HEADACHE & MIGRAINE DISEASE LANGUAGE & IMAGE GUIDE

2018/19

CHAMP

Coalition For Headache And Migraine Patients

This document represents the current consensus of the headache, migraine and cluster disease patient community. Language is constantly evolving and we will update this guide over time so that it continues to accurately represent how people living with headache diseases want our conditions described and portrayed.

Version 1.1 (June 2019)

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Declaration of Rights for People with Headache Diseases

We, the people with headache, migraine and cluster disease, deserve respect and empathy for the serious and sometimes debilitating medical conditions with which we live. We will not be disempowered, minimized or stigmatized by a society that does not understand the complexity and seriousness of our disease. We demand research, treatments and societal support that is proportional to the impact of our disease. This means an increase in funding for research, better insurance policies that make it easier for us to access our treatments and more visibility in the public space.

We are working to educate people on why the terms “patient” and “sufferer” can be problematic. Sufferers, implies defeat, and we are patients only when interacting with medical professionals who manage our diseases – we are people living with migraine, cluster or headache disease 24/7.

We will fight to have our struggle against these painful and disabling diseases honored. We, to the best of our ability, will make headache diseases visible.

Recommendations For All People

1. Honor and believe the struggle of people living with headache, migraine and cluster disease to cope with their pain and many other symptoms.
2. Educate and work to correct the culture that penalizes people with severe headache, migraine and cluster disease.
3. Learn about these diseases and understand the systemic nature of them.

Recommendations For People With Headache Diseases

1. When you can, reject the stigma of headache, migraine and cluster in yourself, and confront it in others. This takes work and time to understand the messages we have received about living with a chronic disease.
2. When you can, be visible as a person with headache, migraine or cluster disease.
3. When you can, participate in awareness and advocacy efforts. Seek out policy makers and advocate for understanding, research and treatment.

Rights Of People With Headache Diseases

1. To live a life of dignity, despite whatever limitations may be caused by our disease.
2. To not be blamed or dismissed for having a headache disease when all we want is effective treatment.
3. To gain 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 Disease Language & Images Matter

Language plays a vital role in how we understand the world. Too often, language can be used to disparage and belittle people living with disease, labeling them as helpless or as victims. This ultimately creates shame and stigma, and illegitimately justifies the notion that people with diseases should be ignored or feared. We see this prominently played out in the headache disease area. Language used by medical experts, the media, the public and stakeholders of our own community can greatly impact how people living with headache diseases are perceived and treated. This, in turn, affects the resources society makes available to support our pain and disability.

Likewise, the images associated with headache, migraine and cluster diseases often do not accurately depict the full range of symptoms connected to these diseases and minimizes the severity of impact on daily lives.

Images used by media or depicted in popular culture often overlook the diversity of races, ages and genders that are impacted by headache diseases. This adds to the mislabeling, misunderstanding, minimization and stigmatization of the individuals living with these diseases.

The purpose of this guide is to help all people who communicate about headache diseases to do so in a more accurate, informed and empathetic manner that treats these conditions and the people living with them with the seriousness and care they deserve.

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Language is constantly evolving, and we will update this guide over time so that it reflects the most updated discussions of the headache patient advocacy community. We do not intend this guide to be used to badger or shame anyone for the language they use. We hope this document will be used as a guiding light to help steer the way to more compassion and understanding for those living with migraine, cluster and other headache diseases.

Dr. William B. Young led and published a 2011 study, *Naming Migraine and Those Who Have It*[1], that convened a diverse consensus panel and analyzed its responses to a series of questions related to the language used for migraine. This guide builds upon that important work.

The Coalition For Headache And Migraine Patients (CHAMP) acknowledges and thanks Dr. Young and his colleagues for launching this conversation. We, the headache, migraine and cluster patient advocacy community, are honored to use this important work as a foundation for our own.

Language Guide

Headache Disease – Overall

CHAMP Recommendation	**Headache Disease(s), Headache Disorder(s)**
Currently Used	Headache(s)
Background	"Headache" is described as pain in any region of the head. It is frequently used to describe the symptom of pain. The public and media also use it to describe a thing or person that causes worry or trouble. CHAMP recommends using "headache disease(s)" and "headache disorder(s)" as preferred terms.
Explanation	Using medical terms including disease and disorder helps people to better understand that these are serious, painful, systemic, disabling conditions, and conveys that these are more than just recurring/ frequent headaches which are commonplace and well understood. Headache disease and headache disorder refer to the overall chronic health condition someone is living with.

Headache Disease – Overall (continued)

CHAMP Recommendation	**Headache Attack, Migraine Attack, Cluster Attack**
Also Acceptable	Headache Day, Migraine Day, Cluster Day
Currently Used	Headache(s), Migraine(s), Episode(s)
Background	Various community stakeholders and members of the public frequently use "headache(s)," "migraine(s)" and "episode(s)" to describe the experience of their diseases. For example, one may say "I get migraines too," or "My brother had a cluster episode yesterday." CHAMP believes the use of these terms individually minimizes the severity of these disabling diseases, decontextualizes them as chronic medical conditions and can fail to emphasize that they are more than a simple headache. CHAMP recommends using the word "attack" in conjunction with headache, migraine and cluster to more accurately describe the occurrence.
Explanation	Strong language emphasizes the seriousness of an event. Adding the word attack helps to explain the unexpected nature of how this disease impacts someone living with it and how quickly it can derail the person's ability to carry out their day. The use of the term "day" is often used in headache research and clinical guidelines and indicates the extended time people experience pain and other symptoms. In addition, the words "attack" and "day" highlight the fact that there are often periods of more severe symptomology that accompany the chronic health condition. Episode is more vague in both severity and temporality and may additionally carry the negative connotation of an overly-emotional response to a situation. For these reasons, CHAMP feels the use of the word episode should be avoided.

Migraine Disease

CHAMP Recommendation	**Migraine Disease, Living with Migraine Disease**
Also Acceptable	Having Migraine Disease, Having Migraine, Migraine, Living with Migraine
Currently Used	Migraine Headache, Migraines
Background	Plural language is not frequently used in other disease areas. For example, the cancer community and the public communicate their disease as "cancer" not "cancers." Likewise, the mental health community uses "depression" rather than "depressions" when speaking about the disease. Traditionally, people have used the term migraines and "migraine headache" to describe the disease, which CHAMP strongly believes minimizes the condition and further stigmatizes those living with it. CHAMP advocates for using migraine in its singular form and often adding "disease" to reinforce the medical nature of migraine, which is a disabling, neurological disease.
Explanation	Use of the plural migraines implies this is something that happens sporadically and then is entirely gone. For many, migraine disease is a chronic condition, for others, while migraine symptoms may not always be evident, they may be triggered at any time, and thus have migraine sensitivity. The term migraine headache overlooks the neurological complexity of migraine, as well as all the non-headache symptoms commonly experienced during a migraine attack. CHAMP advances the belief that the addition of the word disease emphasizes the severity of this chronic medical condition and reduces the public perception that it's "just a headache."

Migraine Disease (continued)

CHAMP Recommendation	**Person with Migraine Disease, Person Living with Migraine Disease**
Also Acceptable	Person with Migraine, Patient Living with Migraine Disease, Patient with Migraine, Migraine Patient
Currently Used	Migraine Personality, Migraineur, Migrainer, Migraine Person, Migraine-Type Person
Background	It's important to recognize that everyone is an individual rather than a label and their disease does not define them. Historically, people have used the terms "schizophrenic" and "diabetic," which dehumanizes the individuals with these diseases by implying that an individual's identity is centered around a health condition. In more recent times, many disease communities have embraced person-first language, using instead "a person with diabetes" and "people with schizophrenia." CHAMP advocates using "person with migraine disease" or "person living with migraine disease" to emphasize the humanity of people over an identity centered around a disease state.
Explanation	The migraine community has long been discriminated against and stigmatized by employers, family, friends, the medical community and the public. Referring to those living with migraine as something other than people further fuels this stigmatization. Using non-handicapping, person-first language is not only a more common expectation, but it is also a critical and necessary step in helping to defeat the stigma. CHAMP prefers "person" over "patient," which can imply passivity, helplessness and dependence upon the care of others. *Note: In some cases, use of the terms "migraineur" and "migrainer" may still be used by members of the community living with the disease. Because of the historical nature of the use of these terms, these individuals may use it as a badge of courage and to build solidarity with others also living with the disease.*

Migraine Disease (continued)

CHAMP Recommendation	**Experience(s) the Pain and Disability of Migraine Disease**
Also Acceptable	Experience(s) the Pain and Disability of Migraine
Currently Used	Suffering from Migraine, Migraine Sufferer
Background	Frequently, people living with migraine disease are referred to by others as "migraine sufferer" or "suffering from migraine." Everyone's experience living with migraine disease is different and personal. Symptoms, level of intensity and frequency vary from person to person. Pain is more of an objective experience, while interpreting it as "suffering" is very subjective and value-laden. It's not always wrong to refer to someone else's suffering, but CHAMP recommends the use of less subjective, value-laden language and urges all to use "experience(s) the pain and disability of migraine disease."
Explanation	An external observer cannot know or assume that one is suffering from a disease. Suffering is a personal reaction to a situation and not something that can be observed or assumed by an external party. The term suffering also implies a level of passivity. *Note: Individuals living with migraine disease may choose to refer to their own experience as suffering or identify as a migraine sufferer and should feel empowered to do so.*

Migraine Disease (continued)

CHAMP Recommendation	**Migraine Spectrum, Migraine Continuum**
Also Acceptable	Migraine Range
Background	Migraine disease is experienced by people at significantly different levels of intensity and frequency; moreover, there are a range of symptoms experienced beyond "just" a headache. Currently, there is no agreed upon term to describe the varying levels of the disease that people experience. CHAMP proposes and recommends the use of the terms "migraine spectrum" and "migraine continuum" to reinforce the various symptomology and variable range of experience of those living with migraine disease.
Explanation	Spectrum and continuum are terms that most people already understand and associate with other diseases that manifest with varying states of intensity and symptomology. These terms can help to better describe the wide range of intensity, frequency and array of symptoms those with migraine disease experience.

Migraine Disease (continued)

CHAMP Recommendation	**Migraine Remission, Break in Migraine Attacks**
Also Acceptable	Stop in Migraine Attacks
Currently Used	Cured of Migraine, Migraine Cure, Migraine Miracle
Background	Throughout 2018, the migraine community has been fortunate to have new therapies approved (and more on the way) for the prevention of migraine. For decades, people living with migraine disease have had few effective options to treat the symptoms of their disease. Many have taken steps to reduce their symptoms by identifying and avoiding triggers. However, there is currently no cure for migraine disease. CHAMP endorses use of the term "migraine remission" as the best way of characterizing a change in the frequency or intensity of migraine symptoms. CHAMP conditionally accepts the terms "stop" or "break" in migraine attacks. Referring to a stop or break in migraine attacks can be an accurate description of the experiences of people living with migraine disease in situations where the additional context of a period is given, e.g., "Janice experienced a break in migraine attacks over the past 6 months when she participated in a clinical trial."
Explanation	While some fortunate individuals may experience a stop or break in their migraine attacks, there is no cure or quick fix and attacks often recur after periods of inactivity. The terms "cure" and "miracle" are misleading and provide people with false hope or assurance. CHAMP recommends language that more clearly defines what has occurred. Remission is widely understood by the public and medical community and already associated with a medical concept.

Migraine Disease – For Further Discussion

Preferred	**Medication Adaptation Headache**
Also Acceptable	Medication Response Headache
Currently Used	Medication Overuse Headache, Rebound Headache
Explanation	The term "Medication Overuse Headache" or "MOH" is currently used by the medical community as part of the 3rd edition of the International Classification of Headache Disorders (ICHD-3). CHAMP is not currently recommending a unilateral change to the term but remains concerned with its use and looks to engage with headache disease stakeholders to discuss and assess a future change. CHAMP believes the term MOH creates stigma by implying that the patient is to blame for taking too much medication. (It could equally be called "Medication Overprescribing Headache" implying a shift in blame onto the healthcare provider, but it is not called this and should not be). The alternate term "rebound headache" doesn't account for the role that medication pharmacokinetics is believed to play in this type of headache. Therefore, CHAMP recommends the preferred term "Medication Adaptation Headache" or "Medication Response Headache." Again, we do not recommend making this change unilaterally at this time, as it is currently used for diagnosis and insurance coverage. Instead we seek further discussion about this proposed change with a broader array of stakeholders.

Cluster Disease

Cluster disease, a form of Trigeminal Autonomic Cephalgia (TAC), is less common than migraine disease, but more prevalent than most people realize. An estimated 1 in 1,000 Americans experience cluster attacks. Cluster attacks are frequently described as the most painful physical experience a person can have. Cluster disease is sometimes referred to as "suicide headaches" because, sadly, the suicide rate for this patient population is 20 times higher than the national average. This heightened suicide rate among people with cluster disease is largely believed to occur because of the intensity of the pain they have been living with for extended periods of time.

The cluster community has shared a diversity of opinions on the terminology they feel most appropriately should be used to describe their disease. This is understandable since for decades medical experts have struggled to find common ways of describing or diagnosing cluster disease. Consequently, CHAMP does not currently make language recommendations regarding cluster disease. Instead, CHAMP is providing a listing of the most commonly used cluster terms and the pros/cons of using these terms.

Cluster

PROS	CONS
The term "cluster" is simple yet descriptive of the nature of the disease, with attacks often happening in bunches.	Cluster does not depict the severity of the disease and lacks any medical association. It also overlaps with many other common uses of the word such as to describe a group of people.

Cluster Disease (continued)

Cluster Headache

PROS	CONS
"Cluster headache" is more detailed and narrowly focused on the disease. This term is what is currently used under the IHS classification and most prevalent in online communications.	Symptoms of attacks include more than just headache pain and the severity of the pain is difficult for other people to understand when their only reference point is their own experience of more common headaches.

Cluster Disease

PROS	CONS
Using "cluster disease" helps to reinforce this as a serious, medical condition	Because cluster disease is not yet commonly used, it could be challenging to change the language and build awareness both inside and outside of the community.

TAC (Trigeminal Autonomic Cephalgia)

PROS	CONS
Trigeminal Autonomic Cephalgia is a technical, medical and serious depiction of the disease.	The term can be difficult to say and remember, and it is not widely used. It is also not entirely accurate because cluster is a prevalent type of condition under the broader TAC category, which also includes other conditions.

Suicide Headache

PROS	CONS
According to statistics, "suicide headache" is a numerically-justifiable name for the disease. It is attention grabbing and reinforces the critical nature of this condition.	The use of this term can be perceived as overly sensational and carries a risk of creating despair amongst those who have this condition and possibly contributing to increased suicide rates.

Image Guide

Just as the words we use greatly impact perceptions, so do the images we choose. CHAMP asks all communicators to be thoughtful when selecting imagery and photographs of people with headache diseases to use in publications, advertisements, blogs and websites. The images selected should accurately and honestly depict what it's like to live with these diseases and the range of how they impact people's daily lives.

Images commonly used in the media most frequently portray only white, middle-aged women showcasing mild head pain. The reality is headache, migraine and cluster diseases do not discriminate. They impact all ages, races and genders. And the symptoms during an attack far exceed just head pain. Most people also experience other symptoms including nausea, vomiting, cognitive impairment, visual disturbances and more.

On the following pages, we have included examples of photos that are commonly used to illustrate the limited representation that is prevalent in current communications. We have also included examples of photos that provide more accurate and diverse depictions of headache, migraine and cluster disease. CHAMP advocates for the use of images similar to these more diverse and accurately representative examples.

CURRENTLY COMMON IMAGES – DO NOT USE EXCLUSIVELY

We are NOT all middle-aged, white, working women

Head pain is NOT the only symptom

We are NOT weak

The following images show how headache and migraine are commonly portrayed using white, middle-aged, women. If this demographic is shown, it should be paired with other images that show more diverse demographics impacted by headache diseases.

We are NOT all white women with children

Our disease is NOT glamorous

SUGGESTED IMAGE EXAMPLES

Neck and shoulder pain/tension

Need for a rest and solitude

Exhaustion and sensitivity to light

CHAMP endorses the following images as examples of preferred images because they show the wider array of associated symptoms and varied ages, gender, races and ethnicities impacted by headache diseases.

Nausea and/or vomiting

Depression and anxiety

Visual aura

SUGGESTED IMAGE EXAMPLES

Cognitive impairment and mental fog

Migraine often decreases with age, but not always

CHAMP endorses the following images as examples of preferred images because they show the wider array of associated symptoms and varied ages, gender, races and ethnicities impacted by headache diseases.

Children also experience headache diseases

Headache diseases interfere with education

Headache diseases impact men

SUGGESTED IMAGE EXAMPLES

Headache attacks also interrupt the work of men

Headache attacks lead to noise sensitivity in men also

Headache attacks lead to light sensitivity in men also

CHAMP endorses the following images as examples of preferred images because they show the wider array of associated symptoms and varied ages, gender, races and ethnicities impacted by headache diseases.

Headache diseases occur in ALL races

Headache attacks impact ALL ethnicities

Headache diseases do not discriminate

SUGGESTED IMAGE EXAMPLES

Headache diseases are disproportionately prevalent in members and veterans of the military

Headache diseases are disproportionately prevalent in members and veterans of the military

POWERFUL IMAGES

People are bombarded by communications, messages and visuals from mass media and social media. Those working to share educational messages about chronic disease are competing against major advertisers and entertainment providers that use images and messages that are captivating and visually compelling. CHAMP believes there are ways to educate all stakeholders on headache, migraine and cluster disease that use engaging, accurate, inclusive and empathetic visuals. The following images are examples of the compelling visuals we recommend.

Intensity of pain

Related depression and isolation

Depression and loneliness

SUGGESTED POWERFUL IMAGE EXAMPLES

Despair and cognitive impairment

Feeling of being less than you could be

Pain and hopelessness

Conclusion

This document represents consensus guidance from CHAMP member organizations and the headache disease patient communities we serve. We reiterate that the purpose of this guide is to help all people who communicate about headache diseases to do so in a more accurate, informed and empathetic manner. This guide should only be used as an educational tool and never to shame anyone for the language they use.

Language is constantly evolving and CHAMP will update this guide over time so that it reflects the most recent consensus of the headache patient advocacy community. If you have any feedback or suggestions for this guide, please email Kevin Lenaburg, Executive Director of CHAMP, at Kevin dot Lenaburg @ HeadacheMigraine dot org.

[1] Young, W. B., MD, Kempner, J., PhD, Loder, E.W., MD, Roberts, J. PhD, Segal, J.Z., PhD, Solomon, M., PhD, Cady, R.K., MD, Janoff, L., BA, Sheeler, R.D, MD, Robert, T., PhD, Yocum, J., RN, Sheftell, F. D., MD (2011). Naming Migraine and Those Who Have It. Headache, 0017-8748, 283-291.

CHAMP Members

HSG Cluster Headache Support Group

the daily headache

Danielle Byron Henry Migraine Foundation

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The Headache & Migraine POLICY FORUM

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