

Living With Lupus

You have recently been diagnosed with a disease known as systemic lupus erythematosus (SLE). It has probably taken time to arrive at this diagnosis. Now that you know, you may feel relieved but also overwhelmed. You probably have a lot of questions about lupus.

You may have a mild or a more serious form, but no matter how severe your lupus is, you will need close medical supervision. You may also need to make lifestyle changes to keep your disease under control and feel as well as possible. At the beginning, you may feel some of these emotions:

- anger or depression over the loss of your former good health,
- uncertainty about what to tell family, friends, or coworkers,
- guilt for having lupus and the burden it may cause your family,
- fear that you may lose your job if you can no longer work regularly, and
- fear that you may die.

These are all normal feelings, and you are not alone in having them. You should give yourself time to adjust to your illness. This may or may not be easy for you. Discuss your feelings and concerns with your doctor and nurse and with your family and friends. Sometimes, talking with other people who have lupus is helpful. If you are having a hard time adjusting to your diagnosis, consider seeking the help of a counselor.

Many physical and emotional issues confront people with lupus, both in the beginning and throughout the course of their disease. The most common issues include the following.

Fatigue: Fatigue is a chronic problem that is usually accompanied by joint pain and stiffness. It can affect many aspects of your daily life.

Changes in personal appearance: You may experience changes in your personal appearance. Discoid lupus (a form of lupus) may cause sores, blotches, or scarring on the face, arms, shoulders, neck, or back. The medications for lupus can also sometimes change your appearance. For example, corticosteroids can cause weight gain, excessive hair growth, or swelling. Some drugs may cause hair loss. These changes in the way you look can be emotionally challenging to deal with.

CARING FOR YOURSELF

- ▲ Learn as much about lupus as possible.
- ▲ Understand that you will experience a variety of emotions, particularly when you are first diagnosed and adjusting to the fact that you have lupus.
- ▲ Adopt a positive attitude.
- ▲ Evaluate your personal strengths and resources, such as family, friends, coworkers, and community ties.
- ▲ Determine what your needs are, then make a plan to address them.
- ▲ Don't be afraid to set goals for yourself, but be flexible.
- ▲ Learn how to manage the physical aspects of your disease and the effects they have on other areas of your life.
- ▲ Learn to deal with stressful situations, because stress and anxiety can make your lupus symptoms worse.
- ▲ Learn to talk with your health care team, family, friends, and coworkers about lupus and the effect it has on your life.
- ▲ Don't be afraid to seek help for yourself or your family.

REMEMBER: Living well with lupus is possible. It is important that you take control of your illness and not allow it to take control of you. Adopting a positive attitude and striving to be happy can make a big difference in the quality of your life and that of your family and friends.

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