

All about migraine

A toolkit to help you support better migraine care for your constituents

This toolkit will provide you with:

1. Key statistics and information about migraine
2. How you can support constituents who have migraine
 - a. Casework
 - b. Encouraging local health leaders to review and plan services to meet needs
3. How you can be a migraine-friendly employer
4. Suggested ways to help 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 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 to campaign for change.

1. Key statistics and background of 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 can include: head pain; problems with sight such as seeing flashing lights; being very sensitive to light, sounds and smells; fatigue; and feeling sick and being sick. However, different people get different symptoms. When someone has a migraine attack, they may not be able to function normally. Migraine attacks usually last for between four hours and three days. Most people don't have any symptoms in between migraine attacks.



Who gets migraine?

- Around one in seven people get migraine – over 10 million in the UK. This is greater than the number of people living with diabetes, asthma, and epilepsy combined.
- Migraine is the third most common disease in the world.
- 10% of school age children in the UK are affected, along with 28% of adolescents.
- 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 10,000 people in every constituency.¹

What impact does it have?

- UK-wide, migraine accounts for an estimated 43 million lost workdays per yearⁱⁱ and 16,500 emergency healthcare admissions for headaches and migraine attacks.ⁱⁱⁱ
- Migraine 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.
- The most recent estimates of the healthcare and productivity costs to the UK economy placed the impact at up to £10 billion per year.^{iv}
- 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.



How can migraine be treated?

Migraine treatment usually includes acute treatment such as painkillers, anti-sickness medication and specially-designed triptans to stop or shorten an attack, but people experiencing more than four attacks a month can ask their GPs about daily preventative treatment. GPs can support most people with migraine to manage their condition with, for example, migraine diaries, or refer them onto further treatments including Botox and Greater Occipital Nerve (GON) block injections.

If three previous treatments have failed, patients can then also be prescribed a new type of preventative drug called calcitonin gene-related peptide monoclonal antibodies (CGRP mAbs) - the first specifically developed for migraine. Several of these drugs are now available on the NHS, having been approved by NICE in England and Wales and by the Scottish Medicines Consortium (SMC).

However, CGRP mAbs are only currently prescribed by headache specialists and some consultant neurologists, so patients must exhaust other treatment options first. At The Migraine Trust we hear from many patients who struggle to get access to these drugs even after having gone through all this and our research report, [Dismissed for too long](#), highlighted patchy access across the UK.

2. How to support constituents affected by migraine

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

We hear from many people who are eligible for NICE-approved CGRP treatments but are having problems accessing them. This comes despite recent confirmation from the Minister of Health that NHS England is legally required to fund medicines recommended in a NICE technology appraisal, including CGRP treatments, and that the NHS Constitution states 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.^v We also hear from people who are waiting many months to see a specialist.

A 2021 survey by The Migraine Trust found over half (**52%**) of respondents who had experienced a migraine attack in the past had not been diagnosed with migraine by a doctor.

A 2019 community survey by The Migraine Trust found only about a third of people were diagnosed on their first visit – this fell to **20%** of respondents from Black, Asian and minority ethnic backgrounds.

29% had to see a health professional at least five times before they received a correct diagnosis, including **41%** of Black, Asian and minority respondents.

Of those who had been diagnosed, half (**51%**) had waited more than a year for their diagnosis.

Only **16%** of English NHS Trusts responding to Freedom of Information (FOI) requests we submitted in 2021 responded that eligible patients could access CGRP mAb treatments.

Findings from our report Dismissed for too long.^{vi}

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 GP surgery, NHS Trust or Integrated Care System/Health Board to investigate.

If constituents are facing issues with their employer due to their migraine, you can recommend our [Migraine: Help at Work toolkit](#) for advice.

Your staff can also call or refer constituents to The Migraine Trust's [Freephone Helpline](#) at 0808 802 0066. This is open 10am–2pm, Monday to Friday.

Outside of these hours you can leave a message and we will call you back within 48 hours (excluding weekends and bank holidays).

You can also contact your local health leaders to ensure that they are taking a strategic approach to understanding and meeting the needs of people with migraine in your constituency.

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

You can write to your local NHS Trust, Integrated Care System (in England) or health board to ask them how they ensure that they are working together to assess and meet migraine needs within the area. This should include using the [NHS RightCare Toolkit for Headache and Migraine](#) 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. You could also convene a roundtable with local health officials and people affected by migraine to discuss migraine care and support in your area.

We know that migraine care is uneven across the UK. For example, through our FOI research we found:

- Only 19 (20%) of the 93 NHS Trusts who responded to our FOI request said they had a specialist headache clinic.
- Significant differences between areas about how many doctors and nurses were dedicated to headache and migraine care. This ranged from none to 4 full-time equivalent (FTE) headache specialist doctors in different parts of the UK, averaging at 0.9 in England.
- Even fewer FTE headache nurses were employed, with most health bodies reporting they did not employ any. The average across the nations was 0.2 per organisation in Wales and 0.7 in England, Scotland and Northern Ireland.
- Every Trust in England reported that Covid-19 had affected services provided by their clinic. In many cases, this had resulted in clinics being run remotely, while a few said clinics had been stopped altogether at various stages of the pandemic. Botox treatment was identified as being particularly affected by Covid-19 pressures.

Showing your interest in optimal services locally by writing to your NHS Trust and ICS/ Health Board will help ensure services are reviewed and gaps addressed.

3. How to be a migraine-friendly employer

"I've suffered from migraines, off and on, since I was a young adult and I know how debilitating they can be. Working for better migraine care locally will improve quality of life for so many of the 10 million people it affects, but I also know that many MPs and their staff are personally impacted and need support as well."

Wayne David MP

"The reason I'm so passionate about this is because I'm a migraine sufferer myself. We need more sympathy and specific policies to support people with migraine at work. People need to realise that migraine isn't 'just a headache' but can be a completely disabling condition."

Rachel Maclean MP

"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

Migraine is most common among adults of working age. 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.

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.

Along with constituents, migraine may well affect members of your own staff. Statistically, it will almost certainly affect colleagues of yours in the chamber. 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 could include:

- Ensuring your staff feel they can tell you, and keep you updated with how their condition develops – this can seem like a daunting thing to do for them initially, especially since there is so much misunderstanding and stigma surrounding the condition.
- Making reasonable adjustments for staff with migraine following discussions with them.
- 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.

The impact of migraine on employment is a huge issue for people with migraine and The Migraine Trust. We understand that even with a supportive employer and the above in place, difficulties at work because of migraine may still occur. This is why our [Migraine: Help at Work toolkit](#) has information, resources and tools to inform and support people to understand and exercise their rights at work.

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

You can help us to bust myths, reduce stigma, and help ensure people are correctly diagnosed. Here are some suggested social media posts:



I support @MigraineTrust's call for #bettermigrainecare for the 1 in 7 people affected. I will work with our local NHS to ensure people get the treatment they are entitled to, and I support making parliament a #migrainefriendly place to work. <https://bit.ly/3GuLhps>



I am supporting @The Migraine Trust's call for #bettermigrainecare. 1 in 7 people live with migraine and it severely impacts how they live and work, but research shows access to the care people are entitled to is patchy across the UK.

I will be working with local NHS leaders in [constituency] to ensure proper access to treatments for my constituents affected by migraine.

I also support making parliament a #migrainefriendly place to work, as an example of how we must all support people living with migraine and lift the stigma they face.

migrainetrust.org/campaigns/better-migraine-care/

You can also support constituents affected by migraine by working with The Migraine Trust to write letters or submit parliamentary questions to relevant ministers, and by supporting Migraine Awareness Week in September.

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.

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-2pm). 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. We aim to respond to all online and email contacts within five working days.

ⁱ Approximate, based on national impact. 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>

ⁱⁱ 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>

ⁱⁱⁱ TNHS. (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/>

^{iv} 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>

^v 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>

^{vi} The Migraine Trust (2021). Dismissed for too long: Recommendations to improve migraine care in the UK. Available from: https://migrainetrust.org/wp-content/uploads/2021/09/Dismissed-for-too-long_Recommendations-to-improve-migraine-care-in-the-UK.pdf



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

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