

Sjögren's Support Group

The first Support Group was started by Mrs. Elaine K. Harris in 1983 in USA. By 1985, this small mutual-aid group became the Sjögren's Syndrome Foundation (SSF) - an international body dedicated not only to patient support, but also to educating the public and the medical community about Sjögren's syndrome and working to defeat the disease. Today SSF has a network of over 100 Support Groups in USA, Canada, South America, Europe and Asia. These Support Groups provide educational, research, advocacy, leadership and personal support to patients. (www.sjogrens.org)

Inspired by the Sjögren's Syndrome Foundation (SSF) in USA, the Sjögren's Support Group (SSG) is an initiative set up and managed by patient volunteers for creating awareness about Sjögren's syndrome in India. Currently SSG is active in Ahmedabad, Gujarat. SSG is a part of SSF's international Personal Support System.

Objectives of SSG:

- To create awareness about Sjögren's syndrome among the general community.
- To provide a platform for patients and their families to share their experiences and extend care and support to each other.
- To provide opportunities for patients to interact with multi-speciality doctors for a better

understanding and management of the multi-system manifestations.

- To develop educational resources for Patient education.
- To facilitate scientific research by creating a link between patients and Research Scientists.

SSG's Activities

- Patient Education programmes.
- Interaction with multi-speciality medical professionals (Rheumatologists, Ophthalmologists, and Dentists etc.).
- One-to-one support through personal/ telephonic contact/ e-mails/ Web based discussions.
- Provide access to relevant educational resources in English.
- Develop/translate educational material in some Indian languages.

Help conquer Sjögren's syndrome!

Whether you are a Patient/family member/Doctor YOU could help by:

- Spreading awareness about Sjögren's syndrome
- Sharing tips on coping mechanisms
- Volunteering to reach out to patients in your area
- Providing assistance/support for translation and production of educational resources
- Contributing/Generating Funds for reaching out to more patients

Become a Member of SSG

and receive these member benefits!!

- Access to Patient Education Programmes.
- Access to Educational Resources available with SSG.
- Access to personal support through knowledgeable volunteers.
- Access to Sjögren's syndrome products information.
- Newsletter and access to E-Group Network. (will be available soon)

Your greatest benefit will be conquering Sjögren's syndrome. Add your voice to SSG's efforts to increase awareness, educate others and encourage research for Sjögren's syndrome in India.

Sjögren's Support Group (SSG)

For more information contact SSG Volunteers:

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Join the Sjögren's Support Group (SSG) Now!!

Kindly send us your details as per the following format:

Name:

Profession:

Age: Female Male

Address for correspondence:

Phone:

e-mail:

Please tick appropriate box:

I am a patient Family member

I am a doctor Other (Please specify)

I would like to help by

Becoming a volunteer

Contributing resources

Mobilising resources

Developing/Translating educational resources

Offering guidance and support for

patient education programmes

Any Other (Please specify)

Please mail to:

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Please help by spreading the WORD!

Sjögren's Support Group



*“If we looked sick,
diagnosis would be easy...
Sjögren's syndrome doesn't show.”*

What is Sjögren's syndrome?

Sjögren's (pronounced SHOW-grins) syndrome is a chronic, autoimmune disease in which white blood cells attack and destroy the moisture-producing glands, causing decreased production of saliva and tears. It was first identified by a Swedish physician, Henrik Sjögren, in 1933.

Although the hallmark symptoms are dry eyes and dry mouth, Sjögren's syndrome also may cause dryness of other organs. It may also involve the kidneys, GI system, blood vessels, lung, liver, pancreas, and the central nervous system. Many patients experience debilitating fatigue and joint pains. Nine out of ten patients are women.

Sjögren's syndrome can be primary when it occurs alone. When it occurs due to other diseases like SLE, scleroderma, rheumatoid arthritis etc., it is known as secondary Sjögren's syndrome.

Symptoms wax and wane. Some people experience mild discomfort, other suffer debilitating symptoms that greatly impair their quality of life. Importantly, early diagnosis and proper treatment can prevent serious complications and greatly improve the quality of life for those with Sjögren's syndrome.

FAQs Frequently Asked Questions about Sjögren's syndrome

Who is most likely to develop Sjögren's syndrome?

Nine of ten Sjögren's patients are women. The average age of diagnosis is late 40s although it can occur in all age groups in both sexes.

What are the symptoms of Sjögren's syndrome?

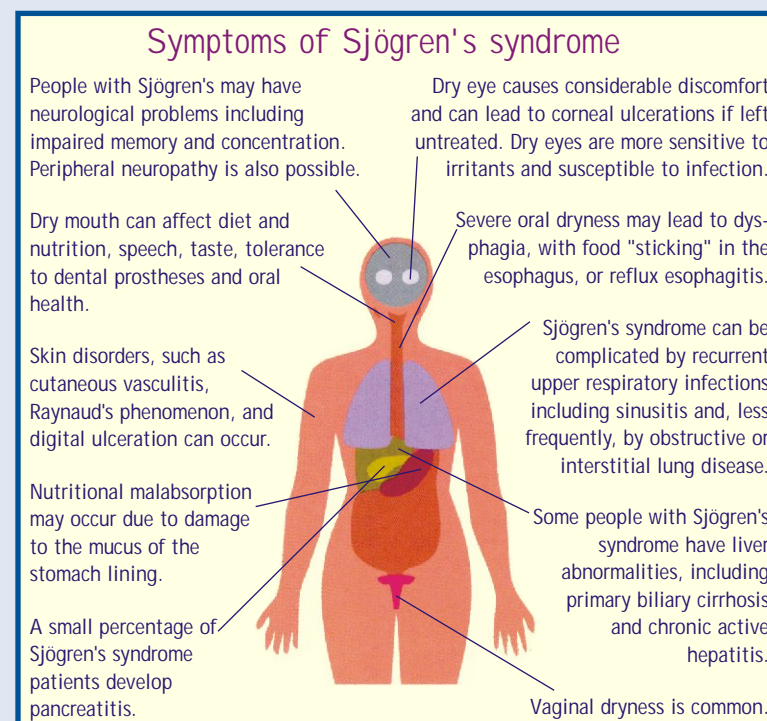
Symptoms may include a dry, gritty, or burning sensation in the eyes; difficulty talking, chewing, or swallowing; a sore or cracked tongue; dry or burning throat; a change in the sense of taste or smell; increased dental decay; joint pain; digestive problems; dry nose; dry skin; and fatigue. No two people have the exact same set of symptoms.

Is it easy to diagnose Sjögren's syndrome?

Sjögren's syndrome often is undiagnosed or misdiagnosed. The symptoms of Sjögren's syndrome may overlap or "mimic" those of other diseases including lupus, rheumatoid arthritis, fibromyalgia, chronic fatigue syndrome, and multiple sclerosis. Because all symptoms are not always present at the same time and Sjögren's can involve several body systems, physicians and dentists sometimes treat each symptom individually and do not recognize that a systemic disease is present. The average time from onset of symptoms to diagnosis is over six years in the USA.

What kind of doctor treats Sjögren's?

Rheumatologists have primary responsibility for managing Sjögren's syndrome. Ophthalmologists, dentists and other specialists also can treat symptoms related to Sjögren's.



How is Sjögren's syndrome diagnosed?

Once Sjögren's syndrome is suspected, you may have to undergo a series of blood tests, including:

- ANA (Anti-Nuclear Antibody): About 70% of Sjögren's syndrome patients have elevated antibodies that react against normal components of a cell's nucleus.
- SS-A (or Ro) and SS-B (or La): 70% of patients are positive for SS-A and 40% positive for SS-B.
- RF (Rheumatoid Factor): 60-70% of patients have a positive RF.
- ESR (Erythrocyte Sedimentation Rate): Measures inflammation.
- IGs (Immunoglobulins): Normal blood proteins, usually elevated in Sjögren's syndrome.
- The Ophthalmologic tests include:
 - Schirmer Test: Measures tears production.
 - Rose Bengal and Lissamine Green: Dyes to observe abnormal cells on the surface of the eye.
- Slit-Lamp Exam for assessing the health of the cornea.

The dental tests include:

- Parotid Gland Flow: Measures the amount of saliva produced over a certain period of time.
- Salivary Scintigraphy: Measures salivary gland function.
- Sialography: An x-ray of the salivary-duct system.
- Lip Biopsy: Confirms lymphocytic infiltration of the minor salivary glands. This test is needed for the diagnosis of Sjögren's syndrome.

What treatments are available?

Over-the-counter products can treat many symptoms of Sjögren's syndrome. There are a small number of sometimes-effective prescription medicines for dry eyes and for dry mouth. Other medications are available for other symptoms, depending on their nature and severity.

What else can be done?

High quality professional dental and eye care are extremely important. Also, there are non-medication strategies for dealing with the various symptoms of Sjögren's syndrome including use of a humidifier and protective gear such as goggles. Often, patients learn the most from one another in support groups.

Will I die from Sjögren's syndrome?

Sjögren's syndrome is serious but generally not fatal if complications are diagnosed and treated early. In one study the incidence of lymphoma (cancer of the lymph glands) was 44 times higher in people with Sjögren's syndrome than in the general population. Sjögren's syndrome patients must be monitored carefully for development of related autoimmune diseases, lymphoma, and other complications.

Is there a cure?

Not yet. But with your help, there will be

With permission from: Sjögren's Syndrome Foundation(SSF), USA(www.sjogrens.org)

“Suspecting the diagnosis of Sjögren's syndrome is the problem. Greater awareness about the condition would aid faster diagnosis. Once diagnosed, therapy for Sjögren's syndrome is possible.

Dr. V.R. Joshi MD

Consultant Rheumatologist, Hinduja Hospital, Mumbai

As a Doctor who also happens to be a patient of Sjögren's syndrome, I believe that a better orientation regarding the multi-organ manifestations of this condition among multi-disciplinary specialists, general practitioners and care-givers will enable a greater understanding and better management of the condition.

Dr. Ramani Atkuri

MD (Community Medicine)

Ganiyari, Chhattisgarh

Educating myself about Sjögren's has empowered me to deal with my disease in a positive manner and taught me how to live well with Sjögren's syndrome.

Kirtida Oza

Ahmedabad, Gujarat

Interacting with other Sjögren's patients has given me the courage to deal with my problems. I no longer feel alone...

Purvi Doshi

Ahmedabad, Gujarat