Lupus can be well managed & most of the time your life can be relatively normal. “Flares” may be associated with certain triggers such as stress, infection, sunlight or something else. You will get to recognise what the triggers are to your symptoms. Knowing this will mean that you can deal better with them. Between “flares” you may feel well & be symptom free.

You will need to find out what works best for you.

- Remember fatigue & tiredness is common so resting is good. Pay attention to your body & slow down especially when you are not feeling well. It is good not to push yourself too hard or a “flare” may happen.

- Learn to timetable rest times after active times.

- Exercise is good for you as it strengthens muscles & keeps joints flexible. If you are feeling unwell you should reduce your exercise until you feel better.

- Always use sunscreen, hats & glasses, as sunlight can make lupus worse. Even some lighting inside the house & at work & school could make your lupus worse. It may be a good idea, in such a case to reduce the strength of the light globes or filter the light.

- Always take the drugs prescribed by your doctor.

- Your diet should include a variety of healthy foods. Don’t eat too many foods that contain high levels of sugars, salt & fats. Eat plenty of fruit, vegetables & protein.

- Drink adequate fluids, in particular water.

- Live well & enjoy life.

- Learn about lupus & how you can help to reduce the effects of lupus & its symptoms.

WHERE CAN I GET HELP?
Autoimmune Resource & Research Centre
Telephone: 02 49214095
email: ARRC@hnehealth.nsw.gov.au
web: www.autoimmune.org.au
What is lupus?

Systemic Lupus Erythematosus (SLE) or simply “lupus” is a condition that can cause inflammation in many parts of the body. It affects people in different ways causing symptoms in different parts of the body – joints, kidneys, skin, heart, lungs & nervous system. Usually only 2 or 3 parts of the body may be affected.

There is nothing you could have done to stop yourself getting lupus. You cannot catch lupus from other people or give it to others.

Lupus is an illness that may go on for years, or for your entire life. It is unpredictable with times when your symptoms are worse (this is known as a "flare") & at other times when you may have few or no symptoms.

What causes lupus?

We don’t know what causes lupus but we do know that it involves the immune system. Our body uses the immune system to protect itself from harmful things such as bacteria & viruses (bugs).

We are not sure why some people have an immune system that does not work properly, however, we do know that when some people get sick it is caused by the system being overactive & causing harm to itself. This is called autoimmune illness. Lupus is one of these illnesses.

Females are more likely to get lupus than males, approximately 9 to 1. Sometimes there is a family history of lupus or other autoimmune conditions.

What are the symptoms?

Lupus can be hard to diagnose as there are a lot of different symptoms that people may have. You probably won’t experience all of them, most people only have some. You generally need to have 4 or more specific symptoms to be diagnosed with lupus.

Symptoms can change over years & can come & go.

You may have periods of symptom flare up & periods of wellness:

- Fits
- Fatigue & tiredness
- Headaches
- Hairloss
- Mouth ulcers
- Shortness of Breathe
- Painful or swollen joints
- Chest pain
- Memory Loss

Kidney problems

Fever

Butterfly shaped rash

Sunlight & lights can cause rash

How is it diagnosed?

Go & see your doctor. He or she will take a history of your problems & symptoms which can give clues to your condition. It is not uncommon for people to have lupus & its symptoms for some time before they get a diagnosis. Your doctor will do a physical examination & order some tests (blood & urine tests usually) to help decide whether you have lupus & to see if your immune system is working properly or is overactive.

If you do have lupus regular blood tests will be done by your doctor to monitor your illness & help keep you healthy.

Your GP may decide you should see a specialist. Many different types of specialists are involved in the care of those with lupus for example rheumatologists (for joints), immunologists (for the immune system) or a dermatologist (for skin).

Your GP will decide which specialist is the best is for you based on the symptoms that you have.

The symptoms you have show what parts of the body are affected & need special attention.

How is it treated?

Everybody has different symptoms so your treatment will be based on your symptoms & problems. Your doctor can explain which ones can help you. The most commonly used drug is prednisolone. This will be given to you in a high dose when you are first diagnosed & maybe to help you when you have a flare. The dose is gradually reduced at times when your illness is quiet & when new drugs are given. Other drugs may be given to help reduce the steroid dose (steroid sparing).

There are many other drugs that are effective in treating specific symptoms your doctor will talk to you about these.

Most drugs work by helping to balance the immune system.

There are some health supplements & aids that can be used to reduce symptoms, for example soap substitutes, eye sprays & special oral care items of mouthwash & toothpaste.