

# People with migraine deserve better

A toolkit to help you support your constituents and staff who live with migraine

## This toolkit will provide you with:

1. What you need to know about migraine
2. Information on how to support constituents living with migraine and struggling to secure adequate care
3. Information on how to promote migraine-friendly work
4. Suggestions about how to raise awareness and show your support for all those living with migraine

The Migraine Trust is dedicated to helping people impacted by migraine, an often-misunderstood and potentially debilitating condition affecting one in seven people. We are the only UK migraine charity providing information and support, campaigning for awareness and change, and funding and promoting research. This toolkit is designed to empower parliamentarians to support constituents living with migraine and push for a transformation in migraine care.

## 1. What you need to know about migraine

### What is migraine?

Migraine is much more than a headache. Migraine is a severe and painful long-term brain condition. If someone has migraine they will have migraine attacks, which can be a whole-body experience.

Common symptoms of an attack include head pain; visual disturbances like flashing light; heightened sensitivity to light, sound, and smell; fatigue, and nausea or vomiting. However, different people get different symptoms. When someone has a migraine attack, they may not be able to function normally. Migraine attacks usually last between four hours and three days. Most people don't have any symptoms in between migraine attacks. Some people experience chronic migraine, when they have headaches on 15 or more days of the month, and migraine symptoms on at least 8 of these.



### Who gets migraine?

- One in seven people get migraine – about 10 million in the UK.
- Migraine is one of the most common health conditions and causes of disability in the world.
- 10% of school age children in the UK are affected.<sup>i</sup>
- People can be affected by migraine at any age.
- Migraine is more common in women than in men – lifetime prevalence has been reported as 33% in women and 13% in men. This is likely a result of hormonal factors, genetic differences and potential under-reporting among men.

One in seven people in the UK live with migraine. That's around 14,500 people in every constituency.<sup>ii</sup>

## What impact does it have?

- 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 upwards of £2.8 billion, or as much as £9.7 billion a year if 'presenteeism' is accounted for.<sup>iii</sup>
- Migraine accounts for 16,500 emergency healthcare admissions for headaches and migraine attacks every year and is the most common neurological reason for consulting a GP, accounting for 2.5 million appointments or around 4.4% of all consultations in primary care every year.<sup>iv</sup>
- People living with migraine commonly have other long-term mental and physical health conditions, meaning that they may have an even greater burden of ill health to cope with.
- For many people, the severity and frequency of their migraine attacks impacts their ability to work, socialise and care for dependents, and has a serious impact on their mental health.
- A survey by The Migraine Trust found 90% of respondents with migraine believe it is just seen as "a bad headache", when in fact 89% reported it harms their mental health and 49% say it has a negative impact on their ability to work.<sup>v</sup>



## How can migraine be treated?

Migraine treatment includes both acute options to manage attacks and preventative options if they become very frequent. Most people can be supported in primary care, with GPs and pharmacists guiding the use of painkillers, anti-sickness medication, specially-designed triptans and tools such as headache diaries, but people experiencing more than four attacks a month or major disruption to their lives may seek preventative medications or a referral to a headache or neurology specialist.

Newer calcitonin gene-related peptide (CGRP) treatments specifically designed for migraine, including CGRP monoclonal antibodies (CGRP mAbs) and gepants, can only be prescribed to prevent migraine when three other preventive treatments, at the maximum tolerated doses, have failed. Several of these drugs are now available on the NHS, having been approved by the National Institute for Health and Care Excellence (NICE) in England and Wales, the Scottish Medicines Consortium (SMC), and by the Northern Ireland Department of Health in line with NICE guidance. However, CGRP mAbs and gepants for preventing migraine can currently only be prescribed by a headache specialist or neurologist, following referral from a GP, which can involve long waiting times.

## 2. How to support constituents living with migraine and struggling to secure adequate care

With one in seven living with the condition, you may be contacted by constituents who are concerned about the care they are receiving for migraine, and in particular if they are having problems accessing treatments that they are eligible for.

We hear from many people across the UK who are eligible for approved CGRP treatments but are having problems accessing them. In England, this is despite confirmation that NHS England is legally required to fund medicines recommended in a NICE technology appraisal, including CGRP treatments, and the NHS Constitution stating that patients have the right to drugs and treatments recommended by NICE for use in the NHS, if their doctor believes they are clinically appropriate.<sup>vi</sup> We also hear from people who are waiting many months to see a specialist, and research we have conducted via Freedom of Information requests has highlighted patchy access across the UK.<sup>vii</sup>

### Casework

If constituents contact your office or present at your surgeries about difficulties navigating their local health system and securing the diagnosis and treatment they need, you could write to the local health system to investigate their case.

You can also refer constituents to The Migraine Trust's Freephone Helpline at 0808 802 0066. The helpline is open 10am–4pm, Monday to Friday and we also offer support online and via email.<sup>viii</sup>

### Encourage local health leaders to review and plan services to meet needs

You can write to your local NHS Trust or Integrated Care Board (in England), Health Board or Health and Social Care Trust to ask them how they ensure that they are working to assess and meet migraine needs within the area. This should include using the Optimum Clinical Pathway for Headache and Facial Pain (in England), the All-Wales Headache Toolkit or the Scottish National Headache Pathway to review and find opportunities for improvement in pathways and care.

If you would like a template letter from The Migraine Trust to do this, please email [campaigns@migrainetrust.org](mailto:campaigns@migrainetrust.org). You could also convene a roundtable with local health officials and people affected by migraine to discuss migraine care and support in your area.

### 3. How to promote migraine-friendly work

*"I think it's really important that other employers consider this. If you've got a great employee and you want to keep them employed, if you want to help them to do a good job, then it's really important to build in some flexibility if you can."*

**Rachel Casey, Director of Strategy at The Dogs Trust on why it makes sense for employers to take migraine seriously.**

Migraine is most common among adults of working age and it can impact working life. Migraine/chronic headache was found to be the second-most frequently identified cause of short-term absence for non-manual employees in a survey by the Confederation of British Industry.<sup>ix</sup> A survey by The Migraine Trust found some respondents with migraine reported shifting to part-time work (29%) or leaving a job entirely (25%) because of their migraine, and that 56% of respondents living with migraine said that their workplace had not made reasonable adjustments.<sup>x</sup>

*"I know the impact migraines have on my ability to work, and know how crucial it is that employers make adjustments to allow us all to keep working."*

**Caroline Nokes MP**

However, this impact can be significantly reduced if people with migraine are supported at work. People with migraine often need very little help from their employer, but this small amount of support can be decisive in enabling them to work effectively with migraine. By contrast, not receiving support from their employer or feeling stigmatised in the workplace can have very serious consequences for people with migraine. **If constituents are facing issues with their employer due to their migraine, you can recommend our ['Help at Work Toolkit'](#) for information and advice.**

The Migraine Trust has also launched a [Workplace Pledge](#), encouraging employers to make small, often low-cost adjustments that can make a huge difference for staff with migraine. This comes with resources on how employers can make low-cost adjustments. **You can support it by highlighting the pledge to employers in your constituency – contact [campaigns@migrainetrust.org](mailto:campaigns@migrainetrust.org) to pledge your support and access social media assets.**

Along with constituents, migraine may well affect members of your own staff. It will almost certainly affect colleagues of yours in the chamber, and The Migraine Trust has worked with parliamentarians who have told us how it has impacted them. As in so many other areas of public life, elected representatives have the opportunity to be standard-bearers in society for how we can best support those affected by migraine.

Steps you could take include:

- Ensuring your staff feel they can tell you, and keep you updated with how their condition develops – this can be a daunting thing for them to do initially, especially since there is so much misunderstanding and stigma surrounding the condition.
- Making reasonable adjustments for staff with migraine following discussions with them – e.g. reviewing common environmental triggers in the workplace, finding a quiet room staff can go to if experiencing symptoms, or reviewing health and wellbeing policies.
- Sharing good practice with other elected officials' offices, both to learn from them and to promote what has worked in your office in terms of supporting staff.

*"As a GP I've seen many cases of migraine and it has also affected loved ones, so I know how debilitating it can be for people in their daily lives. People with migraine need support, in the health system and also in their workplaces."*

**Dr Simon Opher MP**

## 4. Suggested ways to help raise awareness and show your support for all those living with migraine

You can help your constituents and colleagues living with migraine by busting myths, reducing stigma, and helping ensure people are correctly diagnosed. Migraine Awareness Week is each September – The Migraine Trust can supply social media graphics. We would also appreciate your support through letters or parliamentary questions to relevant ministers. We would be happy to meet with you or your staff to discuss key issues, including reducing inequity in access to treatments, the need for greater migraine research and workplace health.



If you have any questions about how to promote better migraine care or would like to work with us, contact our policy and public affairs team at [campaigns@migrainetrust.org](mailto:campaigns@migrainetrust.org).

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If members of your staff or constituents would like direct advice on an issue with migraine, they can contact The Migraine Trust Helpline on 0808 802 0066 (Mon-Fri, 10am-4pm). Outside of these hours they can leave a message and we will call back within 48 hours (excluding weekends and bank holidays). People can also contact us 24/7 via our [online contact form](#) or email [info@migrainetrust.org](mailto:info@migrainetrust.org). We aim to respond to all online and email contacts within five working days.

<sup>i</sup> The Migraine Trust, 'Migraine and children', available at: <https://migrainetrust.org/news/migraine-and-children/>; Kabbouche, MA & Gilman, DK (2008) 'Management of migraine in adolescents', Jun;4(3):535–548, available at: <https://pmc.ncbi.nlm.nih.gov/articles/PMC2526375/>

<sup>ii</sup> Approximate, based on national impact and average constituency population. The 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>iii</sup> The Work Foundation. (2018). Society's headache: The socioeconomic impact of migraine. Available from: <https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/lums/work-foundation/SocietysHeadacheTheSocioeconomicimpactofmigraine.pdf>

<sup>iv</sup> NHS. (1 January 2020). 'Improved NHS migraine care to save thousands of hospital stays'. Available from: <https://www.england.nhs.uk/2020/01/improved-nhs-migraine-care/>

<sup>v</sup> The Migraine Trust (2024) 'Migraine hurts'. Available at: <https://migrainetrust.org/wp-content/uploads/2024/09/Migraine-hurts-report-2024.pdf>

<sup>vi</sup> Migraines: Drugs, Question for Department of Health and Social Care, UIN 88648, tabled on 7 December 2021 – answered 15 December 2021. Available at: <https://questions-statements.parliament.uk/written-questions/detail/2021-12-07/88648>

<sup>vii</sup> The Migraine Trust (2023) 'Heading in the wrong direction: Challenges in migraine care and why people with migraine deserve better' <https://migrainetrust.org/wp-content/uploads/2023/09/TMT-Heading-In-The-Wrong-Direction-2023-FINAL.pdf>

<sup>viii</sup> The Migraine Trust Helpline. Available at: <https://migrainetrust.org/what-we-do/our-information-and-support-service/>

<sup>ix</sup> The 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>x</sup> The Migraine Trust (2023) 'Research reveals that over a third of people have experienced discrimination at work because of their migraines'. Available at: <https://migrainetrust.org/news/research-reveals-extent-of-workplace-discrimination-due-to-migraine/>



## 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.

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Registered charity in England and Wales (1081300) and Scotland (SC042911)

 [www.migrainetrust.org](http://www.migrainetrust.org)

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