

## **The Migraine Trust – NHS 10-year Health Plan submission**

### **Q1. What does your organisation want to see included in the 10-Year Health Plan and why?**

The Migraine Trust would like to see the 10-Year Health Plan set out an approach to addressing migraine as a neurological, women's health, mental health and access to work issue. We welcome the launch of the UK Neuro Forum and look forward to further detail about its membership and resourcing. We recommend a focused workstream led by the Department of Health and Social Care to drive forward access to headache and migraine specialists and medications, the routine adoption of proven pathways, and a strengthening of care in the community, where the majority of migraine cases can be managed.

Migraine is a serious neurological condition which can have debilitating effects such as pain, nausea and visual disturbances. A person experiencing migraine will have migraine attacks, which can be a whole-body experience. Almost 10 million people in the UK are affected by migraine, around 1 in 7 of the population. Moreover, one million people in the UK will live with 'chronic migraine', meaning they experience headache on at least 15 days per month (with eight of these days featuring migraine symptoms) for at least three months. Migraine affects people from all walks of life, but some groups experience a disproportionate impact from the condition. Headache disorders, and migraine especially, are more commonly reported by women than men, with 17% of women affected, compared to 8.6% of men, but the 2022 Women's Health Strategy for England does not refer directly to migraine.

For many of these people, migraine has a significant and devastating impact on all aspects of their lives. Migraine limits daily activity and their ability to work and socialise, and it negatively impacts mental health - it has been associated with depression, anxiety, feelings of hopelessness, and difficulty sleeping. Research by The Migraine Trust found 78% of respondents living with migraine said it impacts their mental health and 65% reported experiencing anxiety as a result of it. At work, the Work Foundation estimated that migraine leads to up to 43 million lost workdays annually, and a survey by The Migraine Trust found many accounts of people living with it shifting to part-time work or leaving a job entirely. In 2023/24 headache and migraine accounted for 638,528 staff absences among the NHS workforce in England, around 2.5% of the total, though this may not account for presenteeism – The Migraine Trust receives many helpline calls from NHS workers who are personally impacted.

Migraine is the most common neurological reason for consulting a GP, accounting for 2.5 million appointments and 4.4% of all consultations in primary care every year. In line with the NHS England-backed optimal clinical pathway for adults with headache and facial pain developed by the National Neurosciences Advisory Group (NNAG) in 2023, 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. Those 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.

However, there is significant regional variation in the availability of NHS services for people with migraine. A 2023 Freedom of Information investigation by The Migraine Trust found that among responding NHS Trusts in England, average waiting times for seeing a migraine specialist nearly doubled from an average of 15 weeks in 2021 to 29 weeks in 2023. 38% of Integrated Care Boards could not confirm that they have a specialist headache clinic in their area, and only 29% of responding NHS Trusts confirmed that patients could access NICE-approved Calcitonin Gene-Related Peptide (CGRP) medications. The 2021 Getting It Right First Time (GIRFT) Neurology Programme National

Specialty Report also identified considerable inequity in patient access to dedicated/specialist neurological services.

This is in part due to workforce challenges. There are fewer than 80 GPs with Extended Role (GPwER) for headache and migraine across the country and GP training on migraine is patchy, regionalised and often relies on a local champion to run. The UK also has only 1.1 Full-Time Equivalent neurologists per 100,000 population, against 4 per 100,000 in France and Germany.

Long waiting lists and challenges in accessing care leads to mismanagement of migraine, which causes problems for the healthcare system as well as for the individual affected. NHS England data has previously estimated that as many as 16,500 emergency admissions for headaches and migraine attacks could be avoided with the right care pathways, but unnecessary hospital admissions for migraine have been increasing across the UK. Headache represents over 30% of new outpatient neurology referrals and is the most common neurological reason for A&E attendance. NHS England also estimated that the NHS spends around £150 million a year on treating migraine. 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. A&Es in England saw 78,080 cases of migraine in 2021/22, a 32% increase on the previous year alone.

**Fiona, who lives with chronic migraine with brainstem aura:** “My migraine attacks come out of the blue, sometimes they last 3-5 days but often I am unwell for weeks or months at a time. Migraine has made me suicidal on three occasions. One time I remember sitting in my car knowing if I got out, I wouldn’t be safe. There’s the pain, losing my job, dealing with the grief of losing the ‘well you’. I’ve been made to feel like a hypochondriac so many times. If I had had appropriate support, I think I would have cost the NHS and society less in terms of mental health fallout. If someone early on had told me ‘I believe you’, or ‘it’s not your fault’ I really think I could have averted my mental health crisis.”

The Migraine Trust would therefore like to see:

- Recognition of migraine as a serious, complex, long-term health condition in the context of wider planning for neurological services, mental health, women’s health and access to work.
- Investment in the health workforce to ensure there are enough clinical professionals with appropriate resources, including GPwERs, nurses with a special interest, and consultant neurologists. This includes delivering on the GIRFT report recommendation to review the organisation and roles of neurologists and neurology trainees to better meet patient needs and maximise training quality.
- Support for GPs through education and the availability of tools to ensure they feel confident supporting people with migraine to identify and manage their condition, and to refer them for additional treatment when it is most appropriate.
- A greater role for pharmacy within primary care for migraine, with efforts to ensure pharmacists are confident in the handling of migraine and that patients see it as an option.
- The establishment of more community-based migraine clinics as part of a shift away from secondary care.
- Consistent and equal access to life-changing calcitonin gene-related peptide (CGRP) medications for eligible individuals and an update to the NICE CG150 guidelines to reflect this new development.

- Guidance to ensure the NNAG Optimum Clinical Pathway for UK Adults Experiencing Headache and Facial Pain is properly implemented by Integrated Care Boards and used by relevant clinicians.

## **Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?**

We welcome the current drive to move healthcare out of hospitals and into the community and stated focus on a “Neighbourhood Health Service” approach. With improved training for GPs and pharmacists on migraine, and more community-based migraine specialists such as GPs with Extended Role, many migraine cases could move out of secondary care.

### **Challenges:**

- **Understanding of migraine and lack of specialisation:** A survey by The Migraine Trust found 39% of respondents had seen a doctor at least 3 times and 24% 6-10+ times before their migraine was diagnosed. Additionally, patients report feeling it is up to them to manage their migraine (66% said this was “always” the case and 23% said “often”). At all levels of the health system, patients living with migraine frequently report being met with a lack of understanding or feeling dismissed. Migraine Trust survey data on patient experiences in primary care also found that 38% of respondents reported not being offered preventive treatment for frequent migraine attacks by their GP before being referred to see a specialist, suggesting optimal pathways are not being followed. 36% said they were not advised to increase the dosage of a preventive medication if it was not working, and 67% of were not advised about the risks of medication overuse headache.
- **GP education and training:** Migraine is usually only covered briefly as part of a neurology session in initial medical training and there is no formal compulsory ongoing training on migraine. GPs will not currently be made aware of new migraine medications in any consistent or formal way.
- **Lack of recognition of the potential for pharmacists:** There is an opportunity for better provision for migraine in community pharmacy, but a current gap in recognition of this and challenges in terms of funding, capacity and public awareness. At the outset of a Scottish Government funded project between The Migraine Trust and NHS Grampian, it was found that only 14% of migraine patients had considered seeking support from pharmacy and a considerable number had never spoken to a pharmacist about their condition, though 77% would consider it, especially if they felt pharmacists had the right expertise.

### **Enablers:**

- **Community clinics:** The NNAG optimal clinical pathway for adults with headache and facial pain noted the potential for community headache clinics, which can be run by neurologists, GPs with specialist interest in headache or other allied health professionals and allow a patient to be seen closer to home. In Oxfordshire under the local Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders, a headache consultant can offer a referral to a community headache clinic as one of three alternatives to a hospital appointment, for example.
- **Wider pharmacy role:** Many migraine patients remain undiagnosed and rely on over-the-counter medicines, meaning that many pass through the doors of community pharmacies for

treatment on a regular basis. In light of this, community pharmacies, particularly through programmes like the Pharmacy First initiative, are increasing their role in the provision of basic care. The Migraine Trust's project with NHS Grampian, which is now in 50% of all Scottish Health Boards, has successfully increased patient and clinician confidence around migraine management in pharmacy. This includes through self-study resources, live training and a public awareness campaign. A 75% increase in confidence was reported among pharmacists with regard to assessing if people presenting to pharmacy have migraine, along with a 62% increase in confidence supplying medication to people living with migraine. A similar project in England to build capacity and confidence among pharmacists should be considered.

- **Independent prescriber status:** From 2026, all MPharm graduates are set to become independent prescribers upon graduation, which will empower them to support patients to a more cost-effective healthcare system. The need for pharmacists to become independent prescribers by 2026 was a driver of willingness and interest among pharmacists in the NHS Grampian project.
- **The New Medicine Service:** Since 2011, the New Medicine Service (NMS) has meant pharmacists can successfully intervene when a medicine is newly prescribed, with repeated follow up in the short term, to increase effective-medicine taking for the treatment of a long-term condition. Migraine is not currently listed as a condition under the NMS, but under the previous Community Pharmacy Contractual Framework a commitment was made to discuss and agree any expansion of the New Medicine Service to other therapeutic areas and migraine could be given consideration for inclusion.
- **Prescribing powers in primary care:** There is a case for the Medicines and Healthcare products Regulatory Agency (MHRA) to explore the issue of prescribing rights for CGRP medications in primary care, which would ease patient access to them. Rimegepant is classed as 'green' in the NHS formulary so in some areas GPs can already prescribe it, and this could be built on.

### **Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?**

#### **Challenges:**

- **Record-sharing and relations between general practice and pharmacy:** Systems for pharmacists to access patient records have been in development since 2014 and it was initially hoped that pharmacies would have access to and be able to update GP records via GP Connect for the new Pharmacy First service. However, it was reported GP Connect functionality was available to pharmacists when the service was first launched in January and there have been concerns among some general practice representative bodies about allowing pharmacists to directly update records, for example.

#### **Enablers:**

- **Technology can also play a role in improving care:** E-referral systems can streamline links between primary and secondary care. In Northern Ireland, a telementoring initiative called Project ECHO has aimed to improve patient consultations and physician confidence in managing complex disorders.
- **NHS led headache diary or app:** This could support building a picture of an individual's symptoms, triggers and any patterns and keeping track of medicines. It could also support identifying where additional support, including for mental health, may be necessary. There is

also the potential for data to contribute to research around headache and migraine more widely, subject to patient consent.

#### **Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?**

##### **Challenges:**

- **Lack of recognition of the costs of inaction:** Patients supported by The Migraine Trust have at times suggested that migraine is not taken seriously because it is not a life-threatening condition. Migraine cases can sometimes progress from episodic to chronic due to delayed diagnosis and inadequate treatment, so earlier intervention is beneficial. As well as the human cost of this, there are also cost implications in terms of the significant public expenditure incurred by a lack of rapid diagnosis or referral to effective and proven treatments.
- **Inequitable access to treatments and services:** In addition to the services mentioned above, this includes access to mental health services. Our 2024 research found half of migraine patients say their mental health has been significantly affected as a result of living with migraine and sadly a third have had thoughts of suicide. 43% of respondents said not having a treatment that works is one of the things affecting their mental health the most. Unequal access to treatments and NHS waiting times were also raised. Over a third (38%) said that feeling like they are not being taken seriously by health professionals has a negative impact on their wellbeing

**Sarah, who lives with chronic vestibular migraine:** “When I mentioned that the [migraine] symptoms I was living with were causing me to experience depression, I was told not to think about it so much. I would leave appointments in tears, and it would take me days to get over them. I sometimes felt I was going mad. I was so depressed, and I began binge-eating as well. I gave up asking for help and felt that I couldn’t face going back to the GP ever again.”

##### **Enablers:**

- **Education and training regarding migraine management and diagnosis:** Education and training for clinicians, developed with key clinician bodies, would build confidence in terms of effective diagnosis, management and awareness of different treatments for migraine.
- **Employers encouraged to provide better support for employees with migraine:** This includes the NHS as an employer.

**Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example: • Quick to do, that is in the next year or so • In the middle, that is in the next 2 to 5 years • Long term change, that will take more than 5 years**

##### **Quick to do, that is in the next year or so**

- Updated NICE guidance (CG150) on migraine, including the inclusion of CGRPs.
- Initial work with relevant clinical and voluntary sector bodies to ensure GPs receive early education and appropriate tools to give them greater confidence in supporting patients with migraine, and exploration.

- Initial work with relevant clinical and voluntary sector bodies on events, pathways, tools, awareness campaigns and outcomes frameworks to strengthen migraine in community pharmacy, particularly before pharmacists become independent prescribers in 2026.

#### **In the middle, that is in the next 2 to 5 years**

- An Action Plan or Task and Finish group to ensure optimal pathways are being properly implemented by Integrated Care Boards and used by relevant clinicians.
- Commit to recommendation 20 in the 2021 GIRFT report, by reviewing the organisation and roles of neurologists and neurology trainees to better meet patient needs and maximise training quality.
- Exploration of the inclusion of migraine in the New Medicine Service and Pharmacy First.
- The extension of prescribing powers in primary care for CGRPs.
- Establishing more community headache clinics.
- Address commissioning barriers that are impacting upon access to relevant preventative services for people affected by neurological conditions, including mental health support and community neurorehabilitation services
- Start working with GP professional bodies to recruit and train more GPwERs in headache, to support specialist community care.

#### **Long term change, that will take more than 5 years**

- A long-term workforce plan to include shortages in the neurology workforce and provide additional support to deliver on the 62,000 extra neurology appointments per year as suggested by the Secretary of State for Health and Social Care ahead of the general election.
- A focus on community care, with more people with migraine able to access treatment and management support within primary care, reducing the number needing to access secondary care and providing more timely care.