

People affected by migraine reluctant to see their doctor and keep their condition private at work due to fear of judgement, says study



The survey, conducted by the European Migraine & Headache Alliance (EMHA), found that the impact of migraine stigma was at the centre of their daily lives

February 7, 2024. A new survey developed by the [European Migraine & Headache Alliance](#) (EMHA) and The Migraine Trust reveals that people affected with migraine feel discriminated against in all aspects of their everyday lives. The study, which captured the experiences of over 4,000 individuals with and without the condition across Europe, found that migraine is more stigmatizing than dementia, Parkinson's disease, and stroke.

Migraine stigma occurs when people affected perceive negative, dismissive, or intolerant attitudes from others due to their condition. This stigma often arises from a lack of understanding. The survey revealed that 26% of respondents who did not have migraine believe that the condition is nothing more than strong headache. Unfortunately, migraine is often equated with a normal headache.

The consequences of migraine stigmatization can be profound and have negative implications. For example, the study revealed that 93% of those affected by migraine believe that the public lacks a proper understanding of the condition. As a result, 35% of them admit

to delaying or avoiding seeking medical advice due to the feelings of embarrassment and the fear of judgment from healthcare professionals. In fact, the survey highlights that 74% of those affected by migraine felt that medical professionals do not take their condition seriously.

Peter Goadsby, Professor of Neurology at King's College London, said: "The data from the survey is a wakeup call to clinicians that highlights an important dimension of burden of migraine to our patients." Goadsby, who is also one of the academics behind the study, emphasises the importance of better communication about the disorder's impact and the ways we communicate about the problem.

In the workplace, 62% of respondents believe that migraine has influenced how their employers assess their value. Interestingly, around 43% of those surveyed have chosen not to disclose their conditions to their employers, despite many acknowledging difficulties in completing work tasks.

Individuals with migraine express feeling additionally stigmatized due to the general lack of understanding about the condition, making them hesitant to share their health status at work. However, a significant 80% of non-full-time workers report experiencing negative impact on their careers because of migraines.

According to the survey, migraine stigma left people with the condition feeling angry, lonely, and sad.

Robert Music, Chief Executive of The Migraine Trust explained: "Far too many people think migraine is just a bad headache. As a result, those living with the condition often face a lack of empathy, understanding, and support. In reality, migraine affects the whole body and can impact every area of life including mental health, relationships and ability to work. It is vital that we start to tackle stigma so that the 1 in 7 who live with migraine are no longer made to feel invisible, be taken seriously or feel like a burden."

Redefining language

The EMHA is advocating for a re-evaluation of the language surrounding migraine diagnosis, which shows that 65% of individuals with migraine feel stigmatized by terms such as - 'disabling,' 'episodic,' 'chronic,' and 'refractory.' The initiative to redefine the language aims to facilitate better understanding among families, colleagues, healthcare practitioners, and authorities.

This year, the EMHA is set to introduce a new categorisation system to effectively convey the severity of migraine, marking a significant step toward eradicating stigma and promoting inclusivity for people affected.

Elena Ruiz de la Torre, EMHA E.D said: "We now have clear evidence that shows how stigma impacts the lives of people suffering with migraine. We want society to recognise how this stigma impacts the lives of those who live with it. Stigma happens at home and in the workplace, but also within the healthcare system itself. Stigma should have no place in healthcare or the workplace. For the EMHA, we believe that communicating migraine in a different way forms part of the solution. In 2024, in collaboration with our scientific committee, we will define a new categorization to help the migraine community."

This survey complements the EMHA's earlier study in 2022, which highlighted the prolonged struggle faced by individuals with migraines in accessing timely diagnosis and proper treatment. This revealed that waiting times are averaging five years for diagnosis and an additional three years for appropriate care.

The 2023 survey was conducted from April 27 to June 30, 2023, spanning 17 European countries and involving 4,210 respondents. It was distributed among EMHA contacts via social

networks and a paid campaign across multiple countries. Additionally, each country's associations actively promoted the survey in their respective languages.

About The European Migraine & Headache Alliance

The European Migraine & Headache Alliance (EMHA) is a non-profit umbrella organization that was launched in 2006. It includes over 33 patient associations for migraine, cluster headache, trigeminal neuralgia and other headache diseases, across Europe. Its head office is in Brussels. EMHA's aim is to speak on behalf of and to advocate for the rights and needs of the 138 million people in Europe living with headache disorders.

EMHA is an active member of the European Federation of Neurological Alliances (EFNA), the International Association of Patient Organizations (IAPO), the European Patients Forum (EPF) and also works closely with organizations such as the European Headache Federation (EHF), International Headache Society (IHS), European Brain Council (EBC) and others.

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