

'ONE LESS THING TO WORRY ABOUT'

For Tracy Dickson, Headway's support was crucial when her 19-year-old son, Brandon, sustained a hypoxic brain injury following a series of epileptic seizures that resulted in a cardiac arrest.

Brandon, who had lived with epilepsy since early childhood, had just completed an apprenticeship in business administration and was looking for work.

"We woke up one night when we heard him having a seizure," said Tracy. "We'd had this numerous times, but he went into a second seizure, then a third and he just kept having them.

"Everything stopped; his heart, his breathing, his eyes faded. We literally watched him slip away. We had to resuscitate him and keep him going and just wait for the ambulance.

"I really thought they'd come and say they'd lost him, but they got him fit enough to take to hospital."

After several weeks in intensive care, Brandon was transferred to Northern General Hospital in Sheffield, a 30-mile return journey for his family. Tracy with Brandon



"We were desperate to be with him." Tracy continues. "To sit and hold his hand and let him know he wasn't on his own. We didn't know if he was aware of what was happening, but we didn't want him to be scared."

The Covid pandemic meant Tracy and other family members had restricted visits.



"That was the hardest. We were going to the hospital every day, but we could only visit for an hour at a time. We went up three or four times a day, backwards and forwards, to the hospital. I felt so scared and helpless."

Tracy applied to the Headway Emergency Fund for support with the family's increasing travel costs.

"I wasn't working at the time, so Headway was a massive help to be able to get us up there when we needed. You can't put it into words how much it meant to us. It was amazing. It doesn't take all the weight off your shoulders with everything you're going through, but it was one less thing to worry about.

"It's a massive thing when you don't know which way to turn. Just to know there is something out there to give you that faith and hope that you're not on your own. I can't thank Headway enough."

Brandon is making a slow recovery, but Tracy describes him as a 'battler'.

"He's still with us and he's fighting," she said. "He has come a long way and he is improving but we're on the edge of our seats all the time for a phone call to say something has happened.

"It's had such a massive impact on us and on Brandon more than anyone. There's still a long way to go but he's started to speak and recognise my voice. He's having to learn everything all over again.

"We feel like we lost our son last year, but we have a new Brandon back. We don't know what his life would have been like, but this is the life he's got now and we're trying to be positive."

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'THE SUPPORT WAS CRUCIAL'

Fellow mum Julie Mueller can fully appreciate what Tracy has been through and echoes her praise for the Emergency Fund after her own son sustained a brain injury in August last year.

"I woke up at 4am to missed calls from Luke's then-girlfriend, also the police on the Isle of Skye and Aberdeen Royal infirmary," explained Julie.

"I spoke with a nurse from the intensive care unit and was told my son had fallen 100ft, hit his head and broken both his legs.

"Understandably I was shocked and extremely worried, it felt very surreal to be woken with the news in the middle of the night, it is every parent's worst nightmare.

"A phone call later in the morning from a doctor revealed that Luke had undergone surgery to repair his legs and was stable but the head injury, which he called a 'diffuse axonal injury', was of major concern and Luke was heavily sedated.

"They were not sure how he would be when he eventually woke up and gave it to us straight: it was a case of 'hope for the best but prepare for the worst'.

"We live in Warrington – 350 miles from Aberdeen. We were unsure of how we could possibly get our large family up there, where we could stay or even if we would be allowed to enter Aberdeen because of the lockdown restrictions there.

"Having to deal with this on top of the worry for Luke was terrible but we wanted to be by Luke's side immediately and there was no doubt that we would all go."



A doctor friend told the family about the support available from Headway, which proved to be invaluable.

"Luke's brother initially checked the website for more information about head injuries, looking to provide some answers and cut through all of the unknown. He stumbled upon the grant that was available and convinced me to apply as the financial burden was increasing with every day we spent up in Aberdeen.

"The financial support was crucial and helped immensely. It was a huge relief to have one less thing to worry about and all our efforts could be spent supporting Luke in his recovery.

"The grant allowed me to stay in Aberdeen until Luke was well enough to be transferred to a hospital closer to home. In total I stayed in Aberdeen for four weeks. With a brain injury I believe that familiar faces and voices were a huge part of reassuring him when he was first waking up in a strange environment, so I was glad to have the opportunity.

"To any others facing a similar situation, I would say for them to make use of the brilliant resources on the Headway website. They provided some clarity and reassurance in a stressful time. Take all the help that is offered so that you can focus your strength on supporting your injured family member."

SUPPORT

The Emergency Fund has been supported by the Stewarts Foundation for the past ten years.

John Cahill, Managing Partner of the Foundation said: "The Stewarts Foundation is pleased to have proposed and then supported the Headway Emergency Fund since its inception ten years ago, so far donating in excess of $\pounds400,000$.

"In the course of our work as injury lawyers, we see the short-term impact on families' finances as their loved ones are in hospital recovering. Thousands of families have now benefitted from this fund which has helped them at a critical time in their lives. We are proud to have been able to assist them in their moment of need."

Peter McCabe, Chief Executive of Headway, expressed the charity's gratitude for the support received: "We are incredibly grateful to the Stewarts Foundation for its continuing support of the Emergency Fund.

"Without such incredible generosity, thousands of families would be faced with making some exceptionally difficult decisions about whether they can simply afford to be at their loved one's side.

"No-one should have to face this terrible dilemma."



STEWARTS FOUNDATION

ABOUT THE HEADWAY ENERGENCY FUND

Why does the fund exist?

The Emergency Fund provides grants of up to £500 in the immediate aftermath of brain injury, to help adult brain injury survivors and their families cope with the sudden practical implications.

Most of our grants (82%) are used to help families be at the bedside of a loved one following a brain injury.

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Who can apply?

Anyone may apply to the Headway Emergency Fund. We are unable to support applicants who do not reside in the United Kingdom.

Only one application per survivor of a brain injury can be considered.

The purpose of the Headway Emergency Fund is to support families facing an increased financial burden following a brain injury. Our resources are limited,

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and Headway will assess the financial circumstances of each applicant when allocating funds and prioritise those in greatest need. We cannot consider applications for families with savings of more than £1,000.

For more information and to make an application to the Emergency Fund, go to:

www.headway.org.uk/ emergency-fund

YOUR INVOICE



Potter Rees Dolan

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Providing high quality legal services for people who have sustained a serious brain injury or who live with a disability as a result of an accident or medical negligence.

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Some of our recently settled cases include:

- £6.5 million secured for a man who sustained a traumatic brain injury as a child when he was struck by a car
- £1.7 million in compensation secured for woman who suffered a severe and life changing brain injury following a misdiagnosis
- £2.85 million secured for a young man who suffered a severe brain injury in an accident at work
- £30 million total damages secured for teenager who sustained a traumatic brain injury in a road traffic accident

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HEADACHES

The whats, whys and hows

Headaches are an ailment that have been recorded and treated since the time of Ancient Egypt and are experienced almost universally. The World Health Organization reports that up to 1 adult in 20 has a headache nearly every day. Despite this, there is still no known perfect cure for headaches.

While most headaches come and go through minor illnesses such as the common cold, they can be particularly persistent and problematic after a brain injury, affecting quality of life and impacting on the survivor's other skills. It is estimated that up to 58% of traumatic brain injury survivors

Tension-type headache

Experienced as a mild to moderate pressing or squeezing sensation, worsened by stress or physical activity. develop a headache one year after their injury, with several different types of headaches being commonly experienced.

In this feature, Consultant Neurologists and headache specialists Dr Colette Griffin and Dr Bee Eng Ong explain why headaches occur after brain injury, and we focus on some of the treatment options available to alleviate headache pain.

The information in this article does not replace clinical guidance.

Cervicogenic headache

Pain starts in the neck and travels to the back of the head, often triggered by neck movements and pressure/stress.

Cluster headache

Severe pain, described as a boring or drilling feeling that often occurs on one side of the head.

Migraine headache

Tends to occur on one side of the head and causes moderate to severe pain, described as throbbing or pounding, and can be preceded by auras (sensations such as seeing lights), sensitivity to light or noise and vomiting.

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Expert comments from DrColette Briffin and DrBee Eng Ong

Headache is one of the most common consequences of traumatic brain injury (TBI). The underlying pathophysiology of post-traumatic headache is not particularly well understood. Several possible causes have been suggested. For instance, the trigeminal system in the brain which supplies sensory input to the head and face (called the trigeminal sensory system) may be disrupted or activated through inflammation, causing subsequent headaches after brain injury.

Specific changes in the patterns of neural activity in the brain, and problems with neuro-metabolism (the brain's process of creating energy in order to function), are other suggested causes of headaches.

Following even a mild traumatic brain injury, there can be changes in the brain at a cellular level, such as inflammation of neurones and metabolic changes.

At a structural level, there can be changes in white matter (areas of the brain where information travels rapidly), the cortical regions (outermost level of the brain) and subcortical regions (areas underneath the cortex of the brain). There can also be changes in brain volume and the development of scar tissue. Any of these problems can cause headaches.

Overuse of medication for headaches following brain injury can paradoxically cause further headaches, known as analgesic overuse headaches. Neck injury can also cause some types of headaches depending on whether specific pain pathways in the body have been affected.

Studies have shown that psychological issues commonly experienced alongside brain injury, such as depression and anxiety, are higher in patients with persistent post-traumatic headache.

Assessment and management of these psychological co-morbidities is therefore necessary, in addition to evidence-based treatment of the headache itself, to improve treatment response.

What are analgesic overuse headaches?

Analgesic overuse headaches, otherwise known as overuse headaches or 'rebound headaches', are headaches caused by taking too much medication. Paradoxically, an analgesic overuse headache can occur if medication for headaches has been overused.

Speak to your GP if you are starting to take medication on a regular basis, as it may be that your medication is not effective at managing the type of headache that you have, and other treatment options may need to be explored. For instance, research has indicated that Paracetamol might not be especially helpful for managing tension type headaches.

Treatment options

Medication

Over-the-counter medication such as Paracetamol or Ibuprofen are often the first course of treatment that people choose to manage headaches. Whilst normally relatively safe, it is important to seek advice from your GP, pharmacist or neurologist before taking any medication, as some may be more suitable than others depending on the type of brain injury you have had and other medications you may be taking.

It is also very important to always adhere to medication dosage instructions, as taking too much can cause analgesic overuse headaches or other serious side effects.

Lifestyle modification

Headaches may be triggered by things such as noise, caffeine, stress or tiredness. These are factors that you may have some degree of control over, such as how many cups of coffee you drink in a day or how early you go to bed. If you can identify certain triggers to your headaches, you may be able to modify your lifestyle to manage them.

As a general rule, to lead a healthy lifestyle make sure that your diet is healthy and you eat meals at regular times, get enough good quality sleep, regularly exercise, drink plenty of water and try to avoid caffeine and alcohol.

Complementary therapies

A complementary therapy is something that you can use alongside medication or other professional forms of treatment.

Examples of complementary therapies include mindfulness, aromatherapy, massage, meditation and acupuncture. These therapies can help to relax you, which may help with alleviating some forms of headache. Complementary therapies are not typically offered through the NHS, so may be costly to access. Consider discussing complementary therapies with your GP or researching a therapy type before booking a session.

You can watch a mindfulness practice session on Headway's YouTube channel, **youtube.com/headwayuk**.

Specialised support

If headaches do not improve over time, it may be necessary to seek specialised support. You should start by discussing your headaches with your GP or neurologist.

You may be prescribed stronger medication; remember to follow dosage instructions carefully.

If your headaches do not settle, you may require a referral to a specialist headache clinic. These clinics offer a range of therapies to help with managing pain, either through direct intervention such as medication, or by helping you to improve your quality of life through a pain management programme.

Botulinum toxin, commonly known as Botox, is associated with cosmetic surgery but it can also be used to alleviate some types of pain, including headaches in some cases. This is only licensed when multiple conventional medications have been tried and been unsuccessful. Remember that Botox must be administered by a headache clinic specialist.

If your headaches are caused by stress that you are struggling to cope with, consider seeking a referral for talking therapy through your GP, for instance with a counsellor or psychotherapist. You may also wish to consider talking therapy services if your headaches are causing you to feel anxious or depressed.

How to cope with headaches at home

1. Identify triggers



Common triggers include stress, lights, noise, smells, alcohol, weather changes and fatigue. Where possible, try to minimise or avoid your triggers, although try not to become too anxious about completely avoiding things if something is out of your control.

2. Consider your diet



Be aware that some types of food may trigger migraine headaches, such as chocolate, cheese, citrus fruit and tomatoes. There is no need to completely avoid these foods, but try monitoring how you feel after eating them, or avoid them for a short while to see if it makes any difference.

3. Keep a headache diary

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Keep a record of your headaches when you experience them. Make a note of the time and the pain intensity of each headache, using a rating system where 0 is no pain and 10 is excruciating pain. Make some notes describing how the pain feels, as this may help with identifying what type of headache it is.

4. Try making changes to your lifestyle



Try to get enough sleep and stick to a regular sleep routine. Introduce relaxation techniques to your routine such as mindfulness. Try to do some gentle exercise everyday and avoid overstraining your eyes, for instance spending long periods of time at a computer/ mobile phone screen or reading.

5. Seek support with medication



You should seek advice from your GP, pharmacist or neurologist before taking any medication for your headache, as some may be more suitable than others depending on the type of brain injury you have had and other medications that you may be taking.

6. Speak to your GP or neurologist



If your headaches do not improve over time, you should speak with your GP or neurologist. You may be prescribed stronger medication or be referred to a specialist headache clinic. If stress is causing you to experience headaches, consider seeking a referral for talking therapy through your GP.





"She sees me for what i can do, not what i can't"

Thomas met his wife, Sophie, seven years after his brain injury - photograph courtesy of Sarah London Photography. Thomas Leeds was born in the '80s in West London. One of six siblings, Thomas had a happy



childhood, developing a passion for design which he planned to study at university following a gap year. But his plans were halted one night in 2003 when, at the age of 19, Thomas was hit by a car while crossing the road, throwing him into the air before landing hard onto the tarmac.

As well as breaking three vertebrae in his spine, the impact broke Thomas' skull and caused a large blood clot (haematoma) to form in his brain, requiring surgery to remove. Doctors said Thomas was lucky to be alive, but it soon became clear that his memory had been severely affected.

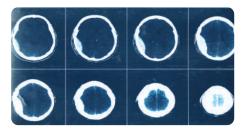
"I had no memory of anything before my accident, or the accident itself, and I didn't recognise anyone who came to visit me," said Thomas.

"Strangely I don't remember feeling alarmed or worried at first. I was on strong painkillers after my surgery and was having to rest a lot, and with no knowledge of having had memories, I didn't know to miss them at first."

With his father being a doctor and his mother also medically trained, Thomas returned home after two weeks to begin his journey of recovery. He made good progress and in 2010 met his wife, Sophie. The couple are now proud parents to two young daughters.

However, as experienced by so many people with a brain injury, life for Thomas and his family is always influenced by the ongoing effects of his condition.

"The combination of memory issues, face blindness (a difficulty recognising people's faces) and worrying about



seizures means that even on my good days, everything from trying to socialise to travelling on a train can be a real challenge. On my bad days the pain, fatigue and sometimes seizures mean that I simply cannot leave the house.

"My short-term memory issues make daily life very different to how it would have been. Sophie and I try to see the funny side. I'm often surprised that 'someone' has eaten my breakfast or magically made my coffee just how I like it - it was me, but I forgot!

"I'm often saying 'well done' to our toddler for dressing herself, and she'll laugh and say 'silly Daddy, you just dressed me!'

"It's easier to laugh these issues off when in the safety of our home or around people who know me and are happy to help, but trying to do things out in the world can be very frustrating and sometimes scary.

"I rely on notes, my phone, photos and my family. I've gotten used to living with face blindness and I'm now very good at quickly trying to deduce who might be talking to me based on other clues, but it does mean that making new friends or meeting people in public places is difficult and sometimes stressful."

Thomas received valuable support from the Headway helpline in the early stages of his recovery, and he credits the incredible support of his family and close friends for helping him through the many challenges that brain injury has thrown his way.

He said: "Having my family around every day, helping me to cope with and adjust to the challenges I faced has been a huge help. They have each cared for me after seizures, helped me to make sense of things and encouraged me to see the positives and live my best life.

"Sophie never makes me feel like a burden, even though she has to help me a lot with my memory every day. She sees me for what I can do, not what I can't, and loves me for who I am. Obviously I love her to bits!

"Our two little girls are already helping me out when I forget things and they are so caring when I'm not well. I'm so proud of them."

Around 10 years after his injury Thomas suddenly found he had regained some childhood memories, which he describes as a huge moment in his life. It was at this point that he had an idea for the plot of an adventure story and his wife encouraged him to start writing.

While writing is a big challenge for Thomas, the act of formulating and tracking the plot and characters acts as a form of rehab and encourages him to keep going.

"I never thought I'd be saying this, but I'm now signed to a literary agency who are putting my first book to publishers this year," said Thomas.

"Initially I wrote the book just for me but now that it is actually on its way to publication, I'm more passionate than ever about seeing a positive representation of brain injury in the media, and I'm thrilled to be a part of that by bringing my experiences to children's books in an adventure story.

"It's important to me that children can see someone with a brain injury and epilepsy and how difficult and different life can be, but also how it doesn't define you and doesn't stop you being the hero of your story.

"I leave a few blank pages in my books because when the hero loses a part of his life, it doesn't stop him being the hero on the next page – he's not lost; he's still on the adventure."



Alongside writing, Thomas has been working tirelessly to raise awareness of brain injury through a series of inspiring talks and interviews in the media. But as has been the case since those early days after his injury, he puts family at the heart of his plans for the future.

"I've been a full-time dad for six years, looking after our two young daughters while my wife Sophie works full time. I'm looking forward to making many new happy memories with them as they grow up."



undergoing tests in hospital

FUNDRAISING AND YOU!



Fundraising for Headway makes an enormous difference to the lives of people affected by brain injury across the UK, but choosing the right challenge can have other, more personal benefits.

It could offer you a chance to exercise or learn new skills as part of your rehab, provide an opportunity to interact with your friends and family when you ask them to support you, or give you a perfect excuse to keep fit while connecting with the wonder of nature.

Here, we look at some of the ways our tireless team of Headway Heroes have supported Headway in 2021, and the benefits they gained from taking on a new challenge...

NICK'S STORY: "Three mountains for ma"

Tackling the demanding Three Peaks Challenge might seem like an almost impossible task for someone who has never climbed a mountain before, but for Nick Henderson, the trauma of losing his mum inspired him to lace up his boots and set off on an epic fundraising adventure, taking in the beauty of nature while raising over £2,000 to help support those affected by brain injury.

Nick explained: "My mum died in December 2020 after sustaining serious head injuries in a road accident. She spent almost two weeks in intensive care. We were told that if she survived, she would probably need 24/7 care.

"It's something we thought about a lot as a family during that time. How would we cope? What support might be available? I realised how much we might depend on a charity like Headway.

"I wanted to set myself a big challenge that would also give me the opportunity to experience something beautiful, to connect with nature and channel my grief into something positive. I could feel my mum urging me on and I wanted to do something that would have made her feel proud. I called it 'Three Mountains For Ma."

Nick successfully scaled Ben Nevis, Scafell Pike and Snowdon in a guided group walk, facing weather that changed from warm sunshine to cold wind and deep snow, but he described it as an 'incredible experience'.

"The experience gave me a new perspective on what's important in life, the power of people working together, the amazing things we're all capable of as humans and the respect we always need to have for nature.

"I'd urge other fundraisers to be proud and honest about their story. That's how you connect with people. Secondly, think of every possible network you could tap into and don't be afraid to ask for donations.

"Third, keep sharing updates and pictures to remind people. You've got to maintain that momentum - and promise everyone that you will stop talking about it... eventually!"



LENKA'S STORY: The West Highland Way

Following the tragic death of a close friend to brain injury in 2020, 41-yearold Lenka Brunclikova, originally from the Czech Republic but now living in the Lake District, decided to take on a gruelling outdoor challenge for Headway across some of the most varied and exciting scenery in Scotland. Lenka hiked the 96-mile route of the beautiful West Highland Way, over rugged mountains and past expansive loch shores.

Talking about the challenge, Lenka explained: "I did the Hadrian's Wall trail last year, on my own with my teddy bear Hugo, and it was an absolutely great experience for me so I knew I would be taking on another trail as soon as possible. "From all the choices I chose the West Highland Way because it's in the amazing nature of Scotland. So I took my tent, sleeping bag



and other essentials and couldn't wait to start my adventure.

"The third day of the trail was definitely the most difficult, with other walkers struggling physically and mentally as well. The section was exhausting and seemed never-ending, with lots of ups and downs. "But I got through it, and to others who are taking on a

similar challenge I'd say enjoy the walking itself, not just the finish. It's not a competition and it's really worth taking your time in this great environment."

Lenka was

joined by her teddy bear, Hugo.

REHABILITATE THERAPY'S STORY: Around the world in eighty days!

Inspired by Jules Verne's eccentric inventor Phileas Fogg and looking for a way to boost exercise levels, the team at Rehabilitate Therapy set their clients off on an ambitious Around the World in Eighty Days challenge – lockdown-style!

One of their clients, Rebecca, mapped the locations that Phileas visited and the distance between them, with 38 others joining in the challenge. Each person set their own targets depending on their circumstances, with some cycling or running while others covered the miles in their wheelchair, either indoors or outdoors.

"The mental health of our clients has been a real challenge through lockdown, and therefore as lockdown number three approached, we had to do something to support them," said Philip 'Phileas' Crowther, Business Director at Rehabilitate Therapy.

"It was wonderful to see clients galvanised and bantering with each other through our Rehabilitate Social groups and challenges, while being involved in the organisation of the challenge. We had Jamie writing a weekly motivational newsletter, Mikey running group fitness classes and Rebecca collating everyone's miles to track our progress around the world – it takes a long time to get from China to San Francisco!"

The amazing efforts of the Rehabilitate Therapy clients led to them meeting the target of travelling around the world, while the company generously donated £750 to Headway in recognition of their fantastic achievement!



Feeling inspired?

If Nick, Lenka, and the Rehabilitate Therapy team have inspired you to start your own challenge, head to headway.org.uk/get-involved or call our fundraising team on **0115 924 0800** to get started!





Support Headway this Christmas and improve life after brain injury



Christmas Cards

All cards sold in packs of 10.



Robins' Party





Festive Geese



Polar Jumper





£3.50 per pack!

Bolt

Burdon

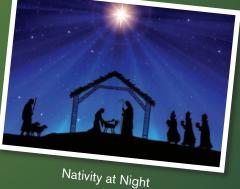
These cards are kindly sponsored by brain injury specialists Bolt Burdon Kemp, so all proceeds will go directly to supporting brain injury survivors, their families and carers.

Kemp

Snowman Build



Christmas Trees



How to order

Head to shop.headway.org.uk or call us on 0115 924 0800 to order your cards now.

Please contact Zak on fundraising.admin@headway.org.uk if you have any questions or would like us to send you a printed order form.



Fairy Light Reindeer

Santa's Friends

Covid-19 and long Covid

Q&A with Dr Aravinthan Varatharaj

When the outbreak of Covid-19 first struck the world in 2020 causing a global pandemic, scientists were desperately attempting to undertake investigations into the impact of the viral infection.

Now, just over a year on, we are beginning to better understand what the virus is and how it affects the body, both in the acute stage and on a longer-term basis. Here, Dr Aravinthan Varatharaj, Clinical Lecturer in Neurology at the University of Southampton, answers some of the common questions about Covid-19 and its impact on the brain.

What do the terms Coronavirus and Covid-19 mean?

Coronavirus is a type of virus that has been around for a while and causes various illnesses, including the common cold. Covid-19 is a disease caused by a new strain of Coronavirus which has spread rapidly around the world.

What are the usual symptoms of Covid-19?

The most important symptoms are a new continuous cough, a change in sense of taste or smell, or a high temperature. In many people Covid-19 causes few or no symptoms and recovery happens within a few weeks. Other people may become very unwell and need hospital care.

Does Covid-19 affect the brain?

All infections can affect the brain. If you have had a cold and felt tired, irritable, or headachy, these effects were probably caused by your body's immune system trying to fight off the infection. This is called sickness behaviour and can often happen with Covid-19. In any case, where someone is seriously unwell, all sorts of changes can occur in their body and these changes can upset the function of the brain. The person can become confused, and this is called delirium. This also often happens with Covid-19, especially in older people.

In rarer cases the immune system can over-react to the infection and the brain ends up getting damaged. I have seen problems like this with Covid-19 but it does not seem to be happening in most people.

Does Covid-19 actually infect the brain?

Certain infections can actually infect the brain itself (encephalitis), the covering of the brain (meningitis), or the blood supply of the brain (vasculitis). This has been reported with Covid-19 but is likely to be in a small number of people. When millions of people are being infected, even if something only happens one in a million times there are likely to be a few cases.

What about mental health?

It is really important to recognise that Covid-19 can have a significant effect on mental health and this is just as important as all the other neurological problems. Mental and physical health are tied together. Many mental health problems may be triggered as part of an acute stress response. Stress is a bit of a loaded term but when I say stress I mean your body, brain and mind reacting to some kind of pressure.

Dealing with a nasty infection like Covid-19 is obviously a pressure, so it is no surprise that sometimes the mind might be affected.

Does Covid-19 cause a brain injury?

As mentioned above there are many ways that Covid-19 could potentially cause a brain injury. There is also a potential link between Covid-19 and stroke, where the blood supply to the brain is blocked or a weakened blood vessel in the brain bursts. A large international study found that the risk of being diagnosed with a neurological or psychiatric condition was higher in the six months after having Covid-19, including conditions such as stroke, dementia, and depression.

What is long Covid?

Long Covid is the name given to the symptoms of Covid-19 continuing at least four weeks after the infection. It includes a wide range of issues, most commonly tiredness and breathing problems. Some definitions use eight or twelve weeks as a cut-off.

What are the neurological symptoms of long Covid?

Many symptoms have been reported including fatigue, 'brain fog', insomnia, dizziness, problems with taste or smell, depression, and anxiety.

How many people are affected by long Covid?

It is difficult to be certain but in a recent survey by the Office for National Statistics 1.1 million people in the UK felt they had long Covid.

Are people with a neurological condition more atrisk of developing long Covid?

The main risk factors for long Covid seem to be being older, female, and overweight. People who have a more severe initial infection, with more symptoms, seem to be at higher risk. People with existing health conditions might be at a higher risk, but the evidence is not clear.

There is some evidence that people with good general health and good mental health are less likely to get long Covid. One study in people with multiple sclerosis (MS) found that people with



Bio

Dr Aravinthan Varatharaj is a Clinical Lecturer in Neurology at the University of Southampton.

He was one of the founders of the CoroNerve Studies Group, which is coordinating UK national surveillance for neurological and neuropsychiatric complications of COVID-19. worse neurological disability were more likely to get long Covid, but we do not yet know whether this applies to people with other neurological conditions.

What can I do if I have long Covid symptoms?

There is plenty of information on www.yourcovidrecovery.nhs.uk. Speak to your GP and consider asking for a referral to a specialist long Covid clinic. Your local Headway group or branch may be able to assist with issues such as coping with fatigue and memory problems.

You may wish to get involved in research and a good place to start is to speak to your local hospital or visit bepartofresearch.nihr.ac.uk.



Top tips for completing welfare benefits application forms

"They are so complex. My father acted on my behalf and he found the forms difficult and stressful."

Applying for welfare benefits is notoriously challenging for many brain injury survivors and their loved ones, although it is unfortunately a necessary one for some. Ongoing issues with employment or difficulties caused by the long-term effects of a brain injury mean that many people must rely on support from welfare benefits.

In this feature, we share some top tips for completing benefits application forms, which is often the first stage of applying for welfare benefits.

"I struggle with them, they make me feel sick and confused." "It was a distressing process for hubby as these forms only highlight the difficulties. It has also taken a few sessions to complete the form as it's so long he couldn't concentrate for three hours in one go..."

- Be mindful of any dates by which you must return the form. This should be included in the letter from the Department for Work and Pensions (DWP) that accompanied your application form. It might help to set an alarm a few days ahead of the date, or to write it down on a calendar.
- Contact the DWP if you feel you may need more time with completing the form.
- Consider asking for help with completing the form from someone who knows you well. This could be particularly useful if you have problems with your memory or insight, as these issues may cause you to forget to include important details relevant to your application.
- If you are requesting evidence from healthcare professionals such as medical reports or letters, ask whether these can be written so that they specifically address the difficulties you describe in your application form.
- If you are submitting medical evidence from many years ago, consider that evidence older than two years might be dismissed, so ask your GP/consultant to confirm that the evidence is still relevant and applicable.
- Many people feel that the application forms are quite lengthy. Take breaks if you need to and tackle one section at a time rather than trying to complete the whole form in one go. If you are worried about writing the wrong thing down on your form, draft your answers on a separate piece of paper first.

"The forms are a nightmare to fill in. Claiming PIP leads to such stress that it was fortunate that I could fill them in for him. I would suggest keeping a diary for a week noting daily tasks you do for them and how they manage tasks on their own. How they feel each day and how pain affects them throughout the day."

- Avoid simply stating whether you 'can' or 'can't' do something. Instead, discuss how safely and independently you can do a task, whether you complete it, how long it typically takes you and how you feel during/ afterwards.
- As well as discussing the effects of your brain injury, consider and explain the effects of any medication you are on, or any rehabilitation you are having.
- Keep a diary of the ways in which your brain injury impacts you for a few days before you complete your form. You can then refer to this information while completing the forms as a general guide to some of the issues you commonly face.

"I went to Citizens Advice. Booked a long appointment sent for the forms. Went for 2-hour appointment. They completed the forms, asking me questions. Form sent off. I was awarded the lower amount on both parts. My thinking was that so many people had had to go to appeal I would go to the experts first."

"I did one question at a time, then a break. I did it on a word document by using Dragon software, I could speak into it and it typed for me. Any speech to text would work. Then you have a saved copy to update next time."

- Once you have completed the form, keep a dated copy for yourself. This will be useful for you to refer to during the assessment that follows, for any future appeals you may need to undertake or generally for your own records.
- Issues like fatigue or memory problems may have an impact on several different aspects of your life, so may need to be repeated in different sections of your application.
- If you need further assistance with completing your form, consider contacting your nearest Headway group or branch or your local Citizens Advice for help.

"Hubby could not have completed them, luckily I have experience in completing benefit forms. I would suggest that you always go to an organisation that can complete the forms with you. They understand the questions and the specific words needed to complete them successfully."

The most important thing to remember while completing your application form is to be honest about the impact of your brain injury. Offer as much detail as you can, including any effects that fluctuate.

You will probably have a chance to explain things in more detail during an assessment that follows, but claims can sometimes be processed based on the information in an application form alone, so it is good to add as much detail as you possibly can at this stage.

For further guidance and tips, see Headway's information on welfare benefits, available at headway.org.uk/welfare-benefits



Inside your incredible brain

In this part of our journey through the brain, we will be looking at some amazing facts about the small but incredibly important structure, **the pituitary gland**.

Small but vital

The pituitary gland is only around the size of a pea, but it has a very important function. It is responsible for producing and storing hormones that regulate many of the body's processes such as maintaining healthy muscles and bones, blood pressure, metabolism and energy.

Connected to hypothalamus

It is connected to the brain by the hypothalamus, another important brain structure involved in hormonal regulation.

The 'master gland'

It is often referred as the 'master gland' because it is responsible for instructing other glands (organs that produce hormones).

Pituitary gland professionals

An endocrinologist is a professional that can help with diagnosing hormonal imbalance problems that may be the result of damage to the pituitary gland.

Impact of damage

Hypopituitarism is a condition in which there is a reduction in hormone production following damage to the pituitary gland, for instance through a tumour. Damage to the pituitary gland can cause hormonal imbalances, which can result in a range of effects depending on which specific hormone is out of balance.

Part of the endocrine system

It is part of the body's endocrine system, the system responsible for producing and regulating hormones.

Produces hormones

The pituitary gland produces eight hormones that are each responsible for different bodily functions. For instance, it produces adrenocorticotrophic hormone (ACTH), which is responsible for maintaining blood pressure and blood sugar levels.

Location

It is located on the underside of the brain, in a structure just behind the nose. Given its position, it is sometimes named hypophysis, which comes from the Greek term for 'lying under'.

Structure

In humans, it is divided into two main sections: the front (anterior) lobe and the back (posterior) lobe, with each having different functions. In other species, there are three sections, the anterior, intermediate and back lobes.

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CREATIVE EXPRESSION

Richard Eason sustained a severe brain injury in a motorcycle accident in 1983.

He experienced multiple physical injuries and damage to his brainstem, but after a long spell in intensive care followed by intensive rehabilitation, he was able to live a reasonably independent life despite the ongoing effects of his injury.

Like many brain injury survivors, Richard felt that although people tried to relate to his situation, they often couldn't truly understand. So he set to work writing a collection of poems about life after brain injury to help others in a similar situation to realise that they're not alone, and to try to give 'able-bodied' people a small insight into the world of disability.

You don't say

Don't you get sick of hearing it said, 'There's someone else worse off than you.' I know, I know, I've heard it all before, it doesn't help even though it's true.

It's well meant but it's usually said by a healthy able-bodied type, who's never been sick or had a bad day in the whole of their jammy life.

If you were worse off than all others, there's one thing you wouldn't have to endure, that's some silly bugger, patting your head saying **'There's someone worse off than you.**'

Richard sadly passed away in 2014, so to honour his memory his son Sam recently set to work re-printing and sharing his father's book of poems.

Richard's personality and wit shines throughout, and here we share You Don't Say', a poem which recounts a situation that is all-too-familiar for many people with brain injury!

Richard's book features a series of illustrations by Denis Blandford

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



Contact Kim Milan 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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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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