



## Exercise, Fatigue and Photosensitivity

Just like everyone else, people with lupus need to exercise regularly or engage in some kind of movement, and most people with lupus can take part in some form of activity. All exercise plans should be discussed with your physician or exercise specialist in order to maximize results and minimize possible harm.

Activities such as walking, swimming, bicycling, low-impact aerobics, certain types of yoga, Pilates, stretching, or using an elliptical exercise machine will strengthen your bones and tone your muscles without aggravating inflamed joints, while also helping to lower the risk for developing osteoporosis. It's also a good idea to vary the exercises, so that different muscle groups all get a regular workout.

If you are experiencing swollen joints or muscle pain, you should avoid or at least limit activities that may be demanding on joints and muscles, such as jogging, weightlifting, or high-impact aerobics.

If you find that you tire easily when you exercise, you should pace yourself. The most important thing to remember is to not give up exercising, as muscles that are not used will quickly become weak.

Regular exercise and even simple low-impact movement will:

- reduce or minimize stress
- help to keep your heart healthy
- improve muscle stiffness
- increase muscle strength
- help prevent osteoporosis
- increase your range of motion

### Fatigue

As many as 80 percent of people with lupus experience fatigue. For some people with lupus, fatigue is their main symptom and can be debilitating, even to the point of forcing them to stop working. It is unclear why extreme fatigue occurs in so many people with lupus, but disease activity, pain, age, and medicines being taken, as well as poor physical and mental health and lack of good social support, all appear to play a role.

In addition, poor coping strategies, feelings of helplessness, depression or anxiety, smoking, and lack of exercise have all been found to be related to lupus fatigue. Before the physician can conclude that fatigue is related to these factors, any "treatable" causes of fatigue (for example, anemia, kidney failure, or hypothyroidism) need to be ruled out.

Physicians experienced with lupus recognize the harmful and even destructive effects that extreme fatigue can have, and research is underway to learn more about how to treat the problem. Getting regular exercise and being part of a

The DVD cover features a yellow background with a large, stylized yellow swirl. At the bottom, there are three small figures in blue, pink, and purple. The title "The Right Moves for Lupus" is written in a blue, sans-serif font, with "A Gentle Fitness Program" in a smaller font below it. The text "The Right Moves for Lupus" is also written vertically on the left side of the cover.

**Further Viewing . . .**  
If lupus has you on the sidelines rather than in the middle of the action, this new low-impact exercise program, designed specifically for people with lupus, may be "just right" for you. Guided by a licensed A.C.E. instructor who also has lupus, [The Right Moves for Lupus Fitness Program DVD](#) offers a gentle fitness routine that you can practice in the comfort of your own home.

support group have been found to help. By making some adjustments, people with lupus-related fatigue will be less likely to push themselves to exhaustion.

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

- Alternate activities with periods of rest throughout the day.
- Establish good sleep patterns.
- Plan ahead; for example, shop for gifts throughout the year.
- Prepare meals in advance.
- Eat a healthy diet and exercise regularly.
- Stop smoking if you smoke.

### **Rest**

Getting the proper amount of rest is extremely important for people with lupus, especially during periods of disease activity (flares). Damaged and inflamed muscles and joints require rest to heal. Rest is also vital in reducing fatigue. Although everyone has his or her own particular sleep requirements, at least seven hours of sleep a night is recommended for people with lupus. It is also important to be aware that too much sleep isn't healthy, either. Spending all day in bed may make muscles weaker, which can contribute to feelings of fatigue. Napping during the day may be helpful and even necessary when lupus activity is causing a flare. Try to allow extra time in your daily schedule for rest.

### **Sensitivity to Light**

Two-thirds of people with lupus have increased sensitivity to ultraviolet rays, either from sunlight or from artificial inside light, such as fluorescent light, or both. Whether or not you are photosensitive you should limit your exposure to ultraviolet rays, especially outdoors, as excessive exposure to the sun can cause lupus to flare.

Everyone with lupus who is going to be outside for more than a few minutes should use a sunscreen with a sun protection factor (SPF) of at least 30 that blocks both ultraviolet A (UVA) and ultraviolet B (UVB) rays. Sunscreen should be applied thoroughly, especially to your neck, temples, and ears -- areas that are often affected by lupus skin problems.

Wearing proper clothing helps, too, such as broad-brimmed hats, long-sleeved shirts, and long pants. If you spend a large amount of time outdoors, you should wear clothing made of sun-protective fabric. Sunbrellas, which are umbrellas made with sun-protective fabric, are also available.

Since UVB rays are most intense between the hours of 10 a.m. and 4 p.m., you should try to plan your outdoor activities for early in the morning, late in the afternoon, or in the evening. Also be aware that UV rays are stronger at higher altitudes and when they are reflected by snow or water.

Ultraviolet rays are also given off by indoor fluorescent lighting commonly found in offices and stores. Light shields that cover fluorescent bulbs can be ordered from several different manufacturers. If you are affected by light sensitivity, look for light shields that have nanometer readings of 380 to 400. This ensures complete filtering of UVB and UVC (especially damaging to exposed skin cells), and almost all UVA. If you are extremely sensitive to light, you may want to consider wearing a broad-brimmed hat when visiting brightly lit stores or other public places.

### **Related Information**

[Staying Active Despite Lupus](#)

May 2010 15 Questions with Sean Hanrahan

[Dr. Barbara Segal talks about what is abnormal fatigue, and what can be done about it](#)  
April 2010 LFA blog entry

[Into the Light: How to Deal with Sun Sensitivity](#)  
Summer 2008 issue of Lupus Now magazine

[Sun Safety Myths](#)  
Summer 2005 issue of Lupus Now magazine

[UV Light & Lupus](#)  
July 2008 webchat transcript with Dr. Victoria Werth

[New Year's Resolutions & Lupus: What Are The Best Ways To Stay Healthy & Exercise](#)  
January 2008 webchat transcript with Dr. Tammy Utset

## **Frequently Asked Questions**

### **I was diagnosed with systemic lupus. Are there any do's or don'ts with regards to exercise?**

Having lupus can make the demands of everyday life challenging. When lupus is active, symptoms of joint stiffness, pain, extreme fatigue, confusion, or depression can make even simple tasks difficult, and sometimes impossible. And, because you may not have any visible signs of disease, the people around you may not realize how much discomfort and pain you are experiencing, or they may not know that you are sick at all.

You should not ignore the limitations that come with this disease. But there are steps you can take to stay active with work, relationships, and events that enrich your life. These actions and strategies can lighten the burden of your illness and allow you to lead a life of accomplishment and achievement.

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**Are there any restrictions on physical activity for lupus patients? Are there any exercises that have been particularly beneficial for those diagnosed with lupus?**

Exercise is to be encouraged in people with lupus, particularly during a time when lupus symptoms are not pronounced. Walking, swimming, bicycling and other aerobic activities are good. Light weights are also good along with resistance. But keep in mind that they will want to exercise in moderation and avoid exercising to the point of exhaustion. Regular exercise will help them function better and improve fatigue and your sense of well being. The Lupus Foundation of America in Piedmont, North Carolina has put together a great DVD called The Right Moves for Lupus. It costs about \$15 and can be purchased through their website.

**I have SLE and have been considering light therapy for Seasonal Affective Disorder (SAD). I was wondering if the lights used for such therapy can trigger flare-ups? (due to UV exposure or any other concerns)**

The majority of lupus patients are sensitive to ultraviolet light. This sensitivity is typically from ultraviolet B (UV-B) but can also be from ultra-violet A (UV-A) in some individuals. The sun and fluorescent lights are constantly exposing us to ultraviolet light. Therefore, it is strongly recommended to lupus patients to avoid ultraviolet light exposure through sun protective clothing, sunscreen, sun block and avoidance. Therefore, when asked by a lupus patient who is considering light therapy for seasonal affective disorder (SAD), we have to ask if the benefit outweighs the risk. There is a potential risk of a lupus flare for the patient using light therapy. However, if the patient demonstrates no photosensitivity and the SAD is so severe that various therapies are not working, it could be considered. I would strongly suggest that a lupus patient considering light therapy for SAD talk with their rheumatologist to weigh the potential risk and benefit.

Photosensitivity -- Photosensitivity refers to the development of a rash after exposure to UV-B radiation found in sunlight or fluorescent light. It occurs in 60 to 100 percent of patients with SLE. Some patients are also sensitive to UV-A (as from a photocopier), and may even be sensitive to the visible light spectrum. Glass protects individuals sensitive to UV-B, but only partially protects those sensitive to UV-A. Blonde, blue eyed, fair skinned individuals are much more photosensitive than brunettes or individuals with pigmented skin; the incidence is also greater in those with anti-Ro antibodies.

More than one-half of lupus patients are sensitive to light. This sensitivity is typically to ultra-violet B (UV-B) but can include ultra-violet A (UV-A) in some individuals.

**I'm concerned about new reports encouraging people to change all incandescent light bulbs to fluorescent bulbs. Don't fluorescent lights produce ultraviolet rays that are harmful for people with lupus?**

The issue of lupus photosensitivity is a complex one and one of the least scientifically studied clinical aspects of cutaneous and systemic lupus. It is my opinion that if a standard fluorescent tube lighting source is shielded by a standard acrylic plastic diffuser, there's virtually not significant risk for people with systemic lupus. These plastic diffusers are available from a variety of companies. However, if a person with lupus is exposed to unshielded fluorescent lighting at close distances for prolonged periods of time, then the cumulative exposure to UVB and UVA could be a problem. You may contact Lupus Now Editor Jenny Palter at [palter@lupus.org](mailto:palter@lupus.org) for a copy of my 1993 publication (a letter to the Editor to the journal Arthritis and Rheumatism) that addresses the issue of ultraviolet light leakage from fluorescent lighting tubes as a risk for lupus photosensitivity.

**I'm going to a three day concert this summer in TN. How can I protect myself from the sun when shade really isn't an option?**

You are correct that you need to protect yourself from excessive exposure to the sun. First, you need to get a wide brimmed hat (I know it is not the best look, but neither is the skin rash). If possible, try to have an umbrella to shade you. You need to use sunscreen on any and all exposed areas and reapply as needed. There is also a company called

Coolibar. They offer a unique range of sun protective clothing, sun hats, sun protective swimwear and multi-spectrum sunscreens. You may want to check out their website. Check with your physician before the concert to make sure that everything is going well with you ... and for any last minute advice.