

Addressing the inequalities in migraine care

Our annual review for 2022



Registered charity in England and Wales (1081300) and Scotland (SC042911).
A company limited by guarantee registered in England (03996448).

the
migraine
trust



“Migraine can be a debilitating and painful condition. Despite thousands of people in Lanarkshire being affected, there is still not enough specialist treatment and support available, and awareness remains low. I am pleased to support The Migraine Trust’s work to improve migraine care and to end the stigma that surrounds this chronic condition.”

Monica Lennon MSP

Monica Lennon MSP, who hosted our event in the Scottish parliament on 19 May 2022, talking to Rob Music, chief executive of The Migraine Trust, at the event.

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Welcome to our look back at 2022, a year of increasing our reach, support and influence

During 2021 the charity renewed its focus and increased its activity to highlight the need for much needed improvements in the care pathway for people living with migraine, increasing our reach, developing new strands of work and building new partnerships to help us achieve our longer term goals. It really felt like we had started to gain traction by the end of 2021.

We entered 2022 determined to maintain that momentum and build on the successes of the previous year to reduce inequity that surrounds migraine, so we can increase our reach, support and influence.

Increasing our reach is vitally important because, while over a million people seek our help and information every year, by visiting our website, attending our information events, and contacting our support services, with ten million living with migraine we know there are many more who may need our help. So there's much to do. In particular, we know we need to do better to engage with a wider range of groups within our society.

That's why we expanded our support service capacity and the ways that people can seek that support, helping break down potential barriers that some might have experienced. On the back of a new report, which focused on children and young people with migraine, we launched a programme focused on helping the one million children with migraine, so that they and those caring for them, have the information they need to allow them to enjoy their childhood and reduce the serious impact that migraine is having on far too many children.

Crucially, we held a series of events in all of the UK parliaments to raise the awareness of issues around migraine care, and the need for improved pathways and greater investment. We were pleased to have gained new parliamentary health champions, who will support us moving forward. We are also delighted to have received a grant from The Scottish Government to educate pharmacists in NHS Grampian around migraine so that they can be a vital source of care within their community.

Looking back over 2022, we are proud that we succeeded in achieving what we set out to do. More importantly, that it had the impact we hoped it would. This impetus needs to not only be maintained, but increased, as we look ahead to 2023. We will be launching a new strategy, which will give a clear focus on the work we plan and need to undertake over the coming years and ensure our new vision of 'a world where migraine doesn't stop anyone from living the life they want' becomes closer to a reality.

Rob Music, Chief Executive
Michelle Walder, Chair



Rob Music,
Chief Executive








Michelle Walder,
Chair

What we wanted to achieve in 2022

In 2022 we wanted to have a greater impact than ever before, through expanding our support services, increasing public awareness, working collaboratively with key organisations, developing our online support and campaigning for change, with an additional focus on activity that addresses some of the problems for the one million children and young people living with migraine.

Here's what we hoped to achieve in 2022.

JANUARY 2022	JUNE 2022	DECEMBER 2022
 <p>Launch a new communications programme on children's migraine that will include new website sections, events, information materials and an awareness campaign for children and young people, their parents and carers, and for schools and GPs</p>	 <p>Continue to grow our Support Service by hiring more staff for it and further increasing its opening hours in order to increase the reach and types of support we give</p>	 <p>Improved patient pathways</p>
 <p>Hold the first in person International Symposium since 2018, that will also include online events so that people can join from all over the world</p>	 <p>Continue to drive forward our <i>Better Migraine Care</i> campaign and influence change</p>	 <p>Improve outcomes for people living with migraine</p>

Why we needed to achieve this in 2022

The urgent case for improving migraine care

The research for our 2021 *Dismissed for too long* report found that:



Our survey of 1,800 people with migraine found that less than a third (32%) were satisfied with the care and treatment they were given.



At just 1.1 full time equivalent neurologists per 100,000 population, the UK has a dearth of neurologists compared to France and Germany with more than 4 per 100,000 population.



A&E attendance for headache and migraine attacks has increased by 14% over the last five years. According to NHS England, nearly 16,500 emergency admissions for headaches and migraine attacks could be avoided with the right care pathways, and £11.5 million could be saved on non-elective admissions.

Migraine is having a serious impact on the lives of people with migraine and there is a huge need for greater help and support to be provided to them

A 2021 Censuswide survey of over two thousand people which found that:



Almost a third (32%) said migraine negatively affected their mental health.



Almost a third (32%) said migraine negatively affected their overall health.



Three in ten (30%) said migraine negatively affected their working life.

Migraine can have a significant impact on the lives of children with migraine in many ways and they are not getting the support they need

Our research in 2022 found that:



72% of children and young people responding to our survey said that their migraine made them feel worried



33% of the children with migraine who took part in our survey found their treatment poor, and none found it to be excellent



90% of children and young people responding to our survey said their migraine made it harder to do their schoolwork. When asked if they think that their school has the information about migraine to help them manage it at school, 64% said no

How we increased our support and reach in 2022

Following the increase in demand for our information and support in 2021, we wanted to expand our capacity to help greater numbers of people. We also wanted to extend our reach to those who might find it harder to seek our information and support.

Key to this was hiring a second dedicated Helpline advisor in March and expanding our Helpline opening hours to 10am-4pm from Mondays to Fridays. This meant we were able to support more people and diversify how people could seek that help.

A key way we achieved this was through launching a new LiveChat service in June, where people can instant message our support service, which 600 people used in 2022. This has been particularly effective at giving information and support to people who would be reluctant or unable to call the Helpline or email our support services and has particularly appealed to a younger demographic compared to those that use our helpline or email services.

In September, we produced a suite of information factsheets on migraine and its management that people can take away and read, or download from our website. This has been an important way of giving information to people who might struggle to read a digital screen and was well received.

Our health information was assessed by the Patient Information Forum in 2022, and we again passed their accreditation and retained their 'trusted health care information creator' award. This is a very important accreditation for us as we have over a million people a year seeking our information to understand and manage migraine.

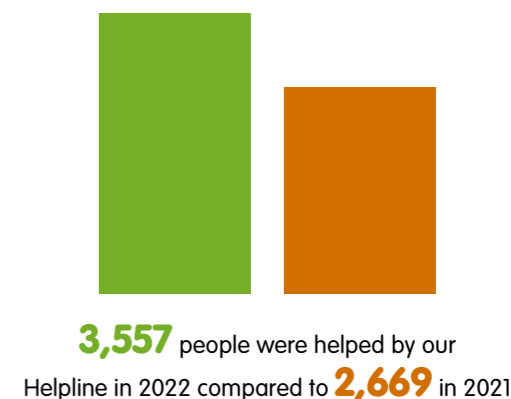
We also launched a new website section for children and young people in September. It has information for children of different ages, as well as their parents and siblings. It has information on migraine in children for those working in schools and healthcare professionals.

To better support people with challenges at work, we updated our managing migraine in the workplace toolkit in the summer, and started holding a series of managing migraine in the workplace events with employers such as Aviva, NatWest and Network Rail. This is ahead of plans for a larger outreach programme that will launch in 2023.

At the end of 2022, we launched an outreach programme whereby a pack from the charity was delivered to 3,500 GP surgeries, to help them support patients with migraine. The pack was developed with several GPs who are headache specialists. This is a six month project where we will use our learnings to look at how we can improve the support and education of people working in primary care, to in turn improve patient support.

We wanted to better understand the impact our work is having for people with migraine. During 2022, we worked with Trust Impact on a new theory of change out of which we have better and clearer outcome measures. We first looked at our support services and will then look to roll this out across other areas of our work. This was an important step in ensuring that those with migraine get the best possible help and support from the charity in 2023 and beyond.

Our growth in 2022



What we did

Helpline expansion and diversification

We hired a second dedicated Helpline advisor in March and expanded our Helpline opening hours to 10am-4pm Monday to Friday. We also launched a new LiveChat service in June where people can instant message our Helpline service.

New website section for children and young people

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Information events

Over 2022, we ran online and in-person Managing Your Migraine events as well as sessions on managing migraine at work to a wide range of employers. Our speakers included Professor Peter Goadsby, Dr Benjamin Wakerley, and Dr Sophie Mitchell.

The impact it had

Increased support

Our Helpline increased the information and support it gave by 33% compared to 2021, with 3,557 of people contacting and receiving help from it, up from 2,669 in 2021. 600 people had sought and received help via our LiveChat service by the end of the year. 79% of people contacting our support service said that the information they received from The Migraine Trust helped them to understand what they can do to take control and reduce the impact of migraine on their life. 85% said that as a result of the information received from The Migraine Trust they feel confident to access/engage with treatment/healthcare options available to them.

Giving children and young people with migraine, and those caring for them, the information they need

The new website section was visited ten thousand times from its launch in September 2021 to the end of the year. The section is now being recommended by the UK's leading paediatric migraine specialists to their patients.

Reaching new people around the UK

We held seven online Managing Your Migraine events (on treatments and research, managing thoughts and feelings around migraine, migraine in women, non-drug treatments, new drug treatments, and how to access care) and two in-person Managing Your Migraine events (in London and Belfast). The companies we worked with included Aviva, NatWest and Network Rail.

How we are helping people

Feedback of people who have contacted our Support Service

"Excellent service! Such a valuable source of information and support. The option of talking to someone who understands is very reassuring and helpful especially when GPs are not as informed about the issues affecting patients with migraine."

"The phone handler was very friendly and empathetic, explained options to me I wasn't aware of. Will 100% phone back and recommend to others."

"I think all the services you provide are extremely helpful and informative thank you so much."

"The chat box was really helpful, quickly answered and brilliant advice. Thank you."

"I feel the information on the website is very useful and helpful. The advice I received following my email was very informative and will really go a long way in helping me speak to my employer regarding the support I need moving forward with confidence."



“It was a pleasure to use the LiveChat option to solve my migraine-related query today. You were so helpful and provided me with all the information I needed. I would happily use the service again and direct other patients to use the website and chat service in the future. Thank you.”

“That short phone call has changed my mindset when I was in a bad place. Thank you, it has really helped me.”

“Excellent response to my email. Very prompt service and giving me such useful information. Very impressed thank you so much.”

“I spoke online to someone who was very reassuring.”

“I think it’s amazing to see a charity be able to help and advise people in real time like that as it’s really what people need when they are reaching out and unfortunately it’s not that common just due to resources and time etc. I’ve really appreciated the replies every time. It’s not even about the advice as more the human connection - to know someone is listening, understanding and reading and taking the time to reply and hear your pain when most people in your day to day life don’t understand.”



Building a coalition for change in 2022

Our campaign for health and policy change to deal with the inequities in healthcare that migraine patients face gained traction and new supporters in 2022.

We developed a toolkit for parliamentarians to help them advocate for people with migraine and support their constituents and staff with migraine. We launched the toolkits at events in Westminster and the three devolved parliaments in Belfast, Cardiff and Edinburgh. This was an important opportunity to initiate new relationships for the charity and develop a group of parliamentarians committed to help people with migraine.



While we had started reaching out to parliamentarians in 2021, those meetings were online due to the ongoing Covid-19 safety measures. It was therefore, particularly meaningful and productive to be able to meet in person. However, what did strike us was that those who were most interested and supportive were already personally affected by migraine, either they or someone close to them lives with it. The clear challenge is to engage those not personally affected by migraine.

There were positive developments following these events including letters calling for better migraine care for people with migraine being sent to Scottish Health Boards including Jackie Baillie MSP, Mercedes Villalba MSP and Foyso Choudhury MSP and Annie Wells MSP, and two to Welsh Health Boards by Mark Isherwood



Mark Isherwood MS

“The Welsh Government should explore ways that it could support pharmacist training on the management of migraine in both adults and children, and work with education partners to ensure that teaching staff have training and information on this issue, so that they can support children and young people effectively. The Migraine Trust would welcome working with the Welsh Government and Health Boards on making progress in these areas.”

Mark Isherwood MS

MS and Wayne David MP. There was also a debate about migraine care in the Welsh parliament.

Our campaign also expanded its call for change when we published our second *Dismissed for too long* report during Migraine Awareness Week. The report highlighted the impact that migraine has on children and young people, and how they aren't getting the help they need in the healthcare or education system.

We sat on the steering group of the National Neurosciences Advisory Group (NNAG) on the development of a new pathway for patients with

migraine, and started work with NHS Grampian on an outreach programme to community, primary and secondary care pharmacists to help people with migraine manage their symptoms and treatments more effectively. This project is able to take place thanks to funding from the Scottish Government. We also joined a working group to develop recommendations on how migraine patients can be best treated within the new Integrated Care System (ICS) structures in England.

Our policy and influencing work in 2022 highlighted the importance and effectiveness of The Migraine Trust in building a coalition for change.



Maree Todd, the Scottish Minister for Public Health, Women's Health and Sport

What we did

Engaging politicians and policymakers in our Better Migraine Care campaign with a new toolkit

We developed a toolkit for parliamentarians to help them advocate for people with migraine and support their constituents and staff with migraine.

Working across migraine sector to improve care pathways for patients with migraine

We worked with the National Neurosciences Advisory Group (NNAG) on the development of a new pathway for patients with migraine.

The Scottish Government provided funding to help train pharmacists to support people with migraine as part of its five-year neurological care and support action plan.

Launched report into migraine in children

We launched the second report in our *Dismissed for too long* series in September 2022. It focused on children and young people's experience of living with migraine in the UK, particularly migraine healthcare and managing it in education. It highlighted the serious impact it had on their mental health and education, and made recommendations as to what needed to be done to increase support for children and young people with migraine.

The impact it had

Successful parliamentary events in each of the four UK parliaments to launch new toolkit

We held events in Westminster, Holyrood, the Senedd and Stormont. They were attended by parliamentarians from all parties. We had productive conversations with several parliamentarians offering their support for our work.

New care pathways for people with migraine

A new optimum clinical pathway for UK adults experiencing headache and facial pain that has now been launched by NHS England.

We have been awarded funding from the Scottish Government to work with NHS Grampian on an outreach programme to community, primary and secondary care pharmacists to help people with migraine manage their symptoms and treatments more effectively.

A campaign to help children and young people with migraine

Following the publication of the report, the British Paediatric Neurology Association's (BPNA) children's headache network announced that it would begin a programme of work to design headache training for primary care professionals. This was one of the key recommendations in our report. In October 2022, there was a debate in the Welsh Parliament (Senedd) on migraine in children and young people and how care can be improved for them. It was led by Mark Isherwood MS following our request to him as the report launched the previous month.

How we supported research into and knowledge of migraine in 2022

Although migraine research has been gathering pace over the last few years, which has led to ground-breaking new medications and understandings of migraine, there is still a lot that we don't know about migraine and how to treat it.

This huge task falls on a very small global community of migraine researchers, and that's why it was important to bring them together in London in September 2022 for the Migraine Trust International Symposium (MTIS), the first in-person international event since the pandemic with over 800 headache and migraine specialists, researchers and those working in the area of migraine attending. They shared the findings of their migraine research and discussed the new understandings about migraine and new treatments based on their work.

As well as supporting the migraine research community as a whole, we continue to nurture the best young scientists which is particularly important as it is such a small research community. We continued to support PhD studentship of Hannah Creaney who is investigating the potential role of the neuropeptide amylin in migraine in the Headache Group research laboratory at King's College London.

During the year we secured support from Pfizer Ltd for two one year fellowships for mid-career migraine researchers. It can be hard to recruit people to research migraine, and there are limited opportunities

for migraine researchers who would like to continue working in this area. These two new fellowships are an important opportunity, to not only support migraine research, but to support and foster those already working in this area.

We also undertook our own research as part of the children and young people with migraine project. This research was to understand the key issues in the area so that we could develop information and support solutions, and policy recommendations.

We ran a survey to understand the current status of access to the new class of calcitonin gene-related peptide (CGRP) migraine medication, the first preventive developed to treat migraine.

We worked with NatWest on a survey to understand the issues that its staff with migraine face and how it can develop its support for them.

By the end of 2022, we had made an important step forward in not only undertaking our own research to increase the understanding of migraine and how it affects people so that they get the help they need, but supporting those undertaking scientific research to improve the treatment opportunities for everyone with migraine.

Our survey into access to CGRP migraine medication found that:

- 44% of those eligible for it hadn't been offered it
- 86% of those offered it said it had improved their migraine more than any other migraine preventive treatment

They described it as:

"Life-changing"

"A complete change – I got my life back!"

Professor Peter Goadsby, trustee of The Migraine Trust

"Not only will these projects support the vital research into migraine but it will also offer a continued career path for the best young clinicians and scientists to remain in the field of headache and migraine."

Rob Music, Chief Executive, The Migraine Trust



Adenosine receptor
ec

- Ingestion of caffeine is a common approach to...
- Caffeine is included in many analgesics (with NSAID) that are...
- Withdrawal from caffeine (caffeine withdrawal)...

Alstadhaug, K. B., Caffeine Withdrawal, *neurology*, 11, 1002

What we did

Held the first in-person and online Migraine Trust International Symposium (MTIS) since 2018

We held the first ever hybrid MTIS from 8-11 September 2022.

Supported research that increases understanding of migraine

Secured support for two fellowships for mid-career migraine researchers.

Supported research into possible new migraine treatments

Ongoing support for Hannah Creaney's PhD studentship research into the potential role of the neuropeptide amylin in migraine.

The impact it had

Bringing together the migraine research community to stimulate new research

MTIS 2022 used the learnings from our MTIS in 2020 era virtual meeting to create a truly modern meeting. It was the first face-to-face meeting for the international headache and migraine community in three years, and was attended by more headache and migraine specialists, researchers and those working in the area of migraine than ever before. We had 779 people attend in-person and 148 people attend online.

Created opportunities for experienced migraine researchers

It can be hard to recruit people to research migraine, and there are limited opportunities for migraine researchers who would like to continue working in this area. These two new fellowships are an important opportunity, to not only support migraine research, but to support and foster those already working in this area.

Determining a possible new treatment

Hannah is concluding her research to determine if targeted modulation of amylin signalling could be a new treatment for migraine.

What we want to achieve in 2023

2022 was an important step in having a greater impact, through expanding our support services, campaigning for change, and focusing activity that addressed some of the problems for the children and young people in the UK who are living with migraine.

We have also been preparing for the launching of our new strategy in 2023, with the development of new strategic pillars for The Migraine Trust that all aim to build a movement for change. These pillars are:

- **Aimed at the individual change** – Empowering people living with migraine

- **Aimed at societal change** – Improving knowledge, increasing understanding, breaking down barriers and stigmas in society
- **Aimed at systemic change** – Advocating for health system change
- **Aimed at evidential change** – Increasing behavioural, society and medical research

We are very grateful for all our incredibly generous supporters, who have allowed us to increase our impact. We hope that this support continues, and we can look forward to increasing this impact further in 2023 and launch our new strategy.



Focus our work in three key areas: healthcare, the workplace and education. Work with organisations in these areas to help people with migraine in healthcare, workplace, and education



Continue to grow our support service to help even more people with migraine, particularly people from groups that we are currently engaging with at low levels



Launch a new strategic plan for The Migraine Trust that will aim to empower people living with migraine, improve knowledge, increase understanding, and break down barriers and stigmas in society, advocate for health system change, and increase behavioural, society and medical research

JANUARY 2022



Recruit and commence two new fellowships to support research that increases the understanding of migraine and new treatments for it, and campaign for more funding for migraine research from a wider range of funders



JUNE 2022

Continue to drive forward our *Better Migraine Care* campaign and influence change through it, particularly by bringing people with migraine together with politicians and policy-makers



DECEMBER 2022

Work with NHS Grampian to launch outreach programme to community, primary and secondary care pharmacists so they can help people with migraine manage their symptoms and treatments more effectively

Thank you to everyone who made our work possible in 2022

We are a small team of staff led by our chief executive, Rob Music.

Our board of trustees is chaired by Michelle Walder, and our trustees are:

Michelle Walder (Chair)
Dr Shazia Afridi MBBS MRCP PhD
Katy Brown
Gary George
Professor Peter Goadsby MBBS MD PhD DSc FRACP FRCP
Stephanie Hayle
Dr Kay Kennis
Philippa Kindersley
Dr Louise Rusk
Wendy Thomas
Mike Wakefield

None of this would be possible without the generous support of those who support our work. We would like to say a huge thank you to everyone who enabled us to work for people with migraine in 2022.