

Lupus Foundation of America, Inc.

How Lupus May Affect My Life

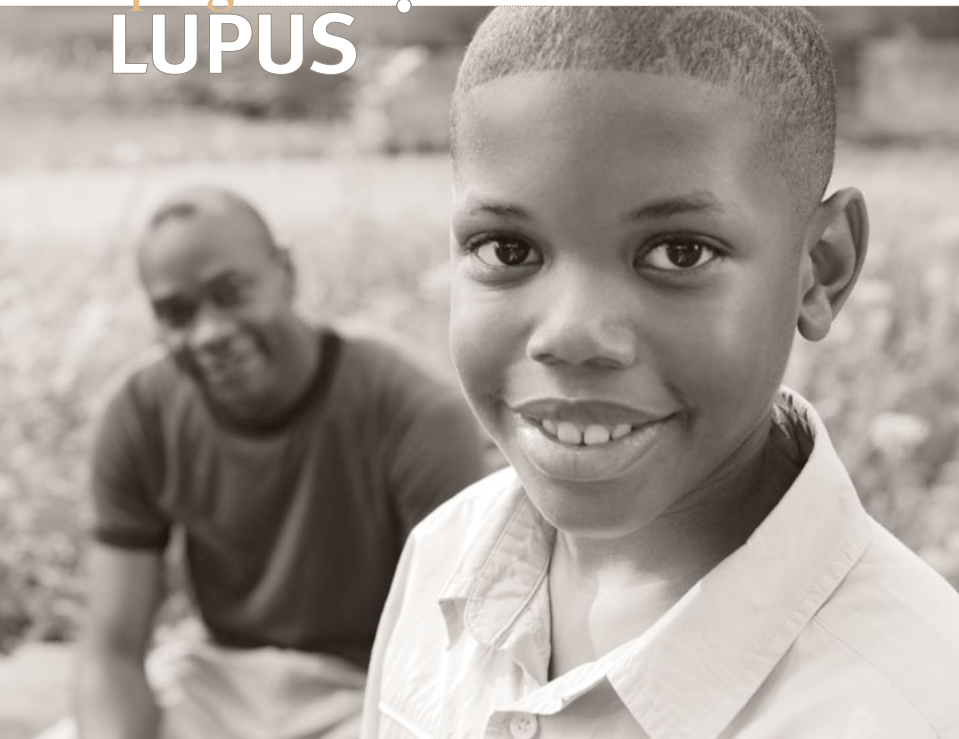
Having lupus can make the demands of everyday life challenging. When lupus is active, symptoms of joint stiffness, pain, extreme fatigue, confusion, or depression can make even simple tasks difficult and sometimes impossible. And, because you may not have any visible signs of disease, the people around 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.

Explaining Lupus

It is not easy to describe a disease with symptoms that are so varied and yet often not visible, with effects ranging from manageable to life-threatening. Lupus is also a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better). Explaining lupus is made even more difficult because the causes of lupus are unknown.

Coping With
LUPUS



Children with lupus should be encouraged to have and strive for goals and dreams.

It is important to let children know that lupus does not have to control all aspects of their lives.

Perhaps a good way to start to explain lupus is to make clear what lupus *is not*.

- ❖ *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 (Human Immune Deficiency Virus) or AIDS (Acquired Immune Deficiency Syndrome).*

You can then talk about what lupus *is*.

- ❖ *Lupus is an autoimmune disease in which your immune system mistakenly sees your own healthy tissues and cells as foreign.*
- ❖ *Lupus is a chronic disease. This means that anyone who develops lupus will have lupus for the rest of his or her life.*
- ❖ *Lupus has many different symptoms and affects each person differently.*
- ❖ *Lupus can cause a mild skin rash or achy joints, or can damage the kidneys, heart, lungs, brain, or other internal organs.*
- ❖ *Lupus is unpredictable. Symptoms can appear, disappear, and change. Knowing this may help other people understand your ups and downs, and also the changes that you may have to make in your life.*

Lupus and Your Family

Family life will inevitably change when a family member receives a diagnosis of lupus. Good communication will be important in making sure that home life remains as normal as possible. Sharing information about the illness, its symptoms, and its treatment can lessen everyone’s fears and concerns. Keeping a sensible schedule is another good idea. Learn to make time for what really matters, say “no” to what isn’t as important, and leave the rest for tomorrow—or the next day.

Being a parent with lupus certainly makes parenting more difficult. As a parent you should try to:

- ❖ *maintain a sensible schedule*
- ❖ *reassign household responsibilities as needed*
- ❖ *arrange for friends or outside family members to help out when possible*
- ❖ *talk to your children about lupus and the changes it may cause in your health and in the responsibilities of different family members*

If your child has lupus you will need to consider his or her emotional and physical well-being. You should become aware of the challenges your child may face, today and in the future. This will allow you both to create short- and long-term strategies. Above all your child should be encouraged to have and strive for goals and dreams. It is important to let children know that lupus does not have to control all aspects of their lives.

Planning to have children and being pregnant are two other areas of family life that demand special considerations when you have lupus. If you are being treated with cytotoxic (chemotherapy) medicines, you may want to talk to your doctor about banking your eggs or sperm. If you want to plan a pregnancy, your team of doctors should include a rheumatologist, obstetrician, and high-risk pregnancy specialist (perinatologist), just in case any problems arise.

Men with lupus may feel a loss of masculinity because lupus develops in women much more often than in men. However, men with lupus are fertile, able to be sexually active, and have normal reproductive abilities. One exception is that treatment with cytotoxic (chemotherapy) medicines can cause sterility in both men and women.

Intimacy Between Partners

Intimacy between partners often will be affected by the symptoms of lupus.

- ❖ *Changes in your physical appearance, like skin rashes or lesions, hair loss, or weight gain may affect how you feel about yourself.*
- ❖ *Joint pain, mouth sores, and vaginal ulcers can slow sexual responsiveness and make both foreplay and intercourse painful.*
- ❖ *Pain, fatigue, depression, and certain medications can lower your interest in sex and intimacy.*

It is possible to keep intimacy and tenderness between partners. Good communication with your partner will help you deal with negative self-perceptions or feelings of rejection. Couples may also wish to work with a licensed therapist for additional guidance.

Special Considerations

A network of friends and neighbors can give the same kind of valuable support as family members. But in order to give support, friends need to have some understanding of the nature of lupus. Let your friends know what to expect when the disease is active.

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, and telecommuting may also help you to keep working.



Good communication with your partner will help you deal with negative self-perceptions or feelings of rejection.

The Americans with Disabilities Act (ADA) says an employer may not discriminate against a qualified individual with a disability or a chronic illness.

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 too much for you to handle, you might benefit from changing to another job, or switching to part-time hours. And, if lupus interferes with your ability to function—physically, mentally, at home, or on the job—it may be useful to seek professional help.

In some cases, not working at all may be the best choice for your health. Your employer may offer short-term and/or long-term disability benefits. Financial and other support services may be available through local, state, or federal government and non-profit agencies.

Traveling when you have lupus may seem too complicated, but there are ways to make traveling much easier.

- ✦ *Airports have wheelchairs, motorized transporters, and attendants to help you. Wheelchairs may be available at museums and other public institutions. A motorized scooter can be rented to take on your trip.*
- ✦ *Ask for a hotel room with grab bars for the bathtub, wider access for the shower, elevated toilet seats, and less furniture to allow for wheelchair access.*

- ✦ *Advance airline check-in, including printing out the boarding pass, is another stress-saver, and can be done on most airline Web sites within 24 hours of take-off.*
- ✦ *Make arrangements to have your prescribed medications available when you are traveling.*
- ✦ *Whether traveling by car, bus, train, or plane, be sure to get up, stretch, and walk around during a long trip to improve blood circulation.*
- ✦ *Ocean cruises offer a chance to relax in your room whenever you want, and usually will include onboard medical care and choices of meal times.*
- ✦ *Bus trips or train rides to areas of interest also offer comfort for travelers.*
- ✦ *Local events and day trips allow you to travel without going far from home.*

Taking personal time is one of the most valuable lessons every person with lupus needs to learn. Living well with lupus often involves making some changes—physical, emotional, spiritual—within your family, within your profession, and within your social circle. But there is a significant difference between viewing yourself as a person with a chronic illness, and viewing yourself as a chronically ill person.

You may find that living with lupus:

- ✦ *makes you more understanding of others whose lives are affected by sickness and pain*
- ✦ *enriches your life by allowing you to share your experiences with others*
- ✦ *gives you a greater appreciation for things you used to take for granted*

The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruellest, 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.