

Autumn 2019

# Headway News



The magazine of Headway - the brain injury association

Let's  
talk tech

**Music  
after brain  
injury**

*Dancing  
On Ice star  
opens up  
about stroke*





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the brain injury association

Headway is the leading UK-wide charity that supports people to rebuild their lives after brain injury through the provision of information and support services across the UK. To find out more, visit [www.headway.org.uk](http://www.headway.org.uk) or you can call the freephone helpline on 0808 800 2244 if you need support.



the brain injury association



## Can tech help?

We truly live in the digital age. A time where you can order a weekly shop on your computer, video call your relative on the other side of the world, or speak to a virtual assistant in the corner of your living room to find out tomorrow's weather.

Technology is transforming every aspect of our lives and in this issue of *Headway News* we focus on what that could mean for brain injury survivors and their loved ones.

Our feature, on page 14, highlights gadgets that help you remember, apps that guide you around town and even software that enables you to communicate. However, it also explores some of the negatives to all this technology.

We also report on an exciting event which took place at one of our groups in Suffolk that brought together experts to explore the tech options available to support brain injury survivors in rehabilitation and long-term care.

The issue of making sure brain injury survivors receive the best possible care is one that Chris Bryant, MP for Rhondda, is extremely passionate about too.

Our interview with Chris, on page 10, explores all the great work he is doing as Chair of the All-Party Parliamentary Group for Acquired Brain Injury in Westminster and what the group's future plans look like.

Elsewhere in this edition, we look at the dangers of carbon monoxide poisoning, find out how a young couple's relationship was affected by brain injury and also hear from *Dancing On Ice* star Alex Murphy.

Alex is sharing her story to raise awareness of how strokes can hit at any age. Make sure to look out for her when the new series of the ITV show begins early next year.

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

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# Your views...

Public transport can be a lifeline for many people, granting independence and freedom. However, the effects of a brain injury can present challenges. We asked for your views on using public transport following a brain injury:

I can't manage the bus without noise cancelling headphones and music. Way too many sounds.

Gail Coleman

I can remember the first time I went on the bus on my own, my anxiety was through the roof but I managed to keep calm. I wrote down on my phone little positive notes that I am able to do this just like everyone else.

Georgie Louise Smith

I absolutely love public transport, I have a disabled person's rail card and a bus pass, I use both regularly.

Holly Robinson

Catching the bus is my main way of independence.

Kev Demery

One thing I find useful is to write down bus/train times and alternatives should one be missed. Writing down the route also helps so that I don't get off at the wrong stop.

Anon

I always ask for the driver to ensure he sees me seated before moving off. When ready to get off, I wait for the bus to totally stop before I get out of my seat.

Freya Perry

It is essential. For me, just being able to get to the bus stop was the first major milestone in the recovery process.

Pete Hurford

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#Headway Heroes

news you may have missed...

# Brain injury brings MPs together

MPs from across the House of Commons came together to show their support for brain injury survivors in recent debate.

Chris Bryant MP secured the debate (you can read our interview with Chris on page 11) and raised the issue of rehabilitation.

Newport West MP Ruth Jones drew on her professional experience as a physiotherapist before her recent election to Parliament, saying: "Research in the field of neuro-plasticity clearly indicates that recovery can go on for weeks, months and even years after an assault or trauma.

*"It is therefore vital that our rehabilitation services can match that, so they must be available for weeks, months and years after the incident. In the later stages, somebody may not require treatment, advice and support every day, but it should be available for them to access when they need it."*

Members from Scotland, Wales, Northern Ireland and England took part in the debate, demonstrating the UK-wide support there is for those affected by acquired brain injury.

Seema Kennedy MP, the Minister for Public Health and Primary Care, responded for the Government.

On rehabilitation, she said: "I will discuss with NHS England what it is thinking, what it is doing on the [rehabilitation] audit and what the next steps are. We need to impress on it the importance of bed provision... I hope that today's debate has demonstrated how seriously this Government and this Minister take ABI and the devastating effects it can have on our constituents."



# ACTION FOR

# BRAIN INJURY WEEK 2020

The date for next year's Action for Brain Injury Week has been announced and will run from 11-17 May 2020.

Hats for Headway Day will take place on Friday 15 May and once again provide a fun way for people to get involved and raise money to support either UK-wide or local Headway services.

The theme for the week will be announced in due course, so keep an eye on our website or our social media pages for further information.

[www.headway.org.uk](http://www.headway.org.uk) and [@Headwayuk](https://twitter.com/Headwayuk)



## Concussion in football back in the spotlight

A new study has revealed that Premier League players who sustained a concussion earlier in the season went on to suffer from a dip in performance.

The research, published in the *American Journal of Sports Medicine*, relates to a 10-year comparison of the incidence of sports-related concussions between 2008 and 2017 in the English Premier League and the United States' Major League Soccer (MLS).

The MLS players were found to have missed an average 7.3 games after a concussion (over a period of 37 days) compared to an average 0.6 games (over a period of 10.9 days) for Premier League players.

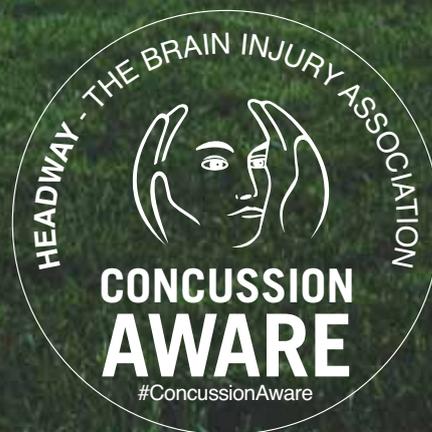
Statistical performance in relation to games started, assists, shots on goal,

and total shots after concussion was reduced in all outfield positions for players in the Premier League.

For the MLS players, there were no significant decreases in performance.

The Premier League was not involved with the study, but has stressed how new concussion protocols were introduced in 2014 that included a

new tunnel doctor and annual baseline testing, and how players have been working with researchers trying to develop a pitchside concussion diagnosis tool.



news you may have missed...

# Renewed calls for boxing ban following deaths

Headway has again called for boxing to be banned after the loss of two young lives in recent weeks.

28-year old Maxim Dadashev and 23-year old Hugo Santillan both died following brain injuries inflicted while in the ring.

Headway's Chief Executive Peter McCabe featured live on Channel 5 News and was quoted in a number of national newspapers calling for the so-called 'sport' to be banned.

"We are saddened to hear of this tragic loss of life and our thoughts go out to Maxim's and Hugo's family and friends," said Peter.

*"Suggestions that boxers understand the risks or that such tragedies are unpredictable are simply not credible. Young boxers are not provided with the information to make an informed choice."*

"So long as the ultimate objective of boxing is to render your opponent senseless by repeated blows to the head, then boxing will remain a dangerous activity.

"In the words of Maxim's own trainer Buddy McGirt after the fight "He seemed OK, he was ready, but it's the sport that we're in. It just takes one punch.

*"The time has come for boxing to be banned."*



Headway's Chief Executive Peter McCabe

# Government watchdog issues hidden disability warning

Headway has welcomed an announcement by the Local Government and Social Care Ombudsman on hidden disabilities.

The ombudsman, which looks into complaints about local authorities, is now urging councils to check their procedures to avoid disadvantaging people with 'hidden disabilities' following the publication of three separate investigation reports into London councils.

The cases highlighted by the ombudsman all show councils not doing enough to enable someone to use their services. They include not making reasonable adjustments to help a woman with autism to repay overpaid housing benefit, and two councils not helping a man with severe dyslexia to deal with parking tickets and permits.

In a statement, Local Government and Social Care Ombudsman Michael King said: "The Equality Act 2010 requires councils to anticipate the needs of people who may need to access their services. This means when councils are alerted to the fact someone might need to be treated in a different way, they should ask that person what adjustments are needed, and consider whether these are reasonable.

*"It can be difficult for people to navigate complex council procedures, yet in all three cases, the councils were made aware that these people needed additional help, but none was given."*

Headway's Public Affairs Manager, Dr Clare Mills, said: "We have seen greater understanding of hidden disabilities in frontline services, such as the extension of Blue Badges to cover hidden disabilities, but organisations must ensure that other procedures are non-discriminatory."



## Working together to improve financial services for people with ABI

Headway is pleased to have been consulted on a research project run by think tank Demos and consumer protection charity Cifas.

The report, *Protected by Design: New Fraud Protections for People at Risk*, was launched on 1 July 2019.

Speaking at the launch event, Headway's Chief Executive Peter McCabe said: "Finding more ways to support people with brain injuries to live independently, and helping families and carers to support them safely, is important.

"Managing money can be one area where effective support can make a big difference to people's lives.

"It is important that providers of financial services realise the huge variations in people's preferences and abilities after brain injury. No two brain injuries are the same but providing personalised financial services may help to address people's individual needs. We are very keen to test how the recommendations from this project can work in practical terms.

"The complexities of brain injury make protecting vulnerable people from financial fraud a challenge. Effects such as impulsivity and a lack of insight are common, while the difficulties in defining mental capacity, particularly with fluctuating conditions such as brain injury where survivors are significantly affected by fatigue, are well known.

"We welcome the involvement of Cifas and Demos in addressing this important but complex issue."

The report makes a series of recommendations which cover defining vulnerability, the development of protective products and services, identifying people who could benefit, and cross-sectoral working.

Special Feature

# Speaking up for brain injury survivors

Chris Bryant MP explains why he is passionate about raising awareness of ABI in Parliament.

MP for Rhondda



Chris Bryant MP has gained a reputation in Westminster as a passionate and eloquent orator – perhaps unsurprising, given his background as an Oxford graduate, an author and a one-time Anglican priest.

Over the last couple of years, he has become known for his ability to speak on almost any subject raised in the House of Commons, and somehow to link it to brain injury.

We caught up with Chris after he addressed a packed room at Headway's *The Way Ahead* conference to find out more about what drives him to speak up on acquired brain injury and champion those affected.

*Q: Chris, how did you first become interested in the issue of acquired brain injury?*

I was born in Cardiff and have lived for much of my life in South Wales. Rugby is in my blood. I even broke my leg playing in a charity match in 2011! And I know so many people, and have met so many constituents, who have spent a long time playing rugby and, as a result, have been affected by concussion.

As a Welshman, rugby fan and former player for the Parliamentary rugby team, I became concerned that not

enough was being done to ensure players and coaches are aware of the dangers of concussion.

In 2013 footballer Hugo Loris sustained a head injury while playing for Spurs and I promised to set up a cross-party campaign in Parliament to raise awareness around concussion.

In 2014 we held an event in Parliament on concussion but the more I learned about it, the more I became aware of the lack of understanding around acquired brain injury and the vast range of causes which can lead to ABI.

In 2017, along with a few colleagues, we decided to re-establish the All-Party Parliamentary Group (APPG) on Acquired Brain Injury and I'm delighted with the support we have attracted from both the House of Commons and the House of Lords, and from politicians of all parties.

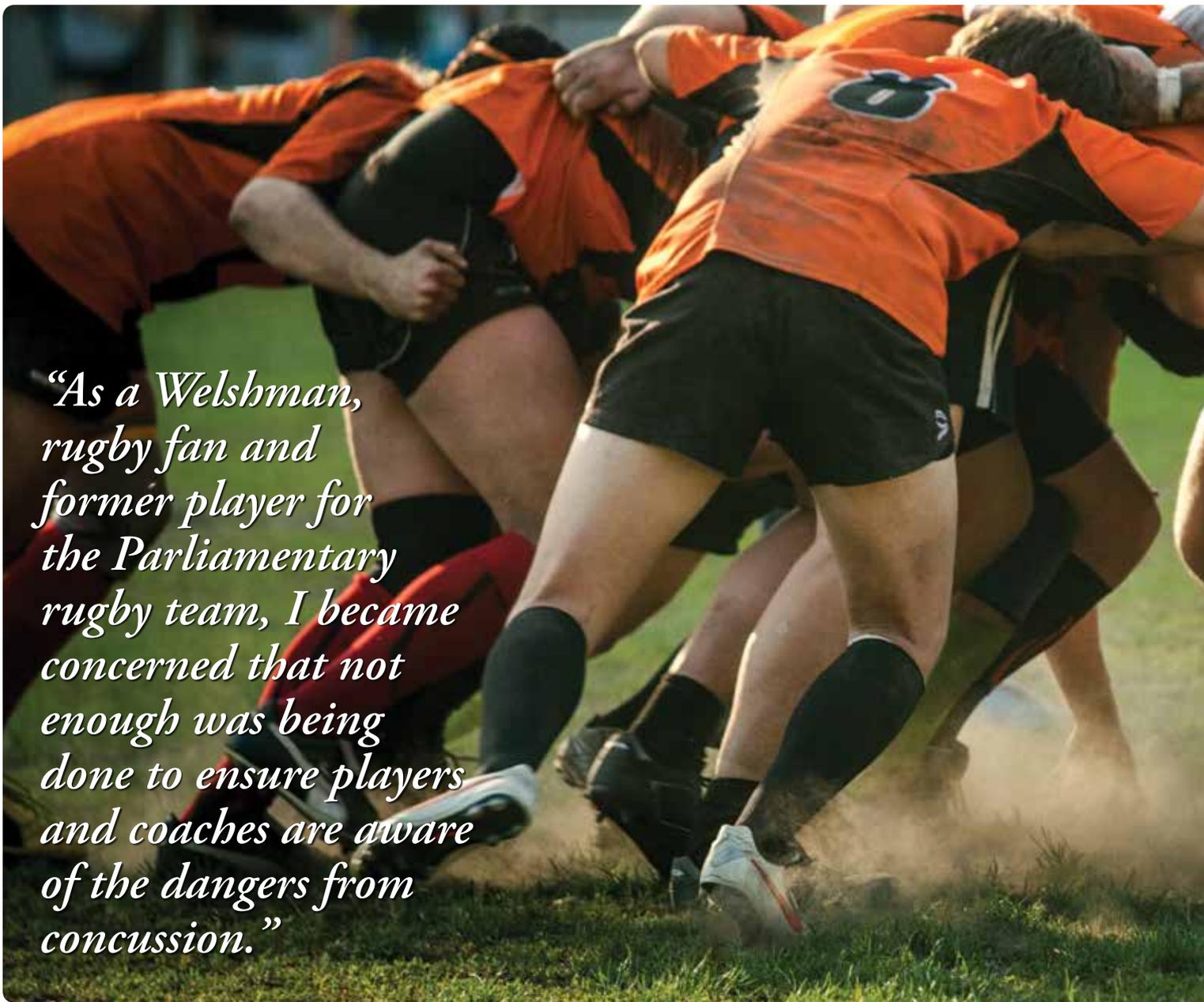
*Q: When we talk to campaigners working to raise awareness, we often find they have personal or family experience of ABI. Is that true in your case?*

I clearly remember one of my grandmother's cousins. She was one of three: there were three sisters who never married – Katherine, Isobel and Alison Gracie.

Alison Gracie had a stroke and then a fall down a flight of stairs. The combination of the two meant that we could see the same person inside, but the mental pain that she was suffering was intense. She would hit her head all the time, using a Scottish phrase—her words, not mine: “MD, MD, MD!” That meant “mentally deficient”, the phrase of the time in Scotland.

I feel passionately that we must move further on from that time and ensure that everyone affected by ABI receives timely and effective rehabilitation.

My own recent experience of being diagnosed with Stage 3 melanoma also brought



*“As a Welshman, rugby fan and former player for the Parliamentary rugby team, I became concerned that not enough was being done to ensure players and coaches are aware of the dangers from concussion.”*

home to me, in a very personal and horrible way, how quickly life can change. One day you have an idea in your head of what the future will probably look like, and the next that's all gone and you don't know what is going to happen next. It's brutal and destabilising. I am so grateful for the care I have received, for the support of my husband and that the treatment I have been given has been a success. But experiences like this make us think about our own mortality, about making the most of our lives and doing what we can to help people in need.

*Q: The APPG has been busy holding a series of roundtable events on*

*neurorehabilitation, education, criminal justice, concussion in sport and disability benefits. You've also hosted lobbying events and the APPG has published a comprehensive report, Time for Change. What's next?*

The *Time for Change* report made a number of recommendations and pursuing those is the top priority. So that includes pushing for full use of the Rehabilitation Prescription and for more neurorehabilitation services,

for in-patients and in the community.

There needs to be more work on developing knowledge of ABI in the disability benefits system, which I know Headway has been working on.

We've also identified some actions to be taken around criminal justice, education and where it all began (for me), on sports-related concussion.

One thing I am passionate about is bringing together ministers from across Government to look at how the work of their departments could do more to support people affected by ABI.

I want to see a team of ministers from Defence, Work and Pensions, Transport, Health and Social Care, Criminal Justice and other parts of the government looking at ABI because a brain injury affects every aspect of people's lives – we can't think of ABI as “just an issue for health.”



*Q: Thank you for coming to speak at **The Way Ahead** conference in July - we know how busy your weekends must be. What was your impression of the event?*

I have met so many talented, passionate and determined people working to change the futures of people with an acquired brain injury since setting up the all-party group, including clinicians, people who work in the charity sector and of course people from Headway.

Some of the most powerful conversations have been with people who have had brain injuries and have spoken about what their experiences have been like.

It's important for me and other parliamentarians to hear these experiences so that we can focus on the right things in Parliament which is why it's been a pleasure to see so many people at the event and have the chance to talk together.

Thank you for inviting me to come along – it was fantastic to be part of such a good weekend.

If you want to keep up with Chris' activities in Parliament, why not follow him on Twitter?

**@RhonddaBryant** – and you can follow Headway too **@HeadwayUK**



Chris pictured with Headway staff, Harriet Bettany (left) and Amber-Rose Perry, at The Way Ahead conference

# LET'S TALK TECH

## How apps and gadgets can help with life post brain injury

Technology is all around us, from the phones in our pockets to the cars we drive, and it is becoming smarter all the time. The seemingly relentless march of progress opens up new possibilities, and challenges, for people with brain injury and their loved ones.

In this feature, we combine feedback from our online communities with the results of an innovative 'Hot House' event that supported the planning of an upcoming Headway brain injury rehabilitation hub in Suffolk, to examine the current and future technologies that could promote independence after brain injury.

### MEMORY AIDS

Memory problems are a very common effect of brain injury, and an area in which technology can be a great help. While rehabilitation to improve memory function in the long-term is notoriously difficult, people can learn strategies and use tools to help support memory.

Most of the population own a smartphone and carry it with them wherever they go, and the standard apps and features they offer can be ideal for supporting memory.

"My phone is my lifeline," said Lisa-Marie Russell on our Facebook page. "I've got all my appointments in my calendar. I set reminders on there that pop-up on the day with what I've got to do."

Different platforms such as Android, iOS and Windows offer a lot of potential for synchronising calendars and alarms across different devices.

There are ways in which other simple features of smartphones can be helpful. RockinRic, from our HealthUnlocked community, shared a powerful way to support his wife's memory:

He said: "My wife, who has memory impairment from an ABI, uses the camera on a smartphone to take pictures every day of what's happened as it saves it in time and date order to allow an accurate record as a technique to look back on."

Matthew Pallet, who relies heavily on Google Calendar to organise his life, cautions about over-use of technology, which can become confusing.

He said: "As with anything, though, this is a double-edged sword. I share a calendar with my partner and it's bloody useful, but I often get overloaded by the mounting reminders and notifications."

### VOICE ASSISTANT

With the increasing availability of reliable voice assistants on our mobiles, many more people are able to easily use technology to support their independence.



TBI\_Survivor over on HealthUnlocked shares how built-in voice recognition features make using digital reminders possible:

*"To be able to just speak to my phone and say, 'OK Google, remind me at 2pm tomorrow to...' helps me not lose track of things that would otherwise just disappear from my mind."*

For others, voice technology has allowed them to achieve more than they ever thought possible after their brain injury.

Donna Siggers explains: "Voice recognition software allows me to write on bad days and likewise when Word speaks back to me it allows me to hear my mistakes. I had to re-learn how to read/write after my head injury but became an author. Tech is definitely my friend!"

## GETTING AROUND

A built-in feature of modern mobile devices is a GPS tracker, which allows people's locations to be accurately pinpointed.

In the early stages after her injury, RockinRic's wife used this feature to support her rehab.

He said: "The physio team used the tracker function on a smartphone while she was learning to walk alone around the large grounds of the care home."

With route-finding often being affected after brain injury, many respondents sang the praises of built-in apps such as Google Maps, Apple Maps and even standard sat-navs, which offer an invaluable way to avoid getting lost!

"Moved to a new city last year and a new flat this year," said Alice Manning on Facebook.

*"When I'm tired my short-term memory is particularly bad including directions, and all the tenements look pretty similar. Finding my way home is so much easier when I can essentially put my phone on sat nav."*



## NOVEL USES

As well as the built-in apps, users were also impressed with many paid-for apps, some of which users have come to rely on. We're sharing a selection here, but you should always seek advice from a trained professional such as an occupational therapist to make sure a particular app is right for you.

Teresa Piskator has found that a novel app called Tile, which tracks the location of special cards (tiles), has helped her to keep track of important items. The tile can be synced up with her phone and when activated emits a beep to help her locate whatever she has attached it to.

She said: "The tiles keep track of car keys and my husband. He has one in his wallet in case we get separated, and a special one in my "survival bag" that also notifies me if I forgot to bring it with me."

For people with communication problems, there are numerous options to help. Carrie Beckwith-Fellows explains how she uses an app called Grid as her 'Augmentative and Alternative Communication' (AAC) device, supporting and replacing speech when needed.

She said: "It has a page that helps me understand and communicate my emotions, a visual timetable for the week, a page with all my food choices, as I don't remember what food I can have to eat, and a page with activities and things to do as I forget."

She also uses an innovative app called Cove. She said: "It is an amazing music diary app where you tap on the screen to make music loops as a way to journal how you feel. I find it excellent for those panic attack or anxiety moments, or sudden flashbacks."

Michael McDonald shared a novel way to help his dad communicate using simple drawing apps on his phone.

He said: "Any of the draw apps are

great for use when I'm with my dad. Post stroke left him with expressive aphasia. He is able to draw using his good hand for his requests and that's ideal if you don't have a pen and paper to hand"

Freya Perry had to give up her artist's studio following her brain injury, however she is now taking the drawing apps to the next level. She said: "I bought a tablet and created art on it. My lifesaver.

"This is me startled by the noise." An example of Freya's artwork, which she created on her tablet.



*"This is me startled by the noise. I'd love a whole art exhibition of my art so I could build awareness of hidden disability."*

You can read a comprehensive list of free and paid apps for people with acquired brain injury on the MyTherapy website, at [www.my-therapy.co.uk](http://www.my-therapy.co.uk).



# THE HOMES OF THE FUTURE

'Smart technology' around the home is also likely to develop further to make it easier for people with a brain injury to live independently.

Heating systems can be set to track an individual's preferred pattern, warming the house as they approach and turning the heating down to a comfortable level for sleeping at night.

Lights, showers and even toilets could increasingly be controlled by smart technology, adding new features to help people with varying types and degrees of disability.

All of these things can be linked together to create a 'smart home', with kitchen appliances, security systems and doors controlled by your smartphone, voice, facial recognition or other input device.

One example is the use of new sensor-led systems in people's home, which will offer a way to monitor welfare with a lower impact on their privacy.

The system can analyse 'normal' patterns of behaviour, such as when lights have been turned on and off, or if the kettle or others appliances have been used, even when people move around into different rooms.

This offers an opportunity to raise an alert to a trusted person, such as a close relative or care agency, or calling for a welfare check when the normal routine changes.

## ACCESSIBILITY

The development of new technology brings with it new challenges for accessibility.

For people with sensory problems in their hands, tremor or other movement disorders, it can be difficult or even impossible to use touch-based devices. For these people, the prospect of increased reliance on this technology is far from welcome.

There are other options for controlling this technology, however. Voice assistants are currently growing in popularity, and they can already integrate with many smart home devices, allowing the control of multiple aspects of the home.

"Alexa, turn on the living room lights" or "Hey Google, turn the oven down to 180 degrees" are examples of commands that could increasingly become second nature for us as smart homes become ever more integrated with our lives.

With brain injury affecting many people's verbal communication skills, there is promise in a new wave of gesture control systems for smart homes. Allowing people to control the TV, adjust the heating and a wealth of other systems with pre-defined movements of the hands, opens up new possibilities and promotes independence for many people.

Of course, in some cases technology may not be available to everyone, and it remains important that other, more traditional support mechanisms are in place.

RockingRic highlights some of the challenges a reliance on technology can cause.

He said: "We have also experienced a down side to learning a new system or technology. When something doesn't happen the way it should it can trigger an aggressive outburst, in some cases, leading to a resistance to embrace or try something new."

It is also the case that over-reliance on technology, particularly in the early stages after brain injury, runs the risk of undermining rehabilitation. If in doubt, speak to a medical professional to help identify the most appropriate ways to use technology to support you.

## HEADWAY SUFFOLK HOT HOUSE

The options for using technology to support people in rehabilitation and long-term care after brain injury were examined at a recent 'Hot House' event which took place at BT's

research campus in Ipswich - a Hot House is an event in which you get a room full of experts to come together and work through a problem in a very limited timeframe.

The event was organised to support the development of Headway Suffolk's exciting and ambitious plans for a new rehabilitation hub, along with long-term housing for clients.

The Professor Stephen Hawking Neuro Centre will include 24 homes in two buildings, where clients will have the opportunity to live as independently as possible. The unit is due to open in 2020.

The Hot House brought together experts from Headway and various industries to examine the options for incorporating innovative design and technology to support the unit's residents. Incorporating a tour of BT's Advanced Research showcase, it fed in many ideas for how technology can be used in rehabilitation and accessible building design.



An artist's impression of the Professor Stephen Hawking Neuro Hub



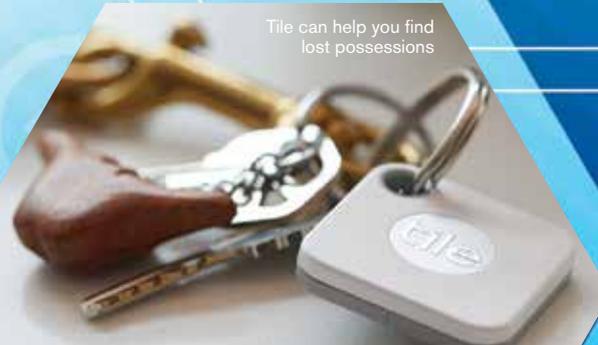
*“Alexa, turn on the living room lights” or “Hey Google, turn the oven down to 180 degrees” are examples of commands that could increasingly become second nature for us as smart homes become ever more integrated with our lives.”*



The Cove app allows users to track their feelings through music



Tile can help you find lost possessions



# MISSION NOT MISSION NOT

Protect yourself and your family from

# CARBON MONOXIDE



Imagine an invisible, odourless gas invading homes, workplaces and vehicles. There's no warning. No sirens. There are very few clues that the attack is even under way. Survivors can be left with lifelong effects.

This is not the latest TV drama like *Bodyguard* or *Spooks*, or the new James Bond film. It's a very real threat. Daniel Craig or Richard Madden can't protect us – but there is a lot we can do to protect ourselves.

We're not talking about a master villain's nerve agent manufactured in a hidden laboratory. Carbon monoxide is found in the air all around us – yet surprisingly few people are aware of the dangers of this gas.

**18** Headway  
News

Even a small amount of carbon monoxide (CO) exposure can damage our brains.

Cases making the headlines usually feature victims of a sudden, severe exposure – perhaps overcome while watching late-night TV in front of a faulty gas fire. These situations can often be fatal. But for those who survive, there can be long-term consequences, many of which are difficult for even medical professionals to diagnose.

## How does carbon monoxide (CO) affect us?

When inhaled, CO binds to our red blood cells, which usually carry oxygen around our bodies. CO molecules take the place of oxygen in the bloodstream, depriving vital organs and tissues of oxygen. CO molecules are also toxic to our organs, including the brain.

People rescued from high levels of exposure are given oxygen to 'push' CO from the bloodstream. Although some people make a full recovery, it can also result in life-changing brain injury.

People who apparently recover immediately may develop Delayed Neurological Syndrome (DNS), between 2-40 days later. Symptoms include memory loss, Parkinson's-like movements, trouble walking, urinary incontinence, difficulties with communications, depressed mood, dementia-type symptoms and, in extreme cases, psychosis.

But many people do not realise that longer-term, lower level exposure to CO

can also lead to acquired brain injury and other health issues. An unserviced boiler in your home or a leaky exhaust on your car could be placing you and your family at risk.

Julie Connolly is a Senior Lecturer at Liverpool John Moores University, researching the experiences of people affected in this way. She said: "People's stories can be heart-breaking. They have developed brain injuries which will be with them for the rest of their lives. But also they have, in some cases, lived with symptoms for some years, been disbelieved or treated for mental health issues, when the cause of their symptoms was carbon monoxide exposure."

Julie explained: "One woman had to change her career entirely. She could no longer cope with the demands of running her own business. Another young woman struggles with hyperacuity, meaning that she has become extremely sensitive to all loud noises, making it hard to cope on nights out with friends or even when on a street with lots of traffic.

**"Some people don't have the same emotional behaviours, and memories are altered. One man I spoke to completely forgot that his wife of 30 years had never liked drinking tea, which she found incredibly upsetting. It sounds like such a small thing but it really emphasised how much they had both been affected."**

# IMPOSSIBLE: IMPOSSIBLE:

## Where does carbon monoxide come from?

When fuels such as gas, oil, coal and wood do not burn fully, carbon monoxide is produced. CO is an invisible, odourless, tasteless poisonous gas.

The main risks inside homes are from appliances which use these types of fuel, such as:

- boilers and central heating systems
- gas fires
- water heaters
- cookers, hobs, ovens and Aga-type appliances
- open fires and woodburners



In some cases, people have been affected by CO entering their home from a neighbouring property, perhaps through an open window or vent. CO has also been known to seep through the walls from a neighbouring property, or into flats above takeaway premises, sometimes with deadly consequences.

It is also found in fumes from barbecues, vehicle engine and cigarette smoke.

## STAYING SAFE:

Be aware of the main **SYMPTOMS** of carbon monoxide exposure. People don't have to have all these symptoms, and this is not an exhaustive list.

- tension-type headache – the most common symptom of mild poisoning
- dizziness
- feeling and being sick
- tiredness
- confusion, difficulty thinking or concentrating
- stomach pain
- shortness of breath and difficulty breathing
- flu-like symptoms but no increased temperature
- emotional changes, such as becoming easily irritated, depressed, making impulsive/irrational decisions.

Be aware of the **ACTIONS** to take if you think you are being affected.

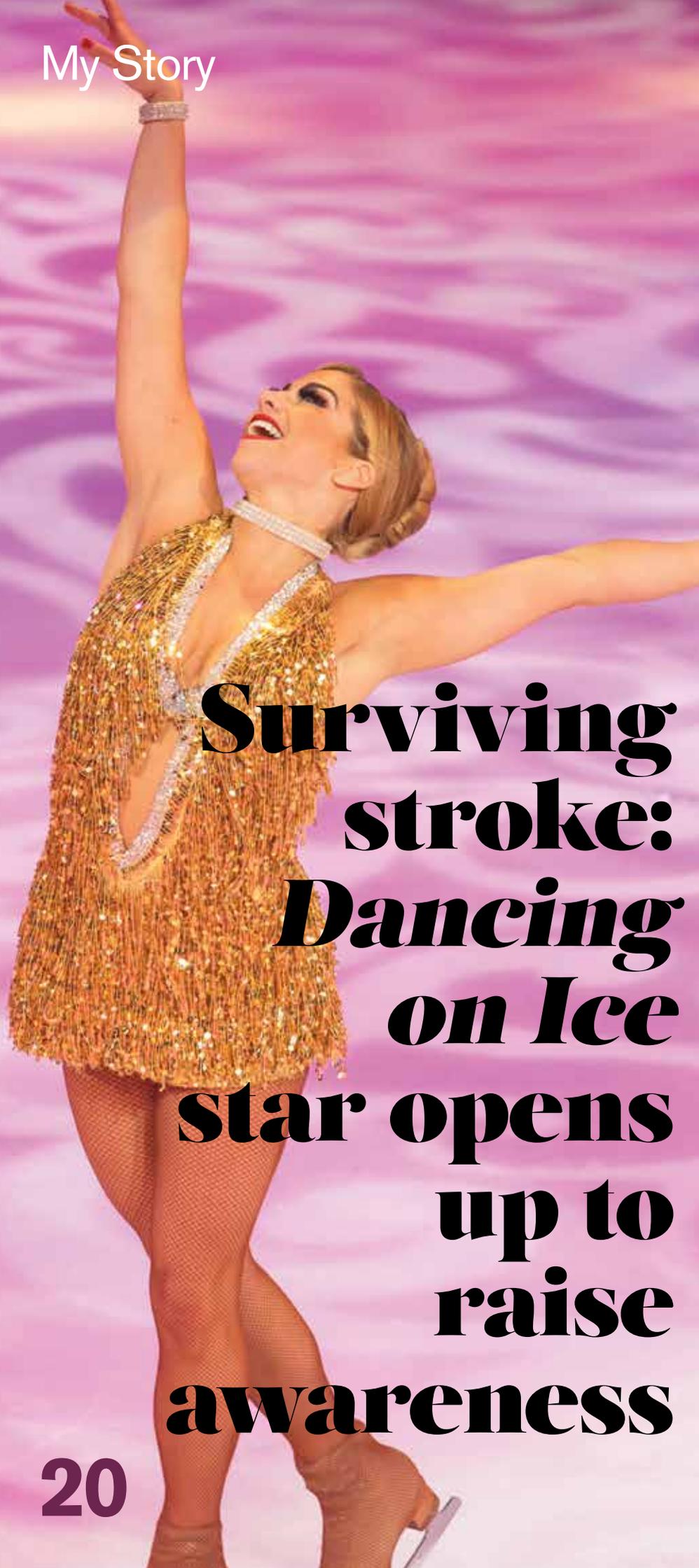
- turn off the source of possible CO
- open windows/doors
- go outside for fresh air
- call the fire service
- seek medical assistance – explain you think you may have been affected by CO
- don't wait before having a blood test, as CO leaves the blood once you are away from the source of the gas

## REDUCE RISK:

- install an audible CO alarm in every room
- test alarms every month
- have all appliances serviced by a qualified professional annually
- have chimneys swept every year

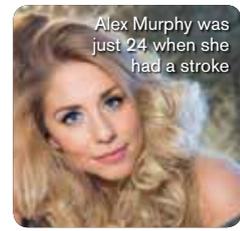
If you rent your home, your landlord has responsibilities to keep you safe. If you are worried about raising issues with your landlord, your local Citizens Advice, council housing team of housing charity Shelter will be able to help you.





# Surviving stroke: Dancing on Ice star opens up to raise awareness

Dancing on Ice star Alex Murphy was just 24-years old when she had a stroke that left her unable to walk, talk and pursue her passion as a professional ice-skater.



Alex Murphy was just 24 when she had a stroke

At the time, Alex was travelling the world on a cruise ship performing to an audience of 1,000 people every night.

However, following a near-fatal stroke in 2012, the USFSA double gold medallist feared she'd never be able to return to the ice again.

Alex said: "I was so worried that I would have to give up on my career as an ice-skater. It was a really daunting time for me. Not only was my body going through all these huge changes, but so were my career prospects.



© By Kind Permission of Stageworks Worldwide Productions [www.stageworkswwp.com](http://www.stageworkswwp.com)

*"I'd done the same routine day in day out, but on this particular day something wasn't right.*

"The second I stepped off the ice I knew something was seriously wrong. I went to put my costume on the costume rack and couldn't lift my arm. I tried to untie my

skates but my hands just wouldn't let me.

*"I went into the bathroom, looked in the mirror and didn't recognise the reflection staring back at me."*

"I started pounding my fists on the sink, trying to spark some kind of sensation in my hands, but nothing. It was then one of my skating colleagues came in to the bathroom and I collapsed.

"I remember regaining consciousness and seeing all these concerned faces looking at me. I kept trying to utter words to tell them that something was wrong, but I couldn't."

Alex spent a total of eight hours unable to communicate.

The pro-skater was later transferred to a nearby hospital in Tenerife, before being taken to a hospital in Miami where it was revealed that the stroke was caused by a condition called patent foramen ovale (PFO), also known as a hole in the heart, which led to a blood clot on Alex's brain.

It was then Alex had to make the difficult decision to undergo high-risk heart surgery.

Thankfully, she managed to make a remarkable cognitive recovery and was back to reading and writing within a few days.

During Alex's recovery, she was offered a spot as a professional skater on the Dutch version of *Dancing on Ice*.

"It was a dream come true for me," she said. "My entire career had led up to this moment so there was no way I could turn it down."

Just one month after the surgery, Alex made her first appearance on the television show and later went on to win the series along with her partner, DJ Tony Wycycinski.

But despite her continued success and determination to not let her stroke define her, Alex found that a number of her colleagues began to treat her differently after learning about her stroke.

She said: "I definitely think I was pitied a lot to start with. People would look at me in a different way, like I wasn't as capable as I was before my stroke.



"I remember people becoming really uncomfortable to ask about my stroke. It's like they think of it as a 'bad' word that shouldn't be said.

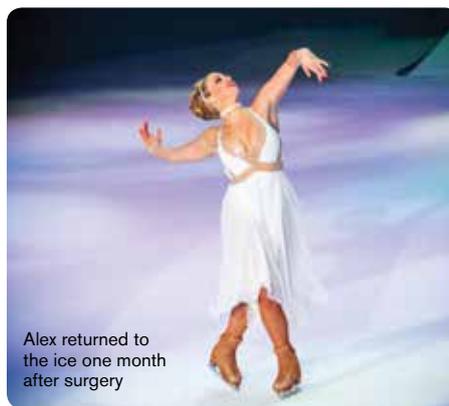
"People are shy and scared of the 's' word. They are afraid to ask questions because it is so scary, but most stroke survivors like myself are happy to share their experience in order to raise awareness."

Since her stroke, Alex has reached the ITV *Dancing on Ice* UK semi-finals twice with celebrity partners, former *Westlife* singer Brian McFadden and *Love Island's* Kem Cetinay.

"*Dancing on Ice* has played a huge role in my recovery," said Alex. "Doing something that you love day after day, and being able to convince a complete stranger and skating novice to love it too, is truly a gift."

Alex is a stroke ambassador and helps to raise awareness of stroke, particularly with young people.

She said: "Stroke can affect anyone, regardless of age. So if I had one piece of advice for young survivors it would be to be patient. You need to give your brain time to heal and rewire."



## Sarah's story

Sarah Scott was a healthy teenager with a lively social life and dreams of becoming a biomedical scientist. Like many others, she never expected that she would have to overcome the effects of a stroke at such a young age.

But ten years ago, one morning changed her life forever.

Sarah, who was just 18 at the time, was reading aloud in her English Literature class at sixth form when she suddenly began to feel unwell. As it was the first lesson in the morning, Sarah assumed she was tired from the night before.

Luckily, some of her fellow students recognised the signs of stroke and raised the alarm. Sarah was rushed to hospital where doctors confirmed that the stroke was caused by a PFO, a hole in the heart.

Sarah spent five months in hospital and rehabilitation, learning how to do the most basic of tasks again. She couldn't walk, talk, swallow, read or write, she had visual impairments and struggled with chronic fatigue.

Sarah said: "All of my friends went to University and I felt very isolated. I couldn't speak, read or write. I had no idea what I was going to do with my life."

Almost a decade on, 28-year old Sarah works as a scientist testing cancer treatments, but she's still living with the ongoing effects of her brain injury, including expressive aphasia.

Sarah now helps to support fellow young stroke survivors in her local community and regularly vlogs about her experience in the hope to raise awareness.

# Play that funky music

**Whether it's singing or playing an instrument, music can play a positive role in recovery and rehabilitation.**

It can help with cognitive functioning, social skills and physical ability, as well as improving self-expression and boosting mood levels.

In this special feature, we look at how Headway groups and branches across the UK use music to improve the lives of brain injury survivors.

## The language of music

Music, like other forms of creative art, can support verbal and non-verbal communication.



Many people experience more than one form of communication problem after brain injury, such as language impairment, speech difficulty or cognitive communication problems.

Singing may help speech stimulation and improve pronunciation, articulation, projection and recall of vocabulary.

Writing, performing and listening to music may also help boost communication skills among brain injury survivors.

Vocal elements of music such as rhythm and pitch can be imitated in spoken language, meaning survivors can transfer skills learnt in music lessons to their everyday speech.

For those who struggle to articulate their thoughts, music allows them to express themselves creatively.

Thomas, who attends music sessions at the Second Chance Headway Centre, Wakefield, said: "Listening to music and singing helps me to express my feelings and it always makes me feel happy."

## Music for the mind

Music can promote emotional wellbeing through relaxing the mind and improving stress and mood levels.

Paul from Headway East Kent said: "Music is important to me because it lifts my spirits and it helps me forget all my worries."

Bev, who takes part in the music sessions on offer at Headway Luton, agreed. She said: "Music makes me feel happy inside. It gives me a boost when I'm feeling anxious or sad."

Research shows that this increase in arousal improves areas of cognitive functioning, such as concentration and memory, which are often impaired following brain injury.

Service users at Headway Birmingham and Solihull find the weekly music sessions bring cognitive benefits.

The sessions aim to educate brain injury survivors through focusing on how music has evolved over time.

While educational, the sessions also help survivors recall memories that may have been lost prior to their injury, through listening to familiar songs from the past.

For many, bringing back special moments that might have otherwise been forgotten can trigger different emotions.

Jane, who attends music sessions at Headway Luton, said: "The music can make me quite emotional at times as it

brings back memories before my brain injury. Sometimes I want to forget about the past and certain people, but sometimes it is healthy to reflect."

## Music as an ice-breaker

Many Headway groups and branches host group music sessions as part of ongoing rehabilitation, providing a means by which service users can socialise, share their experiences and relate to one another.

Sophie Garner, professional vocal coach at Headway Bedford, said: "Coming together each week to enjoy and perform music results in stronger relationships, improved mood and a positive outlook of hope for the future."

Paul, a service user at Headway East Kent, reflects on how attending music sessions has helped him socially. He said: "I find that music encourages me to join in with the group more than I would normally."

Fellow brain injury survivor Julia, who attends the same sessions, echoed those sentiments. She said, "Listening to music makes people smile. It encourages them to interact with each other without even knowing. It brings people together."

## Breaking down the physical barriers

While the effects of brain injury are often hidden, some survivors experience physical problems such as mobility difficulties, weakness or paralysis and sensory impairment. But these need not be a barrier when it comes to performing, writing or listening to music.

Phil Charnock sustained a brain injury in 2015 following a stroke. Phil had always been a music enthusiast and regularly played guitar, but after his injury, it was difficult to participate in the music sessions at Headway East Northants due to limited shoulder mobility.

Luckily the group's resident music teacher, Dave Thomas, worked with Phil to find a solution. They re-strung Phil's guitar to make it a left-handed instrument. Now, Phil can play far more comfortably and looks forward to the sessions.

Research shows that through following rhythmic patterns, people can develop their muscular control and fine motor coordination, as well as increase sensory responsiveness, which may have been lost due to brain injury.

## Chris' story

Chris Wilson, who attends a Headway group in South Cumbria, credits music with the progress he has made following his brain injury.

Chris sustained a traumatic brain injury after being assaulted while on holiday in Tenerife.

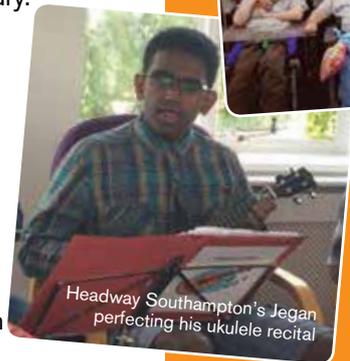
He lost his independence and now struggles with short-term memory loss, cognitive difficulties and weakness on the right side of his body.

But thanks to music, Chris has regained his confidence.

He takes part in music lessons at a local school where he sings and plays the ukulele.

Reflecting on the role music has played in his recovery, Chris said: "Playing, singing and listening to music gives me focus and improves my mood. Socially, I've made new friends with similar and different music tastes, which has enriched my life.

*"Music makes me feel more confident about my life in the future."*



## My Story

# “MY BRAIN INJURY BROUGHT ME AND MY GIRLFRIEND CLOSER TOGETHER.”

One young couple share their experience of how brain injury affected their relationship

Maintaining a positive romantic relationship after a brain injury can be difficult, even more so for young couples who are still getting to know each other.

The common behavioural, cognitive and emotional effects of a brain injury can often act as a barrier when trying to salvage the relationship that existed beforehand.

Some relationships may collapse over time, while others may immediately break down following a spouse's brain injury.

But not all relationships are doomed to fail after a brain injury.

Headway's study into relationships after brain injury found that 35% of brain injury survivors reported that their relationship with their partner had strengthened after their injury, with 38% of partners responding in kind.

18-year-old Jake Elliott and his girlfriend, Katelyn Southwick, demonstrate how relationships can not only survive, but thrive, following brain injury.



*Jake said: “My injury has definitely brought me and my girlfriend closer together and solidified our bond. We know that if we can survive the devastating and life-changing effects of a brain injury, we can survive anything.”*

Jake and Katelyn's whirlwind romance began in 2018 when they met at a summer camp.





Jake and Katelyn celebrating their first Valentine's Day in hospital

Just six months after the pair began dating, Jake was involved in a near-fatal road traffic accident while travelling as a passenger on his way to college with friends.

"I still remember that day so vividly," said Jake. "I was on the phone to Katelyn and I told her I'd ring her back as soon as I got to college. I never rung and the next time she saw me I was lying in a hospital bed surrounded by doctors and covered in wires."

Following the accident, Jake was rushed to the critical care unit at Walsgrave Hospital where he spent ten days in an induced coma on life support and a further three months in hospital recovering. He had sustained two bleeds on his brain and a collapsed lung.

Katelyn was by his bedside every day.

"She was there every step of the way," recalled Jake. "Katelyn's just been incredibly strong and supportive throughout the whole thing. I feel incredibly lucky to have found someone as caring and understanding as she is, especially at such a young age."

Jake is now forced to live with the complex, fluctuating and often hidden effects of his brain injury, including debilitating fatigue, difficulty concentrating and behavioural issues.

He said: "The effects of my brain injury have undoubtedly put a strain on my relationship with Katelyn. But thanks to a strong support system made up of family and friends, as well as the help of professionals such as Headway, we have been able to maintain a healthy and loving relationship."

*"The Headway website in particular was a real saving grace for myself, Katelyn and the rest of my family during the early stages of my recovery. The factsheets and e-booklets helped to educate us on the effects of brain injury and provided essential coping strategies."*

While in the coma following the accident, Jake would not respond to the commands of the nurses, but instead would only listen to what Katelyn had to say.

He said: "Apparently the nurses would ask me to do simple movements like lift my leg or give them a thumbs up and I was completely unresponsive to them. But as soon as Katelyn said 'Come on, Jake. Do as the nurses say', I'd willingly respond."

"According to my parents I would twitch and slightly open my eyes whenever Katelyn walked in to the room or spoke to me."

"My first words were even yes, no and Katelyn."

Jake's dad, Simon Elliott, said: "Katelyn is a real key factor in Jake's recovery and progress. She's been an incredible support not only for Jake, but for the rest of the family too."

*"We can't thank her enough for everything she's done for our son."*

The couple even spent their first Valentine's Day together in the hospital.

"It was a really special and romantic day for the both of us. It wasn't your typical Valentine's Day, but it will definitely be one to remember," recalled Jake.

"We spent the night eating strawberries and chocolate and reflecting on how crazy and frightening the past few weeks had been."

"I even managed to write Katelyn a card. I had to ask for help from my mum but it was still a huge achievement to be able to write for the first time since the injury."

The couple have big plans for the future, both personally and in their relationship.

Katelyn is hoping to attend university in September to study Paramedic Science while Jake plans to take a year off to recover and learn how to cope with the effects of his brain injury. With time he is hoping to accept his unconditional offer to study Sport and PE at The University of Northampton.





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*What makes us unique... is you!*

# Rail staff pump for miles

#HeadwayHeroes

A team of superheroes from GB Railfreight has pumped a railway trolley for 40 miles to help raise more than £1,300 for Headway.

Phil Amos, Liam Day, Josh Jordan-Boddey and David Hunt dressed as their favourite crime fighters to pump their way to the finishing line.

The team wanted to do something a bit out of the ordinary as part of our Challenge 40 year – and they certainly managed it!

Phil said: “We found that the Nene Valley Railway had a trolley and were close by. They kindly agreed to us using nearly the whole length of their line, 6.2 miles between Peterborough and Wansford.

*“We managed to set a fairly steady pace up and down the line getting some very strange looks from the people that we passed, particularly from the cars waiting at the level crossing!”*

“A party of school children at Wansford thought it was funny, and a nurse passing by at Peterborough even gave us some additional sponsorship money when she found out what we were doing!”

The arduous journey ended up taking the team five hours and 30 minutes from start to finish, and they even reached a top speed of 18mph - although that was mainly due to going downhill.



Jo Plant, Director of Fundraising at Headway, said: “We loved finding out about this unique and funny Challenge 40 event - it certainly was different! Well done to all the team for getting to the end - even if they did receive a few strange looks along the way.”



## Raising thousands for Headway in year of fun

Birmingham Law Society has cycled, kicked and quizzed on the way to raise more than £16,000 for Headway during its Challenge Baton year.

The society's President for 2018-2019, James Turner, chose both Headway and the Jeff Astle Foundation as his nominated charities for the year.

James had a very personal reason for nominating Headway after seeing firsthand the effects of brain injury when his partner sustained a traumatic brain injury following an accident in 2002.

Throughout the year, the society took part in a range of fundraising events, including sporting competitions, a Legal Awards Dinner and quiz night.

Other highlights included James taking to the saddle and completing a 1,818

mile motorcycle challenge between Lands End and John O'Groats, as well as the society's flagship event, a Bicentenary Gala Dinner.

James said: “It was a huge honour for me to work with the team from Headway during my year as President.

“Together we worked hard to raise much needed funds to support two vital Headway services.

“We would not have achieved so much if there had not been a real sense of collaboration between the Society and charity.”

Jo Plant, Director of Fundraising at Headway, said: “It has been a great year working with the society.

“This fantastic amount of money will help us support families who are trying to come to terms with the devastating consequences of brain injury.”

# #HeadwayHeroes

Jamie Cruickshanks from  
Stephensons Solicitors  
grabs a team selfie before  
hitting the water



# A TRIP TO REMEMBER

## as corporate teams Go Wild for Headway!

The corporate teams who signed up to our Go Wild event expected a challenge - maybe a slight moment of hardship.

But what they actually got was two days of plunging 30 feet into freezing water, exploring old mine tunnels in the pitch black and screeching across zip wires hanging 200 feet above the ground – plus much, much, more.

Each summer Headway holds an exciting Corporate Challenge event, and

to help celebrate our 40th birthday, this year we decided to do something even bigger and better.

Around 50 people attended from 13 companies to take on all that Mother Nature could throw at them as they trekked, climbed and swam in Coniston in the Lake District.

Led by ex-army and mountaineering professionals from Challenge the Wild, the teams covered more than 20 miles over the two days, taking part in a range of thrilling and frightening activities along the way.

Julie Tucker, Manager at Markham House, Voyage Care, said she was inspired by the support of her team.

She said: “It was extreme. I went through every emotion such as fear, surprise, excitement, terror and pride, to name but a few.

“The team worked to get each other through the challenges, and I could not have done this without them. The challenges were really tough. You had to follow a total stranger into a small stream and then into a flooded tunnel of an old mine, all in complete darkness. Then if that wasn’t bad enough, you then had to slide down into a underground plunge pool.

*“The feeling of accomplishment is hard to describe and for such a great cause, I am so proud to have been a part of it.”*

Heather Petrie, Bolt Burdon Kemp, said each challenge tested participants in exciting and different ways.

She said: "For those scared of water, the cliff jumping and caving pushed them to their limits; for those scared of heights, the abseiling and zip wiring were the ultimate psych out; for those with little legs – well, let's just say that the scrambling felt like a personal attack. The adrenaline coursed through everyone's veins throughout the challenge."

Andy White from HCML said the event surpassed all his expectations.

He said: "I knew the event was going to be fun, but I am not sure I was prepared for how much of a challenge it actually was. I think most people were able to conquer a personal fear with the support of the team. It really was a fantastic event and all to raise money for such a fantastic cause."

Stuart Hughes, from Birchall Blackburn Law, came away from the event pleased that he met the challenge.

He said: "It was a fantastic and friendly event but also challenging enough to make you feel that you've really achieved something - and earned your sponsorship!"

*"Everyone was really supportive and the guide team were brilliant. After the activities had finished, I left feeling tired and happy."*

"And, as well as being a great life experience we got to raise money for an ace charity doing life changing work. I've been telling everyone to get involved next year!"

On the first day, an evening event and BBQ was also held, where Headway Ambassador and Paralympian, Jack Rutter, spoke about his personal experience and journey with brain injury which led him to representing Great Britain at the Rio Paralympics.

It really brought home to everyone how a brain injury can happen to anyone, at any time, and just how important their fundraising really is.

The event has raised nearly £15,000 to date for Headway's UK-wide frontline services.

## Thank you to all the teams that took part

A Chance for Life, Active Care Group, Birchall Blackburn, Bolt Burdon Kemp, FBC Manby Bowdler, HCML (Health & Case Management Ltd), Jefferies Solicitors, McMillan Williams Solicitors, Nestor Financial Group Ltd, Simpson Millar, Spencers Solicitors, Stephenson Solicitors and Voyage Care.

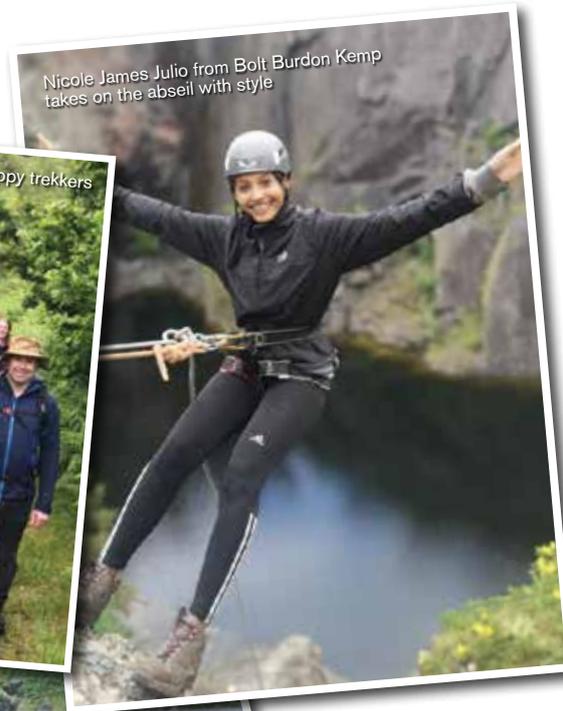
Additional thanks to the following who donated prizes for our intrepid Go Wilders: Concerva, Frenkel Topping, Lanyon Bowdler, Old Square Chambers, Rehab Without Walls.

## Inspired? Get involved!

Would you like to join Headway as a Corporate Member or take part in next year's challenge? Contact [partnerships@headway.org.uk](mailto:partnerships@headway.org.uk) to express your interest!

### Activities included:

- Scrambling and rock climbing up Raven Crag with 300m of ascent.
- Trekking over rugged terrain and hilltops.
- Taking on a Tyrolean Zip over a quarry with a 200ft drop below.
- Jumping 30ft from quarry cliffs into freezing cold water.
- Going into the depths of dark caves and jumping into underwater cave systems.
- Abseiling 150ft down a quarry wall.
- Trekking to Cathedral Cave and exploring old mine tunnels in the pitch black.



## Solicitors tackle gruelling Challenge 40 ride

Staff from Irwin Mitchell Solicitors cycled for an incredible 40 hours to help raise more than £1,200 for Headway as part of our special Challenge 40 year.

A group of 63 committed cyclists managed to cycle a total of 630km - which is the equivalent of cycling from its office in Holborn to Cologne in Germany.

The event involved cycling on four static bikes from 8am to 6pm.

Stephanie Edwards, a solicitor at the firm, said: "Many of our clients have experienced a brain injury and so everyone was very keen to get involved and show their support.



All smiles, the team from Irwin Mitchell dig deep

*"It turned out that a colleague from a neighbouring business had recently sustained a brain injury after a serious fall and so we recommended that his family be put in touch with Headway for support.*

*"So it was great to be able to raise funds but also awareness too."*

Jo Plant, Director of Fundraising at Headway, said: "We would like to say a big thank you to everyone who took part. Not only did it raise vital funds, but the event also resulted in someone in need finding out about the support we can offer. What a great team effort!"

To mark our birthday we wanted to do something special that everyone can get involved in – so we've created Challenge 40.



Find out and sign up for your own challenge on our website.

## Voyage Care sails to fantastic total for Headway

Leading provider of specialist care and support, Voyage Care, has raised nearly £16,000 during this year's Headway Challenge Baton.



Cat Talbot ran 40 miles in 40 days

The company, which provides residential support to people living with brain injuries, already raised £12,000 for Headway in 2017 – smashing its target of £10,000 to support national frontline services - and over the past 12 months they went even further.

Some of their fundraising highlights included:

- Taking on the UK's highest freefall abseil
- A bush tucker trial
- Band night fundraiser
- Snowdonia challenge
- Cakes sales and dress down days
- BBQs and tea parties
- Obstacle races and marathons

The organisation also had staff taking part in Challenge 40, with Cat Talbot from the Lichfield office running 40 miles in 40 days.

Jo Plant, Director of Fundraising at Headway, said: "We cannot thank Voyage Care and their staff enough for the incredible support they have provided to us in the past two years.

*"Last year its staff raised an amazing amount but this year they have stepped it up even further. Their fantastic support will make a huge difference to our work.*

**"Thank you so much."**

Andrew Cannon, CEO at Voyage Care, said: "Headway has been a fantastic charity to support over the last 12 months. Knowing that the money we have raised has been able to help people rebuild their life after brain injury, is a really rewarding feeling."

# FREETHS

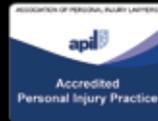
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“Thompsons helped us to settle a legal case for a substantial sum and we now have the financial security we need to access the best possible care and support for Adam.”

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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