

The Fibromyalgia Letter



Dear Family/Friends/Others,

My name is Gisele McDiarmid. I am a Certified Professional Health and Life Coach Specialist, with a background in Nursing and a B.A. in Psychology. I help people diagnosed with Central Sensitivities Syndromes (CSS).

I am writing this letter to explain to you a very serious, chronic, complex, and disabling illness that also happens to be invisible. This illness is Fibromyalgia (also called Fibromyalgia Syndrome, and FM). The person who has given you this letter has been diagnosed and is living with this very challenging illness.

Fibromyalgia is a complex chronic illness that the medical community recognizes as real, even if on the surface it appears to be “invisible”. We say that it is invisible because while the disease is happening inside the body, the person will tend to look normal on the outside.

The Mayo Clinic states that: *“Fibromyalgia is a disorder characterized by widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues. Researchers believe that fibromyalgia amplifies painful sensations by affecting the way your brain processes pain signals.*

Symptoms sometimes begin after a physical trauma, surgery, infection or significant psychological stress. In other cases, symptoms gradually accumulate over time with no single triggering event.

Women are more likely to develop fibromyalgia than are men. Many people who have fibromyalgia also have tension headaches, temporomandibular joint (TMJ) disorders, irritable bowel syndrome, anxiety and depression.”¹

Ongoing research is being done around the world to help the medical community better understand the physiological mechanisms involved in FM, how a person develops it, and how to treat it. At the moment, there is no cure for FM, however a variety of medications and natural treatments have been proven to bring significant improvements to people living with the challenges of FM.

Doctors and researchers agree that FM is Central Sensitivities Syndrome, a neurological disease, specifically of the Central Nervous System that affects every part of the body, causing widespread pain and debilitating fatigue. Since there are nerves in every inch of the body, every part of the body is affected in one way or another. As we are all unique individuals, a person living with FM will experience this chronic disease in their own unique ways. The nerves hypersensitive to all types of sensations (sounds, lights, smells, tastes, and sensations like touch, pressure, temperature, etc.); and the entire body becomes affected through dysfunctions of hormones, the immune system, as well as the digestive system.

Explaining Pain

FM pain is widespread throughout the body. It does not discriminate, and it also does not stay in the same spots, it

can travel from one day and one moment to another. The pain can be on the skin, in muscles, tendons, ligaments and fascia (a thin envelope around all muscles and internal organs). FM causes pain, because there are nerve endings in all of these places. It is often described like an intense and persistent gnawing of the area. But the area always appears normal, unlike a rheumatic pain that will cause swelling and redness, a painful FM area tends to look normal. This is one of the reasons FM is called an “invisible” illness. Other ways the pain is often described is: deep ache, burning, cramping, numbness, stabbing, pins and needles, and severe stiffness.

Some days, a person living with FM will experience awful pain from a gentle hug, the feel of clothing or the weight of a single sheet, the tenderness of a kiss or a caress, or even moderately cold air (allodynia). The intensity of the pain can also vary: some days are better than others. They can also experience sudden flares. This is when the pain just shoots up in sustained high intensity for days, weeks, even months (hyperalgesia).

Explaining Fatigue

The fatigue a person with FM experiences is much more severe than just being tired. There is also no amount of sleep that makes it any better, because their sleep is not restorative. The fatigue is so profound and persistent that it makes life very challenging to live. It gets worse after even mild exertion. Many people describe it like coming down with a nasty flu and then, never getting any better. And these flu-like symptoms go from mild to severe, but they are always there. This persistent fatigue looks like: the flu, mononucleosis (Mono), coming out of anesthesia, pulling an all-nighter in college, the exhaustion of being a new parent, severe jet lag, or having a hangover.

Explaining Fibro-Fog

Who hasn't walked into a room and forgotten why they were there? Or struggled to find the right word? It happens to everyone now and then, so you can say that brain fog is like that, only it tends to be a part of the experience that a person with ME/CFS has most of the time, if not all the time.

It literally feels like the brain is packed in cotton, or that there's a thick wall of fog all around it and it makes it very difficult to see clearly, hear clearly, understand clearly, as well as to communicate clearly. Sometimes, it's like their brain has forgotten the most basic words, so when they try to say something, they start to struggle to make sense. People who have a severe concussion or a stroke will often struggle in this same way, because the neurons in their brains have been affected.

It also affects their memory, so please forgive them in advance if they sometimes have totally forgotten a conversation or even an event that you have shared. Just because their brain doesn't work as well as it should, or that they would like it to, please believe that you are still a very important person in their life and what you say and do are always very important to them – even though they might not always remember them - unfortunately. As hard as they try to remember, their brain doesn't always allow it. The doctors and researchers agree that it does not at all mean that people with ME/CFS are not smart or intelligent, nor does it mean that they have a psychological or psychiatric disorder. Those are not at all the same. The experts have compared Brain Fog to Alzheimer's and dementia, although the mechanisms involved are not exactly the same, how the brain impairments appear is similar.

Some days are better than others for them, so please be kind and show the person you know who has to live with ME/CFS some patience and empathy. It is very difficult, as well as scary and worrisome, for them to live like this.

Ups & Downs

The fatigue from ME/CFS symptoms sometimes is lesser and other times worse. The individual can also get flares and remissions, like a person who has Multiple Sclerosis. The ups and downs feel like living on a roller coaster - they

never know how their day will start or how the sudden turns are going to affect their day, week or month. Sometimes they might even feel unexplained pain all over their body, dizziness or impaired coordination.

Please understand that this roller coaster they live on penalizes them much more than you might realize, since, while you might see them having to cancel one planned activity with you one day, they might have had to cancel all of their social plans for the last month or two or three!

They end up feeling very sad, frustrated, lonely and isolated from the joy and happiness they would have otherwise shared with you and everyone else who means something to them. Please forgive them in advance if they have to cancel on you at the last minute, and please don't hold it against them. They sincerely hope that you will continue inviting them again in the future, and they hope even more that they will be able to show up most of the time.

Thank you for taking the time to read this letter today. It means a great deal to the person who gave it to you, as they hope that together you can work through this thing, you and them. Please understand that they are just like you: they have dreams, goals and hopes for their present and future; they also need to be respected, supported, encouraged, nurtured and loved.

Additional Resources:

- ✚ For more information visit my website: <https://www.giselemcdiarmidcoaching.com>
- ✚ To reach out please email me at: gisele@gmcdiarmid.com

✚ A Simple Explanation of Fibromyalgia:
<https://www.verywellhealth.com/a-simple-explanation-of-fibromyalgia-716142>

✚ The Fibromyalgia Symptoms List:
<https://www.verywellhealth.com/fibromyalgia-symptoms-716139>

✚ Understanding Neurotransmitters:
<https://www.verywellmind.com/what-is-a-neurotransmitter-2795394>

Reference:

1. <https://www.mayoclinic.org/diseases-conditions/fibromyalgia/symptoms-causes/syc-20354780?page=0&citems=10>

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