



# A Chronic Migraine Primer for Friends and Family

You have been given this guide because someone you care about lives with a debilitating, complex neurological disease called Chronic Migraine. There is surprisingly little public awareness and understanding of this disease. My firm belief is that what people living with migraine really want, and need, is respect, understanding and empathy. I hope this information is useful in moving us all toward that end

— Maya Carvalho, founder of [Canadian Migraine Society](http://MIGRAINESOCIETY.CA)

## WHAT EXACTLY IS MIGRAINE?

- Migraine is a clinical diagnosis based on symptoms and medical history. At present there are no tests such as bloodwork, MRIs or scans to diagnose migraine, however your physician may order tests to rule out other diseases. Migraine includes a severe, throbbing or solid, intense headache, typically on one side of the head (but not exclusively) that lasts from 4–72 hours and is often accompanied by other symptoms including nausea, vomiting, light and sound sensitivity. Physical exertion typically makes the pain worse. The pain is different for everyone, but many have described it as being more intense than childbirth — without the reward. Other migraine symptoms include dizziness, vertigo, brain fog, fatigue, neck pain, muscle pain, aphasia (loss of the ability to speak, comprehend language, read, write) and ataxia (loss of muscle coordination, unsteadiness of gait), visual symptoms, cold hands and feet, mood changes, sensitivity to smell, diarrhea, constipation, fever, and swelling. There are some forms of migraine which do not include headache.
- The World Health Organization (WHO) classified severe migraine attacks “as among the most disabling illnesses, comparable to dementia, quadriplegia and active psychosis (*Shapiro & Goadsby, Cephalalgia, 2007*).” Furthermore, *the WHO classified severe, continuous migraine as more disabling than blindness, paraplegia, angina, or rheumatoid arthritis. (Harwood, Sayer, & Hirschfeld., Bulletin of the World Health Organization, April 2004).*
- Chronic Migraine means that the person experiences 15 (or more) migraine days a month. Take a moment to imagine incessant, intense pain and symptoms taking over your life. Many people have four phases of each migraine attack: Prodrome, Aura, Headache and Postdrome — a full migraine cycle can take several days to experience. Given this frequency, and the length of the combined phases of each attack, people with chronic migraine are very rarely symptom free — even on their good days.

- Each person living with chronic migraine is different and their attacks can have very different symptoms. Some people do not have head pain but other symptoms which are equally debilitating. Migraine is a spectrum disorder — each migraine varies, some are more tolerable than others.
- There is no cure for migraine at present. Some people can go into a migraine remission for a few months or years. Some people are lucky enough to find one medication or treatment that works extremely well; but for most of us trying to reduce our migraine attacks it involves a long-term multi-modal approach. It requires an ongoing commitment to the trial and error of numerous medications, treatments, procedures, lifestyle changes, physical therapies and more. All these things *in combination* can make a real difference but there is no magic bullet.
- Some people experience intractable migraine 365 days of their lives. This means that they never get a respite to recharge, reboot, and rally for the next attack — it is always with them. If your loved one has a constant intractable migraine, you should give them a medal. You should realize how strong they are and what a struggle it can be to simply make it to the next day.
- This constant cycle of debilitating symptoms and recovery from those symptoms creates enormous fatigue. This is not the same as being tired— it is a pervasive, serious depletion of energy. Some people can manage a few activities on a good day, others can only ever manage one. Talking on the phone can be hard. Socializing can be hard. Physical exertion can be hard. Everything that requires energy has a cost. We make those cost/benefit decisions every day of our lives in order to maintain relationships and some quality of life. If you can't imagine this, ask about it.
- Most people with chronic migraine have comorbid illnesses such as IBS, Fibromyalgia, Arthritis, PCOS and many others. Try to imagine navigating other illnesses, medications and treatments, on top of chronic migraine. It is a complicated challenge, and in Canada, we rarely encounter healthcare professionals who look at us holistically and coordinate all our medications and treatments. That burden is left to us. It's a huge job, a complex job, and a job that requires endless patience and tenacity. Be proud of your loved one for doing this.

• The most debilitating symptoms for \_\_\_\_\_ are: \_\_\_\_\_

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Things to AVOID saying:

- *“You have a migraine... again?!”* Yes, we do. That is the definition of chronic migraine.
- *“Are you better now?”* No — we are not better. Migraine cannot be cured, but our symptoms might be more manageable on one day than another day. Some people are very lucky and can go into a remission from chronic migraine but this is still not the case for most people.

Things that are HELPFUL to say:

- *“I’m sorry your attacks are so frequent, that must be exhausting, you are an incredibly strong person.”*
- *“How are your symptoms today? How are your pain levels today?”*
- *“What would be the best way for me to support you through this?”*
- *“Thank you so much for coming — I know this will have a cost for you and I appreciate it.”*

## WHAT CAUSES MIGRAINE?

Migraine is a genetic neurological disease that affects 1 billion people worldwide. It is not the same as headache — headache is only one symptom of migraine. Although the causes are not fully understood, it is now believed that migraine attacks originate in the brainstem area and involve hyper-excitability of the nervous system. Basically, neurons misfire and unleash an electrochemical reaction that sends pain signals to the cortex and cause other migraine symptoms.

Things to AVOID saying:

- *“My neighbour’s daughter’s best friend did X and she cured her migraines.”* There is no cure for migraine, and it cannot be conquered by a magic X, Y or Z. Exercise will not stop it, a vacation will not stop it, and drinking more water will not stop it. Some of these techniques may mitigate a few triggers but again, managing chronic migraine requires an involved, multi-modal approach and these types of simplifications tend to diminish the seriousness of this disease.
- *“I had a migraine the other day and took two Tylenol and it went away.”* If two Tylenol eliminated your migraine, it is likely that you had a bad headache and not a migraine. It’s incredibly frustrating for a person with chronic migraine to constantly deal with a lack of validation.
- *“Why do you have to take so many pills?”* or *“You really need to stop taking so much medication.”* Unless you are a neurologist, you have no expertise in how much medication is necessary to manage this illness. Some people need two pills a day and some need six. Be thankful you don’t have to deal with the myriad side effects that we do — it is not fun.
- *“You look great — you don’t look like you’re in pain.”* Most of us do everything we can to hide this disease from people and look like we are not in pain. This is not indicative of how we are feeling on the inside. It is simply a reflection of how hard we want to feel normal, for a few minutes, an hour, or a day. It is also a reflection of how much we value our time with you and

how much we don't want to affect others by looking the way we actually feel. Be flattered rather than questioning our pain.

Things that are HELPFUL to say:

- *“I’m so sorry you have such a serious disease. I hope you find some treatments and medications that can help you manage it.”*
- *“You look amazing — you hide your pain so well.”*

### WHAT ARE MIGRAINE TRIGGERS?

- Triggers are not causes — the cause is genetic. Triggers simply set off the electrochemical reactions in the brain that cause the symptoms. For people with chronic migraine, it is rarely a matter of one trigger, but rather multiple triggers stacking up that tip us over the threshold into a migraine attack.
- Each person with migraine has different triggers, by the time a person becomes chronic, their triggers are often numerous. Triggers can be environmental, physical, and psychological. Some common triggers are weather fluctuations, hormonal shifts, loud noises, bright lights, perfume, too much physical exertion, stress, anxiety, food (fermented, aged, high in histamine or tyramine), alcohol, dehydration, and sleep disturbances.
- The most challenging migraine triggers for \_\_\_\_\_ are: \_\_\_\_\_  
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Things to AVOID saying:

- *“Wow, you seem so delicate and sensitive to everything.”*
- *“Come out with us anyway, you’ll feel better.”* The patient is the expert, if they are telling you they can’t go out, listen and respect that.
- *“You just need to destress. You just need to relax. If you take a vacation, your migraines will go away.”* No, they will not. It IS helpful to get stress under control as a general life goal, but stress is *not* a trigger for everyone and again — it is not a *cause* of migraine.
- *“Oh no — why did you do X? Now you’ve given yourself a migraine!”* Do not blame the person for not being able to control all their triggers. It is a maze of landmines you never want to experience. It is *never* the person’s fault if they trigger a migraine. Remember, triggers are *not the cause* of the disease.

Things that are HELPFUL to say:

- *“It must be so challenging to navigate all those triggers every day. Which triggers are the worst for you? I’ll try to reduce them when we’re together.”*
- *“If doing X is too much for you, I totally understand. I know you would be there if you could. Please do what is best for your health.”*

#### HOW YOU CAN HELP YOUR LOVED ONE WITH CHRONIC MIGRAINE:

- Be flexible with your plans. We are rarely symptom free so it is impossible to plan ahead. We do not know when a migraine attack will hit, how intense each one will be, and how debilitated we will be that day or even the next day. Please try to be understanding if we have to cancel plans. I guarantee we are more upset about cancelling than you are, and we are the ones living with the attack that caused us to cancel — not you.
- **Offer to visit with us on our terms.** Chronic migraine typically makes our lives shrink down until we have limited social interaction. This can be extremely isolating. Every single visit with a friend or family member *means more to us than you know*. You can offer to do it during the hours when our pain is usually lower (ask us), and start with something easy like a cup of coffee so that there isn’t too much physical exertion.
- Ask about our triggers and symptoms and try to pay attention to them. If possible, modify the environment when we’re together to make it as calming and quiet as possible. Do not wear perfume or light scented candles if you know that is a trigger for us. Try to keep loud noises away from us. If food or alcohol is a trigger, do not push any foods or drinks by saying, “Oh, just try it!” or “A drink will take the edge off.” You do not live with the consequences, we do.
- Be conscious of how much we must preserve our energy. We must constantly be pacing ourselves to not push ourselves into an attack. For more information look up [Spoon Theory](#). For most patients that means limiting the duration and number of activities in a day. For many people, one activity is all we can manage. Do not push people to do overdo it and *never suggest* we are lazy. People living with chronic migraine are pushing through 24/7 with pain levels and symptoms you can hardly imagine — try to have empathy.
- Offer to accompany us to our neurology appointments or other doctors appointments. We need advocates with us who can pay attention, stand up for our needs and concerns, and be a second set of ears for the information being given to us. Appointments are typically very short and there can be a lot of stress about getting our questions answered. Having support in this area can make an *enormous difference*.
- Offer to take care of simple errands that might be far too physically demanding for a person with chronic migraine such as grocery shopping, pickups at the dry-cleaner, going to the pharmacy, online shopping, or even just dropping off a simple meal so we don’t have to cook. Driving can be a trigger for many people, so offering pick-ups and drop-offs can also be helpful.