

Migraine news

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Welcome

Welcome to your annual Migraine News. It feels quite a significant moment to be writing to you on the back of an incredibly important few weeks for migraine.

The focus of The Migraine Trust for many years has been raising awareness of the realities of migraine and advocating for better care. We want to see migraine better understood, less stigmatised and for those affected to get the care that they need, as early as possible and in the most effective and accessible way.



It feels as if we are slowly starting to reach a tipping point and migraine is beginning to come into the spotlight. At the end of March, migraine was debated in the UK parliament for the first time in over 60 years. MPs from different parties and representing different countries across the UK came together to share personal experiences, stories from their constituents and discuss what needs to change for the 1 in 7 who live with migraine. I look forward to updating you on next steps which includes a meeting with the Health Minister to further discuss how we can speed up access to care and vital medications including CGRPs, treatments which we know far too many people can still not access. This comes on the back of successful events in the parliaments in Westminster, Scotland, Wales and Northern Ireland, and you can read more about these in this issue.

Along with the debate, we saw migraine in the media spotlight with BBC Breakfast covering migraine on three separate occasions and feeding back to us that they have been overwhelmed by the volume of stories and experiences shared with them as a result. We also recently saw the approval of Atogepant for preventative use by NICE which is a positive step, now the focus must be on ensuring everyone who could benefit from it can access it.

Migraine affects more people than asthma, epilepsy and diabetes combined and it's time that it gets the attention and funding it deserves. I want to thank everyone who has been getting involved with our campaigning and sharing their stories to highlight what needs to change. I feel we are on the cusp of real momentum and we are determined to keep it going. We can't achieve this without your support and for that I am enormously grateful.

This issue of Migraine News is in our new revised annual format. We listened to your feedback and are focusing on information for you as well as stories from people with lived experience. As a small charity, our work is only possible through your generosity so if you are able to donate you can find a number of ways to do that highlighted in the magazine.

Best wishes

Rob Music, Chief Executive

News update



Four year project to look at non-pain related symptoms

There are about 10 million people in the UK living with the disabling consequences of migraine. Traditionally, migraine therapies and research have focused on migraine-related pain (headache). However, patients commonly report several disabling non-pain symptoms hours to days before the headache that warn of an impending attack. As such, these “early warning” symptoms, that can include feeling excessively tired, light and sound sensitivity, and thirst/cravings, provide a unique opportunity to explore what is happening in the brain when an attack starts.

We have recently partnered with researchers at King’s College London (KCL) who identified abnormal activity in an area deep in the brain during this early phase. This area, about the size of an almond is termed the hypothalamus and it normally functions to keep your

brain in a stable state termed homeostasis, helping your brain respond to internal and external (e.g. day/night) environmental changes. Through this collaboration between The Migraine Trust and The Medical Research Council/KCL doctoral training programme we have recruited an exceptional young scientist. Starting in October 2025, they will work in the Headache group under the supervision of Dr Holland and Prof. Goadsby. Over the next 4 years they will investigate how these non-pain symptoms occur and importantly, how we can target them to develop new treatments for migraine that tackle the root of the condition, rather than simply masking the pain.

This has only been made possible by the generous donations we receive and with your continued help, we will continue to ensure that more people have access to the support, information and treatment that they need to manage this debilitating condition.



Putting migraine on the political agenda

Thanks to many of our supporters we have been taking migraine to Parliaments across the UK, running events for politicians to find out more about migraine and understand what they can do to improve care for their constituents and at a local level. We held an incredibly successful event in the

Houses of Parliament in London in November, in Holyrood in December and the Welsh Senedd in January. Thank you to everyone who attended, shared their stories and contacted their local representative asking them to attend. People with migraine deserve better and we’re determined to make that happen.



First parliamentary debate for over 60 years

In March the first debate on migraine since the 1960s was held in the UK Parliament. The debate was secured by Dehenna Davison MP for Bishop Auckland, who resigned from a ministerial position due to the impact of living with chronic migraine.

She started the debate saying: "Migraine is not just a headache. It is a complex, neurological spectrum condition, of which a headache is one possible symptom. This is a very strong message to anyone suggesting migraine attacks can be cured with a

couple of paracetamol - it is time to learn and to be better."

MPs shared stories from their constituents and topics covered by MPs participating in the debate included access to CGRPs, the potential of pharmacy and the impact of migraine on areas of life including work and mental health.

For too long migraine has not been taken seriously and to see it debated at this levels feels like a

significant step in the right direction.

On the same day we saw the debate covered on BBC Breakfast along with a wide range of other media helping to reach even more audiences and put migraine firmly in the spotlight.

One result of the debate is the Health Minister Andrew Stephenson has agreed to meet with us to further look at what needs to change, which is a significant step in the right direction.



Meet one of the newest members of our team:

Andrea

Tell us about your role

I started with The Migraine Trust in September 2023 as Senior Communications Officer. My role is to raise awareness of migraine, and to promote the work we do at The Migraine Trust through a variety of channels, including local and national press, social media and through blogs and features on our website.

What were you doing before you joined us?

I was leading RNID's strategic programme focusing on employment. Making workplaces accessible to staff with disabilities and long-term health conditions is a particular passion for me, and so I've been really excited to have been involved in developing The Migraine Trust's Workplace Pledge campaign!

What do you get up to in your spare time?

Mainly reading, walking in some of Northern Ireland's scenic landscapes and listening to true crime podcasts. I also enjoy watching scary movies with my cat!



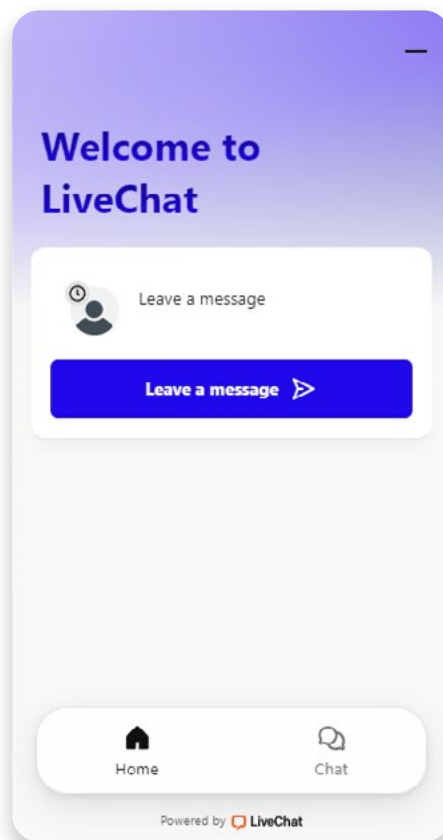
We're taking more calls than ever

If you have ever called our Helpline it's likely you have spoken with Steph or Oscar. Our Helpline dream team provide a supportive space to get answers, information and most importantly listen.

Last year alone they supported over 4,200 people! That number is increasing every year. In 2023 we helped 723 more people than the year before, and 1,771 more than in 2021.

We don't want to miss any call and are working as hard as we can to make sure we can speak to everyone who needs us. In 2022 we introduced a LiveChat function to our website and at the end of 2023 a new Thursday evening shift from 6-8pm which is already proving popular. In 2024 we are focused on securing the funding to recruit a third advisor to help us take some of the 900+ missed calls that we have every year.

If you are able to help fund this, and other work undertaken by The Migraine Trust, then please consider playing our very own lottery (see the enclosed leaflet).



Managing Your Migraine: Join us in September

Join us in London on 8 September from 12-4pm for our next Patient Day which is an informative and supportive event dedicated to migraine.

Whether you're newly diagnosed or have been living with migraine for years, this event is designed to provide valuable information, support, and connection with others.

It is a friendly day with talks from experts, the opportunity to ask questions and to connect with others with migraine or supporting those with migraine. This session provides the opportunity to mingle with and meet other people with migraine, as we must remember that we are not alone!

We look forward to spending this day with you, which will be educational, empowering, and in an understanding and like-minded community and we can't wait to see you there. Visit migrainetrust.org to secure your spot

Ian's story



Navigating migraine while living with other health conditions

There are so many conditions that people live with, and many that co-occur. Some are mental, others physical, and I think it's important that we talk more about the impact everything can have on each other. Everyone is different. Our bodies work in different ways and have different needs.

Migraine, diabetes and macular oedema

As well as living with chronic migraine for over 20 years, I have diabetes and have been diagnosed with Macular Oedema which can affect my vision (as does my migraine). I also have to regulate my blood sugar with my diabetes, any spikes or drops in it can also trigger a migraine.

More recently I've been diagnosed with Obstructive Sleep Apnea which affects my sleep and used to stop me breathing several times an hour. That was causing me to wake most mornings with a migraine due to carbon dioxide building up overnight whilst sleeping.

Managing migraine can be difficult, and managing it alongside other conditions can be even more of a challenge. I've identified some avoidable triggers, quinine is one that affects me, but I have so many unavoidable ones too. It can be frustrating being told to avoid anything that can trigger you when you encounter them just leaving the house.

There can also be potential knock-on effects from some medicines on other conditions you live with. For me, my diabetes medication can leave me dehydrated and affect my migraine and I also had to stop beta-blockers as I can't have them with my diabetes. I've had to try to find a combination of medicines that work, it isn't always easy though and I've tried a range of things. Sometimes they have

worked, others less so or have caused problems. I'm currently on a preventative medication which helps me most of the time.

As I have got older, I have learnt to live with my migraine and better understand how my different conditions and triggers interact.

'My job has helped me understand my condition better'

As a radiographer I deal with migraine patients all the time. Some think they are having a stroke or transient ischaemic attack (TIA); others don't know what their symptoms mean or aren't aware of what migraine actually is. My job has definitely helped me understand my condition better, as well as how migraine relates to other conditions.



When it comes to treatments, it's so important to find a package that works for you. Health professionals also need to be better informed about migraine and how it relates to other conditions, in order to give us the care we need.

The biggest lesson I've learnt throughout my migraine history is don't just accept a diagnosis, do your own

research about the condition, and understand your treatment options. Interact with your healthcare team too, as you are an important member of the team and, if your symptoms change, get them investigated. If you don't understand what is being said, ask questions. Lastly, remember you are not alone and don't suffer in silence.



“Work has been a mixed experience for me. I’ve had some really hard times, even being told I was wasting occupational health’s money with my ‘headaches’.

Working in a hospital can be difficult at times. Strong scents really affect me, and I am photophobic, meaning I cannot tolerate bright light, be this natural or artificial.

My current work is very understanding, and occupational health are superb, they’ve made adjustments from lighting to computers.”

Like Ian, many people who live with migraine can benefit from small and simple adjustments to the workplace environment. Find out more about our new campaign to improve migraine awareness in the workplace on page 24!



Supporting fundamental research to improve the life of people with migraine

Dr Phil Holland, Scientist and leader of the headache research group at King's College London

The Migraine Trust has been a pivotal presence in my career as a researcher, as well as many others working in headache research. Over the years, I have had the opportunity to work closely with the charity to further our joint aims of improving life for people with migraine. I want to share how your support has helped us to make progress in understanding. It is an incredible time with huge advances being made!

Migraine is an issue close to my heart. I have five sisters, including a twin sister who has debilitating migraine with aura attacks.

I've been working in migraine research for 20 years and started my own headache research group at King's College London in 2013. At the time there was very little funding for non-clinical headache research, and I was privileged to receive a small pot of money from The Migraine Trust to recruit a PhD student. We were interested in how our biological clocks that control our sleep/wake patterns influence migraine timing, and how modern pervasive exposure to light (via screens for example) that regulates this circadian timing system might influence migraine biology. We were able to generate pilot data that allowed us to successfully apply for a £375,000 grant from the Medical Research Council (MRC) which in turn enabled us to take on far bigger pieces of research to understand more about attack susceptibility, identify potential new treatment targets and explore the optimum time to take existing medications (termed chronotherapy).

Eighteen months ago, we received further funding from The Migraine Trust in the form of a Fellowship for a young researcher in the lab. Eloisa is particularly interested in why more women get migraine than men and we have been able to identify a potential new neuropeptide target called kisspeptin

(interestingly named after Hershey's chocolate kisses, as it was discovered in Hershey in 1996!)

As a next stage I am writing an application for a grant for more than £500,000 that will enable us to uncover if this reproductive neuropeptide (which is increased in women compared to men) plays a key role in the increased occurrence of migraine in women.

Over the years The Migraine Trust has helped us to support PhD students, and a recent collaboration with the charity, the Medical Research Council and King's will support a new PhD student from October 2024. This work will focus on the non-pain symptoms of migraine. Trying to understand what causes aspects like abnormal fatigue and cognition ("brain fog") and how we can stop them.

The importance of funding PhDs and students cannot be understated. We want to help create the next generation of migraine and headache scientists. People who will hopefully have long careers in the field and contribute to breakthroughs.

We are currently a team of 9 in the research group with 3 scientists, 3 PhD students and 2 undergraduate students. With the continued support of The Migraine Trust, and every one of you who supports the charity, we will continue to further migraine research in the UK. We need this new knowledge so that we can develop novel therapeutic targets. We, and others have had great success in this area recently with several novel therapies that target a neuropeptide called calcitonin gene-related peptide.

I am grateful to The Migraine Trust, The Medical Research Council (MRC), Medical Research Foundation, BBSRC, and several industrial collaborators who have helped us progress. However there remains a major therapeutic gap and not all patients receive adequate relief, we are excited to keep on bridging this gap with the support of The Migraine Trust. ■



Supporting community pharmacy to manage migraine



Robert Music, Chief Executive



When it comes to providing optimum migraine care, we are seeing a lack of capacity in primary care combined with an increase in referrals to secondary care and long waiting lists for specialist

appointments. This is making it incredibly challenging for people with migraine to get the right care they need at the right time. As a result, it is vital we look at all opportunities to improve this situation.

One of The Migraine Trust's key recommendations in its 2023 Heading in the Wrong Direction report was the need to strengthen the role of pharmacy in supporting people with migraine. We believe that by equipping pharmacists with comprehensive knowledge about migraine, including symptoms, treatments, and the risks of medication overuse headache (MOH), we could see enhanced patient outcomes and overall well-being. This will in turn reduce the burden on primary and secondary health care, including A&E attendance and open up new pathways for people with migraine.

Community pharmacy is one of the most accessible NHS services

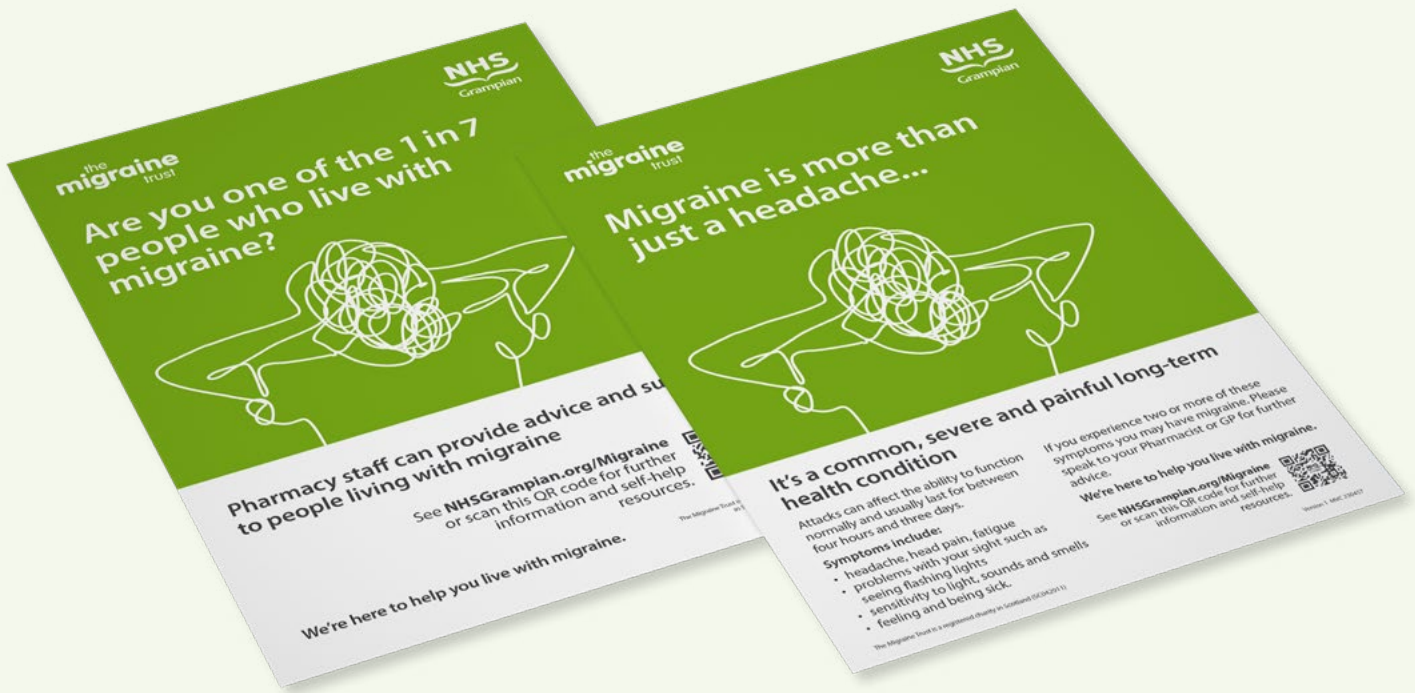
Additionally, community pharmacy is one of the most accessible NHS services. In England, for example 90% of the population live within 20 minutes walking distance of a pharmacy and their services can be accessed without the need for an appointment.

Thanks to funding from The Scottish Government, The Migraine Trust has just completed the first year of a two-year pilot project looking to upskill pharmacists on migraine care while increasing public understanding that their local pharmacist has an expert knowledge in migraine.

The project has been a true partnership, led by The Migraine Trust, working with NHS Grampian, the Pharmacy Medicines Directorate, a GP with a special interest in headache and lead neurologist. This collaborative approach has led to the development and delivery of training and resources for pharmacists on how to help people with migraine manage their symptoms and treatments more effectively. At the same time a local public awareness campaign was run to encourage people with migraine to speak with their pharmacist.



The first year results have been very positive and as a result we've received further funding to widen the work with at least three other Health Boards in year two, as well as embed the learnings from year one within NHS Grampian.



Through a collaborative approach which has championed stewardship and sustainability the project has:

- developed a learning site for pharmacists that includes an eLearning module, recordings of live training sessions and links to resources
- provided training for 73 pharmacy staff in live sessions with over 200 staff engaging with the eLearning module
- redeveloped the NHS Grampian headache and migraine webpages
- supported the development of a Grampian wide public awareness campaign
- provided resource materials for all 132 pharmacies and 74 GP surgeries, and created a bank of resources to be held centrally
- facilitated a public webinar to discuss migraine management in Grampian

When asked how confident they felt when dealing with people with migraine pharmacy staff reported a large increase after being trained. Ahead of the training, 40% agreed they felt confident with none strongly agreeing, but after the training 100% said they strongly agreed or agreed they felt confident.

Knowing the pharmacist in an expert in migraine management

For the general public just 14% said they had accessed support from a pharmacist but after understanding more about their role, 77% said they would now consider speaking with a pharmacist. This number increased to 91% from those that attended our patient webinar in January this year. The main enabler to accessing pharmacy support was knowing the pharmacist is expert in migraine management.

This project is already highlighting that providing comprehensive education and training can empower pharmacists with the knowledge and skills needed to support people living with migraine in their community more effectively, which is crucial for improving patient outcomes and quality of life.

Next steps

We are pleased with the results of year one of this project and looking forward to seeing the outcomes as the project expands wider in Scotland in year two. Encouragingly, we have been approached by experts in other UK countries, wanting to understand more about this work in order to explore ways they can develop pharmacy training within their own community. This is both exciting and positive and we very much believe the results of this project can help provide a model for better practice across the UK. ■

ADHD and migraine: is there a link?



By Oscar Harvey, Information and Support Advisor



Attention deficit hyperactivity disorder (ADHD) and migraine are both neurological conditions. They are separate conditions with their own challenges and symptoms, but research is emerging to show how they overlap. ADHD affects people's behaviour, such as impulsiveness and difficulty with

focus. Migraine involves symptoms that may include head pain, aura, sensitivity to light and sound.

Emerging research

While research is still in its early stages, studies have found people with ADHD, including children, are more likely to have migraine. Children with ADHD have been observed to be more likely to experience headaches and migraine than children without ADHD. This issue extends into adulthood as well, and there seems to be a comorbid link between people with migraine and people with ADHD, particularly migraine with aura. According to a Norwegian 2011 study, about a third of women (out of 572 people surveyed), and 22.5% of men surveyed with ADHD also experienced migraine attacks. The exact link between the two conditions isn't fully understood at the moment, but it's clear from these figures that the rate of co-occurrence warrants more research, including examining whether genetics, environment,

hormones or a combination of these are contributing factors. Below, we explore some of the ways in which the two conditions may be linked, including some of the ways that triggers may be interconnected.

Why might ADHD and migraine be linked?

One possible explanation for the link relates to a common factor in both conditions: experience of stress. Migraine can often co-occur with conditions like anxiety, depression and other mood disorders, and stress can be a common trigger for migraine. Similarly, ADHD frequently co-occurs with anxiety and mood disorders, and a high number of people with ADHD experience stress. This may explain why some people with ADHD also have migraine attacks. ADHD alone, especially when untreated, can affect quality of life and may contribute towards stressful environments and scenarios that can trigger headaches and migraine attacks.

We know that for many people who live with migraine, changes to, or inconsistency of routine can be a trigger for migraine attacks. People with ADHD may struggle with time-management, self-regulation and difficulty sticking to schedules. This may mean people with ADHD who struggle with disorganisation may find their attacks are triggered more regularly. For example, those with difficulty adhering to sleep and food schedules or hydrating regularly may see an increase in their attacks, as these are all common triggers for migraine. Sleep problems and disorders are highly prevalent in people with ADHD, and hyper-focussing for people with ADHD may mean that regular eating and drinking are often missed, triggering a migraine attack.

In turn, migraine may exacerbate ADHD symptoms and create additional stressors, such as missing work, increasing drowsiness, difficulty in moving about and a decrease in productivity. For some people, this can become a vicious circle.

Can ADHD medication cause migraine attacks?

Like migraine, people with ADHD may benefit from a number of different treatment options. Stimulants that increase the level of dopamine in the brain are a common type of medication used to treat ADHD, and headaches are a common side effect of these ADHD medications. They can also lead to a loss of appetite and trouble sleeping, both of which are a trigger for migraine. However, the headache side effect sometimes caused by these medications is usually mild and temporary. ADHD medication therefore will not cause migraine conditions, but rather it's side effects may lead to symptoms that could trigger an attack in someone already predisposed to migraine (such as in the example of appetite suppression leading to skipped meals, which in turn triggers a migraine attack). Conversely, some studies have found that stimulants may help improve peoples' migraine attacks.

A holistic approach to care

The most effective approach to migraine and ADHD is for both individuals and healthcare professionals to recognise that they are connected and view them holistically. This will be helped by ADHD and headache specialists being aware of the link and recognising how the two conditions interact.

Keeping a headache diary to track symptoms, possible triggers and overlap of conditions can be helpful to understand the full picture of how someone's ADHD and migraine may be linked.

Taking steps to improve overall mental and physical health can be helpful in order to minimise the impact of symptoms from both conditions: reducing and managing stress (for example through mindfulness, muscle relaxation, or counselling if helpful), maintaining good sleep hygiene and planning balanced meals.

If you experience any symptoms of migraine or ADHD, we recommend you discuss any concerns with your GP so they can help you work out your personal migraine triggers and the best treatment plan for you. ■

Becky's story

I was diagnosed with migraine when I was 11 but it took ages to be taken seriously. My symptoms were brushed off as grief, stress, puberty, you name it. As well as aura, chronic and hemiplegic migraine I get cluster and tension headaches.

I don't think I've lived a day without head pain. It's sometimes manageable around a six or seven but it can go up to 10. I get around two migraine attacks every month lasting on average four days at a time. There's no warning as they come out of the blue. As well as intense head pain, I can lose my sight or get blurred or double vision.

The right side of my body gets total paralysis and I'll forget how to form words or they sound normal to me but to others they don't make sense. On top of this, my cluster headaches come every two to three months. They are completely debilitating.



My care has been hit and miss. While some people have been great, I've had many doctors say they don't really understand my condition. At times I've felt dismissed. So far no treatment has worked, instead it's been an endless cycle of failed medications and trying to cope with side effects. I've been to A&E several times as the pain was so severe I thought something else was going on.

There are so many things that can trigger an attack from artificial lights to strong smells to certain foods. In previous jobs I have been accused of lying because of taking too many sick days. Migraine really affects every area of life and the impact on my mental health has been huge. I've had some really dark times and reached rock bottom. There's the isolation, the pain, the anxiety, the guilt. You get to the point of thinking anything is better than being in pain. I don't make as many plans as I'm always cancelling which makes you feel more alone, on top of that I know when it's bad I'm not fun to be around anyway.

The world doesn't understand what migraine is and I am so incredibly frustrated with the "here's another pill to try, lie in a dark room and have a paracetamol" attitude that comes with something that is so debilitating. People with migraine shouldn't have to fight to be taken seriously or access healthcare.



"The Migraine Trust is there for people like me, advocating for us and working to improve health and care. Migraine can be incredibly isolating and knowing you aren't alone means so much."

Can you help us be here for more people?

Becky's story sadly highlights the reality for many people who live with migraine, and how they deserve so much better. Better healthcare, better medications and for society to have a far better understanding of the wide ranging impact migraine can have.

The Migraine Trust is working to create change at every point. Although a small charity we punch well above our weight.

We don't want anyone with migraine to feel alone and provide support on the phone and online to everyone who needs it. In the last year we supported over 4,000 people through our Helpline services and our information was viewed over 2 million times. We talk through options, provide answers, give reassurance and work to build confidence so that people feel more able to advocate for themselves and get the care and support they deserve.

Far too many people aren't taken seriously when accessing healthcare and have to fight for the treatments they deserve. We're working to create change at every level. From working with Governments and politicians to raise the profile of migraine to supporting GPs and other health professionals to better diagnose and manage it.

We also invest in research and thanks to our generous supporters we have funded three PHD's and two Fellowships since 2018 to support progress in understanding of migraine and how it can be managed. Most recently our Workplace Pledge and training for workplaces are designed to ensure more people with migraine are supported in employment. This means reasonable adjustments are provided, no one feels they have to hide their symptoms and most importantly no one faces discrimination or has to give up their job.

Everyone has a different experience of migraine and through our campaigns we are working hard to break down myths and stigmas associated with migraine.

No one should face migraine alone and The Migraine Trust is here for everyone who needs us.

However, we can only continue to do this with your help and, as we receive no statutory funding, the ongoing support of people like you has never been more needed. ■



Please will you help us be here for more people like Becky by donating to The Migraine Trust today?

Donating to support our work couldn't be easier - simply scan the QR code, or complete the donation form on the back of this magazine and return it in the freepost envelope provided.

Scan me with your smartphone



www.justgiving.com/campaign/mnspringappeal24

Mental health and migraine



A high number of callers to our Helpline tell us they feel anxious or stressed. Anxiety and anxiety disorders are one of the most common mental health problems that comes with migraine and so if you experience anxiety you are far from alone.

We've spoken to Steph who works on our Helpline about some of the most common questions she hears and how she supports people who call us.



“Does migraine cause anxiety and stress or do stress and anxiety cause my migraine?”

It can actually be either or both. So migraine attacks can lead to anxiety, and anxiety can lead to migraine attacks. We know that stress can be a trigger for migraine.

Sometimes that stress comes from your migraine for example worrying about your migraine attacks. The

symptoms and debilitating nature of migraine can also be stressful so you can end up in a vicious cycle which can be hard to get out of.

“I’m really anxious about my next migraine”

Lots of people feel anxious about migraine and taking steps to feel more in control can help. Writing down your thoughts and worries can help you put names to how you feel and can also help you to offload and process emotions. Keeping a diary with details of symptoms that happen at the beginning of an attack, preventative medication and carrying a rescue pack with you can all help you feel more prepared. Some people find grounding techniques can help to manage an anxiety or panic attack too.

“I can’t cope, I don’t want to be here anymore”

It can be very difficult to cope with migraine and at times it can feel too hard. Speaking about how you feel can help and the support of family and friends can be invaluable. There are lots of organisations who provide professional support including Mind and Samaritans. Make an appointment with your GP who will be able to talk through any mental health support that could be available to you. You could also request a medication review. We can also help by talking you through different self-help options such as supplements and cool packs. Ultimately you aren't alone.

“No-one understands how I am feeling”

Sometimes it is hard for people to understand migraine if they have not experienced it. Use our information sheets or websites to help explain your experience and how migraine impacts you. It might also help to read the stories and blogs on our website to hear other people's experiences.

“I’m really struggling to see my friends and go out, my friends are getting fed up with me”

Tell your friends how you are feeling. You can provide information from our website to help you explain it. It might help to tell your friends what your triggers are and suggest activities you can do that can help you avoid them. This might include more local or home based activities, or shorter events. Try not to feel any

pressure to do things that you are not comfortable with, your health is the most important thing.

“I can’t work, I can’t support my family and I feel so useless”

This is something we hear a lot. Again talking can help so if you feel able to, speak with your family, partner or spouse about how you are feeling. Some people will be eligible for benefit support so do find out if that is you. We have a workplace toolkit which can help you speak with current or future employers about migraine and the adjustments that you might need. Speak with your GP or health professional about any changes to medication or management that could help you.

“Can therapy help my migraine?”

Migraine can have a huge impact on wellbeing. The nature of trying to find a treatment is very challenging for a lot of people and this can add to the anxiety

and stress. There are lots of ways to manage anxiety, and some people with migraine find support such as counselling, CBT or other psychological approaches helpful. This can help you explore and unpack your anxiety. Some people find support groups helpful too. Contact your GP for a referral or many places will accept self-referral. For young people aged 11-24, Kooth is an online support service for people who have anxiety.

“Am I alone in this?”

No. There are unfortunately lots of people who experience stress and anxiety due to their migraine. It can be a very painful, isolating and life-altering condition. There are things that can help and we can support you to find something that might work. We can listen to how you’re feeling and we understand exactly what you are going through. We can signpost you to further support and help you work out your next steps. You aren’t alone going through this. We are here for you. ■

The Migraine Trust Helpline

If you have questions or concerns relating to any aspect of your migraine, we’re here for you.

For support or information about migraine, you can contact our friendly advisors free of charge.

📞 Call us on **0808 802 0066**

✉️ Send us a message at **migrainetrust.org/support**

💬 Talk to us on LiveChat at **migrainetrust.org**



Exploring the connection between migraine and mental health



Emily Wheeler has lived with migraine for over 20 years and is Director of Research Partnerships and Development at MQ, Mental Health Research

My journey with migraine and mental health began in my early teenage years, where anxiety and depression seemed to surface around the same time as my first migraine attacks. These monthly attacks would wipe me out for two to three days at a time. They would include visual auras and numbness in my arms as warnings that one was coming, and then headache and sickness that would see me stuck in bed, unable to do anything but also unable to sleep, and of course, missing school.

Looking back, I've come to understand that my migraine were likely a physical manifestation of the mental struggle I was experiencing—an attempt by my body to signal that I needed to slow down and take care of my well-being. However, it wasn't until many years later that I received an official diagnosis of anxiety and depression and began seeing the link with migraine.

I could almost forget I had migraine

As I navigated through adolescence and into adulthood, I was lucky that both my mental and neurological health seemed to improve, once again demonstrating their link. However, the stresses of starting in the world of work, post university, saw them starting to come back. This time however, the attacks were much less frequent, perhaps two or three a year, and, thankfully, much less debilitating. I was lucky, that period probably lasted a good decade where I could almost forget I had migraine.

However, during the pandemic and the first lockdown, the migraine returned with a vengeance and became chronic. Whilst I still consider them less debilitating than my early experiences (no sickness for example), attacks would last for days but so much so, I found it hard to track if it was still the same attack or a new one had started. This time around, the aura may or may not appear, but either way, it would be followed by dizziness and then the pain. I also started to notice new symptoms. Where the worst of the attack might only last 24 hours, afterwards, I would be left with severe brain fog and fatigue, finding it difficult to find the right words or maintain concentration at work. It was then that I reached out to the doctors again and started a journey to find a treatment plan that would work for me.



Navigating the journey of finding the right dosage was no easy feat

After much trial and error, I was lucky to find a preventative medication that proved effective in reducing the frequency and severity of my attacks. However, navigating the journey of finding the right dosage was no easy feat. Each adjustment brought with it a wave of fatigue that challenged me, changing me from a morning person to someone who struggled to get up at all. Whilst I was able to come off this treatment after 18 months, and enjoyed a good 12 months with many fewer attacks, I have been back on amitriptyline and managing these challenges again for the past six months.

I have a much greater respect for my body

I have discovered that stress, and in its more extreme form, anxiety, is my main trigger but I know this is very hard to control. We also know that some level of stress is good, to motivate us to get going and deliver, be that in work or personally. However, whilst I am very much still on the journey, I have a much greater respect for my body telling me when I need to slow down.

As Director of Research Partnerships and Development at MQ Mental Health Research, a leading global mental health research charity, I've had the privilege of contributing to initiatives aimed

at advancing our understanding and treatment of mental health conditions, including how they interact with many other diagnoses, neurological and physical. Working at MQ, I have seen both the power of patient and public involvement in improving research outcomes, had the privilege of managing and supporting many people who experience migraine and I'm fortunate to have a supportive workplace that understands the complexities of living with migraine and mental health challenges. Their flexibility in accommodating my needs, such as allowing me to start later to prioritise exercise, has been instrumental in maintaining my overall well-being. All these elements of my work have not only deepened my knowledge but also provided me with a platform to advocate for greater awareness and support for those living with migraine and mental health challenges. This year, I was delighted to really mark this stage of my journey by joining The Migraine Trust's Lived Experience Involvement Panel.

Patience, self-compassion and a willingness to seek support

Navigating the complexities of migraine and mental health is an ongoing process—one that requires patience, self-compassion and a willingness to seek support. By acknowledging and addressing the underlying factors contributing to my migraine and mental health struggles, I hope I have taken significant strides towards a brighter and more balanced future. ■

Research roundup



Migraine and sleep

While many report changes to sleep patterns triggering attacks as well as migraine impacting sleep, the full relationship between sleep and migraine remains unknown. A study from University of Arizona Health Sciences' Comprehensive Center for Pain & Addiction has found that sleep deprivation increases susceptibility to migraine-like pain.

The paper 'unravelling the directional relationship of sleep and migraine like pain' was published in February in the journal Brain Communications.

Subjects were monitored and sleep disruption impact was reviewed as part of the study. The team found that migraine-like pain does not influence sleep, but if you have disrupted sleep, your chances of having a migraine attack if you're a migraine patient are much higher. The team say this indicates that a therapeutic strategy focused on improving sleep may diminish migraine attacks. This includes not using electronic devices before bed and following other sleep health tips.

A European focus on stigma

A study by the European Migraine & Headache Alliance (EMHA), a non-profit organisation that represents over 33 patient associations across Europe, has found 93% of those living with migraine believe that the public lacks a proper understanding of the condition. Lack of understanding and stigma meant 35% of respondents admitted to delaying or avoiding seeking medical advice due to feelings of embarrassment and the fear of judgment from healthcare professionals.

74% of those affected by migraine felt that medical professionals do not take their condition seriously.

The study captured the experiences of over 4,000 individuals with and without the condition across Europe. As a result of stigma people reported feeling angry, lonely and sad.

Peter Goadsby, Professor of Neurology at King's College London and Trustee of The Migraine Trust said: "The data from the survey is a wakeup call to clinicians that highlights an important dimension of burden of migraine to our patients." Goadsby, who is also one of the academics behind the study, emphasises the importance of better communication about the disorder's impact and the ways we communicate about the problem.

In the workplace, 62% of respondents believe that migraine has influenced how their employers assess their value. Interestingly, around 43% of those surveyed have chosen not to disclose their conditions to their employers, despite many acknowledging difficulties in completing work tasks.

First line CGRP medications?

The American Headache Society (AHS) has called for new migraine therapies targeting calcitonin gene-related peptide (CGRP) to be considered first line preventive treatments. In a new consensus statement released in March, the AHS encouraged clinicians to use CGRP-targeting therapies as a first line treatment regardless of whether patients have experienced failure when using other preventive therapies. They cited new evidence and extensive clinical experience showing that the safety, efficacy and tolerability of these therapies are equal to or greater than existing first line therapies.

Andrew Charles, President of the AHS said "Moving CGRP-targeting therapies to the first line of treatment could have a transformational impact on the prevention of migraine attacks and their associated burdens."

The AHS is further calling on health insurers to "consider not just the costs of the treatments, but also the costs to patients, their families, and providers when effective and well-tolerated therapies are delayed or withheld".

There is currently no expectation that this will happen in the UK however we will always update you on any changes to our position. ■

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17

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- Make a difference for those living with migraine
- Sign-up for only £1 per week

Lisa plays our lottery: "Living with chronic migraine it means so much to know there's a charity dedicated to people like me. Playing The Migraine Trust lottery is a really simple way to regularly support the charity and know I'm helping their work, with the added bonus of potentially winning each month!"

To start playing visit www.migrainetrust.org
and search for: **lottery**

Players must be 18 years of age or older



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The promoter of this Unity Lottery is The Migraine Trust, 7-14 Great Dover Street, London, SE1 4YR. The Migraine Trust is licensed and regulated in Great Britain by City of London Council. A minimum of 50% of the total lottery proceeds go to supporting the work carried out by The Migraine Trust, 18.4% on prizes and 31.6% on expenses and administration of the lottery.

Why I chose to leave a Legacy to The Migraine Trust



Audrey's experience

"For the first 25 years of my life my abiding memory is blinding headaches, aura and nausea. 'It's just a headache' was the limit of understanding and sympathy I received which made me feel even worse. At 15 I was diagnosed with migraine. I tried 'over the counter' pain relief but these did not help and made me feel worse. I was eventually prescribed a medicine that helped give me some relief but there was no follow up as to its effectiveness.

After getting married I started working in London and travelled into the city often. The migraine attacks were getting steadily worse so I referred myself to the Princess Margaret Migraine Clinic where it was quickly identified my condition was being exacerbated by the medication I was on. I was given a new treatment plan and finally felt that I was being assessed by people who understood migraine both the physical and emotional aspects. My life became bearable again, the difference was incredible.

The information and support provided by The Migraine Trust throughout has been life changing. It has given me the confidence to advocate for myself when interacting with the medical community and my husband has become an even more integral part of my migraine treatment regime. He was already so caring, supportive, and patient but he felt more able to help me navigate the complexities of life with migraine. Our life together, reinforced with a shared understanding of migraine has enabled us to live and work around the world. As my life evolved, migraine attacks with the debilitating side effects became less frequent and have now disappeared altogether. With the benefit of hindsight, I now feel my original GP and the 'specialist' he referred me to didn't understand migraine or its impact on the life of a young woman.

It was an easy decision for both of us to make beneficial bequests in our Wills to The Migraine Trust. It is our hope The Migraine Trust will continue to support clinical research into migraine and how treatments can be developed to help sufferers and their families. Raising awareness of the condition so that everyone can get the care they need is also vital. I am pleased to be playing a part in supporting research into migraine and the development of therapies.

You can find more information about leaving a gift in your Will, or making a codicil to an existing Will by visiting our website and searching 'legacy'. ■

51 years of migraine



Annemarie's experience

My first migraine was when I was about 7. I remember playing rounders and my vision went blurry. 15 years ago they started getting progressively worse. When I have an attack, I feel like everything is moving and I'm going to fall over. I often bump into things because of the light-headedness. After the migraine is settling down, it still takes a while for the dizziness to stop.

'It feels like pushing treacle up a hill'

Living with migraine is debilitating. Mine affect my whole body and they come on with no or little warning. I get physically sick, I get tooth ache, my sinuses play up, everything hurts – even things like lying down and having my glasses on my face are too painful. Then when you're coming out of one it can take two to three days to feel normal - it feels like pushing treacle up a hill. Getting a diagnosis took years. No one seemed to understand and I felt like I was going in circles. I spent about 7 years going to the doctor. I was told it was mental health related, I was too stressed, to drink more water, take a break from work, take paracetamol, lose weight, take more exercise. It got so bad that sometimes I went in crying, and even then, it was 'paracetamol, rest more'.



I've given up all alcohol and caffeine as they can be triggers, but it was far from enough and the pain was unbearable sometimes. When I was finally referred to a headache clinic and diagnosed with chronic migraine, I actually cried because finally someone had listened. Finding a treatment that works has been incredibly hard with lots of bad side effects like feeling woozy and unable to work. It can take months to get each appointment, only to try a treatment that isn't suitable.

'Migraine stops you living your best life'

It's incredibly isolating. It stops me going out due to the fear of ending up stuck somewhere unable to drive home, in crippling pain. People just don't understand. You say migraine and they assume you're overreacting. I feel like I've had to give up so much, so many things I enjoy.

Finding a supportive community

People who have migraine understand. I have a colleague with migraine who is amazing and The Migraine Trust have been so helpful. My neurologist mentioned them and I've been to some Managing Your Migraine events, being in a room full of people with migraine you suddenly feel understood. We need to talk about what it means to live with migraine more.

March(ing) for Migraine!

Annemarie has taken the opportunity to not only raise more awareness of migraine, but also to raise vital funds through The Migraine Trust's March for Migraine challenge. Taking on an incredible 100 miles in the month of March and raised almost £400. "The Migraine Trust have helped me on many occasions and I would just like to give something back." Thank you, Annemarie! ■

Managing migraine at work: The Migraine Trust's Workplace Pledge



Migraine is most common among adults of working age and affects 1 in 7 of the population.

190,000 migraine attacks happen every day in the UK – equivalent to 396 attacks a minute in the average working day. Often, with the right support in place, staff with migraine can thrive in the workplace, and yet, for many, experiences of migraine and employment have been extremely poor.

The impact of migraine on individuals

Our 2023 research into the workplace experience of people living with migraine highlighted some particularly concerning results:

34% of people living with migraine have felt discriminated against at work.

30% have felt harassed or victimised in the workplace, due to their migraine.

56% say their workplace hasn't made reasonable adjustments to help them manage migraine attacks at work.

In addition to the difficulties that living and working with migraine presents, staff with migraine often face the additional barrier of poor understanding of the condition from their colleagues and employers.

We regularly hear from people who share their experiences that migraine is not taken seriously, is erroneously considered 'just a headache' or, in the context of the workplace, thought of as an 'excuse'. Alarmingly, our 2023 research indicated that a staggering 43% of respondents reported that their workplace did not believe them when they had to take sick leave due to a migraine attack.

The impact on employers

The impact of migraine extends beyond those experienced by the individual with migraine. According to Harvard Business Review, employees with migraine miss an average of 4.4 workdays per year due to migraine attacks, and they spend another 11.4 days per year with reduced productivity, which can cost employers even more than actual absences. Our research has further shown the cost from presenteeism was £9 billion.

The Migraine Trust Workplace Pledge

Migraine can undoubtedly impact working life, but this can be significantly reduced if people with migraine are supported at work.

We are calling on employers to reduce the impact that staff with migraine face, by making changes in their workplaces. To do this, we are launching our Workplace Pledge, and asking employers to sign up to demonstrate their commitment to improving the working environment for those with migraine.

Employers who sign up will receive lots of helpful resources to help improve awareness of migraine in their organisation, information about the condition and how they can support members of staff living with migraine.



Organisations that take the pledge will select a number of key actions to take, including making adjustments to physical work environments, offering flexible working options where possible, and reviewing key organisational policies (such as sickness and absence management policies), to ensure they align with best practice for supporting staff with migraine.

Alongside the Workplace Pledge, we've created a web hub with workplace information tailored to employers, colleagues and people who live with migraine themselves. The hub has detailed information on everything from changes that can be made to make a physical working environment better suited to someone with migraine, to tips on homeworking and how employers can take their support further.

For organisations that want to take their commitment further, we have designed costed packages centred around workplace training, with options to tailor sessions around the organisation's bespoke needs.

You can find our new workplace hub on our website, at <https://migrainetrust.org/workplace>, where you can check out our workplace campaign video, which features several people who live with migraine (including Sandip, below) outlining their experiences of work and what they feel needs to change. You might also consider sharing the '[support for employers or businesses](#)' section with your employer and encourage them to sign the pledge!

We are delighted to have had a wide range of organisations take the Pledge already from across sectors including health care, the third sector and creative industries. ■

"At one point my smell sensitivity went off the scale... My work has been really good. Before I told them, I used to open the office at the same time as the cleaners and the cleaning smells would make me physically sick, but I'd just work through it. I requested to work two days a week from home, to be taken away from those smells, and that helped massively. Now I work from home permanently, but if I go in they book rooms with ventilation for meetings, and send memos for people to avoid wearing perfumes."

Sandip



Belfast roundtable explores how to improve care in Northern Ireland



In the past few months, The Migraine Trust has held events in each nation of the UK, bringing together patient advocates, healthcare professionals, and parliamentarians. The aim has been to highlight how migraine impacts people's lives and what needs to change in migraine care.

The Migraine Trust's research report 'Heading in the wrong direction' – launched for Migraine Awareness Week 2023 - found that while migraine patients are being let down across the UK, waiting times for referrals are particularly severe for the 270,000 people living with migraine in Northern Ireland. Additionally, local health bodies in the country vary widely in what services they can provide to residents living with migraine.

This led to a roundtable in Belfast in February with leading clinical experts in headache care and patient advocates to discuss what needs to change, so we can put their findings to the Northern Ireland Department of Health. The roundtable discussion shed light on the true scale of the situation in Northern Ireland, with clinical experts outlining gaps in staffing and investment in both primary and secondary migraine care, while patient advocates highlighted the real-life impact of this: lengthy waiting lists, poor experiences of care and for some, loss of hope. Participants agreed that most people living with migraine should be able to manage their condition in the community with support from primary care services. However, to make this a reality, GPs needed to be better informed about migraine and community pharmacists should be empowered to play a bigger role in supporting patients (a patient advocate recounted a GP saying, "what exactly are you expecting me to do?") Pharmacists were considered to have significant potential to deal with queries including medication interactions and side effects.

It was agreed that clarity on access to potentially life-changing anti CGRP medications was needed. More widely, people with migraine need to see collaboration in the health system, investment in effective migraine management, and awareness about the impact migraine has, so that they can get off waiting lists, live full lives, and be better supported.

A long-awaited Regional Review of Neurology Services is due to report soon, offering us an opportunity to kick-start improvements to headache and migraine services across the country. We will be using these insights and recommendations in a soon to be published paper to help inform that process and enable a much-needed drive for change. ■



Get involved



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September 2024



migrainetrust.org/events/snowdon-at-sunrise-trek

Snowdon Sunrise

Sunday 29
September
2024



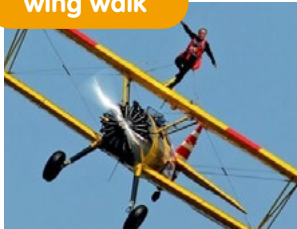
migrainetrust.org/events/scafell-pike-climb

Lots of dates available throughout 2024,
to find out more check out our events webpage

tough mudders



wing walk



bungee



running events



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