Summer 2019

Headway News

The magazine of Headway - the brain injury association

Football's 'dereliction of duty'

The perils of gambling after brain injury



Headway helpline



confidential support and advice on the effects of brain injury



Available to anyone with a question about brain injury – from survivors and carers to students and professionals

website: www.headway.org.uk email: helpline@headway.org.uk

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.











It's time to wake up to fatigue!

We all know what it's like to feel tired or drained of energy, but the effects of chronic fatigue following brain injury are in another category entirely.

Brain injury survivors have described it as if walking through concrete or feeling like they're living in a constant fog.

Pathological fatigue as a result of brain injury can be completely debilitating, frustrating, and for many truly baffling to understand – even by survivors themselves.

Brain Drain: Wake up to fatigue! is our new campaign that we hope will raise awareness and increase understanding of this hidden effect of brain injury.

Launched as part of this year's Action for Brain Injury Week, the campaign has at its heart the real-life perspectives and experiences of those living with brain injury-related fatigue.

More than 3,000 people took part in a study to find out the extent to which fatigue can impact every aspect of life after brain injury, and our thanks go out to each and every person who gave their time and energy to help us shape this campaign.

The results are certainly eye-catching – but perhaps not surprising. They show that for many people the complex and hidden nature of their

condition is widely misunderstood, which can result in them being treated unfairly.

When a trip to the shops, a meal out with friends, or a walk around the park with your children leaves you so drained of energy that you need to sleep for hours afterwards just to recharge your batteries, it is easy to understand just how much impact fatigue can have on everyday life.

Relationships, your sense of identity, and self-esteem can all take a massive hit. All the plans you might have laid out have to be readjusted, scaled down or abandoned.

The experiences of Lottie, David and Julie on page 20 are just three examples of this. But they also show how coping strategies can help.

Throughout Action for Brain Injury Week we shared many stories of brain injury survivors talking about all the issues surrounding fatigue. Make sure you have a read of them on social media (@HeadwayUK) or on our website.

We urge you to share these stories with your loved ones, with your friends and your employers. Let's make as much noise as possible and hopefully we can help people *Wake up to fatigue!*

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Published quarterly by:

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views...

More than 3,000 people completed our Brain Drain: Wake up to fatigue! survey to help us raise awareness and understanding of this hidden and misunderstood effect of brain injury.

As part of the survey, we asked people to describe their experience of fatigue after brain injury in just one word. Here's what they said:

RESTRICTING

CRIPPLING CHALLENGING FRUSTRATING

ESTROYING

ISOLATING

OVERWHELMING **CONFUSING**

...in this issue













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#HeadwayHeroes

news you may have missed...

Dinah Minton 1930-2019



It is with a great deal of sadness that we announce the recent death of Dinah Minton MBE, wife of Barrington Minton, the husband and wife team who, along with Sir Neville Butterworth, Reg Talbot and Philip Lockhart, founded Headway.

Headway was formed when Dinah and Barry responded to an advert that had been posted in the national newspapers by Sir Neville Butterworth. Dinah and Barry, having experienced firsthand the challenges of post-injury rehabilitation following their son Launce's car accident a few years earlier, were quickly on board.

The couple worked tirelessly, combining their talents to form an incredible team. Barry was the business brains and provided the charity's first offices and significant financial backing, whilst Dinah was the face of the charity, travelling

the length and breadth of the country connecting families in need with support. Headway became Dinah's life.

It was their amazing work for Headway that led to Dinah and Barry almost becoming the first couple to receive a joint MBE. Unfortunately Barry died before the honour could be bestowed, and unable to award the MBE posthumously, Dinah received it herself in 1999.

Barry died in November 1998 but Dinah continued as a trustee of Headway – the brain injury association until she felt her time was better spent supporting the local Nottingham Headway, on whose board she served for many years alongside her daughter, Hannah.

Dinah leaves behind two daughters, Claire and Hannah, and a son, Launce. She will be sadly missed by all who knew and loved her.

We thank the Minton family for these words.

EU announces vehicle safety plans

A raft of new safety measures designed to reduce the number of people killed or seriously injured in road traffic incidents has been proposed by the European Union.

New cars, vans, lorries and buses sold in Europe will be fitted as standard with a range of new vehicle safety features, starting in 2022, according to a provisional EU directive on the legislation.

The Department for Transport said the system would also apply in the UK, regardless of Brexit.

The measures include new crash testing requirements, mandatory installation of driver assistance systems including Automated Emergency Braking (AEB) with pedestrian and cyclist detection, Intelligent Speed Assistance (ISA) and Lane Keep Assistance (LKA), as well as a new direct vision standard for lorries and buses to enable drivers to have a better view of other road users around their vehicle.

Peter McCabe, Chief Executive of Headway, said: "Every day we support people whose lives have been forever changed due to sustaining brain injuries in road traffic incidents, so we welcome any new initiatives that can improve the safety of our roads. "These latest technologies will hopefully save lives and reduce the number of people sustaining brain injuries on our roads each year, particularly if accompanied by appropriate educational campaigns aimed at all road users."



MPs unite in brain injury debate

MPs from across the UK came together ahead of Action for Brain Injury Week to praise the work of Headway and other charities working to support people affected by brain injury.

The debate was called by Chris Bryant MP, who chairs the All-Party Parliamentary Group on Acquired Brain Injury and has championed the cause of brain injury on numerous occasions in Parliament.

Chris, who is the MP for Rhondda, said: "I know that many Members in the Chamber today and others, including



Ministers who are unable to participate in the debate due to their ministerial responsibilities, have also visited Headway groups in their constituencies.

"I have been to the group in Cardiff, which does a magnificent job."

Dewsbury MP Paula Sherriff echoed those thoughts: "I recently visited the Second Chance Headway Centre in Wakefield, which supports people with brain injuries.

"I was struck by the spectrum of conditions that the centre deals with, and by the dedication of its wonderful staff and volunteers.

"I encourage all Members to visit a Headway centre in their constituency."

Former Trustee of Headway Ayrshire Bill Grant, MP for Ayr, Carrick and Cumnock, said: "When someone puts their hand out for help, someone has to grasp it, and in many ways Headway does that.

"I have seen for myself how it is able to benefit my constituents and many throughout the UK in other branches of Headway."

The debate included discussion about the need for more consistent availability of specialist neurorehabilitation across the UK.

In addition, Mitcham and Morden MP Siobhain McDonagh highlighted the post-acute, community-based support and rehabilitation provided by Headway groups and branches.

Siobhain's speech was also featured during a report on the debate on BBC Radio 4.

Siobhain said: "The work being done in our local communities by these groups and branches can be a lifeline to families affected by brain injury, helping people to rebuild their lives and become less dependent on costly state support.

"However, Headway cannot do this alone. Local charities are under incredible pressure. Funding cuts are causing harm to the lives of some of society's most vulnerable people who are being cut out of society due to a lack of access to vital support services.

"Unless action is taken to enable people to access the vital support needed to ensure that these services survive, more and more people will be cut out of society and taxpayers will be left footing the bill for the longer-term care of those without the means to care for themselves."

Headway's Public Affairs Manager Dr Clare Mills said: "On behalf of survivors, families and carers across the country, thank you to Chris Bryant and all the MPs who took part in the debate or sent messages of support, and also to UKABIF for its work in support of the APPG.

"We really appreciate your efforts."

DoLS to be replaced

The new Mental Capacity (Amendment) Act has now been passed, despite the concerns of Headway and numerous other organisations over the speed with which the legislation went through Parliament.

The main effect of the legislation is to scrap Deprivation of Liberty Safeguards (DoLS) and replace them with a new system of Liberty Protection Safeguards, with the change expected to come into force in 2020.

Cases dealt with under DoLS will continue under the old system for up to a year to ensure a managed transition of cases to the Liberty Protection Safeguards system.

Headway is now working with the Ministry of Justice on a Code of Practice, which will set out how the changes to the law are used in care settings.



news you may have missed...

Football's 'dereliction of duty'

Football authorities once again have been heavily criticised for failing to protect players adequately from the dangers of concussion.

A number of high-profile incidents in the past few months have drawn fierce criticism from Headway, with the charity's concerns backed by former professionals and medical experts across the world.

In March, Swiss footballer Fabian Schar was cleared to continue playing in a match against Georgia – just minutes after being knocked unconscious, leading to Headway accusing the Swiss Football Association of a 'dereliction of duty'.

More recently, Tottenham Hotspur defender Jan Vertonghen suffered a clash of heads with a teammate in a Champions League semi-final game against Ajax. After an on-pitch assessment, the player was given the all-clear to continue, but needed to be helped from the pitch just a minute later. Headway's views have been widelyshared across national and international media, with coverage figures in excess of 20 million.

Speaking to Sky Sports News, Peter McCabe, Chief Executive of Headway, said: "The time has come for football to introduce temporary concussion substitutions that would allow for longer off-pitch assessments to be conducted by independent doctors.



"Not every head injury will result in a concussion. But allowing players to continue while showing clear signs of discomfort following a head injury is contrary to the 'if in doubt, sit it out' principle at the something worth discussing." heart of all effective concussion

Encouragingly, FIFA may now finally be ready to make changes.

Speaking to The Times in reaction to Headway's comments, FIFA's medical committee head Michel D'Hooghe said: "Introducing substitutes specifically for concussion is a possibility and



Vote now for your Headway hero!



At Headway, we know the incredible lengths people will go to in order to support others affected by brain injury. We also see the inspirational courage of so many people who are determined to defy their brain injury to achieve great things.

We think these people are very special indeed and deserve to be recognised!

The Headway Annual Awards do just that. Nominations are now open for this year's ceremony, which will also celebrate Headway's 40th anniversary.

Do you know someone who achieved something special this year? Or someone who often goes above and beyond when caring for someone with a brain injury? Perhaps a long-standing Headway volunteer who is overdue public recognition and thanks?



The categories this year are:

- Alex Richardson Achiever of the Year sponsored by Slater & 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

Visit **www.headway.org.uk** to nominate your Headway hero!

The closing date for nominations is Friday 26 July.

The Dorchester Hotel

This year's Headway Annual Awards luncheon will be held at a fabulous new venue, The InterContinental Park Lane in London.

For the past 15 years, the Headway Annual Awards have been held at The Dorchester Hotel.

However, in light of news reports regarding homosexuality laws introduced by the Sultan of Brunei, who owns The Dorchester Hotel, Headway has now ended its association with the hotel.



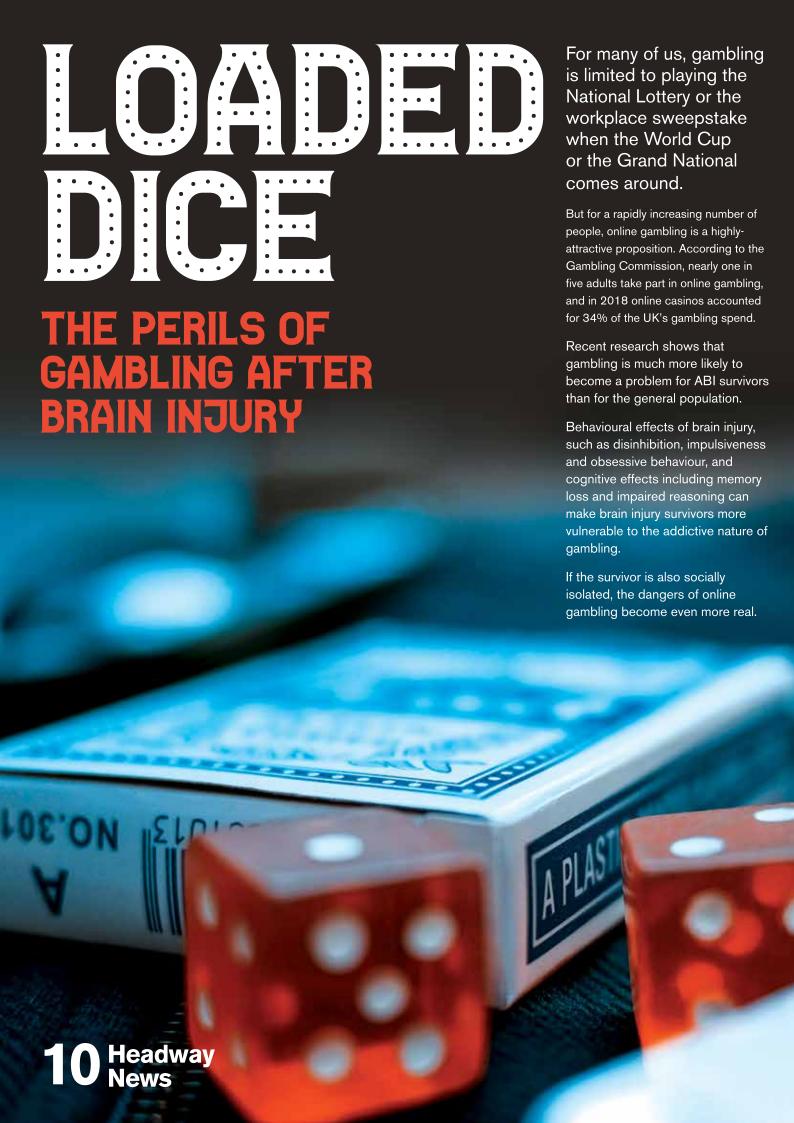
Breakfast time

Headway has featured on BBC Breakfast television news to reiterate its support of the move to enable people with hidden disabilities to apply for Blue Badges.

A Blue Badge entitles the holder to use parking spaces designated for people with disabilities. Many brain injury survivors are left with debilitating fatigue, difficulties processing information, memory problems and other challenges which can make everyday activities like shopping or using health services very difficult.

Speaking on the programme, Headway Chief Executive Peter McCabe said: "People with hidden disabilities need support in many different ways and, for some of them, being able to use a Blue Badge will make a significant improvement to their lives.

"We are very pleased that changes have been put in place to enable brain injury survivors to apply for Blue Badges."



According to GamCare, an independent charity partly funded by betting firms to support problem gamblers, many gamblers report that they get a sense of 'community' from the environment they gamble in.

The organisation states that 'problem gamblers can lose interest in maintaining real personal relationships as their preoccupation with gambling intensifies and they can suffer from social isolation'. When you then add in the complexities and challenges of brain injury, it's easy to see how serious the problem can be.

Finding a community where they can be accepted – without being identified as having a brain injury, or seen as 'different' – can be attractive to an ABI survivor. Online communities can be particularly attractive. It can also be easier to participate in online gambling without the knowledge of family or carers.

Safety nets, such as credit checks, can be bypassed or completely irrelevant if the brain injury survivor has access to significant sums of readily-available cash as a result of a personal injury settlement or criminal injuries compensation payment.

Not everyone with an acquired brain injury will develop a gambling addiction, but it may be useful to be more aware of the risks and the warning signs, to keep yourself and your loved ones safe.



WHAT'S BEING DONE?

Headway has submitted evidence to the All-Party Parliamentary Group (APPG) on Gambling Related Harm to raise awareness of the specific issue of ABI in relation to problem and addictive gambling.

Dr Clare Mills, Public Affairs
Manager, and Luke Griggs, Director
of Communications, recently spoke
at an evidence session which forms
part of the APPG's inquiry into online
gambling, alongside a brain injury
survivor we're calling George.

George bravely spoke to a room full of senior MPs and peers, gambling support organisations, and other witnesses to share his horrendous experiences.

Dr Clare Mills said: "It was a privilege to be able to support George as he spoke so openly about his gambling addiction in a room full of strangers.

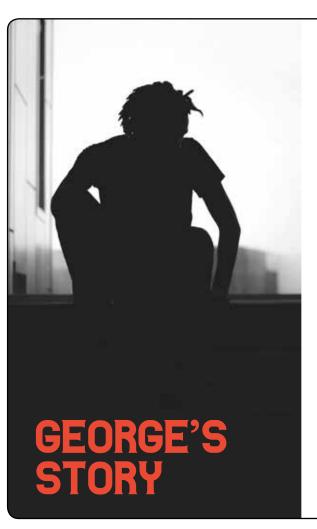
"Research has identified that brain injury survivors are 27% more likely to develop problem gambling or addiction than the general population and that risk is particularly prevalent in people with frontal lobe damage.

"One other witness at the session spoke about his gambling addiction and afterwards told us he had been treated for a brain tumour in his frontal lobe as a teenager, yet this was the first time anyone had suggested to him that there could be a connection.

"The evidence given in the session was harrowing. It cannot be right that someone can register with online casinos as a vulnerable or problem gambler in order to self-exclude themselves and then simply find a way around the system, for example by giving a false date of birth.

"Additionally, serious and urgent questions also need to be asked of the gambling industry to ascertain why no checks are made about the source of funding when a young man in his 20s spends tens of thousands of pounds in a matter of hours.

"The industry must do more to protect vulnerable people from the dangers of gambling and we will continue to speak up about acquired brain injury in Parliament and with organisations who are working to tackle gambling problems."



George was assaulted in 2009. He had been punched in the head, leaving him with lasting trauma to the left side of his brain. He spent several months in a coma and nearly a year in hospital learning to speak again and working to regain his memory. He also had to re-learn how to walk.

After eight years of battling for compensation, he received a settlement in excess of £200,000.

An evening in a casino with a friend was George's first taste of gambling. It quickly led him into the world of online gambling, to which he became addicted.

now in debt.

Although George had money refunded by some gambling safter contacting them to tell the properties of the contacting them to tell the contacting t

At one point, he says he had spent £8,000 then won £275,000 – but the online gambling firm said it would take some time to pay out and he quickly gambled away all the winnings before they had even arrived in his account.

He says that on another occasion he spent £67,000 in 40 minutes, but there was no contact from the online casino to question where the money was coming from.

This is despite having registered with GamStop, the service intended to help addicts block themselves from online gambling. George found it easy to avoid the restrictions which he had asked to be put in place to prevent him gambling.

He soon had no money left and is now in debt.

Although George had money refunded by some gambling sites after contacting them to tell them about his ABI, this has not been the case with all the sites. He has also found that his addiction to gambling meant that money which was repaid had soon gone again – on more gambling.

'VULNERABLE PEOPLE ARE BEING EXPLOITED'

"I'm often told how frustrating people find it seeing a debate in Parliament with only a handful of MPs taking part.

"The reason for this is that much of the work that goes on in Westminster happens away for the glare of the TV cameras.

"All Party Parliamentary Groups are a true example of this. I am a member of many but recently found an important link between two – the Acquired Brain Injury APPG and the Gambling Related Harm (GRH) APPG, which I chair.

"The Gambling Related Harm APPG, is currently undertaking an inquiry into online gambling. In March we heard from those who had been personally affected, including George, who told

us his heart-breaking story of how a brain injury had led to his addiction. Alongside this, we heard from Headway about research into a link between the two.

"People like George are vulnerable, and they are being exploited. As an APPG, we must improve protection for them, and for other addicts, by holding the powerful gambling companies to account."

Carolyn Harris MP



WHO CAN HELP?

If you are worried about yourself or someone you care about, please don't feel you are alone.

Headway helpline: call **0808 800 2244** or **helpline@headway.org.uk**

GamCare www.gamcare.org.uk

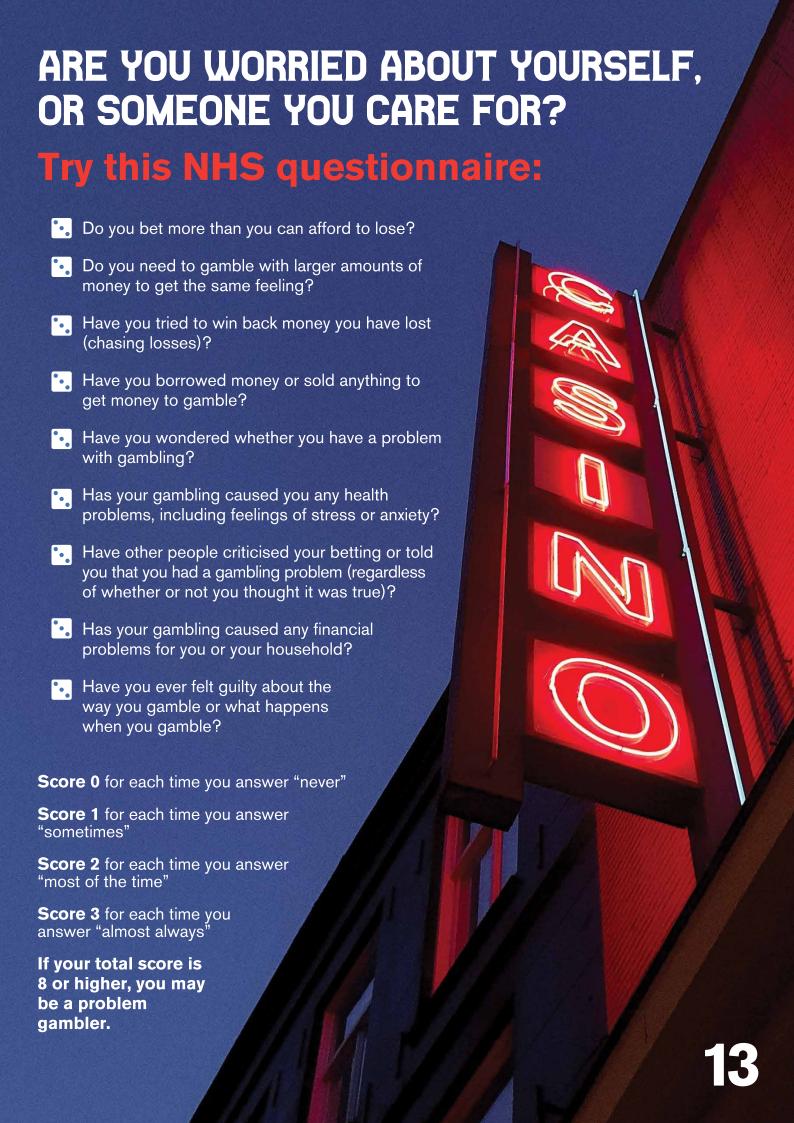
 free information, support and counselling for problem gamblers in the UK. It runs the National Gambling Helpline on 0808 8020 133 and also offers face-to-face counselling

Gamblers Anonymous UK

www.gamblersanonymous.org.

uk – local support groups that use the
same 12-step approach to recovery from
addiction as Alcoholics Anonymous

GamAnon: support groups for friends and family **www.gamanon.org.uk**



Like many other forms "The creative writing sessions at Headway Nottingham have given me the of art therapy, creative opportunity to produce something really writing is a popular special that I'm proud of." rehabilitation aid for many Julie Wedgbury, Fundraising Manager at brain injury survivors. It Headway Birmingham & Solihull, agrees: gives people the chance "Many of our service users have been able to express their emotions and have to express their thoughts, grown in confidence with the help of our feelings and emotions in

Here, we look at how Headway groups and branches across the UK are helping people gain renewed confidence and express themselves using the power of the pen - or more often, the keyboard!

a safe and confidential

place without any

judgement.

More than words

One of the challenges faced by many brain injury survivors is managing or articulating their emotions. Creative writing can often help people to put their thoughts onto paper and process what they are feeling or thinking.

Brain injury survivor Candice, who regularly attends Headway Nottingham, said: "Creative writing has given me such meaning in my world since sustaining my brain injury.

"It has shown me that I still have the ability to write and it has helped me to get in touch with my feelings and now I am able to express them in my poetry. Three years on from my first creative writing class and I'm still surprised at what I am able to achieve.

creative writing sessions.

"Overall, it has proved to be a wonderful avenue for communication and self-esteem among our members."

Sharni Haque is one of those members. In 2017, Sharni suffered a brain haemorrhage that resulted in her being dependant on a wheelchair. Since then, she has found that creative writing has helped to build her confidence and reveal more of her bubbly personality.

Some brain injury survivors find it cathartic to share their story with the rest of the world, whilst others prefer to keep their writing to themselves. Either way, creative writing is a great way of opening up and releasing emotions that may have built up over time.



Headway

Rose Gleeson, an English and Creative Writing graduate, said: "I think it's really important for those with an ABI to have a safe space where they can explore self expression, build confidence and enjoy the creative process.

"The creative writing sessions I tutor at Headway Cardiff do just that."

Phillip Owen is just one of many Headway Cardiff service users to have benefited from that support. Since sustaining his brain injury in 2007, Phillip has written a memoir titled, If I could remember, I would try to forget.

"Creative writing presents a way for me to dissipate my frustrations, and to reiterate how strongly I feel about certain issues, especially incorrect assumptions about the effects of a brain injury," he said.

Lover of literature Ken Hazeldine, who regularly visits Headway East London, echoed those thoughts: "The writing sessions here at Headway have given me the opportunity to get creative again.

"Before my brain injury I was someone who always had a novel on the go, since then I haven't read that much.

"But instead, I seem to have developed a passion for creative writing. I find it really therapeutic."

Simply put, creative writing gives people the chance to explore their life after brain injury with the possibility of reaching out to those in a similar situation.

Cognitive boost

Creative writing also has a number of cognitive benefits for those living with



a brain injury. Not only can it help to improve the cognitive abilities of brain injury survivors, but it can also help to highlight areas for improvement during rehabilitation.

Maintaining focus is key when it comes to creative writing, but a reduced concentration span is common following brain injury. However, creative writing can sometimes help to strengthen this area of cognitive functioning.

Colette, a service user at Headway Oxfordshire, said: "The creative writing sessions at Headway Oxfordshire have been so helpful during my rehabilitation.

"They help with my concentration as I have to focus on the storyline and actually putting pen to paper. I've found that creative writing also helps me to organise my thoughts and put them into a creative manner."



For many with a brain injury, engaging in conversation and being surrounded by a number of distractions and interruptions in a social setting can be daunting, and sometimes impossible to manage.

Writing, on the other hand, gives the author the chance to solely concentrate on expressing themselves by putting pen to paper. The pressure to keep up with the conversation – both verbally

and mentally – is removed and instead, the author can write at their own pace, free from judgement.

"Creative writing has helped me immensely to express myself as I can't get the words out quick enough in normal conversation," says keen blogger and brain injury survivor, Laura-Rose Smith.

"I find creative writing affords me the time to fully articulate my thoughts and feelings."



Creative writing has also helped many brain injury survivors with their memory difficulties.

Phil, a service user at Headway Oxfordshire, said: "Creative writing has really helped with my memory. It helps me to establish timelines in my stories and in my own life, which means I can put everything into perspective."

Blogging after brain injury

The inspiring stories being told by people living with brain injury are not just limited to traditional paper-based writing.

Online blogging is often considered to be just for those who want to rant, rave and put forward their (often strong) views on topical issues. But as the community of bloggers – both amateur and professional – continues to grow, so does the diversity and quality of posts.

More and more people are choosing to express themselves online. This includes

brain injury survivors, who are posting to share their experiences in order to give support to others, or simply to showcase their creative writing talent.

Blogging gives people with brain injuries the opportunity to share their stories and easily connect with those who have experienced similar trauma – something that can be extremely beneficial in terms of developing friendships and support networks.

Sam Robinson, a brain injury survivor who attends Headway Cambridgeshire, is an avid blogger. He posts a monthly blog about life after brain injury, some of the challenges he faces, and how blogging has helped him following the diagnosis of his brain tumour.

His piece *To blog or not to blog* looks at the pros and cons of blogging after brain injury.

Sam says: "Being a blogger has been incredibly helpful in understanding and combating my own brain injury.

"Making myself aware of my feelings and aspirations, through the platform of blogging, means that I can identify and bring them to the surface. This enables me to put plans into action and helps reduce the impact of my worries."

Four top tips to help you get started with creative writing:

Buy yourself a nice diary, journal or notebook. It doesn't need to be expensive. If you have somewhere to showcase all your work, you'll feel proud of what you've accomplished.

Find inspiration in your surroundings. If you don't know what to write about, just take a look around you and write about the first thing that catches your eye. It a friend sat across from you or your beloved pet.

Get a friend or family member to read your work. They can check for any spelling or grammar mistakes. Don't be afraid to make mistakes. It may take a few attempts before you master your first sentence. You might want to start writing with a pencil so that it is easy to rub out any mistakes you make.

The blogging basics:

What is a blog?

A blog is a website or webpage which is made up of diary-style text entries that often document life events.

Who can blog?

Anyone can create a blog. It doesn't matter if you're young or old, tech-savvy or just starting out.

Where do you upload a blog?

There are various different websites that allow you to upload your blog posts – this is often called 'guest blogging'.

Alternatively, you can create a website dedicated purely to your own blog posts.

What should you blog about?

You can blog about anything. Health and wellbeing, travel, and personal development are just a few popular blog-worthy topics. Brain injury survivors may want to blog about their recovery so that they can look back to their first entry and see how much they've progressed.

Caution is advised with this, however. It's important to remember that everything you post is potentially there for all to see. It's easy to post in haste and repent at leisure, so we would always suggest you create a draft before publishing, and speak to someone you trust before deciding on whether or not to post.

Blogging after a brain injury can also a great way of keeping loved ones and friends informed along the rehabilitation and recovery process.

How do you get more people to read your blog?

One easy way to get more people to read your blog is to share it on social media. Some of your Facebook friends may even turn into regular readers.

What restrictions are there when blogging?

While blogging is relatively rule free,

there are a few restrictions in terms of copyright. It's important to remember that when blogging, you don't claim the work or ideas of others as your own.

In terms of photographs to feature alongside your blog, you must ensure that you have permission from the owner of the photograph to host it on your website. If you are unable to get permission, there are numerous stock image sites that allow you to use photographs free from copyright restrictions.

Staying safe

It's important that, before publishing your writing online or in print, you get a trusted friend or family member to read your work. This means that they'll be able to spot any errors and ensure that you're not giving away any personal information.

Think carefully about what you're comfortable sharing, and never give details that could compromise your safety, such as your address and date of birth.

Share your words

If you would like to share one of your poems, short stories, limericks or blog entries, then visit www.headway.org.uk.

You can submit your story via the *Brain injury & me* page where you will be able to tell us about the creative writing you have produced and how it has helped you following your brain injury.

Alternatively, you can send in a snap of your favourite literary creation, with the possibility of it being featured on our Instagram page as part of our #TakeoverTuesday. Just send your pictures to: **website@headway.org.uk** or use the hashtag #HeadwayTakeover in your social media posts.

My Brain suffered a bash,
My emotions became very brash,
I lost control,
In my life as a whole,
And like the hulk I would smash.

Headway Birmingham & Solihull's Mark Hannaby's, My Brain Suffered a Bash

A stroke has damaged my brain,
It has left me in a lot of pain,
I've lost the use of one side,
My emotions I really do hide,
But walking I am starting to regain.

A limerick by Corinne Springer, service user at Headway Birmingham & Solihull



'Yes I understand. I get tired too!' Just one of the phrases that brain injury survivors often hear when they attempt to explain the reality of living with long-term 'pathological' fatigue.

Fatigue – or excessive tiredness – is one of the most commonly experienced effects of brain injury. Indeed, it is the most commonly cited effect reported by the 11,000 callers to our Headway helpline each year.

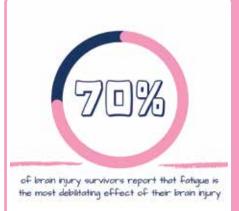
The brain is a control centre that dictates everything we do, think and feel. It is our battery, recharged with sleep and rest.

FATIGUE!

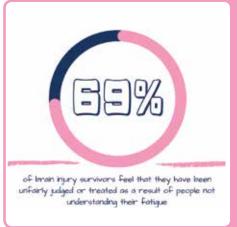
But after brain injury, this battery drains far more quickly and therefore needs recharging on a much more regular basis – sometimes even shutting down without warning.

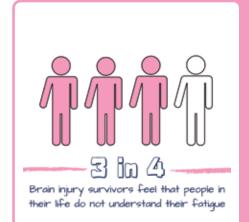
Fatigue can affect one's recovery process and every aspect of daily life. But despite this, as with many of the often hidden effects of brain injury, fatigue can be widely misunderstood – not just by those around us, but even by the individuals themselves.

Launched as part of this year's Action for Brain Injury Week, *Brain Drain: Wake up to fatigue!* gives a voice to those affected, helping to raise awareness of the disabling and stigmatising effects of brain injury-related fatigue.









18 Headway News

STUDY

At the heart of the campaign is our latest survey, entitled *Experiences of fatigue* after brain injury.

It was designed to highlight just how common fatigue is and how far reaching its impact can be, while also examining ways in which we can best support those affected.

An incredible 3,166 brain injury survivors completed the survey, making it the most popular study Headway has conducted to date. Unsurprisingly, we found that people's experiences of managing fatigue are entirely negative – with many respondents labelling their experience as 'frightening' and 'destroying'.

Here we look further into the key findings of the study.

70% of brain injury survivors reported that fatigue is the most debilitating effect of their injury

Whilst fatigue is a personal experience that is different for everyone, respondents said they feel exhausted, lack energy and are unable to motivate themselves, which in turn makes completing ordinary everyday activities, such as bathing and preparing food, a real challenge.

For others fatigue may worsen difficulties associated with their injury, for example, forgetfulness and irritability.

A staggering 88% of respondents said that fatigue affects their behaviour and emotions.

87% of respondents stated fatigue has a negative impact on their life

Respondents overwhelmingly reported that fatigue has worsened their lives.

Self-esteem, independence, employment opportunities, home life, social life, romantic relationships, and financial circumstances were all listed as being negatively impacted. Many reported that their rehabilitation and ability to make a meaningful recovery is also lessened by fatigue.

However, we found that survivors struggle the most with employment

and maintaining a social life, with 83% and 90% of respondents reporting breakdowns in these aspects of their life respectively.

75% of respondents said that people in their life do not understand their brain injury-related fatigue

The breakdown of many aspects of a brain injury survivor's life may be attributed to those closest to them lacking knowledge of brain injury-related fatigue.

Importantly, 80% of survivors reported that their life would be improved if people had a better understanding. Through our *Brain Drain* campaign, we hope to reduce this number dramatically!

'Friends', 'employers' and 'colleagues' were the highest-rated categories of people considered as not having a good understanding – an issue consistent with the findings of previous Headway campaigns A New Me and You, me and brain injury.

However, of those respondents in relationships, a positive 62% feel that their spouse or partner does have a good understanding of their fatigue.

More than two thirds of respondents believe that they have been unfairly judged or treated as a result of people not understanding their fatigue

Increasingly-slurred speech and lower speeds of information processing are just some of the signs of fatigue that often lead survivors to being unfairly judged or treated.

It is common for people to incorrectly assume the individual is being lazy, is depressed, or even that they are drunk.

Survivors are therefore not receiving adequate practical and emotional support from people around them. In turn, this leaves those affected feeling isolated and confused.

Three quarters of respondents indicated that they need help to understand the effect fatigue has on them

While for some people fatigue improves over time, for others it is a condition that they have to learn to manage long term. However, this can sometimes be difficult following brain injury due to insufficient sensory feedback to the brain.

Research has found that talking therapies, such as cognitive behavioural therapy, can increase a person's understanding of their experience of fatigue, its triggers and their ability to respond.

But ultimately the most important thing is ensuring brain injury survivors are surrounded by people who understand.

BREAKING THE STIGMA OF BRAIN INJURY-RELATED FATIGUE

A little understanding goes a long way in helping someone who is living with the effects of brain injury.

Pathological - or extreme - fatigue is a daily challenge and our study demonstrates that survivors predominately feel as though their life has been negatively affected as a result.

By encouraging people to share their experiences and in turn raising awareness of the condition, we hope that together we can help people to wake up to fatigue!

Download our full report at www.BrainDrain.org.uk.

NEED HELP?

To discuss fatigue or any other effects of brain injury please contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.

You can also download the Headway booklet *Managing* fatigue after brain injury from the information library at www.headway.org.uk.



'ADMIT IT AND DON'T APOLOGISE FOR IT'

In 2009, experienced cyclist David Yabbacome sustained a traumatic brain injury after falling off his bike.

Now nearly 10 years after his accident, fatigue continues to have a distinct impact on his life.

David has learnt to cope and accept what life is like with fatigue, while forgiving others who lack insight into his struggles.

He said: "I now realise that it is a part of who I am and how I live. You have to be conscious of fatigue and what living with it is like.

"Admit it and don't apologise for it.

"I try not to get cross with people when they don't understand. I try to explain fatigue and often get the response, 'Yes, I understand. I get tired too!', to which I want to scream 'no, you don't understand...fatigue is nothing like tiredness!'

"Thankfully my wife is brilliant at observing me and seeing the signs of impending fatigue. In social situations she will rescue me by steering me into quiet places to recover. At home she will tell me to pause, and encourage those who are with me to let me pause."



'FATIGUE HAS PUT PRESSURE ON OUR RELATIONSHIP'

Julie Sadler sustained a traumatic brain injury in 2014 when the car she was travelling in was hit by a lorry.

Julie said fatigue has had an impact on her relationship with her husband and also affected the way she sees herself.

She said: "The fatigue has put pressure on our relationship because we have very different body clocks now.

"I can get very irritable when I'm tired and that can lead to me snapping at him. It's tough for both of us.

"He often wants to tell me about his day or something important and I can't take it in. When my fatigue is kicking in I quickly feel overloaded. I have to ask him to save it and tell me in the morning."

Julie loves spending time with her grandchildren but admits she finds it very difficult when she realises she hasn't got the energy to see them.

She said: "The fatigue stops me from being the type of grandmother I want to be. I simply don't have the energy to get more involved and it makes me very sad to think I have lost that opportunity.

"Acceptance is the difficult bit. You have to work hard to pace yourself and it isn't easy, especially when there are things in your life that you liked to do before the injury."



'STUDYING FOR MY EXAMS IS NEAR-IMPOSSIBLE'

In 2018, Lottie Butler sustained a traumatic brain injury after a fall while on a night out with her boyfriend.

Lottie, who is currently in her second year at sixth form, hopes to go on to study psychology and sociology at university, but worries that her ongoing battle with fatigue will get in the way of her education.

"For the first few months following my brain injury I couldn't go to sixth form at all because the process of travelling there, socialising with friends and learning was just too exhausting," said Lottie.

"Fatigue makes studying for my exams near-impossible. Because I'm fatigued, I find it difficult to concentrate, which means I have to focus ten times harder just to read a sentence.

"This in turn strains my eyesight, which then makes me even more fatigued. It's a vicious cycle that I just can't seem to escape.

"Im eager to get my fatigue under control and start learning how to live with a brain injury. For the first time since my injury, I'm feeling positive about my future.

"I know that with the right support and fatigue management, university will be an option for me."

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'WAKEY!' WAKEY!

A key aim of the Brain Drain campaign is to give brain injury survivors tools to help them to better explain their fatigue to those around them.

In addition to the study and the Headway booklet, *Managing fatigue after brain injury*, a new film has been produced to raise awareness of the issue.

The film features brain injury survivor Candice Ridley, who attends Headway Nottingham. It aims to give viewers a brain injury survivor's perspective of typical everyday scenarios and interactions that they can face as a result of their fatigue being misunderstood.

In addition, Candice shares her experience of brain injury-related fatigue in more detail in an accompanying short film, which will form part of Headway's *Brain injury and me* series of personal testimonies.

We would like to say a big thank you to Candice, and also actors Hazi Mistry, Katherine Butterfield and Megan Leask-Walters for volunteering their time to appear in the film.

View the film at www.BrainDrain. org.uk and please help us to raise awareness by sharing it on social media.

UNRAVELLING THE MYSTERY OF FATIGUE

How many of you reading this can relate to the following statements?

"It's like my brain just shuts down...I can't communicate or think any more"

"I try to sleep but my head just whirrs around, or I do sleep but don't wake up feeling refreshed"

"Friends think I'm lazy or not motivated as I let them down at the last minute, or have to leave early"

Fatigue affects many people at some point in time, but it's not always understood as a significant consequence of brain injury.

This type of fatigue feels completely different; more intense, longer lasting, and doesn't necessarily seem to relate to what we have just done. And it

doesn't seem to go away after rest either...so what's going on? Why does fatigue occur? And what can we do about it?

After a brain injury, it seems as if more physical and mental energy is needed for daily life and it feels as if this energy drains far more quickly than before. It's like having lots of apps open at once on a smartphone; things slow down and the battery drains really quickly until 'the computer says no'!

There is no quick fix or magic pill to take, although scientists are looking, so do speak to your doctor about whether medication may help. There may be other medical conditions affecting your energy levels to take into account.

Working with an occupational therapist is a good idea, as they can work with you to find out what factors are relevant for you, how to make activities take less effort, and manage the environment to help you process information more effectively so you can participate in the activities you value most.

So do 'wake up to fatigue'; it's real, it's common and it isn't yet fully understood, but together, through sharing experiences with others, we can learn how to make the most of the energy we have, and live our lives more fully.

Read Donna's feature in full at www.BrainDrain.org.uk.

Donna Malley, Occupational Therapy Clinical Specialist at The Oliver Zangwill Centre



INJURY WEEK 2019

WAKING UP TO FATIGUE

Throughout this year's Action for Brain Injury Week (ABI Week), Headway groups and branches have been busy hosting events to help raise awareness of brain injury.



From practical workshops to creative expressions, Headway's Brain Drain: Wake up to fatigue! campaign has been at the heart of ABI Week events across the UK.

Throughout the week, Headway Southampton ran a number of Brain Drain workshops where brain injury survivors were able to discuss how fatigue affects them, and what practical solutions can be put in place to help.

The Brain Drain workshops were also a hit with service users at many other Headway groups and branches, including Headway North Cumbria and Headway Guernsey, while Headway Birmingham & Solihull invited a team from Occupational Health, Safety and Return to Work Services to its centre to deliver a session on fatigue.

RAISING AWARENESS

A hugely-successful lobbying day took place in Westminster, giving brain injury survivors and the organisations supporting them a chance to meet MPs

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and encourage them to support calls for improved services to be provided throughout the care pathway.

Many Headway groups and branches, along with Headway UK, were represented at the event, which was organised by the All-Party Parliamentary Group (APPG) on Acquired Brain Injury, with those present provided with the opportunity to thank the members of the APPG for championing the cause of brain injury in Parliament.

Meanwhile, brain injury survivors in Northern Ireland were invited by the Southern HSCT Brain Injury Forum to attend a workshop and conference which aimed to raise awareness of the challenges faced as a result of an acquired brain injury.

FUN-FILLED ACTIVITIES

ABI Week is always a good excuse to get creative to either raise awareness or funds - and this year many Headway groups and branches managed to do both.

Headway West London helped to satisfy a few sweet-toothed visitors to Charing Cross and St Mary's hospitals, as well as raise money, by hosting bake sales throughout the week.

baking, holding fatigue-related cake-

making sessions using slow release energy ingredients.

Another Headway group that tapped into the creative skills of its members was Headway Cardiff & South East Wales. Service users of the group's Independence and Wellbeing Centre created a 'fatigue board' where they were able to share their top tips for tackling fatigue, as well as their thoughts and experiences of brain injury.

Just over the border, Herefordshire Headway headed down to its local Coop supermarket to display the poetry and prose members had written about fatigue.

Both Headway Ayrshire and Headway Surrey put on their walking boots this year to take part in sponsored walks in Howard Park, Kilmarnock and Guildford.

mad as a hatter!

Members of Headway Coventry & Warwickshire's support group enjoyed a Mad Hatter's tea party where they wore wacky hats and costumes and shared tea and cake.

Also donning their wonderful Wonderland hats were service users at Headway Swindon who enjoyed an array Headway Birmingham & Solihull also got of Alice in Wonderland-themed activities, including designing their own hats,



taking part in a special craft session and indulging in sweet treats at a Mad Hatter's tea party.

But it wasn't just Headway Swindon joining in with hat-related fun during ABI Week, with Headway Devon's CEO Ruth Wells and Fundraising Manager Victoria Johnston spending an entire day wearing cycle helmets in order to spark conversations about brain injury prevention.

Also on a mission to raise awareness of the importance of cycle safety was the team at Headway Blackpool, which attended two local schools to talk about the serious consequences of not wearing safety helmets when riding bikes and scooters.

In the medIa

The Headway Darlington group was very busy during ABI Week, featuring on BBC Radio Tees every morning to talk about brain injury and its effects. Seven brain injury survivors bravely shared their stories with listeners across the county.

There were also television news features on BBC East Midlands Today, where Lottie Butler opened up about how fatigue is making it hard for her to complete her college course.

Lottie, whose *Brain Drain* video diary is available to view on the campaign page of our website, was accompanied by Headway's Luke Griggs who spoke on the programme about the campaign.

ITV Borders also ran a news feature during the week, with Headway again providing comment to raise awareness of brain injury and highlight how people can get help from their local groups and branches.

This year's ABI Week also saw the launch of Headway East London's podcast: *The World Beyond My Head*. Each episode of the podcast explores topics that have become important to two survivors following their brain injuries.







ACTION FOR

BRAIN INJURY WEEK 2019

Wow! What a creative bunch you are!

Whether it was homemade creations or colourful – and in some cases brave – headgear plucked from the fancy dress box in the loft, you've all done yourselves and Headway proud.

Each year we give a prize for the best individual photo, which this year goes to Sarah Masters for her incredible tribute to Pink Floyd's *The Wall* album.

Sarah said her dad was the inspiration for her design. "Pink Floyd was my dad's favourite band," she said. "As *The Wall* came out in 1979, I thought it would be a perfect way to celebrate Headway's 40th birthday."

Sarah wins an overnight stay for two people at a Countrywide Hotel, a prize generously donated by Conference Care. Meanwhile, the best group shot was won by the team at Coles Miller.

A big thank you to everyone who took part in Hats for Headway Day. If you'd like to see more of the hundreds of photos we received, just search for #HatsForHeadway on Twitter, Facebook or Instagram.

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Winners of the best group shot, Coles Miller, even got their pets involved



The Cardiff office of Hugh James Solicitors took a patriotic approach



Any excuse for cake at Headway Salford





Smiles all round at Headway North Cumbria

#HeadwayHeroes

HOW WILL YOU CHALLENGE



Across the country, Headway supporters are having fun by taking on a host of fabulous challenges to help us celebrate our 40th anniversary and raise funds to support our work to improve life after brain injury...

Hulahooping hero

Headway volunteer Linda Beckett has a chosen a *Challenge 40* event that would put anyone in a spin: hulahooping!

Linda, who has been an invaluable volunteer in our fundraising team for nearly 10 years, said she couldn't wait to start her challenge, which will see her spinning her hulahoop every day for 40 days!

She said: "I heard about *Challenge 40* and wanted to get involved. It's a perfect opportunity to get stuck in and have some fun because you can choose anything really.

"I'm not fit enough to do a run or cycle and that's why I came up with hulahooping.

"I used to do it a lot when I was child so thought it would be a good chance to get back into it. It might also help me lose some weight, which is always nice."





Stretching Challenge 40 to its limits

Brain injury survivor Max Munro is taking part in Challenge 40 by leading a special yoga class.

Yoga teacher Max was just 22 when he suffered two near-fatal bleeds on his brain, a fracture to his skull and a number of broken bones.

However, it wasn't the therapy or rehabilitation that Max credits for his remarkable recovery, but instead his love for yoga.

Max said: "The doctors told me I'd never be able to walk again, but it wasn't until they saw me doing yoga that they realised how wrong they were.

"According to my doctors, the combined mind and body qualities of a sustained yoga practice may be the reason I'm alive today."

Max said he has chosen to take part in *Challenge 40* so that he can help raise awareness of brain injury, as well as the positive impact yoga can have on brain injury survivors.

He said: "I will be leading a special yoga class where both pros and first-timers do 40 sun salutation yoga moves, all in honour of Headway's 40th birthday!

"It doesn't matter whether you've sustained a brain injury yourself, know someone who has or just want to give yoga a try, the class is all about having fun and raising money for an important cause."

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Cycling 40 miles or 40 kilometres



























40 'sun salutation' yoga moves



Walking Hadrian's Wall in just 40 hours















Cycled 400 miles in 40 days

Sandra Stamp

Swam 40 miles in 40 days with sister Angie, while her brain injured brother-in-law Andy swam 40 times













FINISH O





M





Sarah Wait Swam 40 kilometres in 40 days

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MARATHON

BFF0RI

from Headway's Heroes

Team Headway did us proud in this year's Virgin Money London Marathon, with a total of 45 runners donning the Headway vests to tackle the gruelling 26.2 mile course.

The determined Headway Heroes, who have raised a phenomenal £77,000 for the charity so far, were part of the 40,000-strong mass of runners who pounded the streets of the capital for this year's event.

After loading-up on carbs at the Headway Pasta Party the night before the race, members of Team Headway all completed the course in fine style.

'An absolute honour'

Chris Erridge, 38, from Milton Keynes, ran in memory of his late father who passed away following a brain tumour.

In 1980, Chris' dad, Geoff, had surgery to remove a life-threatening brain tumour. Although Chris and his family didn't know it at the time, the impact of the surgery would be lifelong.

Following the operation, Geoff was left with lasting and complex effects of the brain injury, which included chronic fatigue, memory problems and bouts of confusion.

Chris' family were put in touch with their local Headway group in Luton and Geoff immediately started to see the benefits.

Chris said: "It was a new lease of life for my dad following his injury. Their activities would keep him socially and cognitively engaged, as he had to retire early."

However, almost three decades after his operation, the tumour on Geoff's brain returned and this time it was inoperable.

He passed away in 2009, aged 54, in the home he had lovingly shared with his wife and three sons.

Chris said: "It was an absolute honour to run the London Marathon for Headway. The organisation helped my family when we needed it most.

"Training for a marathon is obviously a challenge, but what often gets left out of the runner's 'journey' is how much it asks of those closest to you.

"So I want to thank my wife Elizabeth for all the time I was out running, especially at the weekends, leaving her at home with the children.

I couldn't have done

this without her

support!



memories

of him into

something

positive."



'In honour of my Grampy'

Father and daughter duo, David, 44, and Jemma Moore, 24, ran for their beloved father and grandfather, Anthony.

In 1982, when Anthony was just 25, he was hit by a lorry and left partially paralysed, wheelchair bound and suffering from the complex and hidden effects of his brain injury.

Jemma said: "I know that Grampy Tony and the rest of my family are so grateful for Headway's help and that is why it was such a privilege to run alongside my dad in honour of my Grampy and in support of such a wonderful charity.

"Running the London
Marathon was an absolutely
incredible experience. To be
able to run it alongside my
dad, helping each other along
the way, after the weeks of
training together, was so special
and it will be a day I will never
forget.

"To run for Headway UK and raise money for a charity that has helped my family, means the world to both of us. The atmosphere was amazing and I would love to do it again one day."

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On yer bike!

Having spent more than two decades as professional road cyclists, Matt and Nikki Brammier might have been forgiven for struggling to adapt to a new way of covering the miles, but both completed the marathon in style for Headway.

Married Matt and Nikki chose to support Headway having learned firsthand about the dangers of concussion.

In 2015, during stage six of the Tour of Utah, Matt crashed head-on into a car.

"I ended up colliding with a race vehicle at a pretty high speed," he said. "Luckily I don't remember anything about the accident; my last memory before the crash was coming into the corner.

"After that I don't remember anything until I came around in hospital a few hours later."

Matt suffered severe injuries including a broken pelvis, broken ribs and a punctured lung, but he says his head was never really mentioned by medical teams.

He said: "I had brain scans looking for bleeding but the word concussion was never mentioned to me."



It was only when Matt's wife Nikki, also a professional cyclist, had an accident at the European Cyclo Cross Champs in 2016 that he became aware of the symptoms of concussion and realised how dangerous concussion can be.

Nikki said: "After my accident in 2016 we were made aware of how dangerous a concussion can be if not treated seriously.

"I saw firsthand some of the long-term effects it can leave and we realised how

badly Matt's concussion was mistreated previously."

Matt said the couple loved every single minute of the race.

He said: "We were both pretty apprehensive and nervous before the race.

"It felt like our first bike race all over again. As soon as we started the nerves disappeared and we were both smiling from ear-to-ear the whole way through.

"The sea of people shouting and cheering us on really did give us that extra gear to get through the race so well!

"It was so inspiring to see all of the support from the side of the roads, from all of the supported charities, including massive shouts from Headway, family, friends, and local businesses.

"It seemed like the whole of the city had come out to cheer us on. It was definitely a day we will never forget!"

THANK YOU!

Running a marathon is an incredible achievement and we have no words to express our gratitude to every one of our fabulous runners – and indeed all those who ran to raise money for their chosen local Headway group or branch.

We'll have to settle for THANK YOU!

Inspired? Get involved!

There are so many ways in which you can help to improve life after brain injury by fundraising for Headway. There are plenty of incredible challenges you could take on – but you don't have to be superfit to help!

Visit www.headway.org.uk/getinvolved or give us a call on 0115 924 0800 to have a chat.

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Cary Smith is a member of Headway - the brain injury association's Personal Injury Solicitor's List

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