Melbourne Respiratory & Sleep Services

9459 0555 9455 0786
reception@mrss1.com.au
www.melbourne respiratoryandsleep.com.au
226 Burgundy Street Heidelberg VIC 3084

SARCOIDOSIS

What Is Sarcoidosis?

Sarcoidosis or sarcoid, is a disease due to a particular type of inflammation, called granulomatous inflammation. This is when inflammatory cells congregate together and form 'lumps' called granulomas. In the majority of cases these granulomas disappear with or without treatment. Granulomas that do not heal become scarred. This is known as fibrosis.

Sarcoidosis can affect any organ of the body, but most commonly affects the lungs, skin and eyes.

The disease can develop suddenly and then disappear, or appear gradually and produce symptoms that come and go. In the latter case the disease can continue to recur over a lifetime.

Although sarcoidosis can occur at any age, it is most often seen in young adults and mainly affects people between 20 to 40 years of age. Sarcoidosis occurs in all races and both sexes. However, it does appear to be more common in people of Irish, Afro-Caribbean, Scandinavian Asian, Puerto Rican and German origin.

What Causes Sarcoidosis?

No one knows what causes sarcoidosis. What is known is that it is a common chronic illness and occurs all over the world. It is difficult to know how many people are affected as sarcoidosis can often be mistaken for other diseases. Furthermore, many patients without symptoms may not know they have the condition.

If you are diagnosed with the disease there are many things that you can be reassured about:

- Sarcoidosis often goes away by itself and 60 to 70 per cent of cases clear up in 24 to 36 months. In cases that do last longer the patient can generally continue to have a normal life.
- Sarcoidosis is not contagious. Although it can occur in families, there is no research to show that it can be passed from parents to children.
- Sarcoidosis is not a form of cancer.

How Will Sarcoidosis Make Me Feel?

The symptoms of sarcoidosis depend on what part of the body is affected. Some patients with sarcoidosis have no symptoms at all.

The commonest presentation is:

- An illness with flu-like symptoms of fever, tiredness and joint pains.
- Shortness of breath; known as dyspnoea, and a persistent dry cough. A chest x-ray may show swollen lymph nodes called bilateral hilar lymphadenopathy.
- A painful red, bumpy rash on the face arms or shins called erythema nodosum.
- Sore eyes and blurred vision due to inflammation within the eye, known as uveitis.
- Swollen lymph nodes in the neck, armpits and groin.

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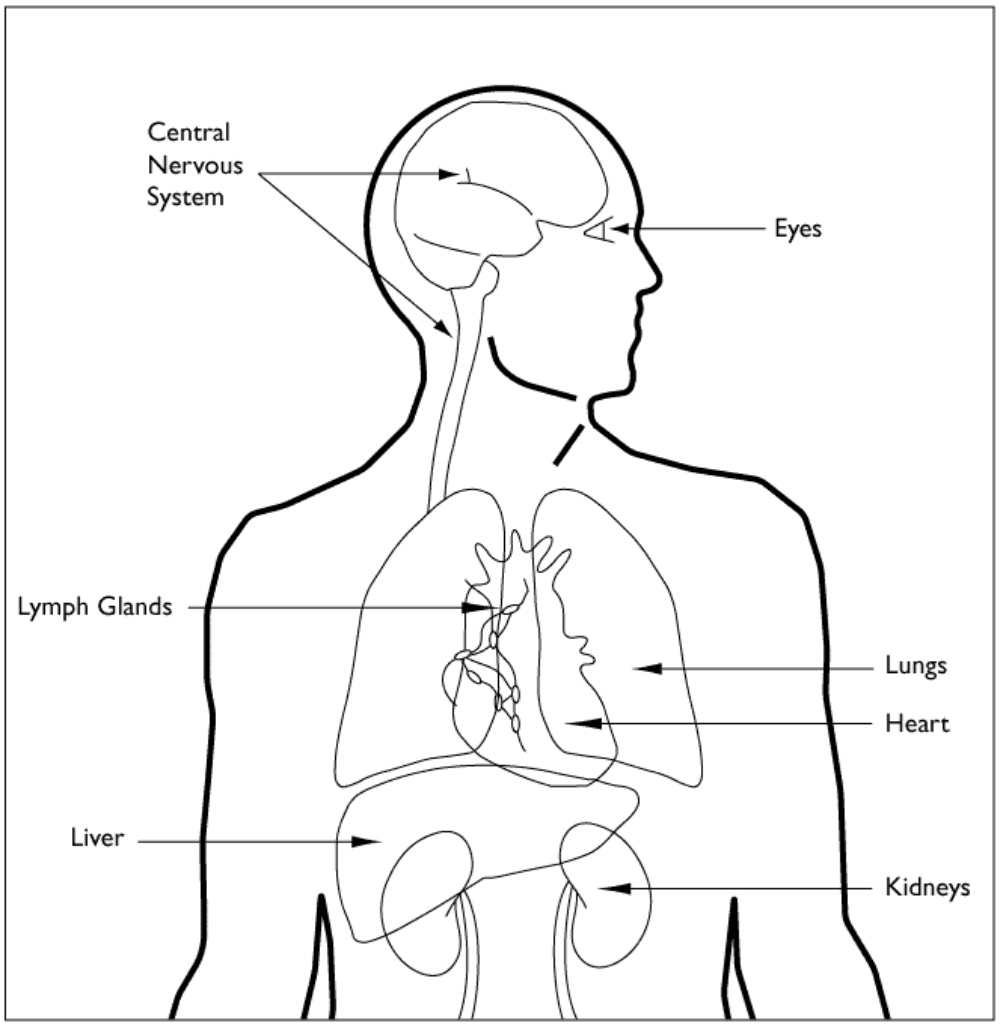
Some Of The Sarcoidosis Sites



How Is Sarcoidosis Diagnosed?

It can sometimes be difficult to diagnose sarcoidosis, as it can appear to be a number of other conditions. Therefore, tests will need to be carried out.

- A chest X-ray will show the areas of the lung that are affected by sarcoidosis and any swollen lymph nodes. Specific blood tests can measure the levels of blood proteins known to be involved in sarcoidosis. They can also show increases in serum calcium levels and abnormal liver function that are often associated with sarcoidosis.
- One specific blood test can measure a blood substance called angiotensin-converting enzyme (ACE). Granulomas produce large amounts of ACE, and so the blood enzyme levels are often, but not always high in patients with sarcoidosis. This blood test can show how active the disease is.
- A Gallium scan will show the parts of the body affected by sarcoidosis and other inflammatory conditions. An injection of gallium is given into a vein and your body is scanned 2 days later.

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- A bronchoscopy may be undertaken if the lungs are affected, to get a small biopsy of lung tissue. This procedure involves a flexible narrow telescope being passed into the windpipe from the nose/mouth. This is a painless procedure and would be fully explained to you.

What Is The Course Of The Disease?

We are unable to predict the progression of sarcoidosis. However, the doctor's findings and your symptoms can provide clues as to how the disease will develop.

The flu-like illness and swollen chest lymph glands can last for 3 to 4 weeks. This is seen as the acute phase of the illness. A milder form of flu follows that can last from some months up to two years, before the sarcoidosis is completely resolved.

If you present with dyspnoea and possibly skin sarcoidosis these symptoms can indicate that the disease may be more chronic and severe.

If you develop lung problems there is a higher chance of the disease persisting.

How Is Sarcoidosis Monitored?

Your doctor will wish to see you on a regular basis to monitor the disease. Your condition will be monitored through:

- Chest X-rays
- Breathing or Lung Function tests
- Blood tests including the serum ACE.

The results of these tests will help the doctors to decide how best to manage the treatment of your particular symptoms.

The Sarcoidosis Clinic will give you access to the specialists in this disease. In this way we hope to be able to offer you the best health care with the minimum amount of disruption to your life. The clinic can provide support and expert advice for your particular condition.

What Treatment Will I Be Given?

The majority of patients with sarcoidosis require no treatment.

Treatment is necessary for patients who have the rarer forms of sarcoidosis that affects their brain, heart or causes a high blood calcium level. If you develop lung problems your consultant will monitor you through outpatient appointments for a few months to see if you get better on your own. If the lung involvement is severe, causing you problems or getting worse, you will be offered treatment.

The main treatment for sarcoidosis is steroids. Sarcoidosis responds very well to steroids. These are usually started at a moderate dose and then reduced gradually over a few months with the aim of stopping treatment after about 1 year.

If patients require a high dose of steroids to control their sarcoidosis, other medication may be used in an attempt to reduce the amount of steroids needed. These may be Hydroxychloroquine, Methotrexate or Azathioprine.

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Occasionally the sarcoidosis may become active again after steroids are stopped. This is called a relapse. Symptoms will respond to restarting of the steroid treatment.

What Are The Side Effects Of Corticosteroids?

It is understandable that you may be concerned about starting steroids. They, like all medicines, do have side effects, which is why the risks and benefits of treatment have been weighed up carefully by your doctor in discussion with you.

You will receive a steroid card that you should carry with you at all times and read carefully.

Risk Of Infection

Steroids at high doses do reduce your ability to fight infection. This means -

a) You should promptly seek medical advice if you think you have an infection.
b) Avoid contact with anyone with chicken pox or measles.

Risk Of Stopping Treatment Suddenly

If you have been taking steroids for more than three weeks, do not stop taking them suddenly without medical advice. This can make you feel very unwell and is potentially dangerous.

Weight Gain

Steroids increase appetite, which can lead to weight gain. It is important that you watch your diet carefully.

Bone Thinning Or Osteoporosis

Long term steroids can cause bone thinning. You will be carefully monitored for this. It is recommended that you:

a) Do not smoke.
b) Avoid drinking large amounts of alcohol .
c) Take part in regular weight-bearing exercise such as walking or running.
d) You may be offered calcium and vitamin D supplements, unless you have the form of sarcoidosis with high urine or blood calcium levels.

This will all help to reduce the risk of these complications.

How Can I Help Myself?

There is no specific diet that is known to help with sarcoidosis. The diet that we have included is beneficial for everyone who wants to eat healthily. It **may** also have 'anti-inflammatory' effects, although this is **not** proven:

Reduce These Foods:

- Reduce your intake of saturated fats. This includes animal fats and dairy products.
- Oils and fats to avoid are vegetable (polyunsaturated) oils and margarines (partially hydrogenated fats and transfatty acids).

Increase Intake of These Foods:

- Use extra virgin olive oil for salad dressing and as a substitute in recipes using oil.
- Eat lots of fruit and vegetables – the present recommended government daily intake is 5 portions of fruit / vegetables a day.
- Eat more salmon, herring and sardines, which are good sources of protein.
- Other good sources of protein are chicken, fish in general, pulses and nuts.

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The majority of people with sarcoidosis are able to have a normal life. Staying fit and having a healthy lifestyle may help to keep your disease at bay. Ask your Dr for more personalised information and advice.

Sarcoidosis Research

At UCL we have an active research program looking at why certain people develop sarcoidosis and why some patients with sarcoidosis develop scarring of the lungs. We are always looking for volunteers to assist us with this research which only requires providing us with a blood sample and answering questions for our sarcoidosis database.

Glossary

ACE - Angiotensin-converting enzyme. This blood test can show how active your disease process is. It is referred to as a serum ACE.

Alveoli - The tiny sac-like air spaces in the lung where carbon dioxide and oxygen are exchanged.

Biopsy - The removal of a small sample of tissue from the body for examination under a microscope, to help in diagnosis.

Dyspnoea - Shortness of breath.

Erythema Nodosum - A type of skin rash causing tender red lumps, mainly on the legs, face and shins.

Lymph Nodes - Small, bean-shaped organs of the immune system found throughout the body. Which produce infection-fighting white blood cells.

Lymph Nodes or Lymph Glands - These are bean-shaped organs which filter out infectious and poisonous material and destroy it.

Lymphadenopathy -Any disorder or disease, or swelling of the lymph nodes.

Granulomas - Small lumps in tissues caused by inflammation.

Uveitis - Redness, pain or tearing of the eyes.