



# Migraine Patient Guidelines

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## PART I OVERVIEW

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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, behavioral 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 disease, the trial-and-error process to find something that works – and keeps working over time – can be long and frustrating.

How do you make sense of all of these possible treatment choices for migraine disease? The most important tool is clear, simple information from a trusted, independent source. That is why this guide – vetted by both medical experts and people living with migraine disease – 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 any important side effects so you can make more informed choices about your treatment.

We'll talk about how migraine disease 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 disease will keep you from missing out from the people and activities you love.

Importantly, we'll also provide information about **advocacy efforts** to help people living with migraine disease. 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 to support policies that benefit people living with migraine disease, to help them gain better access to treatment, and to promote ongoing migraine research is in full swing.

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 and make a difference. We will give you ideas to reach out to those around you who do not understand migraine disease 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.

## PART II PATIENT CHARTER

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

### WE BELIEVE:

- 1** The patient experience is at the heart of medicine; thus the patient must be at the center of all medical decision making.
- 2** The medical process should stay between the patient and their care provider.
- 3** The patient should have access to all treatments deemed appropriate by their care provider.
- 4** Access to care should not be limited by external forces, financial or otherwise.
- 5** Patients should be empowered and educated with the tools needed to make their voices heard.
- 6** 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.
- 7** The medical team should strive not only to do no physical harm, but to do no emotional, mental, or financial harm to the patient.
- 8** Patients should be treated with dignity, transparency, and respect by everyone involved in the health care process.

▲ 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?

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Migraine is a neurobiological disorder 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 disease, but women; those with a family history of migraine; and those with certain other medical conditions (such as sleep disorders, depression and anxiety, and epilepsy) are more prone.

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 have other symptoms.

### \* — 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 disease, 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
- ▶ Fatigue
- ▶ Dizziness
- ▶ Blurry vision
- ▶ Brain fog/cognitive difficulties
- ▶ Word-finding difficulties or other language disturbance
- ▶ Disability that goes beyond the severity of the pain
- ▶ Scalp sensitivity
- ▶ Rarer: diarrhea, other bowel disturbances

### \* — What Is Migraine with Aura?

Just before a migraine attack, around 20 to 30 percent of people start to notice something called an aura. An aura is a cluster of neurologic symptoms that lasts minutes, and usually less than an hour. 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. 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 disease 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**

Up to 30 percent of people with migraine disease get aura symptoms a few minutes to an hour before. Aura can include visual disturbances, such as seeing flashes of light or wavy lines, as well as other neurological changes like numbness or tingling.

### **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 feel nausea and vomiting; sensitivity to lights, sounds,

or smells, dizziness, and fatigue. Migraine symptoms tend to get worse the more physically active you are. There may be brain fog and severe fatigue. The ability to function or work may be affected.

Many people find it necessary to lie down in a dark quiet room to get through the worst of a migraine attack.

**Stage 4: Postdrome**

This is the lingering “hangover” effect you can experience after the worst of the migraine attack is over. You may feel residual scalp sensitivity, fatigue, mood changes, or trouble concentrating. The prodrome 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. Some estimates say around 12 percent of all Americans are affected by migraine disease, or anywhere from 30 to 40 million people.

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

One of the most important migraine risk factors is your family history. If one or both of your parents has migraine disease, there’s a stronger chance you will too. Someone with one parent with migraine disease has a 50 percent risk of developing migraine too. If both parents have migraine disease, 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. Migraine disease can be a lifelong problem for some, but nearly half of people with migraine attacks stop having them by around age 65.

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 on.



## \* ——— How Often Does Migraine Happen?

Migraine disease 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 disease 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.

## \* ——— What Causes Migraine Disease?

We don't yet know exactly what causes certain people to develop migraine disease, but we're continuing to learn more. Two outdated "theories" you may have heard are that migraine disease is caused by the swelling of blood vessels or that migraine is caused by abnormal serotonin levels.

What we do know: The pain of a migraine attack is caused by firing of pain fibers that release inflammatory substances inside the head, including the covering of the brain and blood vessels. These signals may cause your blood vessels to dilate (open up wide), but that is an effect, not a cause, of migraine.

Many other centers in the brain become activated in a coordinated manner with the pain nerves. These centers are responsible for other symptoms of migraine attacks, including light and sound sensitivities, nausea, dizziness, and more.

The aura of migraine is caused by a wave of abnormal electrical and chemical activity that spreads over the brain – most commonly over the visual areas of the brain. These abnormalities initially activate the nerves, causing the lights (visual brain) or tingling (sensory brain) followed by reduced function causing visual loss, or numbness.

## \* ——— Migraine Triggers

Triggers are not the cause of migraine disease, 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 find them even when they do not actually exist. Many people spend years looking for triggers when their migraine attacks are random anyway, and blame themselves for not finding them and controlling their attacks when it is impossible to do so.

Triggers for some are 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.

For some people, the migraine attack causes them to expose themselves to something they think is a trigger. Perhaps the prodrome of your migraine attack causes you 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.

### **Common migraine triggers include:**

**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 disease too, although they may also be beneficial in managing migraine.

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

**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, maybe you can have a glass of red wine without it causing a migraine attack, except during your period, when you have to avoid it.

**Strong odors:** Fresh paint, cleaners with strong chemical smells, or your office colleague who's always doused in perfume may set off your migraine attack.

**Sleep disruptions:** 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 trigger a migraine attack.

**Dehydration:** Not drinking enough water after a workout or getting dehydrated because of hot weather can also bring on migraine attacks.

**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.

**Stress and anxiety**

**Heavy physical exertion or activity**

**Bright lights**

## Loud noises

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 find one that you will use on a regular basis.

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

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.

You can't control some migraine triggers, such as weather, but you may be able to cut others out of your life.

**Stress:** Stress is the most commonly reported trigger. Interestingly, often migraine attacks hit when the stress actually 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 disease, figuring out your own methods for de-stressing is a critical part of self care.

**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.



## 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)

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

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

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? People around you may not always realize that these smells, sounds, or behaviors can cause you to get a painful migraine attack.

## PART IV GETTING DIAGNOSED

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Getting a diagnosis of migraine disease will help you find the best treatment options for your pain. Work with your health care providers — your health care team — to create a plan to manage your migraine disease.

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 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 disease and other headache conditions. You can visit their websites: [www.americanmigraine.org](http://www.americanmigraine.org) or [www.headaches.org](http://www.headaches.org).



## \* ——— Your First Appointment: What to Expect

At your first appointment, let your health care provider (HCP) know the following details about your headaches:

**Description of symptoms:** such as a dull ache that worsens into throbbing pain

**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:** how often your migraine attacks happen over the course of a week, month, or year; and how often are you headache pain free.

**Symptoms other than pain,** such as nausea or light sensitivity

**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 disease, this could help your HCP confirm your diagnosis. There is strong evidence that migraine disease and migraine triggers may be inherited or genetic in nature.

**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 disease. Your HCP may use this list to help confirm that your headache and symptoms are consistent with a migraine diagnosis and not due to 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 disease 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 disease to also have one or more additional

diseases or conditions that are also present and are not just coincidence, also known as comorbidity. Migraine disease is most commonly associated with the following:

- ▶ Stroke
- ▶ 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 disease 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 disease and a specific comorbid condition.

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

## \* — Tests

Test results for people with migraine disease are usually normal. Your HCP may or may not use the following tests to help rule out any other possible causes of your symptoms, or other



## Misdiagnosis and Migraine Disease

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 disease — say, light, sound, or smell sensitivity — you may be mistaking migraine disease 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 disease instead:

**Sinus headaches:** People living with migraine disease 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 disease. 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 disease 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 disease (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 disease.

conditions worsening your migraine disease, so it's important to ask about whether you need these before you start any treatment.

The diagnosis of migraine disease is primarily clinical in nature, which means it is based on your HCP's judgment. 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, cause migraine-like symptoms, or worsen migraine disease. 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.

**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.

## PART V TREATMENT OPTIONS

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

Other medications may help cut down on how often you have an attack or reduce the severity of your episodes. 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 some treatments and see if they work for you. Your HCP will use all the information about your overall health and your type of migraine, to choose, with you, the best options.

**Sometimes a combination of treatments works best.** Don't expect one pill to do it all. You may need to take medications and change your lifestyle or behavior to manage migraine disease 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 disease 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

These types of drugs work mainly to ease pain or curtail a migraine attack. They are available over the counter in lower doses and by prescription in stronger formulas.

These drugs are often called abortive or acute migraine treatments because they stop (abort) the pain and other symptoms.

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 orally.

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

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





## 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 disease. Taking medication (both over-the-counter and prescription) more than is recommended can lead to something called medication adaptation headache. Other names for this 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 is considered medication overuse. Using simple analgesics, such as over-the-counter NSAIDs, 15 or more days a month is considered medication overuse.

A headache that occurs because of medication overuse 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 overusing one or more acute medications 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 a week. If you find yourself needing to take medication more often than that, speak to your HCP. You may need a change in your medication regimen to avoid experiencing a medication adaptation headache.

These kinds of headaches can usually, but not always, be resolved when medication overuse is stopped.

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

**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 that contain acetaminophen, aspirin, and caffeine available over the counter (Excedrin Migraine). These products may work for moderate, but not more severe, migraine attacks.

One prescription drug (Midrin) combines acetaminophen with a nerve stimulating drug called isometheptene and a muscle relaxer called dichloralphenazone. This combination of treatments may be effective at relieving migraine pain, but it may not be a good choice if you have any heart disease risk factors, such as high blood pressure.

**Opioids:** Your doctor may choose to prescribe opioid analgesic drugs, such as codeine, for more severe migraine pain, especially if you cannot take other drugs like triptans or ergots (which we'll discuss next). However, opioids carry a strong risk of dependence or abuse. They can cause strong side effects like constipation, drowsiness, nausea, and others. They can be used in specific cases, but are not considered a first-line treatment for migraine disease for most people.

**Triptans:** Triptans are a group of medications that can help relieve the dilation of blood vessels in your head that's involved in migraine pain and block the pain process. Triptans are available in different forms: pills, nasal sprays, or injections.

Triptans for migraine relief include sumatriptan

(Imitrex), 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 disease and with 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). They 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). It may relieve head pain with fewer side effects. It's available in nasal spray or injection. Ergots are also not recommended for people with heart disease or during pregnancy.

**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. So they are a short-term option only. They work slowly, but are often useful for breaking an occasional attack that is lasting much longer than usual.

**Lidocaine:** The nasal spray containing lidocaine (Xylocaine) can be used for quick migraine pain relief. Lidocaine is a drug that numbs your sensations, including pain. It works very quickly but temporarily. You can use this treatment for short-term relief until a different drug starts to work on your pain.

**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.

## \* — Preventive Treatments

According to Stephen Silberstein, MD, director of the Jefferson Headache Center at Thomas Jefferson University Hospitals, Philadelphia, Pennsylvania, about 40 percent of people living with migraine may be appropriate candidates for preventive migraine treatment, yet the majority of them are untreated.

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. Some preventive treatments are used regularly to manage your migraine condition.



## Migraine Medications and Pregnancy

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

Pregnancy can lead to a change in migraine symptom patterns – and for most people with migraine disease, 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 women with a history of migraine disease may find their attacks get worse when they're expecting. And other women 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. Women who find 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 disease 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 disease 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.

### **CONSIDERED SAFE**

- Acetaminophen (Tylenol) is generally considered safe to take during pregnancy.
- Sumatriptan (Imitrex) is becoming accepted as safe in pregnancy. Other triptans are still considered unsafe because of a lack of information.
- Certain blood pressure medications, such as beta blockers, are also used to prevent migraine attacks and are considered relatively safe to take while pregnant.
- If migraine is accompanied by nausea and vomiting, your doctor may recommend an anti-nausea drug like Zofran.

### **CONSIDERED NOT SAFE**

- NSAIDs such as aspirin, ibuprofen (Advil), and naproxen (Aleve) are not advised during pregnancy.
- Ergots are not considered safe for pregnant women and may cause 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.

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.

You can also try non-drug strategies to prevent migraine attacks, so we'll review some of those here too.

### Calcitonin Gene-Related Peptide (CGRP) Inhibitors

Erenumab (Aimovig™) is a new drug recently approved specifically for migraine prevention. It's a self-injectable drug that you use once a month. It specifically targets and inhibits (blocks) calcitonin gene-related peptide (CGRP), a molecule that plays a role in migraine. You give yourself these shots at home once a month, so it's easy and convenient.

Two other CGRP inhibitors, fremanezumab (Ajovy®) and galcanezumab (Emgality®), were approved a few months later, adding to this breakthrough new class of preventive migraine treatment. Ajovy® is available in either once-monthly or once-quarterly dosages. Emgality is used once a month.

Studies show that CGRP blockers cut the number of migraine attacks or headache days by 50 percent or more in around half of people who take them. These medications may eliminate migraine attacks altogether for a small number of patients. These drugs are still being studied and have not yet been widely adopted by patients, but clinical trials indicate they are well tolerated. Side effects can include pain at the injection site, rash, constipation and nasal congestion.

Other types of CGRP-blocking drugs are awaiting FDA approval, so there will be more options of medications in this category over the coming months and years.

### Botulinum toxin A (Botox)

This is well known as a cosmetic injection to reduce face wrinkles or laugh lines. It is also used to treat many different kinds of medical conditions. Your doctor can give Botulinum toxin A injections on a regular basis to help chronic migraine disease, defined as migraine attacks that occur on 15 or more headache days a month. This drug works by calming muscle contractions that may be involved in the headache pain process. Over time, regular injections work even better to keep these contractions under control.

### 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 amitriptyline, 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 by tricyclic antidepressants.

Two antidepressants, venlafaxine (Effexor XR) and duloxetine (Cymbalta), are serotonin and norepinephrine reuptake inhibitors that are effective at preventing migraine. Mood changes, anxiety, and trouble sleeping can occur after taking this kind of medication, so let your HCP know if you have any new or worsening symptoms. Selective serotonin reuptake inhibitors (SSRIs) are another group of antidepressants that may be used but aren't as effective at migraine prevention. Common SSRI side effects include drowsiness, nausea, dry mouth, insomnia, diarrhea, nervousness/restlessness, and sexual changes, such as a decrease in sex drive.

### Cardiovascular Drugs

Drugs that treat heart or blood pressure problems may also help manage migraine disease by making attacks less severe or frequent. These medications target your blood vessels, which are involved in migraine pain.

Beta blockers like propranolol, metoprolol tartrate, and timolol are effective at migraine disease 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.

Calcium channel blockers, such as verapamil, are effective at preventing or managing migraine disease with aura. Common calcium channel blocker side effects include constipation, nausea, rash, flushing, and edema (swelling), drowsiness, and dizziness.

Lisinopril (Zestril), a type of blood pressure drug called an angiotensin-converting enzyme inhibitor (ACE inhibitor), may also help shorten



## 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 migraine patients: Why are all these disparate types of medications being used to treat migraine disease?

The reason is because migraine is such a complex disease that different classes of medications may be used, depending 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 a medication is approved by the FDA, it can legally be prescribed for uses other than that for which it is indicated, which is called **off-label** prescribing.

Off-label prescribing is 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 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.

migraine attacks or make them less frequent. Side effects of these drugs can include dizziness, drowsiness, diarrhea, cough, and rash.

### Anti-seizure Drugs

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 over weight gain, tremor, hair loss, and liver dysfunction (this last one is rare).

### Hormone Therapy

Women who get migraine attacks tied to their monthly menstrual cycle may benefit from taking hormone therapy. Your gynecologist may prescribe birth control pills, which contain the hormones estrogen and/or progestin, or change your current prescription, to prevent or control migraine attacks.

**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.

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 better?
- 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?

## \* — Nondrug Preventive Treatments

Along with migraine medications, you can try some nondrug devices and treatment options for migraine prevention. These include several FDA-approved neuromodulation devices that are used in the treatment of migraine disease. You can use nondrug therapies any time to help prevent migraine attacks or ease the severity of your symptoms.

### Neuromodulation Devices

Over the past few years, it has become increasingly more common to prevent and treat migraine disease with neuromodulation devices, or stimulators. Their primary function is to dial down brain activity (as opposed to stimulating it). They range in how they work (magnetic, electrical, or altering temperature) and can be either portable or require surgical implantation.

Three non-invasive (meaning, non-surgical) neuromodulation devices have been approved by the

FDA to treat migraine disease.

- ▶ [Cefaly/Cefaly 2](#) – The Cefaly, or transcutaneous supraorbital neurostimulator (tSNS), is placed on the forehead for 20 minutes a day to prevent migraine attacks. A different stimulation program is used for one hour to treat an attack. It works by activating nerves in the forehead electrically, sending signals to the brain to turn down headache pathways. You feel a buzzing sensation during the process. Using the Cefaly should result in fewer headache days slowly over time. There are now three designs: acute, prevent, and dual.
- ▶ [Spring TMS mini](#) – Single-pulse transcranial magnetic stimulator, known as Spring TMS mini or sTMS mini, uses magnetic pulses to stop the pain of migraine attacks. The device is placed on the back of the head and, when turned on, emits a magnetic pulse. In about 40 percent of users who had migraine disease without aura, two pulses were able to stop the migraine attack. It is being reviewed by the FDA see if it can be used for migraine prevention, which would entail using four pulses twice a day, along with pulses on an as-needed basis.
- ▶ [GammaCore](#) – This device is a vagal-nerve stimulator (nVNS) that uses electricity to stimulate the vagus nerve, which is an important nerve that connects the brain to the GI tract. You place the device over a gel that you apply on your neck. Once turned on, it stimulates the nerve for 90 seconds and up to two minutes, for two cycles. A buzzing sensation and twitching in the superficial neck muscles occur during stimulation. It is used to abort a migraine attack but may also prevent it.

### 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, which can also bring on migraine attacks.

Precision tinted eyewear is designed to filter out painful and harsh light that enters the eyes. Through blocking out artificial blue and green light, the severity and frequency of migraine attacks can be reduced. Precision tinted eyewear, or **migraine glasses**, can also help alleviate dizziness, nausea, and exhaustion associated with light sensitivity.

There are two reputable companies that produce a wide range of precision tinted eyewear.

- ▶ [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.

## CBT

Cognitive behavioral therapy (CBT) is the best studied and proven therapy technique to control migraine severity and frequency. A psychologist trains you to reduce the severity of your pain response, manage the stress that triggers attacks, and manage the pain “from the top down,” which means using the mind to make the nervous system less prone to experience 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 attacks in the process.

## Stress Management Techniques

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, but can be used to help with anxiety and depression.

## 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 disease. 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 disease. 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
- ▶ Coenzyme-Q10
- ▶ 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.

While 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.

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

## \* ——— **Surgical Procedures for Migraine Disease**

These procedures may be recommended for people with migraine disease who have not responded well to other therapies.

### **Occipital nerve stimulation**

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.

### **Migraine nerve-releasing surgeries**

Another kind of migraine surgery, considered controversial, is performed by plastic and reconstructive surgeons. Migraine pain at the back of the head might be associated with compression and irritation of sensory nerves and vessels around your head, according to the American Society of Plastic Surgeons. “When these compression points are released during surgery, the severity of migraine may decrease or you may not experience further migraine, according to the ASPS. During the procedure, the surgeon will make an incision and decompress, or “free up” the nerves that may trigger migraines. The location of the incision will vary based on your trigger site(s) and your surgeon's preference, but common sites include your temple, the hairline above your forehead, or your eyelid crease.

Any surgical procedure has risks, so it's important to have a candid discussion with your headache specialist and surgeon to understand the pros and cons of a surgical procedure. Potential complications from this procedure include wound healing problems, nerve injuries, bleeding, issues from having anesthesia, and failure of surgery to ease migraine attacks.

## PART VI LIVING WITH MIGRAINE DISEASE

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

The World Health Organization considers it 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 disease that they are unable to work, have difficulty with their chores and errands, and have to limit attending family and social events.

Migraine disease 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 disease 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 disease is a serious medical condition and requires support and understanding from everyone around you, including work colleagues and managers, family, and friends.

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.



### 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*

## \* ——— Migraine Stigma

Invisible illnesses like migraine disease 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 disease 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 disease 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 disease 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, 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 Disease and Mental Health

Mental health conditions such as depression and anxiety are considered to be comorbid with migraine disease, which means they tend to occur at the same time.

While it's natural to think that experiencing debilitating head pain and other systems could make migraine patients feel anxious and depressed, research suggests the relationship between migraine disease and mental health is more complex. There may be shared genetic risk factors, for example, that make a person more prone to develop both migraine disease and depression.

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

#### 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 disease can help them both feel better. And certain types of antidepressant medication may effectively treat both migraine disease and depression and anxiety.

If you find yourself experiencing depression, anxiety, or significant stress about managing migraine disease, 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 Disease and the Workplace

One survey found that more than half of Americans miss work because of headache or migraine attack, 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 disease 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 disease 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. Try to maintain a regular eating routine — have lunch and snacks at the same time every day.



### Migraine Disease 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 disease, 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 disease or another disability.

- ▶ 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 disease and let them know what works best for you when you feel an 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 disease 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, some 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 29), 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 disease and its impact on your everyday life, as well as how your HCP suggests treating it.

## \* ——— Caregiving for Migraine Disease

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). And ask them about the frequency with which they get 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 disease, 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 the migraine patient 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 disease 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 guilt 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, make sure to (gently) intervene.
- ▶ 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 DISEASE

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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
- ▶ [Using language that reduces stigma](#). 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 and 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 an 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.



## Rights of People with Headache Diseases

Recently, CHAMP issued a guide to help the general public (as well as those in the migraine community) avoid using language, images, and other communications that further stigmatize and alienate people living with migraine disease. The document includes these rights of which everyone living with migraine disease should be aware:

1. **To live a life of dignity, despite whatever limitations may be caused by our disease**
2. **To not be blamed for having a headache disease**
3. **To have access to quality medical treatment and social service provision not limited by external forces, financial or otherwise.**
4. **To advance robust scientific research that addresses the impact of headache disease and chronic pain on people living with these diseases, their caregivers and families, and society**



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 disease 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.

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

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### **JAIME SANDERS**

Jaime Sanders is a blogger and patient advocate who lives in Virginia with her husband and three children. She has had a lifelong journey with migraine disease and lived most of her adult life with depression. From a toddler with abdominal migraine to a wife and mother with chronic migraine, Jaime has learned to turn her pain into empowerment over the past 38 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. As the Migraine Patient Advocate Coordinator for the Global Healthy Living Foundation, Jaime's role is to help 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.



### **WILLIAM B. YOUNG, MD, FAHS, FAAN**

**Professor, Department of Neurology and Director, Inpatient Program, Headache Center Thomas Jefferson University, Philadelphia, Pennsylvania**

William B. Young, MD, FAHS, FAAN is a board-certified neurologist. He is a professor of neurology, director of the In-Patient Program at the Jefferson Headache Center and member of the Pharmacy and Therapeutics Committee at Thomas Jefferson University.

Dr. Young is a graduate of Haverford College in Haverford, Pennsylvania. He received his medical degree from Pennsylvania State University College of Medicine. He interned at St. Elizabeth's Hospital in Boston, Massachusetts, and completed a residency in neurology at Tufts University School of Medicine and The New England School of Medicine in Boston.

Dr. Young is a fellow of the American Headache Society, American Academy of Neurology, American Neurological Association, and the College of Physicians of Philadelphia. He is past President of the Alliance for Headache Disorders Advocacy, physician advisor to the Coalition for Headache and Migraine Patients (CHAMP), and is on the board of Miles

for Migraine. He is a graduate of the Palatucci Advocacy program of the American Academy of Neurology. He is also a peer reviewer for *Cephalgia*, *Headache*, and *Neurology*.

Dr. Young's publications include many peer-reviewed articles, book chapters, and miscellaneous publications. His special interests include migraine stigma, migraine phenomenology, and the treatment of intractable migraine.



## **NATIONAL HEADACHE FOUNDATION**

Founded in 1970, the National Headache Foundation is the oldest and largest foundation for patients with headaches. Its mission is "To cure headache, and end its pain and suffering." Its vision is "A World Without Headache." The Foundation is the premier educational and informational resource for those with headache, health care providers, and the public. The work of the Foundation is through education, raising awareness, advocacy, and research. The Foundation established the Certificate of Added Qualification in Headache Medicine for physicians, nurse practitioners, physician assistants, dentists, and clinical psychologists who treat headache patients. The NHF publishes HeadWise® magazine and NHF News to Know.

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