

Migraine hurts

From physical pain to mental health effects and the pain of being misunderstood: exploring the impact of migraine

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the
migraine
trust

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Migraine is a very common but debilitating neurological condition. It is often invisible, meaning that despite one in seven people living with it, understanding around what it means to live with the condition is very low. Many people hear 'migraine' and think 'headache', and as such the reality of this complex condition is often overlooked, downplayed or simply not realised.

Migraine affects far more than the head. Symptoms can vary from person to person and the impacts can be wide-reaching across family life, work, ability to socialise and mental health.

To research this more deeply, The Migraine Trust surveyed 2,208 people living with migraine between 29 May and 30 June 2024 through SurveyMonkey, to understand the many ways in which migraine hurts.

- 73% were between 35 and 64, 27% were under 35 and 12% over 65
- The sample was split fairly representatively across the UK proportional to population size
- 91% were women, which is higher than the average as migraine is two to three times more prevalent in women than men
- The majority had lived with migraine for more than 10 years (63%). Only 1.2% under a year. Many said it was over 30, 40 or 50 years
- 56% have chronic migraine, 34% migraine with aura, 28% episodic migraine, 17% menstrual migraine, 12% vestibular migraine, 11% hemiplegic migraine, 6% abdominal migraine and 3% brainstem aura. Other types mentioned included cluster headache, silent migraine and intractable migraine
- 48% reported being diagnosed with a mental health condition. Anxiety and depression were the most common, followed by PTSD.

All the quotes in italics in this report were given as part of free text responses.

“[There is a] challenge around migraine perhaps not being life threatening (minus increased risk of suicide) meaning it doesn't get taken seriously when it can have such a huge impact on someone's quality of life (decisions around if able to have children, whether can work, income, poverty, housing, socialising, impact of pain and isolation).”

The impact of migraine on mental health

89% said their mental health has been affected as a result of their migraine with 55% saying the impact is significant. Those with episodic migraine (headache on less than 15 days a month) were less likely to report a significant impact than other migraine types. Impact slightly lessened as age increased:

- Impact on their mental health: 96% of 18-24 year olds and 89% 55-64 year olds.
- Impact that is significant: 75% of 18-24 year olds and 52% of 55-64 year olds

“ Living with hemiplegic migraines is hell. Every day is full of fear and terror. The restrictions and the planning around it/trying to avoid it have destroyed my life.”



What we found

1. Migraine hurts, physically

“I gaslight myself about the pain I’m in. This is compounded by how others can’t imagine how you can be in so much pain and still function, or even that it’s possible to be in so much pain.”

Over two-thirds said that pain has one of the biggest impacts on their mental health.

“ There have been times when I have been so desperately in pain that I have hurt myself trying to distract from the agony, and times when it had crossed my mind to end the pain permanently.”

For many this will include head pain, however while headache is a common symptom of a migraine attack, other symptoms can include dizziness, nausea, sensitivity to lights or sound and visual disturbances or loss of vision. Some people don’t experience head pain at all, and this can make getting a diagnosis even harder.

“People think you just get a bit of a headache, rather than can’t see and can’t move, vomiting etc.”

Stories reinforce that there is no ‘typical’ migraine experience. The symptoms, their duration and their impact can vary from person to person:

“Vulnerability to flashing lights. Loss of balance, mental confusion, inability to make decisions.”

“If you haven’t experienced ‘aura’ I don’t think you would understand how frightening it is. Mine comes on suddenly and I am unable to see properly or concentrate. It doesn’t matter what you are doing ie. driving. I find it frightening.”

2. Migraine hurts in many ways beyond the physical pain

When asked how migraine makes you feel, “anxious” was the most common response (62%), followed by “depressed”, “hopeless” and “lonely”. Others talked about feeling frustrated, bitter or cheated:

“I feel cheated of a happy, peaceful, and fully engaged family life.”

Chronic migraine was more strongly associated with feeling hopeless and depressed, while those with vestibular or brainstem aura were more likely to say lonely.

Many reported feeling low:

“I get quite low because of how long they last [and because] it affects what I can do whilst suffering. I also feel very guilty because I feel like my family suffers too.”

“I often feel that life is more of an existence with migraine.”

Some talked about feeling unable to cope with 34% saying they have had thoughts of suicide due to the impact of their migraine. 7% said thoughts of suicide were frequent and these were more likely to be those with chronic, hemiplegic or vestibular migraine. 6% of those with chronic or hemiplegic said they have self-harmed.

“When my migraine is at its worst, I have had suicidal thoughts, not only because I want the horrendous pain to end, but I feel utterly useless, worthless, and like there is no future where I will not have this agonising condition. The isolation; feeling like a burden on others when I’ve taken time off work again; being spoken to dismissively because I’ve got ‘another headache and should do something about it’ - it all gets very hard to take.”

“When the pain is severe it feels like the only way to get relief would be to die.”

While pain has a significant impact, there are other aspects of migraine that can have a considerable effect on someone’s life. Living with the unpredictable nature of attacks and feelings of guilt or letting people down were the most common (chosen by 78% and 68% respectively). Guilt included feeling like a bad partner or parent. Others spoke about lack of ability to plan ahead as well as the impact of missing out on specific events or life as a whole:

“I have had migraines since I was 12. I am now 20 with no job (PIP claimant) and no solid plans for the future as I am crippled with anxiety, paranoia, and uncertainty. I rarely leave the house alone - even to go to the shops - for fear of an attack. I have been on numerous medications, none of which have helped my condition, and the GP and hospital have been so tedious and dismissive that I now have a deep-rooted fear of the NHS and any other support service. I am isolated, unable to make friends or attend social events, and I am constantly fighting a deep hatred for myself as a result of this condition, which in my teenage years saw me attempt to take my own life.”

“I just want a fulfilling life as that is the person I am, but it is now lost.”

Some people talked about the challenge of living with other health conditions and how these interacted with migraine – for example, how aspects of conditions such as anxiety can trigger an attack or how migraine can make preexisting conditions, including depression, worse.

“It was definitely migraine first mental health problems later for me. There’s a lot of grief involved, from grief of what you have already lost to what you had envisioned in life & will/may well never have from small everyday things to ie a career, children. A lot of loss of identity & not knowing who I am now, so much loss of independence, & things that made me me.”

Significant negative impacts on mental health were reported more by younger people, for example feelings of isolation were most strongly felt by those aged 18-34. For those over 55, the unpredictable nature of attacks was by far the most common negative impact.

There were differences between genders with feeling isolated and reduced feeling of self-worth higher in females than males, whereas males reported a higher level of loss of confidence and were less likely to say migraine makes them stay at home more.

Loss of confidence has a high impact across all migraine types (episodic 49.26%, 64.66% chronic and 71.84% vestibular). While those with hemiplegic migraine were more likely to say that not being taken seriously has the biggest impact on them (43% compared to 24% among episodic and 40% chronic). Isolation was more prominent in chronic (48%) than episodic (26%) respondents:

“I just want a fulfilling life as that is the person I am, but it is now lost.”

“ My life has become very small. Chronic migraine since age 22, massive impact on career, has meant I can only work part time, so feel like a failure compared to my peers, who are mostly in very senior roles as we approach 40.”

Do any of the below apply due to your migraine?	Responses
Participate less in social occasions	80.33%
Low mood	75.42%
Staying at home	69.55%
Loss of confidence	58.87%
Less able to work	58.76%
Feeling isolated	47.93%
Reduced feeling of self-worth	46.35%
Unable to work	34.64%
Suicidal thoughts	22.33%
Self-harming	3.73%

“At the moment I can’t have children – my migraine is the main factor why. This is my dream and to be able to have a break from migraine and to get to a point where I could have children would be amazing.”

Some had positive comments or talked about personal resilience. This was often linked to changes following finding a treatment that has worked:

“OK, now that I have treatment. Before it made me feel stressed, hopeless and miserable.”

3. Low understanding of migraine affects all areas of life

The perception of migraine has long been that it is no more than a headache. Almost everyone who took part in this research (90%) thought most people who do not have migraine think it is just a bad headache, with 55% saying they strongly think this.

“I didn’t understand what it was until it smacked me upside my life, so I’d include myself in the people that thought it ‘was just a bad headache’, but it’s so, so much more than that.”

This misconception is present in the home, in the workplace, in education and in society in general. The consequences include people being dismissed, bullied, not believed and not receiving the support and care they need and deserve. Over a quarter said social stigma around migraine has a direct impact on their mental health:

“ I think one of the biggest things I struggle with is people (Doctors, family, employers) who don’t realise the difference between a headache and a migraine. I feel greater awareness of how debilitating migraines are would help acceptance and prompt more research into treatments.”

While loved ones were often mentioned as an important source of support, only 15% strongly believe friends and family understand the impact of migraine - 26% think they do not understand. A third said not being taken seriously by family and friends has a negative impact on them:

“The isolation is probably the worst part. I can go days not seeing anyone. Then my family - the people I do see - don’t understand. My friends see me as unreliable as I’m always cancelling plans. It can easily become a downward spiral where I just want to hurt myself to release the pain I feel.”

Migraine disproportionately affects women and while a majority of our survey respondents were women, some male sufferers suggested they faced a specific stigma:

“It can be embarrassing sometimes as a man to have migraines as they can be dismissed as just a headache in particular by other men. Creating awareness for men and migraines would help.”

4. Impact on employment and finances is significant

Migraine affects people of all ages, including those in education and retirement, but the impact on people in work was a consistent theme throughout the research, with 49% saying living with migraine has a significant impact on work.

“Brain fog makes me feel stupid during conversations, it makes me concerned I’m going to lose my job and seriously makes me depressed.”

Feelings of fear and guilt were mentioned by many, including people working in healthcare themselves:

“Honestly, I just want not to feel like I’m not letting down work again and that I won’t tip over the sick leave into disciplinary because of my absence record. I am a doctor myself in an NHS trust.”

“Work used to say they understood but showed differently in their actions – I was a Staff Nurse for 43 years.”

Those who talked about challenges in the workplace were likely to mention employers who do not understand or provide adequate support.

“ My employer is not sympathetic to migraine. The reasonable adjustment was that my migraine must end by 11am or be classified as a day sickness. Three days’ sickness results in a disciplinary. I have driven to work not being able to see because of the fear of losing my job through sickness. This causes stress and depression because I am caught between a rock and a hard place.”

“The significance and strain of living with migraines is consistently downplayed by friends/family and mostly by my employer, which makes me feel so isolated and insignificant.”

The consequences of poor workplace experiences included having to leave or cut down on work and decline in mental health. 27% said the impact on employment has had a significant impact on their finances.

“Financially I really struggle for money and worry about the future. Triggers such as noise, lights and fragrance mean I don’t really leave the house ever (plus COVID now of course). All of my hobbies are solitary and indoors as a result. All of these combine to make my mental health worse and to feel like my life is quite diminished.”

“I freelance and find it very difficult to plan as I don’t know when the next migraine might come. Very unsettling. Might have to give up my work which requires fixed, inflexible dates.”

5. Inequity in access to positive care causes further challenges

While lots of examples of positive care were given, delays or challenges in accessing appropriate healthcare were also common themes. 43% said not having a treatment that works is one of the things affecting their mental health the most.

“I really am losing hope at finding something that really works. Migraines are so poorly understood and I’m sick of going back to the GP only to try the next random medication that “might work for some people” even though it’s not licensed for migraines, but there’s not much else to try.”

Inequity in provision of treatments were raised by many too:

“There are treatments available on the NHS, but not in my region, which is so unfair.”

“[I want] doctors to stop refusing to offer newer medications because of cost [and] NICE to stop insisting that sufferers have to have trialled three different medications before they are given them.”

When asked what would help improve their mental health, over two-thirds said new treatments and over half said lower waiting times to further speed access to medication:

“ Treatment is haphazard, inconsistent and GPs just send you away with different drugs, without explaining side effects or other options. I just feel totally worn down by migraine and ignored by the NHS.”

Another theme was feeling misunderstood. Over a third (38%) said feeling like they are not being taken seriously by health professionals has a negative impact on their wellbeing. This included lack of understanding of migraine and symptoms, as well as the impact of mental health on migraine. 15% think health professionals understand the mental health impact of migraine with 24% strongly disagreeing.

“Being taken seriously by my GP and not just going... ‘its just migraines what are you wanting from this conversation, do you want me to book you off work?’”

“Mental health treatments will not be effective unless migraine sufferers can access new migraine treatments through the NHS.”

“I don’t know what the answers are, but I do know that doctors really need to take migraines more seriously. I am saying this not only as a migraine sufferer, but also as a nurse. The negative impact on mental health is so closely related to migraine, symptoms of migraine and the treatment that is not available.”

6. Support is patchy

People mentioned accessing support from a range of places including family, the NHS, faith groups, social media and The Migraine Trust. Some reported positive support networks:

“Excellent GP, and migraine clinic and nurses. Good local faith (Quaker) community. Friends - we all have different health issues!”

When asked what would help their mental health, 46% said meeting others with migraine. Peer support is valued by many, both off and online. Several referenced others with migraine being the only ones who truly understand what living with migraine is like. This included through community or pain-focused support groups, as well as online sources including The Migraine Trust, Migraine World Summit and social media:

“A Discord server that is incredibly active with members from all round the world.”

“I find it really really helpful to talk to other sufferers and to read things from The Migraine Trust. It makes a lot of difference to know you aren’t alone.”

A quarter said they don’t get support. This included those who don’t feel they need it, as well as those who want support but are unable to access it:

“Tend to plough on alone as don’t want to worry others with my frequent migraine problems.”

Only 34% have been able to access mental health support on the NHS and 11% privately. Those who have had professional support generally said it was good but did not last for long enough.

“I was extremely lucky to see a psychologist for 6 sessions via a pain clinic and it was wonderful (and validating, because I was told that the feelings and beliefs I was describing were very common among people who experience chronic pain).”

When poor experiences of professional support were mentioned, it often related to lack of understanding about migraine:

“[Support was patchy], several practitioners had personal experience, others were obviously struggling to take the condition seriously as a medical issue.”

“Ineffective. Therapist didn’t understand migraines and the impact that they have. Instead, they insinuated that migraines are mostly psychological. I spent time trying to explain! Very disappointing, infuriating and invalidating experience.”

Barriers to mental health support included waiting lists being too long, feeling embarrassed to ask for help or not thinking they would be taken seriously. Some talked about lacking the funds or energy to seek support. Not wanting to add to NHS pressures or feeling like a burden were also mentioned as reasons people felt they should not ask for support.

“I’m still on the waiting list, have been on it for 4 years.”

“There are a lack of support services/spaces that are culturally competent. Ignoring the additional layers I have of living with migraine whilst being a Black woman has severely impacted my mental health.”

“I am a Psychotherapist myself so I have other professional friends I can talk to though I don’t like to go on about my migraines there’s almost a sense of shame that I still get them and they’re worse. I just think why me?”

The majority (72%) said the most important thing The Migraine Trust should do is increase awareness of what migraine is, and the mental health impact of living with it.

“I wish you could help shape government policy that requires all employers to provide support for their employees who suffer from migraine.”

“Raise awareness of migraine itself. Encourage people to stop describing headaches as “migraines.”



If your migraine was more controlled, for example through better treatment, what would that mean?

Respondents suggested a reduced impact for the NHS and its workforce in particular, they also talked about cost savings related to fewer appointments and ineffective prescriptions. Some talked about what it would mean for their personal finances or ability to take medication for other conditions that migraine medication interferes with:

“I would spend a lot less on alternative treatment acupuncture, massage, osteopath, Botox etc.”

“I would be more able to take acute medication for my other chronic pain conditions (e.g. I had to stop taking daily NSAIDs about 5 months after my migraines started in 2021).”

Many spoke of the benefits to their mental health and life as a whole:

“I would be able to plan my future.”

“I would be less depressed. I would be more alive.”

“I would be worthwhile as a person and someone who can contribute more and put less strain on my partner.”

“ I wouldn't have to spend all day, every day living in the dark, covering my eyes to stop the pain getting worse and unable to go anywhere where it is bright. I would be able to look at screens e.g. computers again and not be entirely cut off from society.”

Conclusion

There is no one typical migraine experience. Each person will have their own pattern of symptoms and experience of pain. Living with physical pain can have a big impact on mental health, however migraine can cause hurt in many other ways.

Reduced ability to socialise, lack of support in employment and not feeling understood are just some of the factors impacting wellbeing, compounded by difficulties accessing treatments or healthcare in general. The consequences can be incredibly detrimental.

Much needs to change. Lack of awareness across all sectors of society of the reality of migraine is at the heart of the issue. Unless we change the perception that migraine means headache, misunderstanding will continue to pervade. The 10 million people in the UK living with migraine deserve so much better.

At The Migraine Trust we will use the insight from this research to develop our work and give us even greater focus. This includes in the support we offer, our awareness raising activities, our work with health professionals and with policy makers.

We want to see timely diagnosis and care for migraine. The majority of people should be diagnosed and managed in primary care and we will prioritise our work supporting general practice, as well as pharmacy, so that no one has their symptoms dismissed or overlooked. We will advocate for equitable access to new medicines across the UK instead of a postcode lottery of opportunities. Through our workplace programmes we will support more employers to provide supportive working environments with reasonable adjustments. We will also take every opportunity to raise awareness of migraine and tackle the stigmas that cause so much harm.

Finally we will use this report to highlight the true reality of migraine in our work with policymakers, health professionals and organisations across the UK. Migraine hurts in many ways beyond the physical pain and is far more than just a headache.




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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