



PATIENT FACT SHEET

Lupus



CONDITION DESCRIPTION

Systemic lupus erythematosus, referred to as SLE or lupus, is a chronic (long-term) disease that causes systemic inflammation which affects multiple organs.

When healthy, our immune system protects the body from germs and cancers. With lupus, the immune system misfires and attacks "self", the patient's own tissues, in a process called autoimmunity or "loss of self-tolerance".

Most often, lupus starts in young females in their fertility age, although it can sometimes start during childhood [see section on Childhood-onset lupus below]. The disease is more common in some ethnic groups, mainly blacks and Asians, and tends to be worse in these groups.

About 20% of people with lupus develop the disease as children or teens. When lupus starts in childhood, it is called childhood-onset SLE, or cSLE. It is rare to get lupus before age 5 years.



SIGNS/ SYMPTOMS

People with lupus often have symptoms that are not specific to lupus. These include fever, fatigue, weight loss, blood clots and hair loss. They may also have heartburn, stomach pain and poor circulation to the fingers and toes. Pregnant women can have miscarriages. Lupus can flare during pregnancy and can affect its outcome.

The American College of Rheumatology has a list of symptoms and other measures that doctors can use as a guide to decide if a patient with symptoms has lupus.

- **Rashes:**
 - butterfly-shaped rash over the cheeks - referred to as malar rash
 - red rash with raised round or oval patches - known as discoid rash
 - rash on skin exposed to the sun

- **Mouth sores:** sores in the mouth or nose lasting from a few days to more than a month
- **Arthritis:** tenderness and swelling lasting for a few weeks in two or more joints
- **Lung or heart inflammation:** swelling of the tissue lining the lungs (referred to as pleurisy or pleuritis) or the heart (pericarditis), which can cause chest pain when breathing deeply
- **Kidney problem:** blood or protein in the urine, or tests that suggest poor kidney function
- **Neurologic problem:** seizures, strokes or psychosis [a mental health problem]

- **Abnormal blood tests such as:**
 - low blood cell counts: anemia, low white blood cells, or low platelets
 - positive antinuclear antibodies (ANA) result: antibodies that can cause the body to begin attacking itself that are present in nearly all lupus patients
 - certain abnormal antibodies: anti-double-strand DNA (called anti-dsDNA), anti-Smith (referred to as anti-Sm), or antiphospholipid antibodies

Lupus flares vary from mild to serious. Most patients have times when the disease is active, followed by times when the disease is mostly quiet - referred to as a remission. Yet, there is much reason for hope. Improvements in treatment have greatly improved these patients' quality of life and increased their lifespan.



COMMON TREATMENTS

The treatment goals are to suppress the overactive immune system and ultimately induce remission and prevent permanent organ damage. The types of medications required will depend on the symptoms. Treating cSLE requires close monitoring by a rheumatology team experienced in caring for children with lupus.

Common treatment options include hydroxychloroquine (Plaquenil), corticosteroids and immune suppressants. Other medications help control pain, including nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen or naproxen. In 2011, the FDA approved a biologic, belimumab

[Benlysta], for the treatment of active SLE in adult patients and it was approved in 2019 for use in children.

All medications have possible side effects. You should discuss the benefits and risks of recommended medications with your doctor. Based on the response to treatment, your doctor may be able to adjust medications to lower side effects while still controlling the lupus. It is very important that you discuss with your medical team any concerns you have about your medicines, or any changes to your medicines you are considering, to ensure the lupus is treated adequately.



CARE/ MANAGEMENT TIPS

Most people with lupus can live normal lives. Treatment of lupus has improved, and people with the disease are living longer. A good doctor-patient relationship and support from family and friends can help you cope with this chronic and often unpredictable illness. Learn as much as you can about lupus, your medications and what kind of progress to expect.

Take all your medications as your doctor prescribes, and visit your rheumatologist often to prevent serious problems. This lets your doctor keep track of your disease and change your treatment as needed.

Stay active. Exercise helps keep joints flexible and may prevent heart disease and strokes. Avoid excess sun exposure. Sunlight can cause a lupus rash to flare and may even trigger a serious flare of the disease itself. When outdoors on a sunny day, wear protective clothing [long sleeves, a big-brimmed hat] and use lots of sunscreen.

If you are a young woman with lupus and wish to have a baby, carefully plan your pregnancy. With your doctor's guidance, time your pregnancy for when your lupus activity is low. While pregnant, avoid medications that can harm your baby.

Children with cSLE

Hearing that your child has lupus can be frightening. However, by understanding the disease and working closely with the health care team, you can learn how best to take care of your child.

There may be times when children and teens with lupus must take time off from school to allow their bodies to heal. Otherwise, they are encouraged to live as normal a life as possible. Going to school, playing with friends, exercising, having a healthy diet and continuing family activities are all important.