

LIVING WITH LUPUS



**P. D. HINDUJA HOSPITAL
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Auto-immune diseases are those wherein, the cells which usually protect the body from environmental agents (eg. infectious organisms and toxins) turn around and cause damage to the body.

Systemic lupus erythematosus (SLE) or Lupus is one of the most important and complex auto-immune diseases. It typically affects women during their child-bearing age (15-45 years). Its manifestations are varied and it has the capacity to affect any



organ system in the body.

What causes Lupus?

The exact cause of lupus is not known. Some people are born with certain genes which determine their predisposition to lupus. A number of other factors are known to trigger lupus attacks (although these things can trigger lupus, they may affect one person but not another person).

- Exposure to ultraviolet light, usually from sunlight, is known to trigger the disease and symptom flares.
- Hormonal factors are linked to autoimmune disease, though the link is poorly understood. There is some evidence that there is increased risk of lupus with higher levels of estrogen (taken for fertility treatments, birth control pills or Hormone Replacement Therapy). There is also some data to show that post-menopausal women have a milder version of lupus.
- Some infections are suspected triggers. Viral infections like parvovirus B19 can cause lupus flare. Other infectious agents that have been incriminated as probable causative factors include Hepatitis C Virus.

- Chemical exposure has been known to trigger lupus. Suspected chemical toxins include trichloroethylene in well water and silica dust. Hair dyes and straighteners, linked to lupus in the past, are no longer considered to be lupus triggers.
- Some drugs like chlorpromazine and procainamide have been associated with lupus. Recently minocycline which was used in the treatment of acne has also been incriminated in some cases of lupus.

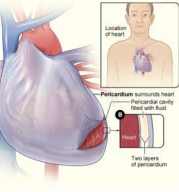
Symptoms of Lupus

It is typically characterized by varying symptoms and they come and go. The times when symptoms get worse are called relapses, or flares. The times when symptoms are not so bad are called remissions.



The usual presenting manifestations include persistent fever, oral ulcers, hair loss and facial rash. The facial rash occurs on the nose and either side of the face (malar area). Usually the patients have been thoroughly investigated and often most common infectious fevers like malaria, typhoid or TB have either been ruled out or have been treated.

System	Manifestation
Kidney	Nephritis (acute, Chronic) And Renal Failure
Nervous System	Headaches, Convulsions, Strokes
Blood	Anaemia, Low White Counts, Low Platelets
Lung	Pleural Effusion, Lung Hemorrhage, Pneumonitis
Heart	Pericardial Effusion, Myocarditis
Muscle	Myositis
Joints	Arthritis

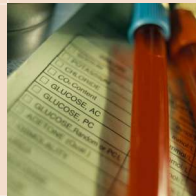


What tests are done to diagnose and assess Lupus?

The basic tests done are, complete blood counts, ESR, creatinine, urine routine and chest x-ray. Antinuclear antibody test (ANA), complement tests are some of the specialized tests done to diagnose and assess this disease. Further testing would also depend on the organ system involved. For e.g. an MRI brain may be needed for assessing neuron-lupus and 2D echo for cardiac disease.

How is Lupus treated?

Till date there is no cure for lupus but like in the cases of hypertension and diabetes it can be very well controlled. The treatment plan for lupus depends on its severity and organ system involvement. Mild disease may need small doses of steroids and medications like hydroxychloroquine. More severe disease requires higher doses of steroid and additional drugs called immunosuppressive agents. Specific organ system involvement will also need the inputs from specialists in that field of Cardiologists for cardiac problems and neurologists for nervous system diseases.



Complications of Lupus

Untreated, the course of lupus is often catastrophic. Prior to 1970's the mortality was high. However with better understanding of the disease and good treatment the 5 year and 10 year survival rates have improved immensely.

Inadequately treated lupus can lead to complications like uncontrolled bleeding, bone marrow failure, stroke, heart failure and kidney failure.

Living with Lupus

Understanding the disease and knowledge of the present scientific advances is vital for the patient. Patient care groups also help in this regard.

The patient must know the following facts

- Lupus is a chronic disease like diabetes and needs constant care.
- Like diabetes, the severity of illness and the medications needed for each patient have to be tailor-made and not universal. However steroids usually form a cornerstone of treatment of this disease.
- There could be periods of quiet (remission) and activity (flare).
- There are no known food items or weather patterns that aggravate the disease except for excessive exposure to sunlight.
- Although the patients need to know regarding the adverse events due to drugs, they also have to realize that the adverse effect of the disease is quite substantial.
- The patient should constantly follow-up with a Rheumatologist / Physician with expertise in treating lupus.
- Prevention of flares is important. One should avoid sunlight and stress.
- Since the patients are on drugs which can increase the chances of infections, patients need to follow some guidelines. Personal hygiene is of utmost importance. One should avoid eating uncooked and unhygienic food. There are vaccines which one need to take to prevent infections. In case other members in the family get infections the lupus patient should talk to his doctor regarding the need for taking precautions.



Special Situations in Patients with Lupus

Lupus and pregnancy

Since lupus occurs in young women, fertility and pregnancy issues are important. Often a consultation with the Rheumatologist and Obstetrician is needed before planned pregnancy. Pregnancy is advised only when the disease is quiescent and the patient is on small dose of drugs. Precautions are to be taken to see that only those drugs that are safe for the mother and child are continued during pregnancy. If the pregnancy is precious, the need for caesarean section needs to be discussed with the obstetrician. The drugs need to be continued during post-delivery period.

Recurrent Abortions and Congenital Heart Blocks

Some patients with lupus have recurrent 2nd trimester abortions. These could be related to lupus. After conducting special tests to confirm that lupus is the cause for this there are treatment modalities to try and prevent these abortions.

A small subset of babies of mothers with lupus can develop congenital heart block while in utero. Tests can be done even before pregnancy to pick up those who are prone for this complication and they can be counseled and treated to prevent it.

Neonatal Lupus and Childhood Lupus

Lupus can occur in a very very small subset of babies born to lupus mothers. This neonatal lupus is mild and limited only to the skin. Further in most, the lupus abates after a year even without treatment.

Lupus can occur even in young children before the age of 16 years. Although the basic concepts are the same, these children may need special inputs from paediatric rheumatologists.

When to seek immediate help/ warning signs?

If you are a diagnosed patient of Lupus, the following are the signs when you should contact your doctor immediately.

Warning Signs

- Unexplained fever
- Cough with expectoration
- Burning urination
- Intense unexplained headache

If there is any new symptom which bothers you, kindly contact your family physician. They may be or may not be related to lupus and your family physician can guide you.

We recommend that if you have Lupus, you should be seen about every three months, even if you're feeling well.

Important websites for patient information on Lupus are

- www.arc.org.uk
- www.uklupus.co.uk
- www.lupus.org



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