

# Migraine news

Issue 129 / Nov 2025

g/brain  
ping/eye  
bing/joy  
rushing/pl  
spoiling/li  
wrecking

Migraine is not 'just a headache'  
it's a debilitating neurological condition

For more information and support visit [migraine.org.uk](#)  
who understand visit [migraine.org.uk](#)



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# Welcome

## Behind the scenes, ahead of the curve: The Migraine Trust's year of influence and what's next.

The Migraine Trust turned 60 in 2025. A huge milestone for a small but, and I am of course biased, well-respected and impactful charity. Since becoming Chief Executive in 2021, I have seen first-hand the passion and commitment of our team, volunteers, and supporters. Together, we've pushed for long overdue change for people living with migraine.

Despite progress, migraine care across the UK remains deeply unequal, and that has to change. Real, lasting improvement will only come when leaders in government and health services recognise that investing in better migraine pathways benefits everyone: patients, the NHS, and the wider economy. Last year we launched our three-year strategy, setting out how we'll move closer to our vision — a world where migraine doesn't stop anyone from living the life they want.

## A year of progress

Over the past year we've worked tirelessly, often behind the scenes, with the NHS, governments, health organisations, and industry to turn our strategy into action. People who contact our helpline tell us how fragmented migraine care can be: many saying they are regularly being passed between primary and secondary care, often without clear answers or a clear treatment pathway. We know GPs are overwhelmed, need more support and training to diagnose migraine confidently, while pharmacists could play a bigger role in local care.

Our two-year pharmacy project in Scotland showed that pharmacists can make a real difference to migraine care. The results sparked wider discussions about how similar models could work across the UK. We've shared the findings at national roundtables and conferences, and I am aware that some experts feel migraine should be part of conversations when looking at adding to current 'Pharmacy First' conditions in England.



To improve consistency in community care, we're working with the Neurological Alliance to pilot a new headache commissioning tool with West Yorkshire Integrated Care System. If successful, it could be rolled out nationally. I also sit on an NHS England task and finish group that's developing guidance for Integrated Care Boards to help address the significant variation in headache care in and outside hospital settings across England.

Over the year we've met regularly with MPs and members of all UK parliaments to build understanding and support. During Migraine Awareness Week, we saw record engagement — with high levels of parliamentary questions raised and many parliamentarians backing our messages. Next, we're encouraging supporters in each UK parliament to secure a formal debate on migraine in late 2025 or early 2026, it's essential conversations around migraine are seen at the highest level.

In 2026, there will be a focus on the devolved nations ahead of elections in Scotland and Wales, and to shine a light on the significant inequalities we continue to see in Northern Ireland — where some Health Boards don't have a specialist clinic or nurse, so making local care impossible.



**“Real, lasting improvement will only come when leaders recognise that investing in better migraine pathways benefits everyone: patients, the NHS, and the wider economy.”**

## Evidence drives change

Evidence underpins everything we do. Policymakers tell us they value The Migraine Trust because we make our case with solid data and lived experience. We will soon undertake research into migraine treatments — and, as always, we’ll ask people with migraine to share their views and experiences.

We recently completed research looking at the impact of migraine in under-represented populations. We took on this work because there’s no data that can be gleaned about what migraine means for different groups, such as those who are Black or Asian, or a lower socio-economic group. We will use the results to develop new work in 2026 to build partnerships and collaborations in order to reduce inequity in work or health settings.

Another of our key goals for 2026 is to secure support for a major study into the health-economic cost of migraine. We know that unequal access to care doesn’t just harm individuals — it costs society billions in lost productivity and avoidable health costs. By showing how better care will save money as well as improving quality of lives, we will have a greater opportunity to highlight why to ministers and officials that migraine needs to be taken more seriously.

## Partnerships and purpose

We are also proud of our partnerships, be that across the NHS, industry, policy, health organisations, and charities in the neurological community. These collaborations give us greater reach and credibility, helping us show that migraine needs to be central to conversations.

We continue to work closely with employers and HR professionals to improve understanding of migraine in the workplace. Our research this year revealed that more than half of employees with migraine had no workplace adjustments in place, while a third had faced discrimination. That has to change — and we’re supporting employers through our Workplace Pledge and guidance so that people can thrive at work without fear or stigma. In 2026 we want to see companies work with the charity through undertaking a deeper dive into their workplace practices around migraine, who staff feel, take necessary actions, and evaluate the benefits of any changes to staff and the company.

## Looking ahead

As we reflect on our 60th year, I’m incredibly proud of how far we’ve come. We may be a small charity, but we’re respected, listened to, and consistently punch above our weight. With more resources, we could of course go even further, faster, but we’ll never stop striving for change. People with migraine deserve nothing less.

Every step we take is powered by you - our supporters, volunteers, and the wider migraine community. You share your stories, answer our surveys, write to your MPs, and help us keep migraine visible. Thank you for standing with us. Together, we’re making sure that migraine is recognised, respected, and properly treated.

### Best wishes

**Rob Music, Chief Executive**

# Leaving a Legacy of Progress: Supporting migraine research and support

Migraine affects millions of people in the UK, and for many of our supporters, it's hugely personal. Whether you live with migraine or support someone who does, I am sure you will understand the need for better treatments, greater awareness and stronger support systems.

Once you've looked after your family and friends, leaving a gift in your will to The Migraine Trust is a practical and lasting way to help drive that progress. We are so grateful for the legacy gifts we receive, which allow us to fund long-term research into the causes and treatment of migraine, expand our information and support services, and advocate for improved care across the UK.

Legacy gifts give us long term stability to plan ahead. They help us invest in multi-year projects, respond to emerging needs, and ensure that people affected by migraine continue to have a trusted source of support and information.

If you already have a will, adding a gift is straightforward. You can do this by adding a codicil, a short legal document that updates your existing will without replacing it. A solicitor can help you do this quickly and securely. You'll need to include our charity name, address, and registered charity number:

## The Migraine Trust

Registered Charity No. 1081300  
82 Tanner Street, London SE1 3GN

As little as 1% of your estate will help us continue supporting people affected by migraine for years to come. To find out more, visit [www.migrainetrust.org/legacy](http://www.migrainetrust.org/legacy) or contact our team for confidential guidance on 0203 9510 150.

*Thank you*



# Migraine, disability, rights and benefits

For many people, migraine is more than occasional pain. When attacks are frequent or severe they can make work, study or even simple tasks nearly impossible. Under certain circumstances, migraine can be classed as a disability. The good news is, this can unlock legal rights and protections, and in some cases, access to benefits that can make a real difference.

## What does “disability” mean under the Law?

Under the Equality Act 2010 (in England, Wales and Scotland) and related legislation:

- A condition is a **disability** if it is a physical or mental impairment which has a substantial and long-term negative effect on your ability to do normal day-to-day activities. “Long-term” means lasting or likely to last **12 months or more**, even if the symptoms come and go.
- Migraine can meet these criteria if it has a significant impact on your normal day-to-day activities (such as walking, talking, travelling or doing basic tasks) – or it would do if you stopped treatment.
- If your migraine is recognised as a disability, you gain certain legal protections — for example, protection from discrimination at work. Employers also have a legal obligation to make “reasonable adjustments” to help meet your needs.

## What employers and workplaces should know

We have just launched two new workplace toolkits, one for employers and one for people with migraine.

You can access them on our resources page: [migrainetrust.org/resources](https://migrainetrust.org/resources). Key points include:

- Employers should understand their legal obligations: if migraine meets the disability definition, they have a duty to make reasonable adjustments in the workplace.
- Reasonable adjustments can often be small and low-cost, but may still make a big difference. Examples include flexible hours or breaks when needed; allowing remote work or adjustments to tasks; providing a quiet space; changes to working environment; and providing equipment such as anti-glare screens or blue-light filters.
- Open communication helps: people with migraine may feel stigma or worry about disclosure. Employers can support by making processes for requesting adjustments clear, maintaining confidentiality, checking in, and being sensitive to changes in attack frequency or severity.

## What benefits might be available?

If migraine significantly impacts your daily life, there are several welfare benefits and supports that may apply. Whether you qualify depends on your individual situation: how severe and frequent your attacks are, your ability to manage daily living, your employment

status, age, and where you live. The rules for who can get benefits are also different for each one and being covered under law for a disability does not mean you

will automatically qualify for disability services and benefits. Always speak with a welfare advisor for advice on exactly what you are entitled to.

**Here are some of the main benefits that may be relevant for people with migraine:**

Benefit / Support	Who it's for / What it does
<b>Universal Credit</b>	For those on low income, out of work or unable to work because of health. You may be entitled to extra if you're assessed as having limited capability for work.
<b>Personal Independence Payment (PIP) (England, Wales, Northern Ireland) / Adult Disability Payment (Scotland)</b>	Helps with extra costs if a long-term condition (like migraine) affects daily living or mobility.
<b>Disability Living Allowance (DLA) for children (England, Wales, Northern Ireland) / Child Disability Payment (Scotland)</b>	If you have a child with a condition that causes difficulties walking or who needs significantly more care than children of the same age.
<b>Attendance Allowance (England, Wales, Northern Ireland)/ Pension-Age Disability Payment (Scotland)</b>	For people over state pension age who have a disability or health condition severe enough that they need help with care or daily tasks.
<b>Statutory Sick Pay / other employer sick pay schemes</b>	If you are off work because of a health condition, like migraine, and you meet the necessary criteria. Check your employer's policies.

**Access to Work grants** can help with paying for practical support at your workplace, including adjustments to your workspace, special equipment and help with travel costs.

If you have a benefit application refused, there are routes to ask for reconsideration or appeal. A migraine diary can help you provide evidence of how your migraine affects you day to day.

### Practical tips

- Keep a **migraine diary**: record how often attacks happen, symptoms, how long they last, how they affect you daily. This helps for benefit applications, legal protection and discussions with employers.
- Gather **medical evidence** such as prescription records and letters from healthcare providers — these strengthen any applications or appeals.
- Seek advice from specialist welfare benefits organisations (Citizens Advice, Turn2us, Scope etc). Use online calculators to get a sense of what you might be eligible for.
- If you're applying for benefits and the decision is refused, don't give up: there are established appeal procedures (mandatory reconsideration, tribunals, etc.).

Migraine can be isolating, but you have rights and options. If your migraine is interfering with your everyday life — work, self-care, transport, home life — it may well be classed as a disability. And when it is, that brings protections and avenues for financial help.

**Knowing your rights, documenting your experience, and accessing help can reduce stress and make a real difference.**

# Using your voice

**Zac Barnett, Policy Officer,  
The Migraine Trust**



As a supporter of The Migraine Trust, you will know that migraine is often misunderstood and underestimated. That's why it is important for people with migraine to be able to use their voices effectively – whether that is to improve society's understanding, to make your workplace migraine-friendly, or simply to ensure you are getting the best care possible. We recently launched a section on our website to help you to use your voice in meaningful ways. Here's an overview of how you can use your voice for yourself and others.

## Speaking to your political representatives and why they are important

Your political representative (your Member of Parliament, the Senedd, the Scottish Parliament or the Northern Ireland Assembly) can be an important ally in improving the state of migraine care.

Whilst there may not be migraine-specific legislation to vote for, there is plenty more that politicians can do behind the scenes. For example, they can lobby Ministers to make sure that the country's health systems take migraine seriously, either in a public debate or in conversation. In England, for example, the Government recently announced its plan to reorganise the NHS over the next ten years. MPs could let Wes Streeting, the Secretary of State for Health, know that their constituents need headache specialists to be stationed in the new 'neighbourhood health centres' envisaged in the plan.

They can also, if they recognise a need in their constituencies, encourage their local health services to dedicate more resources to migraine care.

They might also encourage businesses in their constituencies to treat their employees with migraine with understanding, for example by signing up to The Migraine Trust's Workplace Pledge.





Changing society's view of migraine will require not only better understanding amongst friends, colleagues, employers and the media, but also those in power. To improve your political representative's understanding of migraine, you can read more on the 'Campaign With Us' section of our website.

## Using your voice at work

Too many people face stigma and discrimination in the workplace. In a recent report, we found 15% of people with migraine have been forced to move from full-time to part-time work, 19% have had to leave a job entirely, and 58% have avoided telling their employer about their migraine, worrying that they may not be hired, promoted or taken seriously.

### You can join our campaign to make workplaces more migraine-friendly.

Even if you don't need support for yourself, you can help to make your workplace migraine-friendly for your colleagues and for future recruits by encouraging your employer to sign up to The Migraine Trust's Workplace Pledge

<https://migrainetrust.org/get-involved/the-migraine-trusts-workplace-pledge/>

This allows them to demonstrate that they understand how migraine can impact working life and are taking steps to ensure their staff are supported.

## Sharing your migraine experience

The media plays a huge role in determining which issues we understand and consider important. The most effective way for a newspaper, news site or programme to highlight these issues is often with personal stories. Contacting your local paper to tell them what it is like to live in the local area with migraine, and how it affects day to day life, can help to raise awareness. We are also always looking for stories from people with migraine who want to work with us to share their experiences. Social media is also a great tool to reach new and different audiences.

## Using your voice to secure the best care

Health services are large, complicated organisations, meaning that not everyone receives the best possible treatment all of the time. Sometimes, to make sure you are getting the right care, you will need to have the right information at your fingertips and know where to go when you are not getting the help you need. The 'Tips to Help You Advocate for Your Health' section of our website provides this guidance. It includes tips on the kinds of information that will help your GP to make the right diagnosis, the sorts of treatment you should be eligible for, and who to speak to if you're not happy with the treatment you're receiving. ■



# Managing your migraine: the pathway to better treatment

By Pippa Coulter, Information Manager, The Migraine Trust

If you live with migraine, you may be all too familiar with just how difficult it can be to find a treatment that works. Getting healthcare appointments can take time, and waiting lists for specialist care can be particularly lengthy. You often need to try several different medicines to find one that works for you. On top of this, there is often a lack of understanding about the different treatment options available for migraine – even amongst health professionals.

We recently published a summary of the recommended treatment pathway for migraine in adults in the UK. You can access this on our website at: [migrainetrust.org/migraine-treatment-pathway](https://migrainetrust.org/migraine-treatment-pathway). The pathway is designed to help you navigate your own journey and advocate for your own care.

Below are the main steps in the pathway. It's important to understand that treatment pathways can vary by local area, and also for specific types of migraine.

## 1. Treating the attack (acute treatment)

When a migraine attack strikes, acute treatment aims to stop it in its tracks – or at least reduce the symptoms.

- Many people start with over-the-counter painkillers, like ibuprofen or paracetamol.
- Your GP may also prescribe anti-sickness tablets.
- Migraine-specific medicines called triptans or rimegepant are other options your GP can prescribe.

## 2. Preventing future attacks (preventive treatment) – primary care options

If you're having very frequent attacks or migraine is having a severe impact on your quality of life, preventive treatments may help. These don't usually stop migraine attacks completely. But they aim to reduce the frequency and severity of attacks.

You start with medications from your GP – such as propranolol, topiramate or amitriptyline. Which medicine is most suitable for you is based on several factors, such as whether you have any other health conditions or are taking any other medicines.

You will need to try the medicine for at least three months to see if it works – gradually increasing the dose to the most that you are able to tolerate. If one preventive doesn't work, you can try another type.

### 3. Specialist treatment options

If you have tried at least three preventive medicines at the maximum tolerated dose, for several months each and this doesn't help, your GP may refer you to specialist care. This may be at a headache clinic or with a neurologist.

**There are other preventive treatment options available via a migraine specialist. These include:**

- Botox injections (for chronic migraine)
- nerve blocks (injections at the back of the head)
- CGRP monoclonal antibody injections
- gepants.

Preventive treatment is unlikely to stop all of your migraine attacks – you will usually need to continue taking acute medicine too. You usually only take a preventive treatment for a fixed period of time. Your doctor may suggest gradually reducing the medicine once your migraine is under control.

### Beyond medicine

Treatment isn't all about medicines. Some people prefer not to take medication or find that treatment with medicines just isn't enough.

**Non-drug treatments for migraine include:**

- migraine devices (instruments or appliances that you apply to your body, and gently stimulate nerves involved in pain)
- supplements like magnesium, riboflavin and co-enzyme Q10
- acupuncture
- behavioural techniques to help cope with pain.

It may help to make lifestyle changes too – such as managing stress or getting into a good sleep routine. These things won't cure migraine, but they may have a positive impact or help you cope with attacks better.

**There is no one-size-fits-all cure for migraine. But our treatment pathway can help you to understand your options and to get the best treatment for you.**

# Kathleen's 60-year journey with migraine

For 10 years I unknowingly suffered with abdominal migraine. I would wake at night with awful nausea, vomiting and diarrhoea. I would also experience a 'strange' feeling in my head, not pain exactly but an unusual sensation that was often relieved by placing my head at a lower level than the rest of my body. I went to the doctor who said it 'could be migraine' but because there was no head pain, he just treated the gastric symptoms.

A friend, who was a nurse, first mentioned abdominal migraine. I have to admit my first thought was 'how could it be migraine, there's no headache!' In those days prior to internet searches, you had to go and research, and I still have the book I found all those years ago, where abdominal migraine was outlined and I thought 'a lot of this describes my symptoms to a 'T'!

Then what I termed the 'sledgehammer headaches' kicked in. They arrived in addition to the abdominal part which meant I was often confined to the bathroom for long periods of time. It was difficult to get work colleagues to understand why I could not work through these episodes. I often did once the abdominal symptoms resolved because just having what others thought of as a 'headache' seemed like not a good enough reason not to.

I discovered over the counter migraine specific medication that helped but, wary of rebound headaches through overuse of medication, I only took it if I woke with a really bad head with added nausea. Strangely, I did not seek medical help as I did not deem it important enough to get help with 'headaches'.



“

**“It's not 'just a headache' — we need to advocate for ourselves and, just as importantly, be a bit kinder to ourselves.”**

One of the most welcome comments ever made to me was when I worked as a PE teacher by my deputy headteacher, "My God, Kath, you look dreadful. Whatever is the matter?" She sent me home. For me, looking dreadful when having an attack was helpful and validating if colleagues could see how migraine was affecting me, as it can often be a hidden disease.

On another occasion, after a successful first day of a week-long Ofsted inspection, I awoke the next day with such a horrific migraine attack. My husband had to call the school and let them know I couldn't possibly come in. The day after, I remember speaking to the inspector and explaining that I hadn't been able to come in the previous day due to migraine. I was so embarrassed, but he stopped me and said, 'you don't have to explain any more, I have migraine myself, I know just how bad it can be'. I could have hugged him! It was just so refreshing to speak to someone who understood and a relief to not feel that stigma that's often associated with migraine.

**"It was just so refreshing to speak to someone who understood and a relief to not feel that stigma that's often associated with migraine."**

Alongside migraine, I live with hearing loss and am a hearing aid user. Social events can be challenging – background noise and busy environments are particularly difficult. I experience 'hearing fatigue' – straining to hear or lipread in a busy environment can lead to fatigue and headache, and can be a migraine trigger.

I spent years reading as much as I could and coming to grips with triggers - denying myself certain foods or combinations of foods, holding my breath if needing to walk through perfume departments, using low odour paint, discovering that peppermint essential

oil in an aromatherapy locket helped if I could not avoid sitting next to someone wearing heavy perfume, avoiding flickering lights and strong sunlight whenever possible, banning hairspray and spray deodorant from changing rooms when I was teaching PE and trying not to overwork, which is some hope whilst working full time and rearing 3 children!

Thankfully, I seem to 'manage' my migraine better these days, but it has taken me a journey of 60 years to enable me to do so. During that time, I've learnt a lot. For one, triggers change over time. Trying to figure out triggers can be stressful in itself and sadly, I still feel a 'failure' if a bad attack strikes. I find myself thinking back on what I've eaten or done and am repeatedly recording my attacks and searching for reasons why I have 'failed'.

I have also learnt that regular meals are a big help in my migraine management, and having snacks available if a mealtime is going to be later than planned is

important. I have also learnt that pushing myself to finish a task when feeling the early signs of an attack are a big NO NO. Much easier to practice now that I am retired.

In addition to raising awareness of migraine and getting across the message that it's not 'just a headache' I think we as people with migraine need to advocate for ourselves and what we need. With the best of intentions, people don't always realise or remember what adjustments we need in any given situation and it's our role to gently, but firmly, remind them! It would also be lovely if people with migraine were also a bit kinder to ourselves! ■

# Migraine: What's Next?

**Peter J Goadsby MD PhD, Professor of Neurology, King's College London**

**The last decade has seen tremendous advances in our understanding of migraine and how to treat it. The pioneering work of scientists and clinicians over the decades continues to inspire further progress, with many new developments on the horizon.**

## CGRP targeting therapies

An increasing body of real-world evidence shows that many migraine patients around the world who previously struggled with finding effective migraine treatment have benefited from newer treatments targeting calcitonin gene-related peptide (CGRP) for prevention of attacks, including CGRP monoclonal antibodies (mAbs). CGRP is released by several different parts of the nervous system that are important in generating migraine symptoms, notably head pain.

Patients also now have access to another class of CGRP targeting drugs known as gepants, which block the effect of CGRP at its site of action: its receptor. One such gepant, rimegepant, has been shown to be effective for both acute and preventive treatment. Another medication in this class, atogepant, has also been shown to be effective for migraine prevention, even among some patients who have not responded

to other CGRP targeting therapies. There are several possible reasons for this. Including targeting other receptors that may be relevant in migraine, such as one called AMY1. Another reason may be because as a smaller molecule, it accesses sites that the larger CGRP mAbs may not reach as easily.

Research is currently underway to explore using atogepant as an acute option as well. The fact that this class of drugs may cross the bridge between acute and preventive treatments heralds an exciting time for the future of migraine treatment. It means that patients may not have to juggle multiple drugs at the same time to treat the one disease.

Over time it has become apparent that different migraine patients will respond differently to the same therapy, and CGRP targeting therapies are no exception to this. Studies have shown that a patient who does not respond to one may switch and respond to another. The reason for this is not completely understood. There is ongoing research exploring the structural and genetic differences in the CGRP molecule and its receptor between different people, as well as the possibility that other closely related molecules may be relevant in the biology of migraine.



**The fact that this class of drugs may cross the bridge between acute and preventive treatments heralds an exciting time for the future of migraine treatment."**

## PACAP – a potential new target

One such molecule being explored as a potential target for new therapies, is pituitary adenylate cyclase activating polypeptide (PACAP). PACAP is a chemical found in the brain that is known to be involved in the pathways for migraine. A recent study looking at an antibody targeting PACAP has delivered promising results, showing that it can reduce migraine days in adult patients who have failed other therapies. Larger trials are now underway.

An unanswered question regarding PACAP is what role targeting this pathway through therapies could play in practice. For example, is there potential for a combined regimen targeting CGRP and PACAP together, or would each treatment work for a separate group of people? One study showed that an infusion of PACAP can provoke migraine attacks in people living with migraine, and these attacks do not respond to CGRP targeting therapies. Our knowledge is always progressing and there are further potential targets that work on distinct pathways to CGRP and PACAP, which are being looked at in early-stage animal studies.

## The future: personalised treatment regimens

All of the evidence we have gathered over recent years aligns with the theory that migraine is a complex neurological disorder involving several different pathways. This also seems to fit with the fact that different people report different headache patterns, different non-headache symptoms and different triggers. The future of migraine treatment may lie in identifying which pathways are most relevant to an individual's migraine biology and providing them with a personalised treatment regimen to best target this.

There are several studies exploring this concept further, including animal studies that have shown the possibility that even response to triptans, a long-established acute medication for migraine, may be dependent on sex and hormonal factors. Greater use of genetic research in recent years and the inclusion

of a wider range of people of different ethnicities and background in research populations may help build our understanding in this area

## Beyond medication

Beyond medications, technological progress has also led to advances in neuromodulation – commonly known as migraine devices. Remote electrical neuromodulation (REN) devices for migraine work by a mechanism called conditioned pain modulation. This means stimulation in one part of the body reduces pain signaling in another part of the body. Interestingly, a small study performed on patients with vestibular migraine showed improvement in dizziness symptoms alongside headache, suggesting a possible benefit in symptoms extending beyond just pain, although larger studies are needed to confirm this finding.

Artificial intelligence (AI) can help with current research techniques, allowing for efficient processing of larger datasets that would have previously been enormously difficult to perform. This can allow for the detection of new associations and patterns in genetics and disease characteristics. Research teams are looking to develop AI models for migraine that aim to predict treatment response to different medications based on an individual patient's migraine and demographic characteristics. This paves the way towards a more tailored and precise approach to migraine treatment.

Lastly, planned studies look to explore how migraine evolves over time, from childhood to adulthood. While these studies will take many years, they will provide valuable insights into a great unknown in migraine science: how does migraine start and how does it evolve?

**Ultimately, our scientific advancements and research all come back to one important thing. You – as an individual with migraine. And the future relies on understanding every individual's unique experience and how to make their lives better. ■**

# Simone Round's Story

I was diagnosed with migraine when I was 14 years old, but no one ever really explained what it meant. I would have severe headache and be in bed the day before my period with what I call kaleidoscope vision where my vision fractures into shapes and colours like looking through a kaleidoscope. I grew up thinking I had to just push through it. I learned to ignore the pain, the light sensitivity, and all the other symptoms as best I could.



When I got older, I started working in entertainment for Disney cruise line. I convinced myself that constant eye strain and head pain were just "normal" parts of the job. On ships you don't get a day off and I was getting symptoms like pins and needles, head pain and extreme fatigue. In the end the ship's doctor said that it wasn't manageable to keep going, and my migraine and an unrelated injury meant I had to leave the ship. I was still just using over-the-counter medicines at that point.

I retrained as a personal trainer but exercise started to make the head pain worse! Sometimes I would have to go in while being sick and wearing my dark glasses trying to push through. I moved to working for the gym online, doing social media and things but even the screen got too much, and I had to leave.

Then, in 2020, the attacks started to become daily. I still tried to ignore it, that was my default mode, but by 2023, they had escalated to the point of becoming completely chronic and disabling. Alongside the pain came a wave of frightening new symptoms. I began experiencing hemiplegic migraine attacks, which mimic stroke-like symptoms and leave me incredibly vulnerable. I have only had a few episodes, but I've found them terrifying, and each one feels

as distressing as the last. I went to A&E with my last hemiplegic attack as I was so worried, but they didn't know how to treat me.

When my neurologist said migraine can trigger all these weird symptoms, I was in shock. I always thought migraine was just head pain and I realised I didn't fully understand the condition myself. It's been one of the hardest parts dealing with that lack of understanding from others, whether it's being forced to work while in pain, to having my condition minimised or dismissed. Migraine means so much more than "just a headache." People think of head pain but don't understand all the other pains you experience like from sound. They also don't understand that I need to try and push through for the sake of my mental health, they imagine I should just be in a dark room but I don't want to sit in a dark room all my life. It is a complex, neurological disorder that has stolen so much from my daily life, and at times, my independence.

I understand my migraine more these days. There's no day without pain and my day-to-day pain level is a 6, but it quickly escalates during an attack up to a 10. It feels like being stabbed in the head and I just want to hit my head on the wall. Now 3-4 days before

my period I do nothing. I used to push through, now I don't. The left hand side of my body starts to tingle and go numb, I get kaleidoscope eyes and see things like the outline of people shadows when I close my eyes after looking at them during an attack. Then there's the dizziness, the vomiting, stomach issues, and almost the worst symptom of unbearable fatigue.

A year ago, I was diagnosed with Functional Neurological Disorder (FND), which my neurologist believes might be linked to my migraine. I use a wheelchair due to the impact this condition has had on my mobility and nervous system, and live with bladder problems, seizures and a whole host of additional symptoms.

I can't work anymore but I do some mindfulness training and volunteering when I can. I'm just grateful if I can sit up and read a book or listen to a podcast these days which sounds bleak but I try to have a positive mindset and go for a roll in my wheelchair with my partner.

Migraine can be isolating. Getting out of the house is so much harder with the migraine, I get over stimulated so easily now and not able to go enjoy



**“My migraine nurse is my rock. She listens, supports, and works with me closely.”**

events with friends as I used to. The friends who are still around have been brilliant.

I've tried many treatments over the years. You try one, sometimes it works, often not. Each treatment

attempt requires months of waiting to determine effectiveness, and this process is incredibly draining, both physically and emotionally. Nothing has worked long term yet. With Botox at least I got a smooth brow!

## What helps me cope

- My migraine nurse is my rock. She listens, supports, and works with me closely. I'm in touch with her every 3–4 months and knowing I have that point of contact gives me some peace of mind.
- I use orange-tinted migraine glasses, ice hats, and earplugs to help reduce sensory input.
- I've made all the recommended lifestyle and dietary changes even if nothing completely takes the pain away. My emergency migraine pack and all my drugs are always with me.
- I say no to things when I need to and do my best to take each day as it comes.

The Migraine Trust has been a lifeline for me. Through their social media, website, and helpline, I've found information, comfort, and a community that truly understands what I'm going through. Knowing I'm not alone has made such a difference. Even my headache specialist recommended their website — and it's helped me more than I ever thought possible.

**I continue to raise awareness about migraine and FND because I never want someone else to go through this alone or feel misunderstood. This condition has reshaped my life in profound ways, but I'm still here, adapting, advocating, and hoping for better days. ■**

# Meet the team: Emma and Emma

## 1. Tell us about your role /roles

**Emma C:** Our role is to provide tailored support and evidence-based information to those affected by migraine. We also coordinate projects and events that raise understanding about the condition and empower people living with migraine.

**Emma M:** Yep, that sums it up well!

## 2. What were you doing before The Migraine Trust?

**Emma C:** Before joining the Migraine Trust, I worked with another support line. I've valued being part of a number of helplines over the years, as well as providing support in face-to-face roles, with a welfare and wellbeing focus.

**Emma M:** My background is in social work, and I had the privilege to work in several roles both here in the UK and overseas. I've always volunteered for charities from my teens onwards, but as my own children arrived, I shifted gear a little work wise, transitioning into the charity sector. Initially I worked for the NSPCC Helpline for number of years and then a domestic and sexual abuse helpline where I was co-ordinator for an amazing team/service.

## 3. What do you enjoy the most about working here?

**Emma C:** The best part of the job is those conversations we get to have with callers. It's always a privilege to listen and in turn to share some useful information. Additionally, my new colleagues at TMT are all lovely people and it's a great organisation to work for!



Emma C



Emma M

**Emma M:** Meaningfully supporting people and often hearing the change in tone in their voice between the opening and closing of a call; providing a safe space and ensuring people feel heard and understood and empowered is an honour. And the team is great too, which is a lovely bonus.

## 4. What do you do in your spare time?

**Emma C:** I like to spend spare time out in nature or curled up with a good book.

**Emma M:** Often it's kid focussed in this life stage but travel, theatre, gigs with friends and family are my top picks... and we are partial to a good theme park, especially a Disney one! Also often found consuming large quantities of coffee with a good podcast/book/movie. ■

# Migraine Awareness Week 2025: What migraine really means

**Migraine Awareness Week ran from 22–28 September 2025, and this year’s theme, “Migraine Means”, struck a powerful chord with people living with migraine, as well as shedding light on the impact of the condition for those who weren’t previously aware.**

## Why “Migraine Means”?

Too often, migraine is dismissed as “just a headache.” But those of us who live with migraine know it’s far more than that - it’s a complex, often debilitating condition that can affect every part of life, from work and relationships to our mental wellbeing.

This year’s campaign set out to challenge those persistent myths. By focusing on what migraine truly means, the goal was to raise awareness, encourage open conversations, and most importantly, shift public perception toward a deeper understanding of the realities of living with migraine.

## What migraine means in the workplace

Ensuring people with migraine get the support they need at work continues to be an area of focus for The Migraine Trust. We regularly hear from people who use our helpline that lack of support in the workplace is a huge challenge, so we wanted to reflect that in our campaign. After hosting a focus group with members of our Involvement Panel (people who live with migraine who kindly offer their views and experiences to ensure the work of The Migraine Trust reflects lived experience), we decided to highlight migraine in the workplace as part of the ‘Migraine Means’ campaign.

## What happened during the week?

### Research

At the heart of the campaign were two major surveys — one involving people with migraine, and another involving those without, which we launched during Migraine Awareness Week. The results highlighted a stark contrast: while those of us living with migraine shared the daily challenges and unpredictability of the condition, many without migraine still believed it was a minor or occasional issue.

### Key survey findings:

- Only around a third (32%) of those without migraine correctly identified it as a neurological condition with a staggering 60% thinking it was merely ‘a bad headache’
- Less than two in five of those without migraine would be very likely to believe:
  - Someone who called in sick due to migraine
  - Someone who was unable to finish a work task due to migraine
  - Someone who had to log off early from work due to migraine
  - Someone who was unable to do a big presentation due to migraine.
- 60% of respondents without migraine said that if they were managing a team, they would feel concerned about hiring a qualified candidate who disclosed having the condition.
- 91% of those with migraine had worked while experiencing migraine symptoms, with many using annual or unpaid leave to avoid taking sick days, yet being met with scepticism from colleagues and managers.



- Of those with migraine, only 2% of respondents strongly agreed that their workplace had migraine-friendly policies.

These gaps in the reality of living and working with migraine and the public's perception of the condition were striking and underscored the need for better understanding of what migraine means within society.

## Our powerful new campaign film

Alongside a fantastic film-making team, we released a compelling short film to mark Migraine Awareness Week. "Migraine Means" follows a character managing a migraine attack at work, with a voiceover explaining the invisible impact of the condition. The emotional reveal shows a supportive manager, reflecting the hope that more workplaces will adopt empathy and understanding when it comes to invisible illnesses like migraine.



## Widespread media coverage

The message reached far and wide, thanks to extensive national and regional media coverage including a slot on BBC Breakfast ahead of Migraine Awareness Week, and a piece on BBC News online shortly after, as well as coverage on regional TV and radio, and articles in several workplace-focused publications.

Momentum continued beyond the week, with widespread coverage across BBC news online and BBC television news covering our research into October.

This media exposure helped push the message to millions, opening more eyes to what migraine really means.



Rob Music, Chief Executive of The Migraine Trust joins Ivy who shared her experience of chronic migraine on the iconic BBC Breakfast red sofa

## Reaching more people

On social media, the campaign sparked lots of interesting conversations and, most importantly, reached more people than ever before. On Instagram alone, our campaign video reached an incredible 44,189 accounts, 49% of which were non-followers, meaning we were engaging with people who may otherwise not have known much about migraine, helping to spread awareness.

We also saw higher numbers of people than normal coming to our support services, again showing we are reaching new people.

## The impact – and what’s next

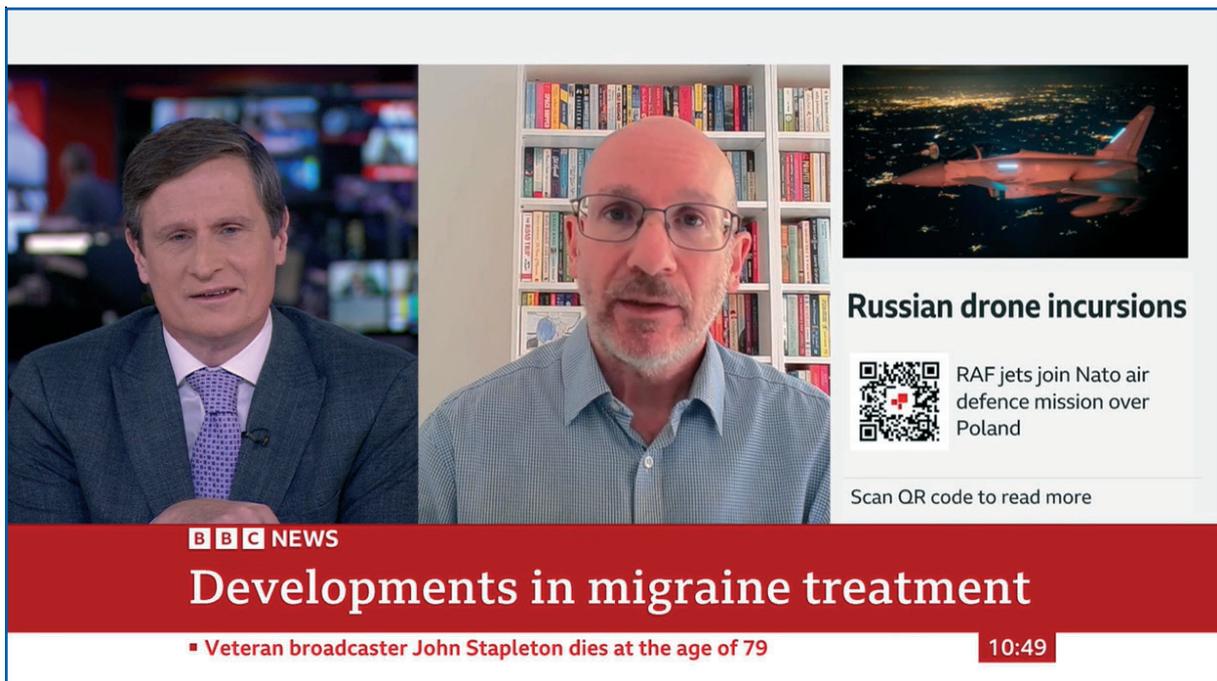
Migraine Awareness Week 2025 wasn’t just about education; it was about empowerment. It reminded us that our voices matter - that by sharing our stories, advocating for ourselves at work, and correcting misconceptions when we hear them, we can reshape the narrative.

We also want to ensure everyone with migraine is empowered to ask for what they need at work.

During Migraine Awareness Week, we launched a range of new and refreshed resources in our website, including toolkits for employees and employers, on migraine in the workplace.

It also allowed us to demonstrate that people that don’t live with migraine have an important role to play in learning about what migraine means and supporting those with the condition in the workplace and beyond. As a result of our campaign focus, we saw an uptick in employers signing our Workplace Pledge – committing to improve their workplace for those with migraine.

**This is only the beginning though. Supporting more people to get into, and stay in work, is a government priority and for us at The Migraine Trust we want to ensure the needs of people with migraine are considered as part of this. We’ll keep working with politicians, businesses, policymakers and many more to increase awareness of what migraine really means and how people should be supported in the workplace. ■**



The image is a screenshot of a BBC News broadcast. It features two men in a split-screen format. On the left is a man in a suit and tie, and on the right is a man with glasses and a light blue shirt. Below them is a red banner with the BBC News logo and the text "Developments in migraine treatment". To the right of the men is a news item titled "Russian drone incursions" with a QR code and the text "RAF jets join Nato air defence mission over Poland". Below the QR code is the text "Scan QR code to read more". At the bottom of the screenshot, there is a red bar with the text "Veteran broadcaster John Stapleton dies at the age of 79" and a time indicator "10:49".

# Amit and Bruce's story

In October of this year, I sadly had to say goodbye to Bruce, my canine companion for the past 6 and a half years, who gave me such warmth, comfort, loyalty and unconditional love. An independently minded and always curious Staffordshire Bull Terrier Crossbreed, Bruce was an incredibly special soul, and as a person living with chronic migraine, his presence was truly transformative for me, helping me through some very difficult times.

I have a long history of migraine, first starting with symptoms in my mid-30s. I now live with chronic migraine with prolonged brainstem aura symptoms. This is a subtype of migraine, where for me, headache and pain are not the main features. During an attack my speech, balance, coordination, general function and thought processes can be severely affected, together with other symptoms of nausea and sensitivity to sounds.

It can be hard to describe just what migraine feels like for me, but I often ask people to picture a heavy ten-pin bowling ball being perched on your little finger: that's how my head feels on my body when an attack sets in, with all the surrounding bowling alley noise of the pins being knocked over, people laughing, lights flashing and background music playing being highly amplified

and therefore intolerable. Then add the feeling of something gripping that ball like a metal clamp, to give an idea of what the sensations experienced during a migraine attack may be like for me.

I have seen numerous clinicians, tried a whole variety of treatments and therapies, in addition to making changes to my lifestyle.

Eventually, I had to retire on ill-health grounds in 2017 and left my professional career. This was a very tumultuous time for me: having to endure a lengthy sickness management process that eventually led to my contract of employment terminated; the need to appeal for my ill-health retirement pension after it was initially rejected; going through the PIP assessment process, getting awarded basic payments, then getting them withdrawn on reassessment when criteria had been changed despite my worsening clinical symptoms; and having to take my employers to Tribunal over disability discrimination issues.

All of this was very isolating, caused substantial stress and really impacted my mental health. It was at this time that Bruce entered my life, tail wagging. I found myself perusing the websites of animal adoption shelters and was immediately struck by one listing - there he was: big brown eyes, a large infectious smile, a tan coloured dog with a white chest and a white marking on his nose - "Bruce 043D".

It didn't take long at all for our bond to build once the adoption was confirmed. Even that first day of bringing him home in the car, I could feel he had established a sense of trust in me. From there, our connection continued to build, and we developed our



**"Our furry friends really can provide so much support to those of us living with health conditions like chronic migraine."**

daily routine: waking in the morning to take my medication followed by cuddles, getting out for our morning and afternoon walks (Bruce on timekeeping duties, of course!) and mealtimes right on schedule.

As a result of having this routine, Bruce would also sense I was having my bad migraine days if I got up in the morning but wasn't able to shower due to lack of balance, and he would be very patient, quiet, and forego his usual demands for outings, being quite happy to potter around in the back garden. If I needed assistance, I would shout "Bruce, here, help", and he would come upstairs and stand by my bed, close enough for me to put my hand on his back so that I could stabilise myself to get up and stand. He then

would walk beside me and somehow had learnt himself the best position to stand behind me when coming down the stairs, so that the weight of his body would support me behind my legs if I started to tip backwards or could put my hand there next to him to maintain balance. I didn't teach him to do this; he just seemed to know what to do! When my migraine attack had lifted, and he would hear me go into the bathroom, the noise of the shower and see me come downstairs changed out of my pyjamas – that was it; action stations, and usual routine back on!

Our furry friends really can provide so much support to those of us living with health conditions like chronic migraine. From encouraging us to keep going and



**"I will be forever thankful for the time I had with him whilst he was physically present."**

bringing lifestyle changes to curling up beside us when we need a bit of comfort on our bad days, their impact can't be overstated.

**Bruce came into my life at a time of change, and a time when living with migraine was becoming increasingly difficult. We somehow understood each other and were able to give what each other needed; this feeling of being understood for who you are, security, affection, warmth and comfort. I genuinely feel that we rescued each other, and I will be forever thankful for the time I had with him whilst he was physically present. ■**

# 60 years of The Migraine Trust, 1965- 2025



**Mark Weatherall, Consultant Neurologist,  
Buckinghamshire Healthcare NHS Trust**

This year marks the 60th anniversary of The Migraine Trust, which was founded on 3rd August 1965. The Trust was the creation of the Medical Advisory Group of the British Migraine Association, the world's first patient advocacy organisation in the field of headache. The Association itself had only been in existence for ten years, having been established in London in 1955 by Major Harold Graham, and re-founded in Bournemouth in 1958 by Peter Wilson, who was to be its guiding force for the next two decades. Following a change of direction in the early 1960s under the influence of the GP and pain specialist Robert Smith, a new, well-connected Medical Advisory Group was created under the chairmanship of the neurologist Russell, Lord Brain.



At the second meeting of the Group in May 1964, Brain reported conversations with Lady Snow (who was also known as the author Pamela Hansford), in which she had indicated her "intention to get together as soon as she could a number of other people who would be more active on the lay side", specifically to constitute a fundraising organisation. At the fourth meeting in March 1965, it was announced that it had been decided to form a separate charity, tentatively called The Migraine Trust. Its objectives were to be:



1. The promotion of assistance for the furthering of research into the causes, alleviation and treatment of migraine
2. The promotion, assistance and encouragement of schemes of research, education, technical training and treatment having their basis the improvement of diagnosing, alleviating and curing migraine
3. The promotion of exchange and propagation of information relating to migraine
4. The furthering of publication for the benefit of mankind of the discoveries made as a result of such researches as aforesaid
5. The establishment of national and international fellowships for research into the causes and treatment of migraine tenable at universities and research institutions anywhere in the world
6. The making of grants for research into the causes and treatment of migraine at universities and research institutions anywhere in the world.

The creation of The Migraine Trust was marked with a dinner at the Apothecaries Hall in London on 18th January 1966. At that dinner, Brain outlined the objectives of the Trust, and its plans for the promotion of research, estimating that the annual sum required to establish its office, journal, and initial research projects would be £75,000 per annum for the first ten years: "if that leads to a cure or mitigation of migraine headaches it will be cheap at the price". Having made private appeals to the directors of several leading pharmaceutical companies, the public appeal was launched at the Royal College of Physicians in May 1966.

The Association's Medical Advisory Group became the Medical Advisory Council of the Trust, meeting quarterly to review and administer its scientific work. Over the next few years the work of the Trust expanded rapidly; by the mid-1970s it had an income of nearly £100,000 per annum, which it used to run a series of annual research symposia, publish a journal (the short-lived Hemicrania) and a regular newsletter (Migraine News), fund more than 40 research projects (divesting about £40,000 annually in research grants), and open walk-in migraine clinics in the City of London and at Charterhouse Square (at an annual cost of round £25,000). It had also acquired the patronage of the Queen's sister, HRH Princess Margaret.

In 1976, the Trust initiated a series of biennial International Symposia that continue (in various iterations) to the present day to share the latest research and scientific advances. The Trust supported what became known as the Princess Margaret Migraine Clinic, which later relocated to the new Charing Cross Hospital in West London. The City of London clinic continued into the 1980s becoming a

separate charity in 2006, changing its name to the National Migraine Centre in 2012, and moving entirely online during the Covid pandemic.

In the 1990s and 2000s The Migraine Trust built up its role in patient support and public advocacy, taking on work previously done by the Association (in 2018, the Trust acquired the remaining assets of the that organisation, by then known as Migraine Action, after it went into administration). In recent years, the Trust has played an important role in ensuring that the National Institute for Health and Care Excellence made new CGRP-modulating drugs as widely available as possible, and working to tackle misconceptions around migraine. Like all charities, The Migraine Trust is subject to the prevailing financial climate, but throughout the ups and downs of the last 60 years, it has continued its focus on supporting high-quality basic and clinical research, and see improvements in the support and care given to those with migraine. In doing so, it has fulfilled the vision of its founders, and improved the lives of countless headache sufferers. Here's to the next 60 years! ■





## Spotlight on Fundraising

**What a year it's been for The Migraine Trust's fantastic fundraisers! From pounding the pavements to live streaming an intricate embroidery brain for eight solid hours, our fabulous fundraisers have truly gone above and beyond to raise awareness and vital funds for the millions of people living with debilitating migraine. Every mile run, every cake baked, and every conversation started has made a real difference – and we couldn't be prouder or more grateful for every single effort.**

Across the UK, more than 50 supporters have laced up their trainers to support our work, each step helping to bring hope and understanding to those affected by migraine. In April, The Migraine Trust was represented at the world's most iconic race – the London Marathon – where our two incredible runners, David and Sean, raced through the heart of the capital. Others took their trainers international, running through the streets of Berlin, Copenhagen, Valencia, Athens and Dublin, spreading our message, and raising thousands of pounds in the process. Every finish line crossed has been a testament to their determination and passion; our runners have shown the world that migraine is not a weakness – it's a cause worth running for.

But it's not all about running – we've seen cyclists and walkers galore too! One of our inspiring fundraisers, Deborah, completed an incredible pilgrimage walk of more than 250 miles from Canterbury to Southampton over 21 days, sleeping in churches where she could, and dedicating each step to people living with migraine. Her journey sparked countless conversations and raised vital funds along the way. March for Migraine, our annual virtual challenge, was also our biggest yet with almost 200 supporters

walking 100 miles across the month to shine a spotlight on migraine and in doing so, raised over £30,000 to support our services. The energy, commitment and compassion of our community never fail to amaze us.

Meanwhile, our 25 Migraine Meet-Ups during Migraine Awareness Week saw supporters coming together in towns and cities across the country to share experiences and stand in solidarity over a cup of tea and a slice of cake. These gatherings remind us that connection and understanding are just as powerful as any finish line when it comes to supporting people living with migraine.

And the excitement doesn't stop there! For the first time ever, we're proud to announce that The Migraine Trust will have a team of 13 incredible runners in next year's London Marathon – a huge milestone for our charity and a sign of just how much our movement is growing. Just two weeks earlier, 10 brilliant runners will be representing us in the London Landmarks Half Marathon – we can't wait to cheer them on as they take on these incredible challenges.

To everyone who has run, walked, fundraised, donated, or simply shared our message – thank you. Your passion, energy, and kindness are driving real change for people living with migraine. Together, we are moving closer to a world where migraine is understood, respected, and better supported. If you would like to get involved with a fundraising challenge for The Migraine Trust, please email [fundraising@migrainetrust.org](mailto:fundraising@migrainetrust.org) for more information – we'd love to have you on the team! ■



Uber Boat  
by thames clippers

RC | Russell  
Cooke