Focusing on change

Our annual review for 2021

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migraine
trust


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Our year in review

> *"I'm doing this to raise awareness of migraine and funds to help people with it. This is a debilitating condition, raising awareness and giving support will hopefully help others."*

Lauren Williams walked ten miles through Wrexham's hills with her friends and family in June to raise funds for The Migraine Trust and awareness of migraine. Lauren, who has hemiplegic migraine, then shared her experience of living with it on BBC Radio Wales for Migraine Awareness Week in September 2021.

Welcome to our look back at 2021, a year of positive change. 2020 was a year of unprecedented change due to the onset of the pandemic, but we entered 2021 determined that we would do all we can to meet the challenges both of Covid-19 and the inequity that still exists for people with migraine.

While 2020 was very challenging for the migraine community, it also showed us that we could help more people with migraine.

That was important because people with migraine have been struggling more than ever. For many, their migraine has worsened significantly over the last two years and the migraine healthcare system is becoming harder for patients to navigate.

Rob Music, Chief Executive

That's why, despite the ongoing difficulties of the pandemic and as we looked to come out of it at the other end, we needed to increase our activity and support in 2021, and it is positive that we saw a big increase in people accessing our services during the year.

What was also very clear is that as the UK's leading migraine charity, we had a vital role to be the voice of our community, to push for change that will improve diagnosis, treatment and care, and we believe the launch of our *Dismissed for too long* report can be a real catalyst for change.

Michelle Walder, Chair

Looking back over 2021, we should be proud of the positive steps taken, the impact we've seen, but of course, we are nothing without the incredible support of our migraine community who were with us every step of the way, pushing for change for people with migraine. And we must look ahead to 2022 and fight harder than ever before to ensure people with migraine get the best care, no matter where they live.

Here is our year in review.

What we wanted to achieve in 2021

The start of the pandemic in 2020 had a huge impact on how we worked as an organisation and on the national environment of care and support for people with migraine. Most importantly, it had a significant effect on people's migraine and the help they needed.

Like so many others, all face to face work stopped overnight but we immediately saw the benefits offered by technologies, that enabled us to work with, reach and help significantly greater numbers of people in 2021. Crucially, it meant that we could be innovative and ambitious in 2021 despite the ongoing difficulties of the pandemic.

Here's what we hoped to achieve in 2021.

Expand and develop our Helpline service to increase the support we can offer people who are struggling with migraine

Launch a new website that aimed to reach more and new groups of people who need information and support about migraine

Deliver a wide range of online and accessible information events about migraine and how to manage it to both current and new audiences we weren't previously reaching

JANUARY 2021 **JUNE 2021** **DECEMBER 2021**

Campaign for better migraine healthcare so that everyone in the UK with migraine gets the treatment they need to manage their migraine

Support the learning and development of those seeking to help people with migraine through the awarding of the inaugural Susan Haydon Bursary

Why we needed to achieve this in 2021

Our information and support is needed more than ever

Our research in 2021 found that:

Two thirds (67%) of people's migraine had worsened since March 2020, their migraine attacks increasing in frequency and severity of symptoms

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

A quarter (25%) said that their migraine negatively affected their family life

Migraine patients are struggling to access the treatment they need

Our research in 2021 found that:

Almost a quarter (23%) of people had been experiencing migraine attacks for over two years before they were diagnosed

Only 13 Trusts in England (out of 128 contacted), and 13 Health Boards in Northern Ireland, Scotland and Wales (out of 26), replied and said they had a specialist headache clinic

Only 15 Trusts in England (out of 128 contacted), and 10 Health Boards in Northern Ireland, Scotland and Wales (out of 26), replied and stated that eligible patients could access CGRP treatment

"Although I was seeing a neurologist, I would still visit my GP when I would experience really bad migraine attacks. He always tried to give me the most basic migraine medication which I had been told not to take by the neurologist. I never received adequate pain relief from my GP until I collapsed in his office and had to be wheeled out in a wheelchair."

Abigail Kabirou

How we grew and developed the information and support we give in 2021

Like many organisations, particularly those that directly support people, we faced an increase in those seeking our help in 2021. Not only were more people desperately wanting our help, but the nature of the support they needed was changing. Many were struggling with worsening migraine as a result of stress and lifestyle changes caused by the pandemic. Others were struggling to access healthcare, from finding it difficult to get appointments with their GPs or consultant, while many with chronic migraine were having treatment cancelled, delayed, or just unable to access it altogether, often resulting in their having to self-medicate, bringing risks of medicine overuse.

There were also many new enquiries from people trying to understand how to access the new calcitonin gene-related peptide (CGRP) antibody medication that they were eligible for. This treatment is so important because it is the first preventive medication designed to treat migraine and its approval to treat migraine on the NHS over the last few years has been a great source of hope for the migraine community. This medication has proved highly effective for many people with migraine and is frequently described by those taking it as "life-changing". This has made the struggle or inability to access it particularly difficult for those who are eligible for it.

The combination of the issues with access to CGRP medication and the impact of the pandemic on migraine has meant that people are increasingly seeking our help for emotional support. They are looking for information about the condition and how to manage it, and how to manage life with a painful and debilitating condition which is still misunderstood and dismissed.

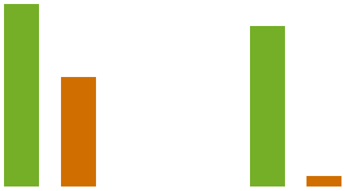
Connecting with the migraine community

Despite the pandemic, we have worked hard to rise above the challenges faced and continued to grow and develop how we support people with migraine.

If anything, the changes to life since the start of the pandemic have enabled us to bring the migraine community closer together. The best example is how many people with migraine have been able to hear from and ask questions of leading migraine specialists in our online events throughout 2021, all while never having to leave their home to do so.

Despite the challenges posed in 2021, we have been able to turn them into opportunities. We now want to continue to use the lessons learnt in how we can help even greater numbers of people from now on.

Our growth in 2021



2,669 people were helped by our Helpline compared to **1,713** in 2020

2,359 people were able to attend our information events compared to **150** in 2020

What we did	The impact it had
Helpline expansion We hired a dedicated Helpline advisor in June and expanded our Helpline opening hours to 10am-2pm Monday to Friday.	**Increased support** Our Helpline increased the information and support it gave by 55% compared to 2020, with 2,669 of people contacting and receiving help from it, up from 1,713 in 2020.
New website We launched a new website in July aimed at helping people understand migraine and how to manage it, with new accessibility features.	**Better online experience** People are spending more time on our website and engaging with it more. The information on the website received the Patient Information Forum approval which has now designated the charity to be a 'Trusted Information Creator'.
Online information events Over 2021, we held five Managing Your Migraine events on topics that included migraine and sleep and access to new treatments, and three question and answer sessions with leading migraine specialists. We delivered nine workshops on how to manage migraine at work to staff from across the Civil Service.	**Reaching new people** We were able to give 2,359 places to people who registered to attend our free online events in 2021. People were able to attend these online events from all over the United Kingdom.

Helping people understand and manage migraine through our Helpline, website, and online events

"As someone newly diagnosed with hemiplegic migraine and struggling to make sense of the condition, its symptoms and its impact, I have found The Migraine Trust to be a great source of information and support.

"Their website is excellent and packed with information and I have attended a number of their online events with experts in the field which have provided some much needed clarity.

"I got a lengthy and thoughtful response to my initial enquiry for help when first diagnosed which also signposted me to a number of other resources which have also been a great help.

"I would strongly urge any fellow migraine sufferers to visit both their website and social media channels for help and support."

Richard Napier

"I have been living with vestibular migraine for several years and I have found it really difficult to find out much about it, including how to manage it. Most of the information online comes from North America.

"The shining exception is The Migraine Trust website. It gives detailed information about the condition in a clear comprehensible way, avoiding technical jargon.

"I subscribed to The Migraine Trust free regular ebulletin, which gives up-to-date information about the latest treatment developments as well as the charity's current activities.

"Recently there was a webinar on Zoom (I am unable to go to any actual meetings so this was ideal). Several speakers spoke about aspects of migraine including one on vestibular migraine and another on new treatments for migraine. These gave me hope that it is not a lost cause.

"As well as responding to emails, The Migraine Trust has a Helpline. When I have contacted the charity, its people have been sympathetic and helpful. It makes a huge difference."

Linnet McMahon

Reducing inequity and campaigning for change in 2021

Having been made aware by those contacting our Helpline of the issues with access to CGRP medication, we launched an investigation at the start of 2021 to understand the scale of the problem and what needed to be done to address it.

We sent Freedom of Information requests to hospital Trusts in England and Health Boards in Northern Ireland, Scotland and Wales to find out who was and wasn't giving access to CGRP medication, and to learn more about the help they gave to people with migraine. At the start of the summer, we ran surveys of the public to find out more about their access to this treatment and their overall experience of migraine healthcare. We then held a Round Table event with leading migraine experts to discuss our findings and decide what needed to be done.

It was clear that the issues with access to CGRP medication were only one problem in a broken migraine healthcare system.

This was unacceptable and we knew that we needed to raise awareness of this and campaign for urgent change to deal with the inequities in healthcare that migraine patients were facing.

We published our findings and recommendations during Migraine Awareness Week, which took place from 5-11 September. The report, *Dismissed for too long*, highlighted how migraine is one of the most disabling conditions in the world, that it affects one in seven people in the UK and is ranked as the third cause of years lived with a disability. Despite this, migraine is largely absent from NHS plans or local public health strategies, receives very little funding for research, and access to specialist care is patchy and inconsistent across the country.

It contained a range of recommendations for how migraine healthcare in the UK can be improved. They included:

- Everyone attending primary care for head pain should be assessed for migraine, with the outcome of the assessment recorded as a positive or negative diagnosis of migraine.

- Support GPs to make an accurate and rapid diagnosis by making migraine treatment and care a core part of junior doctor and GP training.

- Everyone diagnosed with migraine should receive an individualised care plan, developed closely with them. Regardless of whether medication is prescribed, the individual should have their care plan regularly reviewed at an interval decided with their doctor.

- Each nation's department of health should support the recruitment of additional headache specialists and consultant neurologists to bring the UK in line with other European countries.

Our *Dismissed for too long* report and its recommendations were welcomed across the migraine community and gave us clear actions to take forward over the coming months and years. People with migraine were relieved that a spotlight was being shone on the problems with migraine healthcare that they had too long been aware of, while those working to help people with migraine welcomed the chance for the sector to work together to drive change that is badly needed.

The report also received a lot of attention in the media and amongst policymakers. It was covered widely in newspapers, television news, and online media. This was in large part thanks to the migraine community pulling together to launch the report during Migraine Awareness Week. People with migraine shared their experiences of migraine healthcare on social media and by contacting their members of parliament. While migraine specialists spoke about the report's findings in the media.

Working together to launch the report had a positive impact and one that acted as a catalyst for real change, gaining significant momentum by the end of 2021, and which we will work to build on going forward.

Wayne David, MP

"As one of the 10 million people in the UK who live with occasional migraines, I am supporting Migraine Awareness Week to lend my voice to the call for better migraine care. Acting to improve migraine care will relieve the pressure on local hospitals and GP surgeries, reduce the number of working days lost to this illness and improve the quality of life for millions of people."

Wayne David MP

What we did

Launched report

We launched our *Dismissed for too long* report into migraine healthcare in the UK in September. It highlighted the problems in the healthcare system and made recommendations as to what needed to be done to address them.

The impact it had

A new campaign for change

There were 47 items of media coverage of the report including in *The Times, Daily Telegraph, BBC South East* and *ITV Wales* with a reach of over four million people.

25 MPs, MSPs, MLAs and AMs tweeted support for the report's recommendations. We had several meetings with parliamentarians to discuss the report by the end of 2021, including with a UK government minister and the Scottish health minister.

GOOD HEALTH

Monthly drug STOPPED MP Rachel's devastating MIGRAINES

New treatment prevents agonising attacks that blight lives. So why are NHS patients missing out?

GET A GRIP

Millions of migraine sufferers let down by 'broken' system

People who suffer migraines are in need of more support

Our research for a better understanding of migraine in 2021

Despite migraine being a common condition, there is still far too little understanding of it or why people get migraine. This means that, until the recent breakthrough in research that led to the development of the CGRP class of preventive migraine medication, migraine patients could only be offered preventive medication that was developed for other conditions, which often have very negative side effects.

It also means that people with migraine, as our *Dismissed for too long* report highlighted, have to navigate a healthcare system where healthcare professionals often have a low level of understanding of migraine or the support or tools needed to improve this.

We commissioned Censuswide research on 2,000 people, a quarter of whom had migraine, to ascertain current levels of awareness of migraine, its symptoms and how it is managed. We used the findings to help us raise awareness of migraine during Migraine Awareness Week.

The low levels of understanding of migraine are also why we support migraine research through the funding of PhDs, Fellowships and by holding a well respected international research symposium every two years. This year, we also launched a bursary to support the learning and training in headache and migraine for people who would like to use it in a professional capacity.

Created in honour of Susan Haydon, our former Information and Support Services Manager who died in 2019, we offer a grant to support students and professionals with an interest in migraine. The Susan Haydon Bursary launched at the start of 2020 and was awarded to two people, Clair Sparkes for training to become a Physician Associate with a headache speciality at the University of Edinburgh, and Katherine Markel for a Masters in Genetics of Human Disease at University College London.

Clair Sparkes

Katherine Markel

We also funded the PhD studentship of Hannah Creeney who is investigating the potential role of the neuropeptide amylin in migraine in the Headache Group research laboratory at King's College London. While Joseph Lloyd, whose PhD studentship we funded, completed his research and was awarded his doctorate in March 2021. He had been researching single pulse transcranial magnetic stimulation (sTMS) in treating migraine at King's College London and Guy's and St Thomas' NHS Foundation Trust.

This made 2021 an important year for us in completing the circle of supporting new discoveries in migraine, and then supporting the learning of them by people who will use that knowledge to help even more people with migraine.

What we did	The impact it had
Supporting research that increases the understanding of migraine Ongoing support for Hannah Creeney's PhD studentship research into the potential role of the neuropeptide amylin in migraine.	**Determining a possible new treatment** Hannah made significant progress in her research in 2021 in determining if targeted modulation of amylin signalling could be a new treatment for migraine.
Supporting research into migraine treatments Supporting Joseph Lloyd's research into single pulse transcranial magnetic stimulation (sTMS) as a migraine treatment.	**New understanding of migraine treatment** The outcomes of the research suggest that sTMS actions persist beyond the immediate application and are cumulative the longer it is used. This research has advanced our understanding of how sTMS works on the brain to treat migraine.
Public awareness research Commissioning a poll of the public to understand current levels of awareness and understanding of migraine.	**Raising awareness of migraine** The Censuswide survey results were covered extensively in the media during Migraine Awareness Week and are a key part of our communications activity.
Launched new bursary in migraine learning and training Awarding of the inaugural Susan Haydon Bursaries.	**Increasing understanding of migraine** Clair Sparkes was awarded a bursary to train to become a Physician Associate with a headache speciality at the University of Edinburgh, and Katherine Markel was awarded a bursary to undertake a Masters in Genetics of Human Disease at University College London.

> *"It is my hope that my work can help us to understand the underlying causes of migraine and ultimately help the drive to develop new migraine-specific therapies."*
>
> **Hannah Creeney, The Migraine Trust PhD student**

What we want to achieve in 2022

We feel 2021 was a positive step in the right direction to meet the needs of people with migraine, in terms of helping them directly and changing the environment in which they live with migraine.

In 2022 we aim to have a greater impact than ever before, through expanding our support services, increasing pubic 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 800,000 children and young people living with migraine.

We are very grateful for all our incredibly generous supporters, who have allowed us to make positive progress at a time when we needed them more than ever. We hope that this support continues, and we can look forward to a greater impact in 2022.

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

Hold the first in person International Symposium since 2019, that will also include online events so that people can join from all over the world

JANUARY 2022 **JUNE 2022** **DECEMBER 2022**

Continue to grow our Helpline service by hiring more staff for it and further increasing its opening hours so that we can increase the reach and types of support we give

Continue to drive forward our Better Migraine Care campaign and influence change through it

Thank you to everyone who made our work possible in 2021

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:

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 2021.

the migraine trust

migrainetrust.org

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