

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC24: Ymateb gan: | Response from: The Migraine Trust



Supporting people with chronic conditions, May 2023

The Migraine Trust welcomes the Welsh Parliament Health and Social Care Committee inquiry into supporting people with chronic conditions. Our reply is below.

What is migraine and what impact does it have?

- 1.1 Migraine is common and has an impact on the day-to-day lives of up to 10 million people in the UK, on the economy and on NHS capacity, but is also stigmatised and not adequately addressed. However, there are simple steps that can be taken to reduce backlogs in the health system, improve support for migraine and enable people to access treatments that they need.
- 1.2 Migraine is much more than a headache. It is a severe and painful long-term brain disorder which disrupts work, personal and family lives. However, the condition is still often stigmatised and neglected by local health systems. Up to one in seven people experiencing in migraine attacks, which is likely to be include around 350,000 adults in Wales.¹² Moreover, one million people in the UK will have ‘chronic migraine’, experiencing at least eight migraine attacks per month, including 50,000 in Wales.³

NHS and social care services

Access to essential services and ongoing treatment

- 2.1 Research by The Migraine Trust, including Freedom of Information requests to NHS bodies and surveys of migraine patients, has found that despite being common and having wide-ranging impacts, migraine is poorly understood and not adequately addressed. Migraine is subject to underinvestment, largely absent from local health plans or public health strategies, receives little funding for research, and access to specialist care is inconsistent across the country.⁴
- 2.2 In 2021, Freedom of Information requests by The Migraine Trust found reported waiting times from GP referral to first appointment with a specialist in Welsh Local

¹ 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/s10194-022-0140>

² 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/>

³ The Migraine Trust (2021) ‘State of the Migraine Nation. Dismissed for too long: Recommendations to improve migraine care in the UK’. Available at: https://migrainetrust.org/wp-content/uploads/2021/09/Dismissed-for-too-long_Recommendations-to-improve-migraine-care-in-the-UK.pdf

⁴ The Migraine Trust (2021) ‘State of the Migraine Nation. Dismissed for too long: Recommendations to improve migraine care in the UK’. Available at: https://migrainetrust.org/wp-content/uploads/2021/09/Dismissed-for-too-long_Recommendations-to-improve-migraine-care-in-the-UK.pdf

Health Boards varied from 8 weeks in Swansea Bay University Health Board to 42 weeks in part of Cwm Taf Health Board. In 2023, new Freedom of Information requests have further found that in Cardiff and Vale patients are waiting up to 36 weeks even for “urgent” treatment, or 50 weeks for routine treatment. Swansea Bay University Health Board was the only Local Health Board in 2023 that has reported reviewing its treatment pathway, implementing the new optimum clinical pathway for adults for Headache & facial pain published by the National Neurosciences Advisory Group (NNAG)⁵ or planning to appoint a Migraine/Headache Lead to coordinate care and professional development.

2.3 Moreover, calcitonin gene-related peptide monoclonal antibodies (CGRP mAbs) medications are available for the most severe cases of migraine and have been approved by NICE. However, patients must exhaust other treatment options first and many experience difficulty accessing them in their area of the NHS even after this. In 2021, two of the seven Welsh Local Health Boards could not confirm eligible patients could access CGRP mAb treatments. Most boards did not provide data on waiting times, but those that did suggested patients were waiting as much as 26 weeks to access a prescribing specialist. In 2023, Aneurin Bevan Health Board reported waits of as much as 36 weeks.

2.4 To address these types of inconsistencies in care, The Migraine Trust is calling for a focused workstream on improving migraine care, led by NHS Wales. This should incorporate migraine specialists and patient representatives, in order to examine and implement best practice for migraine care throughout the NHS and partner organisations. This could include how best to optimise pathways for migraine care; to ensure consistency of patient access to approved medications; to widen access to training for health professionals that come into routine contact with migraine; to empower GPs, pharmacists and individual patients to ensure that the vast majority of cases of migraine can be managed in primary care or the community; and to ensure patient access to specialists for more severe cases of migraine.

Any barriers faced by certain groups, including women

2.1 Headache disorders in general and migraine especially are more commonly experienced by women than men, with 17% of women affected compared to 8.6% of men.⁶ This is likely the result of a combination of hormonal factors, genetic differences and potential under-reporting among men.⁷ Specialists in headache and women’s

⁵ 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>

⁶ 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>

⁷ European Migraine and Headache Alliance. (2021). ‘Migraine in the EU: Bringing women out of the shadows’. Available from: <https://www.emhalliance.org/wpcontent/uploads/Women-M-Policy-Paper-FINAL23MARCH.pdf>

health have also drawn a link between perimenopause and migraine.⁸ It is estimated that 1 in 10 children in the UK experience migraine, affecting their ability to flourish in school and socialise with their peers.⁹ A reported lack of understanding of the condition in schools and difficulties children face accessing treatment can make these problems worse.¹⁰

The readiness of local NHS and social care services to treat people with chronic conditions within the community

4.1 The UK as a whole has a lack of GPs with a Special Interest in migraine and headache (GPSIs) and community pharmacy is underutilised as a means of managing migraine. Given the general strain on GP practices at the present time, many people impacted by migraine struggle to secure a timely diagnosis or referral to treatment. Medical training on headache for medical students, junior doctors and GPs is brief and may only focus on the 'red flag' signs of more life-threatening conditions rather than 'green flag' indicators of migraine, leaving the day-to-day needs of those who face routine and often debilitating migraines unmet. Due to the lack of consistent training and clear pathways, too many patients with less severe cases of migraine are being referred to secondary care when they could be supported in the community, subjecting them to treatment delays and unnecessarily increasing pressure on the health system. There is potential therefore for this to be remedied through:

4.1.1 Clear and up-to-date training in migraine treatment and care becoming part of medical student, junior doctor and GP education programmes and through the availability of simple resources. This will ensure medical professionals are able to identify and treat migraine. Resources and simple curriculums should be developed in partnership with relevant professional bodies, patient groups and charities, including British Association for the Study of Headache (BASH) and The Migraine Trust.

4.1.2 A pharmacy first approach to strengthen primary care - community pharmacy should be empowered to take on a greater role in case-finding, prevention, prescriptions and management for headache and migraine. This will speed access to care for patients and reduce burdens on both GPs and secondary care through better day-to-day condition management. Pilot work taking place on pharmacy first in Scotland may offer lessons for Wales and other nations.

⁸ MacGregor, A (2022) 'Migraine and perimenopause'. Available at: <https://migrainetrust.org/news/migraine-and-perimenopause/>

⁹ Barnes, N (2020) 'Migraine headache in children', British Medical Journal (BMJ) Best Practice. Available at: <https://bestpractice.bmj.com/topics/en-gb/678>

¹⁰ 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>

Multiple conditions (e.g. interaction between mental health conditions and long-term physical health conditions)

5.1 Migraine is often comorbid with poor mental health. For example, migraine can lead to anxiety and anxiety can lead to migraine - incidence of anxiety in people living with migraine is around four times higher than in those without migraine.¹¹ New market research supported by The Migraine Trust found that 78% of respondents impacted by migraine reported it impacts upon their mental health as well.¹² If someone has frequent painful headaches, it would not be surprising for this to lead to some anxiety. A patient does not know when an attack will strike or how badly they will be affected, and this often has serious implications for planning work, caring for a family and participating in social activities. Acute anxiety is a biologically adaptive response to real or potential threats in the environment. If someone experiences prolonged anxiety this affects neuronal pathways, and could influence neuropathological processes leading to the development or the worsening of migraine.

5.2 A 2021 study showed that in migraine, as the number of headache days increased there was an increased risk of anxiety and depression. Just having three headache days per month led to a significant increased risk of anxiety.¹³ As the co-existence of anxiety and migraine is so common, we should always consider whether anxiety is present. Studies have shown pharmacological treatment for anxiety can also reduce migraine attacks. Not diagnosing and managing the anxiety may mean that migraine remains resistant to traditional medical therapies, and people miss out on effective treatments.

Impact of additional factors

6.1 In 2021, several Welsh Local Health Boards reported in Freedom of Information responses that headache and migraine services had been disrupted as a result of the COVID-19 pandemic, with appointments shifting to being virtual and neurology consultants redeployed to provider cover on medical wards.

Prevention and lifestyle

7.1 A 2018 Work Foundation estimate suggested that migraine costs the overall UK economy at least £6 billion a year, including 43 million lost workdays.¹⁴ Further

¹¹ Kennis, K (2022) 'Migraine and anxiety'. Available at: <https://migrainetrust.org/news/migraine-and-anxiety/>

¹² Bionical Solutions, Lundbeck Ltd. & The Migraine Trust (2022) Migraine Patient Journey Market Research

¹³ Irimia, P *et al* (2021) 'Impact of monthly headache days on anxiety, depression and disability in migraine patients: results from the Spanish Atlas', *Scientific Reports*, 11, Article number: 8286. Available at: <https://www.nature.com/articles/s41598-021-87352-2>

¹⁴ 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>

research by a consultancy commissioned by The Migraine Trust in 2022 suggested the cost could even be as high as £9bn, if “presenteeism” at work is included, and that expanded access to treatments that reduce the frequency and intensity “would incur massive gains in reclaimed productivity” in the economy. Employers are keen to monitor and manage short-term sickness which can be disruptive to staff, increase pressure on managers and affect deadlines and targets. Migraine is unfortunately used as a common excuse for taking sick leave at work. The notion of ‘pulling a sickie’ has done a great disservice to people who experience migraine which means that genuine absence due to migraine and the support an employer can provide, are not always appropriately addressed or considered. Sickness absence policies and monitoring tools which focus on reducing frequent short-term absence often unfairly penalise people with migraine who are unaware of their rights and the support that may be available to them.

7.2 Despite the severe pain experienced during an attack, many people will avoid taking sick leave and will continue to attend work. This is known as presenteeism, when an employee attends work despite being unwell. This is common amongst people living with migraine. A person may even attend work while having a migraine attack due to fear of facing a disciplinary hearing or a capability procedure for sickness absence. Concerns about being seen as unreliable or worries that others may consider they are faking illness are also factors.

7.3 Dame Carol Black’s review ‘Working for a healthier tomorrow’ detailed the benefits for employers and the economy by supporting and managing the health of employees with long-term health conditions such as migraine.¹⁵ Promoting employees’ good health and well-being adds value to an organisation by increasing motivation and engagement of staff which has a positive impact on productivity. Failing to support the retention of staff with long-term health conditions can lead to significant costs in terms of training and development, redundancy or other termination costs (and possible litigation and employment tribunal awards) as well as recruitment costs and poor morale and productivity amongst the workforce. Employees and employers both have a role to play in ensuring that the right support is in place clinically and in the workplace so that an individual with migraine can retain their employment and achieve their full potential.

Details

Elliot Bidgood (Policy Adviser, campaigns@migrainetrust.org), submitting on behalf of The Migraine Trust. The Migraine Trust is the largest research and support charity for people affected by migraine in the UK. Our role is to fund and promote new research into migraine, provide day to day support for people affected by migraine and campaign for change.

¹⁵ Dame Carol Black (2008) ‘Working for a healthier tomorrow’. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/209782/hwwb-working-for-a-healthier-tomorrow.pdf