

Sjögren's syndrome

This sheet has been written for people affected by Sjögren's syndrome. It provides general information to help you understand how you may be affected and what you can do to manage it. It also tells you where to find further information and advice.

What is Sjögren's syndrome?

Sjögren's syndrome is an autoimmune condition. The normal role of your body's immune system is to fight off infections and diseases to keep you healthy. In an autoimmune disease like Sjögren's syndrome, your immune system starts attacking your own healthy tissues. This results in abnormal dryness of the mouth, eyes and/or other tissues. Around half the people who have Sjögren's syndrome also have some form of arthritis (conditions affecting the joints, such as lupus and rheumatoid arthritis). This is known as secondary Sjögren's syndrome. Primary Sjögren's syndrome occurs in people who do not have one of these forms of arthritis.

What are the symptoms?

Sjögren's syndrome can affect many different parts of the body. The glands that produce tears and saliva are most often affected. Common symptoms include:

- dry eyes (including irritation, gritty feeling or painful burning in the eyes)
- dry mouth (or difficulty eating dry foods)
- swelling of the glands around the face and neck.

Some people may also experience dryness in other areas of the body (such as the nose, throat, and vagina) and skin.

What causes it?

It is not known what causes Sjögren's syndrome. It is believed to be the result of genetic factors and/or possible viral infections, which activate the immune system. This is not yet confirmed in research.

How is it diagnosed?

Your doctor or specialist will diagnose Sjögren's syndrome from your symptoms, physical examination

and a range of tests. Dry eyes and mouth require further testing as they can also be caused by many other conditions or medicines. The main clinical test to help diagnose Sjögren's Syndrome is called a Schirmer's test. This test involves using a strip of blotting paper to measure whether the eye produces enough tears to keep it moist. Blood tests and a biopsy of the lip (a small piece of tissue from the inside of the lower lip is removed and examined under a microscope) can also provide important information to help with the diagnosis of Sjögren's syndrome.

What will happen to me?

Usually the outlook for people with Sjögren's syndrome is very positive. Most people with the condition are able to live normal lives without any serious complications. There can be an increased risk for infections in and around the eyes and for problems with the teeth. This is a result of the long-term reduction in tears and saliva. Many people experience fatigue (tiredness), muscle and joint pains, and painful swelling of the salivary glands. In some cases more serious inflammation may affect the lungs, blood vessels, kidneys or nerves, which can increase the severity of the condition. In a small number of people, Sjögren's syndrome may be associated with lymphoma, a cancer of the lymph glands.

Is there a cure?

Currently there is no cure for Sjögren's syndrome. While there are ways you can control the symptoms, you should be wary of any products or treatments that claim to cure the condition.

What can I do?

1 See your doctor for treatment and advice. Your doctor will help coordinate your treatment. As Sjögren's

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syndrome is a life-long disease, it is important to see your doctor regularly to make sure it stays under control. Your doctor may also send you to a rheumatologist, a specialist in arthritis and inflammatory conditions, for further tests and treatment. Regular dental care from a dentist is also important in order to prevent cavities and dental problems. People with dry eyes should see an optometrist or even an ophthalmologist (eye doctor) regularly to check for damage to the eye. See your doctor promptly if you notice excessive redness and pain in the eyes as this could be a sign of infection.

2 Learn about Sjögren's syndrome and play an active role in your treatment. Not all information you read or hear about is trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying. Reliable sources of further information are also listed in the section below. Self management courses aim to help you develop skills to be actively involved in your healthcare. Contact your local Arthritis Office for details of these courses.

3 Learn ways to manage symptoms. Most of the treatment for Sjögren's syndrome is aimed at relieving symptoms of dry eyes and mouth and preventing and treating long-term complications such as infection and dental disease. Treatments may include:

- regular use of artificial tears and lubricating ointments for the eyes to manage dryness
- drinking water and/or using artificial saliva, mouth rinses or sugar free lozenges to relieve mouth dryness
- moisturisers for the skin
- avoidance of drying conditions, eg drafts from heaters and air conditioners, and exposure to dusty or windy weather, and use of a humidifier
- medicines prescribed by your doctor (for example, non-steroidal anti-inflammatory drugs (NSAIDs), corticosteroids or medicines that work on the immune system). See the *Medicines and arthritis* information sheet.

4 Live a healthy life. Stay physically active, eat a healthy diet, stop smoking and reduce stress to help your overall health and wellbeing. See the *Healthy eating* and *Physical activity* information sheets.

5 Acknowledge your feelings and seek support. As there is no cure for Sjögren's syndrome, it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the *Arthritis and emotions* information sheet.

CONTACT YOUR LOCAL ARTHRITIS OFFICE FOR MORE INFORMATION SHEETS ON ARTHRITIS.

Sjögren's syndrome can be well controlled.

Learn about Sjögren's syndrome and your treatment options.

For more information:

Books: Rumpf, Teri et al 2003, *The Sjogren's syndrome survival guide*, New Harbinger Publications, Oakland.

Websites:

Sjogren's Syndrome Foundation (US) www.sjogrens.org

Autoimmune Resource and Research Centre
www.autoimmune.org.au

Australian Rheumatology Association - information about medicines and seeing a rheumatologist
www.rheumatology.org.au

Arthritis Research UK www.arthritisresearchuk.org

American College of Rheumatology www.rheumatology.org

Arthritis Foundation (US) www.arthritis.org

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Your local Arthritis Office has information, education and support for people with arthritis
Arthritis NSW Infoline 1800 011 041 www.arthritisnsw.org.au

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