

Fibromyalgia? Because you asked...

Dear Concerned,

You've recently asked me about fibromyalgia and I'm sure you're wondering what all the hype is about. While most people have heard of it by now, that doesn't mean they know what it is. There's a lot of conflicting information out there and it can be confusing.

After all, if everything you know about fibromyalgia comes from what you see on TV, you might believe I should be out rowing a canoe, gardening, or opening my own bakery and sweets shop. But, instead, you see me not feeling well and not participating in activities that are too taxing or stressful.

To clarify my response, I'm providing it in this written format. It's my way of making sure I don't leave out anything important.

Here's what you need to know...

Health conditions in general, are classified as either diseases or syndromes. Diseases have a specific, definable, biological cause and have a specific set of symptoms. Health conditions that have no definable biological cause and exhibit a variety of symptoms are categorized as syndromes.

Fibromyalgia, therefore, is categorized as a syndrome as are multiple sclerosis, rheumatoid arthritis, migraines, and hundreds of other chronic health challenges. Fibromyalgia likely affects about 10 million Americans (mostly women) and the numbers globally continue to rise.

Now that I've covered some fundamentals, here are five more things that I think are important for you to know about fibromyalgia as well as about how fibromyalgia affects me.

#1 – Fibromyalgia is actually a **systemic** health concern. That means multiple systems of the body are compromised and may experience dysfunction. Many of us exhibit symptoms related to the musculoskeletal, nervous, respiratory, digestive, cardiovascular, immune, urinary, endocrine systems and more.

We're all different. Some fibrofolk experience symptoms that relate to more than one system (or systems) than others. For example, some may experience frequent digestive dysfunction issues and rarely experience cardiovascular issues, etc. This varies widely.

The most dominant symptoms that we do share, however, are:

- 1) Chronic widespread body **pain** that varies in type and intensity day by day (muscles, joints, headaches/migraines, etc.)
- 2) **Fatigue** (this doesn't mean simply tired – it means knocked down, dragged out, run-over-by-a-truck exhausted feeling that lasts for days, weeks, or much longer)
- 3) **Sleep** disturbances (difficulties in falling asleep or staying asleep – also, not feeling rested even after sleep)
- 4) Concentration, memory, and **cognitive dysfunction** issues (grasping for words, forgetfulness, difficulty in completing tasks, etc.). This is oftentimes referred to as **fibrofog**.

There's a plethora of other symptoms, too. Digestive issues are very common as are anxiety and

mood issues, balance and coordination challenges, weight management issues, whole body stiffness, PMS, inability to regulate body temperature and more.

While there are far too many symptoms to list here, the top four listed above are the biggies. Mine vary from day to day and while sometimes I feel some more than others, they're all usually lurking under the surface.

I'd like to say a quick word, here, about depression. As you can imagine, dealing with chronic and relentless pain (and more) leaves its mark. It can leave a person feeling frustrated at best and potentially depressed at worst. Depression can especially develop for those who feel overwhelmed, unsupported, and hopeless about their health circumstances.

Therefore (non-clinical) depression can result from all of the factors listed above. It's not the cause of the factors listed above. This distinction matters for reasons of establishing a diagnosis, a future prognosis, and potential treatment(s) for existing depression.

#2 – No, I didn't "do" anything to cause fibromyalgia. There are multiple reasons that fibromyalgia can develop and it's never just one thing. It takes a combination of factors and some of the most likely include:

- A compromised digestive system* (contributed to by food sensitivities, stress, processed foods, diets and more).
- A family history of immune system dysfunction and/or allergies.
- Infection(s).
- A traumatic physical event or injury (includes surgeries).
- A traumatic stressful/emotional event.
- Vitamin/nutrient deficiencies (*can be contributed to by a compromised digestive system)
- Environmental exposures to toxins (both internal and external).
- Multiple chronic infections leading to repeated use of antibiotics, steroids, or corticosteroids or non-steroidal anti-inflammatory medications.
- Dental issues.

Also, any number of the above factors can lead to:

- Whole body inflammation.
- Chronic yeast and candida issues.
- Compromised adrenal, thyroid, and hormone regulation.

These things set the stage for dysfunctions in multiple systems of the body. That's why there's such a wide variety of symptoms.

#3 – It's important to understand that fibromyalgia and my symptoms are **unpredictable**. I'd love to "know" how I'll feel tomorrow or even next week, but I simply don't. Sometimes I can do something relatively minor (like fixing dinner for my family) and feel awful afterward. Other times, I can participate in something major and feel fine.

But, here's the important part. If I can't predict my own reactions to foods, places, events, circumstances, etc. – I certainly don't expect you to.

I appreciate your concern when you ask if I “should” do this or that, but it’s my choice. I get to decide what I will or won’t choose to do. And, I’ll deal with the consequences of my choices. Additionally, I don’t expect you to know what to do, what to say, or even how to help me. It’s my choice and responsibility when (or if) to ask for help, and to share how I’d like to be helped.

#4 – In a nutshell, it’s important to grasp that having fibromyalgia makes me **hyper-sensitive**. Things that don’t pinch, hurt, or even annoy most people might drive me crazy. A heavy necklace or a large purse can feel like I’ve got an anvil pulling on my neck and shoulders. A simple touch or even an embrace can leave me feeling as if I’d been squeezed in a vise.

Sounds, lights, smells, tastes, and touches can be unusually amplified. Please respect (and withhold judgment) when I express that something may be too loud, too bright, too stinky, too spicy, or too painful.

**I’m not trying to be difficult.
I’m simply trying to share my feelings and experiences.**

And, along with being hyper-sensitive, there are some things I can’t control. While I agree it may look funny, it’s not humorous to me when I startle easily, jump at loud noises, or shriek when unexpectedly alarmed. It’s as simple as a reflex and I can’t change that.

It’s important to note that due to this hyper-aware state, **stress is also amplified**. Therefore, avoiding stress and dealing with the stress I can’t avoid has become my priority. For me, stress isn’t a simple fact of life to accept. Its negative effects are far-reaching and potentially long-lasting.

It is, therefore, an important health mission for me to participate in relaxation activities and care for my body physically, emotionally, and spiritually.

#5 – I appreciate your thoughtful suggestions for how to manage my health challenges, but keep in mind that above all, **I’m doing the best I can**.

Your helpful advice will be taken into consideration. If I apply your suggestion to my current protocol of treatments, I’ll do it because I feel it could benefit my healing process. If I don’t take your suggestion, it might be for any number of reasons. I may have already tried it, I may have researched or read something to the contrary, I may not have the resources to put it into practice, or I may feel it would conflict with something else I’m already doing.

While I may or may not have the time or energy to go into all this detail with you, please know that I value your concern. If there’s anything that I’ve learned, I know that there’s no single pill, practice, or program that will “fix” fibromyalgia. If there were, I’d already be taking it, doing it, or be devoted to learning it.

**Which is exactly what I’m doing now.
I’m learning as I go.**

One of the hardest lessons I’ve had to learn is how to express myself. Although it’s difficult, here are a few thoughts on that topic:

Please don't

- Tell me that you know how I feel. Even if you have fibromyalgia and/or any other health challenge, we're all different and experience our conditions differently.
- Tell me how I should feel. That's up to me.
- Tell me that so-and-so drank this "magic juice" and got better. There are as many treatments that don't work as ones that do. I'm on the journey to discover this process on my own.
- Compare me to siblings, friends, colleagues, who don't have health challenges or even those who do. As I've stated, I'm on my own path to wellness.

Please do

- Tell me that you're thinking of me. Even if I'm not terribly responsive or talkative it's wonderful to know that you're supportive of me and of my health.
- Send me books, magazines, cards, emails, notes, etc. that express that you're there. **Chronic illness can be SO isolating** and every kind word from you matters to me.
- Ask if there's anything specific that I need. Even if I say "no" 50 times out of 51, that one time that I really need something may mean the world to me.
- Continue to search for helpful treatments, protocols, nutrients, supplements, and practices. Just because I don't always implement your suggestions doesn't mean I don't appreciate the help. I'm always open to and encouraged by current news and information.

In summary:

- Remember that my body may bruise like a tender peach, but my will is strong as iron.
- What I'm really trying to say is that inside, **I'm still the same me.**
- **I'm just trying to find my way as best I can.**
- I'd love it if you'd come along with me on this unpredictable journey.

**Not behind me pushing,
Not in front of me pulling,
But beside me – guiding, encouraging, nurturing and supporting**

Are you with me?