

Summer 2020

Headway News



The magazine of Headway - the brain injury association



Rising to the challenge.

PLUS

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Unique Care Provider – Helping you to take control of your loved one's trust fund.



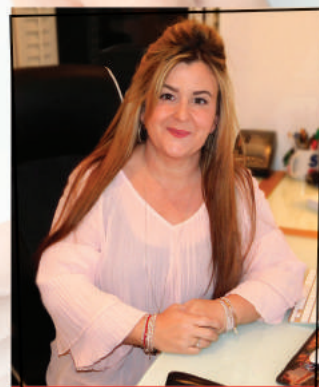
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Supporting brain injury survivors

These are difficult times for everyone and our thoughts are with those who have been affected in any way by the coronavirus (COVID-19) pandemic.

Thompsons Solicitors' team of experts acts exclusively for the injured, supporting adults and children who have suffered brain injuries as a result of:

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Welcome

Welcome to the summer edition of Headway News.

How very different the world is looking since I last wrote to you in March. Shortly afterwards, the UK was placed into lockdown in response to the COVID-19 pandemic. At that point, we had no idea how long the crisis would last, or how deep it would be.

Over 45,000 people have not survived the virus in the UK. My thoughts are with those families who have lost loved ones over the past few months, particularly those associated with Headway who have suffered this experience.

For brain injury survivors and their families, the current crisis is made even more challenging by effects such as memory problems, fatigue, anxiety and difficulties coping with change.

Emotional and behavioural issues such as frustration and lack of insight and awareness can make social isolation as a result of the coronavirus pandemic hard to cope with.

Our recent survey revealed that the lockdown is causing survivors and their families confusion and fear, exacerbating the existing effects of brain injury and causing untold stress and anxiety to the point that they're struggling to cope. It is clear that lockdown is having a detrimental effect on survivors and we have received some particularly poignant comments.

We hope this survey will help the Headway movement make a stronger case for the necessary financial resources to continue to provide support to those affected by brain injury at this challenging time. Brain injury survivors and their families need Headway now more than ever.

One thing that I could be sure of at the outset of the public health crisis was that Headway would rise to the challenge it presented. The Headway

network of groups and branches has displayed extraordinary commitment, creativity and flexibility to continue to provide services for the vulnerable people they support. There has been a willingness to share information, best practice and work together to solve the problems thrown up by the pandemic.

My colleagues at Headway UK have worked tirelessly to continue to provide our direct services and support the Headway network. I would like to say a huge thank you to all those who have gone the extra mile for survivors of a brain injury and their families.

However, all these efforts cannot mask the problems that lie ahead. The report recently published by the Office for National Statistics provided the clearest indication yet of the scale of the difficulties facing the UK. The economy shrank by 20.4% in April - the largest monthly downturn on record. The contraction is three times greater than the decline seen during the whole of the 2008 to 2009 economic crisis and has affected virtually all areas of economic activity.

The reality is that the impact of the pandemic on Headway is likely to be severe and long lasting. Local authorities provide a significant proportion of the funding for Headway groups. Their initial response to the public health crisis was extremely supportive, with most authorities agreeing to fund Headway groups at the same level that they had before the pandemic. I believe this reflects a respect for the work Headway undertakes and a recognition that the cost of providing this service if Headway collapsed would be considerably greater.

However, recent media reports suggest that there is a financial crisis looming in local government which may have a significant impact on the funding of Headway at a local level. Local authorities face a potential £5 billion

funding shortfall over the next year, with several understood to be on the brink of insolvency.

It is not just at local level that Headway faces difficulty. Our most recent forecast indicates a projected shortfall against budgeted income of £2 million in 2020. Some of this loss has been mitigated by the support available from the taxpayer, including the Retail, Leisure and Hospitality Scheme and the Coronavirus Job Retention Scheme. Without this support we would have been facing a financial disaster in 2020 but even with this support, we are forecasting an overall deficit of £450,000 by the end of December.

As the various financial aid packages from the government will not be available to the charity next year or beyond, and with the country set to enter a recession or depression, it is predicted that the severe pressure on Headway's finances will continue throughout 2021 and beyond.

Any worsening of this crisis, for example if we experienced a second wave of the virus, could result in a financial catastrophe for Headway. This is a threat that we must all consider carefully and take the appropriate action to ensure the survival of the charity.

For more than 40 years, Headway has been improving the lives of survivors of a brain injury, their families and carers. We face the most significant challenge in our history to ensure that we can continue this vital work. In the coming weeks and months, I hope we will continue to rise to this challenge as we navigate the difficult times ahead.

Best wishes and please stay safe.

Peter McCabe
Chief Executive

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Your views...

We asked our online community to tell us the things they've learned during lockdown that will be a big help to them in future...

"To stop trying to be who I was. To just relax and be ok with that."

Karen Weatherley

"I've learnt how to bake! Bread and cakes, without any help. I'm spending lots of time in the kitchen."

Lisa-marie Scott

"I've learnt I can't jump with Joe Wicks, it makes my head hurt! But I'm getting good at adapting his workouts."

Joanne Waring

"That I need to rest! I feel much better just doing my own thing indoors."

Lorna Lancaster

"Doing a lot more arty hobbies to try and keep me sane. Also talking more."

Rachel Emery

"As well as working from home & continuing with my Mental Health Course, I bought a Ukulele which arrived 2 weeks ago. Earplugs at the ready!"

Sarah Louise Lennon

"I've learned to just take it a day at a time. This has helped a lot."

Judy Kimble Jarman

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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:

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Nurse-led freephone helpline:

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helpline@headway.org.uk

Website:

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Advertising:

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Continued care in your community

Across the Headway network, groups and branches have shown incredible dedication and resilience as they continue to support those affected by brain injury, even in times of a global public health crisis.

Here we highlight the remarkable work taking place across the UK to support some of the most vulnerable members in our communities.



Staff and volunteers at Headway Derby transformed their services overnight.

Headway Derby

The charity's popular services, including the inspirational women's group, education course and young people's group, continue to run through the provision of online materials such as videos, PowerPoints and interactive webinars.

Headway Oxfordshire

Headway Oxfordshire has launched a series of online interactive classes and activities which replicate the services usually on offer at the Activity and Rehabilitation Centre, including classes on seated exercise, nutrition and cooking, artwork therapy and yoga.

Headway Wearside

Headway Wearside is continuing to support those affected by brain injury through a new remote creative art project which enables brain injury survivors to showcase their creative flair through drawing, cooking and more – all from within their own homes.

Headway Wirral

Brain injury survivors who attend Headway Wirral's day centre can call staff and volunteers to talk through their worries, discuss any extra support that's needed or even just to have a chat.

Headway Portsmouth

Headway Portsmouth replaced the typical face-to-face carers group on offer with a new remote one, and were delighted that the group even set up their own WhatsApp chat to keep in touch.



The team at Headway Portsmouth have been working hard to support carers

Headway Hertfordshire

In partnership with Headway Hertfordshire, six-time stroke survivor Nicola Evans has set up virtual yoga classes to encourage those affected by brain injury to stay active during isolation.



Catherine at Headway Preston and Chorley leads the gentle exercise classes

Headway Preston and Chorley

Headway Preston and Chorley has set up specialist online exercise classes to help brain injury survivors with their physical and mental wellbeing during lockdown.

Headway Milton Keynes

Headway Milton Keynes' art tutor Sophie Bennett leads virtual classes where brain injury survivors are given a topic to focus on and asked to express their creativity through painting, drawing and other art forms.

Headway Surrey

Headway Surrey is continuing to support members through virtual art classes, welfare calls and a helpline.

Headway's ABI Network

Video calls on self-care at home, dedicated social media groups and welfare calls are just a few of the ways Headway's Acquired Brain Injury Network in Northern Ireland is working to support carers throughout the pandemic.

Headway Devon

Headway Devon has been offering tailored support to service users, including teaching one brain injury survivor how to make sausage rolls via a video call.

Headway Southampton

The team of staff and volunteers at Headway Southampton have been running a home contact service where vulnerable adults with a brain injury in self-isolation can get their food and medicines dropped off at their door.



Headway Wearside's cookery classes have gone virtual

Brain injury survivors 'fear for future' due to lost rehab



Headway has produced a survey-led report which explores the impact of lockdown on those affected by brain injury, highlighting the unique and complex challenges both survivors and their families face.

More than half of brain injury survivors have lost access to rehabilitation services as a result of lockdown

measures and now fear for their futures, according to the study.

Early rehabilitation following brain injury can be crucial in helping survivors to regain a degree of independence and relearn lost skills, including walking and talking. But 57% of those who sustained their injuries within the past two years say their access to specialist treatment has been negatively impacted.

Peter McCabe, Chief Executive of Headway, said: "The results of this study are deeply concerning. The first

two years following a brain injury are very important in terms of a patient's long-term prognosis and any delay to receiving specialist rehabilitation can impact their ability to lead an independent life in the future.

"Local Headway groups and branches across the UK are going to extraordinary lengths to ensure help remains available to vulnerable individuals and families during the lockdown. Without this help, the figures reported in our study would no doubt have been much worse.

"However, with local authorities under increasing financial pressure, local charities are facing an uphill battle to survive, exacerbating survivors' fears for the future.

"Unless the government provides local authorities with adequate funding for community-based rehabilitation services, thousands of brain injury survivors and carers will either be left without support or be forced to rely on more costly state-funded care."

'Adult social care must be protected'

Many of the specialist rehabilitation and support services that Headway groups and branches provide are commissioned by local authorities.

Following the outbreak of the pandemic, only 4% of Directors of Adult Social Care from councils across England are confident that their budgets in 2020/21 are sufficient to meet statutory duties, according to a recent report by the Association of Directors of Adult Social Services (ADASS).

Meanwhile, recent studies published in The Lancet Psychiatry suggest COVID-19 could lead to an increase in the number of patients sustaining acquired brain injuries, with any such increase putting further pressure on Headway's ability to support those affected.

Peter concluded: "Funding for adult social care cannot be compromised and must be protected."



Jane's story

For the past five years, 52-year-old Jane Hallard from Gloucester has relied on her local Headway group to help her rebuild her life following a subarachnoid haemorrhage in 2015.

Jane was helping her son to clean his car when she felt like her head had been hit with a "sledge-hammer". After collapsing, Jane was rushed to hospital where she underwent life-saving surgery before spending the next eight weeks in hospital.

The resultant brain injury changed every aspect of her life, leaving her with chronic cognitive fatigue and mental health challenges. It also led to the collapse of her marriage.

"Without the support of my local Headway I wouldn't be able to get through each week," said Jane. "In fact, without their support, I wouldn't be here at all.

"COVID-19 has exacerbated my feelings of anxiety and I have

struggled to cope with the changes to my routine, but Headway has always been there when I needed them, and their support has been crucial over the past 12 weeks.

"I can't bear to imagine a world without Headway in it and I really fear for my future if I can no longer access their specialist support.

"It is difficult to put into words how integral they have been to my life over the past five years and how important they are to my future.

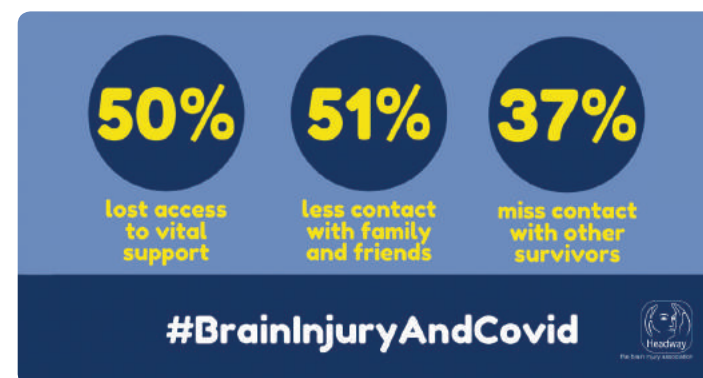
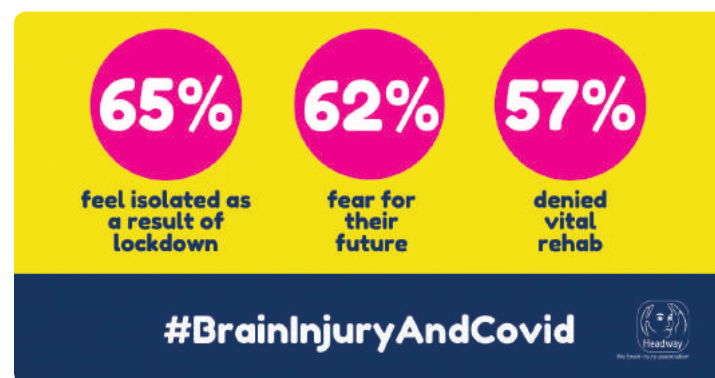
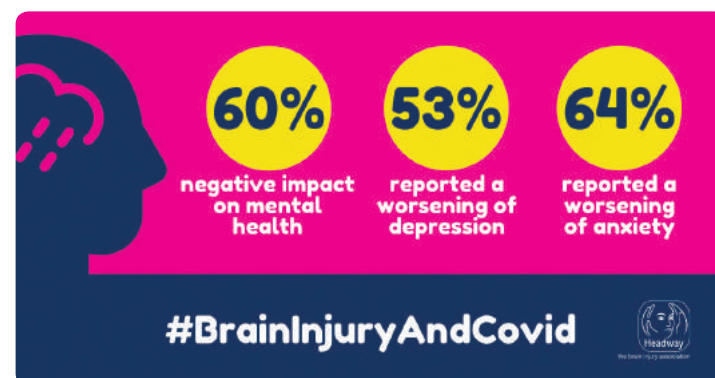
"Lockdown has made the world with a brain injury an even lonelier place, but Headway has ensured that I have always felt supported and they have remained by my side, every step of the way.

"Things came to a head a couple of weeks ago when I found myself sitting in my car at 2am. I had hit an all-time low, felt completely worthless and in that moment, I just wanted to end it all.

"I glanced back at my house and I saw my dog peering out of the window. Seeing his face stopped me in my tracks and the realisation of what I was about to do knocked me sideways.

"The very next morning I called my local Headway and with their support, I was able to talk to a GP and get the medication I need. They have been calling me every week and I really look forward to their phone calls. It is such a relief to have someone to offload to, who you can speak to without judgement and who fully understands your injury."

Read the full report on our website.



You're not alone



Headway's free, confidential helpline is available to anyone with a question about brain injury - from survivors and carers to students and professionals.

Run by a team of nurses with expertise in supporting people affected by brain injury, the helpline is a vital source of information and support.

The service is constantly expanding and last year answered a record 11,216 calls.

Brain injury survivor Doctor Veronica Woods (whose name has been changed for anonymity) and her husband called the helpline in 2012 when they began to struggle with the impact her injury was having on their lives.



Veronica said: "Recovering from the brain hemorrhage was hard work. I was terrified.

The service was exceptional. It provided a calm approach to a problem and provided a wealth of information. This is the first place to tell me where to go for help, I never knew anything before - thank you! Thank goodness it exists.

I spoke with a lady earlier today - I'm not coping financially very well. I must say that she was kind, spoke nicely and listened to me, without judgement, this means a lot to me.

I couldn't walk or do anything by myself anymore.

"The effects of my injury caused a lot of disruption to my family and I felt like no one understood - but then we found Headway.

"My husband and I both called the helpline and they gave us strategies to help cope with everything going on.

"They understood immediately what we were going through and recommended counselling for the family.

"I felt lucky to pick up the phone and hear a comforting voice at the other end of the line. I was so pleased my husband found Headway too - I don't know where we'd be without that support."

Mum-of-two, Tracey Cox, called the helpline while she was recovering from surgery to treat an aneurysm.

Tracey said: "Headway's helpline was a real saving grace for me during my recovery and even still to this day. The nurse on the line made me feel understood and always put my mind at ease. It was great to hear a friendly voice at the other end of the phone."

People contact the Headway helpline with a variety of questions or to discuss issues they need help with, such as the effects of brain injury or any social and practical issues they are facing.

Over the past five years we have seen an 87.5% increase in the number of

people calling in relation to problems with their benefits.

Julie Gaskin, the helpline's manager, said: "There is no standard helpline call - in the complex field of brain injury it is rare that people's situations are alike.

"Most often people have little or no knowledge of brain injury, or of the services that are available to help them before they contact us. Many of our calls are from people who need

a listening ear, they may be having a difficult day or have a question and they don't know who else to ask.

"For many, we are the first person that has understood, listened and explained their injury to them.

"Being part of the helpline team can be emotional and complex, but ultimately it is very rewarding to know you have made a difference to a someone's day."

Pay for a Day and support our helpline



Headway's Pay for a Day scheme is a great way to mark a special date in the calendar while making a difference to people living with the effects of brain injury.

You can fund a full day's running costs for just £558 to mark special dates such as Christmas, Ramadan, Diwali and Hanukkah.

In return you will receive a personalised, environmentally friendly e-card to share with your network in lieu of your cards, as well as a thank you on our popular Twitter page - what a fantastic way to show your support for Headway!

For further details please contact us on partnerships@headway.org.uk.

So glad this organisation exists. Due to the quick response, good information and kindness they provided, I feel much less isolated and hopeful that my relative will make a good recovery. Can't thank them enough.

The truly wonderful lady that I spoke to today deserves a raise. She has sent me so much information that I hope will help me to live my life with health and happiness.

Helpline FAQs

Here we answer some of the helpline's most frequently asked questions, focusing in this edition on COVID-19.

Am I more at risk of catching coronavirus because of my brain injury?

Brain injury has not been listed by the NHS as one of the conditions that make an individual more vulnerable to COVID-19.

Despite this, it is entirely possible that a brain injury survivor may happen to also fall under one of the groups that are at increased risk.

These include people over 70, people who are pregnant and those with certain underlying health conditions. If you need more detail about this, you can visit the NHS website at www.nhs.uk/conditions/coronavirus-covid-19.

There has been a change to my normal routine and I'm not sure how to cope.

Unprecedented situations such as the recent outbreak of coronavirus, which has seen the nation being asked to stay indoors and many services closing, can bring immense disruption to the set routines that many brain injury survivors rely on.

Survivors who are unsettled with this change should, where possible, try to find alternative ways of keeping their routine. For instance, if you attended a Headway group on a certain day of the week, use that time to call a friend to talk instead so that you are still socialising, just in a different way.

Try to maintain parts of your routine that are still in your control, such as what time you wake up, any activities that you do in the house and any times you usually rest.

You could write your activities down at the end of each day, including the time that you did them, to help prompt you the next day and gradually form a new routine.

I feel lonely at home with my brain injury. What can I do?

Staying indoors for an indefinite length of time can be difficult, especially if you are living alone.

Being unable to visit friends and family can lead to feelings of loneliness. Some brain injury survivors might have relied heavily on such outings.

If you are comfortable with using a computer there are a number of online communities you could join to connect with others while at home. Headway's HealthUnlocked community allows you to talk to other people affected by brain injury in a secure online space, and many Headway groups and branches continue to offer remote support.

Remember that our helpline is available if you need emotional support on 0808 800 2244 or helpline@headway.org.uk (Monday – Friday, 9am – 5pm). The helpline can even offer a listening ear if you just need to talk to someone about how you're feeling. You could also consider ringing other charity helplines such as Samaritans on 116 123.

If you are over 60, you might be able to get a regular 'telephone befriender' through Age UK's Call in Time scheme. For more information on this scheme, including criteria for being eligible, call Age UK's Advice Line on 0800 055 6112.

Writing letters used to be the main method of communication between people who weren't able to meet face-to-face – if you are able to write or type on a computer, you could consider reverting to this old fashioned method and write a letter to a friend!

Try to keep busy with activities that you can enjoy around the house, such as reading, listening to music, gardening, or even cleaning. You could also consider trying out new activities that can help with your wellbeing such as art or mindfulness. Even sitting outside in the garden or finding a sunny spot in the house to sit in can help with feelings of well-being.

Use this time, if possible, to live life at a pace that suits you, instead of trying to keep up with the pace of usual life, which can sometimes be challenging for brain injury survivors.



Isolation after brain injury

Following a brain injury, survivors may begin to experience feelings of isolation as they try to come to terms with the effects of their injury and a new way of life.

For some, this can result in them distancing themselves from their loved ones and disengaging with activities and hobbies they once enjoyed.

The ability to socialise may also be hampered by the effects of a brain injury, with fatigue leaving some survivors completely unable to leave their home for days.

We spoke to three brain injury survivors about how their time in self-isolation helped to prepare them for the coronavirus crisis.

Top Tips

Anne Johnston - otherwise known as AJ - has been living with the effects of her brain injury for two years and says that self-isolation has been a big part of that.

In a video on her popular YouTube channel, Anne addresses her experiences of isolation and offers nine top tips for coping.

1. Remember this change is temporary
2. Stay in touch with family and friends by finding ways to connect remotely

3. Make sure you still get some exercise

4. Remember to eat well

5. Keep your brain active by doing puzzles or learning a new skill

6. Keep a journal

7. Write yourself a 'happy list' – What things can you do that make you happy?

8. Write yourself a 'to-do list' – maybe

there's a house project you've been meaning to do for ages

9. Be kind to yourself and to others!

BE KIND TO YOURSELF
AND OTHERS



The effect on mental health

Brain injury survivor Sammy Johns knows how hard self-isolation is for people experiencing problems with their mental health.

"Being forced to self-isolate is very different from choosing to stay at home because you're having mental health issues. Having any kind of control or choice taken away can be extremely upsetting and frustrating, even when you know it's absolutely the right thing to do," said Sammy.

As a way of coping, Sammy has written up a list of things that help her to cope. She hopes that by sharing her list, she will help others who may be struggling:

Remember you're not alone

Reach out to your family and friends, not just by telephone but by video chat. Just knowing someone is there for you can really help squish those negative thoughts.

Pamper yourself

Take a long bath or shower. Try those fancy face masks/body lotions you got for presents that you've never had time to use, take some time just for you.

Arrange an online video chat with a group of your family or friends

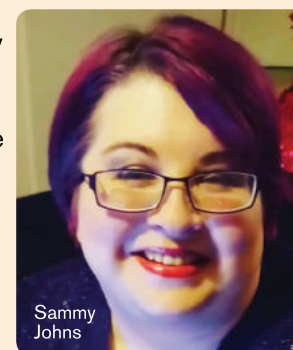
You could even turn it into a watch party. Pick your favourite movie or TV show episode and all watch it together.

Throw yourself a dance party

Create a playlist of all your favourite party songs - they can be golden oldies or the latest top hits - as long as it gets you off the sofa, singing and dancing away. You'll find yourself laughing in no time.

Remember about nutrition

Try looking in your kitchen for supplies and plan out a nice healthy meal for yourself - something that might take a bit of effort for just one person, a roast dinner, tacos or a curry for example.



After Belinda Medlock sustained a brain injury in 2015, she found that the majority of her time was spent indoors, trying to get to grips with the effects of her injury and isolating herself from the world outside.

Chronic fatigue and sensory overload meant that she had to limit the time she spent socialising in busy and noisy environments.

Despite the challenges this has presented along the way, Belinda feels as though her brain injury and its effects have prepared her for this period of self-isolation.

She said: "As most of the world is getting used to isolation and social distancing, it doesn't feel daunting to me. I've had to do it a lot over the last five years, limiting social activities and avoiding noisy, busy places to try to manage the effects of my injury."

In 2015, Belinda experienced a stroke. She was left with slurred speech, weakness in her arm, chronic fatigue and sensory overload.

She said: "I didn't understand the impact of the invisible cognitive effects and it took me a long time to come to terms with this and manage it. It felt bizarre to me that a conversation or a short walk could leave me unable to function."

Belinda was able to get support through the Headway helpline and her local Headway group in Wakefield, and also applied for a Brain Injury Identity Card.

Despite the progress she's made when it comes to coping with the effects of her injury, chronic fatigue still has a huge effect on Belinda's life and can completely incapacitate her, leaving her stuck in the house for days as she tries to recharge and reenergise her brain.

"Life is very different now," she said. "I have to try to manage neuro fatigue and sensory overload every day. To do that I have to limit the things around me such as noise and activity."

"It took a long time to come to terms with the isolation I was experiencing. I learnt the hard way. As frustrating as it is, I know I can't change it, so I've learned to accept that life is different now."

But her experiences of self-isolating have helped her to prepare for the consequences of the coronavirus pandemic.

She said: "I know it can feel scary, frustrating and lonely to self-isolate and shut yourself off from the rest of the world. I found that focusing on the positives really helped. For me, it changed my perspective on things and made me reevaluate how I think about certain things."

"I've kind of become an expert on self-isolation over the past five years, so I can tell you it does get easier."

Feeling isolated after your brain injury and want support?

Contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.

MINDFULNESS AND ME

For many brain injury survivors, mindfulness is an essential practice that helps to regulate their mental health, mood changes, and memory.

Self-isolation, like that imposed during the coronavirus pandemic, is something quite familiar to many brain injury survivors who have adapted coping mechanisms to manage their wellbeing.

Mindfulness isn't a cure, but it can help strengthen the mind and focus attention on the present moment.

What is mindfulness?

Mindfulness is a technique used to concentrate on your immediate surroundings, focusing on what happens moment by moment. It can be transformative for some and allow them to feel more aware of the situations around them, which can be particularly helpful for brain injury survivors.

There are different types of mindfulness that can be effective. Meditation as a way to unwind; mindful focusing, concentrating particularly on your breath and body; or active mindfulness, centring on eating or walking. These are all things that can help you calm your mind and relax.

Mindfulness techniques

Some may find the thought of practicing mindfulness intimidating, but the NHS have some top tips on how to get you started:

1. Notice the everyday.

Noticing the small things in our daily lives has the power to interrupt the 'autopilot' mode we can sometimes find ourselves in. Think about the sensation of the food you eat or the air moving past your body as you walk.

2. Keep it regular.

It can be helpful to pick a regular time to become more aware of the sensations created by the world around you.

3. Watch your thoughts. Some people find it difficult to practice mindfulness. As soon as they stop what they're doing, lots of thoughts and worries can crowd in. It's useful to remember that mindfulness isn't about making these thoughts go away, but rather about seeing them as mental events.

4. Name thoughts and feelings.

To develop increased awareness of thoughts and feelings it may be helpful to silently name them: "I think I might fail this exam" or "this is anxiety".

5. Free yourself from the past and future.

Mindfulness can be especially helpful if you realise you spend time 'trapped' in reliving past problems or 'pre-living' future worries.

We spoke to two brain injury survivors who shared their advice about mindfulness and how to generally promote good mental health during lockdown.

Jodie's advice

Jodie Bacon suffered a brain injury around six months ago and developed post-concussion syndrome (PCS) following the accident, leading her to experience feelings of isolation. But Jodie has described how important mindfulness is as part of her daily activities.

She said: "My routine is so important to me and getting outside for a walk each day, even if my fatigue only allows 50 meters.

"I'd tried meditating before as part of my concussion recovery but since coronavirus arrived, I've been meditating every night after I switch my screens off. It just helps me relax and changes my focus instantly."

Clare's story

Clare Rutter suffered a brain injury three years ago and, like Jodie, also developed post-concussion syndrome. She was delighted that she had been able to return to work before coronavirus forced us all into lockdown.

"I've been self-isolating with my mum as she's one of those classed as medically vulnerable. For the first two weeks I was quite a mess, feeling really low, emotional, my insomnia was all over the place and even found that I was getting on my own nerves! I haven't long returned to work following my head injury three years ago and felt like just as I was starting to get going and get my life back that it was ripped away from me all over again," she said.

"Fortunately it's worked out that I can actually do a lot of work related things from home plus I'm involved in admin on my local coronavirus help volunteers' group."

As well as having a regular routine to help her cope with isolation, Clare realised that spending too much time online and watching TV had caused her to become more anxious.

She said: "I've found that since not being at work that I've spent far too much time online plus watching the news constantly. It took me a while, but I realised that this was affecting me. I've stopped watching the news until the evening where I just have it on for the updates and limit my internet use where possible. Trying to reduce my internet use is actually easier said than done as it's the main way I stay in touch with my family, friends and my local Headway - Headway Ceredigion! I think overall it's about having good self-discipline and sticking to it.

"Doing all this has saved my mental health massively during these difficult and unprecedented times. I'm hoping that my story and techniques can motivate and encourage even one person to do the same."

Help and support

There are plenty of online resources to help with mindfulness if it's something you want to try at home. The NHS website has a guide to mindfulness and the government has issued some advice about mental health and wellbeing during the COVID-19 outbreak.

Some organisations have uploaded free to access materials and resources to help with mindfulness during the coronavirus outbreak. Calm have a dedicated page on their website, as do Headspace.

But of course, if you need someone to talk about coping with your brain injury you can call the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.

Clare enjoying her time outdoors

LIFE AFTER CONCUSSION: CHARLI'S STORY

A concussion, otherwise known as a mild head injury, can occur following a bump to the head. A period of nausea, confusion and dizziness can follow but for most people symptoms usually clear up after a few days.

However, in 10-15% of cases, a mild head injury can lead to the development of post-concussion syndrome (PCS) and the symptoms of this can be anything but mild.

This is something 27-year-old Charli Skinner from London knows all too well.

Thrill-seeker Charli's biggest passions were skiing, sailing and finding the next adventure. She worked for a humanitarian organisation and travelled globally on a frequent basis.

Yet despite her action-packed lifestyle, it was a simple fall in the bathroom that led to her battling the debilitating symptoms of PCS.

After hitting her head on a glass shower screen Charli instantly knew something was wrong.

"It was almost as though I could feel my brain function totally collapsing on itself," said Charli.

"I lost my vision, couldn't move properly and I was in extreme pain."

Charli was taken to hospital with fears of a brain bleed but was shortly discharged with a diagnosis of severe concussion and told to rest until her symptoms passed.



Charli

However, over the coming weeks Charli's condition worsened.

Speaking about this, she said: "My ability to function deteriorated. I was unable to communicate or converse for more than 10 minutes at a time as I couldn't remember and recall information. My balance also became an issue and I was unable to walk in a straight line without falling."

Further investigations showed that Charli was experiencing a longer-term functional neurological disorder from post-concussion syndrome.

A year and a half following her fall, Charli is still recovering and continues to experience the negative effects.

She said: "My brain injury, while technically classified as a 'mild traumatic brain injury' has caused a host of serious, debilitating and long-lasting effects.

"Intense neuro-fatigue rendered me bed-bound for months. Alongside issues with severe nausea, insomnia and constant pain."

Unfortunately, Charli has found the invisible nature of her disabilities led to certain challenges.

Speaking about this, Charli said: "Having a hidden disability has taught me so much about the amount of work that needs to be done to raise awareness of people's access needs.

"You are constantly misunderstood, and the severity of your disability is often dismissed or ignored. I have experienced this countless times in seeking medical care, in the workplace, in social environments and sadly at times from family and friends.

"It is vital that people around the world don't leave it to disabled people, especially those with invisible disabilities, to raise this awareness. Able-bodied people need to act as allies, help to create safe and accessible environments (financially, physically, spatially and mentally). Whether people's illnesses are chronic, acute,

visible or invisible, they should not have to constantly fight for their right to be heard, cared for or to survive.

"Additionally, we need better awareness of the debilitating effects of brain injury. My brain injury was technically classified as a 'mild' traumatic brain injury, but there is nothing mild about any type of brain injury. Better awareness will help people suffering from brain injury of any form to access comprehensive and ongoing rehabilitation at the time it is needed."

"Finally, something that is not often acknowledged in acquired brain injury is the grief you feel for what you have

lost and the intense isolation you experience. From one day to the next you lose everything apart from your ability to survive; you feel a sense of lost identity, you lose relationships, you lose your financial, emotional and intellectual independence and you become someone who has to be cared for in the most rudimentary sense of the word."

When asked what advice she would give to fellow brain injury survivors, Charli says: "Have hope! While experiencing a brain injury is easily the most challenging and horrific thing that has ever happened to me, it has taught me so much; resilience, true gratitude, empathy and understanding for others and their struggles, and hope.

"While you may be struggling day-to-day, you will learn to manage your conditions and things will get better. The most difficult part about recovering from a brain injury is that you have to push your limits to recalibrate and recover, but there is a fine line you have to dance on to make it work. It can only be learned the hard way, but as time goes on it does get easier."



HATS

AT HOME

for Headway Day

From cycle helmets and party hats to fancy dress costumes and homemade creations, we received some truly wonderful and wacky Hats for Headway Day submissions this year.

Despite being under different circumstances, that didn't stop our wonderful supporters from donning their best hats to help raise awareness of brain injury and fundraise for Headway – all from within their own homes.

This year's winning entry for best individual hat came from Headway Somerset's Donna Cleeve who made her very own Spongebob masterpiece with the face paint to match. Donna wins the first ever, limited edition Headway Hedkasye helmet!

Meanwhile, Fosters Solicitors claimed the prize for best corporate group shot, roping in their families and furry friends to make a creative photo collage.

A huge thank you to everyone who got involved with Hats at Home for Headway and a special thanks to our corporate supporters Hedkasye for their kind prize donation.

If you'd like to see more of the hundreds of hat photos and videos we received, search **#HatsforHeadway** on social media!



Donna Cleeves' Spongebob masterpiece won her the award for best hat



Smiles all round at Headway Shropshire

BEST HAT!

BEST GROUP PHOTO!



Fosters Solicitors claimed the prize for best corporate group shot, getting their families and pets involved



Headway ambassador Jack Rutter donned his England football hat



Headway Leeds got creative with this light bulb balloon hat



Headway Bedford's Rob went the extra mile



Tamara Bond made her own hat with flowers picked from the garden



Natasha Boardman Steel ran a workshop on how to make a hat at home



Minster Law added a pop of colour to their photo collage

Nominations now open for the Headway Annual Awards



This is an extraordinary time for all of us.

Now, more than ever, is the time for us to spread positivity as we recognise and celebrate those who go the extra mile.

It's time to tell us who you think is deserving of a Headway Annual Award.

The Headway Annual Awards celebrate the inspirational achievements of people living with brain injury and the dedication of those working to support them.

Each finalist, chosen by a selection panel, will be invited along with a guest to a glittering luncheon at The Landmark London on Friday 11 December.

The categories this year are:

Alex Richardson Achiever of the Year sponsored by Slater and Gordon Lawyers

Carer of the Year sponsored by Barr Ellison Solicitors

Volunteer of the Year sponsored by Anthony Gold

Stephen McAleese Outstanding Contribution to Headway Award sponsored by No5 Barristers Chambers



What we're looking for

The more information we have about the person you are nominating, the better their chance of being shortlisted for a Headway Award!

Share your passion! We don't know the person you're nominating, so don't spare the details – or your feelings about how special they are!

Give us details. How long have they been a volunteer? How much progress have they made since sustaining their injury? What have they sacrificed to care for someone?

Set the scene. How did life change? What was life like before? Why does your nominee stand out from the crowd?

More is more! Keep your information relevant and catchy, but don't hold back. The more information we have, the better.

The closing date for nominations is Friday 24 July 2020. To nominate someone for this year's Annual Awards, visit headway.org.uk/nominate

Activity weekend LAN goes digital

Headway's annual Look Ahead in the North (LAN) event was set to take place in March in the beautiful grounds of Kielder Forest, but due to the COVID-19 outbreak it was sadly cancelled.

But that didn't stop Headway groups and branches from across the region coming together to laugh, dance, sing and keep spirits high in the midst of all the uncertainty – albeit online.

The event organisers, Amy Crosby and Nicola Hughes – both from Headway Darlington – set up a Facebook group called LAN Online Party.

More than 60 brain injury survivors, carers and professionals from across the Headway network came together virtually on 21 March for a night to remember.

The evening consisted of a general knowledge quiz, Hats for Headway Day competition and the renowned LAN's Got Talent where contestants showcased their creative flair. The



well-received event ended with an online disco, where members of the group shared their favourite songs for all to listen to.

A special thanks goes to EMG Solicitors for sponsoring the event.

emgsolicitors

ESCAPE THE WILD FOR HEADWAY

Thursday 13th – Friday 14th May 2021
Ullswater, Lake District

Headway brings you a brand-new corporate adventure for 2020! Are you ready to put your teamwork to the test and take on exhilarating challenges for a great cause?

- Trekking & navigation
- Climbing & abseils
- Scrambling
- River crossing
- Rafting
- Tyrolean zip wire
- Gorges & ravines
- Camp under the stars

Registration £50 per person

Individuals welcome

Minimum sponsorship: £300 per person



Kindly sponsored by



This is a corporate supporter only event, please contact us for all other fundraising opportunities.

Contact us on partnerships@headway.org.uk or 0115 924 0800 for further details.

Headway's HOME HEROES

Headway Home Heroes up and down the UK have been taking on fundraising challenges to help us cope with a severe reduction in income as a result of COVID-19.

the 2.6 challenge

The 2.6 Challenge was an initiative which aimed to raise £67 million for UK charities by the end of April, launched under the banner of 'Save the UK Charities'.

The challenge, which started on the day that was to be the London Marathon, Sunday 26 April, asked people to take part in an activity related to the number 2.6 or 26 and fundraise for their favourite charity.

Thanks to the tireless efforts of our supporters we raised over £13,000 for brain injury survivors and their families.



OUR AMBASSADORS LED THE WAY...



Former Team GB Paralympian Jack Rutter took on 26k in a day by running 16k and cycling 10k.



Headway's Vice President, James Cracknell OBE, took to his rowing machine to cover 2.6km.



Stroke survivor and Dancing on Ice star Alex Murphy swapped the skates for her running shoes and ran 26 miles in a week.



Sky News presenter Tom Macleod did a handstand for 26 seconds and still managed to talk!



90's pop legend, Marc Almond, performed a special rendition of Say Hello Wave Goodbye live on Instagram.



Former England Hockey Captain Alex Danson showed off her skills by doing 26 keepy-ups!

OUR COMMUNITY FUNDRAISING HEROES...



Brain injury survivor Peter Richardson read 26 pages of a book every day for a week.



Amy Dron got involved by cycling 26km on her exercise bike every day for 26 days.



Tamara Bond grew 26 different plants and gave them to her family and friends.



Katy Wing-Jackson hula-hooped for an impressive 26 minutes per day for one week.



The team at JS Parker North East got involved by running and cycling for their collective 2.6 Challenge.

Lois goes the EXTRA MILE

Brain injury doesn't just affect individuals; it can transform the lives of entire families. When this happens, Headway is here to help.

Lois knows just how devastating and far-reaching the consequences of brain injury can be - after all, she's been beside her daughter Sarah every step of the way for the past two years as she's learnt to live with post-concussion syndrome.

Her family also know just how important the support of Headway can be to those struggling to navigate their way through these scary and troubling times.

As a way of thanking Headway for all its support over the past few years, Lois decided to become a Headway Home Hero and take on her own 2.6 Challenge by walking 26.2 miles in 10 days.

She said: "I felt proud to raise awareness of a charity so close to all our hearts. Headway has been there for Sarah through some difficult times and the support on offer has been incredible."

In July 2018, Lois' daughter Sarah sustained a traumatic brain injury.

41-year-old Sarah had always been a keen cyclist and decided that she would embark on an adventure from Lands' End to John O'Groats in memory of her brother who had committed suicide a few years earlier.

But Sarah and her family could never have prepared themselves for what came next.

It was on day five of her 1000-mile trip that the front wheel of her bike fell off while she was travelling at speed, causing her to lose control and crash.

She sustained a mild traumatic brain injury, broken jaw and dislocated shoulder among other minor physical injuries.

Sarah said: "To start with, the significance of the brain injury wasn't apparent. I struggled a lot with headaches, fatigue, concentrating and maintaining attention - and being in loud, busy environments was a no-no!"

It was then that Sarah decided to reach out to Headway.

She said: "The Headway helpline was excellent and I was able to get much-needed support and guidance. I also used the information on the website which was really useful in helping me to understand the brain injury."

Sarah also accessed support through her local Headway group in Warrington.

"I was made to feel welcome at Headway Warrington and my experience of living with a brain injury was validated," she said.

"For all those living with a mild TBI or post-concussion syndrome who like me may have struggled with acceptance of their injury and finding the support and rehab necessary, you are not alone, believe in yourself, access the support on offer at Headway, it can make a difference to your recovery."

To say thank you for the support Headway offered Sarah following her injury, Lois decided to don her walking boots for the 2.6 Challenge and walk an impressive 26 miles over the course of 10 days.

"It was on my 79th birthday that Sarah mentioned the 2.6 Challenge and I suggested we do a 2.6-mile walk. My husband Glyn and I walk almost every day and the beautiful surroundings in our town mean it isn't difficult to cover that distance.

"But Sarah had something else in mind. She suggested that we walk 2.6 miles

for 10 days to cover the length of a marathon. We took on the challenge.

"Glyn, who himself sustained a brain injury a few months before we were married, is an avid walker but I suffer from osteoarthritis so it was more of a challenge for me to do the distances on a daily basis.

"We had some lovely weather for the first few days, but I even enjoyed walking in the rain too as it was all for a good cause."

Other members of Lois' family have also gotten involved with the 2.6 Challenge by walking, dancing, trampolining and jumping on a pogo stick.

As for Sarah's future? For the time being she is focusing on her recovery and learning to come to terms with a new way of life post-brain injury.

She said: "Acceptance has been difficult and slow in coming. I certainly felt a fraud especially when compared to those who have sustained more severe brain injuries. I doubted my symptoms for so long, feeling a failure for not being better after 21 months!

"For me, this is no longer about recovering what once was, but adapting and becoming something, someone better because of this injury."

Lois added: "We have always been proud of Sarah and all that she has achieved, but we are also proud of the way she has faced this trauma. It has been the most difficult challenge anyone should have to face as her life has been turned upside down."



Easy ways to support Headway

The COVID-19 pandemic is unlike anything we've ever had to face. Our 30 shops have temporarily closed their doors and community fundraising events have been cancelled or postponed.

The weeks and months ahead are going to be challenging and we are anticipating a potential drop of £2 million in income this year.

However, brain injury survivors and their families need our support today.

There are a number of easy ways you can continue to support Headway throughout these unprecedented times.

Become a Friend of Headway



As a Friend of Headway, you'll be given access to a wealth of information about brain injury, a logo pin badge, Headway wristband and the latest edition of Headway News.

Throughout the year, you'll also benefit from quarterly editions of our magazine and a monthly e-news bulletin, and access to a free or discounted Will writing service.

Direct donations

Headway relies on voluntary donations to continue the provision of vital services and support to brain injury survivors and their loved ones.

Whether you set up regular monthly donations or just a one-off donation, every pound given will make a huge difference to the lives of those we support.

Amazon Smile

You shop. Amazon gives. Amazon smile is an easy way to donate to Headway. Simply use Amazon Smile each time you're doing your Amazon shopping and they will donate 0.5% of your purchase to help us support brain injury survivors at no extra cost to you!

smile.amazon.co.uk

Facebook birthday fundraisers

What if you could help brain injury survivors just by getting older?! If your birthday is coming up, consider setting up a Facebook fundraiser for Headway to celebrate!

It doesn't have to be your birthday to support Headway through Facebook

fundraisers - you can get involved any time of the year.

It's simple to set up, just head over to our Facebook page (Headway - the brain injury association), click on the fundraisers tab, set up your own page and ask your family and friends to donate.



Virtual fundraisers

Why not host your own virtual fundraiser? Just because physical fundraising events have been cancelled or postponed, it doesn't mean you can't still fundraise for Headway by setting up your own virtual event.

Dream up your own virtual fundraiser - whether that be an online quiz with friends, an exercise class set up on Facebook Live or a concert from your home streamed on your social media - and ask for donations towards Headway through JustGiving and Virgin Money Giving.

To find out more about how you can support Headway, visit headway.org.uk/donate.



THE PRICE OF A PUNCH

One punch can change everything. Although it's over in a second, its power to devastate lives can be felt forever.

Majinder Randhawa lives with this impact every day. She vividly understands how ferocious the pain is when you lose a loved one to a senseless act of violence. She was there, at her brother's bedside, when they turned off his life support machine.

Her nightmare started in the early hours of October 12, 2011, when two police officers knocked on the door of her family home.

She said: "I saw them through the window and woke my sister and we both answered the door.

"One of the officers asked if this is the residence of Jagdip Randhawa. The fact that they were at our doorstep and asking about my brother at that time of morning; we knew it was bad news. They came in and told us to sit down.

"They told us that Jagdip was in Leeds General Infirmary with serious head

injuries and we needed to get there as soon as we could.

"This was the beginning of our whole world tipping off its axis and for everything to change beyond anything we could ever imagine."

Jagdip, 19, had been punched by a man and as he fell, had hit his head on a concrete kerb, causing a traumatic brain injury.

Majinder said when they arrived at the hospital, they were immediately taken to a waiting room.

She said: "I remember walking up to where he was and there were so many machines. He had a tube in his mouth, more tubes in his arms, wires stuck to his chest and there were so many beeps and buzzes from the machines.

"The most precious person in our lives was lying in front of us and there was nothing that we could do to help him."

The family sat in the waiting room for five days, hoping, praying, begging the doctors to save Jag's life. Jag's friends from university, from home and his family were all squashed into the small room willing him to pull through, to get better.

But Jag never regained consciousness.



Jagdip Randhawa

On the morning of October 17, a doctor came into the waiting room and told the family that they had tried everything and that Jagdip was not going to survive his injuries. They told the family it was time to say goodbye.

Majinder said: "We were all around his bedside. My mum was holding his hand and was kissing his cheek when they turned off the life support machine. I can't remember how long after this the nurse came over and said that Jagdip had died.

"In Punjabi, the word 'Jag' means 'the world'. Jag was the youngest member of my family. The pain that we feel is indescribable; we are crippled with it and see no way out of it."

During the criminal trial that followed, the family learned that the man who killed Jag

was a professional boxer. He had many prior convictions for violence and the night he punched and killed Jag, he was on bail for another alleged assault.

Majinder said: "Jag was killed for absolutely no reason at all by someone who had the skills to inflict maximum

damage on another human but none of the discipline that a professional boxer should show."

Majinder is now supporting Headway to raise awareness of the dangers that one blow can carry.

Majinder said: "That one heated moment in time will ruin many lives including that of the perpetrator who has to live with the knowledge that they are responsible for taking someone's life."

Headway
In Memory

This site offers those who have lost loved ones to brain injury a way in which to share precious memories with family and friends in a safe, secure and private space. Visit the site at headwayinmemory.org.uk

If you would like support following a bereavement please contact the Headway helpline on **0808 800 2244** or helpline@headway.org.uk.

Our work with Defra on access to food and essentials

Together with 23 other charities, we've written to the Government's Department for Environment, Food & Rural Affairs (Defra) and supermarkets about the challenges many non-shielded, yet vulnerable brain injury survivors are facing accessing food and essentials during the COVID-19 crisis.

On behalf of the thousands of brain injury survivors Headway and its groups and branches support, we have made specific calls for the following:

- Additional in-store support for people with hidden disabilities, such as a disability champion.
- The roll-out and extension of the sunflower lanyard scheme to identify vulnerable shoppers.
- Seating to be provided whilst waiting in a queue to shop in store.
- For the definition of 'vulnerability' to be extended to include others not currently listed by the Government.
- For additional online delivery slots, click and collect and phone orders.

Defra continues to provide updates about the accessibility of food in the commercial market and we hope that this progress will ensure that all vulnerable members of society, including those affected by brain injury, have access to food and essentials during these challenging times.

For more information about our work with Defra and on accessing food and essentials, visit headway.org.uk/food-and-essentials-during-coronavirus/.



Department
for Environment
Food & Rural Affairs

Things to note

Action for Brain Injury Week postponed

ABI Week, set to take place between 11-17 May, will be rescheduled to later in the year.

Memory Loss: A campaign to remember aims to raise awareness of the ways in which memory problems can affect brain injury survivors and their families.

It also provides our network of groups and branches with an opportunity to come together and talk about topics that are important to those affected by brain injury.

Keep an eye out on our website and social media accounts for a new date!

Hard Hat Awareness Week moves to September

Headway, in partnership with safety manufacturer Centurion, has made the difficult decision to move Hard Hat Awareness Week to 21 - 27 September 2020.

The awareness week, originally scheduled to take place from 8 - 14 June, will promote a series of activities designed to drive awareness of brain injury and encourage best practice around safety equipment.

The results of our survey which look into the use of hard hats in the construction industry and understanding of concussion, will be published at the start of the awareness raising week.

We hope that when the time comes, you will show your support by helping us to raise awareness of using and maintaining hard hats while on site.

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
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"Freeths LLP has a very efficient and client-focused personal injury team which 'achieves good outcomes even in the riskier claims.'"



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

