



Advocating for Migraine Treatment:

A Focus on Insurance Barriers

A “how-to” toolkit on advocating for access to
migraine treatment by removing insurance barriers





Contents

Overview	3
Key Messages	5
It's Time for Action	6
Toolkit Resources	7
Social Media Campaign	8
Sample Newsletter Article	10
Sample Legislative Letter	11
Sample Questions to Ask Your Doctor	12
Sample Telephone Script for Calling Your Insurance Company	13
Guide to Submitting an Insurance Complaint	14
About Us	15



The full summary report, media resources, and toolkit are all available online at MigraineMeanderings.com/insurance-coverage.

This toolkit is also available on HMPF's Partner Resources page: Headachemigraineforum.org/partner-resources.



Overview

Migraine is a complex and often debilitating neurological disease affecting over 42 million people in the United States alone. Approximately 5 million of this number live with chronic migraine, defined as 15 or more migraine/headache days a month. Appropriate medical treatment can help prevent, reduce, and/or stop migraine attacks. However, migraine disease is not managed by a one-size-fits-all treatment plan.

Unfortunately, health insurance plans frequently delay, deny or change physician-prescribed treatments. New data from Migraine Meanderings and The Headache & Migraine Policy Forum exposes the impact of these insurance policies on patients' lives. Four patient surveys investigated the impact of prior authorization, step therapy, non-medical switching, and the need for combination therapy. [The full survey summary report is available here.](#)



Prior Authorization

Before agreeing to cover a treatment, insurance plans must agree on its “necessity” according to their guidelines, requiring the physician to provide more information before approving coverage.



Step Therapy

Often known as the “try and fail” or “fail first” policy, step therapy is where insurance plans force patients to try older or less expensive treatments before approving new ones.



Non-medical Switching

Insurance plans have treatments they prefer and will cover due to cost savings. However, switched treatments may not work as well or may not be medically appropriate for the patient.



Combination Therapy

Effective management of migraine disease often requires more than one treatment. Different classes of medications and medical devices are often combined to maximize efficacy.

Insurance delays, denials and switching are more than just a minor inconvenience. These practices impact migraine patients' quality of life and put a heavy burden on the health care system overall. Migraine attacks often become more severe and/or frequent. Visits to the emergency room, urgent care, and unplanned doctor visits often increase. In addition, patients may miss school, work, social gatherings and time with family, often causing a heavy financial and emotional burden.

This toolkit guides patients and providers on how to use their voices to bring about change. Timely insurance coverage for appropriate and effective migraine treatment is essential.



When asked about their experience with step therapy, 32% of survey respondents reported having to **wait 2-6 months to get the treatment** their physician originally prescribed.

Key Messages



1 Migraine Doesn't Wait

A concerning 64% of migraine patients report encountering prior authorization requirements. 42% say it took more than a week for their insurance company to approve the prescribed treatment, with some never receiving it. While patients wait, their quality of life diminishes, and the cost of migraine rises.

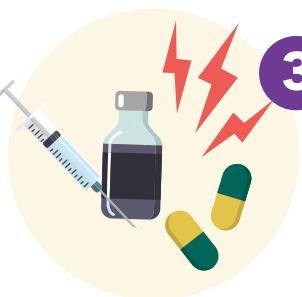
“Delays in treatment access impacted my ability to feel like I could keep going, to feel like I mattered, and to mentally and physically be able to function even on a small scale.”

SURVEY RESPONDENT



2 “Fail First” Should Not be a Treatment Option

Step therapy is a significant hurdle. 93% of migraine patients say they're forced to “fail first” before receiving prescribed treatment. Denying access to prescribed treatments can make it more difficult for patients to sleep, work, fulfill family obligations, and engage in social activities.



3 Migraine Is Not a “One-Treatment” Disease

Insurance coverage for a combination of medications is a challenge for 68% of migraine patients. Physicians often prescribe combination therapy because of evidence that it can reduce migraine frequency and severity more effectively.



4 Poorly Managed Migraine Increases Health Care Costs

Delays and denials to physician-prescribed treatment often land migraine patients in the emergency room. 88% of patients said they've sought emergency or urgent care as a result. Not only does this burden patients, but it also places an undue strain on the health care system.

See the detailed [Summary Report](#) from all the surveys [here](#).

It's Time for Action

If you, your patient, or someone you know living with migraine has been denied access to treatment, it's time to take action. The resources in this toolkit provide a guide to follow for next steps.

By raising awareness of the barriers faced by people living with migraine, we can:

- Break down migraine stigma by educating others
- Help bring about policy changes
- Connect with people going through similar experiences
- Become more empowered & resilient



10 Ways to Advocate for Change:

Raise Awareness

- 1 **Share the social media posts** and images found in this toolkit using suggested hashtags
- 2 **Comment on, like and share posts** on Migraine Meanderings and The Headache & Migraine Policy Forum's social media channels
- 3 **Share infographics** and materials through your newsletter, blog or organizational email blasts
- 4 **Share a short video testimonial** on social media about the insurance challenges you have faced getting migraine treatments
- 5 **Share your story with the media** by writing "op-eds" and letters to the editor

Take Action for Change

- 6 **Send a letter to your state legislator**—a sample letter template is included in this toolkit
- 7 **Call your insurance company** to appeal whenever a treatment is denied—a sample script is included in this toolkit
- 8 **Sign on to letters** to your state insurance commissioner or health plan director
- 9 **Join a state access barrier event** organized by The Headache & Migraine Policy Forum
- 10 **Submit an insurance complaint** to your state commissioner. A sample is included in this toolkit

Social Media Campaign

Take action with us this April!

The launch of our awareness campaign runs from April 1-30, 2024.



Social Media Messages & Images

Use the social media posts and images on the following pages to raise awareness. These graphics and sample posts are all available on the [Migraine Meanderings website](https://migrainemeanderings.com/insurance-coverage/insurance-social-media-graphics).

Download All Social Graphics
[MigraineMeanderings.com/insurance-coverage/insurance-social-media-graphics](https://migrainemeanderings.com/insurance-coverage/insurance-social-media-graphics)



Suggested Hashtags

Use the following hashtags in your posts to magnify the migraine community voice and impact:

#MigraineBarriers

#ListenToPatients

#MigraineTreatmentAccess

#StopInsuranceDelays

#MigraineRelief

#TrustPatients

#MigraineWontWait

Migraine Doesn't Wait—It Chronifies

While patients wait for effective treatment of this debilitating disease, migraine doesn't wait. The disease can get worse, quality of life diminishes, and the cost rises with ER visits and loss of work.



LEARN MORE:
www.MigraineMeanderings.com
www.HeadacheMigraineForum.org

Migraine Meanderings | The Headache & Migraine Relief Forum

WEEK 1: April 1-7

"Fail First" Should Not Be a Treatment Option





When insurance requires migraine patients to try and "fail" prior to approving a prescribed treatment, it leads to an increase in symptom severity and frequency.





LEARN MORE:
www.MigraineMeanderings.com
www.HeadacheMigraineForum.org

Migraine Meanderings | The Headache & Migraine Relief Forum

WEEK 2: April 8-14

-  **X/Twitter 1:** Stuck in limbo waiting for **#MigraineTreatmentAccess** ins approval? Each delay is another day w/debilitating pain. Is timely access 2 health care too much to ask? **#StopInsuranceDelays**
-  **X/Twitter 2:** Why is insurance a barrier to **#migraine** treatment?! 64% of patients face prior authorization delays, & 33% deal w/ switching delays. **#StopInsuranceDelays**
-  **Facebook:** Are you stuck in insurance limbo awaiting treatment approval? Each delay is another missed day managing debilitating pain. Is timely access to health care too much to ask? **#MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients #MigraineWontWait**
-  **Instagram:** Are you stuck in insurance limbo waiting for approval for treatment? Each delay is another missed day managing debilitating pain. Is timely access to health care too much to ask? **#MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #MigraineAwareness #MigraineRelief #TrustPatients #MigraineWontWait**

-  **X/Twitter 1:** People w/ **#migraine** are forced to "fail first" on meds preferred by insurance plans. 93% say this delays effective treatment & worsens symptoms. Do you agree? **#StopInsuranceDelays**
-  **X/Twitter 2:** **#Migraine** isn't just a headache; it's a life-disrupter. Insurance delays impact sleep, work & mental health, while making debilitating symptoms worse. **#StopInsuranceDelays**
-  **Facebook 1:** People with migraine are often forced to use meds preferred by their insurance company instead of meds prescribed by their doctor. Do you think Insurance companies should have the right to override a Drs recommendation? **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**
-  **Facebook 2:** Should insurance companies have the right to force patients to use their preferred meds instead of Dr prescribed meds? 93% of migraine patients surveyed say these policies delay effective treatment and worsen symptoms. Share this post to raise awareness of this practice. **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**
-  **Instagram:** Should insurance companies have the right to override Dr prescribed prescriptions? Migraine patients are often forced to use meds preferred by their health plan rather than their doctor. 93% of patients say these policies delay effective treatment and worsen symptoms. Leave a comment if this has happened to you! **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**



Migraine Is Not a "One Treatment" Disease

Combination therapy can effectively reduce migraine attack frequency and severity, but insurance barriers prevent patients from accessing the treatments their doctors prescribe.



LEARN MORE:
www.MigraineMeanderings.com
www.HeadacheMigraineForum.org

Migraine Meanderings | The Headache & Migraine Policy Forum

WEEK 3: April 15-21

Poorly Managed Migraine is Expensive for Everyone






Insurance barriers to prescribed migraine treatments have a far-reaching impact. They negatively affect a patient's physical and mental health, education, and employment, while putting additional strain on doctors' offices and emergency health care settings.







LEARN MORE:
www.MigraineMeanderings.com
www.HeadacheMigraineForum.org

Migraine Meanderings | The Headache & Migraine Policy Forum

WEEK 4: April 22-30

-  **X/Twitter 1:** Why are health plans pushing **#migraine** patients onto certain meds, instead of what Drs prescribe? Medication decisions should be between dr & patient. **#StopInsuranceDelays**
-  **X/Twitter 2:** #Migraine Combination Therapy can transform lives, but 68% of patients face insurance barriers to dr-prescribed meds—have you? **#StopInsuranceDelays #MigraineRelief**
-  **Facebook 1:** Has your insurance company delayed, denied, or switched your doctor-prescribed medications? People with migraine deserve access to the treatments they need, not denials! Share your experience with insurance delays and denials in the comments below. **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**
-  **Facebook 2:** Even though a combination of treatments often delivers the best results in reducing migraine attack frequency and severity, insurance companies make getting them a nightmare. Share your experience with insurance delays and denials in the comments below. **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**
-  **Instagram:** Has your insurance company delayed, denied, or switched your doctor-prescribed medications? This practice isn't just frustrating, it's unfair and can make migraine symptoms worse. People deserve access to the treatments they need, not denials! Share your experience with insurance delays and denials in the comments below. **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**

-  **X/Twitter:** Did you know the burden of **#migraine** likely exceeds \$28B/year? Insurance plans can reduce this burden by stopping med delays, denials & switching. Do you agree? **#StopInsuranceDelays**
-  **Facebook 1:** Did you know migraine costs the US over \$28 BILLION annually? This staggering figure includes ER/doctor visits, medications, and lost work days. We can reduce this cost if insurance plans stop delaying, denying, and switching medication. Share and comment on this post if you agree! **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**
-  **Facebook 2:** Did you know migraine costs the US over \$28 BILLION annually? If insurance plans stop delaying, denying, and switching medication, we can reduce the burden of migraine disease. Share and comment on this post if you agree! **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**
-  **Instagram:** Did you know migraine costs the US over \$28 BILLION annually? This staggering figure includes direct costs like ER and doctor visits as well as medication, but also lost productivity and both absenteeism and presenteeism at work. If insurance plans stop delaying, denying, and switching medication, we can reduce the burden of migraine disease. Comment on this post if you agree! **#MigraineWontWait #MigraineAwareness #MigraineBarriers #ListenToPatients #MigraineTreatmentAccess #StopInsuranceDelays #TrustPatients**

Sample Newsletter Article

Please feel free to tailor the language below to bring the patient and health care provider voice to your blog, website, newsletter or local newspaper. The below content is optimized for SEO.

Insurance Delays and Denials Impact Patient Access to Migraine Treatment: Advocate for Change!

Migraine is a complex, often debilitating, neurological disease that impacts more than 42 million people in the United States alone. Despite the impact on patients' lives, and society as a whole, health insurance plans frequently delay, deny or switch treatment options prescribed by physicians. Migraine Meanderings and The Headache & Migraine Policy Forum partnered together to learn from the online migraine community about the impact of these policies.

Four patient surveys in 2022 and 2023 explored how insurance coverage impacts patients' ability to access physician-prescribed treatments. In total 12,800 patients; there were 4,500 responses from 1,200 patients; and a summary report can be found here: <https://migrainemeanderings.com/insurance-coverage>.

Challenges patients had getting treatment coverage included insurance companies' policies on combination therapy, prior authorization, non-medical switching, and step-therapy:

- Over **70%** of patients said they take more than one preventive and/or more than one abortive treatment for migraine, with many taking 4 or more. However, approval for more than one medication was a frequent challenge.
- **64%** of patients reported experiencing prior authorization requirements, and 33% experienced both prior authorization and non-medical switching. This places a huge burden on patients as well as physicians.
- **74%** reported that having to try insurance-recommended treatments first led to their disease worsening.
- **28%** reported seeking emergency treatment directly due to these insurance practices. Having to utilize emergency care creates both a physical and financial burden on patients, not to mention the health care system as a whole.

Next Steps

Addressing these migraine treatment access barriers frequently employed by health insurance plans is crucial. Insurance companies should not be able to override or delay doctor-prescribed treatment. We need your help to bring about this change! We encourage you to **download the toolkit** developed to help patients, clinicians, and legislators work together to ensure patient access to migraine treatment. Participate in the **social media awareness campaign**. **Write a letter to your legislator**. Learn how to **file an insurance complaint**. It is time for change, and together we can make a difference!

Sample Letter to Legislators

Please tailor the language below to convey the patient and health care provider voice to your local, state and national policymakers.

Dear [Your District State Legislator],

My name is [Your Name] and I am a migraine patient living in your district.

I am writing to you today to bring your attention to the significant barriers that utilization management requirements are creating for migraine patients like me trying to access approved therapies. As a chronic migraine sufferer who has struggled to find relief for [X] years, I have experienced first-hand the restrictive and demoralizing process of trying to get access to medications that my doctor has prescribed to manage my disabling headaches.

Insurers often require patients to try and fail multiple older, less effective medications before they will cover the newer preventative treatments that specialists prescribe. The process often takes months, requiring extensive paperwork, appeals, and repeat doctor visits. All the while, patients like me suffer from excruciating pain, lost days of work and school, and reduced quality of life. Some of us may end up becoming disabled. By delaying access to clinician-recommended medications, utilization management techniques like step therapy, prior authorization, and non-medical switching prevent timely, appropriate treatment.

I urge you to consider policy reforms that ensure timely approval of migraine treatments. Removing inappropriate utilization control barriers would empower doctors to make evidence-based decisions in collaboration with their patients.

Please support bills that prohibit step therapy requirements and shorten prior authorization deadlines for migraine therapies and treatments. It is crucial to implement policies that facilitate access to vital medications for this disabling disease.

It is time for policies that enable access to vital medications and devices to help treat. On behalf of the migraine community, I appreciate your consideration of this urgent issue. Your support in advocating for policy changes will make a meaningful difference in the lives of countless individuals trying to manage life with migraine.

Sincerely,

[Your name]

Sample Questions to Ask Your Doctor

It's important for patients to understand how their doctor's office manages the process of insurance delays and denials. This can help keep the appeal process moving. Talk with your doctor to clarify the steps you both need to take to receive coverage approval. This can help reduce delays and denials by your insurance plan.

Here are a few questions to help guide the conversation:

- 1 Will this new medication require a prior authorization from my insurance plan?** Always anticipate that a new medication will require prior authorization, but knowing for sure will avoid surprises.
- 2 Can we check to make sure this medication is on my insurance plan's formulary?** Some doctors will check on this for you, while others will ask you to do this yourself. Either way, checking the formulary can help you assess the need for prior authorization.
- 3 Who in your office/practice should I follow up with about any insurance issues?** Write down names, phone numbers, dates, and any other information that may be helpful if you need to follow up.
- 4 In your experience, how long will it take for insurance to approve this?** Knowing how long the process usually takes can help manage your expectations.
- 5 While waiting for approval, I may need to visit the ER. Can you provide a recommended treatment protocol for me to give to the ER doctor?** If you need to go to the ER, it's helpful to have recommendations to receive the best care based on your medical history.
- 6 If my insurance plan denies coverage after an appeal, what are the next steps?** It's possible to make multiple appeals to your insurance company to get medication covered. It's important to know how the appeal process will work if it is necessary.



Talking to Your Insurance Company



Before you call:

- Gather your policy information, doctor's prescription, and any denial letters you received.
- Note the specific medication and reason for denial/delay you received.
- Be calm, polite, and assertive when speaking with the representative. Take notes of who you speak to, when, and what they say.

Script:

Hi, my name is *[Your Name]* and I'm a policyholder with insurance number *[Your Policy Number]*. I'm calling because my recent claim for *[Medication Name]* was *[Denied/Delayed/Switched]*."

My doctor, *[Doctor's Name]*, prescribed this medication for migraine because *[Explain why the medication is necessary]*. The prescription was written on *[Date]*, and you sent a letter on *[Date]* stating it was *[Denied/Delayed/Switched]*.

Who is the best person to speak to about this? *[Once you are speaking to the right person continue]*

Could you please explain why my prescription for *[medication]* was *[Denied/Delayed/Switched]*?

[Possible answers: didn't receive a response from your doctor, medication is not on the formulary, it's required you try X medication first, etc.]

Thank you so much for providing that information. *[If you are confused by their answer or need more information, ask]* I'm not clear on your reasoning; can you provide more details about why this decision was made?

It is essential for me to receive the prescribed medication. What additional information do you need to get it approved? How long can I expect to wait for a decision? When should I follow up to check on the status of this request?

I will summarize what we just discussed to make sure I understand this correctly. The medication was denied because of *[REASON]*, and to reverse this decision, I will *[ACTION]*.

I will also ask my doctor to *[ACTION]*, and the claim will be reviewed right away. Is that correct?

Thank you for your time and assistance. I appreciate your help in understanding my options and moving forward.

After the call/follow-up:

- Talk with your doctor or their office staff and explain what your insurance told you. Ask how long it will take for them to submit the appeal.
- If the medication is denied again, consider contacting your state's insurance department to file a grievance.

Guide to Filing an Insurance Complaint

Persons living with headache disorders have more treatment options than ever before, including new and innovative medications. For some patients, concurrent use of multiple preventive or rescue medications yields the best outcomes. Yet despite their effectiveness, insurance companies are denying patients access to prescribed medications, adding to the stress, anxiety and stigma of living with the disease.

Patients—and their providers—have an opportunity, however, to get help in appealing their insurance company’s denial. Every state provides oversight of insurance companies. Aside from their regulatory role, states also provide liaison services between insurance companies and the consumers they serve.

If you or your patient has been denied access to treatment, you have the right to file a complaint.



Step 1: Try To Resolve The Issue Directly

Before you file a request for assistance or complaint with your state’s consumer services office, you should first contact the insurance company to try and resolve the issue. If you do not receive a satisfactory response, then contact your state’s consumer services office.



Step 2: File An Official Complaint

Information and state-specific links for filing a complaint are available at headachemigraineforum.org/complaint

Aside from the reason for your complaint, be prepared to provide the following information regarding your situation:

- Name and contact information of the patient or provider filing the complaint;
- Name of insurance company, type of insurance and state where the plan was purchased;
- Claim information, including policy and claim numbers, and dates;
- What you consider to be a fair resolution.

Most states are required to follow up in a defined period, usually 30-45 days.



Step 3: Share A Copy Of Your Complaint

The Headache and Migraine Policy Forum is tracking complaints related to care and treatment denials to help follow-up on systemic access challenges. Sharing your story will help other patients get access to treatment. Please email a copy of your complaint to: complaint@headachemigraineforum.org

About Us

If you would like to get more involved with patient advocacy, or learn more about Migraine Meanderings and The Headache & Migraine Policy Forum, please get in touch with us at:



Migraine Meanderings provides patient-oriented resources, encouragement, support and education for people who live with migraine, raises public awareness about this disease, and seeks to empower patient voices.



migrainemeanderings.com
info@migrainemeanderings.com



The Headache and Migraine Policy Forum advances public policies and practices that promote accelerated innovation and improved treatments for headache and migraine sufferers.



headachemigraineforum.org
lindsay@headachemigraineforum.org