

Spring 2022

Headway News



The magazine of Headway - the brain injury association

“Executive difficulties can be really tough”



Executive dysfunction explained
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Are you a Friend of Headway?

Becoming a Friend of Headway member is a great way to support the charity, accessing a range of benefits while helping us to continue improving life after brain injury.

Every member receives a Headway pin badge and wristband, a discount on our award-winning publications, access to a free or discounted will writing service and a copy

of this very magazine delivered four times a year.

There are annual and lifetime options available and a discount for brain injury survivors and their loved ones, and even ways to buy a membership as a gift.

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Neil Dexter, brain injury client, pictured near his home



Welcome

Welcome to the spring edition of Headway News.

Here we are again!

The spring issue is always a favourite here in the Headway offices because it marks a move away from the dark nights as we hurtle towards summer. What better way to mark this than to add some colour into the magazine with a big feature on creative works.

Creativity is many things to many people, but for those who are affected by brain injury it can be particularly important. It's an outlet to express thoughts about the injury and its consequences, a chance to learn new skills, an opportunity to meet people and socialise, a way to help support recovery by practicing things like manual dexterity, planning, memory and writing... the list goes on!

Our *Headway gets creative!* feature, which begins on page 24, looks at the wonderful work being done at Headway groups and branches across the UK, where brain injury survivors are creating some amazing art using a wide range of techniques, from ceramics and photography to drawing and even paint bombs (yes, we're jealous too).

But it's not just about visual arts. Kristin McIlquham felt confused, angry and embarrassed after her father sustained a brain injury when she was just six years old. As with many children in a similar situation, she struggled to fully process and understand what had happened.

Writing a play about the experience as she approached her 40th birthday finally gave Kristin the outlet she needed. The performances help her to express her emotions while offering support to others who might also be struggling with the enormous impact a brain injury can have on families. You can read Kristin's story on page 16.

Adding all this to our regular *Creative Expression* feature at the end of the

magazine and we hope this arts-focused issue lifts your mood, moves you, and above all inspires you on your own creative journey.

Elsewhere, we're feeling a sense of optimism thanks to a big announcement made by the Prime Minister back in December when he committed to developing a new Acquired Brain Injury Strategy.

While still in the very early stages, the strategy provides an opportunity to finally have the needs of brain injury survivors, carers and families recognised and addressed by government.

Over on page 14, we look at the current situation and answer some frequently asked questions about this big news, such as what the strategy could cover and what happens next.

Among all this optimism, we wanted once again to say a massive 'thank you' to the amazing Headway Heroes whose tireless fundraising efforts allow us to keep supporting those affected by brain injury.

As the days get longer you might be thinking of getting out-and-about to take on your own challenge. If you fancy running a marathon, taking in the beautiful British scenery with a big walk or cycle ride, or even heading overseas on a once-in-a-lifetime trek, take a look at our fundraising opportunities from page 20.

We'd love to welcome you to Team Headway!

We hope you enjoy the magazine and don't forget, if you have any comments or ideas for future issues just email them to Andrew on website@headway.org.uk.

The Communications Team



the brain injury association

Who we are

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

Go digital!

Subscribe to our monthly Headway News Bitesize email at: headway.org.uk/join-our-mailing-list

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Your views

Headway's HealthUnlocked community is a friendly, welcoming and knowledgeable community where people with brain injury, and their loved ones, come together for support and sharing experiences.

You can find out more on page 19, but first we wanted to share some of the wonderful feedback from members when we asked what the community means to them...

"I think reading the posts on here made more difference to me in terms of acceptance than months of therapy. Being able to have support here, when going through a bad patch, however small, and being able to talk to other people that just 'get it' - at practically any time of day or night - is just incalculable, because even just post-concussion syndrome is very isolating."

Painting-girl

"It is acceptance, shared experiences, community, friendship, learning, support, help. A like-minded bunch of people coming together for a common goal. One of the rare altruistic havens."

Pairofboots

"I've been a member here for around 9 years now and still call in most days for my 'fix' of the safe atmosphere. I guess Headway is my safety blanket."

cat3

"This forum gave me a safe haven where people understood and could offer empathy and helpful advice. Without it I think the distress and loneliness of TBI could have been literally unbearable."

Aelfwyn

"It is wonderful to be able to connect with others that have undergone similar experiences, to give/receive support where possible and to empathise and show others they are not on their own. I have even learnt some new things about myself and my condition along the way."

lcd8

"As the mother of a son with hypoxic brain injury I have found this forum invaluable. It gives practical, informed advice but also emotional understanding of being thrown into an unknown world - none of us wanted to be here but being understood and supported is a great help."

Nanapal

Visit our website at headway.org.uk/about-brain-injury for information on the effects of brain injury and practical guides to help you cope. You can also get in touch with our helpline to talk through your concerns and get information that is tailored to your circumstances. Contact the team on **0808 800 2244** or helpline@headway.org.uk

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Go green!

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



Latest news round-up

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

ABI Week 2022: See the hidden me

Action for Brain Injury Week this year (16th to 22nd May) will focus on what can be for many brain injury survivors, a hidden disability. *See the hidden me* will raise awareness and understanding of the often misunderstood symptoms of a brain injury, and work to alleviate the challenges, and frustrations, survivors face.

To the outside world, you may look as you did before, but whether it be the day-to-day difficulties, or reoccurring misunderstandings of the effects of your brain injury, *See the hidden me* will empower survivors to talk about when hidden disability has made life more challenging, whilst also asking the general public for more understanding and respect.

The campaign will give a voice to survivors so friends, families, colleagues and professionals can gain a better insight into the invisible battles they may face every day.

ACTION FOR BRAIN INJURY WEEK 2022

16-22 MAY

See the hidden me will help others see the hidden you.

More information about the campaign and how you can get involved will appear on our website and social media soon.

Friday 20th May is...

HATS FOR HEADWAY DAY



Hats for Headway Day will once again be taking place on the Friday of ABI Week, and it's a great opportunity to raise money for Headway while having a little fun.

All you need to do to get involved is wear your hat with pride, make a donation to Headway and post a picture on social media using the hashtag #HatsForHeadway to show your support.

Every silly hat equals more funding towards our vital support for those affected by brain injury, and as always, we'll be running our 'best hat' and 'best corporate photo' competitions to celebrate your amazing contributions!

Keep an eye on our website and follow #HatsForHeadway to find out more.

Government accepts more needs to be done on concussion in sport

The government has accepted that it needs to take a proactive approach to increasing awareness and understanding of concussion in sport and ensuring protocols are observed.

Responding to a report by the Digital, Culture, Media and Sport (DCMS) Committee into concussion in sport, the government's response set out a number of actions it says it will take to address the issue of concussion in sport.

Among these are support for further research, the commissioning of shared protocols among all sports, and a review of the way NHS England collates data about concussion.

The government also committed to delivering a comprehensive communications campaign to ensure that everyone involved in sport, from the athletes to coaches and doctors, is aware of best practice.

Peter McCabe, Chief Executive of Headway, said: "The DCMS Committee heard scientific evidence alongside moving, powerful testimonies from sports people whose lives have been impacted by brain injury.

"This was a robust inquiry and we thank the Chair and his fellow committee members for their diligence and hard work.

"The DCMS Committee's criticism of sport was clear, accusing it of 'marking its own homework' due to a lack of scrutiny from government.

"We are pleased to see the government has accepted most of the committee's recommendations and that its involvement is needed to ensure sport adopts a cohesive, consistent approach to concussion in sport.

"Nonetheless, this response is a little underwhelming in terms of the urgency and level of government involvement.

"Immediate action is required to build on the progress we've made to date – particularly at grassroots level where we need an evolution of attitude when it comes to head injuries in sport.

"For example, shared concussion protocols will help to reduce inconsistencies in the way head injuries are identified and dealt with in sport, but protocols are only of value if they are properly implemented and understood.

"The government's response does acknowledge that the development of protocols will not change behaviours on their own and we welcome its commitment to leading a campaign to ensure everyone involved in sport is concussion aware.

"But we also call on the government to increase its scrutiny of governing bodies and act on its ability to hold organisations to account if meaningful change does not happen immediately."



"We need an evolution of attitude when it comes to concussion in sport."

Latest news round-up

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

New road rules to aid safer cycling

New rules to better protect vulnerable users from harm have been welcomed by Headway, although concerns remain over whether enough has been done to make the public aware of the changes to the Highway Code.

The latest figures from the Department for Transport show that in the year up to June 2021, 4,650 pedestrians and 4,510 cyclists were killed or seriously injured on Britain's roads. With many of the people who use Headway services sustaining their injuries as a result of road traffic incidents, the charity welcomes any update to the Highway Code that aims to improve road safety.



Following a public consultation, changes were made to the Highway Code including new rules around the hierarchy of road users: H1, H2 and H3. The changes see priority given to the more vulnerable on the roads, whether it be to a pedestrian on a junction (H2) or ensuring vehicles don't cut across cyclists or horse riders when they want to turn into a junction (H3).

Importantly, Rule 59 has been strengthened. While it previously stated that cyclists 'should wear a cycle helmet that conforms to current regulations, is the correct size and securely fastened', it now also explains that doing so can reduce the risk of sustaining a brain injury.

The changes to the Highway Code have been welcomed by campaigners such as James Cracknell OBE and David Baker, who both sustained life changing brain injuries as a result of collisions while cycling.

"I welcome these changes in the Highway Code," said David. "I can't stress enough the importance of wearing a cycling helmet. If I hadn't been wearing mine the day of my accident, I wouldn't be here now."

"I was travelling at more than 20 mph when I had my accident. I went headfirst straight into the side of the van and there's only one winner in that battle, and it's the van."

"Without a helmet, I dread to think what would've happened to my head."

Headway Vice President James Cracknell OBE also credits his helmet for saving his life. James sustained a brain injury when the wing mirror of a lorry hit the back of his head while cycling in Arizona.



James, a former president of the London Road Safety Council, welcomed the changes to the Highway Code but cautioned that it was the responsibility of all road users to be respectful of one another.

"Cycling is a passion of mine for exercise, socially with friends/family and for commuting so I would always encourage people to get on their bikes," said James. "However, cyclists are vulnerable and it is right that they are afforded more room on the roads."

"Too often, important safety messages are clouded by debate and division, as drivers are pitted against cyclists and vice versa, when the reality is that every road user has a responsibility to treat others who share our limited and often crowded roads with respect."

"We should all be familiar with The Highway Code – both the changes that have been made and the vitally important rules that remain, such as wearing a helmet when cycling. It might just save your life."



David Baker supports the recent Highway Code rule changes

Football fails again

Headway has hit out at the decision by Senegal to allow Sadio Mane to continue playing following a suspected concussion in his team's Africa Cup of Nations match against Cape Verde.

The striker collided with Cape Verde goalkeeper Vozinha, who was sent off for the challenge and had to be helped off the pitch due to being visibly unsteady on his feet, seemingly as a result of the clash of heads.

Mane, however, remained on the pitch, despite seeming to lose consciousness in the incident. Six minutes later, he scored an excellent goal for Senegal, before laying down on the halfway line. It was only then that the player was substituted.

"On the face of it, this seems to be yet another example of football putting results ahead of player safety," said Luke Griggs, Deputy Chief Executive of Headway.

"This was a sickening collision that clearly left both players in enough distress for

a concussion to have been considered a possibility at the very least. At that point, the principle of 'if in doubt, sit it out!' should have resulted in Mane being substituted without another ball being kicked.

"The image of the player collapsing on the ground and having to be helped from the pitch after scoring his goal should tell you everything you need to know about the impact and the effect it had on his brain.

"Yet again, the desire to win is seen as being worth serious risks to players' health. It is simply shocking that this continues to happen.

"This follows an incident during a Premier League encounter between Liverpool and Newcastle in December, in which a goal was awarded despite Newcastle defender Mike Dean lying on the ground holding his head after a collision with a teammate.

"If football wants to be taken seriously when it comes to concussion, it simply must take action to enforce and strengthen its protocols."



Adam Thomas poses in a jacket he bought from our Cheadle shop!



Emmerdale star leads Clear Out Your Clutter call!

We were delighted to welcome Waterloo Road and Emmerdale star Adam Thomas back to the Headway charity shop in Cheadle in January, as the talented actor and social media influencer popped in with a big bag of donations to help support the charity.

Proudly sporting a stylish jacket he'd bought on a previous visit, Adam dropped off a range of fantastic items including a dolls house and even a Harry Potter wand!

Adam called on his supporters to join in, saying: "If you have got any stuff lying around the house that you're not using or you're looking at throwing away, please don't and donate it to the Headway charity shop, because they need all the help they can get."

Thank you Adam, and we couldn't agree more!

If you have anything you'd like to donate, head to headway.org.uk/charity-shops to find out how. We can even offer a collection service for larger donations around the areas of our shops, so there's no reason to delay that spring clean any longer!

EXECUTIVE DYSFUNCTION EXPLAINED



At the very front of our brain, located just behind our foreheads, is an area called the frontal lobe. This area is responsible for some of our most complicated functions, such as our personality, our emotions, and a range of complex thinking skills that are collectively called our 'executive function'.

The frontal lobe is particularly susceptible to damage, which can often result in changes in the way the brain processes executive functions.

When this occurs, it is known as 'executive dysfunction'.

In this feature we will take a closer look at executive dysfunction and how it can affect brain injury survivors.

WHAT IS EXECUTIVE DYSFUNCTION?

The 'executive function' is a collection of 'higher thinking' skills. Some examples include:

Even when we don't consciously realise it, we rely on these skills when working, completing daily chores, cooking, driving and other everyday activities. Executive dysfunction can therefore cause various challenges and issues for brain injury survivors.

PROBLEM SOLVING

FLEXIBLE THINKING

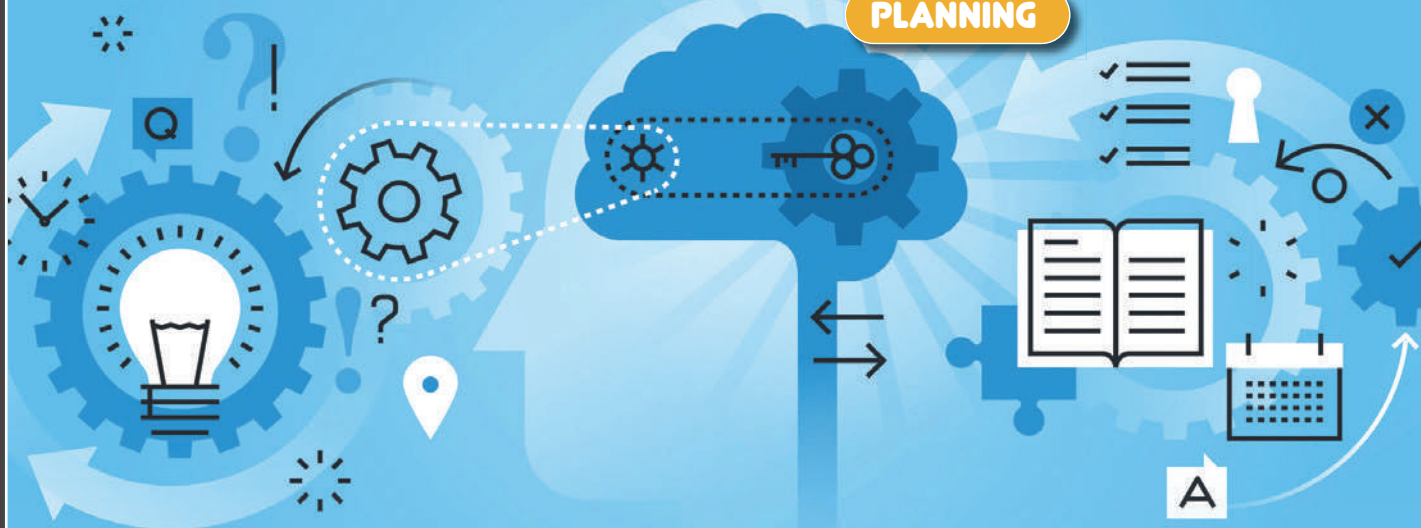
ORGANISING

DECISION MAKING

MULTI-TASKING

SELF-MONITORING

PLANNING



A SIMPLE TASK?

ILLUSTRATING EXECUTIVE FUNCTION...

Let's think about a fairly 'ordinary' everyday task of having dinner.

Firstly we use our **decision-making skills** to decide on what it is we are going to eat. After we have decided, we **plan** the steps involved in preparing the meal, we gather the ingredients we need, decide what we are going to do with each one, plan to cook them so that we can serve everything at the same time. Part of this is to **sequence** things in order of what we are going to do. While cooking, there may be several things going on at once... we **multitask** to address these things at the same time. Something may begin to overcook or burn, we address this by **problem-solving**. And all of this relies on being **motivated** enough to cook in the first place!

Executive dysfunction may cause difficulties with deciding what to have for dinner.

It may be helpful to limit choices to make it easier, for instance choosing between two meals. You could also plan meals in advance to take away the need to make a decision on the day. Buying a recipe book or printing a recipe, and ticking each step as you go along might help with problems with planning or sequencing. Try to plan for delicious and interesting meals to improve motivation, or consider cooking for others as another motivating factor! Set timers to help with keeping on track. Reminding others around that you will need to concentrate and switching off distracting noise such as radios and television sets can allow you to remain better focused, which can help with multitasking.

YOUR TOP TIPS FOR COPING WITH EXECUTIVE DYSFUNCTION

We asked our online community to give their top tips for coping with executive dysfunction. Here's what they shared...

1. TAKE YOUR TIME

"Never rush... it is the number one enemy of executive dysfunction. If you think it will take one hour, allow a minimum of 1.5 hours. If you get finished earlier than expected, it is a win-win."

"I give myself plenty of time to do things and not to rush around, and I also try to write things down so I don't forget."

"My biggest thing is having flexibility in the day, so I don't get overwhelmed and can take my time."

"Forgiveness and validation... it's OK that I struggle sometimes, I'm doing well."

2. SURROUND YOURSELF WITH SUPPORTIVE PEOPLE

"I do what I can and the stuff I can't I'm very lucky to have a partner that does. I think who surrounds you is a huge key to recovery. You need people who lift you up, because then you start to lift yourself."

"Every day brings difficulties but with the right kind of support network (family, friends and even professionals) things do I suppose get a little easier."

3. TAKE NOTES

"I find note-taking really helps. I tend to use my phone for notes and memos."

"My diary is so important... reflecting on conversations I've had straight after and try to work out if I could be more flexible in my thinking (doesn't always work but keep trying). Lists, shopping lists, job lists, always put things in your diary as soon as they come up."

4. HAVE A ROUTINE

"I am VERY rigid with my thoughts/actions. I find it difficult to be spontaneous and prefer to stick to a daily/weekly routine which can be boring but helps me to remain calm and collected (most of the time!)."

"Executive difficulties can be really tough."

TISHA'S STORY

Executive function underpins our adventures, our successes, our challenges, but its location in the frontal lobes of the brain makes it particularly susceptible to damage - something 42-year-old Tisha, from London, knows all too well.

"I'm originally from France, but I moved to London at the age of 18," said Tisha.

"I worked in various fields and danced at professional level for six years. I decided to try something new, and in 2018

I moved to Dubai. I went on a tourist visa then got a full-time job within three months as a Pilates instructor, then found myself working and living in Abu Dhabi."

Tisha had a high level of executive functioning; she worked in senior management and enjoyed a busy social life before her move to Dubai. She was creative and artistic, bubbly and energetic... but this was all to change after a horrific car crash in 2019.

"One morning, I took a taxi to go to work. We'd barely left when the driver decided to run a red light at a major crossing, and we were hit full speed by a huge 4x4.

"What happened after that I only know from the police report, as I have no memory of the accident, and very blurry flashes of the rest of that day."

Tisha suffered fractures to her spine, face and jaw, broken ribs



and a bleed to the brain. However, her surgery was successful, and she was discharged after just one week.

Pain, severe vertigo, financial worries and the stress of attempting a return to work while still recovering from the accident eventually led Tisha to return to the UK. From there she began rebuilding herself after brain injury, with executive dysfunction being one of her most problematic issues.

“Looking back, here are the problems I can isolate as issues with executive function:

“Planning: For me to go to London the neurosurgeon had to talk it through with me step-by-step, because I honestly had no idea. When I got back to London, I realised that I could go to a supermarket, pick something off the shelf and pay for it. But if I tried to think of a meal to cook, or what ingredients I needed, I simply couldn’t.”

“Multi-tasking: I couldn’t manage more than one thing at a time. If I was talking to someone and my attention was caught by noise outside I would end up frozen in the middle, and it would take me ages to get myself back onto the conversation. Trying to do more than one thing at a time would get me in a panic as I couldn’t manage my attention on both tasks.

“Focus and attention: I’ve always been someone whose attention tends to drift off, but in the past I was able to notice it straight away and bring myself back to the task at hand. I started having issues with my attention drifting, but with me not even noticing and getting lost in something else.

“Processing of information: My brain would get stuck sometimes. Best I can describe it is when your computer freezes... you know that spinning circle

on your screen and no matter what you do or press it’s stuck? Well, that was my brain at times!”



Tisha is now beginning to redevelop her executive functions and is planning on moving away from London to the South of France, where she hopes to live a more peaceful life supporting others who are rebuilding their life after brain injury.

“Most people don’t realise that this stage can take months, or even years! I’m very lucky that the damage did not affect my intelligence so I hope I can use that to help others, and also to help raise awareness.

“Working out your own symptoms and executive difficulties can be really tough, especially because every injury is different.

“There are general things that tend to show up, but with executive functions, they will tend to be very specific to you, your brain, your specific injury, and your lifestyle and activity. It’s really worth taking the time to work out what they are, and how you can find compensatory strategies that are specific to you.”



OPTIMISM



AS GOVERNMENT COMMITTS TO ABI STRATEGY

On Wednesday 1 December 2021 during Prime Minister's Questions, Chris Bryant MP asked the Prime Minister to back his Private Members Bill on acquired brain injury.

The Bill, which was due to be debated in the House of Commons two days later, was set to require the government to 'make provision about meeting the needs of adults and children with an acquired brain injury; and for connected purposes.'

In other words, devise and implement a cross-departmental strategy to improve life after brain injury – something charities such as Headway have, for decades, been calling for.

The Bill, however, was never debated as Boris Johnson responded to Chris Bryant by announcing that the Department of

Health would indeed be taking the lead on developing such a strategy.

"This is very good news," said Peter McCabe, Chief Executive of Headway. "For too long, the needs of brain injury survivors and carers have not been met due to inconsistencies in care and rehabilitation across the UK, and differing approaches from government departments.

"A huge amount of credit must go to Chris Bryant, Sir John Hayes MP, and their colleagues on the All-Party Parliamentary Group for Acquired Brain Injury for their outstanding efforts in making this happen."

"The Acquired Brain Injury Strategy represents the best opportunity in a

generation to ensure the needs of brain injury survivors, carers and families are finally addressed in a consistent and holistic manner.

"The effects of brain injury and its impact on all aspects of life – and society itself – have never been fully recognised by government. This has led to a lack of understanding of the nature of the condition, uncertainty as to its prevalence, and underfunding of specialist acute and community-based rehabilitation and support services for those affected.

"Acquired brain injury shares many similarities with other neurological conditions, but it requires specialist rehabilitation and social support strategies. That's why a unique strategy for ABI is essential and we are delighted to support its development."



Peter McCabe joined Chris Bryant MP and other campaigning organisations to urge the Prime Minister to back the ABI Bill

PROGRESS MADE

In recent years, there has been some good progress in working with individual agencies and departments of government.

For example, Headway has developed a partnership with the Department for Work and Pensions, with training provided to Jobcentre Plus staff in Scotland, Wales and England.

In addition, Jobcentre Plus staff now recognise the charity's Brain Injury Identity Card when supporting vulnerable clients, to ensure they can identify customers who have a brain injury at the earliest opportunity.

Similar collaborative practice is occurring in other areas of government. Headway is working closely with Her Majesty's Prison and Probation Service by training prison and probation officers to recognise and understand brain injury and its effects.

Meanwhile, parliament is increasingly engaged with the various issues associated with brain injury and sport, as evidenced by the recent DCMS Committee's inquiry into concussion in sport.

But brain injury affects every aspect of one's life – and the lives of carers and family members – and that is why a holistic approach that spans all government departments is essential.

WHAT HAPPENS NEXT?

The Prime Minister's announcement was followed by a written statement by Gillian Keegan MP, Minister of State for Care and Mental Health.

The statement reiterated the government's commitment to supporting all people living with a brain injury and recognition of the 'strength of support for a more collaborative and cross-departmental approach to ensuring that people with ABI receive the support they need from statutory services.'

In addition to promising a new strategy, the statement outlined plans for a call for evidence and the establishment of a programme board, co-chaired by Gillian Keegan and Chris Bryant.

WHAT COULD THE STRATEGY COVER?

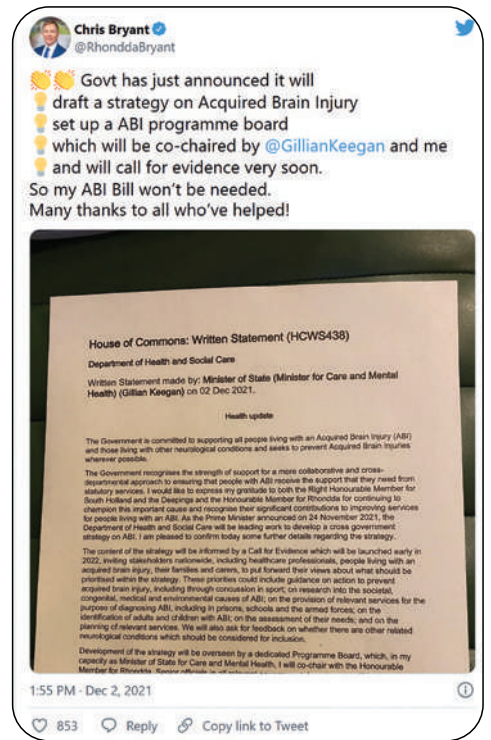
Many government departments will be involved in the strategy, including the Department of Health, the Home Office, and the Department for Work and Pensions.

"One of the most encouraging aspects of this work is the commitment to bring together all areas of government," said Peter McCabe.

"A consistent approach is required, particularly as the needs of brain injury survivors and carers are rarely limited to one service.

"The call for evidence will likely inform the priorities of the programme board, however there are several key issues that we hope will be addressed.

"These include equitable access to specialist neurological rehabilitation that is not time limited and transitions seamlessly from acute to post-acute services, including those delivered by



community-based services commissioned by local authorities.

"Consideration should also be given to all agencies within the criminal justice system receiving training to ensure brain injury survivors are identified at the earliest stage of contact with the police.

"In addition, we would like to see further reform of the disability welfare system that would see a complex system such as brain injury assessed by those with specialist knowledge.

"These are all long-standing but achievable objectives. They will need the full commitment of many people, but this strategy gives us all hope.

"Other equally important areas that we feel should be considered include support for families and carers, improved data collection on incidence and prevalence to inform policy and planning, and greater government involvement in issues with concussion in sport.

"Progress will not be immediate, but we look forward to giving our full support to the programme board at every step of the way."

We will continue to provide updates on the development of the ABI strategy, including any opportunities to share your views, on the Headway website and social media channels.

FROM A CHILD'S MIND TO CENTRE STAGE...

A family's world can be flipped upside down by a brain injury. Adults can struggle to understand and cope with the immense changes that the 'hidden disability' can bring, even if they have been by the survivor's bedside in hospital, given information and offered support.

But what of children, who suddenly see a parent so changed and are unable to make sense of this?

Kristin McIlquham found herself in this confusing situation at just six years

old when her father sustained a life-changing brain injury.

Here, she shares her reflections of what it was like to cope with the ripple effects of a brain injury on the entire family.

Kristin's father, Bill, was in his late 30s living a flourishing life. A popular and creative entrepreneur, he owned a nightclub, was a great singer, had a family and was a well-respected member of his community. Things began to change for him when he started suffering headaches.

"They were extreme headaches," said Kristin. "He went into hospital, where he had three aneurysms that burst on the left side of his brain. My half-brother had

also suffered from a brain haemorrhage at roughly the same age, so it was very scary for us."

Bill was in a coma for five months and gradually regained consciousness. By the time he returned home, he was a changed man.

"He had forgotten who we were," said Kristin. "He had to learn how to do everything again. He would tell rude and inappropriate jokes and he lost the ability to sing in tune.

"He became depressed, aggressive, and irritable. It was like my dad had died and had been replaced by an imposter.

"I felt a lot of anger and embarrassment and I never wanted to bring my friends around to meet him.

"At the time it was very confusing. I had no help or understanding about the situation, I was just a child."

These feelings and experiences remained with Kristin throughout her life. As an adult, she moved into the arts and became an actress and writer. It was only when she began writing a play about her experiences of brain injury that she started to make sense of her perplexing childhood experiences.

"When I was approaching my 40th birthday, I wanted to address what happened to us all," she said. "I began writing this play to help me to understand a little more.

"I describe the play as something that's forced me to confront, kicking and screaming, some of the unfinished

business in my life. It'll be a funny and moving true story about the aftermath of my father's brain injury and the impact it had on our relationship, my life, and, well, pretty much everything."

Kristin began researching others' experiences to help shape the play.

"I can only speak for my experience; I want this play to be seen by other families who have been affected by the same thing. I never saw our story reflected anywhere growing up, yet it affects so many people.

"In my research I was told of a quote a six-year-old said: 'My father died but not in the same way as my bunny rabbit.' I hold onto that.

"I learnt that no matter what age you are, you will always be the child of someone with a brain injury, and whatever feelings that conjures up, well, that is okay. Feelings of embarrassment and anger are totally valid, never feel guilty for having them."

Kristin hopes that her play will help to improve understanding of brain injury.

"I would hope people leave with a little more knowledge of what brain injury is and how it can affect families. For people to think about the blurred lines of memory and to leave feeling a little bit of hope.

"Mainly I want people to have empathy for both sides.

"Brain injury affects the whole family, and it's so important to understand that even family members who can't express themselves, like children, can be affected too."

In November 2021, Kristin performed a work-in-progress version of her play, titled *Headcase*, at the Queen's Theatre in Hornchurch, Essex. The full play will be performed in 2022, and you can find details at www.queens-theatre.co.uk/whats-on/show/headcase

For information and guidance on supporting children, see Headway's booklet **Supporting children when a parent has had a brain injury** at headway.org.uk/information-library.



Krissi Mellquham performs *Headcase* at Queens Theatre Hornchurch - photos courtesy of Alex Brenner



"Brain injury affects the whole family, and it's so important to understand that even family members who can't express themselves, like children, can be affected too."

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Join the conversation

When we launched our online forum on a new platform called HealthUnlocked back in 2012, we wanted a safe space where survivors and their loved ones could come together to share their mutual experiences and support each other through the enormous challenges of adapting to life after brain injury.

It's now almost 10 years on and we've been inspired, educated and thoroughly blown away by the success of the community. It has grown into a vibrant and welcoming online space, with more than 9,000 members from all walks of life and at every stage of recovery coming together with one thing in common – brain injury.

Here, we answer a few frequently asked questions about the Headway HealthUnlocked community to help you get started...

WHO CAN JOIN?

Anyone can join the community, but it's intended as a space for people who are directly affected by brain injury, including survivors and their loved ones.

WHAT QUESTIONS CAN I ASK?

Anything relating to brain injury! We know how broad that is, but people talk about a huge range of issues, from partners looking for support while a loved one is in critical care right through to the practical issues that survivors encounter, such as returning to work and difficulties while out-and-about.

A brain injury can affect everything so there's no such thing as a silly question, and the chances are that another member will have been through a similar experience.

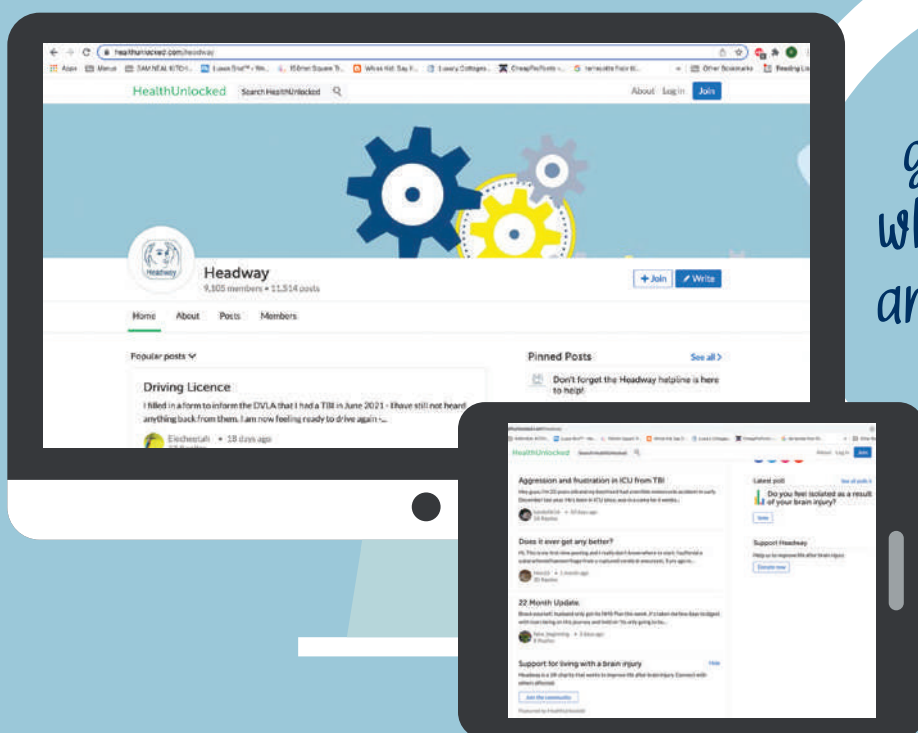
IS THE HEADWAY HEALTHUNLOCKED COMMUNITY SAFE?

The community is as safe as any online forum can be. Members can choose to post publicly or just to registered members, but we do issue guidelines about not sharing personal information and unlike some popular social networks, the registration process isn't too intrusive.

We moderate questions and their answers and will remove anything that breaches our 'house rules', and we're always on hand if you need us to step in and help.

HOW DO I JOIN?

Visit healthunlocked.com/headway to get started. We can't wait to welcome you!



“This forum gave me a safe haven where people understood and could offer empathy and helpful advice.”

Aelfwn, Headway HealthUnlocked member

THANK YOU TO OUR HEADWAY HEROES

Despite the challenging times we've faced over the past two years as a result of the pandemic, your generosity and commitment to our cause has enabled us to continue providing vital support and services to those affected by brain injury.

Whether you've worn a Hat for Headway, taken part in our cycling or walking events, run a bake sale or conquered epic challenges like the London Marathon, we want to say a huge thank you for what you have done and continue to do for us – you're our Headway Heroes!

Fundraising is no mean feat, but it is so rewarding and every pound raised really does make a difference. So, with the change of seasons we'd love to welcome a new team of heroes to join the cause and help improve life after brain injury.



Read on to see some of our new challenges for 2022 and, if you're a keen runner with a London Marathon place, we hope to welcome you to Team Headway!

CAN WE INSPIRE YOU?

Fundraising can take many different forms, and while the big events tend to grab the headlines, they can be a daunting challenge for many people. Don't forget that sometimes just selling a cupcake can make a huge difference in raising vital funds!

If you need more inspiration or support taking on your own fundraising challenge, download our free fundraising guide at headway.org.uk/fundraising-guide, or contact Juma on fundraising.admin@headway.org.uk or **0115 924 0800** to talk things through.

CHALLENGE YOURSELF IN 2022

Here is a selection of our favourite events over the coming year, and you can browse more at headway.org.uk/fundraising

SKYDIVES

Location: Various
Date: Throughout 2022

After exiting the plane at 10,000ft you will freefall for 40-45 seconds travelling at up to 120 mph! At around 5,000 feet the instructor deploys the main canopy and you will begin your five minute scenic parachute descent, landing to the cheers of your friends and family.

For more info visit:
headway.org.uk/skydives

EDINBURGH MARATHON

Location: Edinburgh
Date: 28 – 29 May 2022

Join the UK's second largest marathon through the beautiful capital of Scotland. Enjoy a fantastic route that takes in some of Edinburgh's most iconic landmarks and offers picturesque views along the East Lothian coastline. Full and half marathon options are available, as well as shorter 10k, 5k and junior routes!

For more info visit:
headway.org.uk/edinburgh-marathon

ULTRA CHALLENGE WALKS

Location: Various
Date: Throughout 2022

Walk, jog or run at YOUR pace on the Ultra Challenge Series event of your choice. Whether it's along magnificent coastal scenery, or in stunning open countryside, there's an Ultra Challenge for you.

For more info visit:
headway.org.uk/ultra-challenge

LONDON TO PARIS CYCLE RIDE

Location: Starts in London, ends in Paris!
Date: Throughout 2022

This fantastic cycling challenge connects two of the world's most famous cities! Cycling through beautiful English villages and into the stunning countryside of rural France, you'll pass historical landmarks and famous battlefields from World War I until you reach Paris.

For more info visit:
headway.org.uk/cycle-rides

INCA TRAIL TREK

Location: Starts in Cusco, Peru
Date: Throughout 2022

There are many trails throughout Peru but the original Inca Trail is unrivalled. Leading you along gushing rivers, through ancient tunnels and over high mountain passes to the Sun Gate. The sight of the magnificent lost city of Machu Picchu appearing through the morning mist is one that will live with you forever!

For more info visit:
headway.org.uk/treks



"IT WAS ONE OF THE BEST THINGS I HAVE EVER DONE"

Amy Streater took on the London Marathon in 2021 to support Headway, raising more than £11,000 in the process! As one of our Headway Heroes, we asked her about the reasons for tackling this epic challenge, and her experience of training, running and fundraising for charity.

WHAT MADE YOU DECIDE TO TAKE ON THE LONDON MARATHON FOR HEADWAY?

"In 2019 my 90-year-old grandpa underwent an emergency craniotomy for a brain abscess. Over the following months he had to learn how to eat, swallow and speak again. This ongoing emotional and physical battle was the toughest I have ever witnessed.

"His journey is what motivated me to run the marathon and, although it seemed like a huge and slightly daunting challenge for me, it was nowhere near as tough as the daily fight that he and others recovering from brain injuries face.

"Those suffering with brain injury, like my grandfather, and their families are

the reason that I ran the marathon for Headway. His fight and determination continue to inspire me every day."

HOW DID YOU FIND THE LEAD-UP AND TRAINING?

"I had trained and was ready to run the marathon back in April 2020, however unfortunately it did not take place due to Covid-19. I therefore lost my marathon fitness and when I realised that it might actually happen in October 2021, I started training again - a bit last minute - in July.

"I found the shorter runs enjoyable but the long runs pretty boring when I was on my own. Luckily, I had great support from family and friends and I picked beautiful places to run, including several laps around reservoirs, so that helped to keep the motivation up.

AND WHAT ABOUT THE BIG DAY?

"On marathon day the atmosphere was amazing. Chatting to people before and during the run, finding out their reasons for running. The support along the route was overwhelming and really helped to push me on when it got tough.

"I will never forget running over Tower Bridge and seeing my partner and



Amy celebrates completing the marathon

friends in the crowd cheering me on. I couldn't have done it without them and the support at home as well. Mile 20 onwards was very tough, but the thought of my grandpa's strength helped push me to the finish line."

HOW DO YOU FEEL NOW YOU'VE COMPLETED THE CHALLENGE?

"I have raised a total of £11,066 (without Gift Aid). I feel very humbled by all of the generous people in my life that have donated.

"I'm proud of the money that I raised and for completing the marathon in 4 hrs 33 mins. It now feels strange when you no longer have to run for hours at the weekend.

"I am enjoying having a bit more freedom back, but it was one of the best things I have ever done and I will never forget it."

TAKING ON THE LONDON MARATHON IN OCTOBER?

JOIN TEAM HEADWAY AND IMPROVE LIFE AFTER BRAIN INJURY!

Donate to our Headway Heroes at [justgiving.com/campaign/headway-london-marathon-2022](https://www.justgiving.com/campaign/headway-london-marathon-2022)

The iconic London Marathon needs little introduction. Since the annual event started more than 40 years ago, it's become one of the world's most famous challenges and an essential on every runner's to-do list.

The marathon roared back to life last year after a Covid-related cancellation in 2020 and it's back once again this October, taking in the world-renowned route from Blackheath, over Tower Bridge and past London's landmarks to its epic finish line on The Mall.

As always Headway's team of heroes will be out in force raising funds to help improve life after brain injury while raising awareness in our unmissable yellow running vests!

HAVE A MARATHON PLACE?

If you're taking part in this year's London Marathon, we'd love to welcome you to our team!

While we can't take away the effort of the challenge itself, as a Team Headway member you'll get all the support you

need with training tips, fundraising advice and a chance to promote your JustGiving page on our challenge website.

READY TO JOIN US?

Follow these simple steps to get involved:

- Setup your shiny new fundraising page on JustGiving, which will act as a hub for your fundraising efforts. Visit our campaign page to get started: [justgiving.com/campaign/headway-london-marathon-2022](https://www.justgiving.com/campaign/headway-london-marathon-2022)
- Contact our Fundraising Administrator Juma Khan on fundraising.admin@headway.org.uk or **0115 924 0800** to say hello and tell us you'll be running for Headway. That'll allow us to stay in touch and support you as the big day approaches.



HEADWAY GETS CREATIVE

THE JOY OF ART AT HEADWAY CARDIFF AND SOUTH EAST WALES

Creative activities can be hugely beneficial to people after brain injury. Many survivors report a positive impact from creative activities on a wide range of issues they face, as well as boosting mental health and confidence. They can also help with rehabilitation by encouraging survivors to practice skills such as manual dexterity and memory.

In this feature, we showcase some of the innovative ways that Headway groups and branches across the UK are supporting their members in their creative pursuits.

In preparation for a move to new premises after many years at Rookwood Hospital, members of Headway Cardiff and South East Wales took part in an exhibition to reflect on the group's history, identity and future, while raising awareness of brain injury. The exhibition was supported by funding from Cardiff and the Vale Health Charity.

Members were inspired by Jackson Pollock when creating this artwork, using paint bombs, water pistols and squeeze bottles to produce splatter paintings.

In doing so, they demonstrated that physical disabilities can be circumvented to create impactful, expressive and explosive images, and that the joy of participating in the creative process can be as important as the final work.





SHOWCASING CREATIVITY AT HEADWAY EAST LoTHIAN

Members of Headway East Lothian have access to a range of art lessons as part of their weekly sessions, giving them the chance to express artistic talents and emotions through their work.

Development Officer Joyce Cattanach explains more: "Brain injury survivors at our group have been exploring both rural and urban areas, taking impressions through sound, memory, photos and physical reminders. They brought this back to our group sessions for discussion, then transferred these ideas into physical artistic expressions using words,

voices, paintings and other mediums.

"This has encouraged our members, who are all living with disabilities and life-long conditions, to be more aware of their local communities and how they can relate to them and take a more active part, while building self-esteem, confidence levels, tackling loneliness and social isolation."

The group held a two-week exhibition at Dunbar Town House which gave them the chance to showcase their work.



CREATIVITY FOR WELLBEING AT HEADWAY WORCESTERSHIRE

Art is a fundamental aspect of Headway Worcestershire's Wellbeing Services, with brain injury survivors benefiting from an experienced ABI art teacher who nurtures their ability to express themselves creatively.

Previously, our clients tended to leave their works in the art room. Now, however, the talented artists take home their creations to display with pride!



EXPERIMENTING WITH CREATIVITY AT HEADWAY CAMBRIDGESHIRE

Anna Mumford, Creative Therapies Coordinator at Headway Cambridgeshire, has been putting her skills as a former art teacher to good use by leading art sessions at the group's Chesterton Hub every Friday.

Using a wide range of techniques, the group allows members to experiment with their creativity while unlocking its many positive benefits.

Anna explains how the art sessions helped one client to practice her memory skills: "While working on a particular art project, we started mixing paints together to create different colours. One of our clients, Elaine, struggled to do this due to her memory problems after a stroke, and the following week she couldn't remember the right paints to mix.

"I created cue cards to show which combinations make certain colours, while our Community Rehabilitation Worker, Chloe Woods, used this as an exercise in her sessions with the client. Over time Elaine began to

remember more colour combinations each week, which has been a big success."

Asked what advice she had for others who might be thinking of taking up art after brain injury, Elaine said: "You'll only know if you have a go, so why not try it out and see? You might surprise yourself, and others too!"



THE BEAUTIFUL (AND PRACTICAL!) HEADWAY CENTRAL LANCASHIRE CALENDAR

Following a temporal lobectomy at the age of 11, Daniel McCullough struggled with the effects of brain injury throughout his early-adult life. In his early 20s he finally turned a corner, getting the benefits he was entitled to after a long battle and feeling an "improved mental clarity."

Having always had a creative side, Daniel took to photography when he noticed a decline in wildlife in his local area.

As a member of Headway Central Lancashire, he donated this series of photographs for their 2022 calendar, beautifully capturing the wildlife and landscape of the stunning Lancashire countryside.



BUILDING CONFIDENCE AT HEADWAY SHROPSHIRE

Art Tutor Jo Chandler started the creative sessions at Headway Shropshire in 2021, taking in a wide range of techniques including watercolour, clay, chalk and oil pastels.

"The sessions help in a number of ways, particularly with social interaction, self-expression, building confidence and promoting discussion," explained Jo.

"I've noticed an increase in the length of time clients can concentrate on tasks, and while there can be frustration, there is also enjoyment, relaxation and a sense of achievement."



CREATIVITY WITH CLAY AT HEADWAY GLOUCESTERSHIRE



Kath Cooper has been leading the popular pottery sessions at Headway Gloucestershire for nearly 20 years.

"Being creative with clay offers great benefits on many levels to survivors of brain injuries," said Kath.

"Using repetitive actions such as rolling out slabs of clay, making coils and cutting clay out gives survivors the opportunity to practice physical movement. Adding intricate decoration and modelling using tools or painting on glaze can help survivors practice their dexterity, fine motor, and co-ordination skills.

"One of the most important benefits of pottery at Headway Gloucestershire, other than being very enjoyable, can be the opportunity it provides for survivors to build their confidence in trying something new and making a finished piece of work to take home. This can then be shared with family and friends and can result in a great sense of achievement."



INSPIRED TO GET CREATIVE?

We hope you've been inspired by this snapshot of some of the amazing creative works that brain injury survivors are getting involved with up and down the country.

Many Headway groups and branches offer creative sessions, so if you'd like to find out more head over to headway.org.uk, pop your postcode into the 'Find local support' box and contact your local Headway.

You can also search online for local courses, groups and activities that inspire you and fit your needs.

Whether through your local Headway, independent art group or college, or by simply picking up a paintbrush and starting your own work, see how you feel about giving art a try.

Remember that there's no right or wrong way to do it, it's all about creativity, freedom and expression – and hopefully having fun and seeing some benefits! Also don't forget we'd love to see your creations!

Inside your incredible brain

In this edition, we will look at the most recently evolved part of the brain, **the frontal lobe.**

Basic facts

The frontal lobe is the frontmost part of the brain, located right behind our foreheads. It makes up around 40% of the cerebral cortex (the outer layer of the brain). It is also the largest lobe of the brain.

Common to mammals

All mammals have a frontal lobe. Primates have the largest frontal lobes of all mammals.

Separated by sulci

The frontal lobe is separated from other lobes of the brain by two major dipped grooves in the brain ('sulci'), named the lateral sulcus and the central sulcus.



Neuropsychological tests

Neuropsychological tests can be used to detect frontal lobe injury and identify issues such as problems with concentration, memory and decision making.

Widely connected

The frontal lobe is widely connected to the rest of the brain. For this reason, injury to the frontal lobe can sometimes 'ripple' to other parts of the brain, and the opposite can also be true, whereby injury to other parts of the brain can affect the frontal lobe.

The classic case of Phineas Gage

One of the most famous documented cases of a frontal lobe injury dates back to 1848 when a railroad worker named Phineas Gage was struck in the head by an iron rod, which pierced his face, through to his frontal lobe. Gage survived the accident but was left with major personality changes.

Frontal lobe skills

The frontal lobe is where emotions, personality and executive function skills (planning, judgment, decision-making) are processed. Damage to this part of the brain can therefore affect personality, cause executive dysfunction and affect emotional regulation. Many of the effects of frontal lobe damage are often not visible and may therefore be difficult for others to understand.

Development

The frontal lobe is covered by the frontal cortex, which does not finish fully developing until an adolescent reaches their mid-20s.

When catwalks are barbed

BY EMMA SEASMAN

Shopping and lunch date taken for granted
Recharge with a coffee and up again for round two

I'm pretending my muscles don't burn
I'm pretending my watch isn't ticking to seizure o'clock

I'm dressing for comfort not glamour
Fabrics that mould to the sofa when I need to crash out

"Let's go for cocktails or go out for a meal"
I'm pretending I'm alert hiding my yawn in my (jersey) sleeve

Getting ready exhausts me before the taxi is called
A migraine in the distance promising presence before it arrives

Heel ache times by twenty for Cinderella brained belles
Nights out spoiled by memories of week long recoveries made

Eyeliner eyes glaze through eyelash extensions
Weighing heavy on lids already worn and strained

Dancing for me is a gladiator battle
My chosen cloth light as I'm already weighed down

Patterns of clothing mixed with bright flashing bulbs
Send my brain waves to seizures looking drunken and strange

Pyjamas now; not classic shapes and flattering cut

What fabrics hurt least?

Designs that will never see sun

When fashion becomes function

Fun becomes draining

Designs are abrasive

Where catwalks are barbed

To finish our creative-focused issue, we're dedicating our regular Creative Expression feature to this powerful poem by Headway Sefton member Emma Seaman, who sustained a brain injury due to a brain tumour 10 years ago.

"Creativity has been really important to help with the impact of the brain injury on my mental health," explained Emma. "I attended a creative writing course in 2015, which led to me writing and performing short stories as a therapy.

"Headway Sefton had a huge impact on my recovery and also encouraged me with my creativity. I performed one of my poems at their AGM a few years ago."

CREATIVE EXPRESSION



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Boyes Turner is proud to be an active supporter of Headway. Kim Milan, head of our Personal Injury team, is a Trustee of Headway Thames Valley.

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A special thank you to my lawyer Kim. Her input has changed everything for me. She has given my life a level of security and stability that I never thought I was capable of achieving post-accident.

Jessica Stevens

Contact Kim Milan on **0118 952 7137** or claimsadvice@boyesturner.com
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"Freeths are clearly very concerned for the clients' welfare and tenacious in getting the best for them." Chambers & Partners, 2021



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Prince Evans LLP is a specialist brain injury practice that focuses upon representing the interests of our clients and their families to the full.

We are understanding and knowledgeable of the multiple complexities that are experienced by all when a loved one is affected by brain injury.

We provide a free nationwide no obligation consultation to discuss respective claims and where our expertise can assist; including with potential interim payments, rehabilitation and case management and support. We offer no win, no fee funding.



For more information on how we can help, contact
Gary Smith, Head of Personal Injuries

Call free on 0800 019 0991

Email: gary.smith@prince-evans.co.uk

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



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