



The Australian Sjögren's Syndrome Association Inc

ABN 50 376 812 174
Charity No. 9876747
Deductible Gift Recipient
Beverly Norton J.P.

**39 Main Arm Road
Mullumbimby NSW 2482**

**Phone: (02) 6684 3704
Email: bevnorton@ozemail.com.au
www.sjogrens.org.au**



**Let us help
you to lead
a more
comfortable life**

Dry Eyes?



Dry Mouth?



Dry Nose?



Rheumatic



Disease?

you need to know about

**SJOGREN'S
SYNDROME**



What is Sjogren's Syndrome

Sjogren's (pronounced show-grins) syndrome is a chronic, autoimmune disorder in which the body's immune system mistakenly attacks its own moisture-producing glands. Lymphocytes, a type of white blood cell, infiltrate and destroy these glands causing decreased production of saliva and tears. The hallmark symptoms of Sjogren's syndrome are dry eyes and dry mouth.

Sjogren's syndrome can also cause dryness of the skin, nose and vagina and can affect other organs of the body, including kidneys, blood vessels, lungs, liver, pancreas and brain. Debilitating fatigue and joint pain can seriously impair quality of life.

An estimated 5% of Australians have Sjogren's syndrome, many of whom go undiagnosed. Nine out of ten individuals with Sjogren's are women. While most diagnosed women are of menopausal age or older, Sjogren's may occur in children, teenagers and young adults. Younger women with Sjogren's may experience complications during pregnancy.

The specific cause or causes of Sjogren's syndrome are not known, but multiple factors are probably involved. These include genetics, viruses, hormones, or a combination of all these.

Primary or secondary

When Sjogren's syndrome occurs alone, without the presence of another connective tissue disease, it is called primary Sjogren's. When Sjogren's symptoms are accompanied by a connective tissue disease such as rheumatoid arthritis, lupus or scleroderma, it is called secondary Sjogren's.

Some studies show that individuals with primary Sjogren's have more severe problems with eye and mouth dryness. Enlargement of the glands around the face, jaw and neck may be more frequent. While these two forms are associated with different signs and symptoms, features of the Sjogren's syndrome component are basically similar.

Someone with primary Sjogren's may be concerned about developing a connective tissue disease in the future. While this may occur, it is much more common for an individual with long-standing connective disease, such as rheumatoid arthritis or lupus, to develop Sjogren's syndrome later.



Normal aging may result in shrinking of the tear glands and a decrease in tear production, but recent research indicates that aging does not cause a decrease in saliva production in healthy salivary glands.



What are the symptoms?



The symptoms of Sjogren's are many and varied. No two people with Sjogren's syndrome have exactly the same set of symptoms or medical history. Symptoms may plateau, worsen or go into remission. For some, the symptoms of dry eyes and dry mouth are the prominent manifestations, while others go through cycles of good health followed by severe disease.

If the answer to many of the following questions is yes, you should be evaluated for Sjogren's syndrome:

- Do you have a dry, gritty, burning or foreign body sensation in your eyes? Are your eyes sensitive to light?*
- Do you have difficulty swallowing food? Do you drink water often while talking? Is your voice hoarse?*
- Is your tongue sore or cracked? Do you have mouth ulcers or frequent oral yeast infections? Are the glands under and around your jaw and ears swollen?*
- Have you suddenly experienced an increase in dental cavities and/or tooth loss?*
- Have you noticed a change in your sense of taste or sense of smell?*
- Do you feel tired all the time? Does this fatigue impact on your quality of life?*
- Do you have a connective tissue disease such as rheumatoid arthritis, lupus or scleroderma?*



Diagnosis



Diagnosis is often not an easy task since the symptoms of Sjogren's syndrome can mimic other diseases such as lupus, rheumatoid arthritis, chronic fatigue syndrome, fibromyalgia, multiple sclerosis and Alzheimer's disease. Because different symptoms may be reported to various specialists (rheumatologists, dentists or ophthalmologists), the diagnosis is often missed.

Not all the dryness may be the result of Sjogren's syndrome. Many medications, including those used to treat high blood pressure, depression, colds, allergies and gastrointestinal problems may cause dryness of the eyes and mouth. When completing a medical history form, be sure to include all the medications and over the counter products you are using.

A number of tests can serve as diagnostic tools for the clinician. They include:

- ✔ *Schirmer test to measure tear production and rose bengal staining and slit-lamp examination to evaluate the tear film (performed by an ophthalmologist):*
- ✔ *Measurement of saliva production, examination of the salivary glands to determine the presence of lymphocytes (performed by an oral surgeon or ENT specialist);*
- ✔ *Blood tests for specific markers or antibodies indicative of Sjogren's syndrome (SS-A or SS-B). These tests are not definitive, because not everyone with Sjogren's tests positive for these autoantibodies (ordered by a rheumatologist).*



Treatment



While there is no cure for Sjogren's syndrome, early diagnosis and intervention can affect the course of the disease. Treatment is dependant on symptoms and severity. Sjogren's syndrome may not be life threatening, but it is life altering. With proper management, a comfortable lifestyle can be achieved and enjoyed.

Artificial tears and saliva substitutes can ease the symptoms of dryness. A number of over-the-counter products are available at pharmacies and drug stores.

Prescription medication is now available for the treatment of dry mouth associated with Sjogren's syndrome.

Non-steroidal anti-inflammatory drugs (NSAIDs), steroids and disease-modifying (immunosupressant) drugs are often used to treat Sjogren's syndrome. For individuals with severe complications, more agressive treatments may be necessary.



Anyone can develop non-related medical conditions. Don't ignore seeking medical attention for a problem because you may think it is attributed to Sjogren's syndrome.



**The Australian Sjogren's
Syndrome Association Inc.
Membership Application Form
39 Main Arm Road
Mullumbimby NSW 2483**

Name

Address.....

.....

Suburb

State P/Code

Tel:

Email:

Annual dues include regular post outs of fact sheets, health hints and support groups.

Membership \$45 p/yr

Healthcare Provider \$45 p/yr

Pensioners \$20 p/yr

Additional contribution:

Donor \$10+

Supporter \$25+

Contributor \$75+

Patron \$500

Benefactor \$1000

Founder \$5000

Donations of \$2.00 and over are tax deductible

Deductable gift recipient Payment Method:-

Please make your cheque or money order payable to: **The Australian Sjogren's Syndrome Association Inc.**

We are sorry to advise that at this stage Credit Card facilities are not available.

The Australian Sjogren's Syndrome Association Inc.

TASSA provides patients practical information and coping strategies for living with Sjogren's syndrome. Formed in 2001 due to illness of the founder Beverly Norton, the association acts as a clearing house for medical information and research straight from America and we are striving to be recognized as a national advocate for people with Sjogren's syndrome.

Sjogren's syndrome Association Mission.

- ✔ *to educate patients and their families about Sjogren's syndrome;*
- ✔ *to increase public and healthcare provider awareness of Sjogren's syndrome;*
- ✔ *to initiate research into treatments and a cure.*

To fulfil its mission the Association provides:

- ✔ *The Australian Moisture Seekers Newsletter containing medical news, research updates (from the USA) and tips for daily living (annual dues include a monthly subscription);*
- ✔ *The new Sjogren's Syndrome Handbook, a guide for patients, carers and their healthcare providers on the many aspects of the illness;*
- ✔ *Representation to government health funds for the rights and needs of people with Sjogren's Syndrome;*
- ✔ *Regular updated lists of suitable products.*



Glossary

Antibody: substance in the blood that is normally made in response to infection.

Antigen: a chemical substance that causes the production of antibodies.

Autoantibody: an antibody that attacks the body's own tissues and organs as if they were foreign.

Autoimmune disease: a condition where the body inappropriately produces antibodies against itself, causing damage to tissues. Sjogren's syndrome, rheumatoid arthritis, scleroderma and lupus are autoimmune diseases.

Connective tissue disease: a disorder marked by inflammation of the connective tissue (joints, skin, muscles) in multiple areas. Several such diseases are rheumatoid arthritis, lupus and scleroderma.

Lacrimal glands: two types of glands that produce essential eye fluids. Smaller accessory glands are found in the eyelid tissue and produce "minute-to-minute" tear needs; the main lacrimal glands are located inside the bony cavity surrounding the eye and produce large amounts of tears.

Lip biopsy: an incision of about two centimeters on the inside surface of the lower lip to remove some of the minor salivary glands for microscopic examination.

Lymphocyte: type of white blood cell concerned with antibody production and its regulation. Collections of lymphocytes are seen in the moisture-producing glands of Sjogren's patients.



Non-steroidal anti-inflammatory drugs (NSAIDs):

chemical derivatives of aspirin which generally cause fewer side effects, contain no cortisone and are used to treat joint pains associated with rheumatoid arthritis and other connective tissue diseases.

Puncta: small openings in the eyelid that normally drain tears. Patients with severe dry eyes may benefit from punctal closure to allow tear preservation.

Rheumatologist: a physician specializing in the diagnosis and treatment of rheumatic conditions; usually serves as primary care physician for patients with Sjogren's syndrome.

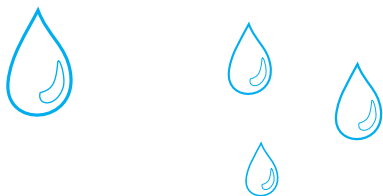
Salivary glands: three pairs of major glands that produce saliva: the parotid, in front of the ear; the sublingual, on the floor of the mouth under the tongue; and the submandibular, below the lower jaw.

Schirmer test: a standard objective test to diagnose dry eye. Strips of filter paper are placed in the lower eyelid and soak tears for five minutes. The value obtained is a rough estimate, in relative terms, of tear production. Lower values are consistent with dry eye.













Sjogren's antibodies: abnormal antibodies, SS-A (Ro) and SS-B (La) found in the blood of some Sjogren's patients.

Vasculitis: inflammation of the blood vessels.

Xerostomia: dryness of the mouth often caused by salivary gland dysfunction. Can occur in diabetes, from drug and radiation therapy and from Sjogren's syndrome.



Tips for daily living

-  If using artificial tears four or more times a day, use preservative-free eyedrops.
-  Use preservative free ointments at bedtime for longer relief from dry eye.
-  Drink frequent sips of water to keep the mouth moist.
-  Maintain scrupulous oral hygiene, brushing and flossing regularly.
-  Restrict intake of sugar to help prevent rampant dental decay.
-  Schedule regular and frequent dental visits.
-  Chew sugarless gum to stimulate saliva production.
-  Avoid alcoholic and caffeinated beverages as they increase oral dryness.
-  Use a humidifier or vaporizer to maintain a comfortable level of air moisture indoors.
-  Avoid draughts from air-conditioners, fans and radiators.
-  Wear protective eyewear to avoid exposure to wind or sun.
-  Use moisturizing lotions for dry skin and saline sprays for dry nose.



More tips for comfortable living can be found in The New Sjogren's Syndrome Handbook and in The Australian Moisture Seekers Newsletter published by the Sjogren's Syndrome Association Inc.

