

Lupus (systemic lupus erythematosus)

Reviewed by SickKids Staff | Last updated: September 15th 2009

Parents can learn about systemic lupus erythematosus (SLE). Learn about diagnosis, treatment and managing lupus.

Key points

- Lupus is a disease that can be difficult to diagnose.
- Lupus can affect many different parts of the body.
- Lupus has many different signs and symptoms and can vary from person to person.
- Lupus can be treated with a variety of medications.
- The disease may have flares and remissions.
- Treatment for lupus may go on for many years.
- Lupus may make your child's social and school life more difficult. You can learn how to help your child cope. Your child's health care team is there to assist and support you.

What is Systemic Lupus Erythematosus (Lupus, SLE)?

Systemic lupus erythematosus is a disease that causes inflammation in many parts of the body. It is also called lupus or SLE.

Inflammation is when parts of the body become hot, swollen, and red. This can happen in areas that you can see or it can happen inside the body where it cannot be seen. The most common body parts involved in lupus include the:

- skin
- kidneys
- brain
- joints
- heart
- lungs

Lupus is a chronic autoimmune disease. Chronic means that the disease can go on for many years, even lifelong. There will be times when the disease is active with symptoms (a flare) and there will be times when it is quiet (remission). The immune system normally helps to fight off infections caused by germs and viruses. In a person with an autoimmune disease, the immune system makes a mistake. Rather than fighting off germs, it attacks a person's own healthy cells. When this happens, the area becomes inflamed.

Symptoms of lupus

The signs and symptoms of lupus can vary greatly from person to person. They can be very mild or they can be much more severe. Specific signs and symptoms of lupus can be related to different parts of the body.

Heart and lungs

Lupus can cause inflammation of the lining around the lungs (pleuritis) and/or heart (pericarditis), causing symptoms such as:

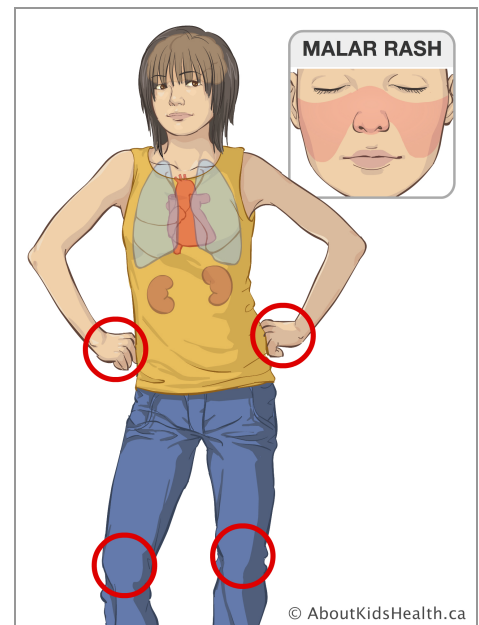
- chest pain
- shortness of breath
- difficulty breathing when lying down
- a feeling of tightness in the chest

Central nervous system (CNS)

Lupus can also cause symptoms related to the CNS. These symptoms are all called CNS features and include:

- headaches
- memory difficulties
- mood swings
- hearing or seeing things that are not there (hallucinations)
- seizures

Kidneys



SLE is a disease that causes inflammation in many parts of the body including the joints, kidney, brain, heart, lungs and skin. Some of this inflammation can be seen (skin) and some of it occurs inside the body (heart and kidneys). A common symptom of SLE is a butterfly-shaped rash over the top of the nose and on the cheeks called a malar rash.

A child with lupus can have problems related to the kidneys, which cause the following symptoms:

- increased blood pressure
- swelling in the hands and feet
- weight gain
- blood or protein in the urine during a check-up

Skin

Skin problems that may arise include:

- a rash over the cheeks and across the bridge of the nose called a 'butterfly rash' (malar rash)
- a scaly, raised, coin-shaped rash on any part of the body that leaves a scar when it heals (discoid rash)
- a rash that comes out when there is exposure to ultraviolet light from the sun or from a tanning booth (photosensitive rash)

Other symptoms of lupus

- hair loss
- sores inside the mouth and nose that usually do not hurt
- pain, stiffness, warmth, and swelling in the joints (arthritis)
- colour changes and/or sores on the fingers and toes (Raynaud's phenomenon)
- extreme tiredness (fatigue)
- fever
- weight loss and decreased appetite

What causes lupus?

The cause of lupus is unknown. It is not a contagious disease and cannot be passed from one person to another. Nothing anyone did, or did not do, caused your child to develop lupus.

Lupus usually occurs between 14 and 45 years of age. It affects more females than males. It can, however, occur at a younger age.

While the exact cause of lupus is a mystery, it is known that the disease occurs more often in some races. We do know that the sun, certain medicines and some infections can make the disease worse. These things are known as 'triggers.'

How is lupus diagnosed?

Lupus is often difficult to diagnose because it can affect many different parts of the body. It has been called "the disease of a thousand faces." To make the diagnosis, your child's doctor will:

- take a full history of all the symptoms
- do a physical examination
- collect blood and urine samples

The doctor may order other tests to check specific areas of the body if they suspect a problem.

Treating lupus

Your child may need to stay in the hospital while the lupus is brought under control. The treatments are aimed at controlling the inflammation in the body and making your child feel better.

Lupus is treated with medicines that control inflammation and that help to prevent your child's immune system from attacking healthy cells. Other medicines may be needed if the lupus has caused damage to specific body parts.

The drugs most commonly used are:

- [prednisone](#): This is a type of steroid that controls inflammation. It may be given by intravenous or orally.
- hydroxychloroquine (Plaquenil). This treats the rash of lupus and helps prevent a flare up of the disease.
- non-steroidal anti-inflammatory drugs (NSAIDs): These help control inflammation.
- immunosuppressive medicines. These help settle down the immune system. These include [azathioprine](#), mycophenelate mofetil (MMF), [cyclophosphamide](#) and [cyclosporine](#).

Many children with lupus will need to take other medicines to help control their blood pressure if they have kidney disease.

Most drugs have some side effects, which are not part of the treatment. When your child is prescribed a medicine, the doctors and nurses will let you know how it works, what side effects can occur and what that might mean to your child.

Living with lupus

Lupus may affect your child's usual activities

Your child may experience tiredness and pain, making it hard to do normal activities. At times, your child may not feel like going out with friends or going to school. Our goal is to help make them feel better and be able to get back to doing all of these things.

Lupus may affect your child's school attendance and performance

Your child may have to miss a lot of school due to illness, being hospitalized or going to doctors' appointments. They may also have trouble keeping up with all the activities and school work. Let the school know about your child's illness. They may be able to offer suggestions on making things easier and decreasing the stress. We can write a letter or contact the school if this is needed.

Lupus can affect the whole family

When a child is diagnosed with a disease, it can be a very scary time for everyone. Sometimes the disease seems to get better and at other times it suddenly seems to get worse. This can be very stressful for the whole family. Other children in the family may resent the extra attention that the sick child needs. There may be feelings of guilt and fear of the unknown. Your child may feel depressed and wonder "why me?"

If these issues arise in your family, you can speak with a counsellor or your child's doctor for support and guidance. They will be able to help you through these hard times and give you ideas to make things a little easier for everyone.

When your child is newly diagnosed with lupus or having a flare up of the disease, they may have some difficulty doing the same things as before. The social workers can help you to adapt to situations and to set realistic goals for you, your child and your family.

Try to keep your child doing the same things that they did before the disease, whenever possible. Daily routines are important to children and often quite comforting. If routines can change as little as possible, this will help your child feel better about how the disease has affected them. Routines can include school, home, chores, visiting with friends and play time. If you are unsure of what your child can do, ask one of the health care team members.

Follow-up care

Your child will be seen in the lupus clinic for follow-up care. In the beginning, it may seem that you are coming to many appointments. As your child's condition improves, the appointments

will be less frequent. Your child's lupus health care team is made up of many doctors and nurses. The team also includes a:

- social worker
- dietitian
- physiotherapist
- teen specialist

At every clinic visit, your child will have some blood drawn and be asked to give us a urine sample. This is done to help the doctor see how active your child's disease is and to see how well the medicines are working. Your child will be given a medication book to keep track of the medicine they are taking. Remember to bring the book to every appointment so that the doctor or nurse can write in any changes to your child's medicine.

After you have met with the lupus team, you will know more about how to care for your child and the plan for future clinic visits.

At SickKids

Follow up care is provided at the rheumatology clinic at SickKids.

[Please visit AboutKidsHealth.ca](https://www.aboutkidshealth.ca) for more child health information.

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