

Our strategy 2024-2027

the
migraine
trust



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“ I owe all my migraine knowledge to The Migraine Trust. It’s helped me understand my condition and my life as a whole. Most importantly, it’s helped me to give myself forgiveness and, in return, hope. I had none for eight years, and now I do.”

- Fiona is 59 and has lived with migraine all of her life



Introductions

People with migraine deserve better, and we're determined to make that happen



Michelle Walder, Chair of the board

We have been working tirelessly since we were founded in 1965 to change the perception of migraine and increase the level of support, care and treatment available for the one in seven people living with this often debilitating condition. Our research has helped make great strides in the understanding of migraine, and the role of factors such as diet, genetics and hormones. We have contributed to the development of new treatments and are committed to supporting the next generation of scientists to build careers in the field of migraine. Every year we support thousands of people providing reassurance, confidence and information. We are working to break down barriers to care and reduce isolation.

The perception of migraine is slowly starting to change but we have a long way to go. Migraine affects more people than epilepsy, diabetes and asthma combined yet for far too long it has been overlooked and underinvested. The stories we hear every day tell of the inequity, frustration and despair that exists. There are glimmers of hope with new care pathways and new treatments yet, as highlighted in our research, far too many are unable to benefit from them. The number coming to us in need of support is increasing and the decline in mental health is stark.

We want everyone, regardless of age, ethnicity, gender or where they live, to have access to the treatment and care they need. We're ready for the challenge and this strategy represents a step change. We will be shouting louder, and reaching further. Access to care shouldn't be a lottery and the wide-ranging impact of migraine must be better understood. That includes across government, healthcare, employers and the community.

The Migraine Trust Board of Trustees fully supports the ambition set out in this strategy and is determined to commit the energy and resources to making it happen.



Robert Music, Chief Executive

Since I started at The Migraine Trust three years ago, I have been equally exasperated by and optimistic about the progress in migraine treatment and care. In the far too recent past there were no dedicated treatments for migraine, but we are now seeing more and more coming through. We are slowly seeing more public figures talking about their experiences of living with migraine and pathways for optimum care are being developed across the UK.

However, this is just the tip of the iceberg. Migraine remains woefully behind other conditions in so many respects. It is the least publicly funded of all neurological illnesses relative to its economic impact. There is little to no data around protected characteristics and migraine prevalence. That means understanding around the wider impact of migraine is low. 'It's just a headache' is still used far too frequently.

Too many people are suffering with debilitating pain. They are faced with waiting lists that are far too long, symptoms that are dismissed and

employers who at best don't understand, but often don't believe them. We know many feel ignored, isolated and even a burden to family and friends. The impact on mental health can be extreme. Some tell us they feel so desperate that they often think about ending their life.

Tackling this is no easy feat. We need change across four areas, and these form the four strategic pillars of our strategy:

- 1. **People:** Empowering through practical help
- 2. **Society:** Improving understanding and reducing inequalities
- 3. **Health systems:** Leading and coordinating change
- 4. **Evidence:** Championing research and innovation

At the heart of everything we do it people who live with migraine. We'll raise the voices of those who feel unheard and work to build services and campaigns that are as accessible and effective as possible. At The Migraine Trust we have the experience, ambition and the drive but we can't do it alone. We will partner with people and organisations who share our goals.

Most importantly, we won't stop. People with migraine deserve so much better and we are rising to the challenge.

Our story

Our vision is a world where migraine doesn't stop anyone from living the life they want

Everyone with migraine deserves the best possible care, treatment and support. We invest in research, campaign for long term improvements and address the stigma and misunderstanding that currently exists. No one with migraine should feel alone and we are here at every step.

This means people with migraine are supported and believed. They are able to

access the medical care they need, when they need it. And they are supported in education, in employment, and in society.

For such a common condition, migraine does not get the recognition and investment it deserves. No one with migraine should have to put up with feeling hopeless or that they want to give up and no one should feel alone.

Our values set the tone and guide our decisions



Evidenced

Every decision we make is evidence based and supports the change we need



People first

The needs of those we work with are central to everything we do



Empowering

We build confidence to achieve positive change



Collaborative

By working together we can achieve so much more



Ambitious

We strive to achieve more than we could imagine

“ The Migraine Trust website has felt like such a safe space to me – particularly when you're first diagnosed, there's not a lot of guidance or support, but seeing others' stories online helped me to feel like it wasn't just me.” A user of The Migraine Trust support services



Haider's story

I have been living with migraine for around 18 years now. It affects my eyes, my balance, and causes me to vomit.

There have been times when my symptoms have been so severe that I have had to go to hospital. Having migraine means constant medical appointments and I've seen so many doctors over the years and tried so many medications, lots with side effects that are hard to deal with. There are so many triggers

for me that an attack can strike at any time. Travel, routine changes, crowded and noisy environments, hunger, stress. Migraine impacts every area of my life.

Sometimes I get migraine attacks continuously for 3 to 4 days in a row or 10 to 12 times in the month. I used to feel so frustrated thinking 'what have I done to cause this or 'why is it happening to me?!' Now that I've come to realise I can't control and manage when the migraine strikes. Some of the worst ones are when they strike in the middle of the night, that can really get into my thoughts and take me to a dark place.

Although my workplace is understanding, I still don't share the full extent of how migraine impacts me. There are practical reasons, but I also don't like being seen as weak or less reliable. It's something I am working on though, as much as I want to push through sometimes I end up falling down on the bed with a head that feels as though it has a 3kg weight on it.

I'm tired and there are times when it is hard to maintain hope. It definitely has worn away at my mental health, little by little.

The Migraine Trust is an incredible resource for people like me. Migraine can be really isolating and finding reliable information can be impossible. Knowing you aren't alone is so important.

Where are we now?

We are incredibly proud of what we have achieved over the last three years. We are a small charity but we punch well above our weight:

£600,000

approximately, **invested in research** since 2018



4,300

supported through our Helpline services in the last year (21% more in 2023 than 2022)



94%

of service users either **agreed or strongly agreed that they could turn to The Migraine Trust for help**



3,500

GP surgeries reached through our 2023 GP campaign with 81% saying they feel confident in diagnosing migraine

2,000,000

views of our information pages in the last year

5,000

people have viewed or attended our **Managing Your Migraine** information and support events

4

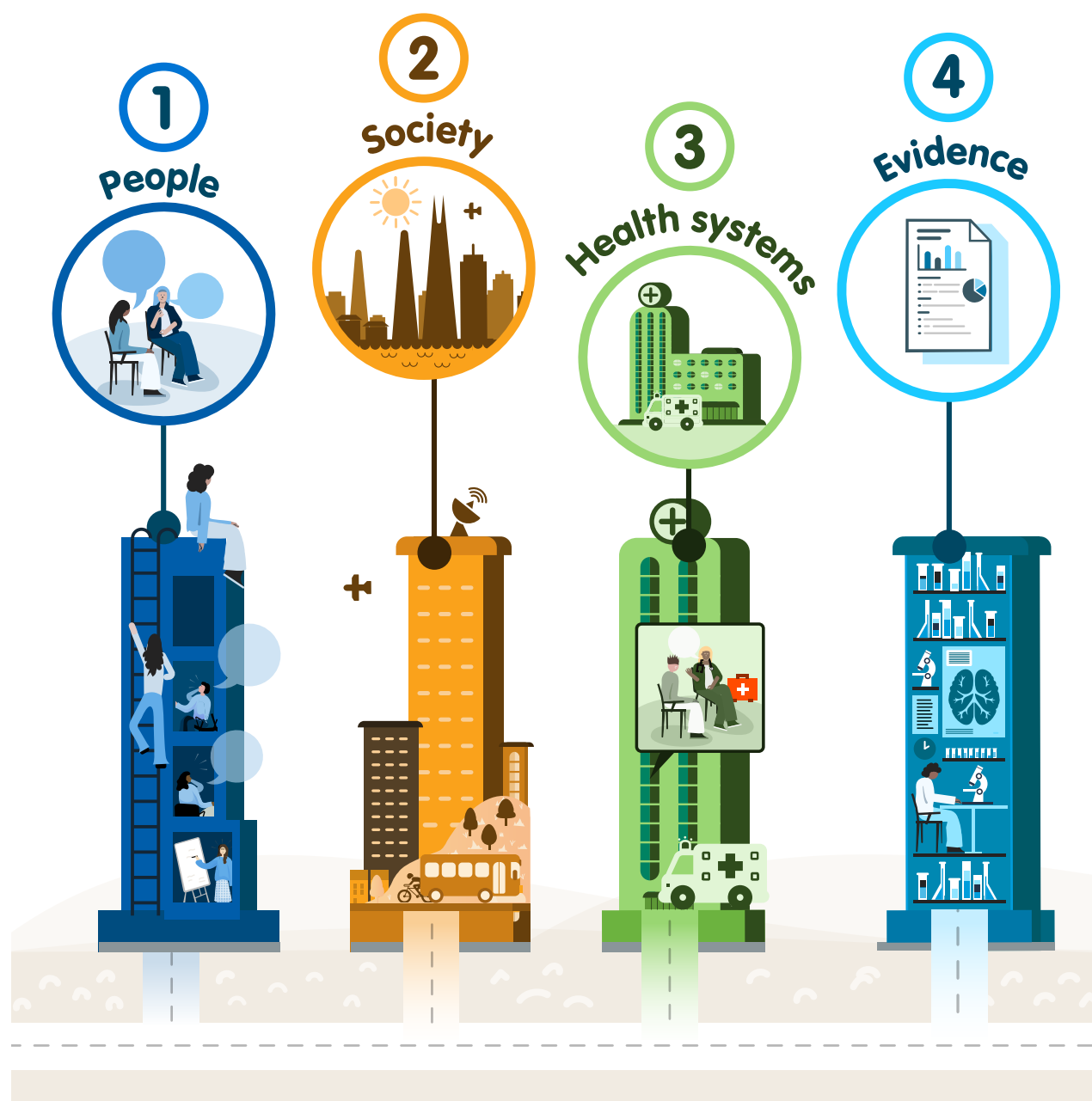
policy reports released over the last 3 years with 31 recommendations helping to make progress in migraine care and treatment



Our strategy

There are four pillars to our strategy.

These are supported by our work in building a movement for change that will enable us to be in the most sustainable and efficient position for the future, and help our ambitions become a reality.



People: Empowering through practical help

No one should face migraine alone or have to fight to get the answers they need. We provide answers, help explore options, build confidence and provide emotional support. We aim to be there for everyone who needs us, when they need us.



WHAT DO WE HOPE TO ACHIEVE:

- » A wider and more diverse range of people know about the charity and feel able to turn to us for help
- » Our service provision is fully informed by the needs of those living with migraine
- » The impact of migraine on mental health is better understood and addressed
- » Up to date and trusted information about migraine can be easily accessed
- » People with migraine feel less isolated and more empowered to make decisions about their health

OUR MOTIVATION TO DO THIS:

- » After using our Helpline services 81% report feeling less isolated and 95% feel more informed about their options and the steps they can take to reduce the impact of their migraine
- » 71% of people with migraine feel it has significantly affected their mental health
- » A recent study showed that as the number of headache days increased there was an increased risk of anxiety and depression
- » 40% say their mental wellbeing needs are not being met at all – my neurolife 21/22

THE RESULTS WE WANT TO SEE:

- » 20% increase in people using our support services by the end of year one alone
- » Steady increase in views of our online health information and downloads
- » Clearer understanding of the mental health needs of the migraine community with a plan spanning the lifetime of this strategy
- » A broader and more diverse range of individuals feeling that The Migraine Trust is for them and addresses their needs.

HOW:

- » Deliver high quality support services and invest in our team to help even more people access the support they need, when they need it
- » Continue to develop evidence based and accessible information based on the needs of people living with migraine
- » Expand our face to face support working with people with migraine to ensure it meets their needs
- » Conduct research into the mental health impact of migraine and use findings to inform our work across every area of the charity
- » Identify demographics who currently don't engage with the charity and work to better understand any unmet support and information needs and how we can address them



Society: Improving understanding and reducing inequalities

The way society views migraine needs to change. That change needs to happen across the life course so that the perception of migraine as an excuse or 'just a headache' is gone. This includes better understanding of how migraine can impact other physical and mental health conditions.



WHAT DO WE HOPE TO ACHIEVE:

- » Migraine is more visible, better understood and taken seriously
- » People with migraine are better supported in the workplace
- » Children and young people are more supported while in education

OUR MOTIVATION TO DO THIS:

- » 90% of children said their migraine makes it harder to do their schoolwork
- » 64% thought that their school did not have the information about migraine to help them manage it
- » 30% of people have felt harassed or victimised in the workplace and 22% faced disciplinary action
- » Migraines cost the UK economy an estimated £9.2bn, over 98% of which comes from lost productivity

THE RESULTS WE WANT TO SEE:

- » Public awareness of migraine is increased and the condition given the same level of recognition as conditions such as the menopause
- » Workplaces pledging to raise awareness and ensure staff with migraine are supported to stay in employment
- » Schools and education providers have the knowledge and resources to support pupils with migraine

HOW:

- » Build on the success of Migraine Awareness Week working with new partners to reach new and bigger audiences
- » Run advertising and marketing campaigns to raise the profile of migraine and tackle stigma
- » Increase the number of resources and initiatives we have to engage employers
- » Work with partners to increase early intervention for children with migraine
- » We'll work with a more diverse range of volunteers, celebrities and partners to share the wide range of migraine experiences that exist

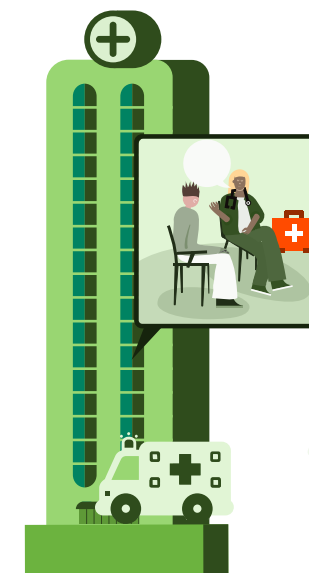
“At times I'd think I don't want to be here, this is no way to live. I didn't want to go out or to family functions. Letting people down made me feel even worse.”

- Sandip lives with chronic migraine



Health systems: Leading and co-ordinating change

Few people with migraine have a simple experience of healthcare. From symptoms being dismissed or misdiagnosed, to long waiting lists and delays in accessing treatments that work. At the same time our healthcare system faces immense challenges, and those working within it do not have the resources they need. Change is needed at every level.



WHAT DO WE HOPE TO ACHIEVE:

- » Migraine is given greater priority within the healthcare system at a national, regional and local level
- » Reduction in inequity in diagnosis, treatment and care
- » Health professionals are better supported to diagnose and manage patients with migraine

OUR MOTIVATION TO DO THIS:

- » Availability of CGRP treatments (the first preventative drugs developed specifically for the treatment of migraine) is inconsistent
- » Of those eligible for CGRP treatments only 52% had been offered it, with many reporting that their GP, neurologist or the local NHS does not prescribe it; that there was a lack of funds available to prescribe it; or that waiting lists are so long that it is out of reach.
- » There is an urgent workforce need in neurology, for GPs with a specialist interest in headache and headache specialist nurses to meet the migraine needs in each community
- » The UK only has 1.1 neurologists per 100,000 people, compared with

4 per 100,000 in France and Germany

- » Neurology had longest wait list in NHS in 2023

THE RESULTS WE WANT TO SEE:

- » More health professionals pursuing training and careers in migraine and headache
- » Increased visibility around migraine within UK parliaments
- » Local health providers are working to address the needs of their migraine communities
- » Pharmacy is seen as a key role in treating and managing patients

HOW:

- » Work with local and national health bodies to prioritise migraine
- » Call for an update of NICE guideline CG150
- » Work with royal colleges and stakeholder groups to better understand and address the needs of key health professionals in diagnosing and managing migraine
- » Continue to build a network of politicians who are committed to improving migraine care
- » Extend pharmacy project across Scotland and other parts of the UK

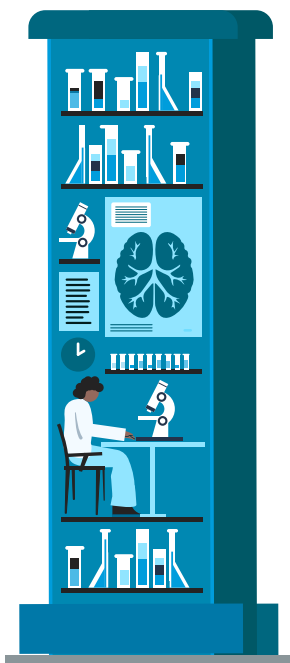
“Through my involvement with The Migraine Trust I've had the privilege of connecting with fellow migraine sufferers, fostering a supportive community that offers solace and understanding.”

Person living with migraine



Evidence Championing research and innovation

We are proud of our long history of investing in research. Our current focus is supporting the next generation of migraine researchers. We want the best talent to build careers in headache and work towards improved outcomes for people living with migraine now, and in the future.



WHAT DO WE HOPE TO ACHIEVE:

- » To support the migraine research community of the future
- » Provide opportunities to share best practice and innovation among the international research community
- » Champion greater investment for migraine research in the UK with a focus on under-researched groups and protected characteristics
- » Improved data regarding migraine prevalence, population and experiences of care

OUR MOTIVATION TO DO THIS:

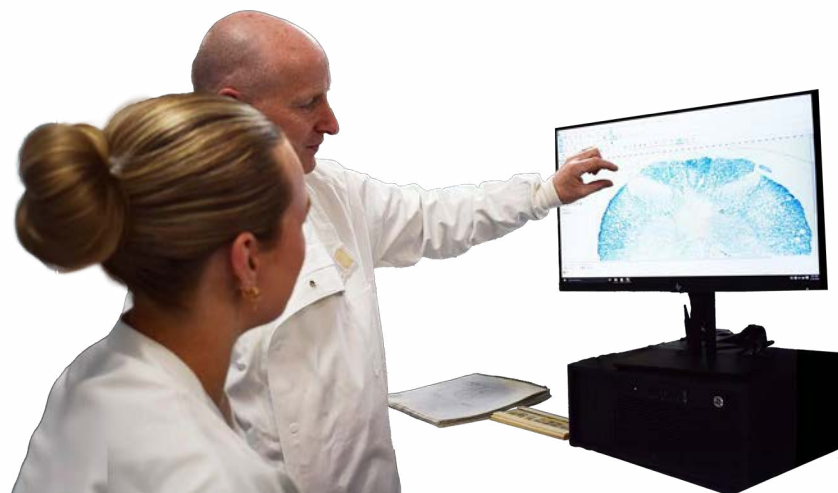
- » Migraine research is significantly underfunded and the least publicly funded of all neurological illnesses relative to its economic impact.
- » There is limited data around migraine prevalence and impact around different populations including protected characteristics, such as ethnicity and gender

THE RESULTS WE WANT TO SEE:

- » A bigger research community through providing a career path for brilliant young scientists
- » Increased funding through national bodies including NIHR for migraine and headache
- » More evidence around the migraine population, potential for different treatments and experiences of care

HOW:

- » Invest in fellowships and studentships to further the advancement of migraine research with two iCASE projects and 2 fellowships funded in year one
- » Conduct a national headache audit in England
- » Bring together international headache and migraine experts every two years at our annual symposium to share best practice, innovation and new research
- » Use our campaigns to call for increased research funding



Sarah's story

Migraine is such an invisible condition, sometimes it's as if it doesn't exist. I struggled for years before I got taken seriously by a health professional.

I've been told my symptoms are anxiety, labyrinthitis, something I just need to deal with. One healthcare professional suggested I "get a boyfriend, to take your mind off it". I've been told to just take paracetamol after describing my intense head pain. When I mentioned that the symptoms I was living with were causing me to experience depression, I was told not to think about it so much. I would leave appointments in tears and sometimes felt I was going mad. I began

binge eating to try and cope and gave up asking for help.

My symptoms include extreme unsteadiness, excruciating headaches and nausea. My vertigo can get so bad I have to stop walking to cling onto a fence or a window ledge to keep me on my feet.

One of the lowest points was a misdiagnosis of having a type of blood cancer. Several weeks and endless tests later I was told it wasn't actually cancer but the ordeal was horrendous. I've felt suicidal at points, anything to make the uncontrollable dizziness stop.

Eventually I was referred to a neurologist and finally diagnosed with chronic vestibular migraine. Although then I was faced with an endless cycle of medicines that made my symptoms worse or had their own side effects.

I'm currently signed off from work. It feels like I have no life. Migraine affects everything. The simplest things are a massive struggle. Going to the grocery shop, I find myself leaning on the trolley for support, and anything that involves bending my head like washing my hair isn't possible. Even taking the bins out can feel like a massive challenge. I've lost friends due to cancelled plans and have had to massively rely on family for support. I was rejected for Personal Independence Payment (PIP) and the financial stress is huge.

There is such a lack of understanding of migraine and in particular vestibular migraine. It's mentally draining. No one should have the same experience that I have had.

Engaging with the migraine community

This strategy is the result of a process of researching, listening and reflecting.

It is based on the many pieces of research we've undertaken with the migraine community about their experiences and most importantly, what needs to change. We consulted with a range of different groups including our Patient Involvement Panel, our staff and Trustees and the medical community. We wanted to understand the issues that were most pressing to them, and what they thought the charity should prioritise.

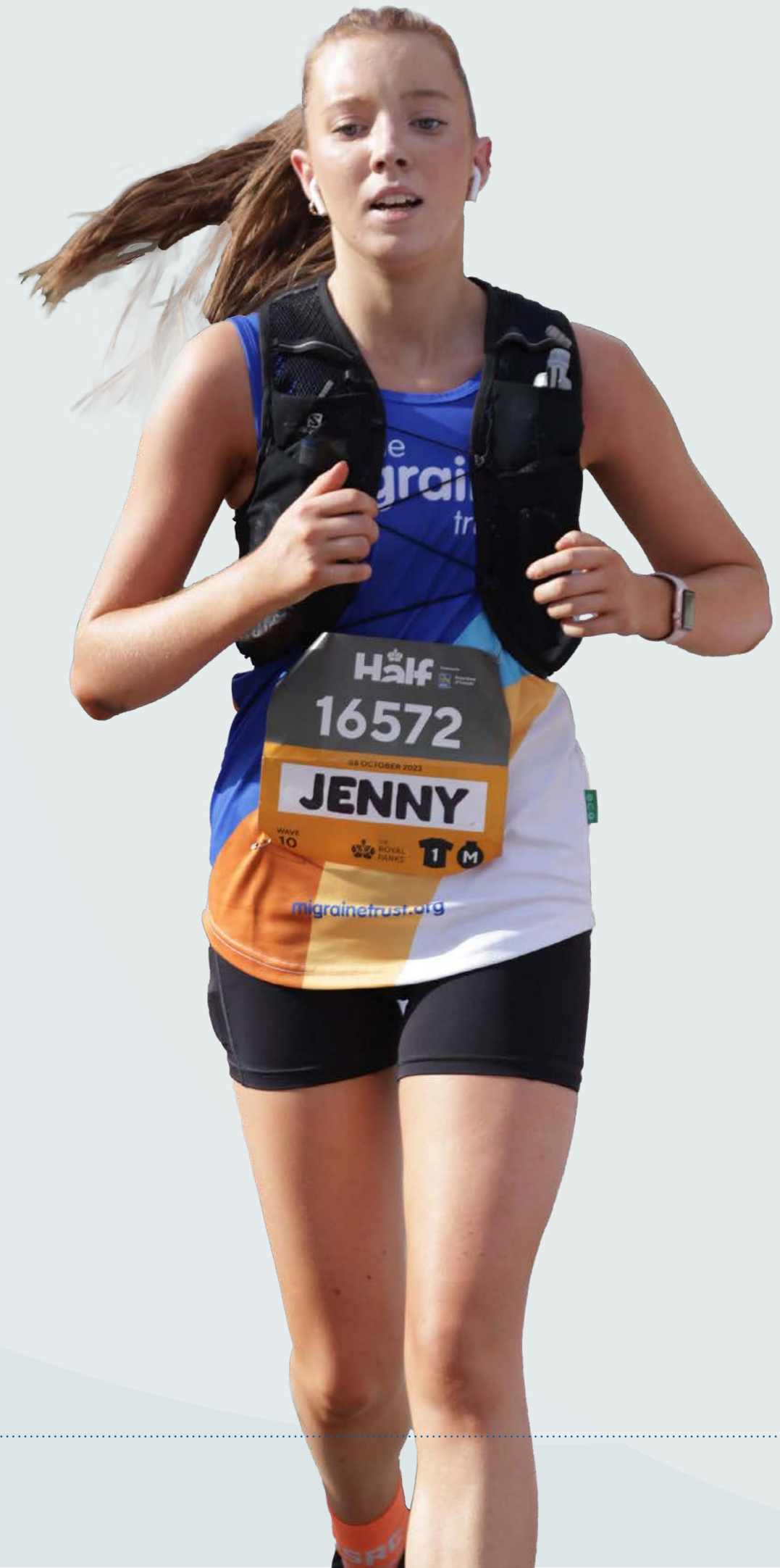
People with migraine are at the heart of everything we do. This includes our community but also those we currently don't reach.

We need to ensure our work reflects the diversity of people living with migraine in the UK. Unless their voices and experiences are in our work, our work will not meet everyone's needs. There are lots of groups that we don't have enough engagement with and improving this will be a key focus. This includes working with partners to reach new audiences and better understand the needs of different communities, ensuring our services and information are accessible and sharing a diverse range of experiences. There is no one migraine experience and it can affect anyone.

“ At a really low point I reached out to The Migraine Trust. It helped so much to talk with someone who understood, who listened to me.

The information I received at a support event was life changing though. There was also a talk about the migraine brain and that made me look at everything differently. Me, the world, migraine. No one had ever explained that my brain might be different.

- Georgie has lived with chronic migraine since she was a child



Building a movement for change

To support the delivery of our strategy we must be in the most stable and effective position.

This means bringing in the best ideas, nurturing the best people, having the right tools and, most importantly, funds to be the charity we aspire to be. Our five guiding objectives will help us do this.

1 True to our values

Everything we do is value driven and supports our ambition

2 Developing our culture

Continue to develop and embed a staff culture of openness, fairness and inclusivity

3 Raise sustainable levels of income

Invest in our fundraising to enable us to generate the income we need to achieve our strategic goals and build for the future

4 Diversify funding

Build and strengthen different funding streams to ensure we are in a stable position and not reliant on one area

5 Smarter

Streamlining processes to find efficiencies and using data more effectively to make decisions and measure impact



Thank you

Our work is only possible through the generosity of our supporters. Thank you for everything you have helped us do, and we look forward to working with you over the next three years.

Donate: migrainetrust.org/donate

Campaign: migrainetrust.org/campaign

Get support: migrainetrust.org/support

The Migraine Trust

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