

The language of migraine

The words people living with migraine use and how they can help us better understand their experiences

Migraine is often misunderstood – for those that don't experience it, it is easily dismissed as a bad headache, rather than recognised as a severe, long-term condition that can have a significant impact on quality of life.¹

We wanted to get to the heart of the people's thoughts, feelings and frustrations about living with migraine and better codify its effects on their careers, social lives and relationships. Crucially, we needed to hear their own words to ensure we're all speaking the same language when it comes to migraine.

We conducted an in-depth social listening audit, using a combination of a specialist tool, Brandwatch, and manual data collection. We based our search on keywords relevant to migraine over the past year in the UK, across X (formerly Twitter), Instagram, TikTok, blogs, forums and news sources. These have been verified for relevance and analysed for the language used in relation to perception and experiences of migraine.



Our findings led us to three key areas:

- Pain and the lived experience of migraine
- The individual nature of the condition
- Lack of knowledge and understanding about migraine

When it comes to pain and lived experience, the words used were emotional and evocative. This was a salutary reminder of the empathy required when treating migraine – it can be deeply frustrating and distressing for both sufferers and healthcare professionals, and the focus during consultations should be on listening and encouraging open conversations.

FINALLY over my migraine, which was easily the worst attack I've had in ages. I feel like I've lost two days, unable to do anything, even move. I feel so sorry for anyone who has them regularly.

Every time I hear about someone finding relief, it makes me smile. Migraines can take so much away from us – glad to know that some people are getting some time back and feeling like themselves again.

The very personal nature of migraine shone through with people sharing their coping mechanisms and symptoms, which speaks to the fact that there is no 'one size fits all' treatment option and healthcare professionals should be open-minded as to what could work best for each patient.

I thought I knew about migraines, having seen my mum live with them for years. But when I got my first one, I was totally unprepared for it.

It took ages to diagnose my chronic migraines, as they're not affected by light and sound so lying in a quiet, dark room wasn't helping.

The lack of understanding was also clear, with people recounting experiences with co-workers and family members who minimise migraine.

My migraines were seen as an excuse to get out of work – colleagues would say it was just a headache and question whether I needed time off.

Our research to date shows there is still plenty of work to be done when educating on the impact of migraine – and this work can start with shining a light on the reality of the condition using the terms of sufferers. Join us in highlighting the real language of migraine and showing it is more than just a headache.



1. What is Migraine? Factsheet. The Migraine Trust. Online. Available at: <https://migrainetrust.org/understand-migraine/what-is-migraine/#page-section-1> Last accessed September 2023