

Lupus

What is Lupus?

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that affects nearly 15,000 Canadians. 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 (a natural substance in the blood or tissue that protects the body from toxins) abnormally attacking healthy tissue. As a result, inflammation can occur in the skin, muscles, joints, heart, lungs, kidneys, blood vessels and the nervous system, causing symptoms and active periods (flares) to come and go.



DID YOU KNOW?

Systemic lupus erythematosus (SLE) is more common in women aged 15-45 than in men.

WHY DO PEOPLE GET LUPUS?

The cause of SLE is still unknown but researchers believe it is a combination of genetic and environmental factors. Lupus can affect men, women and children of any age, but occurs most often in women during their childbearing years. Medications, viruses, sun exposure and prolonged or severe stress may trigger SLE.

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).
- Auto-antibodies (proteins in the body that abnormally attack healthy body tissue) are in the blood and are believed to create abnormalities in the body's defense against viruses and bacteria.
- Antinuclear antibodies (auto-antibodies reacting with the core of our cells) in the blood.

WHAT ARE THE SIGNS & SYMPTOMS OF LUPUS?

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

- General flu-like symptoms (fatigue, fever, loss of appetite, aching muscles and joints).
- Sudden, unexplained weight loss or gain.
- Headaches
- Hair loss to the scalp.
- Fingers change colour when exposed to the cold.
- High blood pressure.

HOW WILL MY DOCTOR DIAGNOSE LUPUS?

Your doctor will make a diagnosis based on your personal medical history, a physical examination, symptoms, and laboratory test results. A definite diagnosis may be hard at first since 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. 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. Some people with mild cases of SLE may require no treatment. **Regular check-ups with your health care provider are necessary.**

HOW CAN I MANAGE LUPUS?

The goal for medications is 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.
- Non-steroidal anti-inflammatory drugs (NSAIDs) are 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 activity of the immune system. Corticosteroids are already in the body, and also produced as a drug. They are used when other treatments fail, when the reason for the flare is unknown, or when SLE is severe. Corticosteroid use must be monitored carefully and must never be stopped abruptly. You and your doctor must discuss an appropriate dosage that provides relief for them. Side effects can include weight gain, a round face, easy bruising, acne, osteoporosis, high blood pressure, diabetes, increased risk of infections and stomach ulcers. Despite these side effects, you must remember that this medication 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 which reduce inflammation and the immune system. They are prescribed for people whose SLE symptoms are difficult to control with Prednisone®, or for people having side effects from Prednisone®. Cytoxan® (intravenous cyclophosphamide), Procytox® (oral cyclophosphamide), Imuran® (azathioprine) and Cellcept® (mycophenolate mofetil) are commonly prescribed drugs in this category. 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. People with SLE taking these medications are required to have regular blood tests and must be monitored closely by their physician.
- Newer biological treatments that target the immune abnormalities that cause symptoms in lupus and may therefore be more effective and less toxic. These treatments are still being tested.

For more information about medications for inflammation contact The Arthritis Society for The Consumer's Guide to Medications, or download it online at www.arthritis.ca/publications

Medications specifically for Lupus

- Anti-malarials are also effective in managing some symptoms of SLE such as fatigue, skin rashes and joint pain. Benefits of this medication may take several months, but it has also shown to prevent lupus flares when taken after remission. The side effects include upset stomach. The eyes may be affected by high doses over a long period of time. Loss of vision can occur if the medication accumulates in the back of the eyes. An eye examination before starting this medication is necessary and regular eye tests are recommended.
- Cytotoxic or immunosuppressive drugs reduce inflammation and activity of the immune system. They are prescribed for people whose SLE symptoms are difficult to control with, or have side effects from corticosteroids. 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. People with SLE taking these medications are required to have regular blood tests and must be monitored closely by their physician.

For more information about lupus medications visit www.lupuscanada.org

LIFESTYLE CHANGES

Controlling flares is important in the daily 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. Adjusting your lifestyle is a good way to avoid triggers that will cause flares.

Revised 04/08 – by Paul Fortin, FRCP, MD, MPH

WHAT YOU CAN DO...

1. Learn about SLE and how to manage it.
2. Consult your physician about birth control and discuss the best time for pregnancy.
3. Talk to your doctor 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 flares is unique. You may be able to detect the early warning signs, which will lead to more effective treatments for you.

You can expect to live a normal life, even though flares will 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.

HOW CAN YOU FIGHT LUPUS?

Call The Arthritis Society

This toll-free number can connect you with trained volunteers who can provide you with support and information.
1.800.321.1433

Join the Free Arthritis Registry

You will receive specific information you need to manage your arthritis and improve your quality of life.
www.arthritis.ca/registry

Enroll in the Arthritis Self-Management Program (ASMP)

ASMP is a six week program for people living with arthritis, their family and friends. Trained leaders with first hand experience of arthritis lead the weekly small, interactive two-hour workshops. Program participants will gain self-confidence in their ability to control symptoms, learn how to develop action plans to manage how arthritis affects their lives, and make connections with others living with arthritis.
www.arthritis.ca/asmp

Use Arthritis Friendly Products

The Arthritis Society is proud to be able to recognize manufacturers that have designed products that are easy to use for people living with arthritis. For a complete list of products that have been commended by The Arthritis Society and deemed "Arthritis Friendly" visit
www.arthritis.ca/arthritisfriendly.

ARTHRITIS  FIGHT IT!

To support arthritis research or to learn more, contact The Arthritis Society:
1.800.321.1433 www.arthritis.ca


The Arthritis Society