



# Understanding Lupus

## How Lupus May Affect My Body

When you receive a diagnosis of a chronic illness such as lupus, many things about your life will change. What you may notice first are the physical changes caused by lupus, as common symptoms like extreme fatigue, aching joints, skin rashes, hair loss, and/or pain all take their toll. You may begin to question your physical ability to keep your job, finish school, be an effective parent, or provide for your family.

Remember that one of the most important tools you have is yourself! Your own awareness is the key to successfully managing lupus. You will want to be aware of your particular symptoms and any changes in your health that could mean new symptoms: what you can do to help prevent flares, and how to know if a flare is starting; and how to identify and control the sources of tension and stress in your life that often go along with chronic illness. We want you to know that, like many people with lupus, you can look forward to a good quality of life overall, if you:

- Follow the instructions of your physician
- Take your medicines as prescribed
- Know when to seek help for drug side effects or a new symptom that might be related to your lupus.

### What Are the Physical Impacts of Lupus?

**Exercise and movement** activities are advised for most people with lupus. Walking, swimming, bicycling and low-impact aerobics will strengthen your bones and tone your muscles without aggravating inflamed joints. Exercise will also lower your risk for developing osteoporosis. Remember to discuss any exercise plan with your doctor.

**Fatigue**, often extreme, is the main symptom of lupus for many people and it can sometimes be debilitating enough to force you to stop your normal daily activities. You will be less likely to push yourself to exhaustion if you accept some adjustments to your usual routines.

**Rest** is extremely important to people with lupus, especially during periods of increased disease activity (flares). It is recommended that you get a least seven hours of sleep a night. Also try to allow extra time in your daily schedule for rest.

**Infections** of all kinds occur more often in people with lupus. The most common infections seen with lupus involve the respiratory system (lungs and heart), the skin, and the urinary tract. You are also at an unusually high risk for developing *Candida* (yeast) infections and shingles (the same viral infection as chicken pox).

**Fever** can be a warning sign of a flare or an infection. If you have a fever of 100 degrees Fahrenheit (F) or higher, you should see your doctor right away.

**Sensitivity to ultraviolet (UV) light** affects two-thirds of people with lupus. Ultraviolet light is from sunlight or artificial inside light (fluorescent light). Whether or not you are UV-sensitive, you should limit your exposure to UV rays, especially outdoors, as excessive exposure to the sun can cause lupus to flare. Other precautions include:

- *Use plenty of sunscreen, especially on your neck, temples, and ears*
- *Make sure your sunscreen has a sun protection factor (SPF) of at least 30 that blocks both UVA and UVB rays*
- *Wear broad-brimmed hats, long-sleeved shirts and long pants, preferably made of sun protective fabric*
- *Plan your outdoor activities for early in the morning, late in the afternoon, or in the evening*
- *Place light shields over fluorescent bulbs in your office*

**Vaccines** against a variety of diseases usually do not cause problems for people with lupus. However, because your immune system may be weakened, you should always talk with your doctor before receiving any vaccine.

**Allergies and allergy treatments** generally do not cause problems for people with lupus. However, if you receive allergy shots it is possible that a lupus flare could be triggered. Therefore it is best to discuss allergy treatment with both your doctor and allergist.

**Pain** is common for most people with lupus, especially joint or muscle pain or headaches. However, the types of pain associated with lupus usually go away when the inflammation and disease activity are brought under control. Chronic and often severe muscle pain is the main symptoms of a disease called fibromyalgia that affects about 30 percent of people with lupus. While pain medicines are helpful, and in many instances necessary, other approaches to pain relief are available:

- Heat and/or cold packs
- Behavioral techniques such as progressive relaxation, meditation, or low-impact yoga
- Healing practices such as acupuncture, acupressure, biofeedback or chiropractic adjustments

**Depression** often accompanies lupus. There are several reasons for this. Depression can be caused by:

- *Drugs prescribed to control lupus (for example, high-dose corticosteroids)*
- *Nervous system/neurological problems unrelated to lupus*
- *The physical effects of lupus on the body*
- *Emotional and psychological stresses related to coping with a chronic illness*

**Memory loss and "lupus fog"** are familiar to many people with lupus. These feelings of confusion and loss of memory may come and go or be continuous, and can make it difficult for you to manage your usual activities. A psychologist or speech-language pathologist can help you learn to manage these symptoms.

**Diet and Nutrition** guidelines for people with lupus are not different than for anyone else: fresh fruits and vegetables, whole grains, and moderate amounts of meat, poultry, and oily fish (such as salmon, sardines, trout, and swordfish), as fish oil has been found to help reduce inflammation.

However, you may have to add or remove certain items from your diet because of the medications you are taking or because of the damage that lupus has done to certain parts of your body.

- *Omega-3 fatty acids appear to decrease the risk of coronary artery disease. Including these fatty acids in your diet is of special importance if you are a woman with lupus, as you are at a 5-10 fold higher risk for heart disease than the general population*
- *Corticosteroids can elevate blood pressure and cholesterol and lipid levels. If you are taking steroids, you should limit your intake of fat and salt as they can also contribute to these conditions*
- *Alcohol can lower the effectiveness of some drugs used to treat lupus*
- *Salty and sodium-containing foods add to fluid retention that causes swelling (edema)*
- *Alfalfa tablets have been associated with reports of a lupus-like syndrome or lupus flares*

Before you add herbs, dietary supplements, or vitamins to your diet, discuss this with your doctor, as these products may interact with drugs used to treat lupus. Dietary supplements should never be used to replace medicines prescribed to control lupus symptoms or medication side effects.

**Cigarette smoking** has been linked to the development of many autoimmune diseases, lupus included. Smoking can cause flares of cutaneous (skin) lupus, so try to stop smoking if you smoke.

## **Tips to Help You Manage Fatigue**

- Alternate activities with periods of rest throughout the day
- Establish good sleeping patterns
- Plan ahead
- Prepare meals in advance
- Eat a healthy diet
- Exercise regularly
- If you smoke, stop

## **To Reduce Risk of Infections**

- Avoid people with colds or contagious illness
- Wash your hands often
- Take antibiotics before surgeries, including dental work
- Watch out for any signs of pain, redness or swelling

## **Tips to Ease the Frustrations of Lupus Fog**

- Pay attention when receiving new information. Repeat it or write it down. Verify any details.
- Focus on one task at a time
- Take good care of your body; exercise, eat well, and get enough sleep
- Learn memory techniques
- Try to stay organized; use a year long calendar to keep appointments, plans, contact information and keep reminders in one place.

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