

Understanding LUPUS

If you do need to stop working, your employer may offer short-term and/or long-term disability benefits. Also be sure to find out about services available through local, state, and

federal government organizations, such as the Social Security Disability Insurance, and nonprofit agencies. The LFA can provide you with resources and additional information.

Live Your Best Life With Lupus

- ✦ Learn all you can about lupus.
- ✦ Be patient as you explain to family, friends, and co-workers how lupus affects you.
- ✦ Talk to your doctor if you have questions about lupus, your medications and their side effects, and lifestyle changes that will help you.
- ✦ Take your medications as prescribed, and tell your doctor about any side effects.
- ✦ Try to do something physically active each day.
- ✦ Don't feel guilty about needing rest and a stress-free environment.
- ✦ Don't be afraid to ask for help.
- ✦ Focus on what you can do, not what you cannot do.
- ✦ If lupus symptoms prevent you from your usual activities, find new ways to relax, exercise, spend time with loved ones, and enjoy life.
- ✦ If you think you are experiencing symptoms of clinical depression, talk to your doctor.
- ✦ Connect with other men who understand what you're going through.

Emotional Well-being

The unpredictability of lupus, with the many symptoms that come and go, the unexpected flares and remissions, and the uncertainty of what each day will bring, can contribute to feelings of unhappiness, frustration, or anger. Usually these feelings subside with time as you learn to adjust to having lupus.

In some cases, though, these negative feelings can be overwhelming and long-lasting. This can be an indication of clinical depression. Symptoms of clinical

depression include:

- ✦ *feelings of helplessness or hopelessness*
- ✦ *inability to concentrate*
- ✦ *problems with memory and recalling information*

- ✦ *indecisiveness*
- ✦ *thoughts of suicide*

Although clinical depression can occur as a symptom of having lupus, it is a separate illness that should be taken seriously.

Clinical depression generally improves with a combination of psychotherapy and medication. You should not feel embarrassed or hesitant about asking your doctor for a referral to a psychiatrist, therapist, or psychologist. Psychotherapy, under the guidance of a trained professional, can help you learn to understand your feelings, your illness, and your relationships, and can help you cope more effectively with stress. Ask for a recommendation for a trained therapist who can help you work through the psychological aspects of living with a chronic and unpredictable disease like lupus. For additional information, please refer to the LFA Patient Education Series fact sheet, *Lupus and Clinical Depression*. You can also find additional information on LFA's website, lupus.org

Living with Lupus

We encourage you to reach out to other men who, like you, are learning to live and cope with lupus. You can connect with other men with lupus on the LFA online message boards at lupus.org; in the "Ask Dr. Paul" column in the LFA's magazine, *Lupus Now*[®]; and through the LFA national network of chapters and support groups, at lupus.org/chapters.

You can find additional lupus information in the LFA Patient Education Series, *Understanding Lupus*, *Living with Lupus*, *Coping with Lupus*, and the fact sheets on the various organ systems.

The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable and devastating diseases, while giving caring support to those who suffer from its brutal impact. Through a comprehensive program of research, education and advocacy, we lead the fight to improve the quality of life for all people affected by lupus. Contact the LFA or a chapter that serves your area to find out how you can become involved in our mission and how we can help you. For more information call 1-800-558-0121 or visit us online at www.lupus.org.

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Lupus and Men

In order to live your best life with lupus, you will want to know as much as you can about the disease, how it may affect you, and how to manage the symptoms. This fact sheet offers information on lupus, as well as coping strategies and suggestions to help you. The LFA has additional information and resources on every aspect of lupus at lupus.org. Also, the archive section of the *Lupus Now*[®] magazine website, at lupusnow.org, includes an advice column for men, called “Ask Dr. Paul,” as well as articles on lupus from the men’s perspective.

Yes, Men Can Have Lupus!

The first thing you may discover is that many people are surprised when they learn you have lupus. A lot of misinformation exists about lupus—including the incorrect belief that lupus only occurs in women. Lupus can develop in anyone, male or female, of any age, including children, teenagers, and adults. We do not yet fully understand what causes lupus, but we do know that having lupus does not diminish your levels of testosterone, or affect your ability to perform sexually, or to become a father. However, medication side effects can play a role in these issues.

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The second discovery you may make is that it can be difficult to find information on lupus in men. It is true that many sources of lupus information will seem to be addressed to women. This is because the disease is more often seen in females than males (approximately nine of every 10 cases of lupus will be in females of child-bearing age). However, the disease is the same—and is treated similarly—in both sexes. The Internet can be a great source of information on the disease, its symptoms, treatments, and prognosis, but be sure you are using reputable sources, such as government sites (.gov), educational institution sites (.edu), and of course the LFA's website, lupus.org. For reliable books about lupus, visit the LFA's online Lupus Shop, www.shoplupus.org.

Understanding Lupus

It is not easy to understand a disease with symptoms that are so varied and often invisible. Here are some facts about lupus that may help you explain the disease to family, friends, and co-workers:

- ✧ *Lupus is an autoimmune disease that causes inflammation and tissue damage to the body.*
- ✧ *Lupus is a chronic disease, which means that you will have lupus for the rest of your life.*

- ✧ *Lupus is not contagious. You cannot “catch” it from someone or “give” it to someone.*
- ✧ *Lupus is not like or related to cancer.*
- ✧ *Lupus is not like or related to HIV or AIDS.*
- ✧ *Lupus can cause a mild skin rash or achy joints, or can damage organs inside the body.*
- ✧ *Lupus is unpredictable. Symptoms can appear, disappear, and change.*
- ✧ *Lupus can range from mild to life-threatening and should always be treated by a doctor.*
- ✧ *With good medical care, most people with non-organ-threatening lupus can lead a full life.*

Causes of Lupus

No one knows what causes lupus. Researchers believe that lupus is caused by a combination of genetics (heredity), hormones, and environmental factors that act to “trigger” the illness or bring on a flare of disease activity. Some known triggers are:

- ✧ *ultraviolet (UV) light from the sun, tanning beds, or fluorescent lights*
- ✧ *drugs that make a person more sensitive to the sun; for example, sulfa drugs such as Bactrim® and Septra® (trimethoprim-sulfamethoxazole) and tetracycline drugs such as minocycline (Minocin®)*
- ✧ *penicillin or other antibiotic drugs, such as amoxicillin (Amoxil®), ampicillin (Ampicillin Sodium ADD-Vantage®), and cloxacillin (Cloxapen®)*
- ✧ *viral or bacterial infections*
- ✧ *physical stress, such as injury, illness, or surgery*
- ✧ *emotional stress, such as divorce, illness, or death in the family*
- ✧ *vaccinations containing live virus*

Treating Lupus

Most people with lupus will be treated by a rheumatologist, who is a specialist in diseases of the immune system, as well as joint and muscle complications. The rashes or lesions from cutaneous (skin) lupus may require treatment from a dermatologist. However, other specialists may be



necessary, such as: a nephrologist, who specializes in kidney problems, a cardiologist, who specializes in heart problems, or a neurologist, who specializes in problems that affect the brain and nervous system.

Family Life

In time you will learn to adapt to the new life you have with lupus, but those around you also will need to adjust to your new way of living. You can help them in many ways. First and foremost is good communication. When you share information about the illness, how it affects you, and its treatment, you will help to lessen everyone's fears and concerns. Also helpful is the knowledge that the course of lupus is unpredictable, so there may be times when you feel well enough to take part in planned activities and other times when you have to cancel those plans. Try to pace yourself with a sensible schedule that includes time for being active every day, as much as you are able, and time for extra rest when you need it. Most of all, make time for what really matters, say "no" to what isn't as important, and leave the rest for tomorrow—or the next day.

Build a Support Network

A network of friends, co-workers, and neighbors can give the same kind of valuable support as family members. But in order to give support, these acquaintances also need to have some understanding of the nature of lupus. Let them know what to expect when the disease is active, don't be hesitant about asking for help, and do accept help that is offered! At times you may find that your friends are not sure how to treat you. This is usually because they don't know very much about lupus or how it affects you. Do your best to educate them, and be patient. Accept that some people are not comfortable when faced with illness in others.

Intimacy Between Partners

Sexual interest may be affected by the symptoms of lupus, by the medications used to treat lupus, and by clinical depression that can

occur in people with chronic illness. But it is possible to keep intimacy and tenderness between partners. Good communication with your partner can help you deal with negative self-perceptions or feelings of rejection. Couples may also wish to work with a licensed therapist for additional guidance.

Fertility Concerns

Men with lupus are not less masculine, and do not experience impotence (erectile dysfunction) more than those without lupus. However, there is a connection between impotence or infertility and medications—in particular, cyclophosphamide (Cytoxan®). Before you begin taking any medications, talk to your doctor or pharmacist about how they may affect you.

Lupus in the Workplace

The workplace is another area that may need special consideration when you have been diagnosed with lupus. Many people with lupus are able to continue to work, although they may need to make changes in their work environment. Flexible work hours, job-sharing, avoiding the sun—especially between 10 a.m. and 4 p.m.—and telecommuting may help you to keep working.

You may be concerned that telling your employer about your lupus diagnosis might call into question your effectiveness in your job, or might cause your employer to think you are no longer a desirable employee. In confronting these work-related issues, you should refer to the Americans with Disabilities Act (ADA), which says an employer may not discriminate against a qualified individual with a disability or chronic illness.

If the physical and/or mental demands of your job become overwhelming or are causing your lupus symptoms to become active, you might benefit from changing to another job, or switching to part-time hours. In some cases, your doctor may feel that the best choice for your health is that you stop working altogether.

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