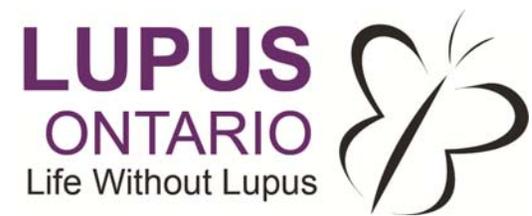


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## Introduction

Lupus is a chronic disease characterized by inflammation in one or more parts of the body. It belongs in the family of autoimmune diseases that includes rheumatoid arthritis, multiple sclerosis, juvenile diabetes, and scleroderma. The most common type of lupus is systemic lupus erythematosus (SLE). It is estimated that lupus affects tens of thousands of people in Canada.

Systemic lupus is a complex and sometimes baffling condition that can target any tissue or organ of the body, including skin, muscles, joints, blood and blood vessels, lungs, heart, kidneys and the brain.

There are other types of lupus which mainly affect the skin. A few individuals develop drug-induced lupus as a response to some medications used to treat other conditions. These symptoms disappear when the person stops taking the medication.

### **Who gets lupus?**

Anyone can: women, men and children. Between the ages of 15 and 45, more women than men are diagnosed with lupus. In those under 15 and over 45, both sexes are affected equally.

### **What causes lupus?**

The cause remains unknown. What we do know is that in lupus, the immune system (the body's defence against viruses and bacteria) is unable to tell the difference between intruders and the body's own tissues. This can result in the immune system targeting parts of the body, causing inflammation and creating the symptoms of lupus.

Because it occurs most often in women of child-bearing age, there may be a link between lupus and hormones, but how this works remains uncertain. Genetic factors may make certain people more likely to develop lupus, but these factors are not fully known yet.

Until science fully understands how the immune system works, the specific cause of lupus remains unknown.

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 are the symptoms of lupus?**

Each person's experience of being diagnosed, treated and living with lupus will be very different.

Lupus can target any of the body's tissues, and is often hard to diagnose. There are many symptoms people with lupus experience and that is why it is called "the disease with a thousand faces".

## Lupus Research

### **What you can do and what the medical community is doing**

Learning about Systemic Lupus Erythematosus (SLE), can help you become aware of specific symptoms and the steps you can take to improve your health. Information can be found in books, on reliable websites and through support groups.

By far the most immediate resource is the internet. In fact, the internet has changed how people learn about lupus. Type "lupus" in the Google™ search engine, for example, and it reveals millions of hits in a fraction of a second. With so many hits, you have to wonder about the reliability of the information. How do you know which sites to trust? Anyone can set up a website and publish anything they want about lupus, truth or bunk, so before you soar into cyberspace, you need to know how to evaluate the information you find. The Health on the Net Foundation ([www.hon.ch](http://www.hon.ch)) and the Internet Healthcare Coalition ([www.ihealthcoalition.org](http://www.ihealthcoalition.org)) offer these suggestions for safe surfing:

- Click on websites created by major medical centres, national organizations, universities and government departments. They provide unbiased information based on major research studies.
- Steer clear of sites that rely on personal testimonials, push a single view-point or sell "miracle" cures. If something sounds too good to be true, it probably is.
- Visit several sites and compare the information before forming your own conclusions.

Before enrolling in any clinical trial, you will be provided with an informed consent document, which you should read carefully. The consent form explains the purpose of the trial, the possible risks and benefits of treatment, and all the procedures involved in the trial. Your witnessed signature is required. It is important that any questions or concerns you have about the research trial are addressed to your satisfaction *before* you sign the consent form. Research trials have risks and benefits. It is possible that the treatment could improve your health or quality of life, but there may be side effects, which can vary from person to person. Be sure to read about them in the consent form.

Clinical trial participants also have responsibilities, which you must understand before beginning. You need to attend all your appointments, follow instructions carefully, and take medications exactly as prescribed. All of these are vital if the information from the trial is to be valid.

Deciding to participate in a clinical trial is *your* decision. Even after signing the consent form, you don't have to continue if you feel uncomfortable about it. You have the right to leave the study at any time.

Questions to ask about a clinical trial

- What is the main purpose of this study?
- How will the study affect my daily life?
- Can I continue to take my usual prescription or over-the-counter medications?
- How many office visits are required and how long does each take?
- What kind of medication is involved and is there a chance I will get a placebo (a product with no active medicinal ingredients) instead?
- What type of procedures are involved (e.g., blood tests, x-rays)?
- What are the possible benefits?
- What are the possible risks and side effects?

## **Safety first**

Even if you choose not to disclose your lupus to people around you, wear a MedicAlert® bracelet or medallion and carry the MedicAlert® card in your wallet, especially when travelling. These are recognized around the world and could save your life in a situation in which you cannot speak for yourself. Ask your pharmacist for details.

*\*Adapted from “A Treasury of Comfort” by Sidney Greenberg.*

### **Information for friends and family – how you can help**

When a loved one tells you that they have a serious, chronic illness, it is often difficult to know what to say and how to help. Some people become distant for fear of saying or doing the wrong thing. Here are some suggestions to help you help someone with lupus:

- Don't try to boost their spirits if they are not feeling receptive to it.
- Don't try to divert them. If the topic of their health is on their mind, then it is important to talk about it. Allow the person the opportunity to talk about their illness and their feelings.
- Try not to be afraid to talk about the illness.
- Reassure, don't argue.
- Swing into action, Get them out of themselves.
- Don't be afraid of causing tears. You shouldn't feel like you're walking on eggshells around the person.
- Communicate – don't isolate.
- Perform some concrete act. You might offer to help with a chore such as grocery shopping or cooking. You might ask “how can I help you?”

**A person with lupus may experience some of the following symptoms;**

- **joint pain, sometimes with swelling**
- **a red rash across the upper cheeks and bridge of the nose**
- **extreme fatigue**
- **an unusual reaction to sunlight**
- **fever (a body temperature above 38 degrees C**
- **a red scaly skin rash**
- **small ulcers inside the nose or mouth**
- **chest pain, worse when lying down or inhaling**
- **swelling of the feet and legs**
- **seizures or severe neurological symptoms**
- **hair loss**

This is far from a complete list of symptoms. Also, some findings are apparent only in blood tests. Thus the diagnosis of lupus must be made through a doctor.

### **Living with lupus: what to expect**

As a chronic illness, lupus is different for each individual. 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” phase, when symptoms may disappear completely for long periods, 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 for people to practice good health and lifestyle habits that will help maintain their well-being.

Lupus diagnosis and treatment are improving. Today it can be treated and controlled. More and more people with lupus are finding that they can be active and productive.

### **What about treatment for lupus?**

While there is no cure yet, with treatment, most people with lupus can look forward to a normal life expectancy. There are many medications that can control symptoms. The treatment plan will depend in part on the type and severity of symptoms.

### **What can I do to live well with lupus?**

One thing that makes a huge difference in living with lupus is the person's role in controlling the disease. We can deal better with the challenge of living with lupus by learning all we can about the condition and by being aware of how our own body reacts.

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.

The strong support of family and friends can be equally important. Membership in lupus organizations can also be helpful and informative.

### **What is happening in research?**

Many doctors and scientists are investigating the causes of and cure for lupus. At medical centres worldwide (including Canada), research has led to improved tests and techniques for diagnosis and better methods for predicting flares. These allow doctors to start treatment sooner, which may improve chances for success.

As part of research, many centres collect and store patient information and statistics. The results of this data can help doctors and patients make better decisions about treatment for an increasingly wide range of symptoms. This, along with today's advances in technology, greater awareness about lupus, and the promise of a cure, gives hope to all whose lives are touched by lupus.

There are many new medications currently being studied and we hope to have many new options for treatment in the coming years.

To learn more about research happening in Canada, visit the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS) website at [www.CaNIOS.ca](http://www.CaNIOS.ca). Lupus organizations across Canada continue to support the work of CaNIOS.

### **Where to find out more about lupus**

Lupus Canada, the Member Organizations and Divisions across Canada can answer many questions and tell you about local programs and services to support people with lupus. The websites also contain vital information, research updates, personal stories, practical resources and links that are helpful to people with lupus and their supporters. Visit [www.lupusontario.org](http://www.lupusontario.org).

#### ***For more information:***

- ***Lupus Canada: [www.lupuscanada.org](http://www.lupuscanada.org). This site includes electronic versions of the Living Well with Lupus fact sheets.***
- ***Lupus Ontario: [www.lupusontario.org](http://www.lupusontario.org).***
- ***The Arthritis Foundation: [www.arthritis.ca](http://www.arthritis.ca)***

requires accommodations on the employer's part (for example, scheduling periodic rest breaks), the employer has an obligation to try and meet your needs up to the point of undue hardship. On the other hand, if you can't meet the job requirements because of your lupus, your employer may have to terminate your employment. You can check with provincial employment standards or an employment lawyer to ensure your rights are being respected.

If your lupus flares after you have been hired, your job is protected. It is a violation of human rights legislation to fire a person after discovering they have a chronic or progressive disease. It may make sense for you to tell your employer and co-workers about your lupus at some point. If they are aware that you have health issues, being secretive may create unnecessary anxiety for you and your co-workers. Provide a brochure or other information about lupus, as understanding the illness may make them more comfortable. Explain how lupus affects you in terms of doing your job. If you require accommodation, tell your employer what you will need to continue to work.

### **At school**

Colleges and Universities usually have a department that provides assistance to students with disabilities or health conditions. Assistance varies by school, so if you're in the process of applying for post-secondary education, find out what services are offered. If you are a new student, make contact with the staff early on, even if your lupus is stable at the moment. It's better to introduce yourself now than when you're stuck in the hospital and about to miss an exam.

These departments can help with many problems. For example, if your joints are too swollen to write or you have trouble concentrating in class, they may arrange for a note taker to help you. They may also arrange extra time for you to write exams, or ask the professor to provide an exam in an alternate format (for example, you could give verbal replies rather than written ones). The staff can also look into physical accommodations, such as accessible dormitories and single dorm rooms that would allow you to get more rest than if you had a roommate. They can also help you with dietary concerns (for example, if your dorm's meal plan isn't suitable).

You are not obligated to tell your professors that you have a chronic illness, but again, it may be better to discuss this with your professors early on, even if you're feeling well, in case you have a flare during the school term and require extra time to hand in an assignment or need to make up a missed test or exam (they may request a doctor's note).

### **Insurance\***

Unfortunately, human rights regulations do not apply to health insurance policies the same way they do to employment. Health insurance companies have the right to question you about your medical history and to refuse coverage based on that history. Even if the health insurance company doesn't ask you directly about lupus, you must disclose all information about your health. If you don't, the company can void your policy. Still, health insurance companies have different policies, so be sure to shop around even if you are refused coverage the first few times. The same principles apply to cancellation and medical coverage insurance when you are planning a trip.

*\*Adapted from "The disclosure dilemma. Should I tell? Must I tell?", Diabetes Dialogue, Spring 2003.*

**Express your needs:** Some people will respond to your news with a sincere and immediate offer to help in whatever way you need. Others may worry that you will expect them to help more than they want to. Regardless of your audience, be sure to explain clearly what you need from them, even if it's just their understanding.

**Educate:** Lupus is poorly understood by the general population, so there is a good chance that people will have no idea what you're talking about or will react based on misinformation about the disease. And because there are often no outward signs of lupus (or the steroids you take give you a "healthy, rosy glow"), there may be some disbelief or skepticism about your symptoms. Informing people about the facts of lupus will help them understand how it affects you and what you are capable of. Offer them brochures or the "Living Well With Lupus - Facts" booklet to find out more about the disease or direct them to reliable lupus websites.

**Listen and understand:** Don't be so focused on what you have to say that you forget to listen to the other person and empathize with them – just as you want them to do for you. They will have questions and concerns, just as you did when you first heard your diagnosis. People's reactions to your news will depend on your relationship with them. The closer you are, the more emotional they may be. Your parents may feel guilty, your husband angry, your best friend frightened. Although these emotions may seem like an extra burden to you, recognize that they come from concern for you. The greatest support you, your friends and your family can offer is to listen to each other.

**Get help:** In some situations, it is helpful to involve a third party. At work, you may want to ask someone from Human Resources or your Employee Assistance Program to help you talk to your boss. At home, a social worker can help your family cope with and understand your disease.

### **At work\***

The fact that you have lupus is your business, and you have the right to keep that information private, even at work. During a job interview, it is illegal for an employer to ask specific questions about your medical history. They can only ask questions directly related to the job you are applying for. For example: "Are there any circumstances in your life that might prevent you from fulfilling the requirements of this job?" or "Do you foresee a problem with attendance?" "If you are reasonably sure that your lupus won't interfere with your ability to show up and do your job, then there may be no need to mention your disease. It is your choice as to whether or not you disclose your health information. The exception is if you are applying for a "safety-sensitive" position (such as an airline pilot or police officer), in which case you must disclose any medical condition that could jeopardize the safety of your coworkers or clients. However, some people choose to tell their employer about having lupus – this could help you to determine how supportive your employer and work environment may be to people with health conditions. But be aware that talking about your health during the interview process could have an impact on an employer's decision to offer you a job. Once hired, you are not required to tell anyone about your condition except if your employer has an absenteeism policy that requires you to provide a medical certificate if you have been absent for a prolonged period of time. You may also have to disclose your medical condition to your employer if you are claiming employee benefits and your company requires claims to be submitted to them directly. Although infrequent, some employers require all staff to have a medical examination for health-benefit purposes. If the exam reveals your lupus (or any other medical condition), this information is not to be shared with your employer. If your condition

## **Blood Disorders in Lupus and Lab Tests That Detect Them**

Blood disorders are common in SLE. Many of the clinical and laboratory manifestations of lupus concern the cells and clotting factors that circulate in the blood. Some important blood issues in lupus include low hemoglobin or red blood cells (anemia), low platelet counts (thrombocytopenia), and excess blood clotting (thrombosis). It is worth noting that problems in the blood (and other types of lupus activity, such as inflammation of the kidneys) can occur without any outward symptoms.

There is no single test for lupus, but the presence of certain antibodies in the blood can help confirm a lupus diagnosis. Antibodies are proteins that recognize and bind to other proteins in the body. Instead of combatting an unwanted foreign agent, such as bacteria or viruses (which is what normal antibodies do), the antibodies in lupus may react against our own proteins and cells, and may interfere with the normal function of body organs or tissue. Such antibodies may be detected by lab tests.

### **Components of the blood**

Blood is made up of cells and serum, a liquid full of protein that also contains antibodies. The cells include:

- red cells (erythrocytes), which contain the oxygen-carrying molecule hemoglobin;
- white cells (leukocytes), which fight infection and can be subdivided into several types (neutrophils and lymphocytes being particularly important);
- platelets, which are involved in blood clotting (special proteins, called clotting factors, are also important).

A full blood count test measures the amount of red cells and hemoglobin, white cells and platelets circulating in the blood. There are also special tests for assessing the clotting properties of blood.

### **Anemia**

A relatively common blood disorder in lupus is anemia, which may affect about half of all people with active disease. Anemia means that there are fewer red cells; therefore less hemoglobin to carry oxygen in the blood than there should be. Hemoglobin is the protein inside red cells that carries oxygen from the lungs to all the tissues of the body. Low red cell counts and the associated low level of hemoglobin in the blood can be the result of antibodies attacking the red cells and causing their destruction, a process called hemolytic anemia. It is more common, though, to have anemia due to poor production of red cells in the bone marrow. This usually occurs as a side effect of general inflammation in the body due to lupus. Anemia is rarely caused by drugs, although this is possible.

Whatever the underlying cause of anemia, the end result is fatigue – a very common lupus symptom – and generally the first and most common symptom of anemia. In more severe cases, the person may become short of breath,

even in the absence of lung disease, because there is not enough oxygen in the blood.

## Leukopenia

A lower-than-normal white blood cell count, or leukopenia, is found on the full blood count in about 95 percent of lupus patients. This is due to the presence of antibodies that destroy white blood cells. Fortunately, this rarely causes a clinical problem because more white blood cells are made by the bone marrow. This means that there are enough of them to fight infection, especially those due to such viruses as influenza.

High doses of certain drugs can also lower production of white blood cells, and this may decrease the body's ability to fight infection. Cyclophosphamide, which is sometimes used to treat more severe conditions of lupus, such as kidney disease, can have this effect. As a result, people taking cyclophosphamide

need to have their white cell count checked regularly so that the drug dose can be adjusted if necessary. This is also true for drugs such as azathioprine, mycophenolate mofetil and methotrexate, although the bone marrow toxicity of these agents at the doses usually used in lupus is lower than that of cyclophosphamide. Regular blood tests give your doctor the chance to prevent this complication by adjusting the drug dose.

## Thrombocytopenia

Low platelets, or thrombocytopenia, in people with lupus is usually due to antibodies and less commonly the result of drug side effects. When the count is very low, there is an increased risk of bruising and bleeding.

## Blood Tests

**Antinuclear antibody (ANA):** A screening test for ANA is standard in assessing lupus because it is positive in almost all patients and is an important diagnostic criterion, though it may become negative in some patients over the course of their disease. False-positive results are fairly common in the general population and the sensitivity and specificity of ANA depends on the technique used. Thus many people with a positive ANA test do not have lupus.

**Anti-Sm:** Anti-Sm is an antibody against a protein found in the nucleus of cells. This test is highly specific for lupus – that is, it is generally only positive in someone with lupus, not in someone without lupus. However, only about 30 percent of people with lupus have a positive anti-Sm test.

**Anti-nDNA:** Another highly specific test for lupus, anti-nDNA is an antibody specifically against double-stranded DNA. Like the test for the Anti-Sm antibody, this test is generally only positive in someone with lupus, not in someone without the disease. Sixty to 80 percent of people with active lupus have a positive anti-nDNA test, and the result can be a useful measure of disease activity. The presence of anti-nDNA is associated with a greater risk of lupus nephritis (inflammation of the kidney).

**Anti-Ro and Anti-La:** These antibodies, seen in about 15-30 percent of people with lupus, are commonly found together. Anti-Ro is found in 30 percent of people with lupus. However, they may be seen in other autoimmune diseases, including the majority of people with primary Sjögren's syndrome. Anti-Ro is associated with photosensitivity, and both are associated with neonatal lupus (a condition occurring rarely in babies born to women with lupus.)

## Talking About Lupus

### "I have lupus"

If you have Systemic Lupus Erythematosus (SLE), these may be the most difficult words you ever speak. How, or indeed, whether you tell people that you have lupus is a personal decision. But it is important to remember that dealing with a chronic illness requires support, and people cannot offer their help if you don't tell them what you need.

### Reaching out

All too often, people with chronic diseases such as lupus are hesitant about telling others about their condition. Particularly if you are young, it may be difficult to reveal what you perceive to be a weakness or something that sets you apart from your friends and colleagues. You may fear their reaction: will they reject you? Pity you? Dismiss your symptoms? Treat you differently than before? Even with friends and family with whom you have shared your diagnosis, you may hesitate to talk about how you feel (emotionally and physically) for fear of becoming burdensome.

However, failing to communicate with the important people in your life isn't the way to deal with these fears, as isolation often leads to depression, stress and ultimately poorer lupus management. Open communication, on the other hand, gives others the opportunity to help support you through the challenges that lupus presents.

For example, one American study on the impact of lupus on married couples found that women with lupus who shared their problems and feelings with their husbands during a lupus flare fared better than other women with lupus who experienced less emotional intimacy with their spouses. The researchers concluded that sharing their problems and feelings gave wives the opportunity to have their feelings validated and to receive reassurance from their husbands that they were accepted and loved unconditionally even though they were ill.

You don't have to share your diagnosis or feelings with everyone in your life, of course. Rather, create a support network of people you trust, such as close friends and family members.

Joining a support group can also be helpful. Lupus is misunderstood by many people, so it is particularly important to have your experiences validated by others who are going through the same thing. Visit the Lupus Ontario website at [www.lupusontario.org](http://www.lupusontario.org) to find a lupus organization in Ontario. If outside Ontario, visit [www.lupuscanada.org](http://www.lupuscanada.org) to find a provincial organization near you.

### How to tell

**Plan ahead:** The first few times that you tell people that you have lupus, you may want to plan ahead and think about what you want to say. Different people need to know different things about the disease. Your employer, for example, will want to know how lupus will affect your ability to work, while your parents may need to hear reassurances that they didn't "cause" your disease through something they did in your childhood.

**Anticipate questions:** Try to anticipate the types of questions that people might ask and prepare to deal with them. Think of a response for questions that you don't want to answer. For example, if a co-worker asks, "Does lupus mean you can't have children?"

### **Disclaimer**

**Systemic Lupus Erythematosus (SLE) is an autoimmune disease that affects thousands of Canadians, mostly women in their child bearing years. Symptoms vary greatly from person to person and treatment is highly individualized. Patients are urged to contact their physician or health care professional with any questions or concerns they might have.**

**Complement:** Complement proteins and their components are markers for inflammation – that is, they help your doctor gauge the level of disease activity.

The most commonly measured components are C3 and C4. These tests are particularly useful in evaluating kidney involvement in lupus and in monitoring the disease over time.

**Antiphospholipid antibodies and lupus anticoagulant:** These antibodies are present in 30 to 40 percent of people with lupus and may cause increased blood clotting (thrombosis).

The antibodies can be detected by a specific test for the type of antibody, or by abnormalities in conventional clotting tests.

The increased clotting tendency caused by the antiphospholipid antibody or lupus anticoagulant can lead to clots in veins (deep vein thrombosis) or in the major arteries (resulting in heart attack or stroke); deep vein thrombosis can sometimes travel to the lungs, causing vessel blockage known as “pulmonary thromboemboli.” In women, the antibodies may also be associated with recurrent miscarriages (itself likely related to placental thrombosis).

A positive antiphospholipid antibody or lupus anticoagulant test plus the presence of blood clots, blood vessel blockage (pulmonary thromboembolism), recurrent miscarriages or decreased platelets (thrombocytopenia) is called “antiphospholipid antibody syndrome”. Low platelet counts may also be a feature. This syndrome affects about a third of people with antiphospholipid antibody (10 to 15 percent of all people with lupus).

### **Test for kidney disease**

**Urinalysis:** Test of urine (urinalysis) can indicate kidney disease. For example, excess protein in the urine (proteinuria) can be an important indicator of kidney disease. The presence of red blood cells and white blood cells in the urine also may indicate kidney disease; alternately, white blood cells in the urine may indicate a urinary tract infection.

**Serum Creatinine:** Creatinine is a waste product that is excreted by the kidney. Loss of kidney function increases blood levels of creatinine. The concentration of creatinine in the blood can be used to assess the degree of kidney impairment.

**24-hour urine collection:** Your kidneys filter the blood and eliminate waste products, including creatinine. A measure of how efficiently your kidneys are working may be done by analyzing the urine collected over a 24-hour period and calculating the rate of creatinine clearance from the body. Impairment of kidney function by chronic or acute inflammation of the kidney (nephritis) due to lupus results in reduced creatinine clearance. The 24-hour urine test is also used to obtain an accurate measure of protein in the urine.

## Cardiovascular Disease and Lupus

SLE can affect your heart in a variety of ways. Some effects are life-threatening (including heart attacks) and others are much less serious. There are several risk factors for heart-related conditions, many of which can be avoided. It is important that you report any chest pain to your doctor so that together you can determine the cause and, when needed, develop an action plan to lower your risk of developing serious complications.

### The Lupus-Heart Connection

Overall, people with SLE have a five-to-six times greater risk for heart disease than people without SLE. The increased risk is most noticeable in young pre-menopausal women with lupus, who may be up to 50 times more likely to have a heart attack than women of the same age who do not have lupus.

The most common heart condition affecting people with lupus is atherosclerosis. It occurs when cholesterol and other fatty deposits clog the arteries, slowing the flow of blood and preventing the delivery of oxygen and nutrients to your heart and other organs. If atherosclerosis blocks the flow of blood to your heart, the result may be a heart attack. If the blood flow to the brain is stopped, the result may be a stroke.

People with lupus often have one or more risk factors for atherosclerosis. A study done by researchers at the University of Toronto Lupus Clinic in 2003 found that women with lupus are more likely to have risk factors for heart disease than their counterparts without lupus. These risk factors include diabetes, high blood pressure (hypertension), early menopause and high LDL (“bad”) cholesterol. Women with lupus may also be more likely to have sedentary lifestyles (probably because of joint pain and fatigue caused by their disease). In addition, the use of corticosteroids for lupus treatment can cause excessive weight gain, another risk factor for heart disease.

Smoking is one of the most important risk factors for atherosclerosis, and could take years off your life. It cannot be emphasized enough that quitting smoking is one of the most important steps you can take for your health.

The good news is that you can take action against many of these factors and reduce your risk of heart disease.

### Change What You Can

You may be more likely to have certain risk factors for heart disease because of your lupus, but you can do something about the following:

**High blood pressure:** High blood pressure or hypertension (consistently above 140/90 mmHg) can narrow and eventually block arteries that carry blood through your body. It also strains the heart, possibly leading to heart attack. Very high blood pressure can cause blood vessels in the brain to burst, resulting in a stroke. Hypertension often has no symptoms, so be sure to have your blood pressure checked at least every year. Eating a low salt or low sodium diet, eating alkalizing foods, and adequate water intake can all help lower blood pressure.

**Get active.** The physical functioning of your body has an enormous influence on your mind and your ability to deal with the day-to-day challenges of living with lupus. Pain, fatigue, and a range of symptoms and problems can stand in the way of engaging in physical activity. But it’s important to find ways to do so. With prolonged inactivity, we become less energetic, lose muscle tone and balance, and place ourselves at higher risk for developing further health problems. The key to starting any exercise or activity program, particularly if you have been inactive for a long period of time, is to start slow, set short-term goals you are sure to reach, and begin by doing something you enjoy. Starting an activity program with a friend may give you the added incentive to stick to it. Gradually work your way up to 30-45 minutes of exercise or more at least 5 days each week. Try to weave your activity plan into your daily routine so it becomes a natural part of your day rather than an “extra” that can quickly be dropped if you become busy. The benefits of physical exercise are numerous and can include:

- Stronger bones
- Increased strength
- Improved sleep
- Decreased blood pressure and better cholesterol levels
- Weight loss or maintenance
- Improved flexibility
- Enhanced energy
- Improved stress management
- Better glucose metabolism, especially for type-II diabetics

Consider an occupational therapist (OT) or physiotherapist (PT) consultation to help you learn to overcome barriers or problems as you learn to include activity in your day-to-day routine. Talk to your doctor or other health care professionals about where you could seek the assistance of OT’s or PT’s. They work in the public health care system and in private practice settings.

**Stop smoking.** This is the single most important action you can take to improve your health immediately. Smoking can aggravate many problems in lupus, such as Raynaud’s phenomenon, and is well known to increase the risk of cardiovascular disease. Due to the inflammatory nature of lupus, people who have it are already at increased risk of cardiovascular disease. Studies have shown that smoking decreases the effectiveness of anti-malarial medications, a very important treatment for many people with lupus. Talk to your doctor about methods to assist with smoking cessation. A nurse, psychologist or social worker with skills in this area can be of assistance. There are also many community resources, as well as services and programs in the public health system.

**Manage your pain and fatigue.** Some of the physical causes of symptoms in lupus can be related to an increase in inflammation and disease activity in lupus. Pain management in lupus is an important physical measure because, if left untreated, pain can lead to increased fatigue and stress and can contribute to depression.

**Don’t ignore the psychological and spiritual elements of our whole-person wellness.** Improving communication in personal relationships, optimizing your community networks, involvement with organizations and causes that you believe in, and spiritual practices such as prayer and meditation may all be helpful to you as you learn to live well with lupus.

## Learning physical measures

**Avoid sun exposure.** Use a sunscreen lotion that has a sun protection factor (SPF) of 30 or over. The SPF prevents ultraviolet A and B rays from causing rashes and/or activating lupus disease activity. Plan outdoor activities to avoid the most intense times of sun exposure between the hours of 10 a.m. and 3 p.m. Wear loose, protective clothing that covers the arms and the legs.

Protect your face with a large brimmed hat. Remember that the intensity of ultraviolet rays increases at higher altitudes, so if you are hiking or skiing in the mountains, be more cautious.

**Eat well.** Optimize healthy food choices. This sounds so simple, but it is difficult to change a pattern of eating foods that, over the years, could be aggravating or causing additional health problems that may or may not be related to lupus. Start by considering and following these few simple “wellness tips”:

- Balance calories consumed with calories burned; the amount of physical activity required to burn off high calorie, fast food meals is much higher than the activities required for lower calorie, generally healthier foods.
- Select natural foods, they are healthier and more nutritious; fast food or prepackaged foods tend to have more calories and fat.
- Choose foods which contain plenty of complex carbohydrates and fibre. This includes a variety of grains, nuts, vegetables and fruits. Ensuring a diet that includes more than 5 servings of different fruits and vegetables per day will help optimize health – enhancing nutrients.
- Keep yourself well hydrated with water – normally at least two litres of water every day. However, some people, for medical reasons such as kidneys or heart failure, should restrict this intake; discuss with your doctor in these cases.
- Be aware of the fat you consume, lower your intake of animal fats (saturated fats), which tend to contribute to heart disease and cancer. Fish oils may be beneficial for those with lupus. Some studies suggest that a diet including fresh cold water fish, such as salmon, or fish oil supplements (containing omega-3 fatty acids), might have a modest anti-inflammatory effect. Watch out for trans-hydrogenated fats (commonly found in processed foods) as these have been linked to heart disease.
- In place of saturated and trans-hydrogenated fats, substitute unsaturated fats, as found in fish, nuts, seeds, and some vegetable oils, especially olive oil.
- Although there is no strong evidence that particular Vitamins or minerals are helpful to maintain health in lupus, it is known that in general, Vitamin C and Vitamin E may have anti-inflammatory effects. B complex Vitamins are popular as “anti-stress” Vitamins. A multi-Vitamin containing at least 400 IU per day is a good choice for lupus patients, since this may help maximize bone strength. Recommendations for optimizing bone strength include 400-800 IU of Vitamin D and 1000-15000 mg of elemental calcium per day as a minimum. If you are taking corticosteroids, if you are menopausal, or if you have osteoporosis (bone thinning) or a history of fractures, you need specific instruction from your rheumatologist about calcium and Vitamin D. Also note that if you have problems with kidney function, daily recommended amounts of calcium and Vitamin D may be quite different, so you need to speak to your specialists about this.
- Avoid extreme diets, and be wary of those that promise ‘miracle results’.
- Many people believe that a healthy breakfast every day is a helpful, energetic start to wellness.
- Limit your intake of caffeinated coffee; to avoid problems with sleep disturbances don’t consume caffeinated beverages late in the day. Cola beverages have been associated with osteoporosis, so try to stay clear of these.

**High blood cholesterol:** LDL cholesterol (the “bad” cholesterol) and triglycerides are types of fat that can clog your arteries and lead to heart attack or stroke. High blood cholesterol levels are associated with high-fat diets, smoking, inactivity and family history. Eating a balanced whole foods diet including white kidney or cannellini beans and lentils, being physically active and smoke-free, and reducing your salt and alcohol consumption can significantly reduce your cholesterol levels. Some people may also require medication known as statins to manage their blood cholesterol.

**Physical inactivity:** Being inactive can double your already higher-than-average risk for heart attack and stroke. Although activity can sometimes be challenging for people with lupus, especially during a flare, you don’t have to exercise strenuously to enjoy the health benefits of active living. Start with a goal of 30 minutes of low-impact activity, such as walking or gardening, each day. Gradually increase the amount and intensity. If activity causes pain, consult your doctor.

**Diabetes:** More than 80 percent of people with diabetes die of heart disease, so if you have lupus, it is especially important to take steps to prevent the development of type 2 diabetes or, if you already have diabetes, to carefully manage your blood glucose levels. Contact the Diabetes Canada for information about diabetes prevention and management.

**Excess weight:** It is not just how much you weigh, but also the distribution of excess weight that can put you at high risk of developing heart disease, high blood pressure, high cholesterol and type 2 diabetes. People who carry extra weight around their middle (apple shape) versus around the hips (pear shape) are at greater risk for health problems. Even a modest reduction in weight – as little as 10 per cent – can significantly reduce your chances of having a stroke or heart attack or developing type 2 diabetes, and dramatically improve your overall well-being.

**Smoking:** The health risks associated with smoking (including exposure to second-hand smoke) are well known: it contributes to atherosclerosis, increases the risk for blood clots, reduces oxygen in the blood, increases blood pressure and LDL cholesterol, and stresses your heart. As mentioned earlier, quitting smoking is one of the most important steps you can take for your heart health.

**Excessive alcohol consumption:** While there is some evidence that a moderate amount of alcohol (particularly red wine) may be good for your heart, too much alcohol can contribute to health problems. How much is too much? If you drink alcohol, limit yourself to not more than one or two standard drinks (one bottle of regular-strength beer; one 5-oz glass of wine; 1 1/2 oz of spirits) a day, to a weekly maximum of nine drinks for women and fourteen for men. Check with your doctor or pharmacist to ensure it is safe to drink alcohol with your lupus medications.

**Stress:** like excessive weight and inactivity, stress presents a double-whammy for people with lupus, increasing not only your risk for heart disease, but also lupus flares. In addition, many people handle stress with unhealthy strategies, such as smoking, drinking and overeating. It is important for you to learn how to reduce and deal with stress in your life. Some strategies include exercise, yoga and other forms of meditation or relaxation techniques. If necessary, talk to your doctor about counselling or medication.

**Lack of Restorative Sleep:** An inadequate amount of restorative sleep puts you at risk for cardiovascular disease, adrenal stress, increased gastrointestinal problems to name a few. If you wake up not feeling rested, ask your doctor if an overnight sleep test in a sleep lab and a consultation with a sleep specialist can rule out or confirm a sleep disorder. Practice good sleep hygiene which means going to bed at the same time every night, no eating or heavy exercise for two (2) hours before bed, no caffeine after 12:00 PM, no excessive alcohol or recreational drug use. Remove all electronics from your sleeping environment which include TV, computer, cellphone or any other device that emits blue light or electromagnetic pollution.

### What you can't change

Some risk factors for heart disease can't be changed. These include:

- **Your Sex:** Men over the age of 55 and post-menopausal women are at greater risk for heart disease.
- **Increasing age:** The risk of heart attacks and stroke increases as you get older.
- **Race/Ethnicity:** People of Aboriginal, African or South Asian descent are more likely to have high blood pressure and diabetes, and are therefore at greater risk for heart disease and stroke than the general population.
- **Family History:** Your risks are higher if a sibling or parent developed heart disease before age 55 or had a stroke before age 65.

If you have any of these non-modifiable risk factors for heart disease, in addition to your lupus, it is all the more important that you take positive steps to reduce your risks in other areas.

### Take Action!

- Lead a healthy lifestyle: eat a balanced whole foods diet, be physically active and live smoke free.
- Achieve and maintain a healthy weight.
- Examine how you deal with stress and find healthier ways to cope.
- Limit your alcohol intake to one to two drinks per day, to a weekly maximum of 9 for women and 14 for men.
- Visit your doctor at least once a year for a check-up, which should include blood pressure and cholesterol monitoring and testing for diabetes. Find out what your blood pressure, cholesterol and blood glucose target levels are, and work closely with your healthcare team to meet those goals.
- If your waist measures more than 102 centimetres (40 inches) for men or 88 centimetres (35 inches) for women, talk to your doctor about weight loss strategies.
- Make healthy eating a lifestyle commitment; avoid fad diets.
- Eat a balanced diet by following the "Eating Well with Canada's Food Guide". Enjoy a variety of foods, and emphasize whole grains, cereals, vegetables and fruit. Avoid saturated and trans fats. Choose lower-fat dairy products, leaner meats and foods prepared with little or no fat. When you do use fats, use olive oil, which is flavourful and high in desirable monounsaturated fat rather than polyunsaturated and saturated fats.

- Challenge your expectations. Some people are perfectionists, constantly striving for excellence. A lifestyle of compulsive perfectionism can become physically and emotionally damaging to a person coping with lupus. Adaptation to new challenges can be encouraging and fulfilling. A new challenge to consider, if you have a tendency to perfectionism, is to perfect the art of adjusting your goals. Be flexible in adjusting your expectations and you may be rewarded with a more positive attitude and increased activity. Keep the outcome secondary and enjoy the process of learning and developing yourself.
- Boost your self-esteem. Maintenance of a strong sense of self-worth is vital to keeping yourself healthy. The better you feel about yourself, the more you'll care about supporting a healthy lifestyle. All the previous suggestions for learning to express and manage emotions and controlling negative thoughts will help you feel more confident in your abilities and improve your self-esteem. Follow these simple guidelines if you have days when you need a bit of support and inspiration:

People who live well with lupus and successfully cope with its challenges share certain characteristics. They have insight and understanding into their personal strengths and weaknesses and have realistic expectations of themselves. They can define their personal goals and find gratification in their accomplishments. Living well with lupus requires a strong sense of self-worth and a feeling of control over their life events. People who live well with lupus believe they can influence their world and shape the course of their illness in their life.

- Structure your day with small goals you can meet.
- Talk to a friend. You know who is willing to take the time to listen.
- Spend time with other people. It helps to feel connected and less alone.
- Help someone. Your life does make a difference to other people.
- Treat yourself to something you enjoy. You are special and you deserve a gift from yourself.
- List the reasons you are liked. People enjoy being with you and it helps to remind yourself of that.
- List the things you do well. Then do one of them.

### Preventative coping strategies for physical health

Lupus is a lifelong, incurable disease that may require lifestyle changes and adjustments. The challenge facing many of those living with lupus is that the disease can affect many aspects of daily life, such as physical functioning, the ability to work outside the home and earn an income, and socializing with friends and family. People living with lupus often need to adapt to complicated medical regimens to control symptoms and prevent disease flares. Making gradual and achievable lifestyle adjustments can help improve quality of life and provide a sense of well being.

Each person with lupus experiences different signs and symptoms so a personalized learning plan is needed. To help yourself live well with lupus, it's important to learn physical measures and develop preventative coping strategies. Some of these approaches may be useful in your situation and others may not be practical. Start with something you think might be enjoyable and something you will be able to accomplish. This will give you confidence to try other methods and will make it easier to add to your own personal plan.

- Deal with emotions. Acknowledge your losses. Try and define what you have lost. People with lupus frequently talk about losing friends, independence, energy, confidence, job satisfaction, financial security, or their prior healthy selves. These are serious losses and the feelings associated with them need to be recognized and understood as a grieving process. This process takes time and talking about your feelings will move you closer to emotional healing. Feelings associated with grieving are depression, anger or frustration, guilt and shame, denial, and acceptance. Give yourself time and admit to your feelings with supportive friends, family or health care providers. The skills of a counsellor, therapist, or spiritual resource may also be consulted for difficulty in coping with emotions. Explore creative ways of helping you deal with emotions, such as music, exercise therapies, art, or journal writing.
- Don't ignore the spiritual elements of your whole-person wellness. Improving communication in personal relationships, optimizing your community networks, involvement with organizations and causes that you believe in, and spiritual practices such as prayer and meditation may all be helpful to you as you learn to live well with lupus.
- Practice positive thinking. Self-talk is the endless stream of automatic thoughts that run through your head every day. Automatic thoughts can be positive or negative. Life after a diagnosis of lupus is different. You are still the same person, but you become aware there are some things about your disease that you cannot control. Some people with lupus can have recurring negative thoughts, such as "I can't do my job anymore" or "I won't be able to take care of myself or "Nobody will ever want to date me". These negative thoughts influence behavior that can sometimes lead to feelings of failure or inability to cope with or alter problems associated with lupus.

Our thoughts and belief systems inform how we think about events in our lives. It's not necessarily the event that occurs, but the thinking about the event that stirs up the trouble. This can feed into a vision of a sad past, negative present and an unhelpful future. Negative thoughts are hard to give up because they serve a useful role at times, such as to protect you from risk, such as risk of failure or rejection. Studies have shown that negative thinkers who focus on their inability to control physical symptoms and emotional problems in their life are more likely to become depressed and physically inactive. Changing from a negative to a positive thinker involves developing awareness of negative thoughts. The process is simple, but takes time and practice. Stop and evaluate what you're thinking throughout the day.

Put a positive (reality-based) spin on your negative thought. Be gentle and encouraging to yourself and don't say to yourself anything you wouldn't say to someone you care about.

Example:

Negative thought – "I can't do all that I used to. I'm no longer competent". Positive thought – "I can do much of what I want to. I can be actively involved in life, as long as I don't overdo it".

To manage stress and emotions, become aware of such negative thoughts and learn to confront them with reality and you may be able to change them. Work on one or two thoughts that you think you can change to make a positive difference in your life with lupus. Make a list of your negative thoughts. Counter them with the real situation. Eventually, your self-talk will automatically become positive.

- Control portion sizes. An easy method for determining meal portions is to use two open hands as your measure for vegetables; one closed hand for carbohydrates, such as whole grain pasta or brown rice, potatoes, corn, beets, sweet potatoes, turnips, carrots, etc., one closed hand for fruit; the palm of your hand for meat/poultry, fish, legumes, lentils or other protein alternates; and the tip of your thumb for fats, such as oil, margarine or butter.
- Live smoke-free. That includes quitting smoking and avoiding secondhand smoke.
- Try to be physically active for at least 30 minutes most days of the week.
- Here's a fun and easy way to increase your activity level: challenge yourself to walk 10,000 steps a day. Wear a pedometer (available at drugstores and electronics stores) while doing your daily activities to measure your progress.
- Listen to your body. Talk to your doctor if any activity causes pain.
- Get help. Ask your doctor for referrals to a registered dietitian, certified diabetes educator and/or physiotherapist as needed. Check the "For more information" section of this booklet for helpful resources.

### **Is it your heart?**

Many people with lupus have chest pains at one time or another. Not all chest pains are a sign of a heart attack. Similarly, shortness of breath may not be a sign of a heart attack, but rather lack of physical fitness.

On the other hand, thousands of Canadians die each year from heart attacks and strokes because they ignore warning signs and don't receive medical treatment quickly enough.

Given your increased risk for heart disease and stroke, it is vitally important that you learn to recognize the warning signs.

#### **Angina**

- Discomfort or pain, generally in the chest, neck, jaw and/or left upper extremity, that is usually triggered by physical activity and relieved with rest and/or medications such as Nitroglycerin. The pain may feel like burning, squeezing, heaviness, tightness or pressure (the pain may be more vague in women).
- Shortness of breath or difficulty breathing, with or without accompanying chest pain, generally triggered by physical activity and relieved with rest and/or medications such as Nitroglycerin.

If you notice symptoms suggestive of angina, seek the attention of a doctor as soon as possible. Note that in some people, severe chest pain and/or shortness of breath, particularly with sudden onset, may signal a heart attack. Very severe, sudden symptoms should be considered an emergency, as indicated below.

#### **Heart attack**

- May begin with the angina-type symptoms described above (pain and/or shortness of breath).
- Pain is usually very severe, comes on suddenly, and does not go away with rest.
- Shortness of breath or difficulty breathing, with or without chest pain
- Nausea, indigestion or vomiting
- Sweating or cool, clammy skin
- Feelings of fear, anxiety, denial

## Stroke

- Sudden weakness or sudden numbness in the face, arm or leg, even if temporary, especially on one side of the body
- Sudden confusion or difficulty speaking or understanding, even if temporary
- Trouble seeing in one or both eyes
- Sudden severe and unusual headache
- Sudden dizziness or loss of balance, especially with any of the above signs

**If you experience one or more of the warning signs of a heart attack or stroke, call 9-1-1 immediately!**

- Consider a cruise. You can visit multiple destinations and enjoy a wide variety of activities without exhausting transfers. Plus, you unpack only once.
- Pack appropriately. Take lots of sunscreen and sun-protective clothing when travelling south. If Raynaud's phenomenon bothers you, bring appropriate clothing.
- Travel with a doctor's note stating that you have lupus and what medications you take. This note is crucial if a prescription refill or medication adjustment is needed while you're away, and it can help you avoid problems at airports. Make sure the note includes each drug's generic and brand names (brand names may differ in other countries, including the United States). In addition, some medications are illegal in other countries, so the doctor's note is particularly important. If necessary, have the letter translated before you leave. Keep a copy in your wallet and another in your luggage.
- Keep medications in their original containers with prescription labels attached.
- If you inject any medication, check with the airline regarding its policy on syringes in carry-on luggage. Each airline has different rules and regulations.
- If you need to take your medication with water and you're unsure about the safety of the water in the country you're visiting, carry bottled water.
- Err on the side of caution when packing your medical supplies. For example, carry a supply of your medications in both your carry-on bag and stowed luggage, in case your luggage is lost.
- Fatigue and dehydration are common when travelling, so rest often and keep tabs on your fluid intake.
- Traveler's diarrhea is common. Ask the travel clinic or your doctor whether you should bring over-the-counter medication to treat this.
- Before you leave, visit Health Canada's website at [www.travelhealth.gc.ca](http://www.travelhealth.gc.ca). It lists travel clinics, health advisories and more helpful information.
- Wear a MedicAlert® bracelet. It is recognized around the world and could save your life in a situation in which you cannot speak for yourself.

## **Preventative coping strategies for emotional health**

Developing preventative coping strategies to live well with lupus can involve learning different ways of thinking, feeling, and acting to adapt to the challenges of a chronic illness that affects your entire life. Successful adaptations may involve addressing a variety of areas in your life, including the intellectual, emotional, spiritual, physical and social domains of day-to-day living. Successful coping means minimizing threats to personal integrity and emotional balance, while maximizing body function. The suggestions below may help you learn and develop different ways of dealing with lupus.

- Communicate needs. One of the toughest tasks is learning to say "no", even when doing so is in your best interests. A note by your phone that says "no thanks" can prompt you to say it as needed. Learn to assert yourself when you know that giving in to the wishes of others will cause you emotional and/or physical distress. Assertive behavior is being honest and open with yourself and others, without placing blame or creating feelings of guilt. Using "I" statements conveys honest feelings and concern for others. An example: "I miss spending time with you and I'd like to go hiking with the group. I will join you at the finish of your hike and maybe we could all have a coffee or drink together. I hope you understand".
- Manage your time and your schedule to avoid overbooking and creating stress. Acknowledging your limitations is difficult. You may not have to give up enjoyable activities. You may have to learn to do things differently or to delegate parts of a task. Be flexible when you ask for help. Others may not do things exactly as you would or as fast as you would like.

Just as you need to schedule time to exercise, you should set aside time for rest. You may need to arrange one or two rest periods each day. Rest doesn't necessarily mean napping, although many people with lupus who experience sleep disturbances may benefit from a brief snooze during the day (just don't nap too long, as this can actually increase insomnia).

Planning ahead and pacing yourself will help prevent overexertion and give you the rest periods you need. Look at what you need to do each day or week, set priorities and focus on the most important items while you have your highest energy levels. Build in flexibility so that you can postpone less important items if you become fatigued. If possible, set aside one day a week that doesn't involve any errands or chores.

Don't overwhelm yourself with large projects. Divide activities into several smaller tasks. For example, instead of spending an entire morning housecleaning, spend 15 minutes dusting on Monday, 15 minutes cleaning the bathroom on Tuesday, etc.

Recognize that stress carries a physical and emotional toll. Try different strategies to help you deal with stress, such as support groups, professional counseling or meditation. Include a relaxing, enjoyable activity every day. Reward yourself with scented bubble bath or set aside time to read a great book.

Don't feel guilty about your need for rest. Recognize that it is an important part of your lupus management.

### **Travel without trouble**

Travel can be fun and exciting – but also exhausting. If you have lupus, there is no reason you can't enjoy travelling the world, as long as you plan ahead. Here are some tips that will help ensure a happy, healthy trip:

- Start with a visit to your doctor to discuss your trip in relation to your lupus. Ask what you should consider in terms of avoiding a flare and what immunizations you might require.
- If you are travelling outside Canada or the United States, you might want to consult with a travel health clinic to discuss your immunization needs. Schedule your appointment at least six to eight weeks before your trip, as vaccines can take several weeks to become effective.
- Ask your doctor for a referral to a doctor or health clinic at your destination in case you need medical assistance while away. Alternatively, check with the International Association for Medical Assistance to Travelers to find a doctor who speaks English. You may also want to check the internet for information about any local lupus associations.
- Be sure to get health insurance in case you need medical attention while you are away. Consider trip cancellation insurance (for yourself and your travel companions) so that you won't lose your money if you have to cancel or come home early due to a flare. Review your insurance options carefully before purchasing, since not all policies cover pre-existing conditions. Keep insurance documents separate from other identification to keep it from being lost or stolen, and leave a copy at home.
- Carefully research your trip so that you can match your destination with your capabilities. If you are particularly sun-sensitive, a trip to the tropics might not be the best option. If you fatigue easily, inquire about how much walking is involved in any excursions. If you have a mobility restriction, use a travel agent with expertise in travelling with a disability, and be sure to inquire about wheelchair or scooter access at hotels and tourist attractions you plan to visit.

## **Infections, Immunizations and Lupus**

People with systemic lupus erythematosus (SLE or lupus), especially those who are on immunosuppressive medications, may be at increased risk for a variety of infections. In fact, despite the significantly improved prognosis for this disease over the past two decades, infections continue to be a leading concern in people with lupus. As a result, infection prevention and immunization programs are of critical importance for people with lupus.

### **Why the increased risk of infection?**

Our environment is filled with micro-organisms – viruses and bacteria – that can cause infections. While most people can fight off these invaders with the body's natural defence mechanisms, people with lupus may have impaired immune systems, most often due to the immunosuppressive drugs (including corticosteroids) used to treat the disease. Genetic risk factors may also play a role. Thus, the risk of infection varies from person to person and over the course of each individual's disease.

The risk for specific infections is also associated with certain complications of lupus. For example, nephrotic syndrome, which causes excessive loss of protein in the urine due to lupus kidney disease, is known to increase the risk of serious infections. Other conditions that increase a person's susceptibility to infections include: neutropenia (low white blood cell count), lymphopenia (low number of immune cells in the blood), chronic kidney failure, diabetes and poor spleen function or surgical removal of the spleen. For people with these conditions, vaccination may be particularly important.

### **Types Of Infection**

The two most common types of infections of primary concern to people with lupus are viral and bacterial. Tuberculosis and fungal infections are less common, but also important.

Some individuals with lupus, particularly those on immunosuppressive drugs, are at higher risk for bacterial infections of the respiratory tract, joints and urinary tract. Common viral infections include cold viruses, herpes zoster (shingles) and Epstein-Barr; less common is viral hepatitis. The most common fungal infection in people with lupus is yeast (*Candida*), which can infect the vagina, throat and esophagus.

### **Is it a lupus flare or an infection?**

Fatigue and fever may indicate a lupus flare or an infection. Unfortunately, active lupus mimics infection, and infection not only mimics lupus, but can also cause a flare. It is very important to take your symptoms seriously; don't dismiss them as "just" a flare.

In order to prevent serious, possibly life-threatening complications, infections must be diagnosed and treated as early as possible. See your doctor if you have a fever that lasts for more than a few days; if you also have any of the following symptoms plus fever, you should seek medical advice urgently:

- A headache plus confusion and/or neck stiffness
- A cough productive of sputum or shortness of breath
- Swollen, tender, red and painful joints with limited range of motion
- Chest pain

- Severe abdominal pain
- Nausea or vomiting
- Burning sensation on urination, increased urinary frequency or flank pain

### **Preventing Infections**

If you have lupus, you should live by the motto “An ounce of prevention is worth a pound of cure.” Protect yourself from infections with some common-sense precautions: handle food safely, avoid people who are ill and contagious, eat a balanced diet and exercise regularly.

The most important precaution you can take to prevent infection is to wash your hands regularly and well. That means using an adequate amount of soap, rubbing your hands together to create friction for at least 10 seconds, and rinsing under running water. If soap and running water aren’t available, clean your hands with waterless hand scrubs, such as those made with ethyl alcohol.

Maintaining a healthy gut microbiome is important because 80% of your immune system is in your gastrointestinal tract. Eat a whole foods diet and avoid substances that damage the GI membranes such as your stomach, intestinal mucosal layer, and colon walls. The clean foods help nourish the beneficial bacteria that help keep pathogens in check.

### **Immunizations**

Immunization is another important step in protecting yourself from infections. Health Canada’s *Canadian Immunization Guide* (2002) sets a schedule of when children and adults should receive various vaccinations. If you’ve received any vaccinations since your lupus diagnosis, you likely haven’t had any difficulties. Passive immunization (i.e., vaccines that use a killed virus) appears to pose no additional risks for people with lupus compared to the general population.

Vaccines that protect against polio, measles and mumps, all use live viruses. There are 2 different vaccines to prevent Herpes Zoster (‘shingles’, caused by the varicella or ‘chickenpox’ virus). Current recommendations are that immunosuppressed individuals not be given live vaccines. Shingrix, an attenuated virus, is safe for lupus patients. Do not take the vaccine with the live virus. However, if you have lupus but are not taking immunosuppressant drugs, you may be a candidate for these vaccines. Discuss with your rheumatologist or other doctors.

### **Flu**

More than just a bad cold, the flu (influenza) is a respiratory infection caused by a virus. Although most people recover from the flu completely, an estimated 4,000 to 8,000 Canadians die every year from pneumonia related to flu, and many others may die from other serious complications of the flu. In particular, the elderly, young children and infants are a group at risk.

Health Canada recommends an annual flu shot for people with chronic conditions, including immune suppression. Although flu vaccines are generally considered safe for people with lupus, some individuals may experience side effects. Up to 20 percent of people with lupus may feel sick or achy for a few days following a flu vaccination – that’s about twice as many people as in the general population.

- Set concrete goals (for example: “walk to work three times this week”) and chart your progress. Post an activity chart on your fridge so that you can see how much you’ve accomplished. Give yourself a reward, such as a new workout top or walking shoes, as you reach each goal.
- Do something you like. You are more likely to stick with an activity if it’s fun. Find out what activities your local community centre offers and try something new.
- Mix it up. Incorporate a variety of activities into your life so that you can pick one according to your energy level. Variety also prevents boredom.
- Schedule it. Lack of time is a barrier to regular physical activity for many people. Allot time for exercise, just as you would any other appointment.

**Yoga:** There are many different styles of yoga, so look for one that is gentle and slow-paced, such as Hatha (whose name suggests “balance” in Sanskrit) and Naram (which means “gentle”). By moving the body into specific shapes, yoga helps increase circulation. This, in turn, nourishes the joints. The meditative aspects of yoga are very calming, helping to reduce stress.

**Tai chi:** This slow and gentle form of exercise encompasses a series of positions strung together into continuous movement. It helps improve strength, balance and flexibility, and can be adapted for people of different abilities, including those using a wheelchair.

**Aquatics:** Water-based exercises (usually done in the deep end of a pool using flotation belts) are not only gentle, they enable you to do things you might not be able to do on dry land. Since water is much denser than air, aquatic exercises provide muscle training with less stress on your joints. Plus it’s fun!

**Walking:** Walking is something you do every day – you just need to do a little more. Invest in good walking shoes and buy a step counter or pedometer. These instruments keep track of every step you take and help keep you motivated by making it easy to set targets. Try adding 3,000 steps to your daily total and gradually build up to 10,000 steps each day.

### **Don’t sweat it**

If the idea of exercising conjures images of endless jumping jacks at the gym, think again. Being physically active is not just about running, jumping or sweating. “No-sweat” exercise such as yoga, tai chi, aquatics and walking offer countless benefits for the body, mind and soul. Such gentle exercises release endorphins without the stress hormones you get from high-intensity activities. The result is a more meditative effect, helping you reduce your overall stress; something that’s great for your lupus management. Note, however, that they may not have some of the cardiovascular benefits of more aerobic exercise.

### **Take a break**

As beneficial as physical activity is; rest is equally important. Fatigue is one of the most common symptoms of lupus. By paying attention to your body, you will learn to recognize fatigue before it becomes overwhelming. Don’t ignore these signs, as exhaustion may put you at increased risk for a debilitating lupus flare.

## Learning to Live Well with Lupus

Activity and rest; the yin and yang of good health, especially if you have Systemic Lupus Erythematosus (SLE). On the one hand, regular exercise helps prevent joint stiffness, promotes a healthy weight and reduces stress. On the other hand, rest can also reduce stress, relieve inflammation of joints, restore energy, and help you deal with the fatigue that is so often the hallmark of lupus. Unfortunately, fatigue may prevent you from being physically active, while the lack of physical activity may make you feel even more fatigued! The key is to find a balance that works for you.

### Health in motion

The benefits of physical activity are well known and worth repeating. When you exercise on a regular basis, you:

- Improve your circulation and lung capacity.
- Make it easier to reach and maintain a healthy weight.
- Help prevent health problems that may be associated with lupus, including type 2 diabetes, heart attacks, strokes and osteoporosis.
- Strengthen your muscles and prevent your joints from getting stiff.
- Reduce fatigue and stress.
- Improve your quality of life, overall health and sense of well-being.

With all these benefits to be gained, it's not surprising that exercise is strongly encouraged for people with lupus, especially during flare-free periods.

"Regular physical activity" doesn't mean running marathons or intense sessions at the gym. In fact, starting slow and exercising moderately are key. Remember, overdoing it can be as bad as not doing anything at all.

Your goal should be to work towards a total of 60 minutes of physical activity a day. Sound daunting? It needn't be, especially if you tackle those 60 minutes of activity in 10-20 minute increments. Remember, every little bit counts.

### A few words of caution

- Always check with your doctor before beginning a new exercise routine. Some people may also benefit from consulting a physiotherapist.
- If you are going to be active outside, be sure to wear sunscreen, as exposure to the sun can cause a lupus flare.
- Listen to your body. Reduce your activity level if you notice unusual or persistent fatigue, weakness, joint swelling or pain after exercising.
- It may be wise to limit strenuous exercise during a lupus flare. This is a time when rest is important.

### Getting started

For many of us, the toughest part of exercising is taking that first step. Here are some tips to get you motivated and keep you moving:

- First things first: check with your doctor before starting any type of exercise program. Together, you can work out the type and amount of activity that's right for you.
- Buddy up. Pairing up with a friend will help get you going on days when your motivation is low.

While it is important to receive your flu shot, some studies indicate that flu vaccines may not work as well in people with lupus as in people without the disease. It is best to receive the high dose flu vaccine if it is available. Thus, avoiding contact with someone who is sick, washing your hands well and frequently, remain key to prevention.

### **Pneumococcal Infections**

Pneumococcal infections are caused by bacteria and include infections of the brain (meningitis), bloodstream (bacteremia), lungs (pneumonia) and middle ear (otitis media). They occur more frequently in people with lupus, but may be prevented with the pneumococcal vaccine which Health Canada recommends for anyone with a chronic disease.

This vaccine is very effective for most people with lupus. Although there have been some reports of lupus flares following pneumococcal immunization, large studies have not demonstrated a relationship between the two. In order to maintain optimal protection, you should be revaccinated after five years.

### **Hemophilus Influenza Type B (Hib) and Meningococcal Vaccine**

Hemophilus influenza (Hib) and meningococcus pose significant threat to anyone who cannot properly produce specific antibodies against invading bacteria or other organisms. People whose spleen has been removed or is not fully functional, are at particular risk.

In a study of people with lupus immunized against Hib, there were no serious side effects or lupus flares, and most people developed protective antibodies. However, there are no studies demonstrating the safety or efficacy of the meningococcal vaccine in people with lupus.

If your spleen has been removed or it is not fully functional, vaccination against organisms such as Hemophilus influenza is very important.

In a study of people with lupus immunized against Hib, there were no serious side effects or lupus flares, and most people developed protective antibodies. However, there are no studies demonstrating the safety or efficacy of the meningococcal vaccine in people with lupus.

If your spleen has been removed or it is not fully functional, vaccination against organisms such as Hemophilus influenza is very important.

### **Hepatitis B Vaccine**

Hepatitis B is a serious liver disease that is transmitted by infected blood and other body fluids. Two vaccines against hepatitis B are available in Canada and are strongly recommended for adults in high-risk categories, such as people on dialysis or organ transplant recipients. Thus, individuals with lupus who require dialysis and/or transplant could consider getting this immunization. No studies have been done to assess the role of the hepatitis B vaccine in triggering or exacerbating disease activity in lupus.

### **Gardasil**

This vaccination, against human papilloma virus (HPV), is an option for both males and females before they become sexually active. It prevents HPV infection, which is a sexually transmitted disease without symptoms, that can be difficult to eradicate and can lead to cervical cancer.

## **Immunizations and Travel**

If you are travelling outside Canada or the United States, you might want to consult with a travel health clinic to discuss your immunization needs. Schedule your appointment at least six to eight weeks before your trip, as vaccines can take several weeks to become effective. If you are travelling to Mexico or overseas, you should be aware of any precautions advised by Health Canada (visit <http://www.phac-aspc.gc.ca/tmp-pmv/index.html>) and speak to your physician as far in advance as possible as it may be necessary to attend a travel clinic and get immunizations over a period of time.

## **Here are some helpful tips to manage and get the most from your NSAIDs:**

- Try to take your medication at the same time each day, and try not to miss a dose.
- Know more about which side effects are considered serious enough to require immediate medical attention.
- Do not adjust dosages without the input of a doctor and do not stop taking your medication because you are feeling better. Speak to a doctor first.
- Use a days-of-the-week pill container to organize your medications. This will help you notice when you've missed a dose. Transfer your medications to a portable pillbox when you're eating out or travelling.

## **Balancing Act: Lupus, Activity and Rest**

Sometimes your doctor may recommend taking additional medications, such as acetaminophen or corticosteroids, to manage the pain associated with active inflammation. Always discuss additional medication use, including over-the-counter drugs and herbal medicines, with your doctor. He or she may recommend that you take NSAIDs only when your lupus arthritis is flaring and not take them when in remission. NSAIDs do not suppress the immune system and should not be used as the only treatment for severe lupus disease. People who have an allergy to sulfa drugs should not take the COXIB called **Celebrex® (celecoxib)**. At this time, most rheumatologists are cautious about recommending certain NSAIDs and COXIBs to those at high risk for cardiovascular events.

If you are a woman who is taking NSAIDs and considering pregnancy, check with your doctor before becoming pregnant or as soon as you know you are pregnant. Some NSAIDs may be safely continued if you are pregnant so notify your physician.

**Side Effects:** Common side effects associated with NSAIDs are stomach upset, bloating, stomach pain and heartburn. Sometimes, stomach irritation can lead to bleeding from ulcers in the gastrointestinal tract. The bleeding may be obvious – red blood passed from the bowel or through vomiting – or it may be slower and revealed through dark or black bowel movements. NSAIDs taken with corticosteroids can sometimes mask the pain and discomfort of an inflamed and irritated stomach, so discuss with your doctor other symptoms to be aware of that might indicate you are experiencing stomach inflammation. Adding a stomach-protecting medication to your regime can also help prevent the stomach from producing too much acid. Always take an NSAID with food. People who have had an ulcer in their stomach or bowel should avoid NSAIDs.

NSAIDs can affect kidney function, and nephritis (inflammation of the kidneys) is a common manifestation of lupus. An NSAID can aggravate kidney problems and therefore its use should be monitored closely, which could include regular urine tests to check kidney function. NSAIDs can also start or worsen existing high blood pressure, so you and your doctor will discuss how to obtain regular blood pressure measurements. Home blood pressure kits can be purchased in most retail pharmacies. It is important to know what your responsibilities will be regarding how often to measure your blood pressure and when to report high measurements to your doctor. Your doctor may also ask you to be alert to other physical signs and symptoms. Fluid retention is also another relatively common side effect of NSAIDs and COXIBs.

People with a history of congestive heart failure should avoid NSAIDs, as they can precipitate worsening of this condition. Abnormal liver tests have sometimes been reported, and your doctor may order liver monitoring blood tests after starting an NSAID.

Rarely, skin rashes or hives may appear. This may indicate an allergic reaction, and should be reported to your doctor right away. NSAIDs should not be used by people with asthma who experience increased wheezing or worsening of asthma symptoms.

**Summary:** NSAIDs are generally well tolerated by people with lupus. Remember to take them exactly as prescribed. Take NSAIDs with food to reduce some of the minor stomach side effects. More serious gastrointestinal bleeding side effects may be decreased with the use of a medication to protect the lining of the stomach. Some NSAIDs may be safely continued if you are pregnant. Notify your doctor if you become pregnant while taking NSAIDs.

## Introduction to Skin Diseases

Skin disease is a very common symptom of Systemic Lupus Erythematosus (SLE). Rashes are often the first visible indication of the disease. Eighty per cent of lupus patients will develop some kind of skin manifestation throughout the course of their disease.

There are numerous rashes associated with lupus, but there are three

main types: **Acute Cutaneous Lupus Erythematosus (ACLE)**, **Subacute Cutaneous Lupus Erythematosus (SCLE)** and **Discoid Lupus Erythematosus (DLE)** sometimes referred to as **Chronic Cutaneous Lupus Erythematosus (CCLE)**.

### Acute Cutaneous Lupus Erythematosus (ACLE)

Also known as:

- “Malar rash”, referring to the involvement of the upper cheeks.
- “Butterfly rash”, referring to the unique butterfly-like shape.

ACLE is the most common skin manifestation of lupus and is often referred to as the “lupus mask” due to its distinctive shape and the frequency with which it is seen in patients.

#### **Characteristics of ACLE:**

- Symmetrical (uniform) appearance that covers both cheeks and the bridge of the nose.
- In some cases, the neck and forehead are also affected.
- Skin is red and swollen, similar to a sunburn.
- The rash is persistent, as opposed to other skin changes that last only minutes or hours.

**Causes and long-term effects:** The precise cause of ACLE is unknown. However, underlying lupus activity can trigger the rash. As is explained below, ACLE is photosensitive, meaning that exposure to ultraviolet (UV) light, including the sun, can trigger an outbreak. (Sun exposure can also trigger or worsen a general lupus flare). An ACLE outbreak can last for weeks or longer but once the rash clears there are usually no permanent effects.

### Subacute Cutaneous Lupus Erythematosus (SCLE)

#### **Characteristics of SCLE:**

- Ring-shaped or disk-shaped patches of red, crusty skin.
- Most often develops on skin that has been exposed to the sun or another form of ultraviolet light.

**Causes and long-term effects:** As with most skin diseases associated with lupus, SCLE is photosensitive – it is triggered or worsened by ultraviolet (UV) light. Some patients experience SCLE lesions as a side effect of medications. This type of SCLE usually clears up once the patient stops taking the medication and traditional SCLE treatments with antimalarial medications and corticosteroids begin. Lesions usually heal without scarring, but some skin lightening or darkening can occur.

## **Discoid Lupus Erythematosus (DLE)**

Also known as Chronic Cutaneous Lupus Erythematosus (CCLE), DLE differs from the systemic form of lupus. Patients with DLE only develop skin disease

and do not exhibit other symptoms associated with the disease, such as arthritis.

There are two types of DLE: localized DLE, in which the lesions are primarily located on the scalp and face, and generalized DLE, in which lesions can be located anywhere on the body.

### ***Characteristics of DLE:***

- Only affects the skin.
- Disk or coin-shaped scaly lesions (similar to SCLE).
- Generally found on the scalp and face, particularly the cheeks and nose.
- Usually painless.

### ***Causes and long-term effects:***

Research suggests that patients with DLE are more photosensitive than SLE patients. Because DLE lesions can lead to scarring, it is important for patients to minimize sun exposure whenever possible. If this scarring occurs on the scalp, it can damage hair follicles and lead to permanent hair loss. A small percentage of people with DLE (five to ten per cent), will go on to develop SLE..

It is important to monitor DLE symptoms and discuss any changes with your health care provider.

Every individual with lupus is different and the stimuli that cause a flare will differ from patient to patient. While some causes are common, sunlight for example, others can be as varied as the individual. Medications, foods, environmental factors and any other number of things can stimulate symptoms. By paying attention to their symptoms, lupus patients can identify triggers and learn to avoid them.

## **Treatments**

When a rash is the only symptom, topical treatments, such as corticosteroid creams, are applied directly to the affected skin. To treat persistent or aggressive rashes, corticosteroids can be injected directly into the skin. Anti-malarial medications (chloroquine (Aralen®) and hydroxychloroquine (Plaquenil®) are also highly effective in treating skin disease .

Patients with systemic lupus and/or lupus of the skin should avoid direct sunlight and ultraviolet (UV) light whenever possible. When going outdoors they should take precautions against sun exposure by using sunscreen with a sun protective factor (SPF) of 30 or greater, and by covering their skin.

## **Non-Steroidal Anti-inflammatory Drugs (NSAIDs) and COX-II Inhibitors (COXIBs)**

NSAIDs are commonly used to treat the pain, swelling and inflammation of arthritis that occurs with systemic lupus erythematosus. They can also be used in combination with stronger anti-inflammatory and immunosuppressive drugs to treat serious inflammation of major organs. Consult your doctor before taking any NSAID. He or she will consider all the factors, including your medical history and other medications you are taking, that may influence the risks and benefits of taking an NSAID.

### ***Types of NSAIDs:***

Patients with lupus along with their physicians can choose from several prescription or over-the-counter types of NSAIDs. COX-II inhibitors (COXIBs) are a new chemical class of NSAIDs. Responses will vary from person to person as each medication has a different chemical formula. The action of each drug will vary depending on disease involvement and dose. NSAIDs are used primarily in pill form and taken by mouth. They can also be applied as creams or given in a suppository. Consider effectiveness, cost, side effects and ease of use when choosing an NSAID.

### ***The action of NSAIDs:***

These medications work by blocking enzymes known as cyclo-oxygenase enzymes (COX). There are different types of COX enzymes. COX-I enzymes produce prostaglandins that protect normal body organ functions, such as the maintenance of a protective stomach lining and ensuring normal blood flow in the kidneys. COX-II enzymes produce the prostaglandins that accompany the immune response and inflammatory process. The prostaglandins produced by the COX-II enzymes cause the pain, swelling and redness of the inflammation. Traditional NSAIDs block COX-I and COX-II enzymes. The newer COXIBs primarily block COX-II enzymes.

***Old vs new:*** ASA (Aspirin or acetylsalicylic acid) is one of the oldest NSAIDs in use. Over the past two decades, several types of the NSAIDs have been introduced. Some of these can have undesirable gastrointestinal side effects due to their COX-I blocking effect. Examples of these medications are indomethacin, ibuprofen, naproxen and diclofenac. Today, in addition to the greater number of standard NSAID and dosing choices, the newer COXIBs may have less risk of gastrointestinal side effects. Some COXIBs have recently been withdrawn from the market because of an increased risk of cardiovascular events, such as heart attacks and strokes. Researchers continue to study their safety and effectiveness.

**What to expect:** As all NSAIDs are chemically different, your doctor will advise you what dosage and how often to take each medication. NSAIDs should reduce pain and swelling associated with lupus arthritis. The effects of taking an NSAID can sometimes be felt after a few hours or sometimes it may take several days. If no positive effects are felt after several weeks, the drug may not be of much benefit. You should not take more than one type of NSAID at any time. NSAIDs and COXIBs are generally not combined.

**Leflunomide (Arava®):** Leflunomide is an anti-inflammatory medication that can help to reduce the pain and swelling of arthritis and can decrease damage to joints. Like cyclosporine, this medication is not used very often in lupus treatment.

**Cyclosporine (Neoral®):** Originally developed to prevent rejection of kidney and other organ transplants, cyclosporine has been used to treat rheumatic diseases, including lupus. This medication modifies the immune system without decreasing cell counts. However, it may elevate blood pressure and reduce kidney function. For these reasons, its use in lupus treatment has decreased.

**Rituximab (Rituxan®):** is a drug based on a protein (an 'antibody') that works by decreasing the activity of white blood cells known as lymphocytes. Studies of people with severe lupus who did not respond to initial treatment with other drugs and were then treated with rituximab have shown great promise. Because this drug is relatively new, must be given by injection, and is very expensive, it is reserved for very severe cases. Recently, reports of a rare but serious complication have arisen, related to a brain infection causing death. However, this drug has been used safely in many people with severe lupus who did not respond to other treatment; thus, rituximab is an option for difficult cases.

**Benlysta™ (Belimumab®):** BENLYSTA™ is a prescription drug used to treat adults with lupus. This medication was approved in 2012 by Health Canada for use in lupus patients. It is also an antibody therapy, like rituximab. People with active lupus often have high levels of a certain protein in their blood. BENLYSTA™ binds to the protein, and it is through this pathway that the drug is believed to work in SLE. This drug is given by infusion, in people with SLE who have not responded to other agents. For more information, speak to your rheumatologist.

**Orencia (Abatacept®):** This drug is, like rituximab and belimumab, an antibody therapy. It is helpful for people with inflammatory arthritis such as rheumatoid arthritis, and some people with SLE have been treated with this drug, when the patient has inflammatory arthritis.

### **Risks and Benefits**

When considering cytotoxic drug therapy, it is important to weigh the benefits against the risks. Doctors use the term "risk-benefit ratio" to describe the comparison of a medication's side effects and beneficial effects. While cytotoxic medications are generally not used if your lupus is mild, these drugs may be very helpful and even life-saving if your lupus is quite active and symptomatic or if you have major organ involvement. Your doctor may order a kidney biopsy or other tissue biopsy before recommending one of these drugs.

### **New treatments**

Researchers continue to look for more effective lupus treatments. Some studies have focused on blocking the expression of genes that may cause some of the symptoms of lupus. Many advances have been made, and trials of such agents are underway, although it may be some time before they are routinely used in lupus treatment.

## **Kidney Disease and Lupus**

Systemic Lupus Erythematosus (SLE) can cause inflammation in major organs. Many, if not most, people with lupus may have some involvement of the kidneys. Sometimes the kidneys are not affected in a serious way, but "lupus nephritis", a potentially serious complication of lupus, can be very grave and often requires immediate medical treatment to prevent permanent damage.

Lupus nephritis has very few signs or symptoms – it can remain undetected for a long period of time. That is why it is important for people with lupus to have regular medical checkups and urine tests, even if they are feeling well or their lupus has been calm for months or years.

### **How Lupus Affects the Kidneys**

Your kidneys are two bean-shaped organs located in the middle of your back, below the rib cage, one on each side of your spine. They are each about the size of a fist. The main function of the kidneys is to remove waste products and other toxins from the body. Each kidney has about one million tiny filters, or glomeruli. Each glomerulus is attached to a tubule (this glomerulus-tubule team is called a nephron). Blood is filtered in the glomerulus, and waste and extra water are collected in the tubule, where they become urine. The urine moves from the kidneys to the bladder through tubes called the ureters and is then passed out of the body.

In systemic lupus, the immune system is overactive, producing antibodies to the body's own tissues. The antibodies combine with the tissues to form immune complexes in the bloodstream. They can cause inflammation, cell death and scarring in any organ, including the kidneys, where they can get trapped by the kidneys' filtering system.

When the kidneys are inflamed, their ability to do this job is impaired, and red blood cells or proteins, which are normally kept in the blood stream by the kidneys, may leak into the urine. Tests may also show that the kidneys have lost some of the ability to remove waste products from the blood, which can become very serious. As blood proteins such as albumin are lost through the urine, their levels may drop in the bloodstream (therefore, serum albumin tests are helpful in diagnosing kidney problems). Albumin helps to regulate the amount of fluid in the body. When there is an insufficient amount of albumin, fluid can build up in the face, hands, feet or ankles and cause swelling or puffiness (edema) that may get worse as the day progresses.

### **Symptoms of Kidney Involvement in Lupus**

There is usually no pain associated with kidney disease, although some patients may notice swelling in their ankles. Most often, the only indication of kidney disease is an abnormal urine or blood test, so it is important to do these tests regularly, even if you are feeling well. Warning signs include:

- Large amounts of protein in the urine (proteinuria, which may cause urine to look foamy); getting up frequently to urinate during the night can be a sign of excessive protein loss.
- the presence of casts in the urine (blood cells that may collect in the kidney to form and be excreted in the urine); they can be seen under a microscope

- red blood cells in the urine (hematuria, which may give urine a pink or cola-coloured tint)
- white blood cells in the urine (leukocyturia)
- low blood protein (hypoproteinemia)
- edema (swelling in parts of the body, such as hands and ankles and around the eyes).

Signs or symptoms of kidney disease that can be confused with lupus nephritis may be caused by some of the drugs used to treat lupus. These problems

usually stop when the medications are discontinued. Two medications that can cause fluid retention or loss of kidney function are salicylate compounds (for example, aspirin) and non-steroidal anti-inflammatory drugs (NSAID's).

### **Diagnosing Kidney Disease**

Urinalysis can estimate how much damage or activity there is in the kidneys by indicating levels of protein and red blood cells. A more accurate test of protein loss and kidney function is the 24-hour urine collection. As the name suggests, the patient collects all urine passed over a 24-hour period in a special container. The urine is analyzed to determine if the kidneys are filtering properly and how much protein is being lost.

Blood tests determine if the kidneys are filtering properly by measuring the levels of waste products. The serum creatinine test checks for creatinine, which is a byproduct of muscle protein metabolism. Other blood tests may help your doctor make a diagnosis. Two commonly used tests are the serum complement test, which measures the levels of proteins in the blood that are typically low in certain types of active lupus, and an anti-double-stranded DNA (also called anti-DNA) test, which measures antibodies that sometimes indicate active lupus.

If your doctor suspects your kidneys are damaged, he or she may order an ultrasound, X-ray or biopsy to find out the extent of the damage. A kidney biopsy is also useful to assess the extent and type of lupus nephritis. In a kidney biopsy, a needle is used to extract tiny samples of tissue, which are then examined under a microscope. A biopsy can provide information to confirm kidney disease, determine whether inflammation or scarring has occurred, and identify the cause.

### **Treatment for Lupus Nephritis**

The course of treatment depends on the degree of damage to the kidneys. In mild cases, treatment may be the same as it is for lupus patients who do not have kidney disease. In severe cases, your doctor may take a more aggressive approach using corticosteroids and/or other immunosuppressive drugs.

There are two major forms of drug therapy used for lupus nephritis: high doses of corticosteroids (such as prednisone) taken orally or intravenously to control inflammation; and 'steroid-sparing' drugs to suppress the activity of the immune system long-term (see section on lupus medications). Corticosteroids and steroid-sparing drugs combat the hyperactivity of the immune system, to prevent more damage to the kidneys.

### **Pregnancy and Lactation**

The use of many immunosuppressive drugs may present risks to an unborn baby. If you are beginning these drugs, talk to your doctor about your long-term plans for pregnancy. Your doctor will be able to suggest contraceptive measures during treatment. If you have uncontrolled lupus, pregnancy should be avoided until the lupus is controlled, as outcomes will be better for the baby and for you. Your doctor may also suggest delaying pregnancy for several months after stopping certain drugs to allow them to be cleared from your system and avoid affecting your unborn baby. Some drugs may pass into breast milk. Expectant mothers who plan to breastfeed and who take any medications should consult their lupus specialists to ensure that breastfeeding is safe for the baby.

**Cyclophosphamide (Cytoxan®):** This agent inhibits cell division and growth, and it is a strong immunosuppressive drug. Cyclophosphamide in lupus treatment is reserved for very serious kidney disease or other internal organ involvement. It has the potential for severe side effects, including the risk of serious infection. Although well tolerated by most people, cyclophosphamide may cause nausea and vomiting, and its use may decrease blood cell counts. Hair loss may also be a problem.

Additional side effects can include temporary or permanent sterility in both women and men. There may be options for limiting this risk, so discuss with your specialist. This drug can also damage a developing fetus if a woman becomes pregnant while being treated with the drug, so using contraception is very important.

Because this medication is cleared by the kidneys and excreted in the urine, it can cause inflammation and bleeding in the bladder. One way to try to prevent this is to drink extra fluids, as directed by your doctor. The drug is usually given by injection in lupus, often with another intravenous medication (Mesna™ or Uromitexan®) to limit adverse effects on the bladder.

**Methotrexate (Rheumatrex®):** Methotrexate may be useful for certain types of lupus activity (e.g. arthritis) when other drugs (e.g., nonsteroidal anti-inflammatory drugs (NSAIDs) or anti-malarials) do not adequately control the symptoms. In fact, methotrexate is often used in combination with these drugs. Some people like this drug because it is only taken once a week. Methotrexate is generally not chosen for very severe lupus.

Side effects of methotrexate may include liver and lung reactions, as well as lowered cell counts. Stomach upset, sores in your mouth, or hair loss may also be a problem. If you are receiving this drug, you should have blood tests to monitor your cell counts and liver regularly; your doctor will modify the dosage if you experience side effects. To reduce toxicity, a supplement (folic acid) is prescribed.

Avoid drinking any alcohol while on methotrexate. This drug should not be taken during pregnancy as it can cause miscarriages and birth defects.

**Mycophenolate mofetil (CellCept®):** Developed to prevent the rejection of transplanted organs, mycophenolate is increasingly used as an alternative to cyclophosphamide for lupus with kidney involvement. It may be useful for other forms of lupus activity also. Mycophenolate works by curbing excessive activity of lymphocytes (a type of white blood cell). It is often well tolerated, although it can cause nausea and diarrhea. When you take this drug, regular lab tests including cell counts, are required.

If you are taking an immunosuppressive drug that may suppress the bone marrow, regular blood tests must be done to monitor your blood cell levels. Because the risk of infection is higher when you are taking an immunosuppressive, it is important to notify your doctor if you develop a fever or any other new symptoms that might suggest an infection (e.g. cough).

Some believe that immunosuppressive drugs may increase the risk of certain cancers. The most common problem is a precancerous abnormality that, if undetected, could lead to cervical cancer. In fact, this condition is quite common even in women without lupus. For this reason, regular gynecological check-ups with Pap Smear testing are recommended for all women, and are especially important for women with lupus. Fortunately, with regular checks (Pap Smears) to ensure that there is no precancerous changes in the cervix, the more serious consequences related to cervical cancer can be avoided, even if you take immunosuppressive drugs.

Other cancers that are more common in people with lupus are lymphoma and lung cancer. However, there is no clear evidence that this increased risk is primarily caused by drug exposures. Though some lymphomas may be related to medication use, research suggests that lymphoma risk may also be increased by uncontrolled lupus. It is important to know that, though they occur more often in people who have lupus than in the general population, lymphomas still only arise in a very small number of people with lupus. Thus, when they are required to control lupus, the benefits of immune suppressive drugs are generally believed to outweigh the risks.

Finally, don't forget that some of the greatest risk factors for cancer are ones that you can modify. These risk factors include smoking, a high-fat diet and obesity. Paying attention to these factors (especially quitting smoking) is the best cancer-preventing strategy that you can take.

### **Types of immunosuppressive drugs**

Various types of immunosuppressive drugs are available to treat lupus. Although they have different mechanisms of action, each drug works to decrease the body's over-active immune response.

It is important that you understand exactly how and when to take your medications, and what the potential side effects are. You need to work with your doctor to make sure that the dosage delivers benefits with as few side effects as possible. The effects of these drugs build up gradually, so you may not notice the benefits for several months. Most drugs used in SLE were not developed for SLE, and thus are used 'off label', meaning that the drugs are used by lupus experts to treat the disease, even though these drugs were not designed or formally approved for use in SLE. However, these are the immunosuppressive drugs most frequently used in the treatment of SLE:

**Azathioprine (Imuran®):** One of the most widely used immunosuppressive drugs for lupus, azathioprine, works by blocking immune cell function. Side effects can include nausea, lowered blood cell counts, and liver inflammation. If you are receiving this drug, you should have regular blood tests to determine that your cell counts and liver remain normal. If the tests indicate a problem, your doctor will adjust the drug dose.

The most commonly used steroid-sparing drugs in lupus nephritis include cyclophosphamide (Cytoxan), mycophenolate (CellCept) and azathioprine (Imuran). Cyclophosphamide has historically been the standard treatment for the most severe forms of lupus nephritis, but has several potential negative side effects. (See section on lupus medications) In fact, all drugs have potential side-effects. Thus, your doctor will aim for optimal control of kidney disease with a variety of medications and dosages that may vary over time, in an effort to limit side effects while maximizing benefit.

If the blood pressure is high, medication to treat this (anti-hypertensive) may also be prescribed. Two very important types of medications for people with active kidney disease are 'angiotensinogen converting enzyme (ACE) inhibitors' (for example Monopril®, Lisinopril etc.) and 'angiotensin receptor blockers' (ARB's), such as Cozaar®. Diuretic agents may be used to relieve swelling due to excess fluid in the body, and your doctor may recommend dietary changes including reduced salt, protein and calorie intake, and possibly restricted intake of water and potassium (found in many foods, especially certain fruits and vegetables).

If the damage is severe and the kidneys fail, dialysis or a kidney transplant may be necessary.

Over the past few decades, we have learned a lot about lupus nephritis and treatment has improved. It is hoped that with additional research, fewer and fewer lupus patients will suffer kidney damage.

## Nutrition, Diet and Lupus

If you have Systemic Lupus Erythematosus (SLE), a well-balanced whole foods, clean diet should play an integral part in your overall lupus treatment program. Your disease puts you at high risk for a number of medical conditions, including osteoporosis and heart and kidney disease. A healthy lifestyle can reduce the likelihood of developing these problems. If you take corticosteroids for the treatment of lupus, a healthy diet is particularly important, as this medication often causes increased appetite and weight gain.

There is no such thing as a “lupus diet”, but there are general guidelines and tips for healthy eating that will benefit anyone with lupus regardless of their disease state. In general, the best meal plan is one that is low in fat, low in sodium, high in fiber and low in refined sugars.

Diets that are high in animal protein may not be appropriate, in part because people with lupus tend to have compromised kidney function. A high-protein diet can put stress on the kidneys.

If you have questions about your diet, find a registered dietitian or registered holistic nutritionist in your area who has experience with lupus. You might ask your doctor for a referral. You can visit the Dietitians of Canada website at [www.dietitians.ca](http://www.dietitians.ca) to find a dietitian close to you. Health Canada has a food guide titled “Eating Well with Canada’s Food Guide”. Visit the website to make sure you’re doing everything possible to maintain a well-balanced diet. ([www.hc-sc.gc.ca/fn-an/food-guide](http://www.hc-sc.gc.ca/fn-an/food-guide))

### Well Balanced is Best

Despite evidence that suggests some nutrients play an important role in lupus management, experts agree that a well-balanced diet offers the greatest benefits. Follow these recommendations as you make choices about what to eat each day:

- Limit your sodium intake to help maintain normal blood pressure and reduce stress on the kidneys, which are often affected by lupus. The kidneys regulate the body’s salt and water balance and remove fluids and waste from the bloodstream. If you have existing kidney disease, you may also have to limit your intake of potassium, which is found in many fruits and vegetables and other foods. Discuss with your doctor.
- Include rich sources of calcium, especially if you take corticosteroids, which interfere with the absorption of calcium and can lead to osteoporosis. Foods high in calcium include milk and milk products, and to a lesser extent, broccoli, greens (chard, okra, kale, spinach, etc.), sauerkraut, cabbage, rutabaga, salmon and dry beans. To increase absorption, consume calcium with an acid-containing food or Vitamin C. Most women do not include enough calcium in their diet and require a supplement. Discuss with your doctor, especially if you have kidney disease.
- Consume rich sources of iron. To increase absorption, you can consume iron with an acid-containing food or one with Vitamin C.
- Sources of iron include cream of wheat, liver, beef, lamb, pork, chicken, turkey, eggs, fish, beans, blackstrap molasses, prunes, apricots, green peas and enriched breads and cereals. Keep in mind that taking calcium with iron decreases iron absorption. You should only take iron supplements if advised by a doctor.
- Enjoy lots of foods high in Vitamin C. These include fresh tomatoes, broccoli, oranges and other citrus fruits, strawberries, cauliflower, cantaloupe, cabbage and green peppers. Cooking or processing these foods quickly depletes their Vitamin C content.

**Managing your medication:** Your dosage of anti-malarials is based on your ideal body weight. Never take more than what has been prescribed by your doctor.

Most rheumatologists now believe it is safe to use hydroxychloroquine during pregnancy. However, you should discuss all potential medical risks, including medications, with your doctor when planning a pregnancy. Do not smoke, as this lessens the effectiveness of the drug.

**What is the Amsler Grid?:** The Amsler Grid is a screening test to assess the macula, which is the centre of the retina. The Grid is a block of evenly spaced vertical and horizontal lines (usually black lines on white paper) with a small dot in the middle. The patient is asked to focus on the small dot, but also to watch for any grid lines in the peripheral vision that are not straight or areas of the grid that are missing in the line of vision. Notify your doctor if any changes in the Amsler Grid home test are noticed.

**Conclusion:** As with any medication, anti-malarials must be taken properly in order to be effective. Speak with your doctor or pharmacist if you are unsure how or when to take your medication.

### Quick Tips

- When taking any medication, make sure you follow the directions.
- Try to take your medication at the same time(s) each day.
- Ask which side effects are considered serious enough to require immediate medical attention.
- Do not adjust dosages without the input of a physician.
- Use a days-of-the-week pill container to organize your medication.
- Always inform every doctor you see about your lupus and all of the medications you’re taking.
- Keep your drugs away from children and pets, and store them in a cool, dry place.
- Do not take any new medications, over-the-counter, naturopathic or otherwise, until you’ve consulted your rheumatologist.

### Immunosuppressive Drugs Used in Treating Lupus

Immunosuppressive drugs can be of great value in the treatment of systemic lupus erythematosus (SLE or lupus). They may help to reduce disease symptoms, prevent damage to vital organs (such as the kidneys and lungs), and help put the disease into remission.

Immunosuppressive drugs are used to control active lupus, especially if there are severe problems with kidneys or other organ systems. They are almost always taken along with corticosteroids and, in fact, are often used to help gradually reduce the dose of corticosteroids. (Ideally, they eventually allow the corticosteroids to be tapered off completely).

Like any medication, these agents may have adverse effects. Because they suppress the over-active immune system, most of these drugs can make you more susceptible to infection. Some of the drugs can cause bone marrow suppression. That is, blood cells are produced in the bone marrow, and these drugs can lead to decreased numbers of red blood cells (the cells that carry oxygen in your blood), white blood cells (the cells that fight infection) and platelets (the cells that aid in blood clotting).

Usually, as the steroid dose is slowly tapered, the body resumes producing normal levels of these hormones. However, after prolonged use of the drug, your glands may have trouble returning to normal. If you have persistent fatigue, light-headedness or nausea as your dose is reduced, alert your doctor.

**Conclusion:** Researchers are hard at work developing new therapies that will, it is hoped, have fewer side effects than steroids. For the time being, prednisone and other steroids are the first-line therapy for lupus because they are extremely effective when taken properly.

### **Anti-Malarial Drugs**

Anti-malarial drugs, such as hydroxychloroquine (Plaquenil®), chloroquine (Aralen®) and quinacrine (Atabrine™), have been used in the treatment of Systemic Lupus Erythematosus since the 1950's. Originally used to protect against the infectious disease malaria, anti-malarial drugs also provide relief from some skin conditions and joint pain. Anti-malarials are effective in controlling lupus arthritis, skin rashes, mouth ulcers, inflammation of the heart lining (pericarditis) and lung lining (pleuritis), and other symptoms, such as fatigue and fever. It is not effective in treating more severe symptoms of lupus, such as organ involvement. Anti-malarials are low-toxicity drugs, but they are also slow-acting. It can take weeks or months to see results.

**Short-term side effects:** These side effects are usually temporary. If they persist, contact your doctor.

- Upset stomach.
- Abdominal bloating and cramps.
- Loss of appetite.
- Nausea, vomiting, loose stools and diarrhea.
- Muscle aches and weakness.
- Some people note changes in hair and skin and have more headaches, but this is not common.

These uncommon, but potentially important side effects should be reported immediately to a physician:

- Blurred vision.
- Extreme nervousness, irritability, dizziness, or difficulty focusing.
- Confusion and seizures.
- Muscle aches and weakness.

**Long-term side effects:** A major potential side effect of anti-malarial use is damage to the retina of the eye. The low doses currently used in the treatment of lupus are rarely associated with this condition; permanent loss of vision has only occurred in a very small number of patients. Still, it is extremely important that you have a thorough eye examination when starting treatment with this drug and every six to 12 months after that, and that your eye doctor be made aware that you are taking anti-malarials. He or she should provide a piece of paper with an Amsler grid, which you should use once a week. Tape the grid to your refrigerator and add it to a chore (for example, do laundry and check eyes).

- Include foods rich in Vitamin B6 (pyridoxine). These foods include whole grain cereals and breads, fish, poultry, meats (especially liver), bananas, nuts, avocados, green beans, potatoes, and green leafy vegetables such as spinach.
- Include foods rich in Vitamin D to improve the absorption of calcium and reduce your risk of osteoporosis. These foods include eggs, fish oils and fortified foods including milk and some cereals; check the labels. Many people, especially in colder parts of North America, are Vitamin D deficient and require a supplement. Discuss with your doctor.
- To reduce your risk of heart disease, follow a diet low in saturated fat and cholesterol. Some research suggests that a low-fat diet may decrease an over-active immune system. Low fat intake also decreases your risk of certain cancers. When you do use fat in cooking, choose olive or canola oil.
- Eliminate “trans saturated” fats as much as possible. They are often an ingredient in baked goods and other processed foods – read the label! If you see “partially hydrogenated oil” on the label, it means the product contains trans fat.
- Omega-3 fatty acids have anti-inflammatory properties. Ground flaxseed, flaxseed oil and walnuts are high in omega-3 fatty acids. Fish with high omega-3 fatty acid content include mackerel, salmon and sardines. Caution however, as some fish, including tuna and mackerel, can contain high levels of mercury or other toxins.
- Tomato products, especially tomato paste, have high levels of lycopene, which may decrease the risk of heart disease and certain kinds of cancer.

### **Foods to avoid**

Certain foods or supplements can theoretically aggravate lupus symptoms.

These include:

- Alfalfa sprouts and supplements that contain alfalfa
- Echinacea
- Soy products
- Genetically modified foods
- Chemical residue from herbicides, pesticides and chemical fertilizers
- Food produced using growth hormones
- Refined carbohydrates from grains and sugars
- Artificial sweeteners
- Artificial flavours and colours
- Hydrogenated or partially hydrogenated fats
- Chemical Preservatives

In addition, there are certain foods that can aggravate migraines, a common condition in lupus. If you suffer from migraines, be sure to talk to your doctor, registered dietician or registered holistic nutritionist about your diet.

## **Weight control, hunger management and portion sizes**

It's simple math. People gain weight when they eat more calories than they expend.

Therefore, the number of calories consumed is integral to weight management.

The revised Eating Well with Canada's Food Guide recommends the types of food you should eat (dairy products, fruits and vegetables, grains and meat and alternatives) as well as the number of portions from each food group per day.

It's important to pay close attention to portion sizes, which have increased significantly over the past two decades. Controlling portion sizes helps limit calorie intake particularly when eating high-calorie foods. For example, bagels or muffins are often sold in sizes that constitute at least two servings, but people often eat the whole thing, thinking that they have eaten one serving.

Here's a "handy" way to measure portion sizes. When choosing a grain product, such as bread, rice or cereal, one portion equals the size of your fist. Similarly, a portion of fruit should be the size of your fist. For a serving of vegetables, consider one portion to be as much as you can hold in both hands. A serving of meat or fish should be no bigger than your palm and no thicker than your little finger. If you choose to add fat, such as butter or margarine, limit the amount to the size of the tip of your thumb.

Another easy way to avoid "portion distortion" is to divide your dinner plate into three sections. Fill half of your plate with at least two kinds of vegetables, one quarter with a unrefined starch (such as sweet potato, brown rice, quinoa, millet or whole grain pasta) and the remaining quarter with protein (fish, lean meat/chicken, legumes, lentils). Add a glass of low-fat cow, goat or sheep milk or non dairy milk such as almond, rice, oat, hemp, coconut etc. and a piece of fruit for a well-balanced meal.

It is also important to control eating between meals. If you feel hungry between meals and need a snack, try one of the following: raw vegetables, lightly dressed salad, a glass of low-fat milk, a plain rice cake or plain popcorn, or a piece of fruit.

### **Other tips for weight management include:**

- Divide the contents of one large package into several smaller containers to avoid eating too much at once.
- Instead of eating straight from the package, transfer a reasonable portion to a bowl or container.
- Keeping food out of sight keeps it out of mind. For instance, when buying in bulk, store the excess in an inconvenient place, such as the garage or basement.
- If you must keep tempting high-calorie foods, such as cookies, chips or ice cream in the house, buy a whole food, low sugar version and put them on a high shelf or at the back of the freezer and move more healthy food to the front at eye level.

### **Advice from Canada's Food Guide:**

- Eat at least one dark green and one orange vegetable every day.
- Have vegetables and fruit more often than juice.
- Make at least half of your grain products whole grain each day.
- Drink fortified soy beverages if you do not drink milk.
- Eat beans and lentils often.
- Eat at least two food guide servings of fish every week.
- Satisfy your thirst with water.

- Puffy, round, moon-shaped face, often called "chipmunk cheeks".
- Water retention (edema). To reduce water retention, avoid salty foods.
- Acne.
- Hair growth on face and body.
- Mood swings including irritability, agitation, euphoria or depression.
- Insomnia.
- Easy bruising due to fragile, thinning skin.
- High blood pressure (hypertension).
- High blood sugar (hyperglycemia); symptoms include blurred vision, thirst and more frequent urination.
- Increased risk of infection.
- Stomach ulcers and upset stomach; to protect the stomach, take steroids with food.
- Hyperactivity.

### ***Long-term side effects***

- Osteoporosis (thinning of the bones); Calcium and Vitamin D supplements and other medications can help prevent osteoporosis.
- Glaucoma and cataracts.
- Muscle weakness.
- Adrenal insufficiency.
- Osteonecrosis (or avascular necrosis); damage to the bones caused by impaired blood flow. It most often occurs in the hips, but can also affect the shoulders, knees and other joints, sometimes requiring joint replacement.
- Premature arteriosclerosis; in combination with other risk factors including lupus itself, long-term use of corticosteroids can lead to a narrowing of the blood vessels by fat (cholesterol) deposits, which can cause heart attacks and strokes.

***Managing your medication:*** If you have a question about your steroids, ask your doctor. It is important that you understand what steroids do, how much you should take and when.

If you've forgotten to take your steroids, take it as soon as you remember. Don't wait until the next day, and do not double the medication you take to make up for a missed dose. Use a pill organizer to keep track of your pills, to remind you when to take the medications, and to help you recognize when you've missed a dose.

When tapering your medication, it's a good idea to ask your doctor to write down your tapering schedule. Use a calendar or tape the directions to your refrigerator or cupboard door. Refer to it when you refill your pill organizer each week. It is also wise to wear a MedicAlert® bracelet or carry a card that provides information about the medications you are taking. Since it is common for your steroid dosages to change, especially if you are tapering your medication, keep the card up to date. You will need to know this information for all of your different doctor's appointments.

Adjusting your dosage of corticosteroids without your doctor's supervision is risky. Abruptly stopping the medication is also very dangerous and could be fatal. Since corticosteroids used to treat SLE, such as prednisone, are very similar to cortisone produced naturally by the body's adrenal glands, the body may stop producing the hormones that drive the natural production of cortisone while on a synthetic steroid.

### **An Introduction to Corticosteroids and Anti-Malarial Drugs**

Corticosteroids, such as prednisone, methylprednisolone and prednisolone, are often prescribed to treat Systemic Lupus Erythematosus (SLE) (Note: corticosteroids are not to be confused with anabolic steroids, which are popular with weightlifters for building muscle).

Cortisone is a steroid manufactured naturally by the body's adrenal glands. It has a distinct anti-inflammatory effect. Synthetic steroids reduce inflammation caused by lupus and suppress immune system activity, but they also cause a variety of side effects, some of which can be quite serious. Side effects occur more frequently when high doses of steroids are taken over a long period of time. When prescribing steroids, your doctor will choose a dose that minimizes the risk of side effects while keeping lupus symptoms under control. Many short-term side effects are reversible and/or treatable. There are also many preventative measures to reduce the risks of several long-term side effects.

### **Types of Steroids**

Prednisone is the most popular steroid used in the treatment of lupus. Taken orally, the synthetic corticosteroid preparation comes in 1, 5, 10 and 20 milligram (mg) tablets. It may be taken as often as four times each day or as infrequently as once every other day. Ten mg per day or less is generally considered a low dose; 11 to 40 mg daily is a moderate dose; and 41 to 100 mg daily is a high dose.

Other steroids can be applied topically as a cream or injected into the skin for discoid rashes. Some may be injected directly into joints to reduce inflammation. Occasionally, very large doses of steroids may be administered for a short period of time intravenously (pulse) to achieve results quickly. Your doctor may also prescribe steroids in combination with other medications, such as anti-malarials, non-steroidal anti-inflammatory drugs (NSAIDs) and cytotoxic drugs.

**Short-term side effects:** The lower the dosage of steroids given over a shorter period of time, the less likely a patient will experience severe side effects. Changes in appearance and mood are more apparent with high doses. Remember that you are unlikely to experience all of these side effects. Taking medication in the morning may help reduce side effects. Short-term conditions could include the following:

- Weight gain caused by an increase of appetite; to manage weight gain, eat a healthy diet and stay active. (Talk to your doctor before beginning any exercise program).
- Redistribution of fat cells, causing the appearance of extra weight in the face, abdomen and upper back, and reduced weight in the arms and legs.

### **Chew on this**

Researchers are constantly studying the effects of certain foods on human health. Much more study is needed before we can definitively state that certain foods or nutrients are beneficial or harmful for people with lupus. Consider the following research, but at the same time, try keeping a journal of the foods you eat and your disease activity. You may see a pattern that will help you manage your lupus and reduce flares.

### **Corticosteroids and nutrition**

One of the most devastating side effects of corticosteroid therapy is its interference with the absorption of calcium, which can lead to osteoporosis. The drug can also stop the absorption of nutrients such as Vitamins B6, C and D, zinc and potassium and interfere with cells' ability to use them. In addition, corticosteroids can cause loss of muscle protein, change the body's ability to handle blood sugar (glucose) and increase fat deposits and sodium retention. In order to counteract the nutrition-zapping effects of corticosteroids, be sure to follow a highly nutritious diet. It's especially important that you consume plenty of calcium, magnesium, Vitamins C, D and K in order to prevent osteoporosis. Currently doctors recommend calcium magnesium and Vitamin D3, Vitamin C and Vitamin K2 supplements when taking high dose corticosteroids.

**Vitamins and supplements:** Some evidence suggests that Vitamins may play a role in influencing autoimmunity. For example, Vitamin D deficiency has been reported to aggravate autoimmunity; some research also suggests that low intake of Vitamin A, beta-carotene and Vitamin C may increase the risk of lupus. Preliminary studies suggest that natural Vitamin E supplementation may decrease lupus activity. Theoretically, moderate doses of Vitamins A and C and beta-carotene may also decrease inflammation, and evidence suggests that omega-3 fatty acids may reduce chronic inflammation. Probiotics are helpful from either fermented foods or supplements.

Evening primrose oil and fish oil may be useful in the management of some autoimmune diseases, such as lupus.

**Hormones:** Hormones have effects on immune function. Some legumes, grains, fruits and nuts contain hormones called phytoestrogens. They may increase immune function, but at this point we know little about the effects of regular dietary phytoestrogen intake. However, soy products contain phytoestrogens known as isoflavones and lignans; these are similar in structure to estrogen hormones and, since estrogen may drive lupus activity in some individuals, there is some rationale that soy products should be avoided by people with lupus.

On the other hand, evidence suggests that the hormone dehydroepiandrosterone (DHEA) may be helpful for the treatment of lupus and that DHEA supplements of 200 mg per day may improve symptoms in women with mild to moderate lupus. Further studies are needed to determine whether DHEA is safe and effective for both men and women with this condition. The production of "natural" medicines is not yet regulated, and there is concern that the potency and consistency of these products may vary widely.

## Osteoporosis and Lupus

Osteoporosis is called the “silent thief” because bone loss occurs without symptoms. Many people don’t even realize they have the disease until their bones are so weak that a minor incident causes a fracture, or their vertebrae begin to collapse and cause a loss in height. At its worst, osteoporosis can lead to painful disability, even death (in fact, more women in Canada die each year as a result of osteoporotic fractures than from breast and ovarian cancer combined).

If you have Systemic Lupus Erythematosus (SLE), you are at increased risk for osteoporosis. The good news is that you can learn about your risks, take steps to reduce them, and prevent loss of bone density and fractures.

### What is osteoporosis?

Osteoporosis is a condition in which the bones become less dense and more likely to break. The hip, spine and wrist are particularly at risk of fracturing. Fractures of the vertebrae (bones in the spine) can lead to height loss and severe back pain.

Women are four times more likely to develop osteoporosis than men. Although it can affect people of any age, it becomes more common after 50.

### What is the link between lupus and osteoporosis?

People with lupus have multiple risk factors for developing osteoporosis. These include:

**Being a woman.** The vast majority of people with lupus are women, a group already at increased risk for osteoporosis.

**Lack of physical activity.** Weight-bearing exercise helps prevent osteoporosis. The pain and fatigue caused by lupus can get in the way of fitness activities, further increasing your risk of osteoporosis.

**Vitamin D deficiency.** Sunlight is the most common source of Vitamin D, which is needed for healthy bones, but people with lupus are advised to avoid the sun to prevent lupus flares.

**Medications.** Some drugs prescribed to manage lupus can increase your risk of osteoporosis. In particular, glucocorticoid (corticosteroid) medications such as prednisone are associated with significant bone loss because they decrease the intestine’s ability to absorb calcium, thus preventing bone formation. The risk of bone loss increases with higher doses (7.5 mg/day or higher) and longer use (three months or more). On average, 30% to 50% of people on long-term corticosteroids will experience a fracture if they are not treated for osteoporosis.

Cyclophosphamide (Cytoxan®), another drug used to treat lupus, can result in premature ovarian failure. The resulting reduction in estrogen production can increase the risk of osteoporosis, as estrogen is an important hormone for maintaining bone density. Other drugs, including anticonvulsants, warfarin

(Coumadin®), heparin and furosemide (Lasix®) may also have negative effects on bone health.

**Management:** Fortunately, most of the symptoms of Sjögren’s syndrome can be managed with over-the-counter medications and practical strategies.

If you have persistently and extremely dry eyes, your doctor may suggest plugging your tear ducts with collagen to increase moisture. For severe Sjögren’s syndrome, your doctor may prescribe medications such as an anti-malarial, systemic corticosteroid and /or immunosuppressive agent.

### Gastrointestinal conditions

Many people with lupus experience a variety of gastrointestinal (GI) problems at one time or another. These might include nausea, vomiting, diarrhea or constipation. The source of these problems may be lupus itself, your medications or another associated condition.

**Symptoms and causes:** Reflux, or heartburn, is common. It occurs when food and/ or acid from the stomach ends up back in the esophagus (the “food tube” that runs from your mouth to the stomach). Reflux can be caused by a weaker-than-normal muscle separating the esophagus and stomach; this is called a hiatal hernia.

Many nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids and chemotherapy used to treat lupus are associated with GI problems, ranging from upset stomach to erosions in the stomach that can lead to ulcers. Peptic ulcers can also be caused by bacteria called H. pylori (about 5 percent of people with lupus have peptic ulcers). These are treated with antibiotics, bismuth solutions (e.g. Pepto Bismol®) or a proton-pump inhibitor (e.g. Prevacid®, Pantoloc®, Losec®, Nexium®).

Functional bowel disease, also called spastic colon or irritable bowel syndrome, is also common and may be associated with intermittent abdominal pain.

**Diagnosis:** You may need x-rays of the upper gastrointestinal tract or an endoscopy (in which a tube is inserted down your throat) in order for your doctor to make a diagnosis of the nature and cause of your GI condition.

**Management:** Most GI symptoms can be managed with medications and practical lifestyle changes. Antacids such as Tums® or Maalox® may offer temporary relief of symptoms. For more serious or persistent problems, your doctor may prescribe medications such as a proton-pump inhibitor. If you have an upset stomach after taking medications, try taking them with food. Talk to your doctor or pharmacist about other tips to reduce the chance of GI discomfort caused by drugs. Another helpful tip is to eat small, frequent meals during the day rather than fewer large ones. To avoid gastric reflux, don’t lie down for at least two hours after eating.

**Symptoms:** The hallmark symptoms of Sjögren's syndrome are dry eyes and mouth. You may find that your eyes are sensitive to bright light or burn or feel scratchy, especially in the morning. You may have a dry cough or scratchy throat, caused by lack of saliva. Another sign may be an increase in cavities, mouth infections or mouth ulcers. Women may experience discomfort during sexual intercourse due to vaginal dryness. Some symptoms of Sjögren's syndrome are similar to those of lupus; in particular, joint pain and fatigue – making it difficult for you to distinguish which condition is causing which symptom. Symptoms range widely in severity, from barely noticeable to debilitating.

**Diagnosis:** In addition to reviewing your medical history, your doctor may arrange special eye examinations or test your saliva and tear production to confirm a diagnosis of Sjögren's syndrome.

### **Moisture management**

These practical tips may help you reduce the annoying symptoms of Sjögren's syndrome:

- Some people find that sucking on sugar-free candies or chewing sugar-free gum helps stimulate saliva.
- Avoid acidic candies, food or beverages, as they may irritate open sores and damage your teeth.
- Take small sips of water throughout the day, but avoid excessive water sipping, as it can reduce the oral mucous film and increase dry mouth symptoms.
- Avoid dehydrating foods, drinks and medications, such as coffee, alcohol and foods with a high sugar content and antihistamines.
- Talk to your doctor about saliva substitutes or prescription medications to increase saliva production.
- Take care of your teeth; brush and floss, and visit your dentist regularly
- Use artificial tears to keep your eyes moist.
- Don't wear contact lenses.
- Wear protective eyewear to protect against drying wind and irritating sunlight.
- Avoid vaginal irritants such as bubble baths, douches, sprays, soaps, etc.
- Women may want to use water-based lubricants, such as K-Y Jelly, during sexual intercourse. Don't use oil-based lubricants (such as those containing petroleum jelly or baby oil) because they may irritate the vaginal lining. Talk to your partner about the need for increased foreplay to promote lubrication.

**Possible concerns:** Saliva helps protect your gums and teeth, so Sjögren's syndrome can lead to tooth decay and gum disease. It is important to tell your dentist if you have Sjögren's syndrome. Get regular check-ups and brush and floss regularly.

The back of your throat and lungs may be affected by Sjögren's syndrome. Be sure to follow up with your doctor if you have a cough or cold that doesn't go away.

Less commonly, Sjögren's syndrome can also cause complications with internal organs, such as the kidneys, liver and pancreas, and the central nervous system.

Finally, if you are a woman with Sjögren's syndrome, talk to your doctor before becoming pregnant. You may need to be tested for an antibody that can cause heart problems in newborns.

**Lupus activity.** Bone loss may also occur as a direct result of your lupus. For example, kidney failure of any degree can lead to low blood calcium levels, impaired Vitamin D production and increased bone loss.

In addition, the loss of bone in people with lupus appears to be associated with processes that aren't fully understood, including the involvement of inflammatory substances called cytokines.

### **Warning signs**

Most people do not realize they have osteoporosis until they have had it for a long time. The first warning sign might be a sudden sharp pain in your back (especially mid-back) that seems to have come on for no reason. A sharp pain in your back, ribs, hip or wrist that doesn't go away after a fall, (even a minor one) could indicate that you have an osteoporotic fracture. Loss of height or curvature of the spine can be signs of compressed vertebrae due to osteoporosis.

It is important to note, however, that many people do not experience any signs or symptoms of osteoporosis until they have a fracture, by which time the condition is fairly advanced.

### **Assessing your risks\***

While there is no single cause of osteoporosis, there are factors that can increase your risk of developing the disease. These include:

#### ***Major risk factors:***

- Age 65 or older
- Vertebral compression fracture
- Fracture with minimal trauma after age 40
- Family history of osteoporotic fracture (especially if your mother had a hip fracture)
- Long-term (More than three months) use of glucocorticoid therapy such as prednisone
- Medical conditions (such as Celiac Disease, Crohn's disease) that inhibit absorption of nutrients
- Primary hyperparathyroidism (enlarged, overactive parathyroid glands)
- Hypogonadism (low testosterone in men; loss of menstrual period in younger women).

#### ***Other risk factors:***

- Rheumatoid arthritis
- Hyperthyroidism (excess thyroid hormone production)
- Prolonged use of anticonvulsants or heparin
- Body weight less than 57kg (125 lbs) or more than 10 percent below your weight at age 25
- Low calcium intake
- Excess caffeine (consistently more than four cups of coffee, tea, or cola per day)
- Excess alcohol (consistently more than two drinks a day)
- Smoking

## Early detection is key

Early diagnosis of osteoporosis is key to preventing further bone loss and fractures. Specialized tests known as bone mineral density (BMD) measure bone density at various sites of the body. These safe and painless tests can accurately detect osteoporosis before a fracture occurs and predict your chances of developing osteoporosis in the future.

If you have lupus, talk to your doctor about your risk factors for osteoporosis and the need for a BMD. If you and your doctor agree that your bones need to be monitored, make sure you are re-tested on the same BMD machine whenever possible.

## Prevention

Never has the saying “an ounce of prevention is worth a pound of cure” been so true. It is not too late to strengthen your bones, stop further bone loss and reduce your risk of a debilitating fracture. Here’s how:

**Calcium rules:** Calcium intake is the single most important predictor of bone strength. In fact, just about every cell in your body needs calcium to stay healthy. If your body can’t absorb enough calcium from the food you eat, it will take the calcium from your bones, leaving them thinner and weaker. To keep bones strong, you should take in at least 1000 mg of calcium each day (1500 mg if you are over the age of 50 or if you are taking prednisone). Good sources of calcium include low-fat dairy products (milk, cheese and yogurt) and calcium-fortified foods and beverages. Almonds and dark green leafy vegetables and apricots are also sources of calcium. Calcium supplements can help ensure that you get enough calcium each day. The most absorbable and bioavailable form of calcium is calcium citrate.

**Don’t block your calcium:** It’s not enough to just get calcium into your stomach – it has to be absorbed and used for bone-building. Cigarette smoke and excessive caffeine, alcohol (and possibly salt consumption), antacids like PPI’s proton pump inhibitors, insufficient magnesium and insufficient Vitamins C, D3 and K2 all undermine your body’s ability to absorb calcium. Try to cut these bone-thinning habits from your lifestyle.

**Add some D:** Vitamin D deficiency is another common barrier to calcium absorption. In essence, Vitamin D is the gatekeeper that allows calcium to leave your intestines and enter your blood; without Vitamin D, the gateway remains closed. While the body can manufacture its own Vitamin D from sunlight, excessive sun exposure can trigger flares in some people with lupus. As a result, you may require Vitamin D supplements in order to ensure the required daily intake of 400 to 2,000 IU. Vitamin D can also be found in foods such as liver, Vitamin-D fortified milk and fish oils.

**Work those bones:** Exercise has long been recognized as an important factor in preventing osteoporosis. For the most benefit to your bones, exercise daily or every other day. Include weight-bearing exercises, such as brisk walking, aerobics, dancing and stair climbing and resistance exercise with a band, strap or 2 m length of waistband elastic. Exercises that improve posture, balance and co-ordination are especially important as these can help prevent bone-breaking falls. Tai chi is a great choice.

Sometimes exercising can be challenging for people with lupus, especially during a flare. However, even low-intensity activities such as slow walking, chair yoga, chair tai chi, gentle stretching on your bed or in a chair can all offer benefits to your overall health. If activity causes pain, consult your doctor or physiotherapist.

## Practical prevention

Although Raynaud’s phenomenon rarely causes permanent damage, the condition can have significant impact on your day to day life. Here are some practical suggestions to manage the condition:

- Know your enemy: cold weather. Check the weather forecast before you head out and dress accordingly. Your cold weather wardrobe should include a hat. When you have a Raynaud’s episode, make note of the temperature so that you become aware of the threshold at which you become affected.
- Wear gloves to reach into the freezer and rubber gloves if you have to immerse your hands in cold water
- Keep your toes toasty. Choose wool or wool-blend socks instead of cotton or nylon. Wear waterproof boots on wet days. If your feet are cold at night, wear loose fitting socks to bed.
- Insulate your fingers. Mittens keep your fingers warmer than gloves. Buy a variety of hand wear to suit the weather and occasion: like light gloves for mild days or driving, woolly mitts or gloves with thermal liners for colder days, and thermal insulated mittens for winter’s worst in the same style. That way if you lose one, you will still have a match.
- It’s important to avoid chilling any part of your body, not just your hands and feet, so be sure to dress warmly on cold days.
- Tuck chemically activated heat packs into your mittens on extremely cold days or if you have to be outside for a long time. If you have numbness, however, be very cautious with the use of these packs to avoid burns.
- Be prepared. Always carry a pair of mittens or gloves in your bag or glove compartment, no matter what the forecast.
- If your fingers are affected by holding a cold glass, use a mug with a handle or an insulated glass.
- Be aware of air-conditioning. Raynaud’s can strike on the hottest summer day if you step into an overly air-conditioned building. Keep a sweater or shawl handy and set the thermostat higher if possible.
- Most importantly, don’t smoke. Cigarette smoke causes blood vessels to tighten and worsen your Raynaud’s symptoms.
- It may help to reduce your caffeine intake. Caffeine is not just in coffee, but also in cola, some teas, chocolate, and some medications.
- Check your medications. Some drugs, such as beta-blockers and decongestants can make Raynaud’s phenomenon worse. Talk to your doctor or pharmacist about your options.
- Control stress. Try guided imagery, yoga or other relaxation techniques. If necessary talk to your doctor about medication.

## Sjögren’s Syndrome

Saliva and tears. Most people don’t give a second thought to these body fluids; until they dry up. Without naturally produced moisture, your eyes and mouth may become so dry that you feel like you’re trapped in a desert.

Sjögren’s syndrome is an autoimmune condition that attacks glands in the soft lining in and around the eyes, mouth and genitals that secrete fluid to keep these areas moist. This condition primarily affects women, especially those past middle age. About half the time, it occurs alone (known as “primary Sjögren’s syndrome”), and about half the time it affects people with other diseases (known as “secondary Sjögren’s syndrome”), particularly lupus and rheumatoid arthritis. The secondary form of the disease is usually milder than the primary form.

## Other Conditions Seen in Lupus

Systemic Lupus Erythematosus (SLE) is often referred to as the disease with a thousand faces because it is associated with a wide variety of symptoms and related conditions.

Three conditions that may be seen in lupus are Raynaud's phenomenon, Sjögren's syndrome and gastrointestinal problems. While the symptoms can be troublesome, there are steps you can take to reduce or prevent them.

### Raynaud's Phenomenon

Cold hands are a sign of a warm heart – or so the saying goes. But sometimes, cold hands are a sign of Raynaud's phenomenon, a condition that makes it difficult for blood to reach the extremities because of tightening of the blood vessels. About one-third of people with lupus have Raynaud's phenomenon or secondary Raynaud's syndrome (if the condition exists on its own, it is referred to as primary Raynaud's syndrome or Raynaud's disease).

**Symptoms:** Changes in skin colour occur suddenly when the extremities (fingers, toes and sometimes ears and nose) get cold; it may also occur with stress. The skin first becomes white, and then red (this may vary in some people). There may be tingling, painful stinging or numbness in the fingers or toes; these symptoms generally resolve with warming. A Raynaud's episode usually lasts a few minutes, although severe episodes may last longer.

Although Raynaud's phenomenon is common in people with lupus, Raynaud's activity is usually independent of lupus activity. In other words, a lupus flare may not be associated with a Raynaud's episode and vice versa.

Although uncomfortable, Raynaud's phenomenon is usually mild and rarely results in permanent damage. People with severe Raynaud's phenomenon, however, may develop painful skin ulcers or, even more rarely, gangrene – on their fingers or toes. Be sure to seek medical help if you have cuts or sores on your feet or hands that don't heal promptly.

**Diagnosis:** To diagnose Raynaud's phenomenon, your doctor will review your medical history, especially regarding the effect of cold on your fingers and toes. He or she may also order certain tests, such as blood flow tests, to help confirm the diagnosis or to distinguish between different diseases.

**Management:** If you experience a Raynaud's episode, encourage blood flow by shaking or massaging your hands and feet and/or running warm water over your fingers or toes or soaking them in a bowl of warm water. If your fingers and toes have gone numb, they may throb and feel sore as the circulation returns.

Your first line of defense against Raynaud's phenomenon, however, should be prevention. Whenever possible, avoid or reduce your exposure to the cold. Since stress is also associated with Raynaud's episodes (not to mention lupus flares!), it is important for you to learn how to reduce and deal with stress in your life.

If your Raynaud's is severe or very troublesome to you, your doctor may prescribe medication to help dilate your blood vessels and improve blood flow, for example, nifedipine or nitroglycerine.

**Prevent falls:** Even a slight fall can cause a life-altering break if you have osteoporosis. Reduce your risk of falling with these tips:

- Wear corrective glasses if you need them.
- Keep your house well-lit and free of small items that could trip you.
- Wear sturdy, low-heeled, soft-soled shoes.
- Eliminate or securely tape down throw rugs, loose wires and electrical cords.
- Install safety handrails and guards, especially in the bathroom.
- If a medicine causes dizziness or lightheadedness, talk to your doctor about alternative medications.
- In the winter, keep your driveway and front walk clear of ice and snow.

### Medication

Osteoporosis has no cure. However, medications that prevent and treat osteoporosis are available\*.

**Bisphosphonates** are a family of drugs used to prevent and treat osteoporosis especially in post-menopausal women and people using steroid medications. Bisphosphonates bind permanently to the surfaces of the bones and slow down bone eroding cells while allowing bone-building cells to work more effectively. Three oral bisphosphonates have been approved for use in Canada for osteoporosis; alendronate (Fosamax®), etidronate (Didrocal®) and risedronate (Actonel®). All three have been shown to increase bone density and prevent fractures of the spine. Alendronate and risedronate have also been shown to prevent hip fractures. Studies suggest alendronate and risedronate may be more effective in treating osteoporosis than etidronate.

The most common side effects of bisphosphonates are nausea, abdominal pain and loose bowel movements, although these are usually mild. Etidronate has been associated with esophageal ulcerations.

**Calcitonin** is a hormone found naturally in our bodies. The synthetic form of calcitonin (Miacalcin® nasal spray) works by slowing bone-eroding cells while allowing bone-building cells to work more effectively. Studies show that nasal calcitonin maintains or minimally increases bone density and prevents fractures of the spine, but bisphosphonates may be better for people at risk of steroid-induced osteoporosis. Calcitonin is sometimes useful to decrease pain related to a recent fracture.

**Hormone replacement therapy (HRT)** is another potential option to slow down bone loss, especially for women who also want relief from symptoms of menopause. After menopause, women make less estrogen and progesterone, which are important hormones for maintaining bone density. HRT has been shown to slow down bone loss and increase bone density, and it may also reduce the chances of spine and hip fractures. However, HRT may increase the chances of developing breast cancer, heart disease, stroke and blood clots, especially if taken for longer than five years. Thus, HRT is used much less often than in times past. If you are on these agents, or are considering beginning them, you should probably be followed closely by a gynecologist.

**Parathyroid hormone (PTH)** and teriparatide are a new class of osteoporosis treatments called bone formation agents. Teriparatide injection (Forteo®) is the first medication approved by Health Canada in this new class. It works by activating bone-building cells so that new bone is generated faster than old bone is broken down. Possible side effects include dizziness, nausea and leg cramps.

No matter which drug therapy you and your doctor choose, remember that a diet rich in calcium and Vitamin D is required to maintain healthy bones.

*\*Source: 2010 Clinical Practice Guidelines for the Diagnosis and Management of Osteoporosis in Canada.*

### **Supplement your bones**

**It is important to have an adequate calcium intake. Calcium supplements such as calcium carbonate, calcium citrate, calcium lactate and calcium gluconate, at 500 to 2,000 mg daily, are the simplest and least expensive way to prevent bone loss. There are many types and brands of calcium supplements. They vary in amount of calcium, type of calcium, whether they include Vitamin D, size of tablet, type of tablet (e.g. chewable, effervescent) and price. Antacids (e.g. Tums, Rolaids) contain calcium carbonate and can be used as a supplement. Some calcium supplements may cause stomach upset, nausea or constipation. Talk to your doctor or pharmacist about which ones may be right for you.**

**To improve your body's absorption of calcium, take your supplement with plenty of water. Take calcium carbonate with food or immediately after eating; other types of calcium are well absorbed at any time. Don't take more than 500 mg of elemental calcium at one time, as your body won't be able to absorb it.**

**Cerebrovascular accidents (strokes):** A fairly large number (some estimate one-third of all people with lupus) have anticardiolipin antibodies or a lupus anticoagulant. These antibodies increase blood clot development (despite the fact that the latter has the term "anticoagulant" in its name – this is a title that has stuck over decades). An estimated one-third of these individuals may develop blood clots in various parts of the body. When a blood clot occurs in the central nervous system, it can cause a cerebrovascular accident, or stroke. Symptoms of stroke include sudden weakness or numbness in the face, arm or leg, or difficulty speaking.

The risk of stroke in lupus may be increased even without anticardiolipin antibodies or a lupus anticoagulant. Depending on the person's risk factors, the risk of stroke may be reduced with medications, such as blood thinners and aspirin. Blood pressure control and cholesterol treatment are important. Smoking should be eliminated.

**Lupus headache:** Compared with the general population, people with lupus are twice as likely to have migraine-like headaches. People with lupus who also have Raynaud's phenomenon are even more likely to have severe headaches. Headaches are managed using painkillers, anti-inflammatory drugs, specific migraine therapies and sometimes tricyclic antidepressants.

**Mood Disorders:** The signs and symptoms of neuropsychiatric lupus may be very subtle, such as mild headaches, altered mental activity or depression. In the most severe form, seizures or partial paralysis can occur. The American College of Rheumatology lists 19 neuropsychiatric syndromes associated with lupus. In one study, neuropsychiatric lupus syndromes were present in 80 percent of people with lupus; these included anxiety disorder (24%), major depressive-like episode (28%), mood disorder with depressive features (19%), mood disorder with manic features (3%), mood disorder with mixed features (1%) and psychosis (5%).

Depression is an important symptom of lupus. Depression in lupus is often wrongly attributed to having a chronic illness and all that goes with it. In fact, lupus itself causes depression, and the management of lupus – treating the underlying disease as well as possibly adding antidepressant therapy – often lifts the depression. Newer, milder antidepressants that have fewer severe side effects are now available.

During severe lupus flares, people with the disease can experience a variety of psychiatric disorders varying from mild personality disorders to severe psychotic behavior. Some people with lupus are wrongly diagnosed as having schizophrenia at the onset of their illness. Treatment of lupus usually results in total improvement in the psychiatric symptoms.

### **Maybe it's your meds**

Medications used to treat lupus can cause side effects that are similar to the symptoms of central nervous system lupus. Non-steroidal anti-inflammatory drugs (NSAIDs) occasionally cause headache, dizziness and, rarely, meningitis-like symptoms. Anti-hypertensive medications may be associated with loss of libido or depression. Corticosteroids are associated with agitation, confusion, mood swings and, in high doses, psychosis. Withdrawal from steroids can lead to fatigue, aching and weakness.

When you are prescribed a new medication, be sure to discuss possible side effects with your doctor or pharmacist. If you experience any of these symptoms, talk to your doctor immediately.

While we don't completely understand the mechanisms by which lupus affects the central nervous system, we know that there are several neurological syndromes that affect many people. Although cognitive impairment is believed to be very common in lupus, few patients undergo specific testing to document it. Symptoms include difficulty finding words and retrieving information. People with the condition often refer to it as "lupus fog".

A five-year study on cognitive function, called Brain CONNECTIONS, evaluated lupus patients every four months with a variety of tests. In one test, participants were given a list of words and asked to recall them after about 10 minutes. Although most participants had problems recalling the words, they were able to pick out the original 10 words from a list of 20 words. This indicates interference with access to the information that exists in the brain.

Researchers with the Brain CONNECTIONS study also measured cognitive dysfunction and biological changes in the participants and found a high incidence of anatomic brain abnormalities. People whose MRIs showed brain abnormalities were more likely to have problems with focused attention and reaction time, and also had higher lupus disease activity. This suggests that both functional and structural damage to the brain is evident early in the disease process, which underscores the need for research into the underlying mechanism of the brain's involvement in lupus.

### **Problems with memory?**

- Get a physical exam to make sure your memory loss isn't due to another medical condition.
- Pay attention when you receive new information. Repeat it or write it down. Verify any details you aren't sure about.
- Don't clutter your life with things that aren't important.
- Focus on one task at a time.
- Take good care of yourself: exercise, eat well and get adequate sleep.
- Learn memory techniques, such as associating a person's name with an image or repeating the name several times in conversation.

### **Important neurological syndromes seen in lupus**

**Central nervous system vasculitis:** The most serious neurological syndrome associated with SLE is central nervous system vasculitis, an inflammation of the brain's blood vessels. Most episodes (more than 80%) take place early, within five years of lupus diagnosis. Antibodies attack the blood vessels, causing inflammation, which can seriously affect the flow of blood.

A relatively small number (some estimate 10 percent) of people with lupus develop central nervous system vasculitis, experiencing such symptoms as high fevers and seizures and possibly psychotic or bizarre behavior. Central nervous system vasculitis usually requires hospitalization and is treated with high doses of corticosteroids and other drugs.

## **Photosensitivity, Sun Safety and Lupus**

Photosensitivity, or increased sensitivity to sunlight, is common among people who have Systemic Lupus Erythematosus (SLE). Sun exposure can cause rashes (including the butterfly or malar rash) and lesions or trigger flare-ups of the disease that could affect internal organs, so it is important to protect yourself. As many as three-quarters of people with lupus are photosensitive.

### **Why are people with lupus photosensitive?**

The reason for photosensitivity in people with lupus is unclear. Several studies have looked at the role of different wavelengths of UV light in lupus. UV is divided into UVA, UVB and UVC (which does not reach us because it is absorbed by the atmosphere). Studies from the 1960's suggested that UVB was the main cause of photosensitivity in lupus, but more recent research show that UVA is also partly responsible.

It is thought that, when exposed to sunlight, skin cell proteins and genetic material such as DNA and RNA start a reaction in people who are genetically predisposed. UV light causes skin cells to express particular proteins on their surface. These proteins, including one known as "Ro", may be the targets of antibodies, which latch on to them. The attached antibodies are thought to attract white blood cells, which attack the skin cells. This leads to inflammation and causes a rash. Normally, cells that are damaged die naturally through a process called "programmed cell death", or "apoptosis". The body then gets rid of the dead cells. In lupus, this cell death in the skin seems to occur too frequently, which may cause more inflammation.

It is thought that other possible factors that lead to a rash in people with lupus are substances produced in the skin after sun exposure, encouraging inflammation and redness. Researchers are working to find the reasons for these abnormal reactions.

### **What kind of skin problems could occur?**

Sun exposure can cause different types of rashes in people who have lupus. One is **acute cutaneous lupus erythematosus (ACLE)**, better known as the butterfly or malar rash that appears on the face, across the bridge of the nose. It usually heals within weeks without scarring.

Another type is **discoid lupus erythematosus (DLE)**, which appears as disk-shaped lesions on skin that has been exposed to the sun. They develop slowly and may take months to heal. They may leave scars.

**Subacute lupus erythematosus (SCLE)** appears as red circles on the arms, chest and back. It may look scaly, like psoriasis, and heals over weeks or months. It may occur again with more sun exposure. (Note that both DLE and SCLE may also occur in people who do not have systemic lupus).

### **How to protect yourself from the sun:**

Wear a broad-brimmed hat and clothing with a tight weave, including a long-sleeved shirt and long pants. Consider buying special sun-protection garments

if you are very sensitive. There are now many options for sun protective clothing that are both stylish and functional in reducing sun exposure. Also consider purchasing sunglasses that are polarized to help reduce glare and brightness for sensitive eyes.

Use sunscreen with a Sun Protection Factor (SPF) of at least 15 on any exposed skin. Make sure it is a broad-spectrum sunscreen (it should have both UVA and UVB protection). Apply liberally 15 to 30 minutes before going out. Re-apply after vigorous activity, such as swimming and towelling off or excessive sweating and rubbing, even if the sunscreen label says it is “water-resistant” or “waterproof”.

Avoid going outside without protection, especially between 11 a.m. and 4 p.m. during the summer months. When possible, stay in the shade.

Do not use sunlamps or tanning beds. There is no such thing as a “safe tan” or a “base tan”.

People who are very sensitive to UV light may wish to avoid using compact fluorescent, halogen and Zenon bulbs and tube lights and use photocopiers with the lid closed.

Windows in your house and car do not filter out UV rays. Prescription window film that blocks 100% UVA and UVB is available for vehicles. For long car rides, you might consider wearing sunscreen and protective clothing if you are exposed to the sun.

Some medications increase the effects of the sun on the body. People with lupus who take these drugs, including tetracycline antibiotics and many others, may burn very easily – this is called a “phototoxic” reaction. Check with your doctor or pharmacist if you should wear extra sun protection while taking these drugs.

### Quick Tips

- **Slip on a shirt or other sun safe clothing**
- **Slop on the sunscreen**
- **Slap on a hat – with a nice wide brim**
- **Slide on the “shades”**
- **Pass on the sun during the intense sun hours of the day**

## The Nervous System and Lupus

Neurological manifestations of Systemic Lupus Erythematosus (SLE) are common and vary from mild to severe. People with lupus can experience bouts of memory loss, headaches, strokes and cognitive dysfunction, which generally means difficulty concentrating or reasoning. These symptoms arise when lupus affects the body’s nervous system.

There are no definitive answers as to how or why lupus affects the nervous system. It is known that the nervous system requires an uninterrupted flow of blood to supply its tissues with oxygen and nutrients necessary for normal functioning.

There are theories regarding how lupus may cause the many symptoms of nervous system involvement:

- Nerve tissue may be damaged when antibodies attack nerve cells or blood vessels.
- Nutrients and oxygen are delivered through blood vessels that feed the brain, spinal cord and nerves. If blood flow is slowed or interrupted, the cells of the nervous system are injured and unable to function normally. Symptoms develop as a result.
- The symptoms vary depending on the location and extent of the tissue injury.

### Understanding your nervous system

The nervous system is made up of the brain, the spinal cord and the nerves throughout the body. It has three distinct parts:

- The central nervous system (CNS) consists of the brain and spinal cord.
- The peripheral nervous system is comprised of nerve fibers that supply the skin and muscles with the power needed for sensation and movement.
- The autonomic nervous system is the nerve supply to glands and other internal organs.

Your doctor may order one or more laboratory tests to determine whether or not your lupus is causing neurological involvement and to what extent. These tests may include magnetic resonance imaging (MRI), electroencephalogram (EEG), electromyogram (EMG), computed tomography (CT) scan, lumbar puncture (spinal tap) or blood tests. X-rays may also be used on occasion to diagnose neurological damage.

- CT and MRI obtain images of the brain that reveal strokes, tumors, bleeding, and abscesses.
- EEG detects abnormal electrical activity of the brain, which may be associated with seizures (epilepsy).
- EMG and nerve conduction studies detect abnormal electrical activity of muscles and nerves
- Spinal fluid analysis reveals distinct changes in the spinal fluid that point to various disorders (infection, inflammation, etc.)
- Blood tests may show bleeding problems, or antibodies that can lead to abnormal blood clotting (e.g., antiphospholipid antibodies, lupus anticoagulant.)

## **Laboratory testing**

Your doctor may use a laboratory test to check for the presence of certain autoantibodies. As with SLE, most people with drug-induced lupus may develop antinuclear antibodies (ANA's), although those with a form of drug-induced lupus related to quinidine often are ANA-negative. The ANAs in drug-induced lupus are primarily autoantibodies that are able to react with a histone-DNA complex, the major component of every cell's nucleus. The laboratory test detects certain antibodies to this histone-DNA complex. Their presence is a marker for lupus-like disease brought on by many drugs. (Hydralazine is the exception, as only about one-third of people with drug-induced lupus have this type of anti-histone antibody). There is no evidence that people who develop ANA without symptoms are at increased risk for developing drug-induced lupus in the future.

## **Drug-induced lupus(DIL) and Systemic lupus erythematosus(SLE)**

SLE is distinct from drug-induced lupus, since DIL generally has milder symptoms than SLE, and no skin or kidney disease. Oral ulcers, hair loss, photosensitivity and central nervous system symptoms are also very rare in drug-induced lupus.

SLE can be more difficult to diagnose in elderly people, since they often do not experience the typical features of the disease. Sometimes the symptoms can be very similar to those of drug-induced lupus. Since many elderly patients take a variety of medications to treat other health conditions, it is important to consider if one of them is known to cause drug-induced lupus when assessing symptoms. People with SLE usually have more abnormal immunological features on laboratory testing.

## **Treatment of drug-induced lupus**

If possible, the medication suspected of causing drug-induced lupus should be discontinued or replaced with a similar drug. In most people who develop drug-induced lupus, after the causative medication is discontinued, the ANA should gradually disappear. Its decline can confirm the diagnosis. It may take months and even years for all symptoms to disappear.

Your doctor may prescribe non-steroidal anti-inflammatory drugs (NSAIDs) to hasten recovery, if appropriate. Corticosteroids may be used for people with severe symptoms of drug-induced lupus, such as severe inflammation of several joints, inflammation of the sac around the heart and, in rare cases, kidney disease.

After the symptoms of drug-induced lupus have disappeared, it is possible for a person to develop them again if he or she takes the same medication that caused them, so it should be avoided if possible.

## **Pregnancy and Lupus**

The peak incidence of Systemic Lupus Erythematosus occurs in women in their reproductive years (ages 15 to 45). Although lupus itself usually does not affect fertility rates, pregnancy planning is an important issue for women with this disease.

Even as recently as the 1980's, women with lupus were often counseled not to become pregnant due to the risk of a disease flare and an increased risk of miscarriage. Approximately 20 to 25 percent of pregnancies in women with lupus end in a miscarriage compared to 10 to 15 percent of pregnancies in women without the disease.

Research and careful treatment have made it possible for more and more women with lupus to have healthy pregnancies. Although pregnancy with lupus may still be considered high risk, most women with lupus are able to carry their babies safely to term.

Planning and counseling should begin before you become pregnant. For the best chance of a healthy pregnancy, conceive when your lupus disease activity is low or in remission, or has been stable, minimally active or in remission for six months prior to conception, and you are taking only medications deemed safe during pregnancy. An evaluation prior to pregnancy should consist of both a clinical and laboratory review so that your doctor has a baseline against which your lupus during pregnancy can be compared. This is especially important if you have a history of major organ disease, such as kidney involvement. Since the normal values for laboratory measurements are different during pregnancy, this baseline is important for the interpretation of later results.

In particular, the anti-Ro antibody, which you should be tested for in your pre-pregnancy assessment, has been associated with heart rhythm disturbances in babies of mothers carrying this antibody. About a quarter of women with lupus have this antibody. It is linked to Sjögren's syndrome and may also be seen in people without autoimmune diseases. Keep in mind that the risk of any problem occurring is only about three percent.

For most women, it is extremely important that the lupus be carefully monitored by an experienced multidisciplinary team so that abnormalities during pregnancy and post-partum are identified, diagnosed and treated promptly.

For some patients, delivery must be planned at a hospital that can accommodate a high-risk patient and provide the specialized care that the patient and baby may need.

## **Lupus flare**

One problem that can affect your pregnancy is the development of a lupus flare. In general, it is uncertain to what extent flares are caused by pregnancy. Flares that do develop often occur during the first or second trimester or during the first few months after delivery. Most flares are mild and can be managed with small doses of corticosteroids.

## **Neonatal lupus**

Babies born to women with lupus have no greater chance of birth defects than babies born to women without lupus. However, mother's with anti-Ro antibodies, but no other auto-antibodies, are at risk to deliver a child with neonatal lupus. The most common presentation of neonatal lupus is an abnormal liver function test, a low platelet count or white blood cell count. Most of these children do not have any problems. In most cases these abnormalities in children will resolve by 6 months of age. However, it is important to know about the low white cell count because if the baby gets sick and has a blood test

the baby's doctor may be concerned about the low count or abnormal liver tests if they are not aware of this association. The next most common feature is a skin rash which tends to be around the eyes but can occur on any part of the body. The rash tends to be circular and is not usually a malar rash. This usually occurs between ages 6-12 weeks but may be present at birth and occurs in 5% to 10% of mothers with anti-Ro antibodies. The most serious problem is congenital heart block (abnormally slow heart rate), this may be a significant problem. Luckily it occurs in only 1% to 2% of mothers with SLE and anti-Ro antibodies. This condition is permanent but can be easily treated with a pacemaker. This is the reason that pregnant women with anti-Ro antibodies should have serial fetal echocardiograms throughout the pregnancy. Lastly children born to mothers with anti-Ro antibodies may have a slightly larger head and should be monitored. However, it rarely, if ever, causes any problems.

### **Planning your pregnancy**

Awareness, monitoring, and careful planning are the keys to a successful pregnancy. Before conceiving, discuss your decision with your doctor, as certain drugs should be discontinued prior to conception. Both you and your doctor should be satisfied that your lupus is under good control or in remission.

If your rheumatologist advises it, select an obstetrician who has experience managing high-risk pregnancies and is associated with a hospital that specializes in high-risk deliveries and has the facilities to care for a newborn with special needs.

Review your work and activities schedule. Be prepared to make changes if you are not feeling well or need more rest.

Consider your financial status. If you work outside the home, your pregnancy and motherhood could affect your ability to work.

Develop a plan for help at home during the pregnancy and after the baby is born. Motherhood can be overwhelming and tiring, and even more so for a woman with lupus. Although most women with lupus do well, some may become ill and find it difficult to care for their child.

### **Other possible complications**

Pregnant women with lupus, especially those taking corticosteroids, are also likely to develop pregnancy-induced high blood pressure (hypertension), gestational diabetes, and kidney complications. Problems may include excessive weight gain, generalized swelling (edema), excess protein in the urine, severe headaches and visual disturbances. Such developments may indicate a serious condition that requires immediate treatment, usually including delivery of the infant.

### **Breastfeeding**

Most medical professionals feel that it is important to try to breastfeed your baby as it is the ideal, low-cost way to provide nutrition in the first weeks or months of life. It takes time for mothers and babies to learn how to breastfeed, and it may take a few weeks to adjust. Because breastfeeding is often a challenge, ask your doctor or nurse for help as soon as you are admitted to the maternity ward, so that you do not become discouraged. Some individuals hire a lactation consultant; the staff on the maternity ward where you deliver can discuss this with you. Sometimes, though, breastfeeding may be difficult for the following reasons:

## **Symptoms of Drug-Induced Lupus**

Drug-induced Lupus Erythematosus (also known as DILE or DIL) can occur as a side-effect of certain medications. Some symptoms overlap with those of systemic lupus erythematosus (SLE). These include:

- Muscle and joint pain and swelling
- Flu-like symptoms of fatigue and fever
- Serositis (inflammation around the lungs or heart that causes pain or discomfort)
- Certain laboratory test abnormalities

Drugs that can cause drug-induced lupus are typically those used to treat chronic diseases. They include medicines used to treat:

- Heart disease
- Hypertension
- Rarely, neuropsychiatric disorders or thyroid disease

Certain other drugs including anti-inflammatory agents and antibiotics may also cause drug-induced lupus. In all, at least 38 drugs currently in use can cause drug-induced lupus. However, most cases have been associated with these three:

- Hydralazine – used to treat hypertension
- Procainamide – used to treat cardiac arrhythmias
- Quinidine – used to treat cardiac arrhythmias

The risk for developing lupus-like disease from any of the other 35 drugs is low or very low (in some cases, only one or two cases have been reported).

It may take several months of therapy with the medication before symptoms appear. For the high-risk drugs such as procainamide and hydralazine, only 5 to 20 percent of people treated for one to two years at currently used doses will develop drug-induced lupus. With most of the other drugs, the risk is less than 1 percent that those taking the medication will develop drug-induced lupus.

There is no evidence that people with SLE are more likely to develop drug-induced lupus. The use of drugs linked to drug-induced lupus has not been associated with an increase in SLE activity or onset of flares.

The high female-to-male ratio associated with SLE is not seen with drug-induced lupus. However, drug-induced lupus usually occurs in males over 50 years old because they are more likely to develop chronic diseases (i.e. heart disease) that require continuous use of those medications known to cause drug-induced lupus.

People with drug-induced lupus may complain of flu-like symptoms, especially muscle and joint pain. Symptoms may appear gradually and become worse after the person has taken the drug for several months. In other people, symptoms start rapidly. They are generally mild, but can become much worse if a patient continues to take the medication that is causing them. By the time a diagnosis is made, most people will have one or more of the following:

- Joint pain.
- Muscle pain.
- Arthritis.
- Fever.
- Heart and lung inflammation.

## **Will having Lupus in childhood affect school, sports, getting a job and eventually having a family?**

The goal of treatment for children with lupus is for them to be able to live a “normal” life that includes school, extracurricular activities, and eventually employment and relationships.

A large health care team is required to achieve these goals – a team that may include a paediatric rheumatologist, paediatric nephrologist, adolescent medicine specialist, psychiatrist, family doctor or general paediatrician, nurses, social worker, psychologist, dietitian, physiotherapist, and occupational therapist. Other specialists may include, for example, an ophthalmologist, gastroenterologist, or orthopedic surgeon, as needed. A team approach will help to decrease the number of appointments (and missed school), and will work to simplify the required medications, while addressing other aspects including diet and exercise.

School accommodations that include a modified gym class or a decreased school load may be required during periods of flare. Many adults have completed university studies and lead satisfying and productive lives that include having children and families despite severe flares of lupus during childhood and adolescence.

It is important to recognize that having a chronic disease during childhood and adolescence is an extra challenge, and that communication with the health care team is essential to learn how to deal with the expected emotions that include anger, depression, and confusion that may occur from the diagnosis of lupus or as a result of having to adjust lifestyle during a flare of symptoms

- A premature baby may not be able to suck adequately. Feeding your baby through a tube at first and then by bottle may be necessary. However, you may still be able to pump your breast milk for your baby.
- If you are taking corticosteroids, you may not be able to produce enough milk.
- Some medications can pass through your breast milk to your baby. Talk to your doctor about whether or not breastfeeding is safe with the medications you are taking.
- Because breastfed babies tend to eat more frequently than do bottle-fed infants, breastfeeding can be very tiring. Options include pumping breast milk so that a partner can help feed the baby by bottle; supplementing breastfeeding with formula; or switching to a bottle and formula entirely. Keep in mind that, depending on what type of formula you use, bottle-feeding can be as time-consuming as breast-feeding (or even more so) if one considers the time required for preparation, cleaning bottles, etc.

Be confident that whatever method you choose to feed your baby, it will be the right decision for everyone concerned.

## **Caring for yourself during pregnancy**

- Keep all of your appointments with your primary doctor and your obstetrician.
- Get enough rest. Plan for a good night’s sleep and rest periods throughout the day.
- Eat a sensible, well-balanced diet. Avoid excessive weight gain. Have your obstetrician refer you to a registered dietitian, if necessary.
- Take your medications as prescribed. Your doctor may have you stop some medications and start or continue others.
- Don’t smoke or drink alcoholic beverages.
- If you’re not already taking a folic acid supplement, now is the time to start. This B Vitamin reduces the risk of neural tube birth defects. The most crucial time for fetal development occurs between five and 12 weeks, so you should start taking folic acid before you become pregnant and continue at least to the end of the first trimester. Prenatal multiVitamins contain the necessary amount of folate (1 mg per day).
- Be sure your doctor reviews with you the normal body changes that occur during pregnancy. Some of these changes – such as extreme fatigue – may be similar to those that occur with a lupus flare. Although it is up to the doctor to determine whether the changes are normal or represent the development of a flare, you must be familiar with them so that you can report them as soon as they occur.
- If you are not sure about a problem or begin to notice a change in the way you feel, talk to your doctor right away.
- Ask your doctor about participating in childbirth preparation and parenting classes. Although you have lupus, you have the same needs as any other new mother-to-be.

## **Rheumatology drugs considered safe in pregnancy**

Acetaminophen  
Aspirin (80 mg/day)  
NSAIDs until 28-32 weeks gestation  
Prednisone  
Chloroquine

Hydroxychloroquine  
Azathioprine  
Cyclosporine  
Tacrolimus  
Heparin

## Potential complications during pregnancy

### **Lupus flare**

- Increased pain
- Morning stiffness
- Fever
- Development of rash that worsens
- Stomach discomfort
- Headache
- Dizziness

### **Pregnancy-induced hypertension**

#### **Mild**

- Blood pressure 140/90 mmHg and over during second half of pregnancy
- Excess protein in the urine (proteinuria)
- Mild, generalized swelling (edema)

#### **Pre-eclampsia**

- Abdominal pain.
- Blood pressure 140/90 mmHg and over during second half of pregnancy.
- Excess protein in the urine (proteinuria).
- Over activity of physiological reflexes (hyperreflexia).
- Swelling (edema), including face and hands.

#### **Eclampsia**

- All of the symptoms of pre-eclampsia.
- Seizures

### **Neonatal lupus**

#### **Baby experiences**

- Transient rash.
- Transient blood count abnormalities.
- Heart block (disturbance in heart rhythm)

## Lupus in Children

### **Does Lupus occur in Childhood?**

Yes, lupus does occur in childhood. Approximately 1 in 10,000 children will develop lupus. Just like in adults, lupus is more common in girls than in boys, and is more common in teens than in children who have not yet started puberty. The average age for lupus to start in children is about 12 years old.

### **Is Lupus the same in children?**

Children and adolescents with lupus can have all the same symptoms as adults, including the characteristic “butterfly rash” on the face. Other symptoms include, rashes on other parts of the body, fevers, fatigue, joint pains, and swelling, hair loss, and Raynaud’s phenomenon (colour changes of the fingers and toes on cold exposure). **Just as in adults**, children with lupus can also have their kidneys, brain, and nervous system, lungs, heart, and other organs affected. Because children are not just “little adults”, the symptoms of lupus may not look like an adult with lupus.

### **How is Lupus different in childhood?**

Children and adolescents who have lupus develop kidney involvement more often than adults, in fact, at least half of children with lupus will develop kidney disease that requires treatment. Additionally, children with lupus more frequently experience headaches, memory and learning issues.

Children also experience other nervous system problems more often than adults with lupus including; hallucinations, seizures, anxiety, abnormal movements or depression. Children and adolescents with lupus often have one or more relatives who have lupus, which suggests that there is a strong genetic link implicated in the development of the disease.

### **What treatments are available for children with Lupus?**

The good news is that there are more medications available for lupus treatment than ever before. While many of these medications have not been tested directly in children and adolescents with lupus, ongoing research studies are helping to determine the most effective drugs to best target specific symptoms. Steroids (such as “prednisone”) and hydroxychloroquine are the most commonly prescribed medications for children with lupus. Immunosuppressive medications (including azathioprine, mycophenolate mofetil, cyclosporine, cyclophosphamide, rituximab, and tacrolimus) may also be used in children depending on the symptoms that require treatment.

Since children are often affected before they have finished going through puberty, it is very important to treat the symptoms very aggressively to prevent permanent problems with growth and development. Medications are frequently adjusted for a child’s size and growth stage. Children metabolize medications differently and therefore usually require relatively higher doses of medications, based on their weight, than do adults.