

# Migraine & Stigma Survey

Highlights & Conclusions

**EMHA** European  
Migraine &  
Headache  
Alliance

The Migraine Movement

# Conclusions

Migraine is a significant health issue, affecting millions worldwide. However, as highlighted in a recent survey with 4,210 responders, there remains a lack of understanding and misconceptions, especially in healthcare and the workplace setting. Through better education, increased advocacy, and making changes to the lexicon used to describe migraine, we can create a more supportive environment for migraine sufferers.

1. The stigma surrounding migraine can significantly impact individuals, leading to negative effects in both personal and professional life. This, in turn, can result in feelings of loneliness, frustration, and sadness. To ensure the well-being of those with migraine, we must put an end to this stigma and push through initiatives such as changing the language used to describe migraine, increasing awareness and education surrounding the condition, and advocating for better support.
2. The study exposed that significant stigma experienced by people with migraine from friends, family, work colleagues, and even their doctors, thereby increasing the burden of their illness.

90% of the respondents were women aged 25-64 years, with 88% of them suffering from migraine.

Most respondents were considered to have severe migraine, experiencing more than 8 disabling attacks per month.

3. Migraine is not a sign of weakness or lack of willpower, yet in context of migraine, stigma arises when individuals who suffer from this condition feel that others view them negatively, dismissively, or intolerantly because of their health challenge. This stigma is often rooted in a lack of understanding of the condition, further compounding the significant pain and suffering already caused by migraine.

According to our individuals with migraine clearly feel stigmatised due to their condition. In the survey, up to 93% of migraine sufferers believe that the general population lacks a comprehensive understanding of their condition. Notably, almost one-third of respondents identified minimising migraine to just a headache as a prevalent misconception. Together, we can dismantle this stigma by challenging misconceptions and fostering open conversations about migraine.

It is crucial to recognise that migraine is not merely a headache; it is a complex neurological disease with varying degrees of symptoms, pain, and intensity, which can differ from person to person and by type. Survey insights reveal that 93% of migraine sufferers and 87% of non-sufferers share the belief that the condition is not well understood by the general population. This lack of understanding needs to be challenged through increased empathy and improved awareness for those living with migraine.

4. Among survey respondents who suffer from migraine, up to 79% identify the workplace as a significant challenge, particularly for those with more severe migraine. Furthermore, 80% of non-full-time workers with migraine note that their condition negatively impacts their employment status. Encouraging employers to adapt a flexible approach in supporting these individuals will promote a more inclusive and supportive work environment for everyone, ensuring that all employees can thrive in their careers.

Survey results have revealed that migraine is more stigmatising than dementia, Parkinson's disease, and stroke. This stigma is often rooted in the misconception that it's merely a normal headache, contributing to workplace challenges, especially for those who suffer severe and frequent migraine. Sufferers often experience feelings of anger, loneliness, and sadness in their workplaces due to the associated stigma.

62% of respondents feel that migraine have affected how their employer assesses their value.

When colleagues de-value the severity of the condition, often dismissing it as a 'simple headache', individuals with migraine experience heightened stigma. Due to this lack of awareness surrounding migraine, sufferers feel more stigmatised, leading to discomfort about sharing their condition at work.

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The discomfort about disclosing migraine also increases with severity – 43% of people have not disclosed their condition to anyone at work.

5. Medical professionals play a crucial role in the lives of those who experience migraine; however, our recent survey reveals a noticeable gap between patients and healthcare providers in the language used to describe migraine. Through simple steps such as adjusting terminology and providing additional training, this gap can be bridged. This ensures a common ground is found, empowering patients, and fostering effective communication, ultimately reducing feelings of stigma.

By implementing initiatives such as investing in better education and changing the language used to describe migraine, we can effectively bridge the gap between patients and medical professionals. Our survey indicates that up to 74% respondents feel that healthcare providers lack an understanding of what it means to experience migraine.

35% of individuals with severe migraine disclosed that they are reluctant to seek medical advice or intentionally delay or avoid it due to the embarrassment they feel.

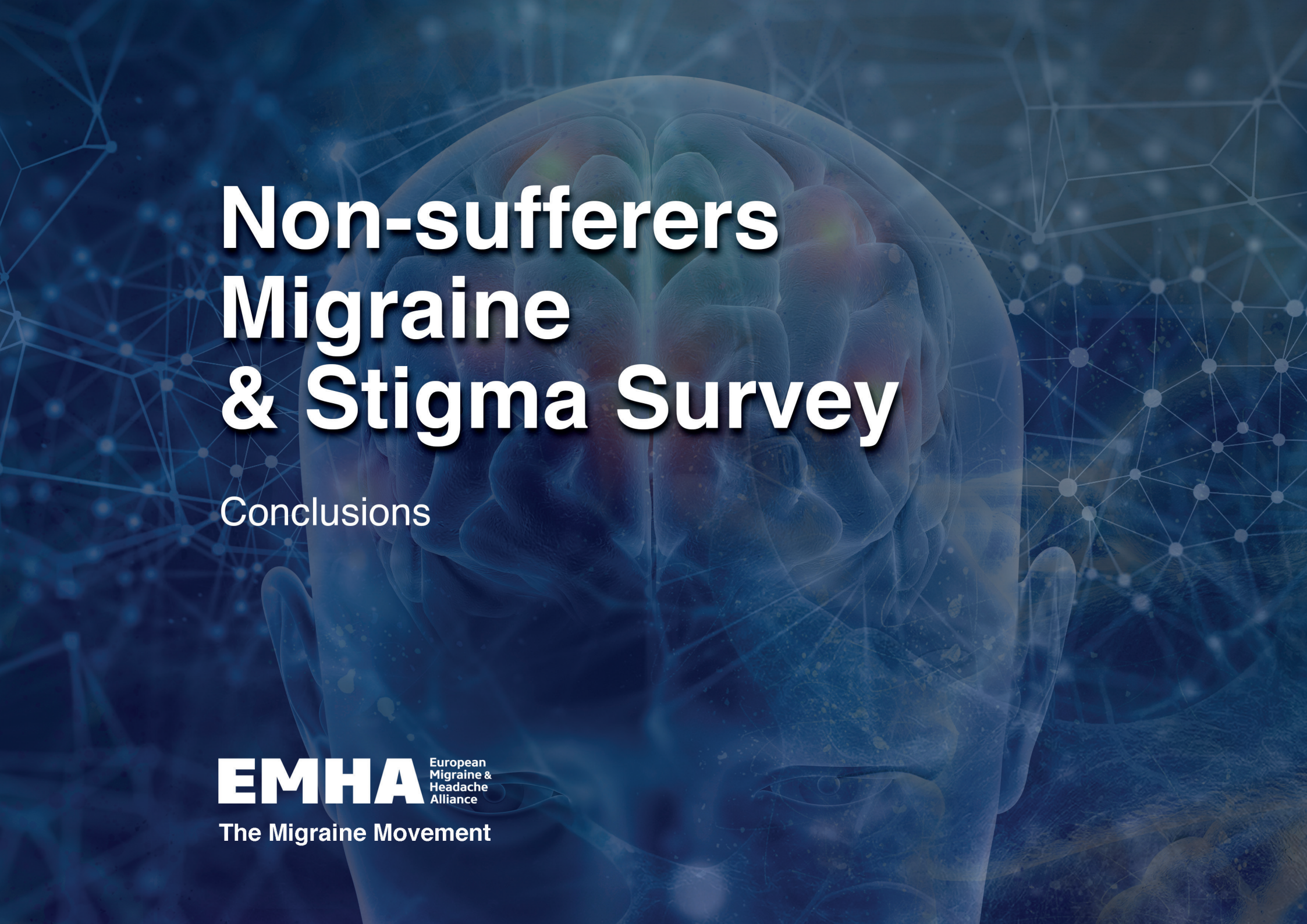
6. Migraine stigma often acts as a barrier for those seeking help and support. Together, we can break this stigma by challenging misconceptions and fostering open conversations about migraine. Additionally, changing the current lexicon used to describe it is crucial.

Also, the physical limitations caused by migraine make individuals feel embarrassed and excluded, with some perceiving that others treat it as if 'it's their fault'. The language used to grade or define migraine, including terms like 'disabling', 'severe', 'chronic', and 'refractory', exacerbates the stigmatisation.

65% of survey respondents felt stigmatised by language such as 'severe', 'disabling', 'episodic', 'chronic', and 'refractory'.

But the impact of migraine extends far beyond physical pain; it can disrupt daily activities, relationships, and mental well-being. Let's work together to create a compassionate and understanding environment to support those with migraine.

7. While we acknowledge the value and progress achieved by current initiatives, we also recognise the need to continuously evolve and improve them. This commitment is essential to better shape the public perception of migraine.



# Non-sufferers Migraine & Stigma Survey

Conclusions

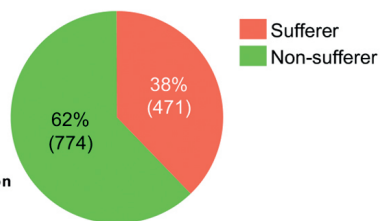
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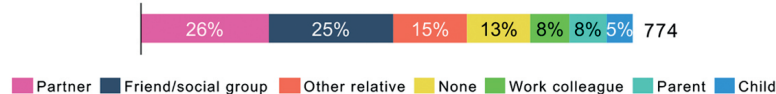
# Main findings

## Demographics

- 1,245 answers have been obtained,
- Most were from **Portuguese, Italian, Spanish and English** speaking people
- 62% (774) of respondents answered that they do not suffer from migraines, of which these are the people of interest in this survey, i.e., the survey is complete if someone answered they suffer with migraines
- Within the non-sufferers, 51% had a connection to migraines through partners or friends
- 13% had no connection at all to migraine



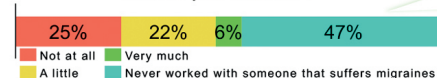
Distribution of relationships with a migraine sufferer of respondents:



## Workplace Setting

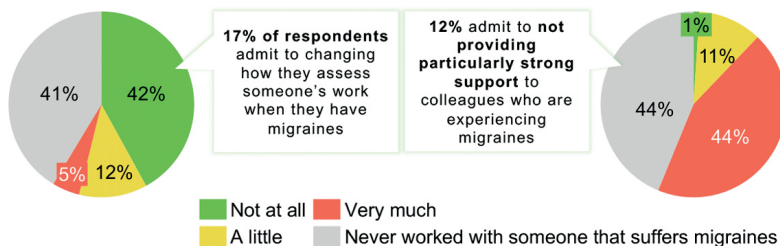
- Stigma is mostly perceived around **medical professionals and work colleagues**

Do medical professionals understand what it is like to live with your condition?

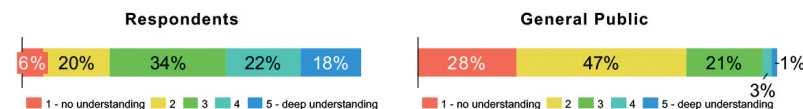


28% of respondents think that that working with someone who suffers from migraines makes their work life somewhat or significantly more difficult

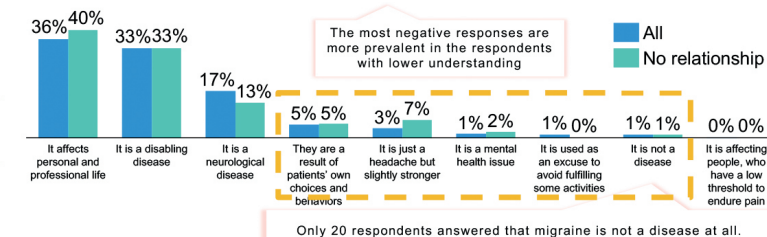
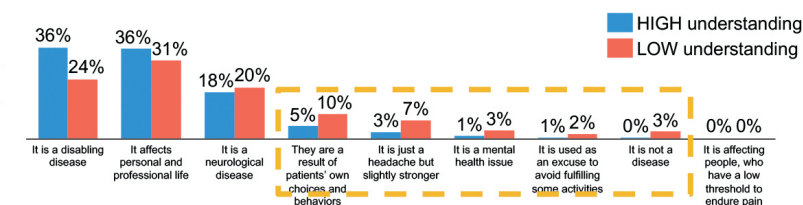
Migraine patients' understanding of medical terms:



## Understanding & Stigma



74% of respondents believe they have a good understanding of migraines, while only 46% of those with no relationship to a migraine sufferer share the same view. However, only 25% of respondents believe the general public has a good understanding of migraines, which drops to 17% in those with no relationship to migraine



- 48% of all respondents believe that those with migraines experience little to no stigma
- This increases to 55% for respondents with no relationship to a sufferer

