

## YOUR LUPUS FLARE PLAN

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This worksheet is designed for you to fill in with help from the **doctor who's managing your lupus** care and treatment. Keep the completed worksheet to use as a guide when you have a lupus flare. 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 receptionist or 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. 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?*
  - *How quickly does it take to get test results?*
  - *How do I find out the results and what they mean?*

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

If you have the onset of a new symptom or the worsening of ones you already experience regularly, then you may be having a 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
  - Numbness, tingling, burning pain (this could be a sign of a nerve problem)
  - 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.)
4. 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 (see #3 for common symptoms):

5. Lupus problems or symptoms that occurred after your diagnosis of lupus was made also may recur during lupus flares. List those newer symptoms (see #3 for common symptoms):

6. **A new 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:

7. What can I do myself at home to help with each flare problem? (such as use ice packs, heat/hot packs, cortisone creams, take a dose of steroids, take any over-the-counter pain medicines, call my doctor to see if I should get a steroid shot, etc):

8. 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](https://resources.lupus.org).
- Cigarette smoke (to include secondhand smoke)
  - Avoid places where even second hand smoke is present. Find help quitting at [smokefree.gov](https://smokefree.gov) or call 1-800-QUIT-NOW.
- Sulfa antibiotics (trimethoprim-sulfamethoxazole and Bactrim®). The proper medical term is “sulfonamides.” 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.

9. For what problems should I seek urgent medical care, such as going to my closest urgent care center or emergency room?

- Numbness on an entire half of body or face, especially if accompanied by weakness, difficulty talking, confusion, loss of coordination, vision problems (These can potentially be a sign of a stroke)
- Temperature > 100.5°F degrees, especially if accompanied by chills (Though fever can occur with lupus, infections must be diagnosed and treated quickly)
- New-onset chest pain or shortness of breath (Heart attacks and blood clots in the lungs occur at younger ages in people with lupus)
- Pain, swelling, and possible redness of the calf area (Sometimes this can indicate a blood clot)
- Weakness of an arm, leg, or side of the face (If due to a stroke, it needs to be diagnosed and treated as soon as possible)
- New-onset severe headache especially if accompanied by nausea/vomiting, fever, weakness or numbness of arm/leg/face, or if it is **"by far the worst headache I've had in my life"** (Some causes of headache need treatment as soon as possible – this includes stroke, meningitis, or bleeding in the brain)
- New-onset severe abdominal pain especially if accompanied by fever, nausea/vomiting, blood in the stool, black asphalt-like stool (Need to make sure it is not an infection, bleeding ulcer, loss of blood flow to intestines, or pancreatitis)
- Sudden onset blurred vision especially if accompanied with blindness in one eye, red eye, fever, headache (Need to make sure it is not a stroke, infection, or some other urgent cause)

#### FINAL STEP

Show your doctor the above to ask if he or she agrees or would make any changes.

Ask your doctor if there is anything else to add in light of your particular lupus problems and medications.