Pathways to Work Consultation Response

1. What further steps could the Department for Work and Pensions take to make sure the benefit system supports people to try work without the worry that it may affect their benefit entitlement?

Migraine forces people to miss between 28 million and 43 million days of work each year, costing the UK economy between £4.4 billion and £9.7 billion.[1] As such, properly supporting those with migraine to retain or re-enter work, where possible, will have a significant impact on the 10 million people living with migraine in the UK and the country's economy.

Firstly, DWP staff must be trained to recognise the severity of migraine: migraine is a serious neurological condition which can cause debilitating pain, nausea and visual disturbances. Given the misconceptions around migraine, staff should be trained to understand its physical, mental and social impact.

The proposal that people who enter work but cannot maintain it should return to their previous benefit rate is a welcome one in theory – but it must be effective in practice. In order for it to truly incentivise attempts to work, it must take into account the fact that migraine (and many other conditions) fluctuate over periods of longer than six months. Indeed, the British Association for the Study of Headache (BASH) notes that those with migraine can have 'freedom from symptoms in between [attacks]', which 'vary in frequency from one per year to a few times per month.'[2] As such, in order to provide people with the security they will need to attempt work, the time period to which this guarantee applies must match the medically-recognised period within which symptoms can remain dormant for a given condition.

3. How could we improve the experience of the health and care system for people who are claiming Personal Independence Payment who would lose entitlement?

Most people living with migraine can manage their condition with tailored treatment, enabling them to work. However, optimal treatment pathways for migraine are often not followed. As laid out below, better training in general practice, consistent access to the correct and life-transforming medication and access to specialists where necessary would reduce pressure on NHS services and enable more people to work.

Firstly, GP training on migraine is patchy, regionalised and often relies on a local champion to promote. Migraine is usually only covered briefly as part of a neurology

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[1] The Work Foundation, *Society's Headache: the Socioeconomic Impact of Migraine* (2018) https://www.lancaster.ac.uk/media/lancaster-university/contentassets/documents/lums/work-foundation/SocietysHeadacheTheSocioeconomicimpactofmigraine.pdf

[2] BASH, *Information Sheets for Clinicians*, p2 (https://bash.org.uk/wp-content/uploads/2023/02/migraine-features.pdf)

session in initial medical training and there is no formal compulsory ongoing training. DHSC should issue guidance to ensure that 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. Meanwhile, there are only around 80 GPs with Extended Role (GPwER) for headache and migraine and the UK; work should be done with GP professional bodies to recruit and train more GPwERs in headache – for example, as is the case with Extended Role training for some other disciplines, encouraging that that training be accredited in a standardised manner by the RCGP or similar. In addition, in line with the Government's aim to move treatment from hospital to the community, more community-based migraine clinics should be established and pharmacists should be trained to recognise and treat migraine where appropriate.

Secondly, access to medication is inconsistent. Life-changing Calcitonin Gene-Related Peptide monoclonal antibodies (CGRP mAbs) are NICE-approved, yet only 29% of NHS Trusts which responded to our FOI requests in 2023 confirmed that eligible patients could access them. All ICBs should be encouraged to provide access to these and the similarly NICE-approved, and more easily administered, CGRP receptor antagonists ('gepants'). The NICE CG150 guidelines should be updated to feature both of these treatments – which are currently not featured, despite being NICE-approved – and to reflect their efficacy. In order to move treatment out of hospital and into the community, the Medicines and Healthcare products Regulatory Agency (MHRA) should explore the issue of prescribing rights for CGRP medications in primary care.

Finally, there is a need for more specialists. The UK has only 1.1 full-time equivalent neurologists per 100,000 population (compared to 4 per 100,000 in France and Germany). As a result, our FOI requests showed that average waiting times for seeing a migraine specialist nearly doubled from an average of 15 weeks in 2021 to 29 weeks in 2023. Long waiting lists and challenges in accessing care leads to mismanagement of migraine, whilst 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.

If, as a result of the above measures, the optimal care pathways could more consistently be followed, we could move towards a more prevention-oriented, community-based and efficiently-resourced health service which would in turn enable many more people with migraine to work whilst reducing pressure on secondary care. For more information on the steps that should be taken to improve treatment, see our submission to the consultation on the NHS's 10 Year Plan.

5. What practical steps could we take to improve our current approach to safeguarding people who use our services?

Firstly, staff must be trained to recognise the severity of migraine: migraine is a serious neurological condition which can cause debilitating pain, nausea and visual disturbances. It also has serious mental health impacts: when we surveyed 2,028 people with migraine in 2024, 34% said they had had thoughts of suicide, 7% said these thoughts were frequent and 6% of those with chronic or hemiplegic migraine said they had self-harmed. As such, DWP staff should be trained to ensure that, where there is the risk of implications for a person's mental health following engagement with their services, they are properly signposted to mental health services.

Meanwhile, it is crucial that people with migraine are not dismissed due to a lack of understanding. Indeed, at all levels of the health system, patients living with migraine frequently report being met with a lack of understanding or feeling dismissed. To that end, the relevant DWP staff should be trained in the medical and social realities of migraine, for example through the Migraine Trust's programmes, which have previously been delivered to civil servants. Whether their access to benefits is affected by the planned changes or not, people with migraine should be taken seriously and should always be referred to reputable sources such as The Migraine Trust or others who provide information verified by the PIF (Patient Information Forum) Tick.

6. How should the support conversation [for those who may no longer be eligible for PIP] be designed and delivered so that it is welcomed by individuals and is effective?

Given that this conversation is designed to identify 'the type of health and eligible care support they need and the potential ways to unlock it, including addressing any health barriers to employment',[3] it should signpost towards the optimal care pathway for people with migraine. As detailed under question 3, this should involve a referral to a GP with adequate training in migraine, or a specialist, so that the person can receive the tailored treatment and support they require.

This conversation should also be an opportunity to inform people as to their rights with regard to having reasonable adjustments made in the workplace, for example by pointing to the Migraine Trust's Migraine in the Workplace Toolkit and providing them with advice on how to communicate their rights and their needs to their employer. If necessary, conversations should be ongoing.

A truly expansive and effective service would avoid placing the onus on employees and would instead act as their advocate, intervening on their behalf when employers fail to meet those needs.

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[3] DWP, *Pathways to Work: Reforming Benefits and Support to Get Britain Working* (2025), para 148 (https://assets.publishing.service.gov.uk/media/67d84aa179f0d993dfb11f97/pathways-to-work.pdf)

Q11: Should we delay access to the health element of Universal Credit within the reformed system until someone is aged 22?

No. The proposal to instead use the savings to pay for 'work support and training opportunities'[4] suggests that what is preventing young people with health conditions from working is a lack of skills or wherewithal, as opposed to a lack of ability on account of a debilitating condition. This is particularly misplaced in relation to migraine given that headache disorders rank third amongst all conditions in terms of the number of years they will adversely affect young adults (15–49 years) over the course of their lifetime.[5]

13. How can we support and ensure employers, including Small and Medium Sized Enterprises, know what workplace adjustments they can make to help employees with a disability or health condition?

An enhanced and more effective service – whether that be through the revised Support with Employee Health and Disability Service or similar – should make employers aware that:

- Migraine is a common and serious condition. It affects almost 10m people in the UK – around 1 person in 7. It is a serious neurological condition which can cause debilitating pain, nausea and visual disturbances, and one million people in the UK will live with 'chronic migraine', meaning they experience the effects on at least 15 days per month for three months. As such, and in order to counter narratives which minimise the severity of the condition, migraine should be listed as a recognised, serious condition which employers should expect to encounter and which they have a legal responsibility to make reasonable adjustments for.

- Often, the adaptations that can be made for migraine are cheap and simple. Whilst the requirements of people with migraine will vary, things such as flexible work times, glare-reducing screen covers or a chair which reduces muscle tension can significantly reduce migraine attacks.

- There are organisations and charities which will provide information on best practice for condition-specific adaptations, for example The Migraine Trust's Toolkit for Employers.

As well as making employers aware of what they can do, a truly effective service would, firstly, impress upon businesses the legal responsibilities that they have under the Equality Act and the consequences of not complying. The onus should ultimately be on businesses rather than employees with disabilities.

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[4] DWP, *Pathways to Work,* p18

[5] Steiner et al, *GBD2021: headache disorders and global lost health*, The Journal of Headache and Pain (2024), para 3 (https://thejournalofheadacheandpain.biomedcentral.com/articles/10.1186/s10194-024-01795-2)

More proactively, though, an enhanced service would work with businesses and industry bodies to encourage them to declare themselves disability-friendly workplaces, for example by encouraging uptake of the Disability Confident scheme, or – in the case of migraine – encouraging them to sign up to the Migraine Trust's Workplace Pledge.

14. What should DWP directly fund for both employers and individuals to maximise the impact of a future Access to Work scheme and reach as many people as possible?

A truly effective service – one which enables people to stay in or return to work - would act as an advocate, making people aware of their right to reasonable adjustments and the sorts of adaptations that may help with their specific condition; providing them with advice on how to communicate their rights and their needs to their employer; and intervening on their behalf when employers fail to meet those needs.

As above, the service should also work proactively with businesses to encourage them to declare themselves disability-friendly workplaces, for example by encouraging uptake of the Disability Confident scheme, or – in the case of migraine – encouraging them to sign up to the Migraine Trust's Workplace Pledge.

15. What do you think the future role and design of Access to Work should be?

See answers to questions 13 and 14.

16. How can we better define and utilise the various roles of Access to Work, the Health and Safety Executive, Advisory, Conciliation and Arbitration Service and the Equalities and Human Rights Commission to achieve a cultural shift in employer awareness and action on workplace adjustments?

See answers to questions 13 and 14.