

Spring 2019

Headway News



The magazine of Headway - the brain injury association

Headway turns 40!

Taming my anxiety monster

*ABI Week
theme
announced*

**Healthy
body,
healthy
mind?**

HATS for Headway's Birth Day!

Friday 24th May

**Help us celebrate our
40th anniversary!**

Simply wear a party hat for the day,
donate £2, and help improve life
after brain injury!

Download your FREE party hat
templates from our website!

headway.org.uk

#HatsForHeadway



Improving life after
brain injury for

40 YEARS
1979-2019

the brain injury association

ACTION FOR

BRAIN INJURY WEEK 2019

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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.



the brain injury association



Life begins at 40...?

Welcome to the first edition of *Headway News* in this, the charity's 40th anniversary year.

Turning 40 is certainly a major milestone and throughout this edition, and indeed the year, we'll be looking at what's been achieved as well as what's still to do – with your help!

The suggestion that life begins at 40 is not one we hold to at Headway – certainly not when it comes to life after brain injury. To do so would be to belittle the incredible work that's been done in the name of Headway over the past four decades to support individuals and families affected.

The charity was founded in 1979 by a small collective of families and professionals who believed a life worth saving should be a life worth living. Advances in neurosurgery in the 1970s had led to more lives being saved following brain injury, but those advances in acute care were not matched by investment in rehabilitation.

The irony is that 40 years after Headway was formed, that same argument could still be made. And yet we know that with the right help, at the right time, there can be life after brain injury.

That's thanks to the incredible dedication of Headway volunteers and staff across the country, who every day do all they can to support people affected by brain injury.

And it's thanks to the generosity of everyone who has run marathons, climbed mountains, or simply taken part in Hats for Headway Day in order to raise money to fund our vital services.

Everyone associated with Headway should be proud about how far we have come, while remaining under no illusion about how much work is still to be done in order to meet the needs of the ever-increasing number of people living with ABI.

So we will be celebrating this year, but here at Headway UK we'll also be putting on our running socks or strapping on our cycle helmets to take part in our new fundraising event in honour of our 40th anniversary.

Challenge 40 is your chance to make a difference in our 40th anniversary year. Anyone can be a part of the Challenge 40 team and you don't have to do anything that requires physical exertion.

Check out our special feature on pages 26 and 27 to see how you can join in the fun and Challenge 40.

The Communications Team



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The magazine of **Headway - the brain injury association**

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Your views...

A brain injury can cause a number of mental health-related issues, such as depression, anxiety and panic attacks. We asked our people on our social media communities for their top tips for coping...

I find getting out in the fresh air in nature helped me when I was feeling low. Exercise, even just walking is brilliant too.

Katherine Moore

A paramedic once told me that if during a panic attack you can try and sing the alphabet or a nursery rhyme or your favourite song or something it helps to regulate your breathing. Also to hold someone's hand and look into their eyes.

Catherine Hammond

My Brain Injury Identity Card helps a lot (with my anxiety). I struggle with money now, so I just show my Headway card when I'm bad and they sort out my money. Saves me explaining myself in front of others in the queue.

Deborah Johnston

Suffered anxiety and panic attacks after my head injury. You've got to remember when they come on that they will pass and remember keep breathing.

Deano Stansfield

I couldn't cope with taking pain killers. I had (and still do, but not so bad) horrible depression. So now I have started painting and other arty stuff – and I actually love it, as I didn't think I'd be able to do anything – yay! I am still improving and it's only five years. Onward and upward.

Sandhy Robinson-Jones

Music has helped me. Singing in a choir, listening to music, the repetition of learning to play piano, and dancing. Depending on where I am, I do any one of these things. Granted I do get some odd looks in the supermarket!

Ellie Lyons-White

I try and ground myself so I focus on one thing. I focus on what I can hear, what I can touch, what I can taste, and what I can smell.

Holly Robinson

ABI Week is
coming...

08



We're turning 40!

10

Healthy body,
healthy mind?

12



Anxiety after
brain injury

20



26

Challenge 40



29

#HeadwayHeroes

06

News you may
have missed...

20

How to train your
anxiety monster

10

We're turning 40!
Celebrating four decades
of improving life after
brain injury

24

Dating after brain injury

12

Healthy body, healthy
mind?

26

How will you
Challenge 40?

14

Headway heroes
honoured in style
We review the Annual
Awards 2018

29

#HeadwayHeroes

18

Financial fraud:
A risk you can't afford
to ignore

news you may have missed...

Thanks a million!



Annual visits to Headway's award-winning website smashed through the one million mark for the first time in 2018.

The major milestone was just one of many reasons to celebrate another

successful year for the charity, with more people than ever before helped by Headway.

"We are absolutely thrilled to see so many people accessing the support we provide," said Andrew Taylor, Website and Social Media Manager at Headway.

"For many, the website is the first place to start looking when seeking specialist help or information.

"We are proud that people affected by brain injury are increasingly finding our site and utilising the support it offers, whether that be the free-to-access publications, or the simple tool to locate local services, such as our network of groups and branches.

"It's also pleasing to see so many other Headway services helping more people than ever before in 2018.

"The charity's nurse-led helpline answered almost 11,000 enquiries - an increase of 11%, more than 2,800 families were supported by HATS nurses, while over 100,000 booklets and factsheets were downloaded from the website.

"The challenge now is to continue to develop these services in order to help more and more people adapt to life after brain injury."

Government criticised on DoLS reform

The Government's haste to push the Mental Capacity (Amendment) Bill through Parliament has attracted widespread criticism from Headway and over 100 other organisations, as well as MPs and peers from all sides.

Many of the intentions behind the Bill, which seeks to reform existing Deprivation of Liberty Safeguards (DoLS) are well reasoned, and Headway has been working with the Department of Health to ensure the complex needs of brain injury survivors, families and carers are considered.

However, when the Bill was presented to Parliament, it did not include all the recommendations put forward previously by the Law Commission.

Dr Clare Mills, Headway's Public Affairs Manager, said: "The failure to produce a Code of Practice and the absence of an independent review of the Mental Health Act are concerning – as is the speed at which the Government seems intent on pushing through this legislation."

Headway's opposition to the Bill in its current form was outlined in a letter published in *The Times* and co-signed by 12 other national organisations, while the charity was also mentioned in a Parliamentary debate.

Meanwhile, the Scottish Government's proposals to reform the Adults with Incapacity (Scotland) Act 2000 are on hold while the implications of changes for England and Wales are assessed.



Sideline concussion tests within sight?

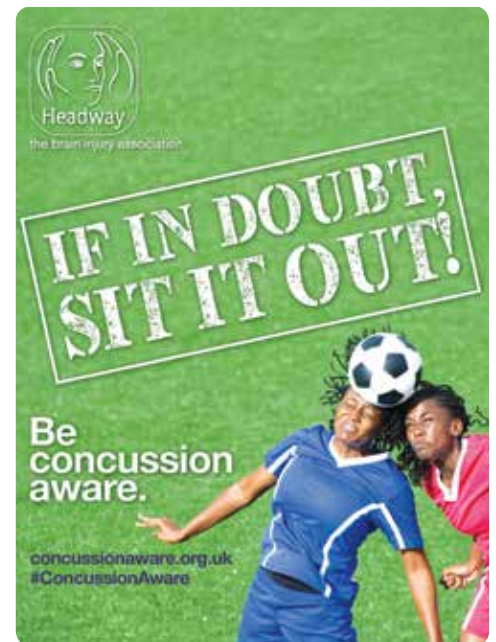
A new study that aims to improve the speed and accuracy of concussion diagnoses has been launched by researchers at The University of Birmingham and University Hospitals Birmingham NHS Foundation Trust.

The study involves saliva and urine samples being collected from injured Premier League players, as well as uninjured 'control' players, by club doctors immediately post-match and at

further time points during the recovery process.

These samples are then being tested in the laboratory at the University of Birmingham using the 'Birmingham Concussion Test', which has been developed following a decade of research led by academic neurosurgeon Professor Tony Belli.

Peter McCabe, Chief Executive of Headway, said: "Exploring the potential use of biomarkers to identify concussion is an exciting area of research that we hope will one day translate into a reliable and accessible sideline diagnostic tool.



"In the meantime, while this research continues to be developed, the focus must remain on educating sportspeople operating at all levels on the importance of taking an 'if in doubt, sit it out!' approach to head injuries in sport.

"It is also pleasing to see the research will investigate the effectiveness of the current Premier League procedures for diagnosis and monitoring of concussion."

Early bath for rugby concussion trial

The trial of a new tackle height law designed to reduce concussions in rugby has been halted after a surprise increase in injuries was recorded.

Matches in the Championship Cup were subject to new rules with players not allowed to tackle above the armpit.

During the trial, commissioned by the Rugby Football Union (RFU), there was a 41% drop in the number of contacts with the head or neck of a ball carrier, but instances of concussion rose among players tackling opponents who were bent at the waist carrying the ball.

According to a BBC report, the trial saw a 67% increase in concussions, from

an average of 0.6 a game in the regular Championship season, to one per match in the Championship Cup.

Peter McCabe, Chief Executive of Headway, said: "The RFU deserves a lot of credit for taking a pro-active approach to trying to reduce the incidence of concussion, even to the extent of trialling new laws.

"While it is disappointing that the trial wasn't successful, the point of such research is to challenge and test preconceived or predicted outcomes.

"We fully support the RFU in its attempts to reduce the incidence rate of concussion in rugby and hope that with more research and a continued willingness to consider tweaks to the laws of the game, progress can and will be made."



New brain injury course for GPs

A new online course to help GPs better understand the often hidden effects of acquired brain injury has been launched on the Royal College of General Practitioners' (RCGP) online training platform.

Written by Headway and the RCGP, the course is available free-of-charge to all GPs as part of the RCGP's *Five minutes to change your practice platform*, which aims to provide time-pressured doctors with bite-sized learning modules and signpost them to more in-depth resources.

"The often hidden effects of brain injury, which can overlap or be confused with other conditions, can make diagnosis difficult for GPs," said Luke Griggs, Director of Communications at Headway.

"By working with the RCGP to develop this training resource, we hope to reduce the number of people slipping through the net and help GPs to ensure people receive the help and support they need."

Dr Jonathan Leach, Joint Honorary Secretary at the RCGP, said: "We are delighted to have launched this latest addition to our online training resources.

"The *Five minutes to change your practice* concept allows us to provide GPs with introductions and updates to certain conditions, while directing them to further information.

"We are extremely grateful to Headway for its support in developing this resource which we hope will assist GPs in identifying brain injury in their patients and ensuring they are directed to appropriate support."



Blue badge boost



The Department for Transport has confirmed that new regulations for the Blue Badge parking scheme will for the first time include provisions for people with hidden disabilities to apply for permits.

The scheme will be laid before Parliament in April. Meanwhile, new guidance for local authorities, which are responsible for administering the scheme and issuing badges, is being prepared.

Dr Clare Mills, Public Affairs Manager for Headway, said: "We are pleased to hear that the plans to extend the scheme are being put into effect and that people with hidden disabilities, including acquired brain injury, will be included in the Blue Badge scheme.

"Once legislation is in place, we'll be asking brain injury survivors, their families and carers to let us know if they still experience problems in obtaining a Blue Badge."

ABI Week theme announced!

This year's Action for Brain Injury Week campaign will focus on one of the most debilitating and misunderstood effects of brain injury: fatigue.

Your brain controls everything you do, think and feel. It is the control centre that dictates your actions and reactions, and the pace at which they happen. It is your battery, recharged with sleep and rest.

But after brain injury, your battery may drain far more quickly and therefore need recharging on a much more regular basis – often every few hours.

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

Through our *Brain drain* campaign, we aim to give a voice to those affected, helping to raise awareness and understanding of brain injury-related fatigue.

Keep an eye on our website and social media channels for more details of how you can get involved, or sign up to our *Headway News – Bitesize* email newsletter for more news on this campaign and all the other work we're doing to improve life after brain injury.



**ACTION FOR
BRAIN INJURY WEEK 2019**

Tributes paid to Headway stalwarts

Bill Jackaman 1925-2019

Stella Jackaman 1926-2018



Bill and Stella

Tributes have been paid to devoted couple Bill and Stella Jackaman, co-founders of Headway West Suffolk, who passed away recently within weeks of each other having been married for 72 years.

Stella, who was 92, died on Boxing Day, while Bill passed away on 14 January this year aged 93.

Bill and Stella supported the charity for more than 30 years, having been instrumental in the launch of the local group in 1985. Stella initially ran the service, while Bill volunteered in his spare time. Stella went on to become honorary president of the charity, while Bill was a trustee and Chair of the board for several years.

In 2014, the group merged with Headway Ipswich and East Suffolk to form Headway Suffolk. While this allowed the couple to step down from their charitable activities, their support of the charity never waned.

Their relentless and selfless commitment to helping people affected by brain injury led to the couple being jointly presented with the Stephen McAleese Outstanding Contribution to Headway Award in 2014.

Bill and Stella have left a lasting legacy in Suffolk and will be greatly missed, particularly by their two children, three grandchildren, and three great-grandchildren.

Peter Shaw 1937-2019

Peter Shaw, Chair of Headway North Derbyshire, has sadly passed away after a short illness.

Peter, who was 81, devoted much of his life to supporting people affected by brain injury after his son, Neal, sustained a devastating brain injury in 1999.

For almost 20 years, Peter acted as Chair of Headway North Derbyshire. In addition to his committee duties, he spent countless hours organising fundraising events, managing the group's activities, supporting members and campaigning with local decision makers for better services.

Peter's dedication to supporting people affected by brain injury, both on a local level and nationally, led to him being named the winner of the Stephen McAleese Outstanding Contribution to Headway Award in 2015.

For almost two decades, Peter led Headway North Derbyshire with dignity and fairness and was a passionate and effective ambassador for Headway. He achieved much and inspired so many to the extent that service users and fellow volunteers referred to him simply as 'Mr Headway'.

Peter leaves behind a son, Neal, and daughter, Tracey, as well as one grandchild. He will be sorely missed by all who knew and loved him.



Peter with his son, Neal, at the Headway Annual Awards in 2015



WE'RE TURNING 40!



Improving life after
brain injury for

40 YEARS
1979-2019

the brain injury association

For some people, turning 40 is an unwelcome milestone – often sparking mid-life crises that involve asking ourselves questions such as ‘how am I 40?!!’, and ‘what have I done with my life?!’

But there'll be none of that at Headway! Instead, we'll be spending the year celebrating all that we've achieved over the past four decades while redoubling our efforts to support people living with the effects of brain injury today.

Our story began in 1979 with the incredible vision and inspirational efforts of a small group of people who believed a life worth saving should be a life worth living (you can read a brief history of Headway on our website).

Five people, one meeting, and a charity was born.

With your help,

we're providing more services for survivors, families and carers than ever before, such as our Emergency Fund, which provides grants to help families cope with the sudden practical implications of brain injury, and the Brain Injury Identity Card.



With your help,

we support thousands of people every year via frontline services such as our nurse-led freephone helpline and our award-winning free-to-access publications.



With your help,

we are able to launch new local Headways across the UK, while supporting our network of groups and branches as they provide vital social support and rehabilitation programmes to survivors, families and carers in their communities.



With your help,

we continue to increase understanding and awareness of brain injury, while challenging those in authority to ensure better services and support are provided for survivors, families and carers.



With your help,

we continue to launch new campaigns, ranging from concussion awareness through to *Right First Time*, which is driving changes to the disability benefits assessment system.

**IF IN DOUBT,
SIT IT OUT!**

But there's still work to be done...

One thing that has changed over the years is the increasing number of people needing support having sustained a brain injury.

Every 90 seconds, someone in the UK is admitted to hospital with an acquired brain injury-related diagnosis. That's

around 350,000 people every year - an increase of 10% since 2005.

With brain injury often requiring long-term – sometimes lifelong – support, pressure on Headway, on a local and UK-wide level, is growing year-on-year. But that only makes us more determined to provide support, protect vital services and speak up for those affected.

We've come a long way since our humble beginnings back in 1979, but we know that there's still so much more to do.

You've helped us get to where we are today. For that, we are extremely grateful. We sincerely hope you will continue to give your support as we strengthen and develop our services to help more and more people to improve their lives after brain injury for the next 40 years and beyond.

Join in the celebrations!

Whether or not you think life begins at 40, it's certainly a major milestone and one we plan to acknowledge throughout the year.

And we'd love for you to join in by getting involved with **Challenge 40!**

We're asking anyone with a passion for improving life after brain injury to take on any challenge they like – as long as it involves the number 40.



For example, you could hold a 40-question quiz night, run or walk 40 miles (whether in one go, or over the course of a month or two...it's up to you!), or bake (and sell!) 40 cakes...the list is endless!

Check out **Challenge 40** on our website and on page 26 for more ideas and to sign up to be part of the team.

Headway - working together for 40 years to improve life after brain injury.



A brief history of Headway

1979

Advertisement placed in *The Telegraph* asking families affected by brain injury to get in touch. Sir Neville Butterworth, Dinah and Barry Minton, Phillip Lockhart and Reg Talbott meet.

1979

On 23 October, 23 carers and professionals attend a meeting, and Headway is born.

1983

First Headway house opens in Gloucester. Today, there are more than 125 groups and branches stretching across the UK and Channel Islands.

1985

Headway moves to new premises in Nottingham, with Reg Talbott appointed its first Director.

1991

HRH Diana, Princess of Wales, consents to become Royal Patron, a position which she held until 1996.

1993

HRH announces her decision to withdraw from most of her public duties at the Headway Christmas Lunch, but remains a Patron for the next three years.

2003

The charity establishes its freephone helpline to ensure no one has to face brain injury alone.

2013

HRH Prince Harry opens Headway's new home in Nottingham.

2017

HRH Prince Harry officially launches the charity's Brain Injury Identity Card.

2018

Annual visits to the Headway website reach the one million milestone, highlighting how far the charity has come in just four decades.



Improving life after brain injury for
40 YEARS
1979-2019
the brain injury association

Healthy body, healthy mind?

In this special feature, we look at some top tips for enjoying a healthy diet after brain injury, and examine ways you can plan and prepare healthy meals while living with the effects of the condition.

What is a good diet?

What makes a 'good diet' varies from person to person and depends on a number of factors such as your level of physical activity, your general health and how your brain injury affects you. Some studies have shown that a Mediterranean diet rich in fruits, vegetables, whole grains, beans, nuts, olive oil and fish may be beneficial after brain injury. This is based on research suggesting it helps to maintain cognitive function as people age.

It's also important to drink plenty of fluids, as dehydration can cause tiredness, constipation and may worsen the effects of brain injury.

What foods can help?

The internet is full of adverts for 'miracle foods' that claim to reverse the effects of brain injury, but sadly there is little evidence to support these claims.

However, some foods promote general good health and may help manage the effects of brain injury. For example:

Choose whole grains, such as wholemeal bread, pasta and brown rice. They release energy more slowly, helping to maintain energy levels throughout the day – especially helpful for people experiencing fatigue.

Extra virgin olive oil is a relatively healthy source of fat and has been shown to have a range of health benefits, including a protective effect on memory function.

Omega-3, a type of fat commonly found in oily fish as well as some seeds and nuts, may help to keep the brain healthy. Studies have shown that a diet rich in omega-3 may help reduce cognitive decline.

Darker-coloured fruits and vegetables such as spinach, kale, blueberries and strawberries, contain high levels of nutrients that some studies indicate could have a beneficial effect on cognition.

What foods should I avoid?

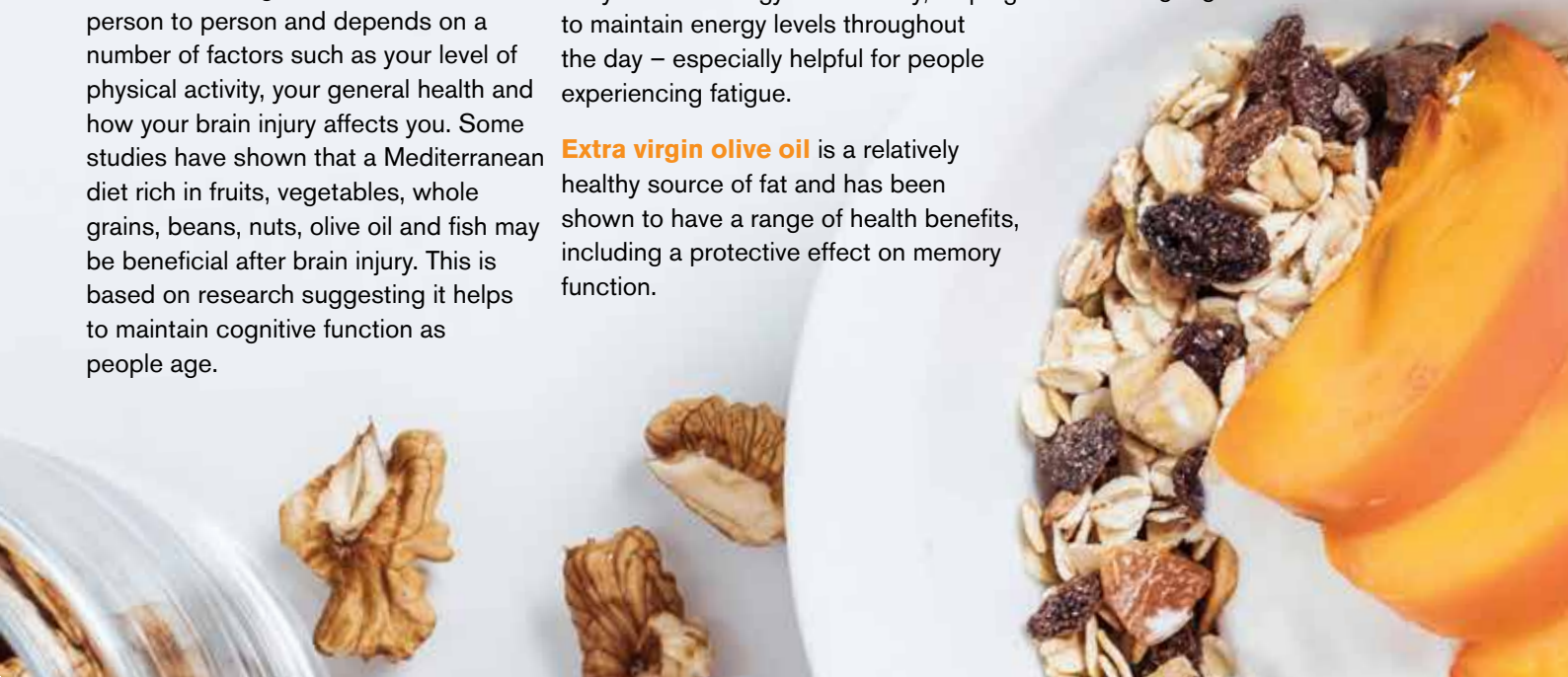
The following top tips can help you stay healthy after brain injury:

Keep your salt levels down. Salt is known to raise blood pressure and increase the risk of stroke. Many people with taste and smell problems add more salt than they should, so use alternatives such as lemon juice to boost flavour.

Avoid sugary food and drink. Sugar can lead to weight gain and other health problems and can cause a 'sugar crash', where energy levels drop – a particular problem for people experiencing fatigue.

Avoid caffeinated drinks. In addition to energy spikes, caffeine can have a negative effect for people who experience urinary symptoms after brain injury.

Limit your intake of processed and fatty foods. These foods often contain high amounts of salt and sugar, tend to have lower nutritional content, and may lead to weight gain.



Be cautious with supplements.

While supplements may be necessary for some people, always speak to your doctor or dietitian before taking them as they could interfere with any medication you are taking.

How do I plan and prepare meals?

The effects of brain injury can make shopping for and cooking food difficult, especially if memory or planning skills are affected. Here are some top tips:

Find and save simple recipes that you can regularly return to.

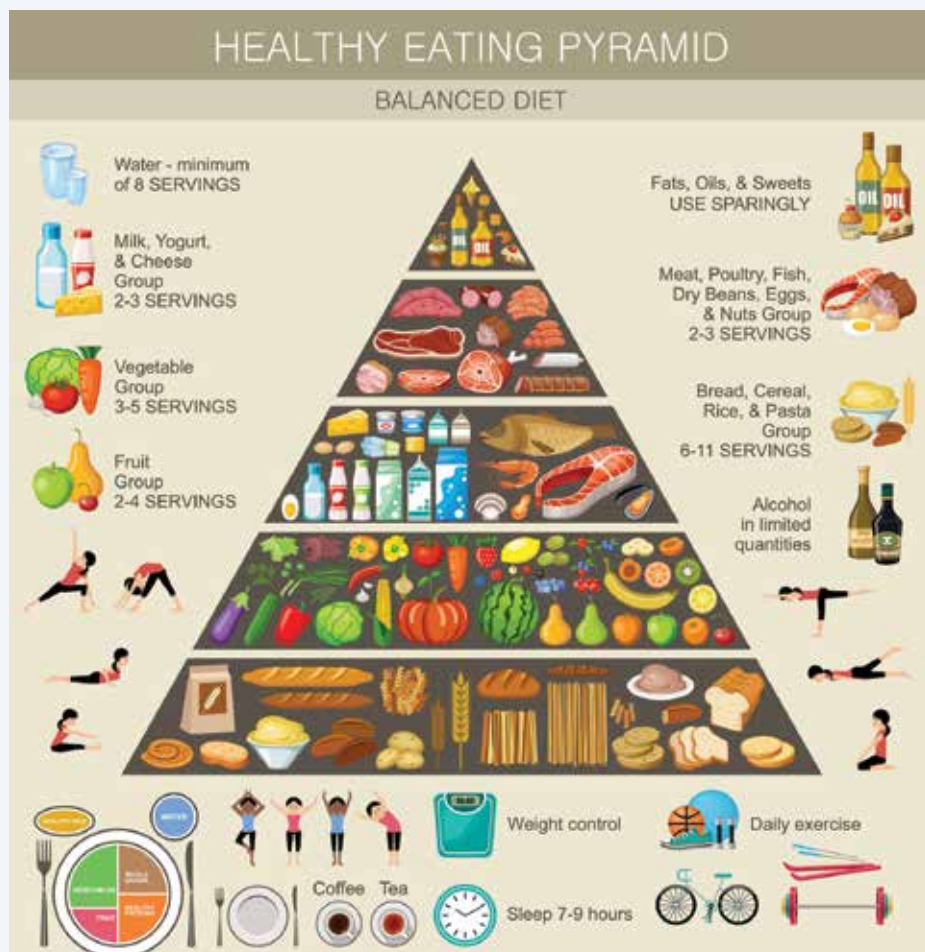
With a meal plan in place, you can add your ingredients to an online shopping order or make a list to take with you to prevent you from forgetting items when you get to the store.

If you experience fatigue, plan your shopping around the times when you generally feel more alert, and when the supermarket is less busy.

When cooking, make extra portions and freeze them in sealed containers. Label each container with the contents and date it was prepared.

If you have problems with taste and smell, pay attention to use-by dates as you may find it difficult to know if food is unsafe to eat.

Avoid under-eating or over-eating by having meals at regular intervals – and don't skip breakfast!



Check the label. Clearer labelling has made it easier for consumers to know what's in their food. If you're struggling to read or understand the labels, don't be afraid to ask someone. You can always use your Brain Injury Identity Card to start the conversation.

If you experience a loss of appetite, set an alarm to tell you when it's time to eat, and speak to a dietitian for advice on getting all the nutrients you need.

Finding the right diet for you

Dietary needs vary from person to person, so if you have any questions or need support, you can speak to:

Your GP, who will be able to provide general information and make any necessary referrals.

A registered dietitian, who can advise you and create a meal plan that works for you.

An occupational therapist, who can advise on aids and adaptations that help you to prepare and eat food.

Remember, a healthy diet is just one way to stay healthy. If possible, combine it with other healthy living techniques such as regular exercise, a good amount of sleep, and staying hydrated.

You can download *Headway's Loss of taste and smell after brain injury* factsheet from our *Information library* on the website.

Or, if you'd like further information or to discuss any of the issues covered, please contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.

Headway
Annual
Awards
2018

Headway **Heroes** *honoured in style*

Eleven Headway heroes, 400 guests, one truly inspirational event.

The majestic Dorchester Hotel in Mayfair was once again the setting for the Headway Annual Awards, which took place in December.

Honouring the incredible courage, dedication and commitment of brain injury survivors, carers and volunteers, the awards are a true celebration of the fact that with the right help, at the right time, there can be life after brain injury.

Here's what happened at the Headway Annual Awards 2018...



Guests were greeted with goody bags, kindly sponsored by CRM Ltd



Sky News presenter Tom Macleod once again volunteered to host the ceremony



Emmerdale actor Emily Head was the guest of honour and spoke to guests about the challenges of portraying a brain injured character in a soap opera



Emily shared her experiences of meeting brain injury survivors at various Headway groups and branches as part of her research for the role



A silent auction gave guests the chance to bid for some incredible items, generously donated by supporters



Headway ambassador Dr Johnson Beharry VC kindly agreed to present the awards



Eric Knowles, star of many antiques television programmes, reprised his role as guest auctioneer

The Headway Annual Awards 2018 ceremony was kindly sponsored by:



Headway Annual Awards 2018



Andy Nicholson, winner of the Stephen McAleese Achiever of the Year Award, with his wife Sharon who nominated him



Carer of the Year finalist Trish was nominated by her son, Stephen



This year's fabulous finalists were representing thousands of others across the UK doing incredible things to improve life after brain injury

IN THE PRESS

Brain injury survivor nominated for award

Headline: Callum Maclean struggled to rebuild life after tumour operation

Press coverage was secured for every single finalist, boosting awareness of brain injury and the profile of their respective Headway groups and branches



MY STEVEN Gwenda Gage 'Inspiration' mum up for carer award

BY KAREN HICKETT
A 58-year-old who has to carry an oxygen tank to breathe is up for an award after surviving 34 years to her brain-injured son.
Gwenda Gage, 58, has been nominated for the nationwide media injury association's 'Inspiration' award as the Carer of the Year.
"The hardest thing is when you're injured jumping from a fourth-floor window to escape a fire in 1994. After the fall Steven had to learn to walk and talk again, and his emotions were affected.
"Gwenda, of Bristol, said: "He gets angry and shouts. It's a bit to cope with."
She is one of three people in the running for the award on December 7.
"Steven is a brave, who nominated him, called her 'an inspiration'."



Gwenda Gage (left) was featured in national newspapers the Sunday Mirror and the Sunday People

Volunteer of the Year winner Susan Kyle (below) was featured in an emotional and incredibly uplifting feature on BBC Look North



Udo Kischka, finalist in the Stephen McAleese Outstanding Contribution to Headway Award, was featured on BBC South Today



Carer of the Year Gwenda Gage receives her award from Dr Johnson Beharry VC and Emma Truin from Barr Ellison Solicitors



Callum Maclean was a worthy finalist in the Alex Richardson Achiever of the Year award for his outstanding work to raise awareness of brain injury

Keep an eye on the Headway website and sign up to Headway News Bitesize!

This will ensure you don't miss out on the chance to nominate someone special for the *Headway Annual Awards* in our 40th anniversary year.

FINANCIAL FRAUD: A RISK YOU CAN'T AFFORD TO IGNORE



We all try hard to keep ourselves and our loved ones safe from danger. But what support exists for the most vulnerable in society?

Cognitive impairment following brain injury can make it hard for people to come to sound financial decisions or to identify when they are at risk of falling prey to financial scammers.

We asked Cifas, the UK fraud prevention service with over 30 years' experience, to tell us how they help people to stay safe from financial fraud and scams.

Financial crime is a serious threat to the UK. Some people can lose their life savings or businesses, which not only leaves them financially devastated but can cause lasting damage to their wellbeing and that of their family.

Even those who recover their money often report varying degrees of emotional and psychological harm as a result of being targeted.

Many people might consider themselves unlikely targets, but fraudsters don't discriminate, attacking all walks of life – rich and poor, young and old – and the increasing sophistication of the methods used mean that even those confident in their ability to 'spot a scam' are falling victim.

People who are considered vulnerable due to age, disability, or illness, for example, are particularly at risk from unscrupulous criminals and sometimes even family and friends.

The *Protecting the Vulnerable* service, provided for free by Cifas, puts extra checks and protection in place for people who are cared for under the Mental Capacity Act 2005, Adults with Incapacity (Scotland) Act 2000 or Mental Capacity Act (Northern Ireland) 2016. If you act as someone's deputy or

hold power of attorney this service may be of interest to you.

"It is important to recognise the epidemic nature of fraud and the impact of the crime on society," said Kirstie Brookman, *Protecting the Vulnerable* lead at Cifas.

"Cifas works with hundreds of UK organisations to protect them and the people who use their services from financial crime.

"Our members range from the largest UK banks such as HSBC and Santander, to charities and government bodies. Together, their customers and service users include some of the most



vulnerable people in society – including people living with brain injuries.

“We are leading the way in tackling the threat to these vulnerable people by creating effective services that protect the individual and reduce the possibility of fraud – including a key service for vulnerable people.”

“These individuals are recorded to our system with a warning about their vulnerable status. Then, if any of our member organisations – which also include all the retail banks and credit card issuers – receive an application for credit, goods or finance in their name, they know to reject it and Cifas will report the incident to the relevant authorities.”

Kirstie told us about a recent case where *Protecting the Vulnerable* stopped an attempted fraud. An attempt to open a bank account in the name of a person registered with *Protecting the Vulnerable* was rejected and reported after the first failed application listed a different address to that of the vulnerable individual.

This was followed by a second attempt that listed the correct address, prompting an investigation that revealed the ‘applicant’ was being impersonated.

This important service from Cifas currently protects more than 5,000 vulnerable people identified by organisations including law firms and

local authorities, as well as individuals.

“We are always looking at other ways to protect vulnerable people from financial crime,” said Kirstie. “Last year Cifas helped launch the All-Party Parliamentary Group (APPG) on Financial Crime and Scamming.

“This group of cross-party MPs looks at the response to fraud by law enforcement, government, and the public, private and charity sectors, and seeks to improve it – as well as support and protect society from the criminals who perpetrate financial crimes.”

The APPG has launched an inquiry into what more could, and should, be done to protect vulnerable people from fraudsters. Headway has submitted evidence about the effects of ABI on cognitive reasoning, lack of insight and vulnerability which will be considered as part of the inquiry.

To find out more about Cifas, you can get in touch at ptv@cifas.org.uk or visit www.appgfinancialcrime.org.



FIVE WAYS TO REDUCE YOUR RISK OF BEING A VICTIM OF FRAUD

1. If you receive a call from someone saying they are from your bank, tell them you will return their call later in the day. Then call your bank on one of its official numbers. Don't call back straight away, and don't dial a number given to you during the call – it could be a hotline direct to the fraudsters.
2. Keep a list of your bank, building society and credit card company's phone numbers in a safe place, so you don't have to spend time looking them up if you are under stress or worried about something.
3. Never share personal or financial information, such as your mother's maiden name, your place of birth, your password, or your bank account details with someone who calls you.
4. If you haven't entered a competition, you haven't won a prize! Don't share any personal details with people contacting you to say you are a winner unless you are sure you entered the competition. This is a really common scam.
5. People you meet online – for friendship, looking for romance, or through shared interests – may not be who they seem to be, especially if you never meet them in real life. Never share personal information with someone you don't know or trust.

How to train your ANXIETY MONSTER

Anxiety disorders are increasingly common.
A recent psychiatric morbidity survey indicates that around three million
people are living in the UK with an anxiety disorder.



Anxiety, depression and other mental health issues are particularly prevalent among those living with the long-term effects of brain injury. For those individuals, their anxiety can feel uncontrollable, and situations that once presented no difficulty can seem impossible.

Being in crowds, being rushed, having to adjust to sudden changes in one's routine can lead individuals to experience a sudden onset of anxiety that can be overwhelming. In their most powerful form, these are often known as panic attacks.

'Anxiety built-up and erupted'

"The panic attacks terrified me," remembers brain injury survivor Tamara Bond. "The first one occurred in a huge department store after a disturbing and unpleasant tube train journey.

"Anxiety built-up and erupted, my natural breathing and heartbeat rhythms were disturbed, and I was unable to swallow."

Tamara, 51, sustained a brain injury after she underwent surgery to remove a hernia growing through her skull on her left temporal lobe. The growth was putting pressure on the brain, causing her to experience frequent seizures.

Tamara said she was pleased to get home but was ill-prepared

Tamara Bond: "My panic attacks terrified me"



for the after effects of the brain surgery, which included memory, cognitive and emotional problems, as well as sensory hypersensitivity.

However it was the regular panic attacks that caused Tamara the most difficulty, affecting her confidence, social life and relationships.

She said: "Noise, distractions and unfamiliar situations triggered the most unexpected reactions that were out of my control.

"One of my early panic attacks occurred while eating a Sunday roast at home. I reacted suddenly after swallowing a mouthful. It felt uncomfortable in my chest as muscles contracted rapidly, causing me to panic.

"It escalated as I found breathing painful and therefore convinced myself that I was choking. The episode left me feeling exhausted with a sore throat, chest pain and a weak voice."

"It also meant I struggled to relax while eating as I was haunted by this severe fear of choking."

Tamara, who is from Suffolk, said the attacks would even affect her when she slept.

"Often I would wake up suddenly gasping, feeling my heartbeat rushing and feeling that I couldn't swallow," said Tamara.

Combined with some of her other brain injury, the attacks began to limit Tamara's social life while impacting on her relationships.

Tamara also reported that she felt guilty about having an attack in the company of her children.

She said: "I felt I was failing as a protective parent – but with time I learnt to accept that they were carers during these uncontrollable episodes.

"My fear of panic attacks has subsided over time. It's almost two years since surgery and my confidence is improving."

Tamara credits this improvement with the help she received from a local neurological rehabilitation clinic, where she had weekly appointments with a clinical psychiatrist and occupational therapist, and support from her local Headway group in Suffolk.

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

The ANXIETY MONSTER

Pamela Ashcroft was run over by a car while walking to catch an underground train to work in London.

She sustained a traumatic brain injury and had to undergo surgery on her knee bone.

As she began the long road to recovery, anxiety reared its ugly head.

"One of the first times I realised that the anxiety had taken over was during a short walk to the shops," said Pamela.

"As I walked along the busy road, I started to feel vulnerable. By the time I left the shop people around me had recognised I was feeling vulnerable and began to ask me if I was okay.

"At first I told them I was fine but on the way out of the shop I had to cross a

road, and at that moment I realised that I was too scared to proceed. A lady kindly offered to walk me home."

Thankfully Pamela was able to get access to a neuropsychologist who recommended acceptance and commitment therapy (ACT).

Pamela said: "We worked on reframing my mental and emotional response to the anxiety, naming it the Anxiety Monster. My neuropsychologist encouraged me to understand the nature of the monster and on which part of the body I would sense it.

"While I was out on a walk on my own, I noticed that the Anxiety Monster's presence was more apparent as I approached traffic and that the feeling was coming from my tummy.

"It would give me sudden commands like 'Turn around and go home'.

"My neuropsychologist encouraged me to turn the monster into a funny character who would give me commands in a voice like Donald Duck's. It then became funny receiving commands from it.

"ACT encourages you to accept your feelings of anxiety, to allow them to be there. However, despite those feelings, you tell the Anxiety Monster 'I know you're telling me not to keep walking, but I'm going to carry on walking anyway'.

"I managed to catch the underground to my final ACT session on my own and now I travel by underground alone to meet friends.

"You can't fix anxiety. It's a human emotion and we wouldn't be able to survive without it.

"However there are ways to calm you down and manage anxiety, such as naming and characterising your own Anxiety Monster, and I hope my tips will help others."

Pamela's top tips for coping with anxiety

Allow it to be there

Accept your feelings of anxiety. When doing an activity that usually creates anxiety for you, tell your anxiety that you know it's trying to protect you but that you believe in the benefit of doing this activity so you're going to do this anyway. Eventually the anxiety will subside.

Observe your thoughts

We are not our thoughts and our feelings. The feeling of anxiety is not you. This becomes clear when you learn to observe your thoughts. Do



this exercise: every time you identify a thought or feeling in your mind, tell yourself 'I'm having a thought that...' or 'I'm having a feeling that...'. Set aside twenty minutes every day to train your mind to do this to.

Set a goal

What short-term goal do you want to achieve through managing your anxiety? This could be using the underground on your own, or joining the gym, or meeting friends. It is important to have something to work towards.

Take graded steps

At first, set smaller goals towards your main goal, for instance to walk a few houses away from your house or

to cross the road. As I increased in confidence, I took bigger steps. For example, I went to the underground platform with a friend, caught the train alone and got off at the next stop. Then my friend met me at the next stop. I built this up to eventually catching the underground on my own.

Challenge negative self-talk

If your inner voice tells you that you can't do something, ask yourself: 'If I buy into this idea will this help me towards achieving my goal?'

Identify and practice challenging aspects of your goal.

My goal was to use the underground

on my own and I realised that one of my main challenges in doing that was using escalators. So I practiced using escalators in a department store first with a friend and then on my own.

Create a calendar of events

Make sure you are doing an activity every day to work towards your goal. Develop a daily calendar of events according to what you feel you can manage but at the same time push yourself and then stick to the calendar.

Keep pushing through

Once you achieve your goal, practice it regularly so that it becomes natural. You can set yourself new goals to keep challenging yourself.



Dr Simon Fleminger

Dr Simon Fleminger, Consultant Neuropsychiatrist, St Mary's Hospital.

Difficulties with emotional control, mood swings, depression, anxiety and irritability are common after brain injury.

They often overlap. Sometimes the person suffering these symptoms doesn't fully appreciate how troublesome they are. So the most difficult hurdle to cross may be acknowledging there is a problem in

the first place, and then being willing to ask for help.

Family can help by gently asking how the person is feeling, asking what they can do to help, trying not to take anything personally, and avoiding arguments or comments that could appear to criticise.

Try to find something that is enjoyable and encourages exercise and activity. Support groups can be invaluable both for the brain injury survivor and their family.

The treatment of emotional and other psychiatric problems after a brain injury is often similar to the treatment for those without a brain injury. Thus self-help manuals, for example as published by Mind for anxiety and depression, can be very helpful. But often an assessment by a clinician is needed.

Psychological treatment may be needed; consider getting a referral to your local IAPT (Improving Access to Psychological Treatment) service if you have one, and make sure the clinician who is assessing you

understands that having a brain injury is no bar to psychological treatment.

Medication may help; for many with troublesome emotional problems a trial, for example of an anti-depressant, is worth considering.

We're here to help

Our *Psychological effects of brain injury* booklet and our *Mental health and brain injury* factsheet provide more information on this topic, and both are free to download from the *Information library* section of our website.

Our free and confidential helpline (0808 800 2244; helpline@headway.org.uk) will also be happy to support you, or talk through any specific questions you may have.

Need support? Contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk 23

Dating after brain injury

Finding the confidence to love again

For people living with the long-term effects of brain injury, the idea of dating can be a daunting and challenging prospect.

Common concerns include the difficulties of dating when you have memory issues, low confidence and communication problems, while family members and carers often have concerns about their loved ones' safety.

Brain injury survivor Kathryn found dating and intimacy very challenging following her haemorrhage but explains that with time, and after many emotional highs and lows, she again felt able to meet people.

Kathryn suffered a subarachnoid haemorrhage caused by a ruptured aneurysm in 2015.

"I was on phone with my partner when I began to feel a little strange," said Kathryn. "It felt as if my life-force was draining out of me, and my head felt woozy.

"I then said 'I feel really ill, call an ambulance'. I remember nothing after that.

"Apparently my speech became slurred and I was making no sense, as if I had had a stroke and was unable to converse. He heard me collapse and go into seizure."

Kathryn's partner phoned an ambulance and she was transferred to hospital for emergency surgery. After a number of operations, Kathryn slowly began to recover.

However, she was left with a host of issues including partial vision, speech and walking problems, cognitive impairment, acute fatigue, anxiety and low-self esteem.

Kathryn said: "Just before my haemorrhage, my partner and I had decided to take a break from each other. But a week after I returned home from hospital, he walked out on me completely and I never saw him again."

This rejection hit Kathryn hard and she felt very isolated as she tried to come to terms with the effects of her brain injury.

She said: "I became anxious, frightened and just shut down. I started to believe I would be alone for the rest of my life.

"I never thought I would have the confidence to love, to share, to be a partner in any way."

Kathryn said it took three years until this situation changed.

She said: "I just suddenly decided 'I am worth more than this', so I went on an internet dating site and posted a profile.

"I had a reply within a matter of minutes and had a lovely evening chatting to a nice guy. It was nice to speak to someone who was attracted to me and the experience gave me a boost. I knew the old Kathryn was still there."

After a short while, Kathryn met another man online who was to become her new partner.



Kathryn

She said: "We spoke a lot on the phone, chatting for hours and hours at a time.

"I told him everything that had happened to me and he was nothing but kind, empathetic, and a fantastic listener – I just let it all out."

"Sometimes you don't want advice; you just need someone to listen."

It wasn't long until the pair met up in person. To help make the date as easy as possible, Kathryn put in place some simple steps.

She said: "Our first meet up was in a local bar. We had something to eat and a drink before watching the world go by for a short time in a nearby park.

"This all required strategic planning on my part. I had to arrive in a taxi,

which meant overcoming a number of tasks I find difficult these days, such as working out the cash payment, undoing my seat belt, and walking into the bar.

"I made sure I got there as early as possible so I had time to relax before he arrived, and I picked a table position I felt comfortable with that was near the toilets so I didn't need to walk far."

Kathryn also took some simple steps to make sure she didn't jeopardise her safety.

She said: "The first time I met him I made sure that he dropped me off at a pub near my house, as I didn't want him to know where I lived until I could trust him, and I got a taxi home from there."

The couple have now been together for six months and their relationship is slowly getting stronger.

Kathryn said: "I feel more normal and it's lovely to be with someone who accepts the effects of my brain injury.

"I'm only seeing him once a week, but daily phone calls have brought me some joy."

Kathryn said she understood why brain injury survivors might be scared of dating or starting a relationship with someone.

She said: "I know what it's like to be scared, to put yourself out there again, but life is for living and you have to stay positive.

"When you are ready, and as long as you have control, you should take the brave step of letting someone into your life."

Staying safe – top tips

Safety concerns can often put people off from starting new relationships following brain injury. But taking precautions, and asking for support, can increase your confidence and keep you safe.

- ♥ Be careful to not share too much information, such as your address or personal details, before you get to know and trust someone new.
- ♥ When meeting someone new for the first time, do so in a public place and tell a friend or family member where you're going, and who you're meeting.
- ♥ Take it slow! If you feel you're not in control of the speed of the relationship, be sure to tell a friend or someone you trust who can support you.
- ♥ Don't feel pressured to tell people about the effects of your brain injury if you don't feel comfortable in doing so.

For more information, download our *Relationships after brain injury* booklet from the *Information library* section of our website.

#HeadwayHeroes

HOW WILL YOU CHALLENGE 40?

Anyone born before 1979, the year Headway was founded, is likely to tell you 'age is but a number!' Anyone nearing a major birthday might tell you otherwise, but nonetheless, at Headway we plan to enjoy turning 40!

To mark our birthday we wanted to do something special that everyone can get involved in – so we've created Challenge 40. We're asking anyone with a passion for improving life after brain injury to take on any challenge they like – as long as it involves the number 40.

40k in just one day!

The beauty of Challenge 40 is that anyone can get involved. You can take on any activity or challenge you like, and it doesn't need to involve physical exertion.

But for former Paralympian and Headway ambassador Jack Rutter, a physical challenge was always on the cards – and what a challenge he's chosen!

Super-fit Jack, who captained the Paralympics GB seven-a-side football team in the Paralympic Games in Rio, is taking part in Challenge 40 by running 10k, cycling 25k, rowing 2.5k and using the cross trainer for 2.5k – a total of 40km in just one day!

He said: "I want to raise funds and awareness for Headway charity because they helped save my life as well as supporting my family through a very challenging time after I sustained a brain injury in an unprovoked assault while out with friends.

"I want every brain injury survivor to receive the help and support they need from this unbelievable charity and hopefully doing this will help that outcome in some way.

"It will be tough because I'll be aiming to do the challenges as quick as possible. They will also work my whole body so I will be shattered.

"I was told by doctors I would struggle to ever ride a bike very well after my brain injury so conquering my fears of



Jack Rutter

cycling 25km after a 10km run should once again show people what is possible."

Swim 40 miles



Wash 40 cars



Run 40 miles



2,560 lengths – or 40 miles!

Sandra Stamp was supported by Headway when her brother-in-law Andy sustained a severe traumatic brain injury in a road traffic accident 20 years ago.

Sandra said: "When Andy sustained his injury our lives were changed forever as a result. Thankfully, Headway was there to provide us with invaluable guidance and support.

"We saw Challenge 40 and wanted to get involved, choosing something we

could all do. So, this year, my sister Angie and I are each going to swim 40 miles, which is 2,560 lengths of a standard 25m swimming pool.

"Andy is also going to join in the fun by going swimming 40 times.

"To make this equally challenging to us all, and because I am a regular swimmer already, I have decided to take up open water swimming and will be participating in The Great East Swim and Swim Serpentine later this year.

"This is way out of my comfort zone, but I have learned this is where the magic happens!

"By completing Challenge 40, we all hope to become fitter and have a real sense of personal achievement, whilst raising vital funds for Headway UK and Headway Essex, charities that mean so much to us."



Andy, Sandra and Angie (right) plan to make a splash with their fundraising

Lunch on the go

Headway staff have also been eager to show their support by taking on challenges.

Clare Mills, Public Affairs Manager, Anna Kerr, Corporate Partnership Officer, and Trust Administrator Emma Lewis are lacing up their trainers and running 40 miles in 40 days – using up their lunch breaks to do so!

Press and Campaigns Manager, James Coxon, has also started his challenge to cycle 400 miles in 40 days in a bid to raise £400.

Clare and Anna both have personal connections to brain injury, which makes the challenge even more important to them.

Clare said: "Both our families know what living with the effects of a brain injury is like so we jumped at the chance of getting involved in this special year."

Anna added: "The thought of how much good will come from this will keep us going on a challenge that will no doubt include a lot of cold runs.

"Once you take into account work meetings, the winter weather and our limited fitness, this is more of a challenge than you might think!"

Meanwhile, James says shedding a few pounds ahead of his wedding later on in the year gives him yet another incentive.

He said: "Every day I speak to brain



Anna, Clare and Emma limber up

injury survivors, their carers and loved ones, and every day I'm inspired by their resolve and courage in rebuilding their lives.

"This challenge will hopefully result in me losing a little weight ready for my wedding day. And on top of all this I get to help Headway continue to support some amazing people across the UK. A clear win-win!"

Bake 40 cakes



Cycle 40 miles



Inspired? Want to get involved? Visit www.headway.org.uk/challenge-40 for more ideas and to sign up.

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Reaping the rewards of digging deep

None of our work to improve life after brain injury would be possible without our generous supporters. The good news is that it seems it's not just Headway that benefits from fundraising for the charity...

Here we say a special thank you to three firms that have gone – and are still going – the extra mile (in several different directions!) to raise funds for the charity.

Taking the Plunge

2018 was a year of adrenaline-filled fun for Saltus Private Wealth Management.

The firm, which provides integrated financial planning and investment management for personal injury awards, raised an incredible £21,000 thanks to its energetic and daring staff.

While some of the team pushed their bodies to the limit by hiking up Scafell Pike or running the London Marathon, others looked to gravity to help them reach their destinations, courageously completing daring skydives or abseiling from tall buildings.

Michael Stimpson, an Investment Manager and a member of the Saltus PI team, said: "We are so proud to have raised more than £21,000 for Headway.

"Personally I experienced a number of firsts in the shape of abseiling, skydiving and marathon running, as well as a couple of lasts – namely abseiling, skydiving and marathon running!

"Our business has benefitted immensely from the team building experience we all had in the Lake District and we are all delighted to have done our bit for such a worthy cause."

Full Steam ahead

It seems fundraising for Headway can be addictive.

Fresh from raising an amazing £40,000 in 2018, GB Railfreight (GBRf) has announced Headway as its Charity of the Year for 2019.

The highlight of last year's fundraising activities was a charity charter event that saw 400 train enthusiasts tour the UK in special carriages pulled by rarely-seen locomotives, as reported in the previous edition of Headway News.

Daniel Matthews, Business Performance Analyst at GBRf, said: "We enjoyed working in partnership with Headway during 2018.

"The vital work of the charity has inspired us to continue our support for another year in order to help raise even more funds to help this special charity."



"To start this year off, we asked all staff to donate unwanted items to be sold in Headway's shops, and as always, our staff were very generous, managing to fill more than a dozen donation bags.

"But this is just the start of what we hope will be another successful year supporting Headway."

Jo Plant, Fundraising Director for Headway, said: "Firms like Saltus make us feel tired just reading about their exploits, while the incredible passion and generosity of GBRf staff is humbling.

"It is hugely gratifying to hear much people enjoy fundraising for the charity.

"It just goes to show that charity giving can be so beneficial to all involved and it sounds like the Saltus and GBRf teams have really benefited from the experience of working with us."



#HeadwayHeroes

QUICK OFF THE MARK

When law firm Simpson Millar chose to support Headway as its Charity of the Year, they said they were committed to hitting their 12-month fundraising target of £20,000. Well, it seems 'committed' was the right word!

After just one month, staff have reached a quarter of the target and are already talking about increasing it.

The firm will be drawing on its runners, cyclists and golfers to raise the money, with a charity ball set to end the year in style.

Ian Cohen, National Head of Personal Injury and Clinical Negligence at the firm, said: "Simpson Millar is honoured to support Headway, especially in its 40th Anniversary Year.

"The work that Headway does on behalf of serious head injury victims is absolutely invaluable. At Simpson Millar we know that when people suffer life-changing injuries, they need support during the litigation process and beyond.

"Our own values of being open and supportive of survivors of brain injury and their families are a perfect fit with



Ian Cohen accepts a Headway Challenge Baton from Dr Johnson Beharry VC

Headway and we are really excited about working closely with the charity over the coming year."

Headway's Director of Fundraising Jo Plant said: "We are delighted that Simpson Millar has chosen us in what is a special year for the charity.

"They have made a fantastic start already and we look forward to hearing all about their efforts over the next 12-months. It looks like they will have a lot of fun."



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DID YOU KNOW...

At Headway, we can help you take on a huge variety of fundraising challenges that will not only raise valuable funds to help improve life after brain injury, but also leave you with incredible memories of completing a once-in-a-lifetime challenge.

But you don't need to strap on your hiking boots or lace up your trainers to make a difference.

There are plenty of less physically demanding ways to support the charity, such as through sponsorship of our award-winning publications, our Pay for a Day scheme that helps fund our helpline, or advertising in Headway News.

Check out what's on offer at www.headway.org.uk/get-involved.

Alternatively, you can drop us a line on partnerships@headway.org.uk or just give us a call on 0115 924 0800 to have a chat about how we can work together to improve life after brain injury.

**Ways to work with
Headway
in 2019**



Corporate supporters taking part in the Orbit Abseil for Headway in 2018

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“Thompsons helped us to settle a legal case for a substantial sum and we now have the financial security we need to access the best possible care and support for Adam.”

Anita, mother of Adam, one of Thompsons' brain injury clients



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

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