Fatigue and Lupus: The Many Different Kinds of Exhaustion

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What Is Lupus Fatigue?

For most people, fatigue is an unwanted visitor that arrives at the end of a busy day.

Its invasion begins when you start to feel whole body tiredness and have difficulty completing physical and mental tasks. Typical cases of fatigue typically resolve after an adequate rest period.

People with lupus, however, tend to have abnormal episodes of fatigue.

Their unwanted visitor has turned into a permanent companion who might show up after the slightest exertion and refuse to leave even after they've managed a good night's sleep – or two.

For them, the frequency, severity, and recovery time looks entirely different compared to those with regular fatigue.

What Does Lupus Fatigue Feel Like?

There are many different ways that lupus fatigue can manifest and, as lupus is notoriously variable, it rarely looks the same in two people.

So please keep in mind that these explanations, which are based on my experiences and those of lupus warriors I know, may not be all-encompassing for every person with lupus.

What Does Physical Lupus Fatigue Look Like?

Mild physical fatigue is often a literal drag as if extra pounds are weighing you down or something creating air resistance as you go about your day.

It doesn't necessarily stop you from accomplishing things, but it will slow you down and make things harder than they need to be. This level of fatigue typically responds well to an afternoon nap.

As fatigue escalates, it starts to feel like it's taking over your life. With moderate fatigue, you may only be able to manage a four-hour workday or find yourself carefully scheduling rest periods throughout the day. It's likely you'll have to start cutting nonessential activities out of your life to cope.

At its most severe, fatigue can be extremely debilitating. For me, intense physical fatigue creates a bone-deep weariness. I start to experience body aches and feel like I've pulled several all-nighters even if I've slept well and spent most of my day resting.

I often feel like my battery is completely drained. Not only is it empty, but there doesn't seem to be any way to

refill it. Sometimes it seems to go into the negative, as if I've borrowed energy and stamina from the week ahead – which I won't be able to repay, of course.

Physical fatigue can be so exhausting that movement starts to feel impossible. This makes it hard to stay motivated, and at this point, others may misinterpret fatigue as laziness.

It's important to communicate with those around you so that they can understand the difference, even though the way you feel can be hard to describe in words.

How Does Lupus Fatigue Affect You Mentally?

Mild mental fatigue makes you seem a bit absent-minded. You might be struggling to find words or remember things, and you'll probably find yourself at the receiving end of jokes about getting older.

Mental fatigue, which is also referred to as 'brain fog,' can make it hard to concentrate or even stay awake. You may experience deep confusion and sluggishness that can make you appear intoxicated.

It can feel like forgetfulness on steroids. You might not be able to make decisions or have coherent conversations. The experience can't be summed up with simple statements such as "I'm tired" or "I can't think straight" because the fatigue can go much further and deeper than many people can articulate.

Understanding Lupus Fatigue Symptoms

It's important to recognize the symptoms of fatigue so that you can pursue the best course of treatment. Some physical and mental signs of fatigue include:

- Lack of energy; feeling tired or continuously exhausted.
- Not being able to start or finish tasks.
- Vision issues.
- Drowsiness or possibly loss of consciousness.
- Dizziness or vertigo.
- Muscle weakness and/or pain.
- Lack of appetite or weight loss.
- Cognitive dysfunction, such as memory impairment, reduced decision-making ability, or trouble concentrating.
- Feelings of sadness, anxiety, anger, depression, or irritability.

Be sure to bring up any signs of fatigue with your doctor.

How to Explain Lupus Fatigue to Others

So how do you explain lupus fatigue to people who don't know what it's like?

One way to start is by clarifying that your fatigue is linked to your disease and not necessarily related to your activity levels. In fact, the amount of fatigue that people with lupus experience tend to be disproportionate from or unrelated to how active they have been.

Communicate that you tend to experience fatigue more frequently – perhaps even constantly – because of lupus and that recovering can be a lengthy process. Share personal details such as how often you have fatigue, its intensity, and how long it takes you to recuperate.

Since lupus fatigue can be physical, mental, or a combination of the two, you can help others to understand by sharing your specific symptoms with them.

Share that physical fatigue can make tasks of any size feel challenging and give examples of what that looks like

in your daily life. With mental fatigue, you may want to prepare a description of your symptoms in advance since you could find yourself trying to explain it while you are experiencing it.

People will be curious about why you're experiencing fatigue on a regular basis. While there are many potential causes of lupus fatigue, it's not always possible to pinpoint which ones are responsible for each circumstance.

For example, it's not fully understood why those with mild lupus or in lupus remission still have high levels of fatigue at times.

Not being able to provide an apparent reason for your fatigue sometimes makes it particularly difficult for people to understand what you are going through. However, it does give you an opportunity to explain how the unknown and the unsolved play a large part in lupus as a whole.

Next page: The causes of lupus fatigue and tips for managing lupus fatigue.

What Causes Lupus Fatigue?

Some causes of lupus fatigue are obvious, such as having a flare – your immune system uses a lot of energy when it's actively attacking your body. While some fatigue sources are directly related to lupus, others are more subtle and therefore harder to identify.

Here are some of the many causes of lupus fatigue:

- Direct UV light exposure from the sun or indoor lighting.
- Many common lupus medications list fatigue as a side effect.
- Additional, underlying medical conditions (such as anemia, hypothyroidism, diabetes, kidney disease, acute infections, etc.).
- Mental health issues, including anxiety, stress, grief, and depression.
- Lupus flare-ups.
- Immunosuppression.
- Adrenal fatigue (which can happen with chronic steroid use).
- Inactivity or overactivity.
- Poor nutrition.
- Using tobacco or illegal drugs.
- Dehydration.
- Pain – especially chronic or intense pain.
- Ineffective breathing (which leads to a lack of oxygen).
- Sleep issues.

Keeping a fatigue journal can help narrow down potential causes. Remember that it's not always possible to find the specific reason behind fatigue and don't be too hard on yourself if you haven't figured it out yet.

How to Manage Lupus Fatigue

It's important to take action if you're suffering from lupus fatigue. Uncontrolled fatigue typically results in poorer health outcomes and can be dangerous in some situations (such as driving). Here are some ideas for managing fatigue.

1. Tackle the Causes

Start by reviewing the possible causes of lupus fatigue for any potential candidates. Carefully examining your life will help to pinpoint sources of fatigue.

Perhaps you need to go over your medications with your doctor or ask for diagnostic tests to rule out suspected

causes. Make sure you are getting enough nutrition from your diet and find ways to manage stress if that is an issue. It may take some trial and error to figure out what contributes to fatigue, but it's important to keep trying.

2. Exercise

You may be surprised how an effective, appropriate exercise can be in treating fatigue. Although it seems counterintuitive to work out when your body feels depleted, aerobic exercise is one of the best non-drug treatments for fatigue when it's done correctly. As long as you are careful not to push yourself too hard, you'll likely experience renewed energy after an exercise session.

For me, there are times where exercising is helpful and rejuvenating. On the other hand, sometimes I feel like I simply cannot go on and I have to end the workout. With time, practice, and perhaps direction from a physical therapist, you'll learn how to define your limits and exercise safely.

3. Learn Pacing Techniques.

Pacing is an essential skill for any lupus warrior. Learning to pace yourself will go a long way in preventing fatigue instead of just managing it after the fact.

Try scheduling rest periods throughout the day based on a schedule (such as taking a break every two hours) instead of a fatigue schedule (i.e., taking a break when you feel tired). Make a plan for each day so that you can accomplish essential tasks while still taking time to listen to your body and give it the rest it needs.

Resting and pacing should be highly prioritized in your life. Be sure to communicate with your friends, family, or coworkers why it's important for you to take breaks and how they help you to keep going. Having support from those around you will help you to avoid overactivity.

4. Track Your Fatigue.

Taking time to study your body for patterns of fatigue can help you to identify, treat, and prevent fatigue. It will also help you to know the difference between your normal fatigue levels and sudden, intense fatigue that may require prompt medical care.

One way to track your fatigue is to use the fatigue severity scale (FSS). The FSS is a nine-question survey that can help you quantify your fatigue levels over time. It's a useful tool for tracking the impact of fatigue as well as your progress.

5. Learn Coping Methods.

Learning how to cope when fatigue is unavoidable, such as during a lupus flare, is crucial.

Accepting that fatigue is part of having lupus can help you to move forward and make any lifestyle changes that are necessary. It's also important to learn not to blame yourself for fatigue that is beyond your control.

If coping with lupus fatigue seems insurmountable, you may want to talk to a therapist.

This will likely be an ongoing struggle and therapy can help – especially if one of your fatigue symptoms is a lack of motivation or feeling like giving up. Therapy will equip you to handle fatigue and your feelings concerning it in a healthy way.

Moving Forward with Lupus Fatigue

Not having control over your lupus fatigue is frustrating – but it doesn't have to stay that way. Continue to be as open as you can about your fatigue and the way it impacts you.

Stay vigilant in monitoring the symptoms of fatigue and taking steps to manage it as best you can.