Your Definitive Guide for Dealing With a Lupus Flare-Up

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Living With a Lupus Flare-Up

Elena and Anna, both lupus warriors, discuss what a lupus flare is and tips for coping with a lupus flare-up.

Lupus flares, or short periods when the disease is active, is one of the hallmarks of lupus SLE. The disease itself is highly individualized, meaning each flare will have different markers for different people.

These may include less “serious” (albeit still life-altering) lupus symptoms such as extreme fatigue, skin rashes, muscle and joint pain, joint swelling, mouth ulcers, low-grade fevers, malaise, sore throat and generally feeling unwell.

A more serious lupus flare-up can mean needing to be hospitalized for long periods of time, as round-the-clock supervision may be required. During more life-threatening flares, lupus may move on from attacking your joints and skin to attacking vital organs.

What Is a Lupus Flare?

Flares can be mild, moderate or severe. There are many interpretations of how a lupus flare should be defined:

According to an international working group convened by the Lupus Foundation of America, “a flare is a measurable increase in disease activity in one or more organ systems involving new or worse clinical signs and symptoms and/or laboratory measurements. It must be considered clinically significant by the assessor, and usually, there would be at least consideration of a change or an increase in treatment.”

The Mayo Clinic states that “signs and symptoms may come on suddenly or develop slowly, may be mild or severe, and may be temporary or permanent. Most people with lupus have mild disease characterized by episodes — called flares — when signs and symptoms get worse for a while, then improve or even disappear completely for a time.”

What Is a Lupus Flare Like?

Clinical definitions aside, the word “flare” itself – “to burn with a sudden intensity” – is more aligned with what we feel as patients. Dealing with a lupus flare can be overwhelming and painful, both physically and mentally, which can cause stress that may increase the severity/prolong the duration of symptoms.

Signs and Symptoms of a Lupus Flare

Systemic lupus erythematosus is caused by inflammation, which results from the body attacking its tissues. Symptoms caused by an increase in this inflammation can affect our ability to do daily tasks, work and may result in hospitalization or prolonged illness.

If you pay close attention to your body, you will notice that the same things start to happen just before a lupus flare.

Lupus Canada lists the following symptoms as flare indicators:

- Persistent (continuing) fatigue which is out of proportion to what you consider your normal fatigue
- Persistent weakness
- Aching all over without any apparent reason
- Persistent fever
- Persistent loss of appetite
- Involuntary weight loss
- Excessive and persistent hair loss
- Recurrent (repeated) nosebleeds
- Sores on the roof of the mouth which burn when spicy foods are eaten
- Unexplained rash anywhere on the body
- Persistent hives
- Skin ulcers
- Recurrent pain in the joints
- Swelling of one or several joints
- Persistent joint stiffness upon awakening in the morning
- Chest pain which increases when breathing in
- Unusual shortness of breath
- Coughing up blood
- Persistent, unusual headache
- Persistent nausea and vomiting
- Recurrent or persistent pain in the abdomen
- Persistent and worsening swelling of the feet and legs
- Persistent swelling of the eyelids
- Blood in the urine or the stools

Being aware of these signs and addressing them early with your rheumatologist is key to reducing an oncoming flare.

Identifying Symptom Patterns

Keeping a symptom journal can help you determine the symptom patterns that lead up to a flare. You can also look back and ask yourself questions like:

- Was there a lot of stress happening in my life?
- Were there any days where I missed my medication?
- Have I started or stopped a medication recently?
- Did I eat anything different?
- Has the weather changed suddenly?
- Was I out in the sun or under fluorescent lighting?
- Was there anything different about the environments I was in?
- How much sleep did I get?

By being your own health detective, you give yourself the opportunity to take preventative action and to inform both your doctor and your loved ones, who can also help identify factors that you may not be aware of.

Next page: Lupus warriors, Elena and Anna both share their tips and advice on how to cope with a lupus flare.

Here's What to Do When Lupus Flares Up

Job Flexibility

This is probably one of the most important aspects of living with lupus, especially if you have big flares frequently. Some people with lupus are on benefits to survive, while others can work a regular 9-5 job.

If you have frequent lupus flares and don't want to collect disability, having a flexible job is critical. Flexibility can range from working for a company as an independent contractor (such as Mary Kay or Avon), or strike out on your own and be your own boss.

If you're one of the lucky lupus patients who can still carry on with a 9-5 job, it is important that your boss and co-workers are aware of what will happen if you have a long flare. This way, your boss will be prepared and your co-workers will be ready to pick up the slack.

Making preparations for this in advance can also reduce the anger some co-workers may feel toward you for having to up and leave. Although it definitely isn't your fault, you'll still have some shade thrown your way, especially if the flare lasts over a week and makes others have to work harder.

Be Prepared

If you were a Scout, you're already familiar with their famous "be prepared" motto. While there is no way to predict a flare or be fully prepared for one, you can always have an emergency kit or a stock of things you'll need during your flares ready to go.

Personally, I'm a big fan of cold foods and popsicles during flares (I have no idea why, perhaps something to do with my rising body temperature?) and like to have cold packs on my joints. To prep for this, I'm always stocked with some popsicles and ice packs in my fridge, just in case.

Enlist Help

Isn't that what friends are for? Don't be afraid to ask a good friend if he or she can come over and help you cook a meal, go shopping or even do some tasks around the house like bathing the dog or changing your sheets.

When you're really sick, a lot of these things seem unimaginable, but with a friend or family member helping, you can really get stuff done.

You may even want to make it known to a local place of worship, or your own (if you have one), that you have lupus. Often, they have teams of volunteers that help aged members of their community, and even if you aren't aged, you can definitely benefit from their help.

Even if you have friends and family helping you, allowing a volunteer to come over to help with a meal or wash your clothes can take a huge load off of those who are caring for you in addition to living their own lives. It might feel weird at first, especially if you are young, but that's what the volunteers are there for — and they will be happy to help!

Be Gentle With Yourself

This is one I struggle with a lot. As a naturally ambitious person, anytime I get a burst of energy during a flare, I'm ready to go out and conquer everything I've fallen behind on. Try to resist that temptation, as it will make you even more tired or ill in the long run.

Instead of setting goals like finishing a big project when you have energy, set smaller, attainable ones. Walk the dog for 10 minutes, load the dishwasher, work on a small section of your project or dust the living room.

These small steps will help you feel more accomplished (especially if you feel restless during a flare for being

unproductive) without pushing you overboard. If you feel you can do more, increase your activity little by little.

Remember, if you become the Tasmanian Devil when you have a burst of energy, you will likely pay for it later. Be reasonable and gentle.

Next page: more great tips for getting through a lupus flare-up.

Entertain Yourself

Sometimes when you're having a big flare, it can be difficult to concentrate on school or office work that you've taken home. However, it is important to keep your spirits up as you can be at a greater risk of becoming depressed when you're in a flare. Because of this, it is important to keep your mind engaged, even if it isn't on something important.

Take this opportunity to catch up on your favorite TV shows or read that book everyone has been talking about. If you're in a really bad flare, it may even take a lot out of you just to do that, but it will lift your spirits in the long run and give you something to look forward to each day.

However, if you're feeling up to it, invite a friend or family member around just to watch movies with you or catch up on their lives. If you're living with a partner or children, make sure you actively take an interest in what they have done that day.

It will help get your mind off of your lupus, even if it just for a few moments, and help them understand that even if you are sick, you still care deeply about them and their daily lives.

Create a Hospital Care Package

Although similar to stocking up on items in anticipating a flare, a hospital care package is for when you're having in-patient treatment. You can create a package for yourself long before you're ever ill by assembling some of your favorite foods, books and DVDs you've been meaning to watch into a bag or box to take with you or have someone bring to you.

You may even want to include a pillow or blanket from home, especially if you think the stay is going to be a long one. The hospital can be a very monotonous place, and the food is never anything to write home about, so extra treats and activities can keep you feeling a little bit better.

Eat Healthy

Eating healthy is tough for most people and it can present a greater challenge when you're having a flare. If you live alone or are the sole caretaker of a family, it can be really tempting to reach for whatever item is easiest to consume in the moment, which is often not the healthiest option.

Try ordering ready-made meals from a Meals on Wheels type program or ordering groceries online to be delivered straight to your door. You can even look up recipes that are extremely easy and healthy — and may take just minutes to make.

If all else fails, there are healthy-ish frozen meal options that are a lot better than take-out or that fifth bowl of cereal. Proper nutrition will help you heal from the inside out.

The Bottom Line...

Lupus flares can affect any part of the body and can range from just experiencing fatigue to organ damage. Sometimes, no matter what we do, a flare will still happen, but if we try to focus on daily awareness, we can try to

lessen the occurrence of severe lupus flares.

Checking in with yourself every day is a great first step in getting a handle on how to manage your flares. Here are a few things you can start reminding yourself daily:

- Remember that mental and the physical is connected. Ensure that you are giving yourself enough rest, both in mind and body.
- Ask yourself what is causing stress in your life. Are there people and/or things that are negatively affecting your health that you can cut out of your life?
- Are you feeling depressed and isolated? Find a way to talk about how you are feeling - seek out a counselor and/ or connect with other people with lupus online or at your local lupus support group.
- If you are photosensitive, limit your time in the sun or under fluorescent lights.
- Your kitchen cupboard can also be your medicine cabinet. Stock it with nourishing food that will give your body the strength it needs to keep your lupus activity low.
- Stretch and move as much as you can.
- Communicate with your rheumatologist as soon as you feel the signs of an oncoming flare. Take your medications as prescribed and ensure that if you are using natural/ alternative medicine, both practitioners are aware of what the other is prescribing.