

Lupus

America's Least Known Major Disease

COPING WITH LUPUS

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LUPUS

Lupus Erythematosus (Lupus) is a chronic autoimmune disease in which the immune system treats the body's own healthy tissue as foreign and produces antibodies to attack one's own body. Symptoms include a characteristic butterfly-shaped rash on the face, headache, fatigue, arthritic joint disease, heart damage, shortness of breath, and impaired kidney function. There is presently no cure. Lupus follows an irregular course of remissions (inactive time) and flare-ups (active times), and may often be incapacitating. An estimated 500,000 to 1.5 million people in the United States suffer from lupus and the disease strikes women nine times more than men. Lupus affects each individual physically. It also affects the person and those that love that person emotionally.

EMOTIONS

While the physical symptoms vary from person to person, people with lupus experience similar emotions. Newly diagnosed patients may have feelings of anger, guilt, sadness, fear, and sometimes, even relief that there is a name, an identity for the symptoms they experience. Lupus symptoms are similar to many other diseases. Since the symptoms come and go, others may not "believe you" when they hear your complaints. Everyone feels fatigued or achy at times. When finally diagnosed, it is a validation. There is a reason for these feelings. They are real, lupus is real.

It is common to go through a grieving process after diagnosis. The process includes emotional stages such as shock, bargaining, denial, anger, and depression. While these can be uncomfortable, they are normal feelings. The person must grieve for what was, for their healthy self, before they can accept what is and what is to be. Acceptance arrives sometime during the final stage of the grief process. The individual can say, "Okay, now I need to live my life with this illness as best I can." At this point lupus becomes one segment of your life and no longer the main focus. Lupus finds its place in your life.

The grieving process can take up to two years before one reaches a level of acceptance. Acceptance is not easy, but once it happens, it provides a level of comfort. It is not unusual if during a flare, the patient experiences grief-type feelings again. Because of past experience, acceptance will return more quickly than before.

LUPUS: THE INVISIBLE DISEASE

Lupus is known as an invisible chronic illness. Appearance is not an indicator of lupus. Looking good and feeling good are not the same. It is frustrating to have someone say how well you look even when you feel terrible. People who look good have a right to feel bad, no matter what others think and say.

FRUSTRATIONS

Side effects of medications is a common frustration. Prednisone can sometimes cause a ravenous appetite and ultimate weight gain. Some people experience mood swings; feelings of euphoria one moment and depression the next. These symptoms are generally reduced when weaned off the steroids. Other frustrations may include:

- Insurance and Medical Concerns: difficulties with health insurance and prescription coverage or lack thereof.
- Physicians: Unable to find a physician they trust.
- Fear of how this affects their employment.
- Family members who do not understand.
- Inability to meet daily activity requirements and the feelings of being inadequate.

People who have lupus or love someone with lupus may experience depression. Symptoms may include:

- Feelings of hopelessness, helplessness, or loss of desire for anything pleasurable.
- Sleeping more than normal or having difficulty sleeping.
- Eating more to "fill up the emptiness inside" or loss of appetite.
- Isolation: Patients may stop seeing or talking to those they care about.

If these symptoms persist, help must be sought. See a therapist, talk to a doctor, spiritual advisor, relative or trusted friend. Every city has a crisis line. Help is available.



www.lupusalliance.org
(866) 415.8787

SIGNIFICANT OTHERS

The patient's support system is deeply affected by lupus. While lupus patients experience various emotions, those who love and support them also have a variety of feelings and emotions, such as:

- Fear they might lose you.
- Anger that this happened and how this affects them.
- Guilt that you are sick and they are healthy.
- Abandoned because you cannot "be there" for them.
- Abnormal - everyone else they know leads a 'normal' life.
- Financial concerns if you are no longer able to work or if they have to reduce their work hours to care for you.
- Resentful of having to take on more responsibilities.
- Afraid they may be unable to satisfy you or be satisfied sexually.
- Helpless because they cannot "fix you and make you better."

If any of these feelings are present, they are normal. These are common emotional feelings everyone experiences dealing with a chronic illness.

COMMUNICATION

Learning to utilize effective means of communication is vital to relationships.

- Make time in a neutral territory to have an open discussion.
- Do not accuse one another and place your loved one on the defensive. Take ownership of your feelings and discuss how things make you feel.
- Do not give each other platitudes. Do not say things such as "Don't worry things will be fine." "I know someone who feels like you and they don't act like you." "Don't be such a baby." Preferred examples are: "I cannot understand how you are feeling, but I am here for you." "It makes me sad to know you feel like that." By these statements, you are validating your loved ones feelings. You are allowing them to feel their thoughts are worthy whether or not you agree.

TAKING CONTROL

The only thing predictable about living with lupus is living with its unpredictability. A person may feel wonderful one day, and be in bed the next. Patients may shy away from making plans for fear of being ill. This can create feelings of isolation. This unpredictability can cause a sense of loss of control. While lupus is often uncontrollable, how one deals with it is controllable. "I cannot control what I have. I can control how I think about what I have." "I cannot control what my loved one has. I can control how I think about what he/she has." Learn to read the body's signals. Know when the "light is green" and you feel wonderful and energetic. Learn when the "light is yellow." Slow down and be careful. Definitely learn to acknowledge when the "light is red". All things stop. Obey the body's signals by resting and caring for yourself or allowing yourself to receive care.

Stress is something most people with lupus or their loved ones feel. It can be stressful living day to day with a chronic illness. During a flare, functioning normally is difficult. Daily responsibilities are a challenge. Even when not in an active period, levels of fatigue may inhibit what other people feel are normal daily activities. It is important to learn new coping and relaxation techniques, how to prioritize, delegate and sometimes say no. It is healing to accept that you do not have to be perfect to accept yourself.

Having lupus does not mean life is over. It can mean a new beginning. Life will present new challenges. Begin to focus on the positives, not the negatives. Accept that which cannot change and be kind to yourself when feeling ill. Take time to grieve and learn new coping skills. Express feelings honestly. Let those supporting you understand how you are feeling. Find a doctor you trust, someone you can be open with. Pace yourself, and learn as much about your illness as possible.

If you are the significant other, accept the fact that you cannot fix lupus and make it better. Help your loved one simply by being there. Obtain your own support system so you can vent your feelings. Make certain you have respite help if you are the caregiver. Accept that the word "selfish" is a positive, not a negative term. It is vital to care for yourself in order to care for your loved one.

Lupus will cause some very difficult days. Become proactive about lupus and not reactive. Remember lupus is only one part of your life. It is not your life.