MIGRAINE AND HEADACHE DISEASE CANADIAN LANGUAGE GUIDE 2023

A COLLABORATIVE PROJECT BY

Migraine™ Canada

MIGRAINE QUÉBEC

Canadian Language Guide

The purpose of the Canadian Language Guide is to ensure that all people who communicate about headache disorders do so in an accurate, informed, and empathetic manner, and that the people living with migraine are treated with the seriousness and understanding they deserve.

Carefully chosen language can help fight stigma and increase understanding of these conditions and can greatly impact how people living with migraine are perceived and treated. This guide is intended for anyone interested in migraine and the burden of stigma or of the disease.

What is Migraine?

Migraine experience is unique to each person. The intensity, frequency, symptoms, and triggers can vary. How an individual responds to treatments will also vary. Experts estimate that 12% of Canadians (4.5 million) live with migraine to varying degrees. Migraine cannot be cured as the tendency to experience migraine attacks is genetic in origin.

Migraine affects the individuals during attacks (the ictal phase) but also between them (the inter-ictal phase). In addition to the head pain phase, the attack may include a prodrome, an aura and a postdrome. Migraine is a complex neurological disorder and its mechanisms have been uncovered piece by piece by research. Knowledge on migraine includes research on the chemical and electrical mechanisms of the brain, in addition to the genetic aspects.

Migraine affects people of all ages, genders, and races worldwide. It can be a life altering and debilitating condition. In cases with aura, temporary neurological symptoms including visual changes, numbness and tingling, and speech problems may occur. Dizziness, vertigo, cognitive difficulties, and neck pain are common with migraine attacks. Migraine cannot be cured - it is a permanent condition that won't go away - but in most cases, it can be managed with the help of good health professionals, treatments and support from family, friends, and others in the migraine community.

Since migraine affects how the brain responds to the environment, therapeutic education, lifestyle adaptation and trigger management are usually the first step of care. But it should be kept in mind that migraine is a disease and that many treatments are available including medications, neuromodulation devices and allied health care services.

Why Does Disease Language Matter?

Language plays a vital role in how we understand the world. When talking about health, sometimes the language we use gives the impression that people did something to deserve being sick, or that it is their fault, when this is not true. The language used can unintentionally be disparaging and belittling to people, labeling them as helpless or as victims of their medical conditions. **In the case of migraine, the language we use can reinforce the misunderstanding that migraine is just a headache.** Choosing language that reinforces these misconceptions makes people with the health conditions vulnerable to being stigmatized.

The stigma people experience ranges from feeling like healthcare professionals aren't taking them seriously or treating them as drug-seekers when trying to access care or medication, through to friends, family and employers acting like they're making it up or exaggerating. Stigma in either a medical setting or the workplace can result in people not receiving the care they need or being financially disadvantaged through reduced opportunity for promotion, cause for demotion or, in some instances, loss of employment altogether. Because of the widespread experience of stigma and the potential implications of that stigma, addressing it head-on is the most important thing we can do to help everyone in the migraine community. A language guide is an important step in that process.

The purpose of this language guide is to promote **consistent and candid communication about migraine and headache diseases in an accurate and respectful way.**

It is our hope a Canadian guide will lead to improved knowledge within society and empathy towards those living with migraine. Migraine and other headache disorders can have a severe impact on someone's life and therefore deserve to be taken seriously.

Who are Migraine Canada and Migraine Quebec?

Migraine Canada (MC) and **Migraine Quebec (MQ)** are both registered charities in Canada dedicated to improving the lives of Canadians living with migraine. Both organizations are working to end the stigma surrounding migraine, as it is something that debilitates millions of individuals in Canada.

Through promoting **awareness, support, education, advocacy,** and **research** we hope to see that Canadians living with migraine and headache disorders are diagnosed, treated, and supported so their quality of life is improved. We imagine a better future for Canadians living with migraine.

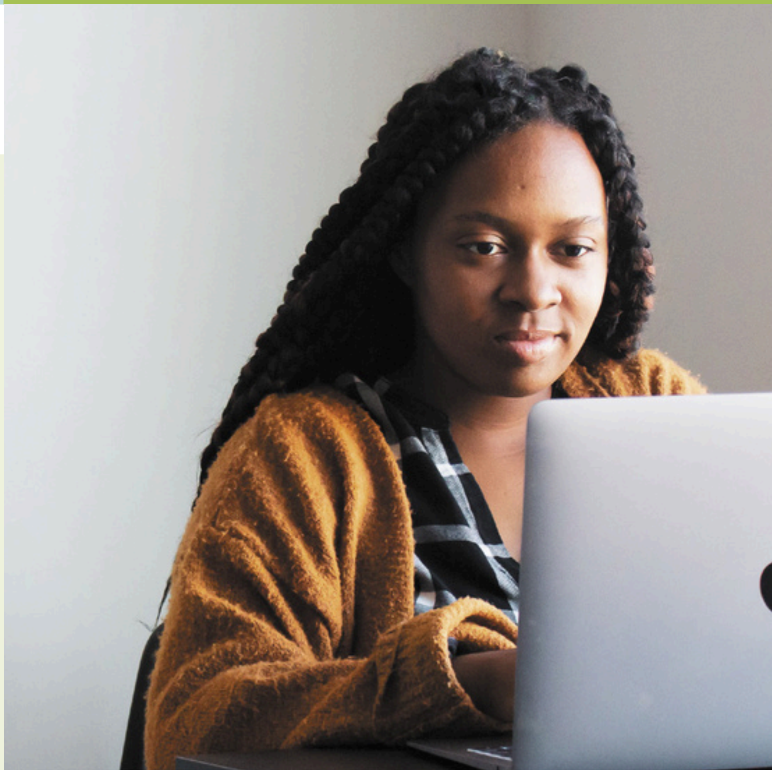
Language is constantly evolving. This guide will be updated over time so that it reflects the most current discussions in the community. It is not intended to be used to make anyone feel wrong or shameful about the words they use. We hope this guide will be used to help steer the way to more compassion and understanding for those living with migraine and other headache diseases.

This Canadian language guide has been developed by Migraine Canada in collaboration with Migraine Québec and in consultation with clinicians and patient experts. We acknowledge permissions granted to repurpose content from Migraine Australia and CHAMP.

> **“Language can change the perception of Migraine and how people view this disease. It’s not just a headache, it is life altering for many, the language used should demonstrate this Disease’s severity”**
>
> *- Christina, lives with migraine*

Talking about people

When we talk about people living with any medical condition it is important to make the person and not the condition be the central part of the conversation. While there are terms that label or exclusively identify a person as being the disease (i.e. asthmatic or diabetic), it is much more respectful to refer to them as a *person living with migraine* instead of *migraineur*. This also allows for specification by subtype where appropriate, for example, *person living with* or *person living with vestibular migraine cluster headache.*



If you are a person living with migraine or another condition, and you are talking about yourself, you can use whatever language you like. **It can be very difficult to explain migraine to others**, so don't make it harder on yourself by worrying about correct terminology. Some people who live with migraine take pride and ownership in the term *migraineur*, while others prefer to describe themselves as a *migraine warrior*.

Using the word sufferer is problematic because it diminishes the individual and makes them feel like a helpless victim. Also, in the case of migraine it is not always accurate: you can live with migraine and not "suffer" much at all. **The symptoms of migraine do cause suffering and disability, but not the migraine condition itself.** People do suffer from symptoms like headache, nausea, light sensitivity and so on; but the term migraine sufferer diminishes the whole person to merely a victim of migraine. **A simple rule is *that suffer* is okay when talking about symptoms but not when talking about the person or disorder more generally.** *Experience*, *living with*, *affected by* are good alternative terms to use instead of the word suffer.

Preferred

- People/person living with migraine
- People affected by migraine
- Person with migraine disease
- Migraine
- Migraine disorder/disease

Acceptable

- People/women/men with migraine
- Person/ woman/man with migraine
- Patient living with migraine disease
- Patient with migraine
- Migraine patient
- Having migraine disease/having migraine
- Living with Migraine

Try to avoid

- People suffering from migraine
- Migraine sufferers
- Migraineurs
- Person suffers from migraine
- Migraine sufferer
- Migraine personality
- Migraineur
- Migraine person
- Migraine-type person
- Migraines
- Migraine headache

> **“I have lived with the ongoing misunderstanding of the *just a headache* condition for years. When I was younger, I used to deny myself and I remember my mother getting angry at me for dismissing my illness as *just a headache*.”**
>
> *- Marta, lives with migraine*

Migraine as a disease

Migraine is a neurological disease that goes beyond individual attacks. For this reason, the commonly used *migraines* is inaccurate as it reinforces the myth that migraine is only a headache or similar temporary discomfort. If you think about the condition, drop the "s".

Some advocate to use the term migraine disease to underline that it is indeed a disease. This might not be ideal, as one would not say epilepsies, asthmas, hypertensions - but asthma disease, epilepsy disease, hypertension disease.

Migraine attacks, migraine days, headache days

For the longest time, people with migraine would refer to *my migraines*, or say *I had seven migraines this month*. Now people tend to remove the ownership of disease, removing the "my". The term *migraine attack* is now used in research and by clinicians. When talking about multiple symptomatic periods, the plural is the attack, not the migraine: *migraine attacks* and not *migraines*. For example: *it wasn't until my early thirties that I started getting weekly migraine attacks*. **It is essential to remember that a migraine attack may last many days in a row**. Therefore, when discussing the frequency, it may be more precise to talk about *migraine days*.

For example, one person may tell a physician that they experienced *8 migraines this month*. It would be better to say *I experienced 8 migraine attacks this month for a total of 12 migraine days.*

Many people with migraine may have days of head pain without other symptoms. These milder headache days may fill the criteria for tension type headache, but they are thought by the scientific community to be part of the migraine spectrum. Therefore, a person might make a difference between *headache day* and *migraine day*.

Episodic and chronic does not reflect the migraine spectrum

One of the most evolving parts of the language used around migraine are the terms *episodic* and *chronic* to describe the frequency of attacks.

The term ***chronic migraine*** has a long history. It did replace the previous term *transformed migraine*. The idea was to put a name on a clinical reality: when migraine attacks become more frequent, the symptoms change, the burden increases, the comorbidities are more common and the response to therapy decreases. People at this severe end of the migraine spectrum were usually not included in clinical studies.

There are limitations regarding this *episodic/chronic* dichotomy:

- The 15 days per month limit is arbitrary.
- Migraine is a spectrum, and patients may oscillate around the 15 days mark, leading to a *variable diagnosis*.
- This emphasis on the 15 day per month does not allow precision beyond *episodic* and *chronic*. A person with 2-4 days per month and a person with 10-12 days per month do not have the same needs.
- In other fields of medicine, chronic refers to a long duration, not an attack frequency. Migraine is a chronic disease, even if the frequency of attacks is low. This is confusing and also deprives migraine of the *chronic disease* status, which has many political and research consequences.

There is no consensus on how to move onwards at present time. The terms episodic and chronic are still used by health professionals, in research and insurance companies.

Potential avenues for progress in the language would include the following:

- Removing the terms episodic and chronic migraine and calling migraine a chronic disease.
- Using the terms "spectrum" and "continuum" to reflect all the possible frequencies.
- When talking about migraine, use monthly frequency as a parameter, for example "I live with migraine with an attack frequency of 6 per month".

Refractory migraine

The other word that is often used when talking about migraine (and other diseases) is ***refractory*****.** There is no official definition of this term, but in medical research it often relates to the number of treatments tried. For example, a person with *refractory attacks* would not control attacks despite many medication trials. A person with *refractory migraine* would not respond to 2, 3, 4 or more preventives.

In general, the term *refractory* is acceptable, but it is not precise.

> **"It is not just an occasional event but an unpredictable, life altering neurological condition that has reduced days of *participating* by at least a third."**
>
> *- Kelly, lives with migraine*

Migraine with aura

The aura is a neurologic phenomenon originating in the brain. It is caused by cortical spreading depression, a wave of electrical changes that travels over the surface of the brain and leads to symptoms. Most auras are visual and have been described since Antiquity. This manifestation of migraine has always fascinated both patients and clinicians. One term used for migraine with visual aura is *ophthalmic migraine*. This comes from the fact that people would naturally think the symptoms come from the eyes. This is not the case and therefore the term *migraine with aura* or *migraine with visual aura* is preferred.

Confusional migraine

Many symptoms may accompany migraine, including cognitive difficulties. In some severe cases, the person may appear confused. The term commonly used is therefore *confusional migraine*. This is not an official diagnosis. The medical community has not been able to prove that the confusion in these cases is indeed an aura caused by cortical spreading depression. Also, confusion with headache can be caused by many severe diseases including brain infections and stroke. Therefore, this term should be avoided.

Silent migraine

The term *silent migraine* is gaining visibility in some communities and on social media. **We recommend not to use this term for a few reasons.** It is true that some phases of the migraine attack may not be associated with pain (leading to the word *silent*), but if one refers to these concepts then the correct terms should be used: prodrome, aura, postdrome. Inter-ictal symptoms, especially in people with chronic migraine, may persist even in the absence of a headache but once again these symptoms have a name (photophobia or light sensitivity, sonophobia or sound sensitivity, allodynia and others). Sometimes, *silent migraine* is used when talking about neurological symptoms not associated with head pain, therefore not filling the ICHD-3 criteria. It would be inaccurate to assume that these symptoms are caused by the same mechanism of migraine, since all we know about migraine has been observed in patients meeting the ICHD-3 criteria.

Therefore, using *silent migraine* when talking about unexplained dizziness or brain fog is inappropriate.

Preferred

- Migraine
- Migraine disorder (The ICHD uses disorders)
- Migraine disease
- Headache disease/disorder
- Symptom free
- Break/Stop in migraine attacks
- Experience(s) the pain and disability of migraine disease
- Prodrome, aura, postdrome, photophobia, sonophobia, inter-ictal symptoms
- Lives with migraine
- Migraine with aura/visual aura

Acceptable

- Having Migraine Disease/Having Migraine/Migraine/Living with Migraine
- Remission

Try to avoid

- Migraines
- Migraine headache
- Headache(s)
- Cured of migraine
- Migraine miracle
- Suffering from migraine/Migraine sufferer
- Silent migraine
- Ophthalmic migraine

Other diagnoses

Medication Overuse Headache

The term *medication overuse headache (MOH)* is currently used by the medical community. The term MOH hopefully will be replaced in the future because it adds to stigma by implying that the patient is to blame for taking too much medication. It suggests a degree of addiction. The term *medication induced chronification* may be scientifically more accurate but is not endorsed by the International Headache Classification. Medication induced chronification in simple terms means the condition becomes chronic because of medication use.

Cluster migraine

Cluster headache is a primary headache. Some symptoms are similar to migraine, but many are completely different. These are two different entities. The term "cluster migraine" is sometimes used and should be avoided. **This term may be misleading since it may carry different meanings.**

- A patient who has both cluster headache and migraine, with clearly defined attacks.
- A patient whose attacks are not clearly cluster headache or migraine.
- A patient whose migraine attacks come in periods (clusters)

For this reason, we recommend not to use this term.

> **"The discussion of triggers is completely triggering (sic), in that they are so often full of blame, it is all our fault, when it isn't our fault, it is a neurological disorder."**
>
> *- Natanya, lives with migraine*

Secondary headaches called migraine erroneously

In the patient community, it may occur that someone with a secondary headache will use the term *migraine*. Sometimes, the term may have been used by the treating health care provider, to justify why migraine treatments were considered. It is always best to clarify the correct diagnosis. **Headaches occurring after surgeries, traumas, infections, strokes should be named appropriately.** Even if they may cause symptoms characteristic of migraine (i.e., nausea, photophobia) they should not be called "migraine". Even if the same pain networks are involved, the cause and the prognosis are not the same. It might also make a difference from an insurance point of view. The situation might be complex if a person living with migraine then develops a new secondary headache, but according to the ICHD-3, then both diagnoses should be used for clarity and optimal medical care.

Preferred

- Migraine attack(s)
- Cluster attack(s)
- Headache attributed to/caused by/related to…viral infection, stroke, trauma, sleep apnea, etc.

Acceptable

- Medication Overuse Headache (still scientifically appropriate but carries undue stigma)
- Rebound headaches
- Migraine episode(s)
- Headache day
- Migraine day
- Cluster day

Try to avoid

- Cluster migraines
- Migraine (if the diagnosis is a secondary headache)

Discussing with people living with migraine

Due to the complexity of migraine and headache disorders, treating migraine can be frustrating and challenging for healthcare professionals. People living with migraine understand there is no cure for their condition. Most people are just looking for a decrease in pain, intensity and/or frequency - not a miracle cure. Clinicians should be mindful and sympathetic when speaking to their patients. It is also important to recognize when to refer patients to a specialist and never tell a patient there is no hope leaving patients feeling even more alone and isolated.

When talking about migraine it's important not to imply that it is curable or cured. Acquired disorders like cancer or infections may be cured, but not migraine. It is possible to be free of symptoms, but not free of the underlying genetic disposition. Some talk about being in *remission* when they are symptom free, which is problematic because it is too heavily associated with cancer, but it is acceptable. Using terms like *stop* or *break* are also acceptable. It's accurate and easier to say the person living with migraine is currently free of symptoms or does not currently experience attacks. Under no circumstances should a treatment of any kind, whether it be a medication, therapy, or surgery, be reported as *curing* migraine.

Good to say

- *I hear regularly from patients about the pain and symptoms of migraine.*
- *Let's see what else we can do.*
- *Can you keep a diary of your migraine attacks? It will help us decide what's next.*
- *We have tried all available options but there are new medications coming to market in the near future.*
- *I believe I have offered you the treatments I am familiar with but let me refer you to someone*
- *with better expertise.*
- *I won't give up trying to find something that will give you relief.*

Avoid saying

- *I think you are exaggerating.*
- *You can't have so many days of migraine in a month.*
- *We've tried everything.*
- *We are out of options.*
- *There is nothing left I can do for you.*
- *I'm sorry but I can't help you anymore.*

Migraine is not a metaphor for unpleasant things

Possibly the most damaging aspect of language for migraine stigma is the misuse of the word migraine when another meaning is intended. The most common way migraine is misused is when the speaker means *severe headache*. We often see this in general conversation, or in news stories talking about someone with another medical condition that had a symptom of severe headache.

It is important to recognize that while most people living with migraine do get head pain, it is only one of a large array of symptoms, and there are plenty of people living with migraine who do not experience headache. Migraine and headache are not interchangeable terms.

The other common way that migraine is misused is as a metaphor to describe the pain or discomfort caused by a social problem. For example, news stories have used *migraine* to mean a *big problem* for the government, sponsoring teams, or companies. Commentators may complain that the actions of politicians or other government figures *gave them a migraine*. We recommend only use the word migraine if you are actually talking about migraine.

In summary, everyone should stop using the term migraine to talk about something annoying, distressing, or inconvenient.

The word **migraine** *should only be used by someone who has been diagnosed by a healthcare provider to have migraine.*

Images can be powerful

Just as the words we use greatly impact perception, so do the images chosen. All communications, including images, should be selected with thought and consideration. **Images should accurately and genuinely illustrate what it's like to live with these diseases and the range in which they impact people's lives.**

Many images used in the media frequently portray only white, young or middle-aged women massaging their temples and wincing. Quite often, they appear on a bright background, with full hairdos and make-up. Many look like *models* and not *normal people*.

The reality is migraine impacts all ages, races, and genders. The symptoms during an attack far exceed just head pain. Most people experience other symptoms including nausea, vomiting, cognitive impairment, visual disturbances and more. These symptoms are often difficult to represent.

The images we have included in this guide are examples of acceptable images.

Source: The World Health Organization (WHO) states that the disabling effects of severe migraine are "comparable to dementia, quadriplegia and active psychosis" (Shapiro RE, Goadsby PJ, Cephalalgia 2007). Furthermore, the WHO classified the constant nature of chronic migraine as "more disabling than blindness, paraplegia, angina or rheumatoid arthritis." (Harwood RH et al., Bull, World Health Org. 2004).]

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