

A Guide for Relatives and Companions of Lupus Patients

What is systemic lupus erythematosus SLE?

Lupus is an autoimmune, chronic, inflammatory disease that can affect any organ or system in the body. No matter how mild or severe lupus is, close medical attention and lifestyle changes are required. The patient may have taken years to arrive at a diagnosis.

What does lupus mean to me as a relative or companion?

You and the patient may feel anger or depression over the change in health, uncertainty about what to tell family, friends or coworkers, guilt for having the disease or that the other person has the disease, fear of job loss, lost income, lost social activity. You or the patient may fear that the person will die.

These are normal feelings. Both you and the patient will need to discuss your feelings and concerns with members of the medical team, family and friends. Consider seeking help from a counselor.

There are many physical and emotional issues including the following:

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

Changes in personal appearance such as sores, blotches, scarring, rashes, swelling, weight gain, excessive hair growth, hair loss can be emotionally challenging to deal with.

Changes in physical ability can cause feelings of isolation because the patient's fatigue and need to rest keeps them from maintaining normal work and social schedules. You may feel frustrated when they cannot take part in outdoor activities due to sun sensitivity. The patient often feels it is easier to stay home than make plans and later cancel them because they are too tired or not feeling well.

Psychological effects of lupus and corticosteroids can cause anxiety, mood changes, forgetfulness, depression, personality changes, memory loss and other psychological problems.

Depression, feeling sad watching the person struggle to control lupus or in the patient as a side effect of medication needs communication with your doctor, family and friends. It is important that you cope with these feelings or you will not be able to help the patient cope with their feelings.

Concern for the future can cause the patients stress as the course of the disease is unknown, as well as planning for their job, family, vacations and life in general.

Lupus patients are hypersensitive to everything, light, sound, pain, sleep disturbances, movement, changes in sexual desire and ability, etc. which can lead to self-doubt, guilt and loss of self esteem.

Family members can be overwhelmed about the diagnosis and may have a difficult time understanding and adapting to the disease. You may feel confused, helpless and afraid. Because of the patient's physical limitations, traditional roles and responsibilities within the family may need to change. It is important that everyone talk openly and honestly with each other. It is also important that you learn about the disease so you can better understand the physical and emotional condition of the patient and the changes in your family, friendship or work relationships that may result.

What can we do for someone who has lupus?

There is no cure for lupus. Fatigue, pain, lack of mobility, loss of cognitive functions can all make basic activities of daily living difficult. The lupus patient has suffered multiple losses.

Be very specific when you offer help. Can I take you grocery shopping, to a medical appointment, church, pharmacy? Pick up the kids from school or an activity, babysit? Take care of an older adult living in the household? Fix a dinner, pack lunches? Do laundry, change beds, vacuum, cut grass, shovel snow, put away groceries? LISTEN patiently with open body language. It is often extremely helpful for both the patient or for you to have the opportunity to be truly heard, to have someone listen to your concerns without judgement or criticism, by someone who is simply there for you.

As a relative or companion it is important for you to ask for and accept help when you need it. The patient is not the only one who needs support.

For information www.lupusontario.org or call 905-415-1099 or 1-877-240-1099

Revised August 14, 2017