

Living Well with Lupus



BC LUPUS SOCIETY

together we can conquer lupus

If you or a loved one has been diagnosed with lupus, then this pamphlet will provide some effective ideas on how to cope and to live well with lupus. Although lupus is not well-known, as many as 10,000 people or more in British Columbia are affected. Lupus is a serious and chronic disease, but the outlook is improving. Research is bringing new treatments and lupus specific drugs are being developed. The first new lupus medication in over 50 years has been approved for use and there are others undergoing trials.

WHAT IS LUPUS?

Lupus is a chronic autoimmune disease that attacks any organ of the body in unpredictable ways. It can affect any tissue or organ including skin, muscles, joints, blood and blood vessels, lungs, heart, kidneys and the brain.

Chronic means that anyone who develops lupus will have this disease for life, but symptoms can improve (go into remission) and flare (get worse) repetitively. The most common type of lupus is systemic lupus erythematosus (SLE). There is also Cutaneous Lupus Erythematosus which mainly affects the skin but can evolve into SLE. Some individuals may develop drug-induced lupus in response to a few medications, but symptoms for this type will disappear when the patients stop the medication.

LUPUS IS NOT...

Lupus is not contagious, not even through sexual contact. Lupus is not similar to cancer although lupus can sometimes be treated with a common chemotherapy drug. Lupus is not similar to HIV.

WHO GETS LUPUS?

Lupus can affect anyone, but between the ages of 15 and 45, nine times more women than men are diagnosed with lupus. Under 15 and over 45, both sexes are affected equally. Women of colour are two to three times more likely to develop lupus than Caucasians.

WHAT ARE THE SYMPTOMS?

Lupus is often called *'The Disease with a Thousand Faces'* because it affects each person differently and making diagnosis difficult. Each person's experience will be unique; how they were diagnosed, how they're living with lupus, and how they are being treated. If you have lupus, you may experience some or all of the following symptoms:

- Joint pain, sometimes with swelling
- Prolonged or extreme fatigue
- Sensitivity to sunlight and UV rays
- Headaches
- Butterfly shaped rash across the upper cheeks and bridge of the nose
- Skin rashes
- Anemia
- Small ulcers inside the nose or mouth
- Chest pain, worse when lying down or inhaling (pleurisy)
- Swelling of the feet, legs, hands and/or around eyes (edema)
- Seizures or severe neurological symptoms
- Cognitive impairment, foggy thinking
- Hair loss
- Frequent fevers
- Abnormal blood clotting problems
- Fingers turning white and/or blue in the cold (Raynaud's Phenomenon)

This list is far from a complete. There is no single test for lupus, but one valuable tool is a blood test showing the presence of certain antibodies. *If you suspect lupus, it is important to see a doctor for referral to a rheumatologist for confirmation and follow-up.*

WHAT CAUSES LUPUS?

We don't know the cause yet. We do know that in lupus, the immune system (the body's defense against bacteria and viruses) is unable to distinguish between intruder cells and those

belonging to the body. The immune system then targets parts of the body, causing inflammation and creating other lupus symptoms.

Researchers think there may be a hormonal connection, because it mainly targets women of childbearing age, but how this happens is still unknown. Genetic factors may mean that some people are more likely to develop lupus. Some believe that the environment plays a part in developing lupus by acting as a trigger for someone who is genetically susceptible. Research into genetics and the immune system is still ongoing to find the specific cause.

However, it is important to know that:

- While lupus can be a serious condition, in most cases it can be treated and controlled;
- Lupus often goes in cycles, with periods of time in which symptoms may disappear completely;
- Diagnosis and treatment are improving, allowing people with lupus to live increasingly active and productive lives.

WHAT TO EXPECT

Each person's experience will be different, but there are some common stages that characterize lupus. It often appears in cycles, which can consist of:

- a lupus "flare" with severe acute symptoms, needing medical attention
- a "chronic" phase when symptoms may continue but are less severe
- a "remission" when symptoms may disappear completely for long periods of time, though they can return.

In the chronic phase, and especially in the remission phase (when it's easy to forget to take care), it is important to practice healthy lifestyle habits.

TREATMENT FOR LUPUS

Your family physician should refer you to a rheumatologist for your treatment plan. There may be other specialists involved depending on what organs lupus has affected. While there is no cure yet, with treatment, most people with lupus can look forward to normal life expectancy. There are many medications that can control symptoms. Each treatment plan will depend in part on the type and severity of your symptoms. Research has shown that antimalarials such as hydroxychloroquine (Plaquenil®) and chloroquine protect organs from lupus effects. Corticosteroids such as prednisone are used in flare situations, and while very expensive, the monoclonal antibody belimumab (Benlysta®) is also available for use in treatment.

RESEARCH DEVELOPMENTS IN LUPUS

New medications are currently undergoing trials and there are great hopes that they will be approved for lupus treatment. Researchers internationally and in North America are working to find a cure and to provide more effective treatment options. International communication between researchers and medical practitioners ensures that advances and improved tests and techniques for diagnosis and for predicting flares are shared. These allow doctors to start treatment sooner, which improves chances for success.

The BC Lupus Society has been providing funding support for research initiatives both locally and nationally, including research scholarships, clinical support, and research projects. Currently we sponsor our own Lupus Research Scholar, Dr. Antonio Aviña, MD PhD, as well as participate in ongoing support of national research initiatives.

CHILDREN WITH LUPUS

Children with lupus often do poorly because they don't follow through with their treatment, not because the right treatment isn't available. Critical issues include learning to balance school with the limitations imposed by active lupus, recognizing the warning signs of a lupus flare, and continuing to take prescribed medications even when feeling well. It is even more important to provide children with education on how to cope both in the short and the long term, and to give support and supervision to ensure treatment is effective.

WHAT CAN I DO TO LIVE WELL WITH LUPUS?

Your strongest tool in living well with lupus is understanding your own role in managing the disease. You can better cope with the challenge by learning all you can about lupus, by being aware of how your own body reacts and how to maintain your health and energy.

Sometimes flares follow a clear pattern, with the same combination of symptoms every time. An informed patient can watch for warning signs and alert the doctor early on. While false alarms happen, catching a flare in its early stages can make treatment easier and more effective.

With this information as a basis, a good working relationship with your doctor is crucial to the success of your treatment. There are several things you can do on a regular basis to ensure that your lupus is better controlled:

- Keep a journal record of your symptoms and your ups and downs. Keep a list of questions for your next doctor's appointment. Be your own advocate - your involvement will be key to managing symptoms and flares.
- Take your medications as prescribed. Sometimes patients avoid certain drugs because of fear of side effects. While no drug is totally free of adverse effects, the drugs are

effective agents to relieve symptoms and control the disease.

- Avoid the sun. Cover up and wear sunscreen.
- Get exercise. For any chronic disease, exercise is an important tool for self-management. It can help with problems of weight gain caused by meds, fatigue, and blood pressure and, in addition, it combats stress and helps improve both mood and sleep quality.
- Eat healthy foods including dark green leafy vegetables and consider taking vitamin supplements. Vitamin D deficiency is common when you have sun sensitivity and the lack may hinder the immune system. Omega 3 fatty acids, found in fish and some vegetable sources may also assist the body to fight inflammation.

The support of family and friends can be equally important in living well with lupus. Membership in lupus organizations and support groups is also helpful and informative.

There is a Lupus Clinic operating at the Mary Pack Centre near Vancouver General Hospital. Headed by Dr Jennifer Reynolds, the clinic accepts referrals from physicians to confirm diagnosis and make initial treatment recommendations for patients who may have lupus. Patients are then referred to a private rheumatology practice for ongoing management and follow-up as necessary.

The BC Lupus Society is a provincial volunteer based non-profit organization dedicated to supporting people whose lives are affected by lupus. Our annual membership includes a subscription to our printed quarterly newsletter the Lupus Lighthouse, and discounted or free entry to our annual symposium and other events.

Our provincial contacts volunteer their time to provide information and support in their

communities. We also have a number of support groups throughout BC that meet regularly.

OUR MISSION

- To support advances in research and treatments
- To create public awareness
- To provide education and support to people affected by lupus

OUR VISION

- That early diagnosis and optimal treatment will be available to everyone with lupus
- That the public at large will be aware of lupus
- To ensure community based support networks and services

Our program goals are to actively assist lupus patients to sustain quality of life following diagnosis, and to provide reliable information and guided support.

WHERE TO FIND OUT MORE ABOUT LUPUS?

The BC Lupus Society offers resources, reading material and education events. Each year in the fall we host a symposium featuring key speakers and researchers on a variety of Lupus topics. Our newsletter, the Lupus Lighthouse contains articles and updates on lupus research, self-help and events. Visit www.bclupus.org for further information.

To become a member, purchase books or to request more information contact:

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