

YOUR LUPUS FLARE PLAN

This worksheet is designed for you to fill in with help from the doctor who's managing your lupus care and treatment. The term "rheumatologist" is used because rheumatologists are generally considered the experts in treating systemic lupus. However, you may be seeing a primary care provider, a dermatologist, or an immunologist.

1. **If I think I'm having a flare, will my rheumatologist want to see me immediately?**
 - *If yes, what should I tell the office appointment scheduler to make sure I'm seen as soon as possible?*

 - *What should I do if I'm told that the next appointment is several weeks away?*

2. **What's the best way for me to explain my current symptoms to my rheumatologist, or to the physician assistant (PA) or nurse practitioner (NP)?**

3. **What will my rheumatologist do to get my symptoms under control as soon as possible?** *(For example, you may be told to start taking prednisone, to increase the dose of prednisone you're already taking, or go to the doctor's office for a cortisone shot in the buttock.)*

4. Should I have blood and urine tests done during every flare?

- *If yes, what is the procedure I should follow to have the tests ordered and done quickly?*

5. How will I recognize symptoms of a lupus flare?

This is a list of common symptoms that could indicate a lupus flare. Check all that you're currently having:

- ☐ **Fatigue**
- ☐ **Joint pain**
- ☐ **Joint stiffness** upon waking
- ☐ **Hair loss**
- ☐ **Sores** in mouth or nose
- ☐ **Chest pain** that hurts upon breathing in
- ☐ **Fingers that turn blue and white when cold** (due to a circulatory condition called Raynaud's phenomenon)
- ☐ **Skin rash or sores**—several different kinds of rash can occur so see a dermatologist who is familiar with lupus for any new rash
- ☐ **Fever** (*Note: if you have fever see a doctor immediately to find out whether the fever is due to an infection or due to lupus. You can choose any one of these doctors: primary care provider, rheumatologist, urgent care center, emergency room.*)

6. The symptoms you had when you were first diagnosed with systemic lupus will often repeat themselves during lupus flares. List symptoms you had when you were diagnosed:

7. **Health problems or symptoms that occurred after your diagnosis of lupus was made also may recur during lupus flares.** List recurring problems and symptoms:
8. **A symptom you've never had before might mean a lupus flare is underway.**
A new symptom also could be due to something else (for example, a medication side effect or a viral illness). Write your new symptoms here:
9. **There are certain flare triggers that are commonly experienced by people with lupus.** Check all that you've experienced in the past two weeks:
- ☐ **Ultraviolet (UV) light exposure**
(sunlight, snow, around water, stage lights, halogen lights, black lights, tanning beds, nail curing lamps, fluorescent lights, bactericidal lamps, arc lamps, mercury lamps, metal halide lamps, phototherapy lamps, welding equipment and plasma torches, counterfeit currency detectors, dental and printing polymerizing equipment)—Stay strict about UV protection. Find out more at resources.lupus.org and in books about lupus.
 - ☐ **Cigarette smoke** (to include secondhand smoke)
Avoid places where even second hand smoke is present. Find help quitting at smokefree.gov or call 1-800-QUIT-NOW.

- ☐ **Sulfonamide antibiotics** such as trimethoprim-sulfamethoxazole (found in brand names Septra® and Bactrim®). Tell all health care professionals that sulfonamides are among your allergies, and always carry an up-to-date list of your medications and allergies that includes sulfonamides.
- ☐ **Echinacea herbal supplements**
This herb is marketed as an immune booster. Because lupus is caused by an overactive immune system, anything that boosts the immune system should be avoided.
- ☐ **Alfalfa sprouts & mung bean sprouts**
These contain an amino acid called L-canavanine which boosts the immune system. Make sure these aren't being added to food you eat out, and don't use them at home.
- ☐ **Stress**
We can't completely get rid of stress, but we can take action to decrease stress. Lifestyle changes can help you avoid stressful situations and decrease stress in your life. Prioritize YOU!
- ☐ **Low vitamin D**
Inflammation of lupus can be triggered if you have a low level of this vitamin in your blood. Ask your rheumatologist to check your vitamin D level regularly, and if you're told to take a vitamin D supplement, consider it as one of your most important lupus medications and take it as directed.
- ☐ **Not taking medications as prescribed**
One of the most common reasons for a lupus flare is that the person isn't taking the medications as prescribed. Your rheumatologist will consider changing your treatment if you have a flare, because it will seem that the medicines aren't working. But that might be the wrong solution. It's always better to tell your doctor that you're not taking your medicines regularly, and explain the reasons, so that together you can come up with solutions.