HOPE IN PAIN | MIGRAINE MEANDERINGS

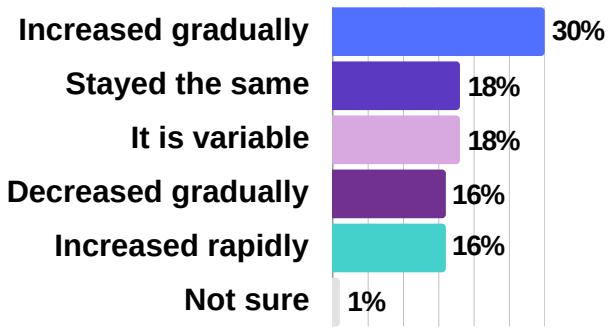
SURVEY REPORT:
Has Your Migraine Worsened?

EMPOWERING *Patient Voices*

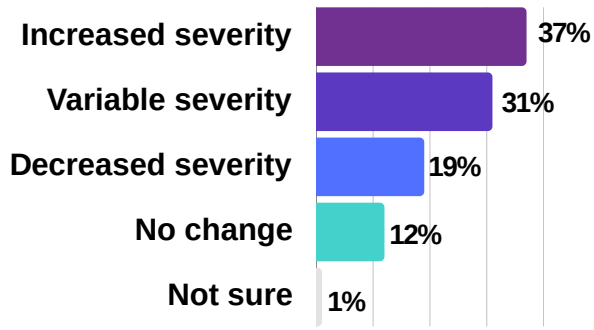
Hope In Pain and Migraine Meanderings recently conducted an online survey to better understand how people's migraine has progressed over time. The survey, completed by **580 respondents**, was distributed online via social media channels, our website, and by email.

Overall, most respondents report worsening or fluctuating migraine frequency and severity, and many feel their treatments are becoming less effective. Over the last few years, they report:

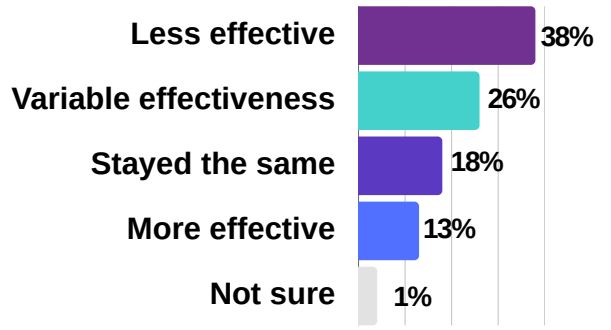
HOW THE NUMBER OF MIGRAINE DAYS/MONTH HAS CHANGED:



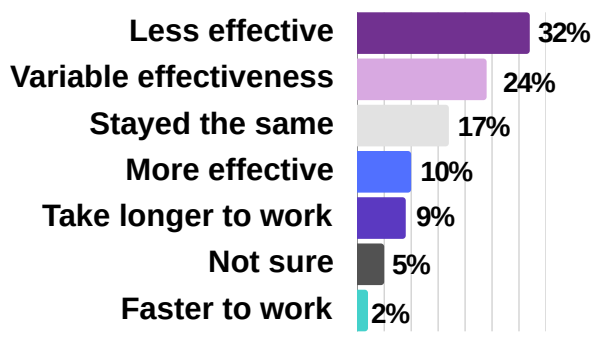
HOW SEVERITY OF MIGRAINE ATTACKS HAS CHANGED:



HOW RESPONSE TO PREVENTIVE TREATMENT HAS CHANGED:



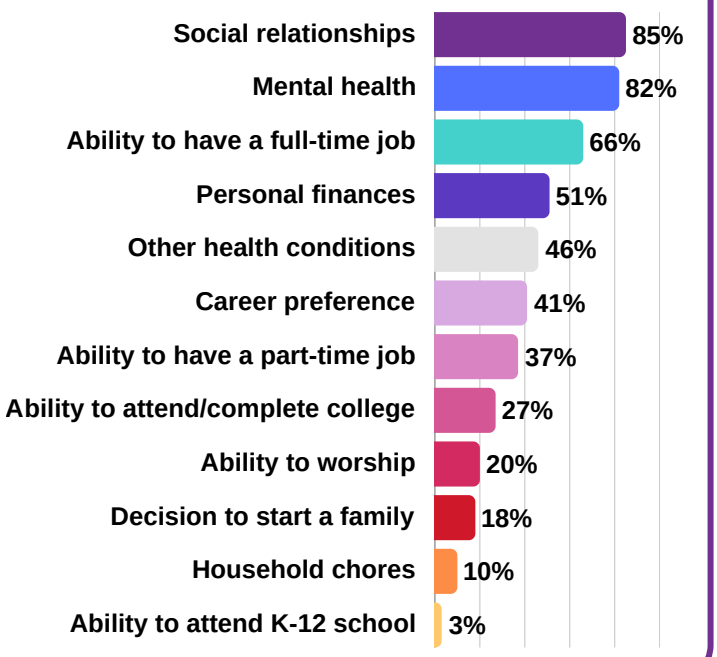
HOW RESPONSE TO ACUTE TREATMENT HAS CHANGED:



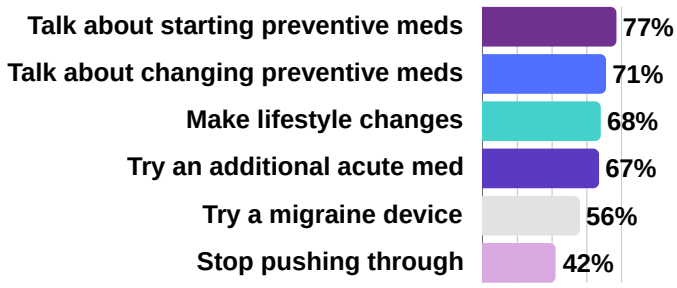
KEY INSIGHTS:

Migraine often gets worse, not better, over time, and its course is generally unpredictable. Survey responses indicate that migraine has progressed for many patients: **nearly half report rising attack frequency**, **over a third report rising severity,** and a **substantial amount report declining treatment effectiveness**. These findings point to a critical need for more effective disease management strategies, as well as broader access to new medications and other treatment options for people with migraine.

AREAS OF LIFE IMPACTED BY LIVING WITH MIGRAINE



WILLINGNESS TO IMPLEMENT CHANGES



"I know my migraine has progressed throughout my life, and I am watching my 13 year old son going through that progression himself... almost exactly like it did for me."

—Survey Respondent

KEY INSIGHTS:

Awareness of migraine as a progressive disease is lacking: About **66%** reported that **they were aware** migraine disease could chronifiy/get worse over time. In addition, **only about half (52%) said they know how to slow or reverse progression**, and **only 35% have ever heard** about disease progression from a healthcare provider. This is a striking gap showing that the information pipeline from clinicians to patients isn't where it should be; patients have to self-educate.

Mental health and social relationships are affected more than career or employment: This is noteworthy, as the popular narrative around migraine tends to focus on missed workdays and productivity loss. This data suggests the **relational and psychological toll** (isolation, strained relationships, anxiety/depression) is even more pervasive.

There's a clear belief–behavior gap: 70% of respondents believe "pushing through the pain" contributes to progression — however, answers indicate that it's the thing they are least likely to change. People expressed a preference to add a new medication or device instead of rest. **Patients understand the need intellectually, but face real barriers** (work, caregiving, stigma) to acting on it.

Migraine is a near-constant strain: **88% report symptoms between attacks (the interictal phase)** including fatigue and brain fog, which impact daily functioning — **migraine is not just burdensome on "attack days."**

Unclear understanding of how preventive treatments reduce progression: Many respondents note that the goal is to "reduce frequency and/or severity of migraine attacks." Others note that it is to "improve the ability to function." But very few mention that it can help reduce the risk of disease progression.

Patient Voices

Respondents said:

"How am I supposed to stop the progression when I can't get the medication that may give me at least a small amount of help?"

"Doctors lack of knowledge, or willingness to address migraine disease quickly, often leads to chronic migraine, and patients are often oblivious to this risk. I wish I would have understood this from the beginning and I would have advocated for myself better."

"I wish I had known a long time ago that migraine is progressive, but I didn't know; I don't think even researchers knew. I never read it anywhere until the last 2-3 years. So I did a lot of the wrong things to treat myself. And I pushed through because I had to work, had a family, and it was just life. If I had known about migraine progression, I would have sought out preventive meds years ago and treated myself very differently."

"Literally NONE of the doctors I have seen have said anything about progression."

"It feels like it's too late for me; I'm already chronified. But I still keep trying, and research gives me hope."

"Migraine essentially ruined my life in every way you can think of. I'm so tired of being sick, managing symptoms, being in pain, and missing out on life."

"I always wonder, if I had been properly diagnosed (it took 6 years), would that have prevented the progression to chronic migraine?"

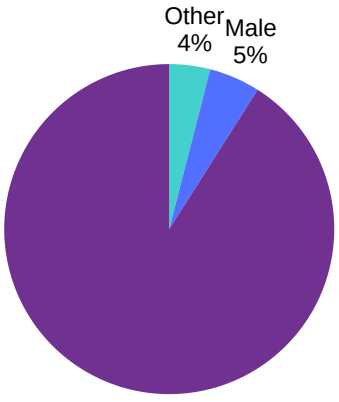
"Migraine forced me to give up my dreams of finishing college and going to medical school. I wish I'd have known when to speak up sooner that the medication wasn't working so I could have found something that helped. Maybe my migraine wouldn't be as bad as it is now."

RESPONDENTS' DEMOGRAPHICS

AGE

18-25	2%
26-40	16%
41-55	37%
56-64	24%
65+	18%

GENDER



EMPLOYMENT

1 in 4

are on permanent disability

Combining "not working" and "short-term disability," roughly **44%** of survey respondents are outside the traditional workforce.

INTRACTABLE MIGRAINE

36%

have intractable migraine — attacks that last more than 72 hours

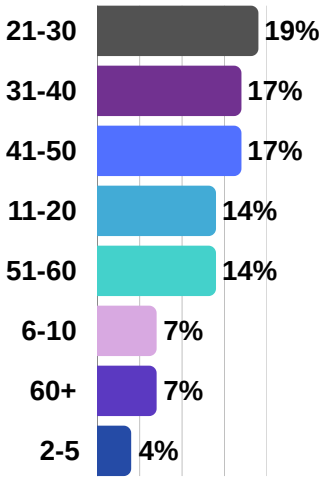
HEADACHE DISORDER DIAGNOSES

56%

have 2+ headache disorder diagnoses

Only 44% of respondents report having just migraine.

OF YEARS WITH MIGRAINE



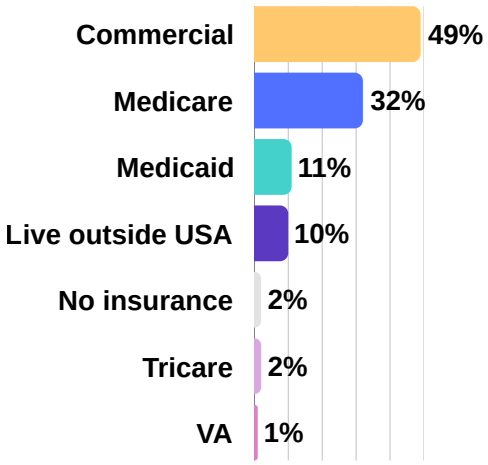
FREQUENCY

82%

have chronic migraine (15+days p/mth)

- **9.5% are High Frequency Episodic** *(9-14 days/month)*
- **8.5% are Low Frequency Episodic** *(1-8 days/month)*

INSURANCE TYPE



In Summary

The results of this survey highlight the very real ways migraine progression impacts patients' lives. Even though patients realize lifestyle changes are key to stopping disease progression, **there appear to be real barriers** to making those changes. This topic was discussed in our upcoming focus group and needs to be explored in greater depth.

Additionally, patients do not understand the role preventive medications have in reducing migraine progression risk. The survey highlights the need to **develop educational resources** to increase patient knowledge.

This survey data also shows that **more information is needed** as to why doctors managing migraine care are not explaining the risks of disease progression to patients.

Recommendations

- Establish a Standardized "Progression Conversation" Prompt for Clinicians
- Develop Patient-Facing Education That Applies Below the Chronic Threshold
- Address the Barriers Behind "Pushing Through"
- Invest in Peer Support as a Complement to Clinical Care
- Advocate for Reduced Access Barriers to Preventive Care

"The point is NOT made enough. The consequences should be made more clear. For example, "If migraine becomes chronic your ability to function in the world will stop." *—Survey Respondent*

Migraine Meanderings

Hope in Pain

Migraine Meanderings is a dba of Hope in Pain, Inc.,
a 501(c)3 charity dedicated to raising awareness and providing educational resources and support to people who live with migraine.