

# Migraine Patient Guidelines

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## PART I OVERVIEW

If you live with recurrent or frequent migraine attacks, you already know that there are many possible treatment options: over-the-counter medications, prescription drugs, herbal remedies, lifestyle changes, and mind-body therapies—not to mention products like cooling masks or mobile phone apps to dim your screen during a migraine attack.

No matter what combination of treatments you use to treat migraine, the trial-and-error process to find something that works — and continues to work— can be long and frustrating.

How do you make sense of all the possible treatment choices for migraine? The most important tool is clear, simple information from a trusted, independent source. That is why this guide — carefully checked by both medical experts and people living with migraine — was created. You're looking for treatments to help you reduce your pain, shorten the duration of your symptoms, and prevent migraine attacks in the first place.

The migraine treatment and prevention information you'll find in this easy-to-understand booklet is based on current recommendations from leading physician associations, including the American Headache Society and the American Academy of Neurology. We'll review how each type of treatment works to ease your migraine symptoms or help prevent migraine attacks, and let you know about important side effects so you can make more informed choices about your treatment.

We'll talk about how migraine can affect each person in different ways and how your symptoms can change over time. We'll share the steps you can take that may help you prevent migraine attacks, so you can live a fuller, more enjoyable life without the worry that migraine will keep you from missing out on the people and activities you love.

Importantly, we'll also provide information about advocacy efforts to help people living with migraine. Advocacy is activism — it is a focused, sustained effort by a group of people connected by their common interest, cause, or concerns to guide, shape, and influence public policy. With more migraine treatment breakthroughs coming to market, advocacy is in full swing in support of policies to benefit people living with migraine, improve access to treatment, and promote ongoing migraine research.

There's never been a better time to raise your hand and get involved. We'll tell you how you can tap into this powerful information to make a difference. We will share ideas to reach out to those around you who do not understand migraine or who have negative or harmful misconceptions about it. We'll also give you tips on how to reach out to other people who have migraine for questions or emotional support.

This guide was created by the Global Healthy Living Foundation, a community of people with chronic pain conditions such as arthritis, inflammatory bowel disease, and others. Our patient charter explains more about our organization and why we support projects like this guide. When you are informed about your treatment choices, you can be more in control as you make decisions about your health care in partnership with your clinician.

## PART II PATIENT CHARTER

Our patient charter reflects our guiding principles, or the deeply held beliefs that drive our community's many efforts in chronic disease education, support, advocacy, and research.

# **WE BELIEVE:**

- The patient experience is at the heart of medicine; thus the patient must be at the center of all medical decision making.
- The medical process should stay between the patient and their care provider.
- The patient should have access to all treatments deemed appropriate by their care provider.
- Access to care should not be limited by external forces, financial or otherwise.
- Patients should be empowered and educated with the tools needed to make their voices heard.
- Elected officials, insurance providers, drug manufacturers, and all those associated with the health care system shall make it their goal to ensure the patient is the focus of all decisions.
- The medical team should strive not only to do no physical harm, but to do no emotional, mental, or financial harm to the patient.
- Patients should be treated with dignity, transparency, and respect by everyone involved in the health care process.

<sup>▲</sup> The information in these guidelines should never replace the information and advice from your treating health care provider. It is meant to inform the discussion that you have with health care professionals, as well as others who play a role in your care and well-being.

## PART III WHAT IS MIGRAINE?

Migraine is a biological disorder of the nervous system in which attacks of pain and other neurological and physical symptoms usually last from four to 72 hours. Migraine is a recurring disease that affects about 12 percent of Americans. Anyone can develop migraine, but it is more common in women, people with a family history of migraine, and those with certain other medical conditions (such as sleep disorders, depression, anxiety, and epilepsy).

The most common description of migraine is unilateral (one-sided) head pain with a pulsating or throbbing quality. But many people have bilateral pain, or pain that does not throb. All patients with migraine also have other symptoms during their attacks.

# Other Migraine Symptoms

Many people who've never experienced a migraine attack may think that migraine is "just a bad headache." As a person living with migraine, you know this is anything but true.

In fact, intense head pain is just one symptom among many migraine symptoms. During a migraine attack, you may experience some or all of these associated symptoms:

- Nausea or vomiting
- Sensitivity to lights, sounds, or smells
- Mood changes, feeling sad, irritable, angry, or anxious
- Fatigue or sleepiness
- Dizziness, feeling numb or weakness
- Blurry vision or other changes in vision
- Trouble thinking clearly, sometimes called "brain fog" (cognitive dysfunction)
- Word-finding difficulties or other speech and language disturbances (aphasia)
- Disability that goes beyond the severity of the pain
- Pain that increases with movement or activity
- Scalp sensitivity (allodynia)
- Rarer: diarrhea, other bowel disturbances

# What Is Migraine with Aura?

Almost one out of three people with migraine start to notice something called aura before the pain and other symptoms of a migraine attack begin. During this time, the symptoms evolve or change. Aura can include visual, sensory, speech, motor, or other central nervous symptoms. Visual changes are among the most common characteristics of aura. These visual effects may last for a few minutes to an hour as your migraine worsens. You may notice:

- Flashes of light
- Zig-zag or wavy lines
- Blind spots or temporary loss of vision
- Distorted shapes or images
- Trouble reading

Vision changes may seem like they're happening in only one eye, but they are most common in both, even when people feel sure they are occurring in only one. Close each eye and look at a blank white wall to see if the aura is in both eyes. An aura can be dangerous if it strikes when you're driving or walking.

In addition to vision changes, some people may also experience "pins and needles" tingling in an arm or leg during an aura. All of these symptoms are related to temporary changes happening in your brain before and during a migraine attack.

# Stages of Migraine

A migraine attack has up to four distinct phases, although not every person experiences all four stages with any single attack, and some people may never experience certain stages. Understanding the symptoms associated with each phase can help you anticipate a migraine and better manage it.

#### **Stage 1: Prodrome**

Some people living with migraine can notice the earliest signs that a migraine attack is coming. This prodromal period can begin anywhere from a few hours to a few days before the actual headache occurs. Symptoms can include light sensitivity, irritability, fatigue, difficulty concentrating, neck stiffness, nausea, or changes in your appetite. Some people notice they may be urinating more than usual.

#### Stage 2: Aura

About one in three people with migraine get aura symptoms a few minutes to an hour before the full attack hits. Aura can include visual disturbances, like seeing flashes of light or wavy lines, and other neurological changes like numbness, tingling, speech changes, or weakness.

## Stage 3: Headache

This is the most intense portion of a migraine attack. Symptoms can last anywhere from a few hours to a few days. Throbbing, pulsing, one-sided head pain is the most well-known symptom of a migraine attack, but you may also have nausea and/or vomiting; sensitivity to lights, sounds, or smells; dizziness; and fatigue. You may also experience pain on both sides of your head, and not just one. Migraine symptoms tend to get worse with physical activity and you may have a desire to be still. You might have brain fog and severe fatigue. Your ability to function or work may be affected.

Many people find it necessary to lie down in a dark quiet room until their rescue medications kicks in or to get through the worst of a migraine attack.

## **Stage 4: Postdrome**

This is the lingering "hangover" effect many people with migraine experience after the worst of the migraine attack is over. You may feel residual scalp sensitivity, fatigue, mood changes, or trouble concentrating. The postdrome period can last anywhere from another 24 to 48 hours after the main migraine attack.

# \* — Who Does Migraine Affect?

According to the Centers for Disease Control and Prevention (CDC), about 20 percent of adult women and nearly 10 percent of adult men in the United States have experienced migraine attacks or severe headaches at least once in the last three months. 60 million Americans have migraine according to the 2016 Global Burden of Disease Study with migraine being the 2nd leading cause of disability among Americans under the age of 50.

Women are more likely to develop migraine than men, especially before menopause. At some ages, about 75 percent of people with migraine are women. Migraine attacks often occur right before, during, or after a woman gets her monthly period.

One of the most important migraine risk factors is family history. If one or both of your parents has migraine, there's a stronger chance you will too. Someone with one parent with migraine has a 50 percent risk of developing migraine too. If both parents have migraine, the risk jumps to 75 percent.

Some people start to experience migraine attacks in their teens or twenties. Most people have their first migraine attack before they turn 40, but migraine can also begin after that age. Migraine can be a lifelong problem for some, but nearly half of people with migraine attacks stop having them by around age 65.

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Migraine symptoms may change throughout your life. Some older people may notice the signs of an aura, but without the throbbing head pain that used to follow. In fact, some adults first seek migraine treatment at the eye doctor because they have been experiencing visual disturbances, only to be referred to a neurologist for migraine. Some people may have frequent or regular migraine attacks at one time in their life, followed by years of remission, only to experience attacks again later.

# How Often Does Migraine Happen?

Migraine affects everyone differently. The frequency of migraine days can vary greatly — from a few times a year to a continuous migraine without any headache-free periods.

You may have heard someone refer to themselves as having either episodic or chronic migraine disease.

Episodic migraine means you have fewer than 15 headache days per month, while those with chronic migraine experience 15 or more headache days per month.

Episodic migraine can be further split into two categories: low-frequency episodic and high-frequency episodic. Low-frequency episodic migraine is less than eight headache days per month. High-frequency episodic migraine is between eight and 14 headache days per month.

People who have high-frequency episodic migraine have about the same disability as those who have chronic migraine.

There are certain risk factors that can increase the risk of transforming from episodic migraine to chronic migraine. These risk factors include overusing your as needed medications, stressful life events, having another pain condition, head trauma, depression, anxiety, obesity and issues with sleep.

From the perspective of a person with migraine, delays in treatment can cause episodic migraine to become chronic. Common delays include insurance barriers like prior authorization, step therapy and non-medical switching, and not seeking treatment from a health care provider.

# **\*** — What Causes Migraine?

We don't yet know exactly what causes certain people to develop migraine or all the causes of migraine attacks, but we're continuing to learn more. Recently, advances in understanding have even led to new treatments.

Until very recently, migraine was thought of as a disease of the blood vessels, in part because migraine attacks to cause changes in blood vessels and some of the effective treatments block those changes. We have learned, however, that these blood vessels changes are an effect and not a cause of a migraine attack.

The process of a migraine attack, as we currently understand it, begins with overactivity in an

area within the back of the brain, called the brainstem. As a result of that overactivity inflammatory substances are released from nerve cells. These inflammatory substances have a positive feedback loop that prolongs the overactivity and releases even more inflammatory substances. The resulting high levels of inflammatory chemicals cause other changes in the brain, nerves, and blood vessels at different phases of a migraine attack that cause the wide variety of migraine attack symptoms.

# — Migraine Triggers

Triggers are not the cause of migraine, but they can tip a susceptible brain into starting a migraine attack. Recently, we have learned that migraine triggers may be less important for many people than previously thought. To some extent we have been trained by our culture to look for triggers and advised that once we identify these culprits, migraine is cured. This is a myth. Research shows that there are multiple factors that create a perfect storm and contribute to a migraine attack. While you may be able to identify a few specific triggers and eliminate them, there is no guarantee your migraine attacks will improve without also having medical treatment for the condition.

Migraine attacks also heighten sensations in ways that may sensitize a person so that they become more likely to have an attack when they have that sensation again. Many people spend years looking for triggers — when their migraine attacks are random anyway — and blame themselves for not finding and controlling supposed triggers for their attacks when it is impossible to do so.

For some people, their migraine attack causes them to expose themselves to something they think is a trigger. Perhaps the prodrome of your migraine attack causes a person to crave chocolate. Eating the chocolate does not trigger the migraine attack, but people could be tricked by their migraine into seeing things that way.

For other people, triggers are obvious and important, and they can be anything – food, stress, noises, weather — that set off migraine attacks for you. Your migraine triggers may not be the same as others' migraine triggers, and your triggers can change over time. Identifying your migraine triggers may help you learn to avoid or manage them.

## Common migraine triggers include:

Blue light and bright lights: Light sensitivity is a symptom of migraine that people may experience very early in an attack, and studies suggest that people with migraine may respond to blue light differently than people who don't experience migraine attacks. Blue light has also become much more common as screen time has increased because digital screens send out mostly blue light.

Dehydration: Not drinking enough water after a workout or getting dehydrated because of hot weather may make a migraine attack more likely.

Foods, drinks, or food additives: Salty or processed foods (which are often higher in sodium), aged cheeses, smoked or preserved foods, the artificial sweetener aspartame, or foods with the preservative MSG can be migraine triggers for some people. Alcohol and caffeinated beverages are other common triggers. Some people find that red wine is a migraine culprit. You may

observe that food and drink can be stronger triggers when they're combined with other migraine

triggers. For example, a woman with migraine may be able to have a glass of red wine without it causing a migraine attack, unless she is also having her period, when she has to avoid red wine.

#### Extreme exercise or too little exercise:

Regular exercise has been shown to decrease the frequency of migraine attacks and also has many other health benefits, making it essential to a healthy life. For some people with migraine, however, exercise—especially extreme exercise—can trigger migraines.

Hormonal changes in women: Women may get a migraine attack before or during their periods because of fluctuating levels of the hormone estrogen. Women may also experience migraine attacks while they are pregnant or going through menopause, because these are times when estrogen levels are in flux. Birth control pills (which contain hormones) or hormone replacement therapy during menopause could trigger or worsen migraine too, although they may also be beneficial in managing migraine.

Loud noises or noisy environments: Sound sensitivity is a symptom of migraine that many people may experience very early in their attacks. This makes it difficult to determine if sound is the cause or the effect of an attack. More importantly, if you are sensitive to sound, especially right before or during a migraine attack, you may need to avoid noisy environments or use noise-canceling headphones, earplugs, or other methods to reduce your exposure to sound.



## How to Keep a Migraine Diary

For some people, maintaining a very simple diary is best. Keep track of pain severity (usually a 0-10 scale) and any medications you take to treat that attack. This kind of record can also help assess if your migraine treatments are working.

Tracking the details of your migraine attacks, along with any potential triggers that may have been involved, can help you pinpoint the most important triggers for you. A comprehensive migraine calendar may include:

- When the symptoms started
- Where the pain is
- Other symptoms besides headache
- The medication you take
- How long the attack lasts

Try to pair the details about your migraine attacks with any lifestyle habits that could be triggers, such as:

- Food and drink (including missed meals or dehydration)
- Medication you take for other health issues
- Stress
- Sleep
- Exercise
- Weather
- Menstrual cycle (for women)
- Your environment (loud noises, bright lights, strong odors)

**Medications:** In addition to birth control pills, certain drugs can trigger migraine attacks in some people. Vasodilators, such as nitroglycerin, which are used to treat heart conditions, open up your blood vessels, and this could set off migraine attacks in some people.

**Strong odors:** Fresh paint, cleaners with strong chemical smells, or your office colleague who is always doused in perfume may make your migraine attacks more likely to occur.

**Sleep disruptions:** A night or several nights without sleep can be a trigger for migraine. If you're traveling and get jet lag or have to camp out in an airport overnight waiting on a flight when you'd normally be sleeping, this may increase likelihood of a migraine attack. Just as not enough sleep can be a trigger, sleeping longer than usual may also trigger attacks.

**Stress and anxiety:** Stress and worry are the most commonly described migraine triggers and may increase muscle tension and pain in the neck and shoulders or simply activate the nervous system—both make migraine more likely, and multiple relaxation techniques have been shown to reduce migraine attacks.

**Weather changes:** Barometric pressure swings, such as before a storm or when there's a shift in the weather pattern, could trigger migraine attacks.

You may have other migraine triggers. Keep track of them so you can talk with your health care provider at your next medical appointment. One app, N-1 Curelator, uses special statistical techniques to see what your strongest triggers may be. There are many other apps on market. The most important thing is to find one that you will use on a regular basis.

# **\*** — How to Avoid Migraine Triggers

You can't control some migraine triggers, such as weather, but you may be able to eliminate or reduce the occurrence of others.

One of the best things you can do to reduce your odds of a migraine attack is keep a consistent routine. Try to go to bed and wake up at the same time every day. Eat your meals at similar times because going for long stretches between meals can trigger migraine attacks. Stay hydrated and exercise regularly.

**Blue light:** Some people find that limiting screen time, taking frequent breaks when working on computers, or using filters or glasses that block blue light can decrease their migraine attacks.

**Food and drink:** If certain foods or drinks seem to set off migraine attacks for you, try to cut them out of your diet whenever possible. If you're in a restaurant, ask your waiter if any dishes contain these foods or additives (such as MSG). Ask if your dishes could be made with less salt or without red wine.

Remember that just because you've heard that a certain food is a migraine trigger for some people doesn't necessarily mean it will be a trigger for you. There's no need to deprive yourself of foods you love if you track your symptoms and don't see any associations.

**Exercise:** It is important to find the right type and amount of exercise for you as an individual—something you enjoy and will do regularly that doesn't trigger migraine attacks for you. Moderate exercise that increases the heart rate without causing overheating includes yoga, a brisk walk, a gentle bicycle ride, swimming, and many other activities. Some headache specialists will refer people with migraine to physical therapists to help find the right exercise program for them.

Medications: If a medication seems like it could be affecting your migraine, talk to your health care provider. You may be able to switch to a different treatment for that condition.

Stress: Stress is the most reported trigger. Interestingly, often migraine attacks hit when the stress is declining, not at the time of maximal stress.

We all have stress in our lives. It is impossible to avoid stress at times. However, you can learn new ways to manage your stress, such as taking a walk, doing yoga, listening to music, or talking to a friend or counselor. Focus on the people and activities that make you happy or relaxed, not the ones who drive up your stress levels all the time. Don't think of stress management as a nice-to-have; when you have migraine, figuring out your own methods for de-stressing is a critical part of self-care.

As for the triggers you can't control, it's perfectly fine to ask people around you if they wouldn't mind making changes to help you reduce your exposure to migraine triggers, especially if they are your friends, loved ones, coworkers, or neighbors.

Ask your friend to skip the heavy cologne when you meet for dinner. Suggest a restaurant that isn't so loud. Let your neighbor know that you can hear the music blasting from their speakers — could they turn it down or play it at a time when you're usually out of the house? See if you can have bright lights over your desk turned off and use a soft desk lamp for lighting at work instead. People around you may not always realize that the lights, smells, sounds, or behaviors can cause you to get a painful migraine attack.

## PART IV GETTING DIAGNOSED

Getting a specific diagnosis of migraine is important because it creates the opportunity to work with your health care providers to find the best treatments for you that are known to be effective for treating migraine.

Your first step may be to talk with your primary care provider (PCP). This may be your internist, family doctor, ob-gyn, physician assistant (PA), or nurse practitioner (NP) whom you see at your regular physicals or checkups. Let your health care provider know about your migraine symptoms, including when and where the pain occurs, how long head pain lasts, other symptoms that seem to go along with your head pain, and if you've noticed anything in particular that seems to trigger a migraine attack. Also let them know how it is affecting your life including your job, personal life and ability to do chores or self-care.

# Which Health Care Providers Treat Migraine?

For migraine diagnosis and management, your doctor may refer you to a neurologist, a physician who specializes in brain and nerve conditions,

including migraine disease and headaches. The neurologist will give you a physical exam, a neurological exam, review your symptoms,

and run a few tests to confirm your migraine diagnosis.

You could also be referred to a headache specialist. A headache specialist is a health care provider who has specific skill in diagnosing and treating headache disorders. Some headache specialists are UCNS (United Council for Neurologic Subspecialties) certified but not all are. The UCNS provides certification to health care practitioners in headache medicine as well as accreditation to fellowship programs.

Additionally, the National Headache Foundation administers a Certificate in Added Qualification (CAQ) in headache medicine.

If you live in an area where neurologists or headache specialists are not available, you may be able to have a telemedicine appointment with one of these specialists or may be referred to a pain management specialist. According to the American Society of Regional Anesthesia and Pain Medicine (ASRA), a pain management specialist is a physician with special training in evaluation, diagnosis, and treatment of all different types of pain.

The American Migraine Foundation and the National Headache Foundation offer lists of health care providers in a geographical area who are experienced in treating migraine and other headache conditions. You can visit their websites: www.americanmigrainefoundation.org or www.headaches.org.

# Your First Appointment: What to Expect

At your first appointment, let your health care provider (HCP) know the details of your headaches listed below. Keeping a headache diary that tracks these items and sharing it with the HCP at your first visit can be very useful.

Description of symptoms: how your headache feels--is it a dull ache that worsens into throbbing pain or maybe you have a sensation of being stabbed?

Severity: how intense the pain is or how hard it is to tolerate (most HCPs prefer the 0-10 pain scale)

Location: where on your head the pain seems to focus most of the time

Duration: how long your head pain and other symptoms last, from the first signs until you feel that you can return to normal activities

Frequency: reporting how many days each month you have no pain or discomfort in your head or neck can give your HCP the most accurate description of how often you are living with the pain of migraine attacks

Symptoms other than pain: such as nausea, vomiting, light/sound/smell sensitivity, dizziness, weakness, numbness, speech changes, or balance issues.

Disruptiveness: how your symptoms interfere with your life, such as your ability to sleep or work, your ability to go out with family or friends, do chores, or exercise; and how long and often you have to stay in a darkened, quiet room

Early warning signs: if you notice aura symptoms, feel anxious beforehand, or have other telltale signs that you're about to have a migraine attack

Possible triggers: if you've noticed any stressors, foods, drinks, activities, weather conditions, odors, or other factors that seem to set off migraine attacks

# History and Questionnaires

Your HCP will ask you some detailed questions about your own medical history, your family medical history, and your social history. Here's what these terms mean.

Medical history: Your HCP will want to know if you have had or have any health conditions such as:

- High blood pressure
- Diabetes
- Chronic pain
- Surgery for any reason

Any injuries, such as a car accident, a fall from a ladder, etc.

Tell your HCP if you've also sought treatment from another physician or natural health practitioner for headaches, or if you've tried treating them on your own with over-the-counter (OTC) medication. Your HCP will also ask you about any medications you take for any reason, including medical marijuana.

Family history: If your parents or others in your family have or had migraine, this could help your HCP confirm your diagnosis. There is strong evidence that inherited genetic factors influence whether or not a person has migraine and migraine triggers.

Social history: Tell your HCP if you are or have been a smoker, alcohol user, drug user, or coffee/ caffeine drinker. Your occupation, such as whether you work in a job with strenuous physical activity, may be important to mention too. All of these details may be important to consider during your migraine diagnosis.

# Diagnosis Criteria

There are certain criteria for diagnosing migraine. Your HCP may use this list to help confirm that your headache and symptoms are consistent with a migraine diagnosis and not caused by another kind of health problem:

You've had at least five headaches that:

- Last between four and 72 hours whether untreated or not treated successfully with some type of medication or other intervention
- Meet at least two of these descriptions: moderate to severe pain; pain located in one area of your head; pulsing pain, either caused or made worse by activities (like climbing up the stairs of your house)
- Include nausea and/or vomiting and/or sensitivity to light and/or sound during your headache
- Are not caused by any other health condition, such as infection, head injury, etc.

Keep this in mind: Migraine is unique to the person with the disorder. Your head pain and other symptoms may not be exactly "textbook" or just like another person's symptoms. There are many different head pain types. Your HCP will be able to make sense of your symptoms and signs and give you an accurate diagnosis.

Don't worry if you can't remember the dates, years, or your exact age when your migraine symptoms began. Think about where you were or what you were doing (such as what apartment you were living in or what job you were in at the time) when your migraine symptoms first occurred. This can help you recall the time span and frequency of your headache episodes.

## Comorbid Conditions

It is very common for someone diagnosed with migraine to also have one or more additional diseases or conditions that are also present and are not just coincidence, also known as comorbidity. Migraine is most commonly associated with the following:

- Stroke and Cardiovascular Disease
- Fibromyalgia
- Neck pain
- Patent foramen ovale (a birth defect that causes a hole in the wall between the upper chambers of the heart)
- Depression, bipolar disorder
- Anxiety, panic disorder
- Epilepsy
- Asthma

It is important that you receive an accurate diagnosis of the type of headache you have, as well as any comorbid condition(s).

The types of treatments you will be able to use for migraine may vary and change depending on the comorbid conditions you have, as well as co-existing conditions like heart disease or high blood pressure. One or multiple medications may be prescribed to treat both migraine and a specific comorbid condition.

As with treating migraine, lifestyle changes, a healthy sleep routine and diet, and following treatment plans as instructed will help in managing your co-existing conditions.

# \* — Tests

Your HCP may or may not use the following



# Misdiagnosis and Migraine

When it comes to headaches, misdiagnosis is common. For one thing, there are more than 200 headache types classified by the International Headache Society. If you've been trying to manage your pain on your own, diagnosed yourself with Google, or aren't attuned to some of the more subtle symptoms of migraine — say, light, sound, or smell sensitivity — you may be mistaking migraine for another kind of head pain.

That's a missed opportunity to get more better, effective treatment, particularly now that a new class of preventive medications is becoming more widely available. Research shows the following conditions may actually be migraine instead:

Sinus headaches: People living with migraine can have symptoms that seem similar to allergies, including sinus pain and pressure and a runny nose. In a study of nearly 3,000 patients, almost 90 percent of those who thought they had sinus headaches actually wound up being diagnosed with migraine. These patients were taking medications such as decongestants, antihistamines, and nasal sprays to treat their so-called sinus headaches, but were largely dissatisfied with how they felt. And no wonder, since it was actually migraine that was triggering their symptoms.

**Neck pain:** In a recent Italian study, researchers discovered that after patients were seen by a headache specialist, 75 percent of patients who had diagnosed themselves with cervical neck pain actually had a form of migraine (without aura).

**Dizziness:** Many people who go for treatment of dizziness or vertigo actually have migraine disease. Sometimes, there is no headache or the headache is not prominent, yet the cause of the dizziness is migraine.

tests to help rule out any other possible causes of your symptoms, or other conditions worsening your migraine, so it's important to ask about whether you need these before you start any treatment.

The diagnosis of migraine is primarily clinical in nature, which means it is based on your HCP's judgment of your symptoms as you describe them. Tests may also be needed to safely start medications.

## These tests are primarily used to rule out other causes of severe headaches.

Blood tests: Blood tests can indicate signs of infection, inflammation, toxins in your body or, more rarely, tumors that may affect your brain or nerves, to cause migraine-like symptoms or worsen migraine. Blood tests may also indicate if some medicines are unsafe for you.

Imaging tests: Your HCP can look at detailed images of your brain and blood vessels on scans. These tests include magnetic resonance imaging (MRI) and computerized tomography (CT) scans. These images can show problems like bleeding in your brain or infections that may cause headaches. Usually, these are only necessary if your migraine started after age 40 or if your existing pattern of headache attacks (of any kind) has changed.

Spinal tap: If your HCP suspects that the cause of your headaches is bleeding or an infection, you may need a spinal tap (lumbar puncture). This is a procedure in which a physician removes a small amount of spinal fluid for analysis in a lab.



# **Not All People With Migraine Are Treated Equally**

Many people with migraine not only have to deal with the stigma of migraine (discussed further in Part 6. Living With Migraine: The Stigma of Migraine), they also have to deal with living in a society that treats them unfairly because of their race/ethnicity, gender, sexuality, or ability. Our health care system and medical education and research are not immune to racism, sexism, and other forms of discrimination. Studies have shown that White people who go to the emergency room for a severe migraine are more likely to receive a correct diagnosis and a migraine-specific medication than Black people or other people of color. Similarly, people who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ+) are more likely to have chronic migraine but less likely to the type of treatment they need compared with people who do not identify as LGBTQ+.

Discrimination based in public policy (written and unwritten) is considered a structural problem—built into the society in which we live. Attitudes (spoken and unspoken) and acceptance of policy and historic discrimination are interpersonal. Both are social determinants of health (SDOH)-characteristics of daily life that are not biological or genetic but still affect our biological health. The most impactful SDOH are income level, race or ethnicity (especially being Black or Hispanic/Latinx in the United States), sexuality, gender, disabilities, and immigration status. These all affect whether people have medical insurance, live where it is safe to exercise outdoors, are exposed to pollution, find healthy food easily, and access many other resources including having a regular health care provider or being able to see a headache specialist.

Some people face multiple types of discrimination and multiple negative SDOH. For example, a Black, transgender, disabled, lesbian woman faces discrimination and disparity from multiple directions that each affect the other. This is not intended to show "who has it worst," but is intended to help understand the complex layers of inequality in our society. BIPOC (Black, Indigenous, People of Color) are disproportionately represented in lower socioeconomic status ranks, lower-quality schools, and in poorer-paying jobs, tracing back to historic patterns of legalized discrimination and segregation.

SDOH affect migraine, and if you experience discrimination, you may have a harder time seeing a headache specialist, being prescribed the best treatment for you, or controlling lifestyle factors that affect migraine. Although you may not have the same opportunity as others to use all the information in this guideline, knowledge can be power. We hope knowing more about migraine and the many options that exist for improving migraine will be one step in a journey toward better health for you.

One of the most important parts of self-care for people with migraine is understanding that migraine is a medical condition, not just a headache, and treatment is available. Many people with chronic conditions of any kind also find networking with others who have the same health condition and advocating for everyone to have access to what they need to treat their illness can be empowering. You may feel you do not have a lot of time or energy to do this, given everything you are facing but there are many ways to participate. See Part 7: Advocacy for Migraine to learn more.

## PART V TREATMENT OPTIONS

You and your HCP have many options to treat your migraine. There are medications that can help you ease the pain and symptoms of a migraine attack after it has started.

Other medications may help decrease how often your attacks occur and reduce the severity of your attacks when they do happen. As you consider your medication options, here are a few things to keep in mind:

Not every medication will work for every person the same way. You may need to try different treatments and see which works for you. Your HCP will use all the information about your overall health and your type of migraine, so together you can choose the best options for you.

Sometimes a combination of treatments works best. Don't expect one therapy to do it all. You may need to take medications and change your lifestyle or behavior to manage migraine effectively. Diet adjustments, stress management, or changing your routine can be powerful treatment too.

If you think you may be pregnant or plan to become pregnant, tell your HCP right away. Some medications that treat migraine may not be safe to use during pregnancy or breastfeeding. If you start migraine medication and then find out you are pregnant, let your HCP(s) know immediately.

## - Acute Treatments

Acute treatments are used after a migraine attack has begun with goals of reducing the pain and other symptoms you are experiencing and shortening the length of the attack. These are also called abortive treatments because they are intended to stop (abort) the pain and other symptoms. Some acute medications are available over the counter, and others require a prescription.

One of the most common mistakes in migraine treatment is taking an acute medicine that gets vomited or does not get absorbed quickly because the stomach stops working normally during attacks. Many acute treatments can work if the medicine is given as an injection, nasal spray or powder, or suppository rather than taken by mouth.



NSAIDs (Nonsteroidal Anti-Inflammatory Drugs): NSAIDs include some very well-known medicines like aspirin, ibuprofen (Advil, Motrin), naproxen sodium (Aleve), indomethacin (Indocin) and others. The NSAIDs help reduce the inflammation involved in migraine pain.

NSAIDs can cause stomach upset or severe stomach problems, such as bleeding or ulcers, if you



## **Medication Adaptation Headache:** What Is It?

It's important to follow your HCP's directions on how often to use certain medications to treat migraine. Taking medications (both over the counter and prescription) more than is recommended can lead to something called medication-adaptation headache. Other names for these are rebound headache (ambiguous) and medication-overuse headache (stigmatizing). This is a worsening of the migraine attacks over weeks to years due to taking too much acute medicine.

Each medication class has a specific threshold for how much of it you can take per week or per month. Taking more than the recommended amount can backfire, resulting in additional headache symptoms. Using triptans, ergots, combination analgesics, or opioids on 10 or more days a month may result in these worsening headache symptoms.

Using simple analgesics, such as over the counter NSAIDs and those with caffeine additives. 15 or more days a month can lead to medicationadaptation headache.

A headache that occurs because of medication overuse is a separate condition than the original headache disorder and is defined by the International Classification of Headache Disorders (ICHD-3) as headaches that occur on 15 or more days per month, in someone who already had a preexisting headache disorder, who has been using one or more acute medications more than recommended to treat their symptoms for three months or longer.

In most cases, you shouldn't be taking medication for acute symptoms more than two days per week. If you find yourself needing to take medication more often than that, speak to your HCP. You may need a change in your

take them regularly or in high doses. Some people cannot take NSAIDs because of the stomach pain or upset they feel.

Steroids: Glucocorticoids, also called steroids or corticosteroids, may be used for migraine relief. Steroids like prednisone or dexamethasone are available by prescription only and are used to quickly get inflammation under control. However, steroids can cause serious side effects with long-term use, including cataracts, osteoporosis, diabetes, weight gain, and more, making them a short-term option only. They work slowly but are often useful for breaking an occasional attack that is lasting much longer than usual.

**Analgesics:** Analgesics are medications that treat pain, but don't reduce inflammation. The most common analgesic is acetaminophen (Tylenol). It may help you ease the pain of milder migraine attacks, but probably won't work for more severe episodes.

There are also combination drugs containing acetaminophen, aspirin, and caffeine, that are available over the counter (Excedrin Migraine). These products may work for moderate, but not more severe, migraine attacks. Combination treatments, especially those containing caffeine carry a high risk for medication-adaptation headache and are typically not recommended by headache specialists.

A combination of acetaminophen and ibuprofen (Advil Dual) is also available over the counter and may help with mild-to-moderate attacks. Some people may be unable to use this if stomach issues occur.

Lidocaine: A nasal spray containing lidocaine (Xylocaine) can be used for quick relief of migraine pain. Lidocaine is a drug that numbs your sensations, including pain. It works very quickly but temporarily. You can use this

medication regimen to avoid experiencing a medication-adaptation headache.

These kinds of headaches can usually, but not always, be resolved when optimal preventative treatment is started to reduce the number of days acute medication are needed per month.

treatment for short-term relief until a different drug starts to work on your pain.

Opioids: Opioid medications should be avoided for migraine treatment because they have strong side effects like constipation, drowsiness, nausea, and others as well as a high risk for dependence and addiction.

Triptans: Triptans are a group of medications that block some of the actions of serotonin, which is one of several chemical signals released by nerves during a migraine attack. Triptans also reduce the blood vessel dilation (opening wide), release of other chemical signals, and pain-fiber activation that are all caused by a migraine attack. Triptans are available in different forms: pills, nasal sprays, or injections and are more effective when used early in a migraine attack.

Triptans for migraine relief include sumatriptan (Imitrex, Tosymra), rizatriptan (Maxalt), almotriptan (Axert), naratriptan (Amerge), zolmitriptan (Zomig), frovatriptan (Frova), and eletriptan (Relpax).

Injected triptans may cause a reaction at the site where the needle enters. Other side effects may include dizziness, drowsiness, muscle weakness, or nausea. Triptans aren't recommended for people living with migraine who also have certain heart disease risk factors, such as diabetes, high blood pressure, high cholesterol, obesity, or smoking. They're also not safe to take during pregnancy.

Ergots: Ergots (also called ergotamines) are drugs that are often combined with caffeine in a pill (Cafergot). These treatments may be more effective at easing migraine pain when used early in an attack. Ergots are usually most effective if you have migraine attacks that last more than 48 hours (two days). Ergomar, available sublingually (under the tongue), may also be effective.

Ergots may make migraine-related nausea or vomiting worse. Using ergots could lead to medication-adaptation headache. One option is dihydroergotamine (D.H.E. 45, Migranal), which may relieve head pain with fewer side effects. Dihydroergotamine is available in nasal spray or injection. Ergots are also not recommended for people with heart disease or during pregnancy.

Lasmiditan: Lasmiditan is a first in class medication for a new family of acute treatment medications called -ditans and was approved by the FDA in 2020. Lasmiditan activates serotonin receptors as triptans do but does not affect the blood vessels as triptans do. Lasmiditan is an oral medicine taken once for a migraine attack.

Lasmiditan can cause driving impairment and it is recommended that people do not drive within 8 hours of taking it. Other side effects include dizziness, fatigue, sedation, nausea and vomiting, and muscle weakness. Lasmitidan also has a small potential for addiction.

Gepants: The gepants are part of a new class of drugs that block the activity of another substance released by pain-related nerves during migraine attacks, called CGRP (calcitonin



## **Migraine Medications and Pregnancy**

If you have migraine and are thinking about becoming pregnant or suspect you might be pregnant, it's important to tell your HCP right away, because many of the medications you take to manage your migraine are not recommended during pregnancy.

Pregnancy can lead to a change in migraine symptom patterns — and for most people with migraine, that's a good thing. Between 50 and 80 percent of people might notice a reduction in migraine attacks during pregnancy, particularly in the second and third trimesters. Experts don't know exactly why but suspect it's due to a rise and steadiness in levels of the hormone estrogen. However, some people with a history of migraine may find their attacks get worse when they're expecting. And others may experience migraine attacks for the first time while pregnant.

Worsening of migraine symptoms during pregnancy is a serious complication. Patients who experience bad migraine attacks during pregnancy may be at increased risk of developing preeclampsia, a condition characterized by high blood pressure that can lead to preterm birth and, in rare cases, even be life-threatening for expectant mothers. Anyone who finds their migraine symptoms don't improve during pregnancy need to work closely with their ob-gyn and neurologist or headache specialist to monitor their health and develop a safe treatment plan.

The best thing you can do to manage migraine during pregnancy is to focus on prevention. Avoid known triggers, such as certain foods, drinks, or environmental conditions that make migraine worse. Get adequate sleep and stay hydrated. Carve out time for stress relief, such as taking prenatal yoga classes.

If you need to take medication to treat migraine during pregnancy, it's critical to work with your HCPs. Many commonly used migraine medications need to be avoided during pregnancy because they've been linked to birth defects in babies or may be associated with pregnancy complications such as bleeding or miscarriage.

Never take a medication during pregnancy without first clearing it with your HCP. To be extra cautious, talk to both your ob-gyn and the doctor who treats your migraine disease.

gene-related peptide). The gepants may be as effective as triptans for stopping or decreasing migraine symptoms but, unlike triptans, can be used by people with heart disease or heart disease risk factors.

Rimegepant was approved in February 2020 and is available as an oral tablet that dissolves in the mouth. Nausea may occur with rimegepant. Rimegepant is taken once for a migraine attack.

Ubrogepant was approved in December 2019 and is an oral tablet taken with water. Side effects of ubrogepant include nausea and sleepiness. A second dose of ubrogepant may be taken 2 hours after the first if a repeat dose is needed.

Nausea Medicines: Nausea medicines like chlorpromazine (Thorazine), metoclopramide (Reglan),

promethazine (Phenergan) or prochlorperazine (Compazine) can be very effective for migraine even if you do not experience nausea. If you have headache pain and nausea during your migraine attack, you may get a double benefit.

Neuromodulation Devices: Neuromodulation is the use of electrical pulses to modify the activity of nerves. The devices that deliver neuromodulation for acute treatment of migraine are external (worn on the outside of the body). Most require a prescription, although one (Cefaly) is available over the counter. With this non-drug option, there is no risk of medication-adaptation headache. All but one (Nerivio) are also approved for preventive treatment (covered below).

The Cefaly device is available over the counter and is worn on the forehead to deliver electrical stimulation to nerves in the forehead, face, and neck for 60 minutes during a migraine attack.

The Nerivio remote electrical stimulation (REN) device is available with a prescription. It is worn on the upper arm, and you use an app on your own smartphone to turn it on when you begin experiencing a migraine attack. Typically, the device is left on for 45 minutes of stimulation.

The gammaCore Sapphire device is also available only with a prescription. After putting gel on the end of the device, you hold it to a nerve in your neck for two pulses that are each two minutes long. The treatment can be repeated two more times over two and a half hours if needed.

The SAVI device is held to the back of the neck to deliver 3 pulses of magnetic stimulation, which can be repeated every 15 minutes for up to 1 hour. The company that produces this device filed for bankruptcy in 2020, however, so it is unclear how long the device will be available.

Side effects of external neuromodulation devices are rare and include tingling, warmth, redness, itching, muscle spasms, and mild discomfort where treatment is performed. With the SAVI device brief light-headedness/dizziness, ringing in ears, and nausea also occurred. People who have implanted medical devices, such as pacemakers, other neurostimulators, cochlear implants, or any other device that has an electric battery or signal should not use these therapies. People with any metal in their skull (other than dental fillings) should not use the SAVI, Cefaly or gammaCore Sapphire devices.

# — Preventive Treatments

Preventive treatments make migraine attacks less likely to happen, reducing frequency of attacks for many and even eliminating them for some people. The American Migraine Prevalence and Prevention (AMPP) study showed that approximately 40% of people who have episodic migraine (less than 8 migraine attacks/month or less than 15 headache days/month) would benefit from preventive treatments. Unfortunately, only 3% to 13% of people with episodic migraine receive preventive treatment.

There are several types of medications that your HCP can prescribe to prevent migraine attacks, or at least make migraine attacks less frequent or severe. These are typically taken daily.

Others are medications you take when you've had or know you're about to have a migraine trigger, such as your menstrual period, a stressful event like a job change, or air travel. These drugs are also called prophylactic treatments.

## Monoclonal Antibody (MAb) CGRP Blockers

Monoclonal antibodies (MAbs) are proteins that bind to and block the function of another protein in a highly specific manner. Monoclonal antibodies that bind to CGRP or its receptor reduce how often migraine attacks occur by 50 percent or more in around half of people who take them. These medications may eliminate migraine attacks altogether for a smaller number of patients.

The four MAbs that block CGRP activity, erenumab (Aimovig), eptinezumab (Vyepti), fremanezumab (Ajovy), and galcanezumab (Emgality) are the first approved treatments developed specifically for migraine prevention. In clinical trials, these treatments were safe for people with some heart disease or heart disease risk factors. There were few side effects, consisting of injection site soreness, rash, and constipation. Since FDA approval, there have been reports of constipation, sometimes severe, and new or worsened high blood pressure (hypertension) after taking erenumab.

Erenumab, fremanezumab, and galcanezumab are shots you give yourself at home once a month, which can be easy and convenient.

There is also the option with fremanezumab to take three shots at once every three months.

Eptinezumab is given as an intravenous infusion in a clinic, doctor's office, or infusion center once every three months.

## **Botulinum toxin A (Botox)**

Although you may think of cosmetic use to reduce face wrinkles or laugh lines when you hear Botox, it is also used for many other medical conditions, including prevention of migraine. If your migraine



## Off-Label Drugs and Migraine

"Why am I taking a blood pressure medication for my migraine?" "My doctor just prescribed me an antidepressant for migraine, but I'm not depressed." These are common concerns among people with migraine disease: Why are all these unrelated medications being used to treat migraine disease?

Migraine is a complex disease involving many different chemical signals in nerves, muscles, and blood vessels. Various types of medications affect how these signals are released and interact with other biologic signals and one another. The medicine that affects these signals in the most effective way for you as an individual depends on what kind of migraine attacks you have, how often you get attacks, and what other health conditions or risk factors you have.

The Food and Drug Administration (FDA) is responsible for determining the safety and effectiveness of prescription and non-prescription medications. All drugs must go through a multi-phase approval process, in which different kinds of studies are conducted to prove a drug is safe and effective, a process that can take years and cost millions of dollars. Once a drug is approved by the FDA, it's given an "indication," which is an official recognition that the medication is safe for a particular medical condition.

Once the FDA approves a medicine, it can be prescribed for uses other than what it was approved for, called off-label prescribing. This is a common practice because once a drug is found safe, if it is effective for other conditions, it may even become the standard of care.

Off-label prescribing has been especially common for migraine disease because historically, headaches haven't been as well researched as other diseases. Many of the drugs used off-label for migraine disease are already available in

includes 15 or more headache days per month, botulinum toxin A injections may be an effective preventive treatment. Botulinum toxin prevents release of chemical signals from nerve endings, which not only stops muscles from contracting but also causes other changes in the sensitivity of pain-related nerve fibers.

#### **Nerve Blocks**

A nerve block is an outpatient procedure in which anesthesia is injected into or immediately around a nerve involved in the migraine process. This includes the occipital nerve at the base of the neck and back of the head, the supraorbital or supratrochlear nerves above the eyebrow, the auriculotemporal nerve in front of the ear at the temple, and the trigeminal nerve at the cheek. Nerve blocks work very well to provide pain relief to specific areas and reduce or eliminate migraine for people who have not had relief from other treatments. Nerve blocks should be given only by neurologists or anesthesiologists who specialize in headache and/or pain treatment. Improper injection of anesthesia can result in permanent damage to a nerve.

generic form, so it's unlikely that companies would go through the time and expense to get them formally approved to treat migraine disease.

Off-label prescribing is particularly common in migraine because there has been so little investment in the care of patients with migraine. Dosages of certain drugs may be different when they are used off-label compared to the approved indication. For example, the dosage of antiseizure drugs is lower for treating migraine disease than it is for seizures, which could mean fewer side effects.

Any time your HCP prescribes a medication, it's a good idea to ask a few questions to understand why it's being recommended for you:

- Why do you think this drug will make me feel
- How does this drug work to improve my symptoms?
- What side effects should I be aware of or worried about?
- How soon can I expect to feel relief of my symptoms?

#### **Antidepressants**

Antidepressant drugs are not just used to treat depression or anxiety. They can also help treat many medical conditions that involve pain. These drugs can help regulate brain chemicals, such as serotonin, that are involved in setting the pain response of a migraine in motion.

Tricyclic antidepressants, especially nortriptyline, may help prevent migraine attacks. Tricyclics can have side effects like weight gain, dry mouth, constipation, sleepiness, and others. Some tricyclics have fewer side effects than others. People with insomnia and neck pain may have more benefit because these other conditions are also treated effectively with tricyclic antidepressants.

Two antidepressants, venlafaxine (Effexor XR) and duloxetine (Cymbalta), are serotonin and norepinephrine reuptake inhibitors (SNRIs) that influence release of brain chemicals and are effective at preventing migraine. Selective serotonin reuptake inhibitors (SSRIs) are another group of antidepressants that may be used to prevent migraine, although these are not as effective as SNRIs. Mood changes and anxiety sometimes occur in the first weeks of taking SNRIs or SSRIs. Side effects include nausea, dizziness, difficulty sleeping, high blood pressure, abnormal bleeding, vision changes, low sodium, low appetite, and changes to sex drive and sexual function. As with any treatment, it is important to let your HCP know if you have any new or worsening symptoms.

## **Cardiovascular Drugs**

Drugs that treat heart disease or blood pressure problems may also help manage migraine by making attacks less severe or frequent.

Beta blockers like propranolol, metoprolol tartrate, and timolol are effective at migraine attack prevention. They may take a few weeks to work effectively. They're also not recommended if you're older than 60, are a tobacco user, or have certain heart or vascular conditions. Common beta blocker side effects include fatigue, cold hands and feet, and weight gain. Beta blockers aren't typically used in people with asthma because of concerns that they can trigger asthma attacks.

Certain blood pressure medications, the angiotensin converting enzyme (ACE) inhibitors and angiotensin receptor blockers, may also help shorten migraine attacks or make them less frequent. Side effects of ACE inhibitors can include dizziness, drowsiness, diarrhea, cough, and rash. ARBs usually have fewer side effects, which include dizziness or feeling light-headed.

#### **Anti-seizure Medications**

Drugs used to treat seizures, a type of neurological condition, may also help cut down on the frequency of migraine attacks. These include topiramate (Topamax), which is available as a pill. Common side effects include tiredness, dizziness, nervousness, tingling in hands or feet, and issues with concentrating, paying attention, and memory. Valproate (Depakote) is less often used these days because of concerns weight gain, tremor, hair loss, and liver problems (this last one is rare).

## **Hormone Therapy**

People who menstruate may have higher frequency and severity of migraine attacks during menstruation and this is thought to be related to rapid decreases in estrogen levels. For some people who experience such menstrual migraine, estrogen supplementation during menstruation may be helpful. Another option is to prevent the estrogen decrease by taken hormones continuously, especially if they are also being used for birth control. Menopause is another time of estrogen fluctuation that can affect migraine.

Hormone replacement therapy and contraceptives risk the increase of stroke, however, which may also be increased by migraine with aura. Because of this risk, hormone treatments are advised against for people who have migraine with aura or who are in the period of and around menopause, when stroke risk is also higher.

#### **Neuromodulation Devices**

The neuromodulation devices discussed in the previous section on Acute Migraine Treatments can also be used to prevent migraine attacks. As described earlier, these devices modify the sensitivity of the nerves involved in migraine. Side effects are rare and include tingling, warmth, redness, itching, muscle spasms, and mild discomfort. With one (SAVI) side effects also included dizziness, ringing in the ears, and nausea. People who have implanted medical devices should not use these treatments, and only the Nerivio devices is safe for people with metal in their skull (not including dental fillings). The Cefaly device is used for 60 minutes a day for preventive treatment and acutely for 20 minutes. The gammaCore Sapphire is used three times per day for prevention with two pulses that are each two minutes long. With the SAVI device, two pulses are used in the morning and at night for prevention.

## **Occipital Nerve Stimulationa**

The occipital nerve is located at the base of your neck. During this procedure, the surgeon implants a small device near the base of your skull with leads that connect to a generator that sends electrical impulses to the occipital nerve. The generator is often implanted under the collar bone, but it can also be placed in the abdominal or buttock area. This procedure may improve migraine attacks for some people, but the results are limited, and more research is needed. Risks of the procedure include infection, pain, and muscle spasms, as well as possible surgical adjustments of the device needed after the initial procedure.

**It is important to note** that your HCP may prescribe a drug treatment that is not listed here. Migraine is such a complex disease in which different classes of medications may be used that are not as commonly prescribed.

# \* — Integrative Treatments

Migraine is a complex disease and each individual's experience with migraine attacks and medications is unique to them. Not every medication works for every person and some people prefer to limit how much medication they use. There are nonmedication options that can be integrated into the care you develop with your health care provider. Many of these are useful as preventive care and can also be helpful as acute treatment to reduce the symptoms of a migraine attack.

Light Modifications Precision Tinted Eyewear: Light sensitivity, or photophobia, is a common symptom of migraine disease. Oftentimes, light sensitivity can persist even when you don't have a migraine attack. The glare of fluorescent lighting, television screens, computers, smart devices, and the sun can trigger migraine attacks and other headaches. They also contribute to eyestrain and can reduce the quality and duration of sleep, all of which may make migraine attacks more likely to occur.

Precision tinted eyewear is designed to filter out painful and harsh light that enters the eyes. Although these have not been well studied, some people find blocking artificial blue and green light with these glasses can reduce the severity and frequency of migraine attacks. Precision tinted eyewear, or migraine glasses, can also help alleviate dizziness, nausea, and exhaustion associated with light sensitivity.

Glasses that block blue light have become more commonly used and more commonly available, but most were not designed specifically for people with the light sensitivity of migraine. There are two companies that produce a wide range of precision tinted eyewear that has been designed for people with migraine.

▶ TheraSpecs – TheraSpecs was founded by Hart Shafer and Kerrie Smyres. Kerrie, who



lives with debilitating chronic migraine disease, and her husband Hart were on a quest to find the perfect precision tinted glasses for her. Through Hart's research and multiple tries to get the right glasses, TheraSpecs was born in 2012. They produce both indoor and outdoor glasses with or without a prescription. There are several styles to choose from.

Axon Optics – Axon Optics has used the latest research on pain pathways associated with migraine disease to develop their SpectraShield FL-41 migraine lens. These lenses reduce the exposure to blue and green light as well as certain types of artificial light. They offer indoor and outdoor glasses that prescriptions can be added to and contact lenses.

Narrow-Band Green Light (Allay Lamp): Research has shown that while blue, yellow, red, and white light can increase the pain of a migraine attack and worsen light sensitivity, green light decreases pain for some people. A very specific color of green light within a narrow wavelength band also sends smaller signals to the brain than other colors of light which may decrease activation of nerves involved in migraine attacks. The Allay lamp provides that exact narrow band of green light. Studies are still needed to understand how effective the lamp is at relieving migraine symptoms acutely. Some people say using the lamp regularly also decreases the frequency and severity of migraine attacks for them.

## **Cognitive Behavioral Therapy**

Migraine is not a psychiatric disease or psychological problem—it is a biological disease process that is not "just in a person's head." Like all diseases, however, migraine is affected by your overall health and well-being, which includes managing stress and emotions. Cognitive behavioral therapy (CBT) is the best studied and proven psychotherapy technique for reducing migraine severity and frequency. A psychologist helps you train yourself to manage pain "from the top down," to manage the stress and emotions that can make migraine attacks more likely. In this way, you may be able to use your own mind to make your brain and nervous system less sensitized to the biologic migraine process that causes pain and other migraine symptoms.

#### **Biofeedback**

Biofeedback is a technique where you learn to train your brain to manage pain and other conditions, like stress, that can affect migraine.

You must learn and train to master biofeedback; it's not something that happens overnight. You can work with a therapist who specializes in biofeedback who will place electrodes (little sensors) on areas of your body. You will learn to sense your muscle tension, changing body temperature, or other feelings associated with the onset of migraine. Readouts from these sensors show you how these sensations in your body change at different times.

With the help of your biofeedback therapist, you can learn how to control some sensations or reactions in your body, with the goal of easing your migraine

## **Lifestyle Changes**

Healthy changes, such as losing weight if you need to (which may help you sleep better); quitting smoking; and cutting back or quitting drinking alcohol may help you prevent or control migraine. Talk to your HCP if you think you need help to lose weight, sleep through the night, or especially to quit smoking or drinking.

Sleep hygiene can help you get better quality sleep. Make sure your bedroom is as dark and quiet as possible. Keep the room cool and comfortable. Cover up any clocks that have annoying lights. Set a sleep schedule and stick to it if you can. If you have severe primary insomnia, CBT for insomnia (CBT-I) is more effective than daily pills and much safer.

## Massage

Try massage therapy to help you relax sore muscles and ease anxiety. Let your massage therapist know that you have migraine. Regular massages may help reduce the frequency of your attacks.

## **Acupuncture**

An ancient pain relief practice, acupuncture needs to be performed by a licensed expert. Your HCP may be able to refer you to an acupuncturist in your area. Your acupuncturist will insert very thin needles into places around your body while you lie back and relax. Acupuncture may help ease headache pain, but it's not exactly clear why it works.

## Herbs, Vitamins, and Supplements

Some studies show promise for a few supplements, but more research is needed to be sure if they work, what doses are recommended, and if they have any side effects or safety concerns. Some promising supplements for migraine treatment include:

- Butterbur (you will need your doctor to monitor your liver function)
- Riboflavin (vitamin B2)
- Vitamin D
- Magnesium
- Feverfew

You can buy these supplements in pill form in supermarkets, drugstores, vitamin stores, or online. They may help reduce the frequency and severity of migraine attacks in some people, but more research is needed before anyone can say for sure that they really work as a treatment.

Although butterbur is the most effective natural treatment, you must make sure that it is "pyrrolizidine free" and that testing is done routinely by a reputable lab. Pyrrolizidines can creep through the production process and cause liver damage. The American Academy of Neurology recommends people using butterbur for migraine treatment have their liver function monitored by their HCP.

## Talk to your HCP before you try any herb, supplement, or vitamin to treat or prevent migraine.

These products could interact with your medications or not work at all and be a complete waste of your time and money. Vitamins, supplements, and herbs are not regulated as strictly as medication. The quality and potency of different brands or products available in retail stores can vary a great deal.



# **SEEDS for Successful Lifestyle Management of Migraine**

Dr. Jennifer Robblee and Dr. Amaal Starling, neurologists at the Mayo Clinic in Scottsdale, AZ who specialize in the treatment of migraine and other headache disorders, created the SEEDS memory tool for lifestyle modifications to help people with migraine. SEEDS stands for sleep, exercise, eating/drinking, diary, and stress management as detailed here.

**S**LEEP: Too much or too little sleep can both make migraine attacks more likely. Do your best to go to sleep at the same time every night and wake at the same time every morning. Put devices down and stop all screen time at least one hour before bed. Use your bedroom only for relaxing bedtime routines, sleep, and intimacy. If you still have difficulty with sleep talk to your physician or headache specialist and consider CBT for insomnia (CBT-I), which is more effective and safer than sleep medications.

**E**XERCISE: Exercise can help you lose weight if you need to do so, which may help you sleep better. Exercise can also help with stress management and has been shown to have positive effects on any symptoms of depression or anxiety that often come with having a chronic disease. There is also emerging evidence that regular moderate exercise may reduce the frequency of migraine attacks.

EATING & DRINKING: Both skipping meals and overeating or drinking too much at a single meal can trigger migraine attacks. Try to eat lots of leafy greens and fresh vegetables for overall brain and heart health and have meals and snacks on a regular schedule that works for you. Drink plenty of water because dehydration is also a well-known trigger for migraine attacks—a good goal is to have 8 ounces (1 cup) of water 8 times a day. Eliminate caffeine if possible, or at least be consistent in how much you have each day because caffeine

withdrawal is as likely as caffeine intake to trigger an attack. Similarly, limit alcohol consumption to 1 to 2 drinks per day or less, and do not smoke cigarettes or cigars.

DIARY: Use a headache diary to keep track of your migraine attacks, potential triggers, what treatment you used, and whether or not it worked well for you. Try to find one that also tracks whether you were able to continue activities during the attack (green light), were partially limited (yellow light), or were unable to function (red light). This can help you and your HCP better understand the specifics of your migraine and find the best treatments for you as an individual.

STRESS MANAGEMENT Stress is a big migraine trigger for many people. Experiment with different healthy stress management techniques to find what works for you. These can include:

- Exercise like walking, dancing, or swimming
- Gardening
- Meditation
- **Guided imagery**
- Relaxation therapy
- Yoga or tai chi

If you struggle to control your stress or anxiety, counseling or psychotherapy may help. Mental health professionals such as social workers, psychologists, or psychiatrists can work with you to identify the sources of your stress and find ways to help you control it. You may particularly want to consider working with someone who specializes in cognitive-behavioral therapy (CBT), a therapy technique that may help you learn to control your pain sensations more effectively and can be used to help with anxiety and depression.

## PART VI LIVING WITH MIGRAINE

Whether you've been living with migraine for years or only recently started experiencing migraine attacks, you know that migraine is so much more than a "bad headache." Migraine is a debilitating neurological disease.

The World Health Organization considers migraine the third-most disabling disease in the world, as measured by days of healthy living lost. It is not uncommon for people to have such severe migraine that they are unable to work, have difficulty with their chores and errands, and have to limit attending family and social events.

Migraine can take a dramatic physical and emotional toll on patients. An attack can last for days, causing you to miss work and social gatherings with family and friends.

Parents may struggle to be present for their kids — after all, how can you make dinner, fold laundry, or help with homework when you can't bear to get out of bed?

People with migraine are more likely to have depression, anxiety, difficulty sleeping, and other chronic pain and fatigue. People who get migraine attacks with aura, or visual and sensory disturbances that precede an attack, have a greater risk of heart attack and stroke.

None of this is to make you feel like a martyr who is going to be debilitated for the rest of your life. Rather, it's to help you feel validated about the reality that migraine is a serious medical condition and requires support and understanding from everyone around you, including work colleagues and managers, family, and friends.



# **Patient Voices:** What a Migraine Really Feels Like

Since becoming chronic 11 years ago, I pretty much stay in an active migraine attack. The level of severity fluctuates but there are hallmark symptoms I always have. There is always a deep-set pain behind my eyes, predominantly the left eye. I am always fatigued, nauseous, light-headed, and dizzy. When the pain intensifies, it feels like a sledgehammer is being slammed into my eye socket. My neck and shoulders are tight and feel like they are on fire. My hair and teeth hurt as well. I cannot concentrate, and my memory is horrible. I experience some variance of this on a daily basis. – Jaime Sanders

Migraine feels like my body and brain have been hijacked. Nothing seems to work normally during an attack. In addition to the pain, I get clumsy and weak, I can't think clearly and use the wrong words (like roof instead of refrigerator), I get so fatigued that I can't hold my body upright, all my senses become heightened. It feels like my brain is malfunctioning and can't quite manage its normal functions.

- Kerrie Smyres

Migraine is a thief. It steals time of our lives and robs us of our identities. It is a struggle to be understood when even the medical community won't recognize the severity.

- Cat Charrett-Dykes

In the following pages, we'll review information that you might want to pass along to family and

friends so they can learn more about what you're going through when you experience migraine and better understand how they can help you.

# – Migraine Stigma

Invisible illnesses like migraine are more challenging for people on the outside to understand. And that can make patients reluctant to speak up because they don't want to complain or feel like a burden.

The phrase "migraine stigma" can mean different things to different patients. Maybe you feel like your work colleagues treat you differently after you've been out sick with a migraine attack. You may feel guilty cancelling Saturday dinner plans because you feel a migraine attack coming. You may avoid talking about migraine with your extended family during holidays because you know they don't really get how terrible you feel, and you're tired of complaining.

In fact, research from Thomas Jefferson University in Philadelphia shows that people with chronic migraine experience as much social stigma as patients with epilepsy, which is a disease that has more obvious symptoms. The study found that migraine stigma is both external and internal.

External stigma could mean getting treated differently by colleagues, family, and friends.

Internal stigma is often tied to anxiety and fears of what-ifs. People with migraine may preemptively worry that their attacks will cause people to treat them differently or get anxious about missing work deadlines if they experience a migraine attack. These subjective experiences of stigma can be as damaging to your health as overt discrimination or the loss of social relationships, reports Harvard Health Publishing.

A third kind of migraine stigma is found in policies, laws, and regulations. Why is there not a blue book listing of criteria to get social security disability for chronic migraine, when migraine disease is the third-leading cause of disabled days in the world?

One powerful way to fight against migraine stigma is education and advocacy. History shows that the only way for a disease to be destigmatized is through patient participatory advocacy, according to neurologist William B. Young, MD, in a recent article in the journal Practical Neurology. It's critical for people with migraine disease and their families and friends to participate in advocacy initiatives, to help reverse migraine stigma, promote continued research into migraine treatment, and help ensure people can get access to new treatment. You can read more about how to get involved as a migraine advocate in the next section.

# Migraine and Mental Health

Mental health conditions such as depression and anxiety frequently occur together (are comorbid). If you find yourself experiencing any of the following symptoms of depression and anxiety, bring them up with your HCP.

#### **Depression symptoms:**

- Feelings of sadness and hopelessness
- Loss of interest in usual daily activities, including hobbies, exercise, and sex
- Changes in sleep patterns (sleeping more or less than usual)
- Changes in weight
- Feelings of worthlessness or guilt
- Trouble thinking or concentrating
- Feeling angry, irritated, or frustrated, even over minor issues
- Frequent or recurrent thoughts of death or suicide If you have active thoughts of suicide, help is available at all hours in the US from the National Suicide Prevention Hotline: 800-273-8255

## **Anxiety symptoms:**

- Feeling nervous
- A sense of impending danger or doom
- Increased heart rate
- Rapid breathing
- Trouble concentrating because of your worries and fears
- Difficulty sleeping because of your worries and fears
- Gastrointestinal (GI) issues, like nausea or stomach pain
- Inability to stop worrying

Treating your mental health condition along with migraine can help them both feel better. Certain types of antidepressant medication may even effectively treat migraine and depression and anxiety.

If you find yourself experiencing depression, anxiety, or significant stress about managing migraine, it's important to seek out a mental health professional, such as a psychologist or psychiatrist, especially someone who has experience dealing with pain management.

# \* --- Migraine and the Workplace

One survey found that more than half of Americans miss work because of headache or migraine attacks, but more than 40 percent don't tell their manager why. They're worried their employer doesn't think that head pain is a good reason for missing work.

But people with migraine know all too well that it's nearly impossible to have a normal workday when you're in the throes of a migraine attack or recovering from the aftermath of one.

According to WebMD, about 157 million workdays are lost each year in the U.S. due to migraine attacks. Ninety percent of people with migraine say they "can't function normally" on days that attacks occur. About one-third of them say they have to go to bed when that happens.

Your workplace may have migraine triggers that you can't always control. Depending on your specific work circumstances, you can ask about accommodations such as:

- Turn off fluorescent lights, or ask to sit near a location where fluorescent lights don't need to be on (such as near a window)
- Get an antiglare screen for your computer monitor
- Sit away from the office kitchen (if certain smells are a trigger)
- Ask colleagues to avoid wearing certain perfumes or colognes (if those smells are a trigger)

There are also certain migraine triggers you can try to control:

- Don't let yourself get too hungry or thirsty.
- Keep snacks and a water bottle at your desk.



# Migraine and Medical Disability

Short-term disability: Short-term disability is offered by many employers as part of a health insurance package, covering 90 days of paid time off work. If you have migraine, you can use these days to recover and try new treatments, and the money you receive can be used at your own discretion. This means you can put it toward covering any new treatments or medication you decide to try, or to pay for normal life expenses while you're not working.

Long-term disability: After the 90 days, you will need long-term disability insurance. This is also offered by many employers, and covers a percentage of your salary (usually around 50 to 70 percent) while you're on medical leave. Each employer requires different materials to approve long-term disability, but they usually include medical records, a note from an HCP, and updates following HCP visits.

Social Security Disability Income (SSDI): Outside of your employer, the federal government offers Social Security Disability Income, or SSDI. Many employers require you to apply for SSDI in addition to applying for their own insurance benefits. SSDI can be more beneficial than employer benefits because recipients are also eligible for Medicare, and when you retire, your SSDI earnings will go towards your Social Security retirement income. This means your retirement income will be higher than if you stop working at a younger age because of migraine or another disability.

- Try to maintain a regular eating routine— have lunch and snacks at the same time every day.
- Build stress relief into your day by taking short breaks, such as a five- to 10-minute walk outside.
- Don't cram too many meetings into your day. When you can, space out meetings and calls to minimize stress.

It's also smart to prepare for what to do if you start to feel a migraine attack coming on:

- Keep your medicine with you, in your desk, briefcase, or purse
- Have a heating pad or cold compress you can put on your head
- Talk with your manager or an HR representative about migraine and let them know what works best for you when you feel at attack coming on. Maybe you can find a small, dark room to lie down in while your medication kicks in, or maybe you're better off leaving right away to rest and work from home if necessary.

# Migraine Disease and Loved Ones

Migraine attacks can have a negative impact on your personal relationships. The frequency, severity, and duration of migraine attacks can be unpredictable, which makes it even harder for you (and your family and friends) to cope.

In the Chronic Migraine Epidemiology and Outcomes (CaMEO) study, up to 57 percent of people with migraine reported reduced participation in family activities. Migraine patients expressed concerns about being unable to attend everyday activities with their partners and children, challenges taking care of household responsibilities, and missing major events such as family holidays, parties, or vacations. People reported feeling guilty, sad, and frustrated about how migraine impacts their family.

Even worse, almost 24 percent of people with episodic migraine disease and nearly 44 percent of people with chronic migraine disease said their spouses did not really believe them about their headache pain.

Getting more support from your family and friends can simply depend on how much they know about the biology of migraine attacks and how severe and debilitating they are. People who've never experienced migraine have no idea the way it affects your entire body. They can't fathom the impact of having that degree of pain over a course of many hours or even days. Some people might think you're exaggerating the pain.

It is up to you to help educate them, so they can better understand what you're going through.

Here are some tips from Migraine.com to start having those conversations.

Share these migraine patient guidelines. This document is a great way to quickly educate your loved ones about migraine symptoms and the extent to which they can impact your quality of life. It also explains the trial and error of experimenting with treatment that many people living with migraine disease must endure. If anyone thinks migraine disease is "just a bad headache" this document should help them understand that it's anything but.

Pay attention to signs of depression: It's common for people living with migraine disease to experience depression, which can deeply affect your ability to connect with your friends and family. If you find yourself experiencing depression symptoms (see page 31), talk to your doctor about your treatment options. Certain antidepressant drugs can also help treat migraine symptoms.

Be honest about having a migraine attack. If you need to cancel plans or are unsure if you can commit to an event, be honest and direct about the reason. Tell people you're having a migraine attack and you need to stay home, take medication, and ride out the symptoms until you feel better. You might want to avoid using the word "headache" because the headache might imply your attack could be easily managed with over-the-counter medications and isn't as debilitating as a migraine attack.

Bring loved ones to your HCP visits, so they can hear firsthand how you talk about your migraine and its impact on your everyday life, as well as how your HCP suggests treating it.

# Caregiving for Migraine

If you have a loved one who gets migraine attacks, it can be very upsetting and challenging to watch them suffer and not be sure of how you can help.

The most important thing you can do as a caregiver for a migraine patient is understand their condition. Ask them about their symptoms. Some people with migraine disease get aura; some don't. Some get more nausea symptoms than others. Ask about what triggers affect them, so you can make sure you're not contributing to those triggers in any way (for example, with certain scents in your personal care or household cleaning products). Ask about the frequency of their migraine attacks and what treatment options they typically use.

All of this will help you better understand how migraine disease affects their everyday life and routine and will allow you to have more empathy. Know that people with migraine disability are heavily stigmatized by society for a disease that is not their fault. Emotional support and kindness are the best things you can provide to someone who experiences migraine disease.

If you live with someone who has migraine, you can do many things during a migraine attack to help your loved one. It's always a good idea to ask your loved one what they need from you. Maybe the best thing you can do is leave them alone in a cool, dark bedroom until their medication kicks in, and that's really all they want. But here are some suggestions from migraine patients of ways caregivers can be helpful during a migraine attack:

Give a person having a migraine attack peace, quiet, and personal space. This is especially important if you have young children around the house. As a caregiver, you can entertain the children, or better yet, take them out of the house to allow your partner to rest and recover.

- Remember that migraine is more than just head pain. You can read about all the different physical symptoms that migraine patients can experience during an attack on page 4. In addition to throbbing head pain, your loved one may also have nausea or vomiting, an inability to do everyday tasks (or even get out of bed), sensitivity to sounds and lights (some people need near-total darkness and silence), and fatigue.
- ▶ Be flexible about changes in plans. Migraine patients experience a lot of quilt about cancelling social plans because of attacks. They worry that people might get tired of them "bowing out" or that people won't believe how sick they actually are. You can help advocate for the migraine patient by supporting them in these conversations and letting others know how serious their symptoms are.
- Do extra chores around the house. Data also shows that migraine patients feel bad about not keeping up when it comes to housework or being unable to help children with their homework and activities. As a caregiver, one of the best ways you can help a migraine patient is to pick up the slack without being asked.
- ▶ Help the migraine patient stick to their routine. Skipping meals and getting dehydrated can be important migraine triggers for many patients. If you see your loved one running around without taking the time to eat regular meals, you can offer to make them a snack or bring them water to drink and gently suggest they take time to slow down and care for themselves.
- ▶ Help your loved one destress. Maybe you help them free up time to go to the gym, give them a gentle shoulder massage while you watch TV at night, or offer to take a certain errand or chore off their plate.
- Keep an eye on your loved one's migraine symptoms and frequency of attacks. Does their current treatment plan seem to have things under good control? With new medications (CGRP inhibitors), as well as Botox and surgical procedures, migraine patients have more options than ever before. If your loved one's condition seems to be worsening, help them advocate with their HCP to escalate treatment.

## PART VII ADVOCACY FOR PEOPLE LIVING WITH MIGRAINE

Advocacy is a very powerful force when it comes to improving the lives and treatment options for people with migraine disease. Advocacy includes:

- Support for research for new and more effective treatments
- Organized efforts to reach out to lawmakers to support important bills that make treatments more affordable or accessible
- Public education and health promotion to make employers, insurers, schools, and local governments more aware of migraine-related issues or the needs of individuals who have migraine disease
- Spreading awareness of new research findings so people with migraine disease can tap into more effective treatment and prevention options
- <u>Using language that reduces stigma</u>. Expect to slowly train yourself out of using language that has been around for a long time but that promotes migraine stigma.

Patient perspective and active involvement is a vital, necessary part of successful advocacy. You can join our advocacy efforts to help support research, make treatments and medical care more accessible for everyone, educate lawmakers and other decision makers about important legislation, and other initiatives.

Join the 50-State Network. The 50-State Network is a grassroots advocacy organization created by CreakyJoints cofounder Seth Ginsberg. The 50-State Network is driven by patients who are living with many different chronic pain conditions. They offer their perspective and passion to efforts to shape public policy and health-related legislation at the state, local, and federal levels. Join the 50-State Network today and sign up for email updates about important legislation and advocacy efforts that are happening right now.

Connect with the Headache Migraine Policy Forum. The mission of the Headache and Migraine Policy Forum is to advance public policies and practices that promote accelerated innovation and improved treatments for headache and migraine patients. This group encourages the advancement of headache science and innovation; supports the education of patients, health care providers, and other stakeholders about policy issues that impact access to new and existing therapies; highlights the need for improved, multimodal means of preventing and treating headache and migraine; and furthers access to appropriate prevention and treatment options for all patients.

Get involved with CHAMP (Coalition For Headache And Migraine Patients). CHAMP is a nonprofit organization whose mission is to provide support to patients with headache, migraine and cluster diseases, as well as their caregivers. Through bringing together organizations and leaders in the migraine and headache space, collaboration, communication and education is enhanced to help the migraine patient more effectively on their journey. CHAMP continues to work on identifying

unmet needs of those with headache, migraine and cluster diseases to better support them. Subscribe to their newsletter to get access to the best curated information and resources from the leading headache, migraine and cluster-focused organizations that are members of CHAMP.

Participate in Headache on the Hill. This is organized by the Alliance for Headache Disorders Advocacy (AHDA). The AHDA brings health professionals, migraine and cluster headache advocates, and patients themselves to unite on our requests or "asks" of Congress. These asks are typically focused around improving awareness about the impact of headache disorders and in turn impacting the available research funding.

## Teach someone about the reality of migraine disease

If you have disabling migraine attacks, you probably encounter ignorant and hurtful statements about migraine disease all the time. Have positive conversations that help people understand the reality of migraine disease. Explain to them what they can do to make things better, and not say things that make it worse. Learn from your experiences how to have better conversations that turn people away from being stigmatizers.

Why should you get involved in migraine advocacy? Because without your input, lawmakers and policy professionals simply don't know the pain that you live with and how important it is to support research. You make advocacy personal and powerful.

You can truly change the course of migraine treatment development, so more people can have access to the best treatments and medical care. You can add your voice and personal experiences to the advocacy efforts in full swing right now and create a world where everyone who experiences migraine disease can see a headache specialist, get an accurate diagnosis, and start treatments that work to relieve and even prevent these painful attacks.

What can advocacy do? The research we support now could create more accurate, sensitive testing for migraine or its triggers. Research can identify more effective drugs and create tests to help personalize treatment, so people do not have to endure as much trial and error to find the right medicine. More effective health policies can ease the process of getting diagnosed and treated at an affordable price for everyone.

Together, we can create a better world for everyone who lives with migraine disease, and one day, a world where there is a cure for these painful, debilitating attacks. Advocacy is the powerful vehicle to carry us to a migraine-free future.



## REVIEWERS



## **JAIME SANDERS**

Jaime Sanders is a blogger, patient advocate, and consultant for CHAMP's Diversity in Headache Advisory Council (DiHAC) who lives in Virginia with her husband and three children. She has had a lifelong journey with migraine and lived most of her adult life with depression and anxiety. From a toddler with abdominal migraine to a wife and mother with chronic intractable migraine, Jaime has learned to turn her pain into empowerment over the past 40 years. Through her advocacy work and blog, Jaime's mission is to make a very invisible disease visible to the rest of the world and validate the real pain of millions. She works with several nonprofit organizations in a collaborative effort to educate, empower, and uplift migraine patients and their caregivers. In her previous role as the Migraine Patient Advocate Coordinator for the Global Healthy Living Foundation, Jaime's role helped to recruit migraine patients into an advocacy role to change legislation and insurance policies to improve patients' access to care. Creating migraine- and mental health-specific content is one of her passions, as it helps to keep her connected to those communities while also offering support, compassion, and validation for illnesses that are highly stigmatized and misunderstood.



#### **DEENA KURUVILLA, MD**

Deena E. Kuruvilla, M.D., is a board certified neurologist, headache specialist and Director of the Westport Headache Institute. She has served as assistant professor and associate program director for the Headache fellowship at the Yale School of Medicine and is a medical advisor for Healthline.

Dr. Kuruvilla completed her medical internship at the Mount Sinai School of Medicine in New York. Subsequently, she completed her Neurology residency at Brown University in Rhode Island, where she was chief resident. She went on to complete a fellowship in Headache and Facial Pain at the Montefiore Headache Center and the Albert Einstein College of Medicine.

Dr. Kuruvilla has conducted research studies on medical devices, complementary and integrative medicine and procedural approaches for the treatment of headache disorders. She is the former chair of the complementary and integrative medicine section and current chair of the women's health section of the American Headache Society. She has also been an invited reviewer and author for many peer-reviewed publications including Headache, Cephalalgia, JAMA, and the British Medical Journal.

Dr. Kuruvilla's research and clinical work has been widely featured in the press, including Prevention Magazine, the Food Network, Neurology Today, the Hartford Courant, and the Wall Street Journal.

#### **HEADACHE AND MIGRAINE POLICY FORUM**



Lindsay Videnieks is Executive Director of the Headache and Migraine Policy Forum (HMPF), a diverse stakeholder coalition bringing together policy-minded partners that care about patient access. HMPF identifies state and payer level access challenges and uses a campaign approach to help mobilize the migraine community to engage on policy advocacy.

Ms. Videnieks has two decades of experience advising non-profit institutions on strategies to support public policy goals and to secure funding through the federal appropriations process. She previously worked in the office of Congressman John E. Baldacci (D-ME) as well as on his re-election to the U.S. House of Representatives. Lindsay graduated from the University of Maine at Orono with Bachelor of Arts degrees in Political Science and English and received her Juris Doctor from the Catholic University Columbus School of Law. She is admitted to practice law in Maryland where she also lives with her husband and three children.

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