



# My Lupus

*What I Need to Know*

BC LUPUS SOCIETY



1-866-58-LUPUS [www.bclupus.org](http://www.bclupus.org)

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This information in this document is intended solely for person to who it was given by the health care team.



Developed by the health care professionals of the Pediatric Rheumatology Program with assistance from the Department of Learning & Development.

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**Notes:**

## What's in the future for me?

When first diagnosed with lupus you may feel your life is in an upheaval and have little control over it. There are major changes you are forced to make such as frequent clinic visits, medications and learning all about a disease you probably have never heard of. Although these adjustments are sometimes difficult, their importance will lessen as you become more familiar with living with lupus. As you start to feel better your daily routines of school and social events with friends become a priority and lupus is not always in your thoughts.

There is no doubt that lupus may complicate your life at times. For some women who become pregnant, having lupus can increase the risk of miscarriage or cause a flare of their lupus. Close monitoring by a physician is required.

If you decide to travel for an extended period of time this may take more planning. However if you are sensible and take precautions there is no reason why any of your future plans should have to change.

Your career goals, marriage and a family are all realistic and important goals to look forward to.

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Hopefully this booklet has answered some of your questions regarding lupus. Having a good understanding of lupus will enable you to take responsibility for yourself and your treatment program.

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## Introduction



This booklet is intended to provide you with information about lupus. Lupus is a complex disease and it will take you and your family time to understand all the information. We hope that you will refer to the booklet from time to time as questions arise. You may have wondered why you need so many blood tests or why you have to take medicine. Having a good understanding of these and other issues may help you feel less worried and allow you to take more control over your disease.

Your parents may also want to read this booklet so they too will have a better understanding of lupus. However it is important to remember that this is your illness and you are ultimately responsible for looking after your own health

Having lupus can affect relationships. This may be because you do not feel good about yourself, or because you do not know how to handle aspects of your disease and treatment around your friends. The tips and suggestions in this booklet will help you face these daily challenges.

If you have just learned that you have lupus, you may find reading all this information overwhelming. It may be better to read it gradually, when certain questions or issues arise.



Please remember your family, friends, and health care team are the best people to talk to and help support you at anytime.

## What Should I Tell My Friends?

What you choose to tell your friends about lupus is a personal decision. Some of you may only want to tell your very close friends, while others may choose not to tell anyone about their disease. Remember if no one knows about your disease it is hard for them to be able to help. Often giving a simple explanation is all that is needed. For example, "I have lupus, which is a disease that causes inflammation to my skin and joints and makes me tired".



If you need to take large doses of prednisone for a period of time and you gain weight, some people at school may ask you questions. An explanation like, "I have to take a medicine which will help me get better but it makes me put on weight", will help them to understand.

You will be surprised how understanding and helpful your friends can be, as true friends should be.

## Will I have to miss a lot of school?



Unfortunately our clinics and visits to specialist are scheduled during school time. We will try and make your appointment times as convenient as possible. When you are first diagnosed, you will be coming to the clinic fairly frequently (usually about every two weeks). As your lupus improves the frequency of visits decreases to about every three months.

Absence from school may be a problem early on in your lupus. It will not take long before you feel well enough to attend school full time. You may feel unable to participate in physical education on a regular basis. This is temporary and we encourage you to get back to sports and activities as soon as you feel able. Talk with your nurse or therapist if any of these areas are difficult for you. Lots and lots of young people with lupus have graduated from high school and gone on to University.

emotional (feelings), and practical (financial) problems brought on by your lupus.

- Talk to your doctor and nurse. Having your health care team know how you're feeling can be helpful.
- Read and be a contributing writer to our newsletter, "The Loop".
- Come to Rheumatology's three day summer camp for young people with rheumatic disease. Camp provides and opportunity for you to meet other young people with lupus. Ask your nurse for more information.
- Continue to be involved in the activities you enjoy. You shouldn't have to stop doing sports or other activities in or outside of school. It is important to change as little as possible in your normal routine.
- Feeling good about yourself can help lessen negative emotions you may feel.. Here are some ideas on how to look and feel better:



- Cover skin rash with a makeup foundation.
- Use astringents and soaps to help your acne. If these don't work ask your doctor who can prescribe a stronger cream.
- If you hair is thinning use a mild shampoo, try not to wash your hair every day, and don't use rubber bands or clips that may pull your hair. Avoid hair dyes and other strong chemicals.
- If you have a rounder face due to prednisone try a hairstyle that pulls attention from the cheek and jaw area. Avoid full front bangs, short, cropped hair, or hair pulled tightly to head.
- Recognize your strengths. Make a list of all the positive things you can think of about yourself. Ask others to help you.

## What is Lupus

Systemic lupus erythematosus (SLE) is a disease that causes inflammation in many different parts of the body. Inflammation is a process that causes parts of the body to become hot, painful, swollen, or red. It can affect the skin, causing a rash, or the joints causing arthritis. It can also cause inflammation to organs you cannot see such as kidneys, heart, lungs, and the nervous system. If the inflammation is not treated properly, it can sometimes cause permanent damage.



Lupus is a chronic illness, which means it may go on for many years, perhaps life long. This however does not mean that you will be on medications or feel ill forever. This is because the disease can be effectively treated.

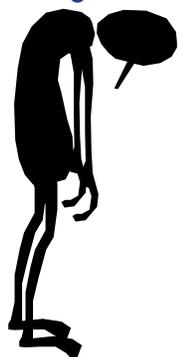
Lupus is characterized by unpredictable periods of flares and remissions. There will be times when your lupus is quite active, a "flare", and there will be times when your lupus is quiet, a "remission". There is no easy way to predict when you will have a flare. However, if a "flare" is detected early, by seeing our doctor regularly and having regular blood tests it is easier to treat.

## What causes Lupus?

The cause of lupus is unknown. We do know the symptoms of lupus are caused by an abnormal reaction of the body's immune system. The immune system protects our bodies against infections caused by foreign invaders such as germs and viruses.

In someone with lupus instead of the immune system only attacking the invader, it attacks the body's own cells. The end result is different areas of the body becoming inflamed.

## Why Me?



Nothing you did, or did not do, caused you to get lupus. Lupus is not contagious which means you didn't catch it from someone, nor can they catch it from you. We do know lupus is more common in girls, usually over the age of six and seems to occur more often in Asian, First Nation, African, Hispanic, and Indo-Canadian peoples.

In some families, there may be more than one person with lupus, or other people in the family may have rheumatoid arthritis or other autoimmune diseases. This is not very common, but seems to happen more often in the families of children who get lupus as compared to adults with lupus. The risk of your brothers or sisters or eventually your own children developing lupus is low.

## What are the signs of Lupus?

The signs and symptoms of lupus can vary widely from being very mild to more serious. Generally, at the time of diagnosis is when you feel the most ill. Specific signs of lupus can include:



- **Malar Rash:** A butterfly-shaped red rash over the cheeks and across the bridge of the nose.
- **Photosensitivity:** Exposure to ultraviolet light, like sunlight or a tanning booth can cause a bad lupus rash, or a lupus flare (when the disease gets worse).
- **Mouth Sores:** Sores on the tongue and the inside of the mouth.

## Will I have to see other doctors?

Over the course of your illness you may have to see other specialists at the hospital. You will see the nephrologists if you have kidney involvement or the dermatologist if you have skin involvement such as a rash or acne. If you have worries or concerns about how you're coping, you may see a psychologist. We try and keep your appointments to a minimum, but sometimes these specialists are important in helping to treat your lupus.



## Why do I feel angry and sad?



Feeling angry and sad are normal emotions when dealing with lupus. You may feel like you are on an emotional roller coaster. At times you feel in control and can handle it, while other days you feel frustrated and afraid.

## Here are some helpful tips:

- Learn about your disease; never be afraid to ask questions. Having knowledge about lupus helps you be in control and know what to expect. Lupus has its ups and downs, one minute you feel great, the next you may feel rotten. Knowing this is a natural part of lupus may help you prepare.
- Talk to someone. Talking may help you feel better and help you learn other ways to handle problems. Keeping your feelings bottled up inside can make you feel worse. Talking to friends and family helps them to know how you feel and allows them to try and help you. It may be helpful to talk to a social worker who is trained to assist with the social (friends, school),





These include:

- **Anti-nuclear antibody test (ANA)**

The ANA test is positive in almost all patients with lupus. However, a positive ANA test, by itself, is not proof of lupus since the test can be positive in many other conditions and in many healthy children. On the other hand, a negative ANA argues against lupus but does not rule out the disease completely.

- **Anti-double-stranded DNA antibodies (anti-DNA)**

This test is generally positive in lupus. It is done at most clinic visits as a rise in levels can be helpful in indicating a disease flare.



- **Extractable nuclear antigen antibodies (anti-ENA)**

This is a group of tests. One of them, a positive anti Sm antibody test, is a strong indicator of lupus (Sm is a protein found in the cell nucleus).

- **Serum Complement (C3)**

C3 is a protein which is normally found in the blood, and is part of the normal response to infections. In active lupus, C3 is 'used up' or decreases and this can be measured in the blood.

- **Erythrocyte Sedimentation Rate (ESR)**

This test becomes elevated with any type of inflammation. This test is not specific to lupus and can go up in various illnesses such as colds or flu.

- **Full Blood Count (CBC)**

This counts the number of cells in a sample of blood. The white blood cells, red blood cells, and/or platelets are often decreased in lupus.



## My symptoms are:

| Symptom         | Date | Date |
|-----------------|------|------|
| Fatigue         |      |      |
| Rash            |      |      |
| Arthritis       |      |      |
| Kidney problems |      |      |
| Mouth ulcers    |      |      |
| Fevers          |      |      |
| Hair loss       |      |      |
| Anemia          |      |      |
| Chest pain      |      |      |
| Other           |      |      |
|                 |      |      |
|                 |      |      |
|                 |      |      |

## My Schedule of Tests

| Procedure, test, etc. | Date | Result |
|-----------------------|------|--------|
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |
|                       |      |        |

## Other Medications:

Name: \_\_\_\_\_

Dosage: \_\_\_\_\_

Frequency: \_\_\_\_\_

Reason for taking medicine: \_\_\_\_\_

\_\_\_\_\_

Name: \_\_\_\_\_

Dosage: \_\_\_\_\_

Frequency: \_\_\_\_\_

Reason for taking medicine: \_\_\_\_\_

\_\_\_\_\_

Name: \_\_\_\_\_

Dosage: \_\_\_\_\_

Frequency: \_\_\_\_\_

Reason for taking medicine: \_\_\_\_\_

\_\_\_\_\_

Name: \_\_\_\_\_

Dosage: \_\_\_\_\_

Frequency: \_\_\_\_\_

Reason for taking medicine: \_\_\_\_\_

\_\_\_\_\_

- **Urine Test**

This is an important test to ensure there is no kidney inflammation. If the kidneys are inflamed, red blood cells, and/or protein may be found when the lab tests the urine. There is not usually enough blood to see yourself. A urine sample will be requested at each clinic visit.

## What other tests will I have to have?

Lupus can cause inflammation in different organs in your body and it is necessary for the doctors to periodically do medical tests to ensure these organs are healthy. There are tests other than those listed below which may be done in particular circumstances; for example a head magnetic resonance imaging (MRI) test might be done if you have some problems indicating brain involvement. Some of the common routine investigations include:

- **Pulmonary Function Test (PFT)**

This test looks at the functioning of the lungs. It is a routine test that is usually done once every couple years to ensure lungs are not inflamed.

- **Echocardiogram**

This is a test that looks at the functioning of your heart. This is often done at the same time as your PFT.



- **24 Hour Urine**

The rheumatology doctor or the kidney doctor may ask you to collect samples of your urine over a 24 hour period to look for protein. This is usually done on a weekend so it does not interfere with school. This test helps the doctors determine if there is inflammation in your kidneys.

- **Kidney Biopsy**

A biopsy is where a small amount of tissue is taken from the kidney with a long needle and examined under





### Education

Being knowledgeable about your disease will help you to make sensible and informed decisions. Recognizing your own symptoms and knowing subtle changes in your body will help you manage your disease.

## My Treatment Plan

### My health Care Team

| Team Members                  | Telephone |
|-------------------------------|-----------|
| Doctors:                      |           |
|                               |           |
|                               |           |
|                               |           |
|                               |           |
| Nurse                         |           |
| Social Worker                 |           |
| Physio/occupational Therapist |           |
| Secretary/Appointments        |           |
| Others:                       |           |
|                               |           |
|                               |           |
|                               |           |
|                               |           |

- Pneumococcal Vaccine (Pneumovax)**  
 This vaccination is recommended for all patients with lupus. It protects you against Pneumococcal pneumonia, a bacterial infection which causes a serious infection in your blood. Some patients with lupus are especially prone to getting severe infections with Pneumococcus. This shot is usually given in the first year of your illness and repeated about every five years.
- Varicella Vaccine (Chicken Pox Vaccine)**  
 This vaccination protects you against getting the chicken pox. You may have already received this vaccination. If you haven't and have not had the chicken pox we will ask that you receive the immunization when you are not taking prednisone.

### How will I get better?



There are medications to help you get better. The treatment is aimed at decreasing inflammation in your joints, skin, kidneys, or other organs and avoiding a lupus flare. Your treatment regime will change from time to time depending on how lupus is affecting your body. Sometimes, when the disease is quiet, you may not need any medicines.

Here are some of the drugs you may become familiar with:

- Prednisone**  
 This is the most effective drug in controlling lupus. It is a steroid but is not the same kind of steroid drug that some athletes take. This drug works to decrease the inflammation caused by your lupus.



The side effects are related to the dose you take and how long you take it. When you are diagnosed you will probably have to take higher doses of prednisone, but as your lupus improves your dose will be lowered very gradually. Some side effects you may notice are:

- ⊗ increase in appetite
- ⊗ increase in weight
- ⊗ “puffy face”
- ⊗ acne
- ⊗ mood swings
- ⊗ stretch marks
- ⊗ slower growth
- ⊗ hair on your face

You may also develop side effects that you can't see such as:

- ⊗ Weak or brittle bones
- ⊗ Avascular necrosis. This is rare but prednisone can cause the blood supply to the bone to decrease, causing part of the bone to die.
- ⊗ High blood pressure
- ⊗ Increased susceptibility to infection
- ⊗ Cataracts. This is a cloudy area which develops on the lens of the eye. These cataracts are different from the cataracts older people get, and they usually do not affect vision.

After reading about these side effects I'm sure you feel anxious about prednisone.

- ☺ Prednisone is the best drug in treating your lupus.
- ☺ Most of the side effects will go away as your dose is lowered.

Prednisone is similar to chemicals naturally produced by your body. Treatment with prednisone fools the body into shutting off its own steroid production. These chemicals are vital to regulate normal daily body function. Therefore never stop your prednisone abruptly or you can become extremely sick. Your doctor will reduce your prednisone slowly, guided by your symptoms and blood test.

- Plan to eat foods high in calcium (e.g. 2% or skim milk, cheese) to help keep bones strong. It is difficult through diet alone to receive enough calcium so your doctor may prescribe a calcium supplement such as Tums.
- Remember that prednisone causes you to feel hungry and this increase in appetite is not your fault. If you try and control the type of food you eat (fruits and vegetable rather than burgers) this will help to slow any weight gain.



### Medi-alert Bracelet

If you are taking prednisone you should wear a medi-alert bracelet. This bracelet identifies your diagnosis and the medications you are on. In the event of an accident, medical staff need to know that you are taking prednisone.

### Contact Doctor

You will get ordinary colds just like anybody else, however sometimes people with lupus can get serious infections. If you develop a high fever (greater than 100°F or 38.5°C), or feel increasingly unwell, always get in touch with a doctor quickly.



There is always a Rheumatology Doctor on call 24 hours a day for emergencies related to your lupus.

### Compliance

The most important aspect of managing your lupus is taking your medication and attending clinic for regular check ups and blood tests. If you have some of the side effects of prednisone, particularly weight gain, continuing to take your medications is more difficult. It's normal to lose your interest in following your treatment plan now and then. Remember to discuss your frustrations and worries with your family, your doctor and your nurse.

- Avoid the sun from about 10 am to 2 pm. This is when the sun is the strongest.
- Protect exposed areas when you're in the sun (don't forget your ears). Wear a hat and long sleeved shirts.

In fact these precautions are sensible even for people who don't have lupus as too much sun exposure can cause skin cancer and premature aging of the skin.

## Rest

Fatigue is often a symptom of lupus when the disease is active. This will improve but it is important to pace yourself and not over do it. Don't participate in activities so that you get exhausted. Ask for help when you need it. Listen to your body and if you feel tired, rest even if it's only for 10-20 minutes.



## Exercise

When lupus is active you may not feel like participating in all your sports activities. Once you are feeling better it is important to get back to doing all your previous physical activity. Usually there are no restrictions to physical activities because of lupus. Exercise helps strengthen your muscles and bones, keep joints flexible and controls your weight. Your doctor may recommend you see a physical therapist or an occupational therapist who can show you more specific exercises.

## Diet

No special diet will cure or prevent a flare of your lupus. A well-balanced diet that includes a variety of foods is important to healthy nutrition. There are a few key points to remember:

- Avoid foods high in salt, such as fast foods.



## Methyl prednisone IV

This drug is similar to prednisone except it is given in the early stages of your lupus when it is quite active or may be given later if your lupus flares. An IV, or intravenous, is a way of giving a medication through a vein in your arm.



There are fewer side effects when giving prednisone intravenously, but may not be as effective as prednisone by mouth.

## Hydroxychloroquine (Plaquenil)

This is a drug that most children with lupus will be on long term (for many years). It may treat the rash in lupus, and is helpful in improving some abnormalities in the blood. Plaquenil is helpful in preventing a flare of your lupus once your lupus is in remission. It has relatively few side effects. Plaquenil can affect your vision, however at the dosages that we use in our clinic, this has not been a problem. We do ask that you have your eyes checked every few years by an eye specialist (ophthalmologist).

## Azathioprine (Imuran)

This is a drug that helps reduce inflammation in major organs such as the kidney. It may also reduce the need for high doses of prednisone. Imuran can have side effects such as decreasing the ability for the body to fight infections. Blood tests are done regularly to monitor this.



## Mycophenolate Mofetil MMF (Cellcept)

Cellcept is a drug that suppresses the immune system. It is often used for kidney inflammation and may replace Imuran if that drug has not been effective. Cellcept is also used once a course of cyclophosphamide has been finished. Cellcept and Imuran are never given together.

- **Cyclophosphamide**

This is an immunosuppressive drug that helps decrease the activity of the cells causing inflammation. It is usually used to treat active kidney disease, other active organ disease (for example in the lung or brain) or if the disease can not be controlled using other medications. Cyclophosphamide works fairly quickly, and can be life saving or kidney saving for many patients. This medication is given by IV in the Medical Day Unit, usually once a month for at least 6 months.

- **Rituximab**

This is a drug that acts very specifically on a certain antigen (B cells) which plays a role in the inflammatory response in lupus. This drug is usually used for very active lupus affecting organs.

Many kids with lupus need to take other medications to help control their blood pressure (if they have kidney disease). There are many other medications that may be used to treat your lupus depending on your particular problems; your physician and nurse will give you this information when necessary.

## What should I expect when I come to the Clinic?

There are many doctors and other health care professionals that you will meet when you come to clinic. We are very fortunate to have a big Rheumatology Team to help you cope with your disease. There are times when you will have many appointments, we try very hard to make sure you miss as little of school as possible.



You may be seen by the clinic nurse first. You may then be seen by a rheumatology fellow who is a pediatrician training in rheumatology. This doctor is usually with the clinic for 2 years so you will get to know them quite well. You will always see one of the rheumatology doctors. It is necessary to examine you at each visit and you will often have a blood test as this assists the doctor in determining your disease activity.



The clinic visits are very important as they let doctors monitor your disease activity and make adjustments in your prednisone. It is also a good time for you and your parents to ask questions about your disease, treatments, and other problems you may be having.

Research is an important part of our clinic, and our group has one of the most active pediatric lupus research programs in Canada. You will almost certainly be asked to participate in lupus research. Remember, you are never obligated to participate in research but by doing so you help other children and teens with lupus in the future.

## What can I do to help my Lupus?

There are things that you can do to help yourself get better in addition to medications:



### Sun Protection

Sun protection is important. Sunlight can make your lupus worse or trigger a flare.

Use a sunscreen lotion with a sun protection factor (SPF) of 30 or higher. Apply 30 minutes before going into the sun.

- Use sunscreen lotion even on cloudy days.