

Lupus Fatigue & Lupus Malaise

Do you ever have days where you just can't seem to make it out of bed? I'm talking about lupus fatigue and lupus malaise.

You know, the days where your body has just given up and mentally you can not even process a simple conversation. I find myself zoning out often, as if my brain is 'too tired' to even comprehend something someone is saying. I HATE days like that.

A total of 53–80% of systemic lupus erythematosus (SLE) patients identify fatigue as one of their primary symptoms. – Source: Int J Clin Rheumatol

What is lupus fatigue?

With over half of lupus patients identifying fatigue as one of their primary symptoms, lupus fatigue is one that many lupus patients struggle with. Lupus fatigue can be caused by a variety of factors including physical activity, sleep quality, vitamin D deficiency, and having other health issues like Fibromyalgia. Lupus fatigue could also be caused by lupus treatments and even related to lupus activity itself.

What is lupus malaise?

Lupus malaise is the overall general feeling of not feeling well. It is hard to describe, but where your body actually feels like it is sick. Many people lump lupus fatigue and lupus malaise as a symptom. I can definitely tell a difference in the two, malaise makes me just "feel sick".

<http://lupuslyfe.com/wp-content/uploads/2020/04/lupus-fatigue-and-lupus-malaise.mp4>

I have lupus and I'm exhausted!

I don't underestimate the pain that I live with, but I feel like I am still able to live a somewhat normal life with it most days (or at least a life I have grown to know and accept). I am lucky enough to work from home fully right now, so I can still work and still help my kids with our new version of homeschooling (thank you Covid-19).

BUT...when the fatigue & malaise strikes, it is incredibly debilitating.

How can I live a life if I can't even get out of bed? It takes a toll on me mentally. It's hard to explain to someone who doesn't suffer from symptoms of malaise and brain fog. I am not just talking about being 'tired'. I'm tired everyday lol. This is a 'my body gives up on its own' kind of tired. I have no control over it. I feel as though I am inadequate and unable to really be of any help to anyone because frankly, I can't even seem to help myself on those kind of days. Sometimes, I let it get the best of me.

And you know what? ***That's OK.*** That's right, I said it! Some days, we ALL need to let fatigue win for the day. I know for me personally, it's hard to say no or not right now to people. If you allow yourself to become overwhelmed, it can lead to stress. Stress is a major lupus flare trigger for me. I'm an anxious person...hence my issue lol.

How do I deal with lupus fatigue?

Our body does a pretty good job telling us when it is time to take a break, but do we always listen to our body? I find myself constantly trying to push forth and get things done that I have planned. On days that I feel good, I try to do so much all in one day. I may be able to get a lot accomplished, but I am usually paying for it. When I go too hard, it can

take me days or even weeks to recover. This can be extremely frustrating. It seems that I take one step forward and then end up two steps behind. I feel like having a chronic illness is a catch 22 many times.

You can check out these natural stress relieving tips if you are like me and need to destress!

Its days like this that I struggle to find that peaceful balance that my chronic illness life requires. Its hard to discuss with friends or family who can not fully comprehend how hard living a 'normal' life can be for someone who is constantly battling their own body. I am working on finding ways to cope with this fatigue, yet I feel it is a lupus symptom that I think is highly misunderstood.

What helps me with lupus fatigue?

- **Benlysta:** Benlysta is about the only thing that seems to *REALLY* help with both fatigue and malaise for me. I have had to come off of it a few times over insurance/surgery etc, and the only issue is that it generally takes a few months before I really begin to notice a difference. BUT...it is seriously life changing and well worth the wait. I recently restarted Benlysta auto-injections at home and can not wait to kick this fatigue/malaise slump I have been in since my kidney cancer surgery.
- **EmergenC:** I started this once the flu ran through our house in early March. I still take it because I feel like it gives me more energy or at least a heightened sense of motivation.
- **Lupavita:** I recently added Lupavita to my routine and will be writing of a review of it once I am done. I have had low Vitamin D levels (around 14) in the past and was looking for ways to add in some extra. I also like the fact I can get a turmeric dose and magnesium

dose at the same time.

- **Multi-Vitamin:** I know that I do not eat as well as I should so taking a daily vitamin helps me meet requirements for a variety of vitamins and minerals. Vitamins always have helped give me a boost, so they are a quick way to help.
- **8+ hours of Sleep:** I am working on making sure I get at least 8 hours of sleep a night. This is so hard some days, but is one of the most important things for me to focus on personally.
- **Nap Time:** Who says naps are just for kids? I gauge myself midday to see if I need a quick nap to make it through the rest of the day.
- **Weekly Meal Prepping:** This doesn't necessarily help my fatigue, but it makes my life way more manageable throughout the week. I am working on getting better and more consistent with weekly meal prepping.
- **Meditation/Prayer:** The universe and friends keep reminding me to take a few minutes to myself each day to calm my mind. It is hard to dedicate even a few minutes alone with kids, but these gentle reminders from loved ones let me know how important it is for me to remember to take care of myself as well.
- **Yoga:** Not only does gentle yoga help ease my joints and muscles, but it helps me really wake up in the mornings. you can check out some of my favorite Youtube videos for lupus and fibromyalgia [here](#).

Remember, its important to speak with your doctor before adding any physical activity or supplements to your lupus regiment.

Living with lupus and extreme fatigue:

I wish I had a magic cure to share with all of you who suffer

deeply from lupus fatigue and lupus malaise, but unfortunately I am still searching for that 'cure' as well. Please don't ever give up hope, even on those days you find yourself lying in bed crying. Screaming out to someone to save you from the war your body has been fighting within itself. It's exhausting and I know that.

Yet, there seems to be a glimmer of hope on the horizon of tomorrow.

If you find yourself struggling, don't feel guilty about taking a day to recover. If we can't take care of ourselves, how can we take care of others? Self-care really is so important and it may not seem like a lot, but it can go a long way for you mentally. Prayers and good vibes to all those suffering from lupus fatigue and lupus malaise right now. Comment below some ways that you help fight lupus fatigue. Never forget, we fight together!