## Survey Summary

Insurance's Impact on Patient Access to Migraine Treatment

Migraine Meanderings





## Introduction

Migraine is a complex neurological disease that affects more than 42 million people in the United States alone. Approximately 5 million of those people have chronic migraine, meaning they have 15 or more migraine/headache days a month. Migraine disease is so much more than "just a headache."

Migraine Meanderings and The Headache & Migraine Policy Forum partnered together to ask the migraine community how their insurance coverage impacted their ability to access doctor-prescribed treatments for migraine. Unfortunately, health plans frequently create barriers for patients trying to access prescribed treatments, and even make it difficult for patients to see certified headache specialists.

Four surveys were completed in 2022-2023 to address the biggest challenges people with migraine experience when accessing medical care. The key to disease management is to have a treatment plan that the patient and the medical team develop together. Those treatments need to be approved and covered by the insurance company. However, all too often, after the insurer conducts a review of a medication, they then begin a process of delaying, denying, or switching the medication (non-medical switching) that the doctor has prescribed.

The surveys conducted explored how delays, denials, and non-medical switching by the insurer impact the health and well-being of people living with migraine. Survey participants were recruited through social media, email, and Migraine Meanderings' support community and website. In total for the four surveys there were 1,945 responses from over 500 people with migraine disease..

The following report summarizes the results of four patient-facing surveys, as well as action steps that can be taken to help bring about change. "Insurance companies should not have more power over my health decisions than my doctor or I do."

*—Migraine Patient* 

#### **Survey Demographics**

#### GENDER

- 94% female
- 4% male
- 2% other

#### AGE

- **56+: 24%**
- 41-55: 44%
- 26-40: 28%
- 18-25: 4%

#### **INSURANCE TYPE**

- 36% Medicare/Medicaid
- 67% Commercial Insurance
- 8% Other

#### FREQUENCY

## On average, respondents report having migraine:

- 60% 15 days or more/month
- 25% 8-14 days/month
- 15% 1-7 days/month

# Survey Reports KEY FINDINGS

## SURVEY #1: **Prior Authorizations and Non-Medical Switching for Migraine**

"Prior authorization is a health plan cost-control process by which physicians and other health care providers must obtain advance approval from a health plan before a specific service is delivered to the patient to qualify for payment coverage"—according to the American Medical Association (AMA).

64% of survey respondents reported experiencing prior authorization requirements, and 33% experienced nonmedical switching in addition to prior authorization. This is a huge burden on patients physically, emotionally and financially. "I ended up admitting myself for inpatient mental health care because my depression from fighting my insurance compounded other conditions, and I knew I needed help."

# 42%

of participants report that it took more than one week for their insurance company to approve their prescribed treatment.

—Migraine Patient

Insurance delays and denials cause patients to feel stressed, anxious, hopeless and depressed. They disrupt patients' ability to sleep, work, manage family obligations, and be in social settings. They also negatively impact patients' overall health, causing more frequent and severe migraine attacks, and the worsening of other conditions.



Read the full survey report on page 11.

## SURVEY #2: Step Therapy for Migraine

Step therapy is when the insurer requires the patient to try one or more different medications before approving a new medication prescribed by a doctor. Most insurers have a list of medications that are preferred. Often these are less expensive and have been on the market for a while. The requirement is for patients to try the insurer-recommended medication for a specific amount of time and "fail"—meaning the patient needs to prove it is not a successful treatment before the new medication will be covered.



of participants report that their insurance has required them to follow step therapy prior to approving a medication/treatment prescribed by their health care provider.

In addition, 42% of participants said their insurance company requires them to try 3-5 medications before approving the medication their health care provider originally prescribed. 89% of participants agree that the inability to access the treatment they need has impacted their ability to manage their migraine. 74% stated that it led to their disease worsening.

Barriers to access created at the hands of insurance companies directly affect all aspects of a patient's life. These barriers have an intensely negative impact on patients' physical and mental well being, hindering their ability to work, attend school, socialize, and more. "Step therapy, imposed by the insurance company, is a conflict of interest and an interruption of the relationship between the doctor and patient who know better what the patient needs."

*—Migraine Patient* 

.

Read the full survey report on page 14.

## SURVEY #3: Combination Therapy for Migraine

Often, patients with migraine need more than one prescribed treatment in their migraine toolbox. Medications and other therapies are essential to reduce migraine symptoms and both prevent and stop migraine attacks. Patients with multiple migraine days per month are recommended to take prescription treatments to prevent attacks, as well as treatments to reduce and stop them.

100% of participants reported that they take at least one preventive and/or one abortive treatment for migraine. 42% of those who use a combination of preventive treatments say the NUMBER of migraine attacks has decreased. 44% of those who use a combination of preventive treatments say the SEVERITY of their migraine attacks has decreased, resulting in a reduced number of abortive medications they need.

Despite the success patients report with taking a combination of migraine treatments, insurance often poses barriers to accessing them. In some cases, forcing patients to choose between a preventive and an acute medication. "My treatment plan has been limited by what my health insurance is willing to cover."

*—Migraine Patient* 

## 68%

of participants have experienced insurance issues accessing the combination of medications their doctor prescribed.

The inability to access the combination of treatments they need negatively impacts patients' ability to manage their migraine. This ultimately adversly affects their education, careers, relationships, financial stability, comorbid conditions, and overall quality of life.



Read the full survey report on page 16.

## SURVEY #4: Migraine in the ER and Urgent Care

Despite the often debilitating nature of migraine attacks that drive patients to the ER and urgent care, these are challenging places to receive migraine treatment. The environment itself is difficult—the harsh lighting, smells, and crowds—and the doctors there are often not trained on the latest migraine research and treatments.

88% of participants went to the ER or urgent care due to the lack of access to a healthcare professional who could treat their migraine. However, the situation in the ER is little different, with lack of training in medical school on how to best treat migraine. In addition, patients often feel they will be labeled as "drug seekers" when they require prescription medication in the ER setting.

> of participants sought treatment at the ER or urgent care directly due

to issues getting abortive or rescue medications that their healthcare professional prescribed for them. "The ER should be a last resort. It is a miserable, uncomfortable place where you roll the dice as to how you are treated and whether you will receive pain relief."

-Migraine Patient

When insurance companies delay or deny coverage of effective treatment options, patients may need to seek emergency care. Managing chronic conditions in the ER is a financial and physical burden on both the health care system and the patient.

28%



Read the full survey report on page 19.

# NEXT STEPS Taking Action

## NEXT STEPS

## **Taking Action**

#### **Next Steps on Social Media**

- 1. Share the social media posts and hashtags found in the Toolkit
- Comment on, like and share the Utilization Management posts on Migraine Meanderings and The Headache & Migraine Policy Forum's social media channels this April
- 3. Share the social media images and article found in the Toolkit through your newsletter, blog or organizational email blasts
- 4. Share a short video testimonial on social media that talks about the insurance challenges you have faced
- 5. Share your story with the media by writing "op-eds" and letters to the editor

#### **Next Steps with Insurance Companies**

- 1. Share this survey report with your insurance company by sharing a link to the report on social media and tagging the company
- 2. Consider filing an insurance complaint if your insurance company has denied treatment needed to manage your migraine attacks
- 3. Write an op-ed for your local newspaper about your experience navigating your insurance company's restrictions

#### **Next Steps with Legislators**

- 1. Share the findings in this report by tagging your state legislators via social media to raise awareness about how delays, denials, and non-medical switching impact the health of people living with migraine
- 2. Work with migraine advocacy groups to meet with your state legislators outside of regular session to educate them about migraine disease and follow-up with their staff members
- 3. During your meetings with state legislators, express your support for state reform measures on issues such as step therapy, prior authorization, non-medical switching, and co-pay accumulators
- 4. Send a letter to your state legislator usig the template found in the Toolkit.



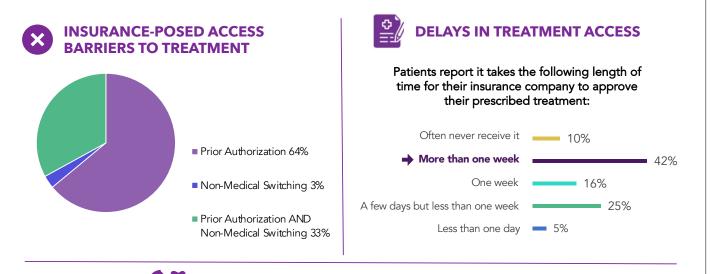


## **SURVEY REPORT** Prescription Delays, Denials and Non-Medical Switching



Migraine Meanderings and The Headache & Migraine Policy Forum recently conducted an online survey to determine how people with migraine are experiencing delays in accessing migraine therapies due to insurance denials and non-medical switching. The survey, completed by **498 respondents**, was distributed online via social media channels and through email.

#### THE RESULTS

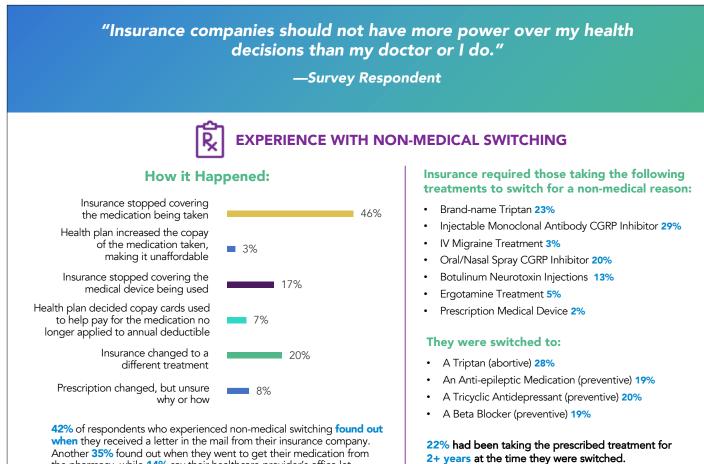


#### **EXPERIENCE WITH PRIOR AUTHORIZATION**

#### Insurance delays and denials negatively affect:

How Patients Feel:		Their	Their Ability To:		Their Overall Health:	
86%	Stressed/Anxious	67%	Sleep	<b>26%</b>	Had to go to the ER/urgent care for treatment	
<b>67</b> %	Angry	61%	Work	<b>78%</b>	Had migraine attacks more frequently	
44%	Hopeless	<b>69</b> %	Manage family	77%	Had more severe migraine attacks	
<b>63</b> %	Exhausted/Weary		obligations	24%	Developed new or additional migraine symptoms	
<b>42%</b>	Depressed	<b>67</b> %	Be in social settings	<b>39%</b>	Made other health conditions worse as a result	
<b>30%</b>	Afraid	<b>12%</b>	Go to school	<b>6%</b>	Saw no difference in migraine attacks	

"[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



Another **35%** found out when they went to get their medication from the pharmacy, while **14%** say their healthcare provider's office let them know.

#### Non-medical switching negatively impacts patients':

#### **Ability to:**

<b>36</b> %	Sleep
41%	Work
<b>43</b> %	Manage family obligations
41%	Be in social settings
<b>8%</b>	Go to school

#### **Overall Health:**

14%	Had to go to the ER/urgent care for treatment
<b>50%</b>	Had migraine attacks more frequently
<b>49%</b>	Had more severe migraine attacks
<b>20%</b>	Developed new or additional migraine symptoms
<b>32%</b>	Made other health conditions worse as a result
<b>6%</b>	Saw no difference in migraine attacks

**50%** of respondents say non-medical switching was a significant disruption.

**52%** say losing access to the treatment that worked for them has impacted their ability to manage their migraine.

**49%** say losing access to the treatment that worked for them has negatively impacted their mental and emotional well-being

	SURVEY	DEMOGRAPHICS
--	--------	--------------

GENDER		AGE	AGE		INSURANCE TYPE	
90%	Female	5%	18-25	38%	Medicare/Medicaid	
8%	Male	23%	26-40	<b>66</b> %	Commercial Insurance	
2%	Other	42%	41-55	<b>6%</b>	Other	
		<b>19%</b>	56-65			
		9%	65+			

#### FREQUENCY

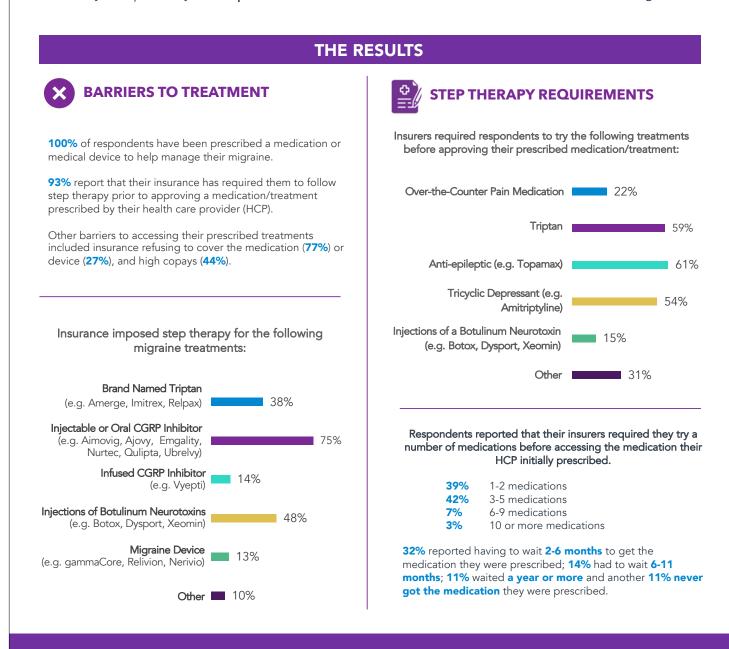
On average, respondents report having migraine:

<b>17%</b>	1-7 days/month				
<b>24%</b>	8-14 days/month				
<b>59</b> %	15 days+/month				



## **SURVEY REPORT** Step Therapy for Migraine and Other Headache Disorders

Hope In Pain and Migraine Meanderings recently conducted an online survey to better understand the experiences people with migraine and other headache disorders have had with insurance step therapy. The survey, completed by **431 respondents**, was distributed online via social media channels and through email.



#### MIGRAINEMEANDERINGS.COM | HEADACHEMIGRAINEFORUM.ORG

The Headache

& Migraine

"Step therapy is awful, especially when I have already tried the medications the insurance company wants me to try. It's a hassle to get the documentation from doctors and to send to insurance. All we want is some relief from our pain and insurance companies make it incredibly difficult!"

—Survey Respondent



**STEP THERAPY APPEALS** 

- About 60% of respondents' HCPs sent a letter and/or called insurance with their medical history to appeal the step therapy requirements.
- About 46% of respondents called and/or wrote a letter to their insurance companies to appeal the requirements themselves.



#### **IMPACT ON QUALITY OF LIFE**

During the time respondents were taking the insurer's required medication(s), instead of the medications / treatments their health care provider prescribed, quality of life was impacted for many:

- **57%** had migraine attacks more frequently
- 34% developed new or additional migraine symptoms
- 41% developed more severe migraine attacks
- 31% had to go to the ER or urgent care for 1 or more migraine attacks

89% of respondents agree that the inability to access the treatment they need has impacted their ability to manage their migraine. They also agree that it has:

- Led to their disease worsening (74%)
- Negatively impacted their quality of life as well as their mental and emotional well being (89%)
- Negatively impacted their work and career (72%)
- Negatively impacted their education (30%)



"During the waiting period. My migraine went from episodic to chronic. Still dealing with insurance and it has been years. Also dealing with copay cards and unexpected bills worth \$40k for things insurance "mistakenly" covered."

"[Step therapy] is barbaric and contributed significantly to the worsening of my disease."

"Step therapy, imposed by the insurance company, is a conflict of interest and an interruption of the relationship between the doctor and patient who know better what the patient needs."

"I now have heart issues because of certain meds, and the migraines are worse! Step therapy is unnecessary and harmful!"

"It's extremely frustrating to pay your insurance premiums every month, and then have to struggle and fight for the medications that you need."

"Once I went through all the hoops and time to get the medication approved I discovered that my copay was going to be \$650 per month. Not the cost of the medication, just the copay. So after all the work and the waiting I still couldn't get the medicine."

"I will bounce back from the worsening of my physical health, but I am permanently scarred mentally and emotionally from the trauma of not being able to access medicine that would give me some level of functionality. "

"The use of any treatment should be a decision made jointly by the patient and physician without interference by the insurance company, who does not have the best interests of the patient as its goal."

#### 

- GENDER
  - **96%** female 56+: **25%**
  - 2% male
     41-55: 42%

     26-40: 30%
- **2%** other
  - 18-25: 2%

AGE

#### INSURANCE TYPE

38% Medicare/Medicaid70% Commercial Insurance3.5% Other

#### FREQUENCY

On average, respondents report having migraine:

62% 15 days or more/month25% 8-14 days/month13% 1-7 days/month

## **SURVEY REPORT** Combination Therapy for Migraine



Migraine Meanderings and the Headache and Migraine Policy Forum recently conducted an online survey to better understand the experience people with migraine have with combination therapy for migraine. 516 responses were gathered via social media and email.

#### THE RESULTS



#### FREQUENCY

On average, respondents report having migraine:

60% 15 days or more/month25% 8-14 days/month16% 1-7 days/month



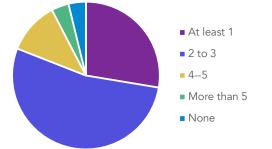
#### TREATMENT

**100% of respondents** take at least one preventive and/or one abortive treatment for migraine.

**65%** say their doctor has discussed different treatment options to create a personalized treatment plan and are open to new options

#### ABORTIVE TREATMENTS

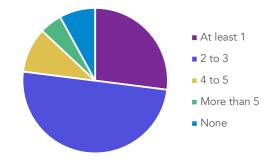
**75% of respondents** have been prescribed more than one abortive treatment at a time.



- 60% have been prescribed a combination of abortive treatments to stop different types of migraine attacks.
- About 55% have been prescribed fast-acting medications to take if their regular oral medications don't work or the nausea/vomiting is too severe.

**71% of respondents** have been prescribed more than one preventive treatment at a time.

**PREVENTIVE TREATMENTS** 



**42%** of those who **use a combination of preventive treatments** say their number of migraine attacks has **decreased:** 

- 22% experience a 25% decrease
- 16% experience a 50% decrease
- 10% experience a 75%+ decrease

"Having to meet specific criteria in order to access certain types of drugs scripted by my team of professionals is frustrating. They recommend a specific treatment and I can't follow it until I jump through insurance hoops. Insurance companies should not be able to dictate medical steps in my journey to treat my chronic illness. My team of dedicated professionals and I should have a much bigger say in the steps I take." —Survey Respondent

#### 

**44%** of those who use a combination of preventive treatments say **the severity of their migraine attacks has decreased, reducing the number of abortive medications they need.** 

- 23% experience a 25% reduction
- 16% experience a 50% reduction
- 10% experience a 75%+ reduction

## 

- About 80% have been prescribed a monoclonal antibody (Aimovig, Emgality, Ajovy, Vyepti) in combination with at least one other preventive treatment.
- About 60% have been prescribed a botulinum neurotoxin (such as Botox, Dysport or Xeomin) in combination with another prescribed preventive treatment.
- About 65% have been prescribed a botulinum neurotoxin (such as Botox, Dysport or Xeomin) in combination with another prescribed abortive treatment.
- About 54% been prescribed multiple CGRP inhibitors for preventive and/or abortive treatment.
- Less than 22% have ever received **preventive medication through IV infusion** in combination with another drug to prevent migraine.

#### **BARRIERS TO MEDICATION ACCESS**

- 68% of respondents have experienced insurance issues accessing the combination of medications their doctor prescribed.
- 38% say the inability to access the combination of treatments they need has impacted their ability to manage their migraine and has negatively impacted their quality of life.
- 41% say the inability to access the combination of treatments they need has negatively impacted their work, career, social life and relationships.

Respondents say their insurance has denied the following combinations of medications:

#### Other

An NSAID in combination with another abortive treatment

An ergotamine medication in combination with another abortive treatment

More than one gepant in combination for preventive AND abortive treatment

More than one gepant in combination for abortive treatment only

A CGRP monoclonal antibody and a prescription abortive medication

A CGRP monoclonal antibody and another preventive medication

A botulinum neurotoxin and a prescription abortive medication

A botulinum neurotoxin and another preventive medication

#### SURVEY DEMOGRAPHICS

#### GENDER

- 95% female
- 3% male
- 2% other
- AGE
- 65+: **7%**
- 56-64: **18%**
- 41-55: **41%**
- 26-40: **30%**
- 18-24: **4%**

#### **INSURANCE TYPE**

- 67% Private commercial insurance33% Government-funded insurance
- **10%** Other



#### **PATIENT VOICES**

Respondents had the following to say about their experience with combination therapy for migraine "Although insurance has denied treatments "Eventually things usually go through, and medications, I'm often able to access but there's a lot of calling the them via coupon programs. So I still am insurance company and doctors and able to get the care that I need." pharmacy before I can actually take what's prescribed." " After an initial rejection, the doctor appealed and I was able to get the medications I needed. The delay was no fun, but the issues were resolved." "My treatment plan has also been limited by what my health insurance is willing to cover." "Step therapy was a huge barrier, as was my doctor's unwillingness to mix CGRP preventives with CGRP abortives." "Unfortunately for me, it comes down to cost and "Thankfully my doctor and I are constantly going up no time to fight it." against my insurance and have gotten things approved. The biggest struggle is the devices as they are expensive and I cannot afford them." "Many physicians view "Dealing with Insurance is like playing roulette...you combination therapy as have lots of numbers and hope the ball stops on your unnecessary." number."

## SURVEY REPORT Migraine in the ER & Urgent Care



Migraine Meanderings and the Headache and Migraine Policy Forum recently conducted an online survey to better understand the experience people with migraine have in the emergency room and urgent care. Five-hundred responses were gathered via social media and email.

#### THE RESULTS



## PREVENTIVE TREATMENTS

About 99% of respondents use treatment options to prevent migraine attacks.

Prescription oral medication (94%)

Prescription injectable medication (76%)

Prescription infused medication (17%)

Medical devices (35%)

OTC supplements (83%)



About 99% of respondents use treatment options to stop an existing attack.

#### OTC medications (89%)

Prescription oral medication (93%)

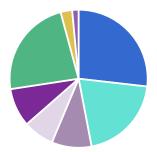
Prescription nasal spray (53%)

Prescription injectable or infused medication (66%)

Medical devices (33%)

SEEKING TREATMENT AT THE EMERGENCY ROOM OR URGENT CARE

Respondents report the following symptoms led them to seek treatment at the ER and/or urgent care:



- Pain (89%)
- Nausea, vomiting or dehydration (67%)
- Aura or other visual disturbances or changes (31%)
- Aphasia (speech disturbance) (24%)
- Stroke-like symptoms (30%)
- Status migrainosus (77%)
- Dizziness/vertigo (9%)
- Other symtpoms (5%)

Since being diagnosed with migraine, respondents estimate going to the ER or urgent care:

- More than 10 times (44%)
- 6-10 times (20%)
- 1-5 times (36%)

In the PAST YEAR, respondents have gone to the ER or urgent care:

- 1-5 times (52%)
- More than 5 times (7%)
- 0 times (41%)

"Being a frequent flyer to the ER, they now know me well. Decades ago I was discriminated against for having migraine disease. Called a drug seeker. But through advocacy for myself and others I'm fortunate enough to get the treatment needed and with empathy."

—Survey Respondent

## 

**88% of respondents** went to the ER or an urgent care facility **due to lack of access to a healthcare professional who could treat their migraine**. They report the following issues prevent them from seeing a headache specialist who could more effectively treat their migraine:

Headache specialist not available outside of appointments (33%)

No headache specialist available in-network for my insurance (7%)

Copay to see a headache specialist too expensive (5%)

No headache specialist in my geographic area (14%)

Primary care physician/general neurologist won't refer me to a headache specialist (6%)

Other (16%)

**28% of respondents** sought treatment at the ER or urgent care due to issues getting abortive or rescue medications that their healthcare professional prescribed for them. **They reported the following barriers:** 

- Insurance coverage/denials (19%)
- High out-of-pocket costs or copays (13%)
- Insurance required step-therapy that didn't work (9%)
- Pharmacy didn't have prescribed medication in stock/available (7%)
- Pharmacy didn't want to fill a prescribed medication (3%)
- Other reasons included: doctor won't prescribe any medications, medications don't work, already took the max number of doses, doctors office slow to refill prescriptions

### QUALITY OF TREATMENT AT THE ER OR URGENT CARE

#### **KEY FINDINGS**

- 52% of respondents found the healthcare providers at the ER or urgent care to be knowledgeable about migraine.
- 63% of respondents believed that the ER or urgent care trusted their description of symptoms.
- 44% of respondents reported that the ER or urgent care implied that they were there seeking drugs and not due to severe
  migraine symptoms.
- 29% of respondents said the treatment they received at the ER or urgent are did stop their migraine attack: 37% said it stopped their attack but their symptoms returned less than 24 hours later; and 27% said the treatment did not relieve their symptoms.
- 27% said the ER or urgent care prescribed an opioid for pain management.



FREQUENCY	AGE	HEALTH INSURANCE TYPE
On average, respondents report	<b>3%</b> 18-25	63% Commercial insurance
having migraine:	<b>29%</b> 26-40	36% Medicare/Medicaid
32% 1-14 days/month	<b>49%</b> 41-55	2% No insurance
68% 15-30 days/month	<b>13%</b> 56-64	8% Other
,	<b>6%</b> 65+	



Respondents had the following to say about about their experience going to the emergency room or urgent care for migraine

"I refuse to go any more due to being treated like a drug seeker."

"The ER staff does not seem to comprehend, or perhaps believe, the severity of pain some migraines can cause patients. They leave you sitting under fluorescent lights —a migraine trigger—for many hours!" "While my symptoms might have been taken seriously or believed, I never felt comfortable in the ER and always felt like I was a bother being there. I don't seek treatment even when advised to go to the ER by my headache specialist because I feel like there is a stigma. I work in healthcare and I know chronic pain isn't always taken seriously, especially in the ER, so I just choose to suffer at home now."

"The treatment for migraine in ER/UC is complicated by our overstressed medical system and the fact that there are some who seek inappropriate treatment without adequate follow up." "Migraine cocktail does the trick, but knocks me out. Not good when you are the [caregiver for] a baby. Need better prevention, and even better, to find to cause of migraines."

"The ER should be a last resort. It is a miserable, uncomfortable place where you roll the dice as to how you are treated and whether you will receive pain relief." "Many times ER staff are not educated on migraines enough to know that they all don't present the same way."

"I felt like I was shamed and not listened to by the urgent care doctor."



www.MigraineMeanderings.com www.HeadacheMigraineForum.org