

Lupus

What is Lupus?

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that affects nearly 17,000 Canadians. SLE is the most common and serious type of lupus.

Other types include discoid lupus erythematosus (DLE) and sub-acute cutaneous lupus (SCLE), where skin rashes and sun sensitivity are the primary symptoms.

About 0.1 per cent of these milder types of lupus develop into SLE.

In SLE, the immune system that protects the body from viruses and bacteria malfunctions and generates antibodies that attack healthy tissue. As a result, inflammation can occur in the skin, muscles, joints, heart, lungs, kidneys, blood vessels and the nervous system.



DID YOU KNOW?

Even though lupus can affect men, women and children of any age, it occurs nine times more often in women during their childbearing years (age 15 to 45) than in men. Medications, viruses, sun exposure and prolonged or severe stress may trigger SLE.

WHY DO PEOPLE GET LUPUS?

The cause of SLE is still unknown, but researchers believe it results from a combination of genetic and environmental factors. Some genes may predispose us to lupus, while others may protect us. Similarly, some environmental factors may trigger the onset of lupus, while others may be protective. The onset of clinical SLE may therefore be attributed to one combination of specific genes and environmental factors in the absence of others.

HOW WILL LUPUS AFFECT ME?

- A red rash across the cheeks and nose (butterfly rash), ears, scalp, arms or chest.
- Sensitivity to sunlight or ultraviolet light.
- Small, painless sores in the mouth or nose (mucosal ulcers).
- Arthritis in the hands, arms, shoulders, feet, knees, hips or jaw. The pain may move from joint to joint. It may also be warm, red and swollen.
- Inflammation in the lining of the lungs (pleuritis) or inflammation of the lining of the heart (pericarditis), which will cause chest pain when lying down or taking deep breaths.
- A mild or severe decrease in kidney function, which can cause weight gain or swelling of the feet and legs.
- Seizures or psychosis (disturbance in mental functioning, which results in the loss of touch with reality).
- Decreased blood cell count (lower amounts of circulating red blood cells, white blood cells or platelets).
- Autoantibodies (proteins in the body that abnormally attack healthy body tissue) are in the blood and are believed to create abnormalities in the body's defence against viruses and bacteria.
- Anti-nuclear antibodies (autoantibodies reacting with the core of our cells) are in the blood.

WHAT ARE THE SIGNS AND SYMPTOMS OF LUPUS?

The symptoms of SLE are different for each person and may be similar to those of other medical conditions, making diagnosis difficult. These symptoms can be mild or severe and may include:

- General flu-like symptoms (fatigue, fever, loss of appetite, aching muscles and joints).
- Red rash over face and/or on sun-exposed skin.
- Sudden, unexplained weight loss or gain.
- Chest pain, with shortness of breath in some positions.
- Headaches, with clouding of consciousness.
- Hair loss to the scalp.
- Change in the colour of fingers and toes when exposed to the cold.
- High blood pressure.

HOW WILL MY DOCTOR DIAGNOSE LUPUS?

Your doctor will make a diagnosis based on personal medical history, symptoms, a physical examination and laboratory test results. A definite diagnosis may be hard at first, as SLE can involve almost any single or combination of organs or tissue in the body. Signs and symptoms of SLE can be different for every person with the disease.

TREATMENT

Once your diagnosis is confirmed, there are many treatments that can help you manage the symptoms of lupus. Treatment is based on the type of symptoms and their severity. You can live well with lupus, but a treatment tailored to your lupus is extremely important. **This is why regular check-ups with your health-care provider are necessary.**

HOW CAN I MANAGE MY LUPUS?

Adopting a healthy lifestyle is essential. This includes healthy nutritional habits, exercising, keeping an ideal body weight, smoking cessation, healthy sleeping habits and a low-stress lifestyle. Additionally, medications will be needed to bring SLE symptoms under control, bring about a remission and help you manage your disease. Early treatment can reduce permanent tissue damage and minimize the amount of time a person with SLE requires high doses of medications.

Medications for inflammation

- Acetaminophen is taken for mild pain relief, but is not an anti-inflammatory medication.
- Non-steroidal anti-inflammatory drugs (NSAIDs) are often used when acetaminophen does not control the pain. Many types are available with or without a prescription. You may have to try different NSAIDs before you find the one that is best for you.
- Corticosteroids are anti-inflammatory hormones that reduce inflammation and suppress the immune system. They are used when other treatments fail, when the reason for a flare-up is unknown or when SLE is severe. Corticosteroid use must be monitored carefully and must never be stopped abruptly. You and your health-care provider must discuss an appropriate dosage that provides relief for you. Side effects can include weight gain, a round face, easy bruising, acne, osteoporosis, high blood pressure, diabetes and increased risk of infections. Despite these side effects, you must remember that prednisone can be life saving and remains the most rapid and effective drug to control moderate to severe lupus activity.
- Cytotoxic or immunosuppressive drugs are powerful drugs that reduce inflammation and control the abnormal immune system in SLE. They are prescribed for people whose SLE symptoms are difficult to control with corticosteroids or for people having side effects from corticosteroids. Although side effects may be serious and could include decreased red blood cell counts, increased risk of infection and a risk of developing certain types of cancer, they are commonly used because their benefits exceed their risk in a great majority of people. However, people with SLE taking these medications are required to have regular blood tests and must be monitored closely by their health-care provider.

For more information about medications for inflammation, you can download *The Consumer's Guide to Arthritis Medications* at www.arthritis.ca/publications.

Other medications used to treat lupus

- Antimalarial drugs were originally designed to treat malaria. However, they are also effective in managing some symptoms of SLE, such as fatigue, skin rashes and joint pain.
- Hydroxychloroquine has also been shown to be effective in preventing flares of SLE and in protecting people with SLE against later development of blood clots and tissue damage, and even death. Examples of this medication are: Aralen® (chloroquine) and Plaquenil® (hydroxychloroquine). The benefits of this medication may take several months to appear. Side effects include rare allergic skin reactions or upset stomach. More serious, however, could be that the eyes are affected by high doses over a long period of time. Loss of vision can occur if the medication accumulates in the back (retina) or front (cornea) of the eyes. An eye examination before starting this medication is necessary and yearly eye tests are advised.

Advances in lupus treatment

- An impressive array of new treatments are now being tested for lupus. Recent studies suggest that there will be an increasingly important role for biologics in the treatment of SLE. These treatments target the immune abnormalities that cause symptoms in lupus and may therefore be less toxic than current lupus treatments.
- Research has never been so active in SLE. Basic scientists and clinical researchers are united in studying the mechanisms of this disease and how to improve its outcome. Networks of researchers are being formed to better address the needs of lupus patients. In Canada, the Canadian Network for Improved Outcomes in SLE (CaNIOS), which can be accessed at www.canios.ca, has been actively performing national research studies in SLE for 15 years. Exciting discoveries in genes predisposing to lupus may lead to improved screening tests and treatments. Several new biomarkers in development will allow for targeted treatments and better monitoring of how the disease is responding to intervention. Better understanding of the mechanisms leading to the immune abnormalities seen in SLE are leading to improved treatments. Finally, recognition that SLE is a complex chronic disease that impacts a person in all dimensions of life has led to the development of more comprehensive and better managed treatment programs.

More information about lupus medications can be found online at www.lupuscanada.org.

Last revised: August 2010 by Paul R. Fortin, MD, MPH, FRCPC.

WHAT YOU CAN DO

1. Learn about SLE and how to manage it.
2. Consult your health-care provider about birth control and discuss the best time for pregnancy.
3. Talk to your health-care provider when considering complementary therapies to manage your SLE.
4. Seek support and counseling for stress.
5. Get immunized regularly.
6. Exercise and eat a well-balanced diet.
7. Apply sunscreen regularly.

Each person's pattern of lupus is unique; you may be able to detect the early warning signs of a flare, leading to earlier and more effective treatments.

You can expect to live a normal life, even though flare-ups come and go. Most people with an early diagnosis of SLE can look forward to a regular life by following the advice of their physician, taking their medication as prescribed and seeking help for new symptoms or medication side effects.

LIFESTYLE CHANGES

Controlling flares is important in the day-to-day management of SLE. It is best to avoid risk factors, such as sun exposure, excessive fatigue, uncontrolled stress, poor diet, smoking and excessive alcohol use. Lifestyle changes are a good way to avoid triggers that will cause flare-ups.

Physical activity

Being physically active with lupus or other types of arthritis can help avoid future flare-ups. There are many benefits to physical activity, which are discussed in *The Arthritis Society's Physical Activity & Arthritis* guide. This publication shows you the types of activity appropriate for treating your arthritis.

Healthy eating

Healthy eating is a crucial part of managing a chronic condition like lupus. A balanced diet ensures you are getting proper nutrition and will help your body metabolize your medications. To learn more, read *The Arthritis Society's Nutrition & Arthritis* guide.

Both *Physical Activity & Arthritis* and *Nutrition & Arthritis* can be accessed at www.arthritis.ca/publications.

Enrol in the Arthritis Self-Management Program (ASMP)

Held over six weeks in weekly two-hour sessions, ASMP is led by trained instructors with first-hand experience of living with arthritis. Participants gain self-confidence in managing pain and fatigue, handling stress and exercising with arthritis.

www.arthritis.ca/asmp

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