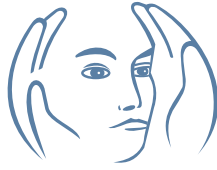


Summer 2021

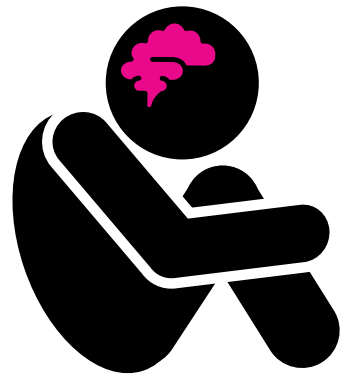
# Headway News



The magazine of Headway - the brain injury association

**ACTION FOR BRAIN INJURY WEEK**

## A LIFE OF LOCKDOWN?



*Reach out to help out!*



**ABI Week 2021:**  
A life of lockdown?

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**How to manage  
isolation**

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



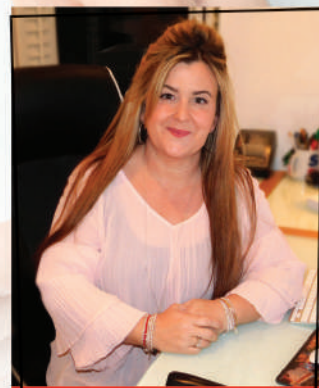
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## 100 years of fighting for the injured and mistreated

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As we mark our 100th year, we will – as we have since we started – represent and fight only for the rights of the injured, never the guilty party or their insurers.

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0800 0 224 224 [www.thompsons.law](http://www.thompsons.law)

Adam, Thompsons' client



# Welcome

## Welcome to the summer edition of Headway News.

The arrival of summer has brought with it a sense of cautious optimism. The pandemic may be far from over, but the UK vaccination programme continues apace, delivering a level of confidence for many and helping society to continue its tentative steps towards reopening.

Whether this involves a return to the office, socialising with family and friends again or even attending larger events, it's fair to say that after many weeks in lockdown, much of the population will be excited about the months ahead. But we also know that for those who live with the long-term effects of brain injury, things aren't quite so simple.

Action for Brain Injury Week (ABI Week) began on 17 May with the launch of a campaign to raise awareness of the social isolation that many people experience as a result of brain injury. *A life of lockdown?* highlights the challenges that brain injury survivors and their carers face in everyday life, at a time when public understanding of the impact of isolation on mental health has perhaps never been higher. From page 10, we highlight a range of personal stories and experiences of people whose lives have been changed by brain injury. We explore the issue further with an expert view on the issue of social isolation, followed by tips and ideas on how to cope.

It is important to add that anyone affected by isolation should not suffer in silence, and Headway is here to help. You can find out how we can support you at [headway.org.uk/supporting-you](http://headway.org.uk/supporting-you), and you can contact our helpline on 0808 800 2244 or [helpline@headway.org.uk](mailto:helpline@headway.org.uk) to talk things through.

As always, ABI Week provides an opportunity to recognise the incredible work of Headway groups and

branches. Their continued support has been a lifeline for many since the pandemic began, connecting brain injury survivors and carers and helping to reduce their feelings of isolation.

From virtual tea parties and fun-filled activities to webinars and workshops on the theme of isolation, Headway groups and branches were particularly active during ABI Week. You can read about what went on across the UK on pages 14 and 15.

Also in this issue, we highlight our exciting partnership with the Department for Work and Pensions which has led to a recognition of the Headway Brain Injury Identity Card by JobCentre Plus staff. We hope that this will make life easier for the many brain injury survivors who are claiming essential benefits, helping to ease the application process and avoid potential sanctions due to a lack of recognition or understanding of their condition.

We continue the *Inside your incredible brain* feature with an in-depth look at the role of the brainstem, and conclude with a powerful poem on the theme of isolation by the Headway Glasgow Writing Group.

We hope you enjoy this issue of Headway News and we wish you a safe and happy summer.

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](http://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](mailto:headway.org.uk/tick-yes)

## Essential contacts

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0115 924 0800

[enquiries@headway.org.uk](mailto:enquiries@headway.org.uk)

### Nurse-led freephone helpline:

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[helpline@headway.org.uk](mailto:helpline@headway.org.uk)

### Website:

[www.headway.org.uk](http://www.headway.org.uk)

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# Your views

With the Covid-19 lockdown measures easing, people are once again returning to some sort of 'normality', whatever that may be. But for many people with brain injury, the struggle to get back into the routines and pressures of society is a familiar and difficult challenge that they have long faced as a result of their injury.

We asked our online communities how they feel about re-emerging into society...

The one thing I find that helps with my brain injury is routine. Any change to that takes a few weeks to adapt to. I would imagine when the commute to work starts again and I go back to working in an open plan office with colleagues, I'll find it particularly draining. However, talking with colleagues they're all worried about this change for themselves too.

Elizabeth Moxey

More anxiety I think. I recently found Headway, had a tumour removed from my left frontal lobe, fatigue is a big issue and social skills. The one thing I miss though is going for a cuppa.

Rob Steele

I think managing is our best attribute! We have survived this long fellow head injured people. Who is to say we cannot do this!

Emma Chivers

I feel safe at home if I'm honest, apprehensive about going back to "normal". My stress level will certainly increase a fair amount initially.

Phil Cunliffe

Definitely apprehensive. In the past 12 months, I've only been into shops a few times and that was our local supermarket, so I've become a bit 'institutionalised' and suspect it will take a while to build up confidence.

Andy Anstruther

A tad anxious if I'm honest, I use my local shop with confidence as I know them and they know me, but I am fretting as I know I've regressed in the way I cope in a town or supermarket. With so many more rules to stick to when out it is daunting. But I also know I will relearn with good support from friends and family, I will wait for the initial rush of shoppers to be over, and I will use my Brain Injury Identity Card if I feel I need to.

Kathryn Caddy

Visit our website at [headway.org.uk/about-brain-injury](https://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](mailto:helpline@headway.org.uk)



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## Go green!

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



# Latest news round-up

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

## Brain injury survivors call on government to provide specialist benefit assessors

Brain injury survivors and their carers have met with the Minister for Disabled People, Work and Health, Justin Tomlinson MP, to share their experiences of navigating the benefits system.

Building on Headway's *Right First Time* campaign, the Minister had the chance to hear the views of brain injury survivors on what changes they would like to see in the benefits system.

Survivor Marco Gambi told the Minister: "My experience is that there are various mental and physical issues that are either disregarded or misunderstood in assessments.

*"I find assessments can be degrading, especially when assessors can make you feel like you're not being taken seriously."*

Dee Blackwell, mum to brain injury survivor Gareth, wants more understanding.

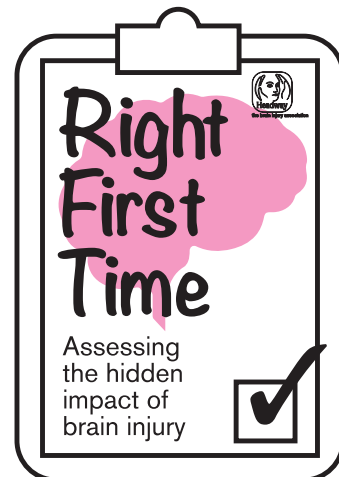
She said:

"Every time I support Gareth at an assessment it appears that assessors don't know much at all about brain injury.

*"Worrying about not being understood or believed only adds to the anxiety of what is already a very stressful situation."*

We hope that the feedback provided at the meeting will be reflected in the government's upcoming National Strategy for Disabled People, which is due to be published soon.

Headway has committed to meet with the Department for Work and Pensions again in the coming months to further contribute to their consultation activities.



## Department for Work and Pensions to recognise Headway ID card

Following the announcement of a partnership between Headway and the Department for Work and Pensions (DWP), Jobcentre Plus staff in England, Scotland and Wales will now recognise the Headway Brain Injury Identity Card when supporting vulnerable clients.

Read more on page 26...

## VOLUNTEERS: - WE NEED YOU!

Our charity shops have re-opened their doors to a roaring trade, but we urgently need volunteers to help us stay open and provide our customers with the excellent service they expect from Headway.

We have shops across the Midlands and North West of England, and we'd love to welcome you to the team!

Interested? Visit [headway.org.uk/donate/volunteer/](http://headway.org.uk/donate/volunteer/) to find out more.



*"The Headway family welcomed me with open arms, I asked so many questions because I wanted to help with everything possible."*  
- Abbie Hutsby





# Headway ambassadors give concussion evidence to DCMS Select Committee

MPs have heard compelling and moving evidence from Headway ambassadors Eleanor Furneaux and Monica Petrosino on the issue of concussion in sport, as part of an inquiry run by the Digital, Culture, Media and Sport (DCMS) Select Committee.



Eleanor Furneaux shares her experience at the DCMS inquiry

Eleanor represented Team GB in bobsleigh before retiring at the age of 24 following concussion, while Monica was a Team GB ice hockey player before suffering a similar injury and retiring at the same age.

Their evidence followed Headway's contribution to the inquiry during the first hearing on 9 March.

Eleanor had been competing in Germany when she sustained two knocks to the

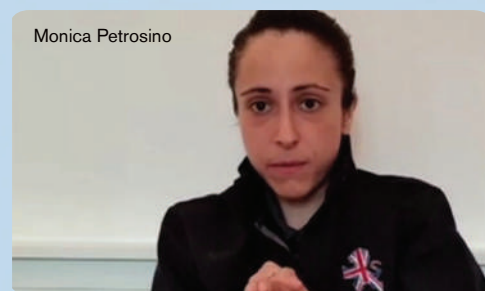
head in three days. The first resulted in her helmet being cracked, but rather than having it replaced by Team GB, Eleanor simply spent the evening sanding it down to buff out the crack.

*"I spoke with my coaches, who were obviously aware of the knock but said they would give me the benefit of the doubt. I knew I needed to train in order to be in the best position for the race on the Friday."*

"I felt fine by Friday. I got halfway down the course with a lot of speed – more than I was used to – and ended up skidding out of control. My head then hit the ice and everything went black. I can't really remember the rest."

The session ended with the committee asking Eleanor and Monica if they fear for their futures on the back of greater understanding and research linking concussion with long-term neurological conditions.

"I do," said Eleanor. "I don't like to think about it because in my opinion the damage is already done."

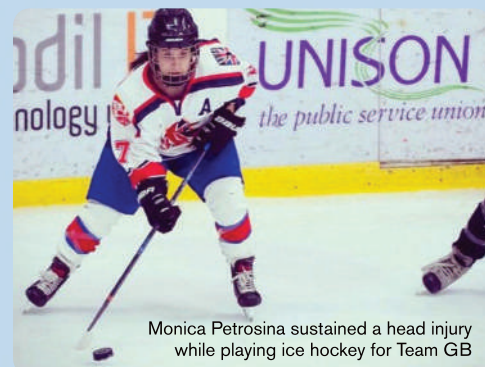


Monica Petrosino

In a moving conclusion, Monica provided a deeply personal insight into her own health developments.

"Very recently, I got admitted to hospital due to some left-sided weakness and loss of continence. I've been referred to neurology in order to test for multiple sclerosis.

"It was the biggest shock of my life when they said to me 'have you ever hit your head at any point? Have you ever had a traumatic injury?', and I obviously spoke about my concussion."



Monica Petrosino sustained a head injury while playing ice hockey for Team GB



# GRAND GESTURE FROM JOCKEY'S FAMILY

The family and friends of Liam Treadwell, who rode 100/1 shot Mon Mome to victory in the 2009 Grand National, have been praised for raising funds and concussion awareness in the jockey's memory.

Liam sadly passed away in June 2020, but his legacy as a jockey and campaigner lives on – enhanced by the efforts of his family who raised more than £6,000 for Headway in the build-up to this year's race.

Dozens of people joined together to walk, run, cycle or horse ride for four miles and 2.5 furlongs – the distance of the Grand National – in order to raise the money.

Over the course of his career, Liam – like many jockeys – suffered some falls resulting in concussions, including one serious head injury that kept him out of the saddle for six months.

He bravely chose to speak out about his experiences of living with brain injury in the hope that the sport and his fellow jockeys take no chances with concussion.

"Liam's iconic victory in the 2009 Grand National is something we will always remember," said Liam's brother, Nathan.

*"As a family, we are tremendously proud of Liam the jockey, but we're equally proud of his determination to improve concussion awareness."*

"Liam's passing left us all absolutely devastated. Life will never be the same without Liam, but we want to do all we can to honour his memory and continue his work.

*"We are incredibly grateful to everyone who took part in the event or sponsored those who did. We smashed our target and we're already thinking about how we can make next year's event bigger and better."*

Peter McCabe, Chief Executive of Headway, said: "Liam's winning ride on Mon Mome will forever be remembered and I'm sure this year's Grand National Day will have evoked some powerful memories for those who knew and loved him.

"We are very touched that Liam's family and friends have chosen to support Headway in his memory."





# Sue Kyle

1955-2021

Headway is mourning the loss of one of its most passionate campaigners.



Sue Kyle, who was named Volunteer of the Year in the Headway Annual Awards in 2018, passed away on 22 April after a three-year battle with lung cancer.

Sue was born prematurely with asthma and soon developed epilepsy. In 2007, Sue underwent brain surgery to help reduce the seizures, but she was left with lasting effects of brain injury including short term memory loss and fluctuating emotions.

She also developed chronic obstructive pulmonary disease (COPD), the name for a group of lung conditions that cause breathing difficulties.

But none of her health issues limited her zest for life or consideration for other people.

Having benefitted from the support of Headway Hull and East Riding, Sue and her husband John devoted their lives to raising awareness of the charity and the support available.

Sue and John raised thousands of pounds for the charity by obtaining raffle prizes from shops and businesses across Hull and the surrounding areas, with Sue never one to accept a 'no' from any potential donor.

She never forgot to thank them, presenting each donor with a certificate showing how much they had helped raise and contact details for the local branch. They always responded by inviting her back, saying "any time Sue" – an offer she didn't refuse!

Sue's wit and relentlessly upbeat attitude touched Headway service users, staff and volunteers not just in Hull but across the country – as reflected by the standing ovation given to her by 400 guests when she was announced the winner of the Volunteer of the Year award in 2018.

Sue will be greatly missed but remembered with a smile by all those who knew and loved her. We offer our support to her husband John at this time.



Sue with her husband, John.  
Photo by  
Richard Addison,  
Hull Daily Mail

# A LIFE OF LOCKDOWN?



Covid-19 has been tough on everyone. Repeated lockdowns have left people isolated and lonely, with a well-documented negative impact on mental wellbeing.

But what if you experienced isolation every day? What if brain injury had robbed you of the confidence to engage with society, while the family, friends and networks you relied on for support drifted away?

This is the reality for many brain injury survivors and their loved ones. People like Belinda Medlock, who sustained a stroke at the age of 47 which left her with ongoing cognitive issues and chronic fatigue.

"Throughout the Covid-19 pandemic, there has been a lot of awareness raised about the negative effects of isolation and the damage it can do to a person's mental health and wellbeing," said Belinda.

*"Unfortunately for brain injury survivors like me, isolation is very common and is often long-term due to the ongoing effects of the injury and a lack of understanding in how to support them."*

Our *A life of lockdown?* campaign, which was launched during this year's Action for Brain Injury Week, aims to give a voice to those affected by brain injury and raise awareness of this all-too-common impact of brain injury, with the simple message of 'Reach out to help out'.

The campaign offers a range of information to help explain why the often invisible effects of brain injury can lead to isolation, while offering simple guides and tips to help brain injury survivors overcome these feelings – encouraging friends, family and colleagues to offer support whenever they can.

Headway Chief Executive Peter McCabe said: "The Covid-19 pandemic has brought the effects of isolation into sharp focus, but this is an issue that brain injury survivors and their loved ones can face on a daily basis as a result of their condition.

"The complex effects of a brain injury can cause profound changes to a survivor's personality, emotional control and behaviour, as well as their cognitive ability, causing significant barriers to them fully engaging with society.



Belinda Medlock

*"In addition to this, many carers and close family members can feel isolated as the pressures of caring make it more difficult for them to communicate or interact with friends and family, often leading to their own social and support networks drifting away."*

"Through services like our local groups and branches, the UK-wide helpline, award-winning information and the Brain Injury Identity Card, Headway is committed to providing people with the support they need to live lives that are as full and independent as possible.

"Through the *A life of lockdown?* campaign, we hope to champion the cause of those affected by brain injury at a time when awareness of isolation has never been greater, calling for people to understand the effects of brain injury and reach out to help out."

Because of its very nature, the true extent of isolation among the brain injury community is unknown but it is an issue that is commonly encountered by those who turn to Headway for help. In a recent poll of our online communities, 81% told us that they had experienced isolation as a result of their brain injury.





## *‘Lack of understanding’*

For Belinda, helping those around her to understand the effects of her injury was a turning point which allowed them to see the reasons for her isolation and be there to support her.



She said: “It was the lack of understanding that I found most difficult. For a long time, I think people thought I isolated myself due to anxiety.

“But as time has gone by, people understand that it’s the effects of my brain injury that restrict me, such as my cognitive functioning and sensory overload.

“I would say to anyone who is isolated after a brain injury to talk to friends and family and explain why it is that you feel isolated. Read other people’s experiences, I’ve found that there are always others out there who are experiencing the same as you are.

*“As we emerge from lockdown, isolation for many survivors will continue. It’s more important than ever to be aware of the implications that come with a brain injury and that we find the right support. I’m hopeful that some good will come from this and that more support will be given.”*

**You can find out more about *A life of lockdown?* at [headway.org.uk/isolation](https://www.headway.org.uk/isolation).**

Read on for more information on the campaign, including top tips to help cope with isolation, stories from brain injury survivors and a look at Action for Brain Injury Week across the UK.



# DON'T LEAVE ME BEHIND

## Perspectives on social isolation

By Dr Simon Fleminger, Consultant  
Neuropsychiatrist.

Alice is in the bar with her friends for the first time since her brain injury. But she finds she cannot keep up with the conversation, think of anything to say or remember the name of who she is talking to. She refuses an offer of a glass of wine and has to go home early because she gets tired so quickly.

Within a few weeks she either avoids going to the bar because it makes her too anxious, or she is no longer being invited. Like many after a brain injury, she gradually loses her social network and becomes socially isolated. Even when she is in company, she feels lonely.

Being socially isolated or feeling lonely is bad for one's health. In the elderly, being socially isolated is as bad for physical health as smoking or being obese. The psychological and emotional impact is even worse. Social isolation makes people depressed and anxious, is associated with drink and drug abuse, and puts people at risk of suicide.

And there are lots of reasons why people become socially isolated after a brain injury. Perhaps they have lost their job and the social life that went with it. Activities such as sport, which help maintain social networks, may be limited by poor mobility or eyesight, or simply insufficient money. Friends and peers may have moved on with their lives, leaving the brain injured person behind.

In some brain injury survivors, changes in behaviour make them less inclined to take part in social activities. They may be self-conscious because of scars, a limp or slurred speech. Anxiety or

depression, aggravated by low self-esteem and feelings of worthlessness may make them avoid meeting people, or mean they have no interest in doing so.

For others, the problem is that friends are less inclined to keep in contact. The survivor is now too irritable, makes inappropriate comments or swears too readily. They may simply no longer be fun to be with.

Often friends and family think that all is OK, when in fact it is not. They don't make contact, not because they don't want to, but because they are not sure they are wanted. Sometimes things only improve after the survivor asks for help.

## So how can we help those who have become socially isolated after a brain injury?

First by understanding what the problem is. For many survivors the most difficult thing, as in Alice's case, is social conversation; so activities such as outings and visits, or watching a film or cooking a meal, are likely to be easier than, for example, a meeting in the pub. Group activities such as art classes or working in a workshop, allow gentle social interactions without big demands on conversational skills. Social services and organisations such as Headway have a part to play.

But for all of us, don't forget that social isolation and loneliness are common after a brain injury and may be difficult to spot. Be proactive, not reactive. Don't wait for the phone call, but instead write or phone or go round, and ask "What would you like to do, what can I do to help?"

Let someone know they're not alone.

## Reach out to help out.

Dr Simon Fleminger





"As lockdown measures begin to ease, I think everyone will struggle to return to the new 'normal'. Even those without a pre-existing brain injury will struggle to get out of bed in the morning.

They may understand more of what those of us with a brain injury go through each and every day. My advice is to empathise with others and be grateful for the small things!"

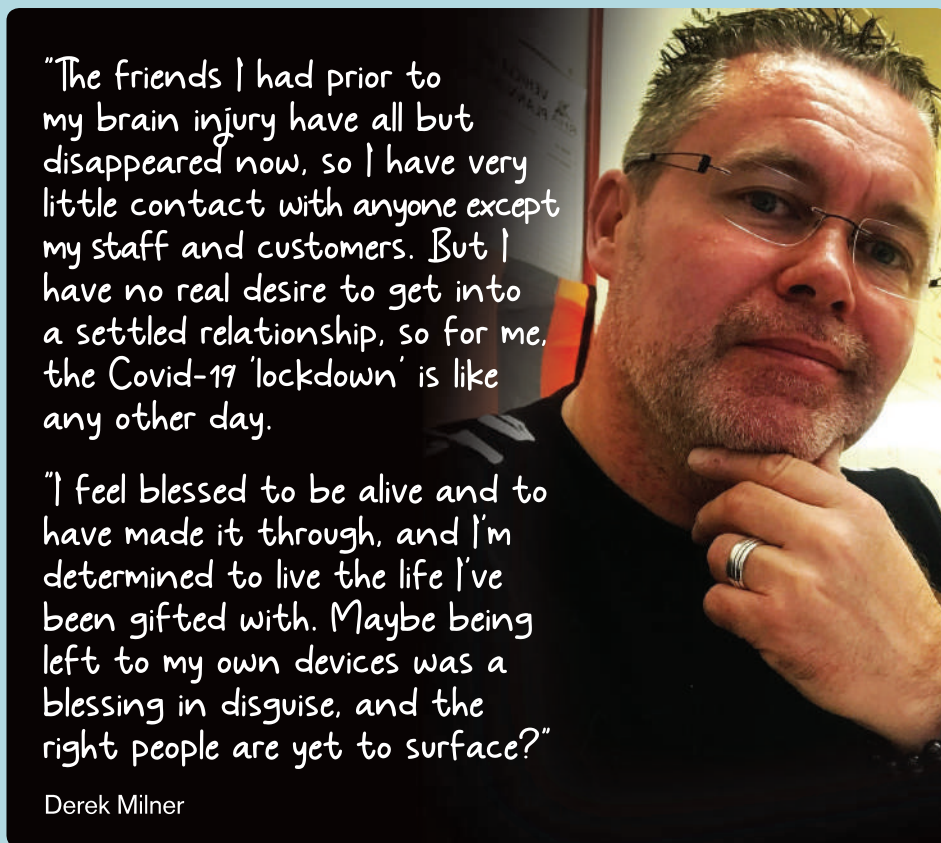
Elizabeth Wilkins



"The friends I had prior to my brain injury have all but disappeared now, so I have very little contact with anyone except my staff and customers. But I have no real desire to get into a settled relationship, so for me, the Covid-19 'lockdown' is like any other day.

"I feel blessed to be alive and to have made it through, and I'm determined to live the life I've been gifted with. Maybe being left to my own devices was a blessing in disguise, and the right people are yet to surface?"

Derek Milner



*"The lockdowns have been tough on us all, but having a brain injury can leave you feeling like this a lot of the time. If one thing can be taken from all our experiences it is that you never know what someone is going through, so please be compassionate and understanding.*

*"Connecting with nature is a great way to feel less isolated. On my daily walks I often stop just to listen to bird song and practice mindfulness, living in the moment and appreciating the things I have around me."*

Melanie Connell







But lockdown didn't stop groups and branches from being as busy and active as ever, and ABI Week was no exception!

From fun-filled activities to serious discussions, we take a look at some of the ways ABI Week was marked across the country.

### **Celebrating the community spirit**

Lockdown has been difficult for so many people, but the sense of community spirit and genuine care that has shined through the darkness and kept services running was celebrated by many groups and branches through ABI Week.

Headway Somerset recognised and thanked their volunteers through a touching social media post, while Headway East Lothian celebrated the innovation, creativity and funding that kept their services going, as well as the local partnership they formed with Age Scotland and their local arts and crafts centre through lockdown.

Headway Dundee and Angus also teamed up with composer Matilda Brown, the Royal Scottish National Orchestra and Tayside Health Arts Trust (THAT) to create a moving film showing the story of a train travelling around the world following lockdown.

### **Raising awareness**

ABI Week is always a time to shine a spotlight on the challenges of brain injury, but this year the campaign gave survivors a chance to raise awareness with others who have now experienced issues of isolation through lockdown.

Headway Swindon cleverly used the concept of 'lockdown' and saw

service users writing their feelings and thoughts on padlocks to give a powerful visual representation of how they felt. Headway Bath relaunched their social media channels and used them to raise awareness online.

Meanwhile, Headway Hertfordshire saw local press and radio success when they shared the story of Sarah from Potters Bar, who sustained a brain injury in 2018. Sarah experienced loneliness and depression following her return home, but with the support and advice of the group, has learned new computer skills that help her to connect with others and feel less isolated.



### **Virtual afternoon teas**

Teacups and saucers were in hands for service users and staff at Northern Ireland Headway, who hosted a virtual afternoon tea complete with music, comedy, drama and even a mocktail making session! Service users shared feelings and experiences of lockdown through song, drama and discussion.

Headway East Lothian also delivered afternoon teas to members across the county ahead of their Hats for Headway Day online picnic, which welcomed new friends, featured a movie quiz, and finished with a prize draw.

### **Looking back and looking ahead...**

Headway East London, Headway Birmingham and Solihull and Headway Bath took ABI Week as an opportunity to reflect on the challenges of the past

# **ABI WEEK ACROSS THE UK**

## **A life of lockdown?**

Since the nation first entered lockdown in March 2020, Headway groups and branches across the UK have had to think of creative ways to continue supporting their members who, as a result of their injury and compounded by lockdown, may have faced increasing levels of social isolation.



year, while also thinking about the positive aspects of lockdown such as living a slower pace of life and communities coming together. Considering these experiences, they discussed future plans as we emerge out of lockdown with Headway East London creating a 'Manifesto for the future'.

Members at Headway Birmingham and Solihull thought about the new skills they could learn in the future. They were encouraged to try their hand at something new, which was enjoyed by all and led to some hidden talents being discovered!

Leicestershire, Leicester and Rutland Headway celebrated the one-year anniversary of their digital day centre with a very special party, including reflections on the last year, poetry and a special lockdown quiz.



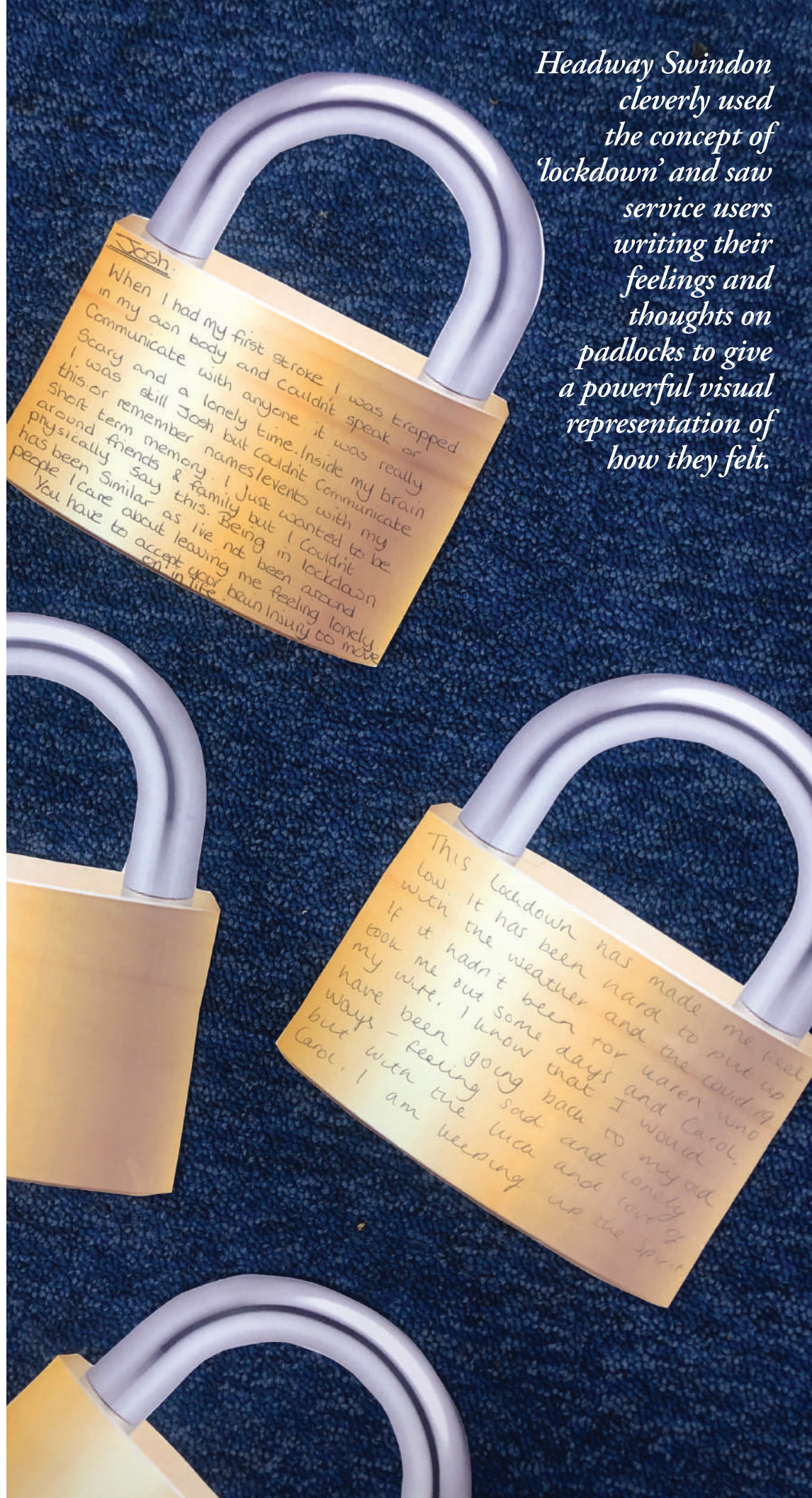
Headway Birmingham and Solihull client Steve Lynch decided to express his gratitude to staff at the group with a hand-made thank you card

## Webinar on social isolation after brain injury

Groups and branches were invited to attend a webinar with Consultant Clinical Neuropsychologist Dr Giles Yeates talking about isolation through lockdown following brain injury.

There were almost 70 people in attendance and the hour-long session became an open discussion session in which survivors, members and staff discussed their experiences and feelings through lockdown. The webinar is available to watch on Headway's YouTube channel.

*Headway Swindon cleverly used the concept of 'lockdown' and saw service users writing their feelings and thoughts on padlocks to give a powerful visual representation of how they felt.*







# HOW TO MANAGE ISOLATION

We've put together a list of top tips to help you cope with and overcome the challenges of isolation, suggested by brain injury survivors and experts in the field.



# TOP TIPS FOR BRAIN INJURY SURVIVORS

Remember that different things will work for different people, so don't be afraid to experiment! Try a few of the tips, adjust them to suit you and keep track of your feelings to help build your plan for managing isolation.

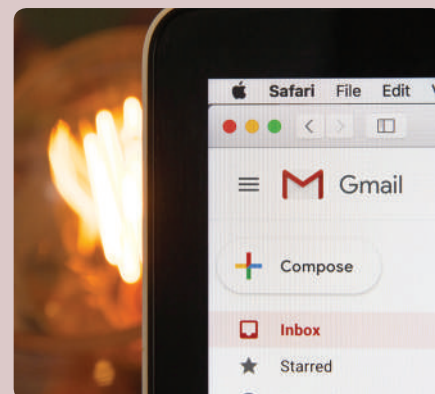
## COMMUNICATE

- Try to explain the impact of your injury to friends, family and colleagues. Tell them how it makes you feel and how they can support you. Use Headway's information to help.
- Find new ways to socialise, as government guidelines allow. Try online chats via Zoom if you can't leave home, a walk with a friend in a quiet park if you struggle with noise, or a catch-up in a familiar location if you have difficulty with planning routes.
- Join online communities of like-minded people, such as [healthunlocked.com/headway](https://healthunlocked.com/headway), to help you share experiences and thoughts with others who understand.
- Contact your local Headway group or branch to find out how they can support you in your area, whether it's via their outreach teams, in a day centre or through remote meetings.

- Find a method of communication that works for you. If you are no longer comfortable with or able to talk on the telephone, why not send an email or write a letter to a friend instead?
- If you are thinking of someone and missing them, reach out to them. It might be that they miss you too, so send them a quick message to say hello.
- The Headway Brain Injury Identity Card helps explain the effects of your brain injury and get the support you need. Visit [headway.org.uk/idcard](https://headway.org.uk/idcard) to find out more.

## FIND THINGS TO DO

- If you are isolated at home, make a list of things you want to do and the goals you want to reach, big or small, to give your days structure and purpose.
- Get outside if you can - fresh air is good for mental health, and small day-to-day interactions such as saying hello to people who pass by can help you to feel less isolated.
- Consider volunteering, which can be very rewarding, allowing you to develop skills while meeting people who share your interests.



## FOCUS ON THE LITTLE THINGS

- Try to take time out to appreciate small things, especially in nature, such as watching the clouds in the sky.
- Remember that recovery after brain injury takes time and any improvements, even if they are small, are worth celebrating.
- Try mindfulness - a technique that allows you to focus on how you are feeling in the present moment rather than being distracted by things around you or unhelpful thoughts.

## SEEK PROFESSIONAL SUPPORT

If your isolation is causing you to experience negative emotions such as depression or anxiety, talk to your GP.

They may be able to refer you to specialist services such as counselling,

psychotherapy, cognitive behavioural therapy (CBT) or a neuropsychologist.

You can also contact the Headway helpline on **0808 800 2244** or **[helpline@headway.org.uk](mailto:helpline@headway.org.uk)** to talk through your feelings and get guidance on further support if you need it.



# HATS FOR HEADWAY DAY

Judging the best hat competition gets more difficult every year – how do we choose one standout entry from so many wonderful, creative and often wacky hats?!

But we must choose a winner, and this year the prize goes to Headway Coventry and Warwickshire member and former Headway Achiever of the Year, Nat Parr.



In creating her handmade hat, Nat was inspired by her time in the garden during lockdown. She said:

*“My hat is called ‘Shielded by Nature’ because I feel I have been shielded by the nature in my garden.*

*“I have painted the mouse because there’s a little mouse I’ve seen. I made the blue tit by needle felting and made the hat.”*

Nat wins a Facebook Portal to help her keep in touch with friends and family even when they can’t meet face-to-face.



Meanwhile, the best group photo award goes to Potter Rees Dolan for their fantastic effort which combines some fine headgear from the team, their families and even their pets!

A HUGE thank you to everyone who supported Hats for Headway this year.

You can browse the entries by searching #HatsForHeadway on Twitter, Instagram and Facebook.

## BEST GROUP PHOTO



Best group photo - the team, family and pets from Potter Rees Dolan



Hats for Headway Day is kindly sponsored by



# RECORD BREAKERS

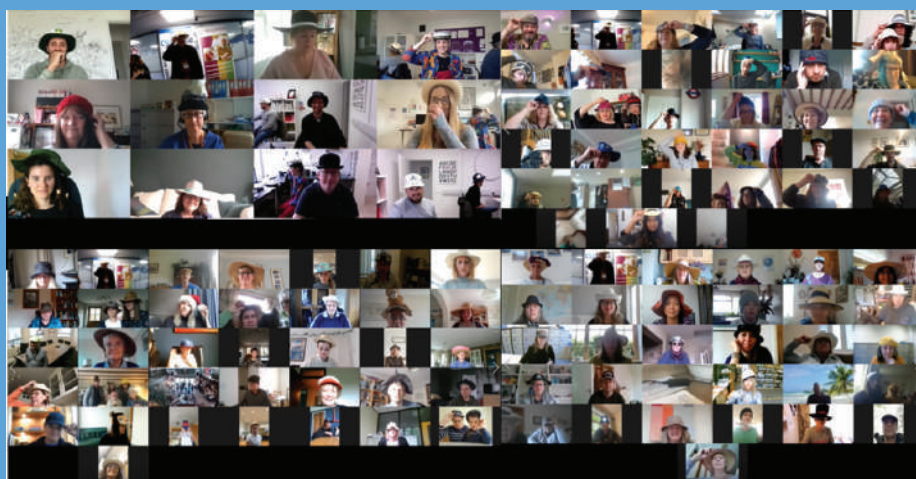
On Hats for Headway Day, Headway Norfolk and Waveney brought together 120 supporters and staff from around the globe in their epic attempt to break the world record for most hats thrown simultaneously online!

Faye Anderson, Communications Officer at Headway Norfolk and Waveney, said:

"Normally, we ask people to wear bright, silly hats for the day, but this year we wanted to go a step further.

"Seeing everyone throw their hats in the air simultaneously was incredibly uplifting and a great way to mark the end of Hats for Headway Day, while spreading an important message."

The group has sent the evidence to Guinness World Records and we'll find out soon if the attempt has been successful!



Some wonderful colourful headgear on display from the team at Headway's Alcester shop





# Stepping into spring for Headway

The devotion of our corporate supporters never ceases to amaze us, and this year we were lucky enough to have staff from the offices of Irwin Mitchell Solicitors across the UK taking on an epic challenge for Headway. Ahead of the spring equinox, the team set themselves a target of walking 2,222,222 steps between them, while raising £2,222 for charity.

We spoke to Lynne Carrick-Leary, Business Development Manager at Irwin Mitchell LLP, to find out more...

## Why did you decide to support Headway?

"Irwin Mitchell has had a long-standing relationship with Headway, and in my 14 years with the company I have seen first-hand the work they do both nationally and in local acquired brain injury communities.

"With the pandemic, we all realised that the charity sector will be hit very hard and

wanted to continue to support Headway in whatever way we could."



Kirstin Hill and Louise Gavan recruit a canine fundraiser

## How did you come up with the idea for the challenge?

"I'm a devout walker, and after taking on the Great Wall of China with a colleague in 2016 for Headway, I wanted to do a challenge that anyone in the firm could participate in locally, within the current pandemic guidelines.

"As we were all getting winter-fatigued, the joy of 'stepping into spring' was the obvious choice."



The team had to cope with some wild weather to reach their target

## What were the benefits of taking on a virtual challenge as a team?

"We have a fierce but friendly competitive attitude between our offices! As we could not see our colleagues face-to-face, such a challenge inevitably brought us closer together as we have shared our progress across a group chat.

"It's been a lovely feeling to see so many enthusiastic colleagues wanting to walk and be so proactive in their fundraising."

## How much have you raised and how great does that make you all feel?

"I am so impressed with my colleagues, who collectively walked 59,633,964 steps, which equates to 23,854 miles, with one team member achieving 915,000 steps!

"We finished with over £6,500, which of course we are delighted with!

"Not only have we surpassed our fundraising and steps challenge, but I have been so proud of the team's commitment and dedication to the cause, especially in the current times."

If your company would like to take on a fundraising challenge for Headway, contact us on [partnerships@headway.org.uk](mailto:partnerships@headway.org.uk) for advice and support.



Lynne Carrick-Leary battles through the mud



# ESCAPE THE WILD FOR HEADWAY

Thursday 30th Sept – Friday 1st Oct 2021  
Ullswater, Lake District



Headway brings you a brand-new corporate adventure for 2021! Are you ready to put your teamwork to the test and take on exhilarating challenges for a great cause?

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

Registration £50 per person

Individuals welcome

Minimum sponsorship: £300 per person

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

Contact us on [partnerships@headway.org.uk](mailto:partnerships@headway.org.uk) or 0115 924 0800 for further details.

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wellbeing  
walks



HIKE FOR  
HEADWAY

# OUR RUN FOR JAMIE

Zoe Rainaki and her sister Jodi Atkinson became true Headway Heroes when they took on the 2021 Royal Parks Half Marathon to raise vital funds for the charity.

In August 2020, at the age of 46, their brother Jamie experienced a sub-arachnoid haemorrhage (SAH), with serious complications including further bleeds and a Covid-19 infection. The family turned to Headway for a listening ear and support during this enormously difficult time, and received a grant from the charity's Emergency Fund to help them financially.

With the ongoing pandemic meaning they were unable to visit Jamie in hospital, the determined sisters decided to take on a fresh challenge...

"We had never run before, so once we signed up we downloaded the Couch to 5k app and then thought 'what have we done?!'", said Zoe.

"We soon focused all our thoughts into our training. It made us feel like we were doing something for Jamie. Emotions were high at this point.

*"On the morning of the marathon we were feeling excited wearing the vest top with the Headway logo and our brother's name on the back of it. It was the day we had focused on and hoped that Jamie would be out of hospital to see us run."*



"At times we did struggle, but we had our goal in sight and no matter what, we were going to finish.

"Our brother and family were waiting for us at the finish line, and seeing Jamie there made it all worthwhile.

*"When we signed up for this marathon I never knew that my brother would be living with me and would need 24-hour, one-to-one care, so I didn't manage to get out running for three weeks prior to the marathon. Instead I was caring around the clock for Jamie."*

"My mum asked us to postpone the run until next year, but this was never going to happen - we were determined to run this marathon.

"We feel very proud of our achievement and we have raised £2,884.50 for Headway. I would encourage anyone to never give up hope and to always believe you can do anything if you put your mind to it."



Jodi and Zoe proudly wear their Headway running vests



Jamie

## PUT ON YOUR RUNNING SHOES! ...and improve life after brain injury.

Running is a wonderful activity for those who are able, boosting fitness like nothing else while helping to improve your mood and mental wellbeing. It offers a perfect chance to set a personal challenge while helping to support a cause that you're passionate about.

If you're thinking of taking on a running challenge for Headway this year, you might be wondering how to approach your training for the big day. Here are some top tips to get you started...

### START EARLY

Like the race itself, think of training as a marathon, not a sprint. Start a few months before the race day to give yourself plenty of time to work up to longer runs while coping with any disruptions that life might throw at you.

### START SLOW

Whether you're running 26.2 miles or 5k, don't feel like you need to be running the full distance on day one. Start with what you're comfortable with and gradually increase the distance as the weeks go by – you'll soon be surprising yourself!

### TREAT YOUR FEET

Invest in some good quality running shoes. They don't have to be expensive, and your local sportswear shop should be able to offer advice. Your feet will thank you for it!

### SET REALISTIC GOALS

Set yourself a clear but realistic training plan, outlining your goals for each week as you work up to the race day. To get you started, head to [virginmoneylondonmarathon.com/training/training-plans](http://virginmoneylondonmarathon.com/training/training-plans).

### ADD VARIETY

Running the same route every day can quickly lead to boredom and impact on your motivation levels. Use maps

or speak to friends and family for interesting routes in your area.

### GO EASY ON YOURSELF!

We all have good days and bad days and it's important not to over-train, so don't worry if you find things difficult one day. Listen to your body, slow things down, regroup and try again tomorrow.

### Find out more

You can find lots of information online to help you train for a run – websites like [runnersworld.com](http://runnersworld.com) are packed full of guides and tips to get you in shape for the big day, and you can find a wealth of essential information at [virginmoneylondonmarathon.com/training/training-hub](http://virginmoneylondonmarathon.com/training/training-hub)

Don't forget our Fundraising team is here to help you, every step of the way. Email Rachel on [projects@headway.org.uk](mailto:projects@headway.org.uk) if you need any support.

# “SMELL CREATES AN INCREDIBLY IMPORTANT CONNECTION”

In 2005, Duncan Boak was living and working as a musician in Leeds, a talented 22-year-old guitarist hellbent on developing a career in the music industry and involved in a range of exciting projects.

After a long day in a recording studio and needing to unwind, Duncan joined a group of friends on a night out. As he climbed the steep stairs into a bar, he tripped and fell backwards, hitting his head hard at the bottom.

Duncan was admitted to hospital and remained unconscious for 24-hours, with scans showing bruising to his brain. Despite the severity of his injury, however, he was discharged after just a week.

“I was sent home with a box of paracetamol, a box of codeine and very little else,” said Duncan.

“I stayed with my parents for a fortnight to recuperate, I was very tired and wasn't eating very much. Then I went back to Leeds and tried to carry on as if it was business as usual.

*“I wanted to put it behind me and initially everything seemed to be alright, apart from the fact that I couldn't smell.”*

As the weeks went by Duncan became concerned that there had been serious damage to his brain, however with many changes occurring in his life he did not give much thought to the loss of his sense of smell as a result of the injury.

He said: “I started to become quite depressed. I was still playing my guitar and writing music, but I wasn't eating much and became very thin. I started to have a difficult time with my girlfriend, and she ended our relationship a couple of months after the accident.

“I went to the doctor but was told there's nothing much that can be done about my sense of smell and if it hadn't returned within a year, I would have to learn to live with it.

*“So, a year on I thought ‘nothing has changed, I can't do anything about it, and nobody has heard of this’. I thought I've just got to disengage with it and get on with my life. I did that for the next six years.*

“I was aware that my life and the way I felt about things had changed, and my ability to form the sorts of relationships that I had before the accident had been affected. I didn't seem to have the same

depth of emotional feeling and capability, and I didn't understand why.

“Smell creates an incredibly important and emotionally evocative connection with other people, and if you take that away it creates a distance. It's something I still find challenging.

“In 2011, after another relationship had ended, a friend sent me an article in *The Guardian* with an extract from a book called *Season to Taste* by American chef Molly Birnbaum. I went on to read the entire book and it was an enormous light bulb moment for me.

“I started to learn for the first time about the sense of smell, how it contributes to our lives and the many emotional and quality of life impacts of smell disorders. I realised that I wasn't the only person on the planet with this issue.”

Duncan began researching the sense of smell and techniques that may help, and eventually made contact with Professor Carl Philpott, who had founded the first NHS taste and smell clinic in the previous year. It was at this point that he realised he wanted to use his negative experience to positive effect and fulfil a need that was unmet, so he founded Fifth Sense, the charity for people affected by smell and taste disorders.

“I wanted to create an organisation that would support other people and stop them having the same experience that I did.





"I came up with the name Fifth Sense because smell is often seen as the fifth and least important of the senses, but it's also saying to people that we only have five ways in which we connect with the world around us. They're all equally important, they just work in different ways.

"The people we represent often face a lack of understanding and empathy, including from the healthcare profession. That can result in them not getting the care and attention they need from doctors.

***"The vision of Fifth Sense is to transform society's understanding of the importance of smell and taste, and, through doing so, transform the lives of those affected by smell and taste disorders."***

"I've seen time and time again that if you can have a conversation with someone and get across to them the significant contribution smell makes to our lives,

they're better able to understand the impact of losing it.

Asked what advice he would give to people who find that their sense of smell and taste has been affected by brain injury, Duncan said: "Talk about it and get support. There is an enormous amount of value to be had in connecting with someone who understands, and that's one of the key reasons why Fifth Sense exists, to help people make those connections."

Fifth Sense provides support, advice and information to people affected by smell and taste disorders. Visit [fifthsense.org.uk](http://fifthsense.org.uk) to find out more.

You can also find more information in the Headway factsheet Loss of taste and smell after brain injury, which you can download from [headway.org.uk/information-library](http://headway.org.uk/information-library).



Duncan Boak





# DWP to recognise Headway ID card

Jobcentre Plus staff in Scotland, Wales and England will now recognise the Headway Brain Injury Identity Card when supporting vulnerable clients, following the announcement of a partnership between the charity and the Department for Work and Pensions (DWP).



The partnership was launched during a training call with more than 500 Jobcentre Plus staff in attendance.

Director General for Work and Health Services at the DWP, John Paul Marks, said: "We are committed to understanding more about the conditions affecting the people we support on a day-to-day basis and ensuring they receive the best possible support."

"This is why I am so pleased to be joining Headway to demonstrate our commitment to supporting our vulnerable customers."

"The Brain Injury Identity Card will make a positive difference to the way we support these vulnerable customers. The card will help ensure our staff can identify customers who have a brain injury at the earliest opportunity."

Peter McCabe, Chief Executive of Headway, added: "We are delighted that the DWP has agreed to recognise the Brain Injury Identity Card to help improve identification of survivors and ensure they are treated with compassion and receive appropriate support."

*"Survivors of brain injury face discrimination on a daily basis as a result of the effects of their injury being misunderstood. It is vital that staff working for the DWP have a better awareness of the effects of brain injury and how to support them."*

jobcentreplus





Headway's *Right First Time* campaign indicated that a significant proportion of brain injury survivors were initially refused benefits they were entitled to, but this was subsequently overturned upon mandatory reconsideration or appeal. Many felt this was due to an insufficient understanding of what brain injury is and the effects it can have.

The Headway helpline also regularly receives calls from survivors who have been subjected to benefits sanctions due to missed appointments, for example. However, memory loss is one of the most common effects of brain injury and can result in survivors having difficulty remembering the dates or times of appointments.

Staff in Jobcentres across the country have been provided with information on the ID card and instructions on how to 'pin' this information to customers' records. This will ensure everyone involved in a customer's support is aware of their condition and the support they receive can be tailored appropriately.

## How to apply for a Brain Injury Identity Card

Anyone over the age of 18 with a verifiable brain injury can apply, and the card is provided to successful applicants free of charge. Each card is personalised, helping the card holder to explain the effects of their brain injury and request any support they may need.

To apply for a card or for more information please visit our website at [www.headway.org.uk/idcard](http://www.headway.org.uk/idcard).



# *“Try and see the person, don't be judgemental”*



## Gerald's story

Gerald Heffernan was a professional coach driver, working a busy schedule that involved travelling up and down the country with coachloads of tourists from all around the world.

But a sudden diagnosis of encephalitis put the brakes on Gerald's career, causing him to experience a wide range of symptoms that stopped him from being able to get back behind the wheel.

“I was living a pretty normal life,” said Gerald, recalling his days from before the injury. “I was working full-time, doing a lot of travelling with busy hours. I was quite active, living life to the full.

“I was attending a training session one day and I started getting really nasty headaches. Over the next couple of days, they were getting progressively worse and I was having seizures. Eventually I went into hospital.”

After several tests and scans, Gerald was diagnosed with encephalitis, an inflammation of the brain. It wasn't until he was returning home that the impact of his injury became apparent.

“I remember my father driving me home and I started getting motion sickness. For me as a professional driver that was really odd.”

At home, Gerald also had problems with communication, co-ordinating his movements and walking. He continued having seizures, which prevented him from returning to work.

*“When I realised that because of my seizures I wouldn't be able to drive, my world stopped.”*

“Getting my application in for benefits was difficult. I had to start again due to problems with the login and registering my details. When I met the Work Coach, he hadn't heard of encephalitis. I found it a little patronising; I was explaining about memory issues and he said, ‘oh I forget things, I know what you're going through.’ I said, ‘no, you haven't got a clue.’

“I was put forward for a medical review and wasn't expected to look for work, which was good because it took unnecessary pressure off me. But initially I had applied for ESA, and for whatever reason I was moved onto Universal Credit.”

The process of being forced onto Universal Credit was frustrating for Gerald and he felt bullied by the Work Coach. However, after a while, he no longer needed to go to the Jobcentre or have reviews. Gerald still felt that there was some basic training lacking among Work Coaches and emphasised the importance of treating applicants with dignity and care.

“Try and see the person, don't be judgemental. Lose the stereotypes, lose the judgements, and if you can help them, help them. That person's in a bad place, physically, emotionally and mentally. Help that person, because one day it could be you in that position.”

# Inside your incredible brain

In part two of our journey through the brain, we will be looking at some amazing facts about **the brainstem**.

## Latin name

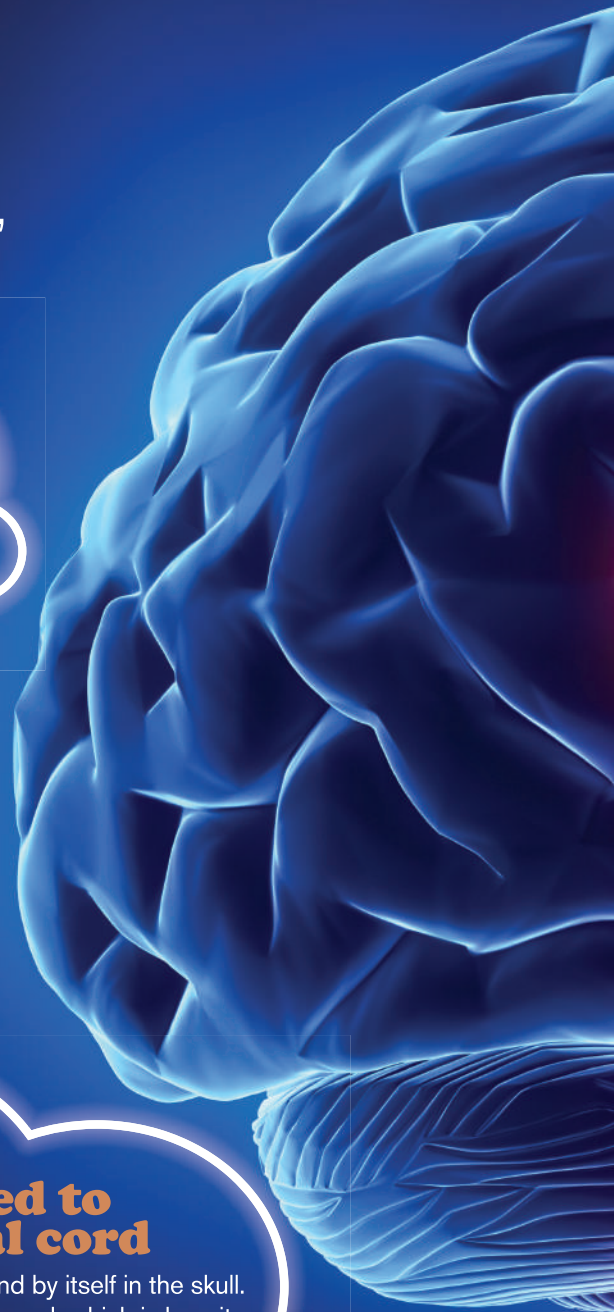
The Latin name for the brainstem is *Truncus encephali*.

## First part to develop

The brainstem is the most basic and primitive part of the brain – this means that it was the first part of the brain to evolve and is the first part to develop when a foetus grows. The brainstem is the area responsible for primitive reflexes in babies and infants such as grasping and rooting.

## Attached to the spinal cord

The brain does not float around by itself in the skull. It is connected to the spinal cord, which is how it receives information from the rest of the body. The part of the brain directly connected to the spinal cord is known as the brainstem.







## Basic functions

Despite being small, the brainstem is responsible for our most basic and vital functions, such as breathing, sleeping, consciousness, movement, and heart rate, among others. As the brainstem is responsible for so many basic functions and is such an important area, injury to it can lead to coma, locked-in syndrome or can even be fatal.

## Connects the brain

The brainstem is the location for pathways connecting different parts of the brain, such as the pons (meaning 'bridge' in Latin), which connects the cortex, the uppermost part of the brain, with the cerebellum, a structure at the back of the brain.

## Structure

The brainstem is made up of four parts called the diencephalon, the pons, midbrain and medulla oblongata.

## Key area for research

Research published in the American journal Science Advances has suggested that the midbrain could be a key area for investigating brain injury in contact sports. The research found reduced white matter (a type of brain tissue) in the midbrain following hits to American football players' heads.

# CREATIVE EXPRESSION

*Fresh Start* is a poem  
by members of the Headway  
Glasgow Writing Group.

It explores the theme of isolation after brain injury, bringing together contributions from members of the group to examine what isolation means to different people - whether due to the Covid-19 pandemic or because of brain injury.

The group has been meeting every Tuesday for a number of years, previously in Headway Glasgow's centre but over Zoom during the pandemic.

Mitchell Robertson, the group's facilitator, said: "Thinking about the theme of isolation, the group gives a strong sense of community. People come in and out of it from week-to-week but no matter who's here, everyone is hugely supportive of each other."

## FRESH START

by Headway Glasgow Writing Group

Ignorance  
Anger  
Out of sorts

After my ABI my memory problems and emotional outbursts  
Made it really difficult to keep friends or make new ones.  
Looking back and today,  
I am grateful of the support of my family who love me  
Because I was not an easy person to know.

Living with an ABI is the quietest.  
Always be true to yourself and keep in touch with friends and family  
And go out for the birds and the animals  
That roam around your garden in search of food.

Lots of noise  
Strangeness  
Too many challenges

After three and half months of recovery from my ABI  
I struggled to come to terms with what had happened to me.  
It was like a grieving process,  
The old me was gone, and in its place was a disabled person  
With a walking stick and a diagnosis of epilepsy.  
I got by with the support of my wife and two daughters.

Since the onset of COVID,  
I really miss not seeing my friends and other family members  
And taking part in things that interest me.  
I miss very much going to Headway  
And the garden project based at Bellahouston Park.

Ignorance in public  
Off the wall  
Not again

It has been difficult to keep in touch with people during lockdown,  
I am glad I learned to use zoom,  
But too many groups a week make me feel tired  
Because it can take up quite a lot of concentration.  
Isolation has never called at my door,

The support of my family help me on my climb,  
There is a new me  
But my family and friends still see me  
Although sometimes I don't.



# Leading Personal Injury and Medical Negligence Lawyers



Boyes Turner is proud to be an active supporter of Headway. Kim Milan, 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.



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or [claimsadvice@boyesturner.com](mailto: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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Jane Goulding "is one of the best and most experienced claimant's solicitors working in this field at present." The Legal 500, 2021

"Freeths are clearly very concerned for the clients' welfare and tenacious in getting the best for them." Chambers & Partners, 2021

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## 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.

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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](mailto: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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