

Pregnancy

Seventy percent of lupus pregnancies are successful. People with lupus are normally fertile but often don't conceive if there is inflammation. Kidney failure, severe hypertension, and myocarditis are strong reasons for not becoming pregnant. Women with antiphospholipid antibodies who have previously miscarried may be given aspirin or Heparin during pregnancy. Women with anti-Ro/SS-A antibody should be advised of a 5-15 percent risk of their child being born with a transient lupus rash, and about a one percent chance of a more serious heart problem that can be detected with fetal ultrasounds at weeks 18 and 24. It is especially important to find out what medicines are safe to take during pregnancy. Although most lupus activity decreases during the second trimester, mild post-delivery flares can occur.

Take Care of Fevers or Infections Promptly

Call a doctor if your temperature is over 99.6°F. It could be a lupus flare or an infection. Be careful before taking sulfa-based antibiotics, which are usually prescribed for bladder and female-related infections. They tend to make people with lupus more sun-sensitive and can lower blood counts. Up to 30 percent of people with lupus are allergic to sulfa drugs.

Ask About Cognitive Behavioral Therapy

Some people with lupus will have difficulty remembering names and dates, balancing their checkbook, and processing thoughts. Termed cognitive dysfunction, cognitive impairment, or "lupus fog," this is a reflection of vascular spasm which can reduce the amount of oxygen getting to the brain. These symptoms come and go. Cognitive behavioral therapy may involve psychologists, speech therapists, and physical therapists who can help people cope with this by initiating biofeedback and specific strategies to improve concentration.

Discuss Alternative Therapies with Your Lupus Specialist

Biofeedback, relaxation techniques, and meditation are usually helpful. Certain herbs, vitamins, special diets, forms of massage, and chiropractic or osteopathic manipulation may help, harm, or have no effect on the disease. There is no place for colonics in people with lupus, as bowel perforations have occurred. Consult with your lupus specialist before spending a lot of time, money, and energy on unproven alternative medical approaches.

Don't Be Afraid to Ask for Help

The Lupus Foundation of America (LFA) offers information about doctor referrals, lupus books, patient information brochures, and newsletters. Most local chapters have support or discussion groups, sponsor guest speakers, and maintain a list of mental health professionals who can assist you. The SLESH (systemic lupus erythematosus self help) course sponsored jointly by the LFA and the Arthritis Foundation may also assist you in sharpening your coping strategies to help you live better with lupus.

The Lupus Foundation of America

The Lupus Foundation of America (LFA) was established in 1977 to educate and support those affected by lupus and find the cure. The LFA supports research, education, awareness, patient services, and advocacy.

The Lupus Foundation of America is the only nationwide organization exclusively serving individuals, families and friends affected by lupus. The LFA has hundreds of local chapters and support groups throughout the United States, as well as international affiliates around the world.

The LFA is a grassroots, volunteer-driven organization. Contact the LFA or the chapter that serves your area to find out how you can become involved in our mission.

For information about lupus or to locate the chapter nearest you, visit our website at www.lupus.org or call toll-free 1-800-558-0121.

Become a Lupus E-Advocate and help pass federal legislation that will benefit people with lupus. Send an e-mail message to advocacy@lupus.org and enter SUBSCRIBE in the subject line. You'll receive periodic advocacy updates and other breaking lupus news and information.



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Lupus: Basics for Better Living

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Foundation of America, Inc.

Although there is no "cure" for lupus, you can make lifestyle adjustments that help fight the disease and give you an improved sense of well-being. Many of these don't require spending money or seeing a health care provider. After all, we've known for years that the "head bone" is connected to the "lupus bone," and that stress and difficulty in coping are associated more with disease flares. In this pamphlet, we offer you ways to do things to help yourself.

Make Sure It's Really Lupus

Even though 10 million Americans have a positive antinuclear antibody (ANA), only one million have systemic lupus erythematosus (SLE). One survey found that only one-third of people who had been told they have lupus actually fulfill the American College of Rheumatology (ACR) definition for the disorder. Positive ANAs, fatigue, aching and other lupus-related symptoms can be found among individuals with thyroid disease, cancer, recent infections (especially viral), fibromyalgia, rheumatoid arthritis, pregnancy, and multiple sclerosis, among others. Has your diagnosis of lupus, given by your primary care physician, been confirmed by a Board Certified Rheumatologist or other recognized lupus specialist? If your disease has been confirmed as being lupus, read on.

What Kind of Lupus Do You Have?

Chronic cutaneous lupus is a skin disorder. The skin precautions discussed later in the brochure are important, but fewer than 20 percent of these individuals will ever develop systemic lupus, and most generally feel well. **Drug induced lupus erythematosus** can be brought on by over 70 different prescription drugs, but disappears within days to months of the drug's discontinuation. Some people fulfill criteria for systemic lupus, but also meet the definitions for rheumatoid arthritis, scleroderma, or polymyositis. These individuals have **mixed connective tissue disease** if anti-RNP is present. The information in this pamphlet applies to these patients, but they should also find out about the associated disorder. Seventy percent of people with lupus have **systemic lupus erythematosus**, or SLE. About half have organ-threatening disease (defined as heart, lung, kidney, liver, or serious blood involvement) and half have non organ-threatening disease (e.g., rash, fatigue, fever, aching, and/or pain on taking a deep breath, but normal urinalysis, EKG, and chest x-ray). Finally, many people with early lupus-like symptoms don't meet the ACR criteria but have an **undifferentiated connective tissue disease** process. Studies have shown that, while many of these people will develop SLE over time, others will develop rheumatoid arthritis, have mild persistent symptoms, or find that the symptoms just disappear.

How Can You Help Yourself?

PHYSICAL MEASURES

Be Careful in the Sun

Two-thirds of the people with lupus have problems with ultraviolet A and B (UVA and UVB) radiation from the sun. If you are going to be outside for more than five minutes, use a sunscreen. Choose a preparation that has a sun protection factor (SPF) of at least 15 and blocks both UVA and UVB rays. UVB sun exposure is greatest at midday, so do your outdoor activities early in the morning, late in the afternoon, or in the evening, and wear protective clothing. Ultraviolet radiation is also greater at higher altitudes. The UV exposure at sea level in one hour is the same as the exposure in five minutes at an altitude of one mile, like in Denver, Mexico City, or on a ski slope.

Diet

People with lupus should eat a nutritious, well-balanced diet. There are some suggestions that fish, or specifically eicosapentanoic acid in fish oil, might have modest anti-inflammatory properties. The results of double-blind controlled studies showed that eating the equivalent of two fish meals a week clearly helps rheumatoid arthritis pain. An amino acid, L-canavanine, is found in alfalfa sprouts and can activate the immune system and increase inflammation in people with lupus. Other foods in the legume family have only a fraction of the L-canavanine that sprouts do and are safe to eat. People with lupus taking corticosteroids should limit their sugar, fat, and salt intake.

When You Hurt, Apply Heat

Moist heat soothes painful joints much better than dry heat. Soaking in a hot tub, sauna, jacuzzi or taking a hot shower is useful. Ice or cold applications are advisable only for acute strains or injuries during the first 36 hours after injury.

General Conditioning Exercises

Activities such as walking, swimming, low impact aerobics, or bicycling help prevent muscle atrophy, or wasting, and lower your risk for developing thin bones (osteoporosis). On the other hand, if your joints are swollen or you have fibromyalgia, be careful before doing a lot of weight lifting, rowing, high impact aerobics, or engaging in tennis, bowling or golf. If exercise tires you easily, pace yourself with frequent rest periods.

If there is synovitis (inflammation of joint membranes) or acute joint inflammation, the joint should be put through its range of motion to exercise it; isometric strengthening such as with Pilates or stretching are the best exercises for this.

Consult a Rehabilitation Specialist

Physical therapists assist people with muscle strengthening programs, exercises, and gait training. Occupational therapists

help to lower stresses to painful areas, evaluate workstations (especially those with a computer) to ensure proper body mechanics, and recommend a variety of assistive devices. Vocational rehabilitation counselors may train you for a job that involves less sun exposure or less emphasis on repetitive motions involving an inflamed hand or other parts of the body.

Don't Smoke

Tobacco smoke contains an aromatic amine, hydrazine, which can cause flares of cutaneous lupus. Smoking also worsens the symptoms of Raynaud's phenomenon and impairs circulation to a greater extent in people with lupus than in otherwise healthy people. In addition, recent research suggests that antimalarial therapies, such as Plaquenil, are less effective in smokers.

DEVELOP PREVENTIVE COPING STRATEGIES

Don't Let the Weather Psych You Out

People with lupus are sensitive to changes in barometric pressure. If the weather goes from hot to cold or wet to dry, you might be a bit achier. This will pass. The best climate for people with lupus is one with the fewest changes in the barometer.

Control Fatigue

Fatigue in lupus is caused by inflammation, anemia, and chemicals known as cytokines, among other sources. Pace yourself. Have periods of activity alternating with periods of rest. People who stay in bed all day only become weaker; on the other hand, supermoms and dads who put in a 20-hour day without a break can cause their disease to flare.

Develop a Good Doctor-Patient Relationship

It's important that your physician is accessible and will take the time to discuss disease management issues. For instance, will your physician tell you if pregnancy is advisable or not, whether or not to take birth control pills, which antibiotics you need to be careful with? Will your physician write a jury duty letter or fill out a disability form if needed? In return, it's vital to prepare for and keep your appointments, be honest with your physician, take medication as prescribed, and respect his/her time. It would also be helpful to plan ahead and decide what to do in case of an emergency.

Genetic and Prognosis Counseling

Women with lupus have a 10 percent chance of having a daughter with lupus, a 2 percent chance of having a son with the disease, and a 50 percent chance that their children will have a positive ANA. Twenty percent of patients with non organ-threatening SLE will develop organ-threatening disease, usually within the first five years after diagnosis. Patients with non organ-threatening disease have a near normal life expectancy if antiphospholipid antibodies are not present. The rate of survival for people with organ-threatening lupus is 75 percent at 15 years.