

# Heading in the wrong direction:

Challenges in migraine care and why  
people with migraine deserve better



the  
**migraine**  
trust

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## 1. Foreword

By **Rob Music**, Chief Executive of The Migraine Trust

For millions of people across the UK, migraine remains a debilitating and stigmatised health condition. Misunderstanding of migraine means it is often dismissed as ‘just a bad headache’ meaning those affected, especially living with chronic migraine, struggle to access the care and treatment they need.

Migraine is a common condition affecting one in seven adults and one in ten children in the UK. Yet it is consistently overlooked in national health strategies, for example in the upcoming Major Conditions Strategy for England.

Our support services hear from patients every day who are not getting the care they need. Care is incredibly inconsistent, with symptoms being dismissed or not understood, waiting times for specialist care are worsening and access to new life-changing treatments is patchy. Many GPs are not aware of the latest treatments, and do not have the resources to offer support.

We cannot continue on this path. Too many people are struggling to cope with debilitating migraine attacks alone. We hear from many who feel they are fighting for access to treatments or preventative medicines, and resorting to private healthcare. The stigma of migraine along with the lack of understanding drastically impacts all aspects of life. Relationships break down, people lose their jobs and all too often people tell us they cannot continue living in pain. This report contains the experiences of many people whose mental health is severely affected. The overriding feeling is one of being ignored, misunderstood and left alone.

Not only are patients struggling, but poor management of migraine is putting unnecessary additional strain on an already struggling NHS. We know that GPs are overwhelmed and understaffed, with a widespread shortage of GPs, consultants and nurses specialising in headache to meet the need that we know exists. We are also seeing rising A&E admissions for migraine across the UK. Coupled with lack of understanding of the condition, this means patients are not being treated in the right place or at the right time, if at all.

People living with migraine deserve so much better. We need a major push to improve management and understanding of migraine in the UK, with it being treated as a significant health condition. The starting point for this should be a national drive in all four nations to make sure pathways are adopted consistently, GPs have up-to-date training on migraine treatment and care, pharmacists are empowered to support more patients, and specialist community migraine clinics are available to those who have more complex cases.

For such a common and debilitating condition, migraine has been overlooked for too long. We must start to take migraine seriously and improve care so that people with migraine can live better – let’s get started.



## 2. Executive summary and recommendations

Around ten million people in the UK have experienced migraine or live with migraine. For many this has a severely debilitating impact on their daily lives, mental health and ability to work.<sup>1</sup>

*“People just don’t realise and understand how disabling migraine is. Migraine has 100 percent destroyed my life”  
– person living with migraine*

### Impact of migraine

- 1 in 7 adults experience migraine<sup>2</sup>
- 1 in 10 children and young people experience migraine<sup>3</sup>
- More than one million people in the UK have ‘chronic migraine’, experiencing headache on at least 15 days per month, with eight of these fifteen days featuring migraine symptoms, for at least three months<sup>4</sup>
- There were over 33,000 hospital admissions for migraine in England in 2021/22, a 21% increase on the previous year and 31% in the past five years<sup>5</sup>
- 29% of migraine patients report moving from full-time to part-time employment because of their migraine and 24% had left a job due to their migraine
- Migraine costs the UK between £6bn and £10bn from ill-health and lost productivity at work<sup>6</sup>

Most people who live with migraine should be successfully supported in primary care by their GP, who can diagnose migraine and advise on medication options and lifestyle adaptations in line with British Association of the Study of Headache (BASH) guidance. Some, especially those living with severe or complex migraine, may need to be referred to a healthcare professional who specialises in migraine, such as a GP with a Special Interest in Headache, or a neurologist, often supported by a migraine specialist nurse.

Sadly, many do not get the care they care need. This report brings together information from Freedom of Information (FOI) requests to Integrated Care Systems (ICSs), Health Boards and NHS Trusts, insights from patients and interviews with GPs.

It finds that migraine remains overlooked and misunderstood, and that as a result those living with migraine are being let down by the health system.

Some struggle to be taken seriously, being dismissed as having a headache, and have ended up in A&E as a result. Hospital admissions for migraine are increasing, yet NHS England estimate that 16,500 emergency admissions for headache and migraine could be avoided with the right care pathway.



Waiting lists are long with many facing inappropriate referrals or a lack of referral. At the same time, a lack of understanding, and a limited specialist workforce in primary care mean patients are often dismissed. Patients have told us they feel as if health professionals have given up on them, aren’t interested and just don’t understand what living with migraine means.

### Key findings:

- Our Freedom of Information requests found waiting times for specialist care for migraine have increased across the UK:
  - In England, waiting times have nearly doubled from 15 weeks to 2021 to an average of 29 weeks in 2023<sup>9</sup>
  - In Wales, waiting times increased to 27 weeks up from 23 weeks in 2021<sup>10</sup>
  - In Scotland, waiting times increased to 29 weeks up from 9 weeks in 2021<sup>11</sup>
  - In Northern Ireland, some Health and Social Care Trusts reported waiting times of 13 to 20 weeks for “urgent” referrals and waits of 18 months or more “routine” cases<sup>12</sup>
- Access to new approved medications is inconsistent and hindered by rising waiting times<sup>13</sup>
- The availability of specialist doctors and nurses varies across the UK and headache cases are still handled by general neurology doctors, who are also rarer here than on the continent<sup>14,15</sup>
- There are less than 80 GPs with Special Interest (GPwSI) for headache and migraine across the UK, and GP training on migraine is patchy, regionalised and often relies on a local champion to run<sup>16</sup>
- Most ICSs and Health Boards have not yet systematically reviewed the migraine needs of their population and planned services to meet these needs<sup>17</sup>



**Waiting times for specialist care have doubled across parts of the UK in just 2 years**

We have found some positive examples of migraine care planning locally and nationally, including optimum pathways being developed in England, Scotland and Wales. However this progress is patchy and these pathways have yet to be implemented in most places.

Support for GPs through training and simple tools could help them to better support people with migraine to identify and manage their condition, and to refer them for additional treatment when it is most appropriate. This is particularly important at a time when new migraine treatments are emerging, and would enable GPs to take advantage of all options and navigate the changing migraine treatment landscape. With short consultation times and unprecedented pressures on GPs and across the NHS, better education would help GPs to support their patients and ensure that all cases can be handled appropriately in primary care, or referred on to secondary specialist care when needed.

Improving migraine care, so that patients receive the treatments and support they need wherever they live in the UK, will have a significant positive impact on hundreds of thousands of people’s wellbeing, ability to work and mental health, and can relieve pressure on the NHS by ensuring more cases of migraine are prevented or managed successfully in the community.

## Recommendations

1. **A national drive to improve migraine care:** Governments and NHS bodies in each of the four nations of the UK should each develop a focused workstream (e.g. a Task and Finish Group or Action Plan) to drive forward the implementation of best practice and training on migraine across their healthcare system. This should include:
  - a. **Ensuring optimal pathways are implemented across each country,** such as through a consistent roll-out of the Optimum Clinical Pathway for Headache and Facial Pain in England, the All-Wales Headache Toolkit and the upcoming Scottish National Headache Pathway.
  - b. **Increasing the availability of headache specialists,** e.g. GPs and nurses with a special interest who can run clinics in the community, and consultant neurologists.
  - c. **Developing and rolling out training and resources for GPs:** Training and resources for GPs should be developed and disseminated across the UK to ensure they are up to date with the latest treatments, and are able to identify and treat migraine and refer on when needed. This should be driven by national NHS bodies, in collaboration with the Royal College of GPs and The Migraine Trust.
  - d. **Ensuring all guidance for healthcare professionals are updated with information on the latest treatments,** for example, NICE Clinical Knowledge Summaries.
  - e. **Strengthen the role of pharmacy within primary care for migraine:** Building on existing pilot work in Scotland, community pharmacy should be empowered to take on a greater role in prevention, prescriptions and management for headache and migraine.
2. **ICBs and Health Boards to review the migraine needs of their populations and assess whether existing services meet those needs,** this includes workforce planning, GP training and access to specialist clinics.
3. **An audit of national migraine data:** Public health agencies across the UK should work with partners to audit the migraine data that is available and identify gaps in reporting across incidence, access to treatments and the interface with health inequalities.
4. **Public awareness campaigns and resources:** Greater awareness and education is needed to reduce stigma and strengthen support in society, the workplace, educational institutions and health services regarding headache and migraine. This should be led and coordinated by health departments in each country.



## 3. Methodology

- New FOI requests to NHS Trusts, ICSs and Health Boards (sent February 2023), asking questions about treatment, planning and training for migraine
- New research by The Migraine Trust conducted between December 2022 and February 2023 for respondents who self-declared that they were eligible for treatment with specially-designed calcitonin gene-related peptide (CGRP) medications, which asked them about their experiences accessing CGRP (446 respondents)
- A new survey by The Migraine Trust conducted in 2023 into patient experiences in primary care (500 respondents)
- Interviews undertaken with six GPs on how to help GPs to support people with migraine in the community and to refer appropriately
- A survey by The Migraine Trust conducted in 2023 into experiences of people living with migraine in the workplace (1,002 respondents).

A full list of the FOI questions is included in the Appendix.

*"No one seemed to understand or be able to help and I felt like I was going in circles. I spent about 7 years going to the doctor. I was told it was mental health related, I was too stressed, to drink more water, take a break from work, take paracetamol, lose weight, take more exercise. It got so bad that sometimes I went in crying, and even then I was told to take paracetamol, to rest more. The pain was unbearable sometimes."*

– person living with migraine

### **Antoinette has lived with migraine since she was a child:**

*"When I have a migraine I can hardly walk or keep my eyes open. I lose my speech, jumble my words, I'm vomiting. I'm usually in bed, in the dark for several days in crippling pain. Over the years it's been hard to find medical professionals who listen and understand just how debilitating a migraine is. I had a fantastic GP at one point who would turn the lights down, close the blinds, talk in a calm way. I'd sit there with frozen peas on my head and my sick bowl next to me. He knew just what I needed. Others seem to say 'we don't know how to handle it'. Everything just takes so long. Waiting lists are huge and there aren't enough doctors or hospitals with appointments or even clinics. I've been referred from hospital to hospital and seen so much different people. With migraine you have to try so many different things to try and find something that works, it means you just end up waiting and waiting."*





## 4. Migraine impact in the UK: why migraine matters

### About migraine

Migraine is a severe and painful long term health condition. A person experiencing migraine will have migraine attacks, which can be a whole-body experience. Common symptoms of an attack can include:

- head pain
- problems with sight such as seeing flashing lights
- being very sensitive to light, sounds and smells
- fatigue
- feeling sick and being sick

Migraine attacks usually last for between four hours and three days. Most people don't have any symptoms in between migraine attacks.

### How many people live with migraine?

Up to 1 in 7 people experience migraine attacks and prevalence of the condition is increasing worldwide.<sup>22</sup> In the UK, around 10 million people in the UK experience migraine attacks regularly.<sup>23</sup> This is more than the number of people living with diabetes, epilepsy and asthma combined. More than one million people have 'chronic migraine', meaning they experience headache for more than 15 days per month, with at least 8 featuring migraine symptoms.<sup>24</sup>

*"I felt my pain levels were not taken seriously... After everything I'd tried had failed and I was basically suicidal, I had to pay privately for Botox for five years before I was referred back to neurology, who then allowed me to have it on the NHS. 18 months ago my wonderful migraine nurse realised the Botox had stopped being effective and urged me to try CGRP injections. These injections have been life-saving, but I still have to be approved every six months to continue with them, which in itself is very stressful. It took nearly 20 years to get the treatment I needed"*

– person living with migraine



1 in 7 people experience migraine attacks

Around one in 10 children aged 5 to 14 years are estimated to have migraine



### Who does it affect?

Migraine affects people from all walks of life, but some groups experience a disproportionate impact from the condition.

Headache disorders, migraine especially, are more commonly reported by women than men, with 17% of women affected, compared to 8.6% of men.<sup>25</sup> Women are also twice as likely to report experiencing headache for 15 or more days per month.<sup>26</sup> This is likely the result of a combination of hormonal factors, genetic differences and potential under-reporting among men.<sup>27</sup>

Around one in 10 children aged 5 to 14 years are estimated to have migraine.<sup>28,29</sup>

### Impact on daily life and mental health

For many of these millions of people, migraine has a significant and devastating impact on all aspects of their lives. People living with migraine consistently report reduced health, wellbeing and quality of life.<sup>30</sup> Living with migraine can also have negative impacts on family members and relationships, including reducing peoples' ability to take part in housework, exercise and social activities and increasing stress on their close relationships.

*"One of the things about living with migraine is that constant anxiety that even if you haven't got one on a given day, you're anxious about getting one or putting yourself in a position where you're going to get one"*

– person living with migraine

*"It can feel embarrassing as you sometimes feel that people might think you're playing the headache card to get out of things. People don't understand that the 24 hours before and after the migraine itself are also heavily affected. You're not seen as someone with a health condition. Colleagues never see you in agony feeling sick and looking terrible, like family do"*

– person living with migraine

Many people living with migraine also experience mental ill-health. Incidence of anxiety is around four times higher in those with migraine.<sup>31</sup> Migraine can lead to anxiety, and anxiety can lead to migraine – there is a complex interplay between the two conditions.<sup>32</sup> Research by The Migraine Trust found that 78% of respondents impacted by migraine reported it affects their mental health - of these, 65% have higher levels of anxiety or more episodes of anxiety and 85% have lower moods or more episodes of low mood.<sup>33</sup>

## Stigma and lack of recognition

Despite its prevalence and impact, migraine remains poorly understood. The European Commission Directorate-General for Research and Innovations have said that by prevalence, migraine is one of the most under-funded and under-researched “high-burden” health conditions in Europe.<sup>34</sup> Stigma around the condition may also contribute to the relationship between headache frequency and migraine outcomes.<sup>35</sup>

*“I’m not sure how well understood migraines are. I’ve been open and honest about how I’m getting on, but I think assumptions are often made which are unhelpful”*

– person living with migraine

*“I’m always told ‘it’s just a headache’, ‘take some tablets and it will go’”*

– person living with migraine on their experiences at work

## Impact on workplaces and the economy

Lack of understanding of migraine from employers can have serious consequences on the ability of people living with migraine to work.<sup>36</sup> A survey by The Migraine Trust found 29% of respondents had moved from full-time to part-time work due to their migraine and 25% had left a job as a result of it (rising to a third among those with chronic migraine). 43% felt their workplace had not believed them when they had taken sick leave due to a migraine attack and 34% had felt discriminated against at work.<sup>37</sup>

In addition to the financial and mental health impact on the individual, this has a knock-on effect on the economy. The Work Foundation estimated that people living with migraine are forced to take between 28 million and 43 million days off work due to migraine each year, putting the cost to the UK economy at between £4.4 billion and £9.7 billion a year.<sup>38</sup> Another estimate commissioned by The Migraine Trust put the cost at £9bn and concluded that expanded access to treatments that reduce the frequency and intensity of migraine attacks could see gains in terms of reclaimed productivity in the economy.<sup>39</sup>

This is in spite of the fact that a small amount of support from an employer can often enable a person living with migraine to work effectively. For example:

- Disregard a reasonable amount of disability-related sickness absence to ensure that people with migraine are not put at a substantial disadvantage by any absence-management procedure
- Flexible working to help people to manage time and reduce stress
- Supporting changes to workspaces such as ensuring desks and chairs support good posture, better lighting or reducing window glare

As many as 25% had left a job due to their migraine

The cost to the UK economy at between £4.4 billion and £9.7 billion

*“I’ve had mixed results - some managers have immediately discounted me from promotions or high level tasking, others have been cheerleaders”*

– person living with migraine on their experiences at work

*“In my previous job, it wasn’t taken seriously until I started throwing up, then my boss would refuse to be in the same room as me as he ‘might catch it’”*

– person living with migraine on their experiences at work



## Impact on health systems

According to NHS England, as many as 16,500 emergency admissions for headaches and migraine attacks could be avoided with the right care pathways.<sup>40</sup> Yet we are seeing hospital admissions for migraine increasing across the UK. Headache represents over 30% of new outpatient neurology referrals and is the most common neurological reason for A&E attendance, and NHS England also estimated that the NHS spends around £150 million a year on treating migraines.<sup>41</sup>

In 2021/22, there were 33,562 admissions for migraine to NHS hospitals in England – this was a 21% increase on the previous year, and a 31% increase over five years.<sup>42</sup> A&Es in England saw 78,080 cases of migraine in 2021/22, a 32% increase on the previous year alone.<sup>43</sup>

In 2020/21 there were over 2,000 admissions to Welsh hospitals for migraine, including 957 emergency admissions, and 1,277 inpatient cases requiring overnight stay.<sup>44</sup> In Northern Ireland hospitals, there were 820 hospital admissions in where migraine was the primary diagnosis in 2021/22, a 23% increase against the previous year - this included 566 emergency cases<sup>45</sup>.

Many as 16,500 emergency admissions for headaches and migraine attacks could be avoided with the right care pathways

## 5. The challenges and solutions for migraine care

### Primary care

Migraine is an extremely common condition in primary care, with headache and migraine accounting for around 2.5 million GP appointments each year in England alone, and GPs play a key role in diagnosing people and supporting them to manage their condition.<sup>46</sup>

When asked about their experience of GP migraine care, some patients gave positive examples of empathetic, patient-centred care they had received in general practice:

*“I’m very happy with my GP’s attentive approach to diagnosing me with migraines and with the preventative treatment and advice I have been given, and continue to receive, through regular reviews”*

- person living with migraine

*“The GP was very knowledgeable on migraine, gave really good advice, very supportive and referenced how neurologists would treat it. After a recent silent migraine attack, the GP talked me through symptoms, how to help prevent, treat etc”*

- person living with migraine

However, many others were less positive. For example:

*“I wish a GP had warned me earlier about medicine overuse migraines because I think that could have prevented the current situation I’m in now where I’m on a high dose of amitriptyline”*

- person living with migraine

*“GPs do not understand migraine. To them it’s a headache and they have nothing to offer. They switch off if a patient keeps returning with the same problem. Also, patients obviously attend the GP when they are not in the middle of a bad migraine. I did once see my GP when I had a migraine and vomiting, it surprised him as to how ill I was”*

- person living with migraine

*“Poor migraine ‘care’ from my GP led to unnecessary disability and job loss”*

- person living with migraine

Delays in diagnosis, inappropriate treatment plans and problems accessing specialist care are all too common experiences:

*“It took 7 years from being referred by my GP to dental, sinus and finally headache specialists to get a diagnosis. My GP was originally treating me for neuralgia!”*

- person living with migraine



23% of patients who responded to the survey reported they needed to see a neurologist in secondary care before securing a diagnosis. This could indicate a lack of confidence and understanding of migraine by GPs and unnecessary secondary care referrals. Many also reported being referred before being supported with available treatment options in primary care:

- Almost 4 in 10 (38%) were not offered preventive treatment for their frequent migraine attacks by their GP before being referred to see a specialist
- More than a third (36%) were not advised to increase the dosage of a migraine preventive medication if it was not working
- The majority (67%) of patients were not advised about the risks of medication overuse headache by their GP

23% of patients reported they needed to see a neurologist in secondary care before securing a diagnosis.

*“[I was] referred back to a different amazing GP, who was switched on and prescribed candesartan. This has been life changing”*

- person living with migraine

*“I am a GP myself and I have felt completely abandoned by the NHS with this issue. I have had to self-diagnose and self-treat to a degree. It’s been shocking”*

- person living with migraine

### Training and resources for GPs

There is no formal compulsory ongoing training for GPs on migraine, meaning it is patchy, regionalised and often down to a local champion to run. Migraine is usually only covered briefly as part of a neurology session in initial medical training, with the focus being on identifying life-threatening ‘red flag’ headache conditions rather than on ‘green flags’ that point to migraine, or how it should then be managed. This is despite the high prevalence of migraine in the population and the number of GP consultations related to it.

In addition GPs are not made aware of new migraine medications in any consistent or formal way and instead pick up piecemeal information from newsletters, colleagues and patients.

*“There’s a massive issue with education for GPs. In medical school, neurology is a small part. Unless you have specifically chosen to do neurology you will not have any formal training”*

- GP

Guidance exists, including robust and comprehensive guidelines from the British Association for the Study of Headache (BASH) to help doctors in the diagnosis and management of common headache disorders and recommended treatments.<sup>47,48</sup> However, GPs report that awareness of the guidelines is low.<sup>49</sup> NICE clinical knowledge summaries are more often used by GPs, but are not as comprehensive as the BASH guidelines and migraine information are out of date – they need to be updated with information on recently approved treatments.<sup>50</sup>

We are currently in a time of rapid change in the availability of migraine treatments and without appropriate training and tools to help GPs, they will be ill equipped to navigate the changing migraine treatment landscape. Materials and case studies should cover:

- Making a diagnosis in headache (including misdiagnosis, for example treating for a tension headache)
- Managing migraine for women
- Medication overuse
- Green flags
- Preventive medications
- How to manage common cases of migraine



### GPs with Special Interest in Headache (GPwSIs)

There are fewer than 80 GPs with Special Interest (GPwSIs) in the UK.<sup>51</sup> Training for GPwSIs does not follow a formal structure but includes regular sessions over the course of 12 months with a consultant neurologist. Training is therefore dependent on local relationships and requires ongoing close working for a GPwSI to have access to scans and to a Multi-Disciplinary Team (MDT) of professionals who can support migraine care.

GPwSIs working with other MDT professionals can improve local integration and allows patients who need to see a headache specialist to be cared for in a community setting. This is convenient for the patient and relieves pressure on secondary services. Research shows that GPwSI services can satisfy the needs of patients with similar headache impact at costs that are lower than those for secondary care services.<sup>52</sup>



### The role of pharmacy

Community pharmacy is one of the most accessible NHS services. In England, 90% of the population live within 20 minutes walking distance of a pharmacy and their services can be accessed without the need for an appointment.<sup>53</sup>

In 2018 the Work Foundation suggested that pharmacy bodies could help more people self-manage migraine and avoid medication overuse, in turn reducing the socio-economic impact of migraine.<sup>54</sup>

Pharmacists are experts on the safe and effective use of medicines, and in the management of a variety of conditions. With training and support they can, for example, advise on the prevention of medication overuse headache<sup>55</sup>, advise on medicines management or signpost people to the appropriate service that will meet their particular needs. There will be many cases of headache or migraine that could be handled in pharmacy, thereby freeing up hospital and GP capacity for more serious conditions - this will include more severe cases of migraine itself.



**Conner lives with migraine:** "I have been on over eight different medications with none of them being specifically made for migraine. My current medications of Candesartan and Nortriptyline seem to be working well although if this fails then my next step is Botox which I don't really want to have. However, if it helps my migraine then I will try it.

When I get a migraine attack, my first warning sign is I yawn a lot and have a pain in my right jaw. This then moves on to a dull pain on the right hand side of my head, it's intense. I also get a watery eye and sometimes feel sensitive to sounds. If I can take a triptan at the first sign of my head becoming sore the migraine attack can be relieved in as little 30 minutes, however, if I leave it longer the attack can go on for a few days."

### Pilot project in NHS Grampian to train pharmacists in migraine care

A pilot led by The Migraine Trust, NHS Grampian, the Pharmacy Medicines Directorate and leading expert GPs and neurologists has seen partnerships forged with community, primary and secondary care pharmacists. This will lead to the development and delivery of training and resources on how to help people with migraine manage their symptoms and treatments more effectively.

People with migraine often require combinations of medications, may need explanation or discussion around choosing the correct treatment, or may need to change doses or medications if treatment is unsuccessful, but pharmacists generally lack specific training about migraine care. This work could provide a model for better practice across the UK. The work has included a survey of pharmacists in Grampian to identify knowledge gaps and focus groups to ascertain what kind of training would be beneficial.

The project is ongoing and, by 2023 had engaged 80 local pharmacists. A focus group of pharmacists and a patient-led focus group have been established to address training and resource needs. A key deliverable will be the development of an eLearning programme and resource page on NHS Education for Scotland's platform Turas, which will include modules and resources.<sup>56</sup>

**Megan, who lives with vestibular and chronic migraine:** "There are just so many barriers to migraine care. I've had GPs tell me just take paracetamol, others who don't seem to understand what migraine is. One time I went to A&E unable to cope with the pain, but I wasn't triaged and was sent home. At points my migraine has been so bad I've been at rock bottom. The head pain can be indescribable, but I also experience dizziness, blurred vision, disequilibrium, vomiting. My symptoms sometimes last weeks, even months. There's a huge inequity as some people can access migraine treatments like CGRPs [calcitonin gene-related peptide antibodies monoclonal antibodies drugs] and others can't. Then there's the cost of things like acupuncture, supplements. Not everyone can afford it."





## Access to specialist services

While most patients can be supported to manage their migraine in the community with the support of their GP or pharmacist, some chronic or complex patients require specialist care and access to treatments that can only be prescribed by a specialist. For these patients, GPs can refer to neurology or to a specialist headache clinic.<sup>57</sup> Clinics should be delivered in either primary or secondary care and be run by neurologists, GPs with a Special Interest in Headache, or headache nurse specialists.

In 2021, NHS England's Getting It Right First Time (GIRFT) report found there was "marked variation" in access to neurology services across areas.<sup>58</sup> In response to FOI requests by The Migraine Trust in 2023, many ICSs and Health Boards could not confirm that they have a specialist headache clinic in their area. The responses also show that waiting times for headache services are increasing, suggesting rising demand for migraine care amidst widespread health system pressures.

	England	Wales	Scotland	Northern Ireland
ICS/Health Board areas with specialist headache clinics	26 out of 42 ICSs (63%)	3 of 7 Local Health Boards (43%)	7 of 14 Health Boards (50%)	3 of 5 Health and Social Care Trusts (60%)
Average waiting time from GP referral to first appointment with a specialist (weeks) by responding NHS Trust/Health Board	28.8 (an increase from 15 weeks in 2021)	26.7 (an increase from 22.7 weeks in 2021)	29.3 (an increase from 9 weeks in 2021)	116.9 <sup>59</sup> (117 weeks in 2021)

**Table 1: clinics and waiting times in England, Scotland, Wales and Northern Ireland**  
(Source: FOI requests by The Migraine Trust in 2021 and 2023)

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. Many people with migraine are treated by a neurologist, however the UK only has 1.1 neurologists per 100,000 people, compared with 4 per 100,000 in France and Germany.<sup>60</sup>



**Abigail has lived with hemiplegic migraine since she was 16:** "Sometimes it feels like you don't get taken seriously until you're collapsing or can't handle the pain. I've tried lots of treatments, had many hospital appointments and the occasional A&E trip. As a Black woman I've also noticed doctors have a perception of my pain tolerance being higher because of my skin colour too. Sometimes I've felt gaslit by health professionals, to the point I've been questioning if I'm in as much pain as I think. I understand the NHS is under immense pressure, but I feel like I've been left to try to manage my migraine alone. We also need to fight the stigma that a migraine is a headache, sometimes I do just get a headache not a migraine, the two are completely different."

## Access to medications

There are a variety of treatments recommended for different migraine needs and more treatments have come on stream in the past three years. However, there are significant issues with patient access to these potentially life-changing approved medications.

*"My GP was reluctant to prescribe a different triptan for me due to cost implication. I was initially given sumatriptan which worked but gave side effects. So I needed to change but also to have something soluble so it would get in my system quicker. The option at the time was Maxalt melts and it took a lot of appointments before he finally gave in"*

*- person living with migraine*



Calcitonin gene-related peptide monoclonal antibodies (CGRP mAbs) medications can help reduce the frequency and severity of migraine attacks. These are the first ever drugs developed specifically for people with migraine and are administered by injection or intravenously, either monthly or every few months. A number have been approved by the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) since 2020; some for preventive use and some for acute treatment.<sup>61</sup>

Yet our FOI responses show that new CGRP medications are not available in all Trusts and Health Boards, as CGRP treatments need to be prescribed by a secondary care specialist, even where they are available people are facing increasingly long waiting lists to access appointments.

New research by The Migraine Trust among people who reported themselves to be eligible for CGRP mAb treatment (meaning they had tried three other unsuccessful preventive treatments) found that:<sup>62</sup>

- Only 52% had been offered access to CGRP mAb treatment
- Of those who had successfully obtained CGRP mAb treatment, 86% suggested the treatment had reduced the frequency of their migraine attacks; 90% said it reduced the frequency of their symptoms; and 89% said it has improved their quality of life
- Those unable to access reported being told 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 too long so clinicians were opting not to prescribe
- 77% of those who were waiting had been waiting for more than six months

*"I was told nine months ago that the migraine nurse would be in touch in a month, possibly two. I'm still waiting"*

*- patient seeking access to CGRP mAbs*

FOI requests made by The Migraine Trust show that CGRPs are still only available in some NHS Trust or Health Board areas:

	England	Wales	Scotland	Northern Ireland
Can eligible patients currently access Calcitonin Gene-Related Peptide (CGRP) medications through Health Board/Trust areas? (responding NHS Trust/Health Board)	Available in 24 Trusts in 2023 (29% of responding English NHS Trusts)	Available in 4 of 7 Local Health Boards (57%)	Available in 12 of 14 Health Boards (86%)	Available in 3 of 5 Health and Social Care Trusts (60%)

**Table 2: Access to CGRP medications in England, Scotland, Wales and Northern Ireland**  
(Source: FOI requests by The Migraine Trust in 2021 and 2023)

For more detailed data, please contact [campaigns@migrainetrust.org](mailto:campaigns@migrainetrust.org)

In 2023, the NHS began appraising a new class of CGRP medication, which are known as gepants and can be taken orally. They have been shown to be very effective and patients are less likely to report problems with medication overuse headache compared with conventional acute treatments.<sup>63,64,65</sup> In the summer of 2023, these were approved by NICE and SMC for preventive treatment (after at least three other treatments have been tried) and acute treatment (where at least two triptans have been tried but did not work well enough). These have been reported to be more effective and have fewer side effects than triptans for many patients, and it is vital they can be accessed by eligible patients going forward.

*"It has given me my life back. I can plan things more and enjoy my life. I can also look for a new job again in the new year"*

*– patient receiving CGRP mAbs*

### Local planning and leadership on migraine care

A lack of understanding and prioritisation of migraine as a health condition means many local ICSs and Health Boards are taking limited action to assess the migraine needs of their population and ensure there are services to meet those needs.

We are seeing some progress, but our research shows that many areas have not reviewed their local migraine needs and new national best practice has not yet diffused throughout the system. This results in poor patient experience with GPs who do not have the latest information on migraine treatments and long waits for specialist migraine care.

### England

There have been some promising national developments in England for migraine but these have yet to be translated into action at a local level in most places.

- In 2021, NHS England published the Getting It Right First Time (GIRFT) report to address inconsistencies in access to appropriate neurology services and put forward a variety of recommendations, including suggesting that Trusts and ICSs should establish specialist clinics for the most common neurological disorders locally at all sites; review local provision of treatments for chronic neurological conditions to ensure patients can access care as close to home as feasible; and review and audit readmission rates for headache.<sup>66</sup>
- In December 2022 NHS England appointed a National Clinical Director (NCD) for Neurology<sup>67</sup>
- In February 2023, the National Neurosciences Advisory Group (NNAG) and NHS England built on GIRFT by launching a new Optimum Clinical Pathway for UK Adults Experiencing Headache and Facial Pain<sup>68</sup>



### Principles of the Optimum Clinical Pathway for UK Adults Experiencing Headache and Facial Pain (NNAG)

1. The majority of patients with primary headache will manage their own condition
2. All patients with headache and facial pain disorders should be signposted to online support and information for self-management and work/school related issues
3. Management of primary headache disorders in general practice, and referrals for specialist assessment, should utilise the latest version of the BASH Headache Management System
4. Imaging should be utilised only where clinically indicated, and where the referrer is able to interpret the result of the scan or access appropriate advice
5. Triage should be done by a clinician experienced in the management of headache disorders
6. Specialist treatment services (Botox, CGRP mAbs) may be separate from, or embedded within, headache clinics depending on local circumstances
7. Neuromodulation and/or in-patient treatments should be delivered through regional/national services

The 42 ICSs in England now have responsibility for planning services, improving health and reducing inequalities across geographical areas. All 42 ICSs responded to FOI requests, of which twelve reported that they had recently reviewed or found opportunities for improvement in pathways and care for headache and migraine. In different areas of the country this included reviewing pathways for headache or benchmarking their current practice against the NNAG recommendations, planning to recruit more specialists, or establishing working groups, for example. However, this also means that 30 ICSs have not yet started to review or improve migraine care in their areas.

### Scotland

In Scotland, half of the country's fourteen Health Boards reported that they had undertaken work to review their headache and migraine pathways. For example, NHS Grampian reviewed referrals coming into the service over the period of one month and has had a dedicated migraine and headache lead in place since 2008. However, some Boards reported doing little in the way of headache service planning or reviews, and have cited waiting times, a lack of resource, or competing clinical commitments as reasons.

A Scottish National Headache Pathway has been under development and was cited by three Boards as part of their future plans.<sup>69</sup> This pathway has been developed to aid assessment, diagnosis and management of headache disorders and offer guidance on management. The pathway is intended to be relevant to those working across primary care including community pharmacy and general practice and those working across secondary care including emergency care, acute/general medicine and neurology. The pathway is currently being considered for sign off and it is anticipated that it will be published and implemented in Autumn 2023.

Some Scottish Health Boards are also actively looking to work with GPs to improve this aspect of patient experience or enable patient management in the community. This is a good start, but the Scottish Headache Pathway must be implemented across the country once launched and good practice emerging in some areas of the country must be replicated.

NHS Tayside has a migraine lead and reported holding an informal weekly review of new pathways/treatments for headache, including the headache specialist doctor and nurse. This led to the identification of a need for pathways to have a clear starting and stopping criteria for injectable medications, to changes in staffing, and a potential change of the area's headache phoneline to an email system for faster patient access.

Greater Glasgow and Clyde has a monthly meeting to review the area's headache services and pathway, and agree any potential modifications to the pathway. This had led to discussions about best use of medications, planning for a new low pressure headache pathway and the initiation of new clinical trials. The Board are awaiting the development of central Scottish headache pathway for further guidance.

30 ICSs have not yet started to review or improve migraine care in their areas



### Wales

In Wales, the All-Wales Headache Toolkit has recently been developed by NHS Wales in partnership with the Neurological Conditions Implementation Group and the Institute of Clinical Science and Technology. It is freely available for healthcare professionals in Wales. The toolkit was designed to break down the complex headache algorithms into simple steps, and includes pathways, tutorials and live virtual events featuring local and international experts in headache management. The success of this toolkit prompted the development of a patient self-management app to support people living with headache disorders in the community, fully aligned with the healthcare professional resources, and this is likely to be ready for launch in early 2024.<sup>70</sup>

In Wales, most Health Boards responded saying they had not reviewed services or worked to improve practice around migraine in primary care, citing a lack of local migraine services in the first instance or a lack of internal capacity for a review.

Swansea Bay University Health Board reported it had updated access to treatments following a review of its pathways, and already has a headache and migraine lead available for the service in the Board.

Cardiff and Vale University Health Board reported providing teaching sessions to local GPs on migraine, while Cwm Taf Morgannwg University Health Board noted that the Board and Health Education and Improvement Wales (HEIW) provided online modules for GPs and other health care providers that included headache and migraine.

### Northern Ireland

In Northern Ireland, although severe problems remain with waiting times, several Trusts report recent reviews have led to changes in local approaches to migraine care.

In Belfast for example, a review led to the initiation of CGRP treatment for chronic migraine patients, increased headache clinic capacity, the resumption of a helpline and the development of a Regional Headache Forum. Northern Health and Social Care Trust used Waiting List Initiative (WLI) funding from the Northern Ireland Department of Health to review the area's waiting list and set up virtual clinics to review patients referred with headache as a pilot.

South Eastern Health and Social Care Trust introduced a Neurology Active Referral Management system to provide timely appointments for the management of headache, ran a series of neurology roadshows with local GPs (including diagnosis and management of headache) and reviewed the NNAG pathway guidelines with local headache doctors, concluding that the Trust would need a specialist headache nurse to implement the guidelines properly and work with primary care.



## 6. Conclusion

Migraine is a common condition that has a severe and debilitating impact on millions of lives across the UK. Yet, despite its wide-ranging impact, it remains overlooked in major national and local health systems strategies and too many patients are dismissed and unsupported.

New medications could be transformative for many, but a lack of education and awareness amongst GPs about best practice for migraine care, and a shortage of migraine clinics and specialists, mean that many patients are not receiving the treatment and care they need. This is resulting in unnecessary A&E presentations and increasing waiting times for specialist care.

The data we have and accounts from patients using our support services show that migraine patients badly need better care, and that change is needed across the system. Through better management in primary care and the community, and with more planned provision of specialist resource in secondary for more severe cases, we can enable migraine patients to live full lives and reduce pressure on the NHS.

*"I was finally referred to a head clinic and that's where I was diagnosed with chronic migraines. It took about 9 years. I actually cried because finally someone had listened to me."*

*– a person living with migraine*



## 7. Appendix

### Freedom of Information questions to ICSs

#### Section 1: Commissioning and care planning

- 1.(a) Within the past year, have you reviewed or found opportunities for improvement in pathways and care for headache and migraine?
1. (b) (i) If yes, what did this review find?
1. (b) (ii) If no, what has prevented this so far?
1. (c) Do you have any plans to implement the findings of the optimum clinical pathway for adults for Headache & facial pain published by the National Neurosciences Advisory Group (NNAG) in February 2023?
2. (a) Have you reviewed the migraine needs of your local population (e.g. numbers of people living with migraine who are diagnosed and not yet diagnosed) and planned services to meet these needs (e.g. by offering opportunities for training in migraine management to GPs, as well as adequate access to secondary and tertiary specialists)
2. (b) If not, are there plans to do so?
3. (a) Do you plan to appoint a Migraine/Headache Lead in your area (e.g. to coordinate migraine care, share guidelines among colleagues, or lead needs assessments, service development and health care professional education across the area)?
3. (b) If not, are there alternative arrangements in place to coordinate migraine care?

#### Section 2: Specialist headache clinics

4. (a) Do you have specialist headache clinics in Trusts within your ICS area?
4. (b) (i) If yes, please give details.
4. (b) (ii) If no, please give details of the clinic(s) Trusts in your area would refer out to.

#### Section 3: Training

5. (a) Do you have any education or training programmes with GPs or pharmacists in your area on migraine? (E.g. regarding GP/pharmacy education, patient management in the community, patient information or referral pathways)
5. (b) If yes, or if any are planned, please give details.
5. (c) If no, please explain any reasons (e.g. budgets / other priorities / other organisations' responsibility).

#### Section 4: Inequalities

6. (a) Are you aware of local inequalities of access to headache specialist services amongst any groups (e.g. by gender, ethnicity, disability, socio-economic groups)?
6. (b) If yes, please give details of the inequalities and any work you are doing or planning to address this.

## Freedom of Information questions to NHS Trusts, Health Boards and HSC Trusts

### Section 1: Commissioning and care planning

1. (a) Within the past year, have you reviewed or found opportunities for improvement in pathways and care for headache and migraine?
1. (b) (i) If yes, what did this review find?
1. (b) (ii) If no, what has prevented this so far?
1. (c) Do you have any plans to implement the findings of the optimum clinical pathway for adults for Headache & facial pain published by the National Neurosciences Advisory Group (NNAG) in February 2023?
2. (a) Have you reviewed the migraine needs of your local population (e.g. numbers of people living with migraine who are diagnosed and not yet diagnosed) and planned services to meet these needs (e.g. by offering opportunities for training in migraine management to GPs, as well as adequate access to secondary and tertiary specialists)?
2. (b) If not, are there plans to do so?
3. (a) Do you plan to appoint a Migraine/Headache Lead in your area (e.g. to coordinate migraine care, share guidelines among colleagues, or lead needs assessments, service development and health care professional education across the area)? (HEALTH BOARDS AND HSC TRUSTS ONLY)
3. (b) If not, are there alternative arrangements in place to coordinate migraine care? (HEALTH BOARDS AND HSC TRUSTS ONLY)

### Section 2: Specialist headache clinics

4. (a) Do you have a specialist headache clinic in your Board/Trust area?
4. (b) (i) If yes, please give details.
4. (b) (ii) If no, please give details of the clinic you would refer out to.
5. (a) How many people did you support through your specialist headache clinics in 2021?
5. (b) How many people did you support through your specialist headache clinics in 2022?
6. What is the average waiting time from GP referral to first appointment at the specialist headache clinics in your Board/Trust area (current or for when you last had data)?
7. How many full time equivalent (FTE) headache specialist doctors are employed by your Board/Trust area (in secondary care or GPs with an extended role)?
8. How many FTE headache specialist nurses are employed by your Board/Trust area?

9. (a) Do you have plans in 2023/24 to increase headache specialist services?
9. (b) If yes, please give details.

### Section 3: Access to Calcitonin Gene-Related Peptide (CGRP) medication

10. (a) Can eligible patients currently access Calcitonin Gene-Related Peptide (CGRP) medications through your Board/Trust area?
10. (b) (i) If yes, how many people are accessing CGRP medication through your Board/Trust area?
10. (b) (ii) If yes, which of the following CGRP medications can they access: Ajoovy/fremanezumab, Emgality/galcanezumab, Vyepti/eptinezumab, or Aimovig/erenumab.
10. (b) (iii) If yes, what is the current waiting time to access a prescribing specialist?
10. (b) (iv) If yes, is the administration of CGRP treatments monitored by a headache specialist?
10. (b) (v) If yes, is the administration of CGRP treatments subject to any additional restrictions or criteria?
10. (c) If no, do you refer and fund it out of area? Please give details.

### Section 4: Training

11. (a) Do you have any education or training programmes with GPs or pharmacists in your area on migraine? (E.g. regarding GP/pharmacy education, patient management in the community, patient information or referral pathways)
11. (b) If yes, or if any are planned, please give details.
11. (c) If no, please explain any reasons (e.g. budgets / other priorities / other organisations' responsibility).

### Section 5: Inequalities

12. (a) Are you aware of local inequalities of access to headache specialist services amongst any groups (e.g. by gender, ethnicity, disability, socio-economic groups)?
12. (b) If yes, please give details of the inequalities and any work you are doing or planning to address this.

## 8. References

- <sup>1</sup> Stovner, L.J., Hagen, K., Linde, M. et al (2020) 'The global prevalence of headache: an update, with analysis of the influences of methodological factors on prevalence estimates'. *J Headache Pain* 23, 34. Available at: <https://doi.org/10.1186/s10194-022-01402-2>
- <sup>2</sup> The Migraine Trust (2021) 'The State of the Migraine Nation, Who is living with migraine in the UK? Rapid research review'. Available at: <https://migrainetrust.org/wp-content/uploads/2021/08/State-of-the-Migraine-Nation-population-rapid-review.pdf>
- <sup>3</sup> The Migraine Trust (2022) 'Dismissed for too long - The impact of migraine on children & young people'. Available at: <https://migrainetrust.org/wp-content/uploads/2022/08/Dismissed-for-too-long-The-impact-of-migraine-on-children-and-young-people-September-2022.pdf>
- <sup>4</sup> Natoli J.L., Manack A, Dean B, Butler Q, Turkel CC, Stovner L, Lipton RB (2010) 'Global prevalence of chronic migraine: a systematic review'. *Cephalalgia* 2010;30(5):599-609. Available at: <https://pubmed.ncbi.nlm.nih.gov/19614702/>
- <sup>5</sup> NHS Digital (2022) Hospital Admitted Patient Care Activity. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity#latest-statistics>
- <sup>6</sup> The Work Foundation (2018) 'Society's headache: The socioeconomic impact of migraine'. Available at: <https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/lums/work-foundation/SocietysHeadacheTheSocioeconomicImpactofmigraine.pdf>
- <sup>7</sup> NHS Digital (2022) Hospital Admitted Patient Care Activity. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity#latest-statistics>
- <sup>8</sup> NHS RightCare. (2019). 'RightCare: Headache & Migraine Toolkit optimising a headache and migraine system'. Available from: <https://www.england.nhs.uk/rightcare/wpcontent/uploads/sites/40/2020/01/rightcare-headache-andmigraine-toolkit-v1.pdf>
- <sup>9</sup> Responses to FOI requests by The Migraine Trust to NHS Trusts in 2021 and 2023
- <sup>10</sup> Responses to FOI requests by The Migraine Trust to Health Boards in 2021 and 2023
- <sup>11</sup> Ibid
- <sup>12</sup> Responses to FOI requests by The Migraine Trust to Health and Social Care Trusts in 2023
- <sup>13</sup> Responses to FOI requests by The Migraine Trust to NHS Trusts, Health Boards and Health & Social Care Trusts in 2021 and 2023
- <sup>14</sup> Responses to FOI requests by The Migraine Trust to NHS Trusts, Health Boards and Health & Social Care Trusts in 2021 and 2023
- <sup>15</sup> Nitkunan, A., Lawrence, J. and Reilly, M. (2020) 'Neurology Workforce Survey conducted by the Association of British Neurologists 2018-2019'. Available from: <https://acnr.co.uk/articles/neurology-workforce/#:~:text=Abstract,and%2035%25%20of%20trainees%20responded>
- <sup>16</sup> Interviews with GPs Dr David Kernick, Exeter; Dr Kay Kennis, Bradford; Dr Louise Rust, Northern Ireland; Dr Richard Wood, Oxford; and Dr David Watson, Scotland
- <sup>17</sup> Responses to FOI requests by The Migraine Trust to NHS Trusts, Health Boards and Health & Social Care Trusts in 2023
- <sup>18</sup> National Neurosciences Advisory Group (2023). 'Optimal clinical pathway for adults with headache and facial pain'. Available at: <https://www.nnag.org.uk/optimal-clinical-pathway-for-adults-with-headache-facial-pain>
- <sup>19</sup> NHS Wales Neurological Conditions Implementation Group (2023). All Wales Headache Toolkit. Available at: <https://allwales.icst.org.uk/programmes/all-wales-headache-toolkit/>
- <sup>20</sup> The Scottish National Headache Pathway (part of Scottish Government Modernising Patient Pathways initiative) was in development at the time of writing. See: <https://www.headacheacademy.com/speakers/>
- <sup>21</sup> A planned National Audit of the National Neurosciences Advisory Group (NNAG) Headache Pathway - led by The Migraine Trust, The Walton Centre, NHS England and King's College London - may also explore what data is being collected across different systems, present gaps and opportunities for improvement.
- <sup>22</sup> Stovner, L.J., Hagen, K., Linde, M. et al (2020) 'The global prevalence of headache: an update, with analysis of the influences of methodological factors on prevalence estimates'. *J Headache Pain* 23, 34. <https://doi.org/10.1186/s10194-022-01402-2>
- <sup>23</sup> NHS England (2020) 'Improved NHS migraine care to save thousands of hospital stays', 1 January 2020. Available from: <https://www.england.nhs.uk/2020/01/improved-nhs-migraine-care/>
- <sup>24</sup> Natoli J.L., Manack A, Dean B, Butler Q, Turkel CC, Stovner L, Lipton RB (2010) 'Global prevalence of chronic migraine: a systematic review'. *Cephalalgia* 2010;30(5):599-609. Available at: <https://pubmed.ncbi.nlm.nih.gov/19614702/>
- <sup>25</sup> European Migraine and Headache Alliance. (2021). 'Migraine in the EU: Bringing women out of the shadows.' Available from: <https://www.emhalliance.org/wp-content/uploads/Women-M-Policy-Paper-FINAL23MARCH.pdf>
- <sup>26</sup> Stovner, L.J., Hagen, K., Linde, M. et al (2020) 'The global prevalence of headache: an update, with analysis of the influences of methodological factors on prevalence estimates'. *J Headache Pain* 23, 34. <https://doi.org/10.1186/s10194-022-01402-2>
- <sup>27</sup> European Migraine and Headache Alliance. (2021). 'Migraine in the EU: Bringing women out of the shadows'. Available from: <https://www.emhalliance.org/wp-content/uploads/Women-M-Policy-Paper-FINAL23MARCH.pdf>
- <sup>28</sup> Barnes, N (2020) 'Migraine headache in children', *British Medical Journal (BMJ) Best Practice*. Available at: <https://bestpractice.bmj.com/topics/en-gb/678>
- <sup>29</sup> The Migraine Trust (2022) 'Dismissed for too long - The impact of migraine on children & young people'. Available at: <https://migrainetrust.org/wp-content/uploads/2022/08/Dismissed-for-too-long-The-impact-of-migraine-on-children-and-young-people-September-2022.pdf>
- <sup>30</sup> The Migraine Trust. (2020). 'What is the impact of migraine in the UK? Rapid research review'. Available from: <https://migrainetrust.org/wp-content/uploads/2021/08/State-of-the-Migraine-Nation-impact-rapid-review.pdf>
- <sup>31</sup> Karimi, L et al (2021) 'The Migraine-Anxiety Comorbidity Among Migraineurs: A Systematic Review', *11, Sec. Headache and Neurogenic Pain*. Available at: <https://www.frontiersin.org/articles/10.3389/fneur.2020.613372/full>
- <sup>32</sup> Migraine Trust. (2020). 'Who is living with migraine in the UK? Population rapid research review'. Available from: <https://migrainetrust.org/wp-content/uploads/2021/08/State-of-the-Migraine-Nation-population-rapid-review.pdf>
- <sup>33</sup> Bionical Solutions, Lundbeck Ltd. & The Migraine Trust (2022) Migraine Patient Journey Market Research. Total survey respondents, excluding screen-outs and data clean, n = 381 included in the analysis.
- <sup>34</sup> Van Tuyt, L et al (2023) 'Scoping study on evidence to tackle high-burden under-researched medical conditions'. Directorate-General for Research and Innovation (European Commission), January 2023. Available at: <https://op.europa.eu/en/publication-detail/-/publication/eaec32303-96e3-11ed-b508-01aa75ed71a1>
- <sup>35</sup> Seng, E.K. et al (2022) 'The unique role of stigma in migraine-related disability and quality of life'. *Headache*. 2022; 62: 1354-1364. Available at: <https://headachejournal.onlinelibrary.wiley.com/doi/epdf/10.1111/head.14401>
- <sup>36</sup> The Migraine Trust (2022) 'Migraine in the workplace'. Available at: <https://migrainetrust.org/wp-content/uploads/2022/05/Migraine-in-the-workplace-toolkit-1.pdf>
- <sup>37</sup> The Migraine Trust (2023) survey of 1,002 people which ran from February to March 2023 on social media
- <sup>38</sup> Office of National Statistics (2023) 'Sickness absence in the UK labour market'. Available at: <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/sicknessabsenceinthelabourmarket>
- <sup>39</sup> External consultancy, for The Migraine Trust (2022) 'Clinical and economic burden of Migraine Economic impact of Migraine - 18th May 2022'. Available at: <https://drv.ms/p/s1An4ubcuNQODXg69CObZRa3nCRUPYsw?e=AduRqk>
- <sup>40</sup> NHS RightCare. (2019). 'RightCare: Headache & Migraine Toolkit optimising a headache and migraine system'. Available from: <https://www.england.nhs.uk/rightcare/wpcontent/uploads/sites/40/2020/01/rightcare-headache-andmigraine-toolkit-v1.pdf>
- <sup>41</sup> National Neurosciences Advisory Group (2023). 'Optimal clinical pathway for adults with headache and facial pain'. Available at: <https://www.nnag.org.uk/optimal-clinical-pathway-for-adults-with-headache-facial-pain>
- <sup>42</sup> NHS England (2020) 'Improved NHS migraine care to save thousands of hospital stays', 1 January 2020. Available at: <https://www.england.nhs.uk/2020/01/improved-nhs-migraine-care/>
- <sup>43</sup> NHS Digital (2022) Hospital Admitted Patient Care Activity. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity#latest-statistics>
- <sup>44</sup> NHS Digital (2022) Hospital Accident & Emergency Activity 2021-22. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-accident-emergency-activity/2021-22>
- <sup>45</sup> Digital Health and Care Wales (2022) Patient Episode Database for Wales. Available at: <https://dhcw.nhs.wales/information-services/health-intelligence/pedw-data-online/>
- <sup>46</sup> Department of Health (2022). 'Acute episode based activity downloadable data 2021/22'. Available at: <https://www.health-ni.gov.uk/publications/acute-episode-based-activity-downloadable-data-202122>
- <sup>47</sup> NHS England (2020). 'Improved NHS migraine care to save thousands of hospital stays', 1 January 2020. Available at: <https://www.england.nhs.uk/2020/01/improved-nhs-migraine-care/>
- <sup>48</sup> British Association for the Study of Headache (2022) Guidelines. Available at: <https://www.bash.org.uk/guidelines/>
- <sup>49</sup> British Association for the Study of Headache, Guidelines - For Clinicians. Available at: <https://bash.org.uk/for-clinicians/>
- <sup>50</sup> Interviews with GPs with a specialist interest in headache'
- <sup>51</sup> National Institute for Health and Care Excellence (2022). 'Migraine'. Available at: <https://cks.nice.org.uk/topics/migraine/>
- <sup>52</sup> Todd, A. et al (2014). 'The positive pharmacy care law: An area-level analysis of the relationship between community pharmacy distribution, urbanity and social deprivation in England.' *BMJ Open*, 4(8). Available at: <https://pubmed.ncbi.nlm.nih.gov/25116456/>
- <sup>53</sup> The Work Foundation (2018) 'Society's headache: The socioeconomic impact of migraine'. Available at: <https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/lums/work-foundation/SocietysHeadacheTheSocioeconomicImpactofmigraine.pdf>
- <sup>54</sup> Hedenuud, T. et al (2014). 'Medication overuse headache: Self-perceived and actual knowledge among pharmacy staff. *Headache*', 54(6), 1019-1025. Available at: <https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/lums/work-foundation/SocietysHeadacheTheSocioeconomicImpactofmigraine.pdf>
- <sup>55</sup> The Migraine Trust for NHS Scotland (2023) 'Status report - Partnering with pharmacists to improve migraine management'.
- <sup>56</sup> NICE guidance recommends admission or referral beyond primary care when: a serious cause of headache is suspected; The person is in severe, uncontrolled status migrainosus (migraine lasting for more than 72 hours); a complication of migraine has developed; atypical symptoms are present; the diagnosis is uncertain; optimal treatment in primary care has failed; or when preventative treatment is being considered in children or pregnant or breastfeeding women <https://cks.nice.org.uk/topics/migraine/>
- <sup>57</sup> NHS England (2021) 'GIRFT national report aims to improve access to both inpatient and outpatient neurology services'. Available at: <https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/11/Neurology-overview.pdf>
- <sup>58</sup> South Eastern Trust reported maximum waits of 13 weeks, but elsewhere the Belfast and Southern Trusts have reported waiting times of 13-20 weeks for "urgent" referrals and waits of 18 months or more "routine" cases
- <sup>59</sup> Since March 2020, certain CGRP mAb treatments have been approved for use in England by NICE. Erenumab and galcanezumab have been approved for both chronic and episodic migraine, while fremanezumab has been approved for just chronic migraine. In Scotland, the Scottish Medicines Consortium (SMC) recently allowed the use of galcanezumab, following permission of erenumab and fremanezumab in 2019. A fourth CGRP mAb drug, eptinezumab, was approved by NICE and the SMC for preventive use in early 2023. Available at: <https://www.nice.org.uk/guidance/TA871> <https://www.scottishmedicines.org.uk/medicines-advice/eptinezumab-vyepti-abb-smc2547/>
- <sup>60</sup> Conducted between December 2022 and February 2023, the survey drew 500 respondents, of whom 446 respondents believed themselves to be eligible for CGRP mAb treatment (meaning they were told the definition that they needed to have tried three other unsuccessful preventive treatments).
- <sup>61</sup> Such as triptans, non-steroidal anti-inflammatory drugs (NSAIDs), and other painkillers
- <sup>62</sup> Moreno-Ajona D, Villar-Martinez MD, Goadsby PJ. (2022) 'New Generation Gepants: Migraine Acute and Preventive Medications'. *J Clin Med*. 2022 Mar 16;11(6):1656. doi: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8953732/>
- <sup>63</sup> The Migraine Trust (2023) 'We welcome the decision by SMC to approve migraine medication Rimegepant for use in NHS Scotland'. Available at: <https://migrainetrust.org/news/we-welcome-the-decision-by-smc-to-approve-migraine-medication-rimegepant-for-use-in-nhs-scotland/>
- <sup>64</sup> NHS England (2021) 'GIRFT national report aims to improve access to both inpatient and outpatient neurology services'. Available at: <https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/11/Neurology-overview.pdf>
- <sup>65</sup> Brain Tumour Research (2022) 'NHS England confirm new clinical leadership for neuroscience'. Available at: <https://www.braintumourresearch.org/media/news/news-item/2022/12/02/nhs-england-confirm-new-clinical-leadership-for-neuroscience#:~:text=Dr%20Niranjan%20Nirmalanon%20Consultant%20Neurologist,East%20Suffolk%20%26%20North%20Essex%20NHS>
- <sup>66</sup> National Neurosciences Advisory Group (2023). 'Optimal clinical pathway for adults with headache and facial pain'. Available at: <https://www.nnag.org.uk/optimal-clinical-pathway-for-adults-with-headache-facial-pain>
- <sup>67</sup> FOI response from NHS Grampian, May 2023
- <sup>68</sup> NHS Wales Neurological Conditions Implementation Group (2023). All Wales Headache Toolkit. Available at: <https://allwales.icst.org.uk/programmes/all-wales-headache-toolkit/>





## About The Migraine Trust

The Migraine Trust is dedicated to helping people affected by migraine. We are the only UK migraine charity providing information and support, campaigning for awareness and change, and funding and promoting research.

Visit our website to subscribe to email updates and news, access migraine information and to learn more about The Migraine Trust including our support services, research and events.

 [migrainetrust.org](https://migrainetrust.org)

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