

Patient and Family Information Leaflet

Sjögren's Syndrome

What is Sjögren's syndrome?

Sjögren's syndrome is a chronic autoimmune disease. It occurs when the body's immune system (which usually protects the body from infections) attacks its own tissues and organs.

In Sjögren's syndrome, the saliva-producing and tear-producing glands are most commonly affected, leading to symptoms such as dry eyes and dry mouth. Less commonly, the disease may affect other parts of the body, such as the joints, skin, lungs, kidneys, nerves or digestive system.

Sjögren's syndrome occurs more frequently in middle-aged women. It can occur on its own or with other autoimmune diseases such as Systemic Lupus Erythematosus (SLE) or Rheumatoid arthritis (RA). While the disease is generally mild, there is a small increased risk of lymphoma (a type of cancer affecting the lymph nodes) associated with the condition.

What causes Sjögren's syndrome?

The exact cause of Sjögren's syndrome is not fully known, but is thought to be contributed by a complex relationship between genetic, hormonal and environmental factors

- **Genetics:** A family history of autoimmune diseases can increase your risk.
- **Hormones:** It is more common in women, especially around middle age.
- **Environmental triggers:** Infections or other external factors may trigger development of the disease.

What are the signs and symptoms of Sjögren's syndrome?

The two main symptoms are:

- Dry eyes – patients may experience a gritty or burning feeling, like sand in the eyes. Use of moisturising eye drops may help to relieve such symptoms.
- Dry mouth – difficulty eating dry food without accompanying fluids, increased dental cavities.

Other symptoms may include:

- Pain and swelling of the salivary glands (under the jaw or around the cheeks).
- Joint pain, swelling or stiffness.
- Fatigue.
- Dry skin.
- Vaginal dryness.
- Bloating of the abdomen.

Symptoms may vary from person to person depending on the organs affected and severity of involvement.

How is Sjögren's syndrome diagnosed?

Diagnosing Sjögren's syndrome can be difficult because symptoms often develop slowly. Dry eyes and mouth may be attributed to other conditions such as ageing, previous eye surgeries e.g. lasik and medications including antihistamines. There is no single test to diagnosis Sjögren's syndrome, and it often involves a combination of:

- Detailed medical history and physical examination

- Blood tests including blood counts, inflammatory markers, kidney and liver tests, and antibody tests such as anti-SSA/Ro, anti-SSB/La antibodies.
- Eye tests, like the Schirmer's test (a simple test using a filter paper to measure tear production over 5 minutes)
- Imaging tests like X-rays / ultrasound scans / CT scan may be performed depending on the suspected organ involvement.
- Lip biopsy may be required in some patients to confirm the diagnosis – this involves a minor procedure to take a sample from the inside of the lip to look for inflammation in the small salivary glands.

What is the treatment for Sjögren's syndrome?

Sjögren's syndrome is a chronic condition. While there is no cure, medications are available to relieve symptoms and control the disease.

Most people can lead active lives with appropriate treatment.

- Dry eyes: Artificial tears, eye drops and gels can relieve discomfort.
- Dry mouth:
 - Saliva substitutes, regular mouth rinse, sugar-free lozenges to stimulate saliva secretion.
 - Good dental care to prevent tooth decay and regular dental reviews.
 - Staying well hydrated.
 - For patients with severe dry mouth, an oral medication (pilocarpine) may be considered to stimulate saliva flow.
- Dry skin: Regular moisturisers can help reduce dry skin.

- Vaginal dryness: Lubricants and topical hormones (oestrogen) cream or pessary (a medication inserted inside the vagina) can alleviate symptoms.
- **Non-steroidal anti-inflammatory drugs (NSAIDs)** such as diclofenac and naproxen may be used for arthritis and inflammation of the salivary glands.
- **Steroids (corticosteroids)** are strong immune suppression medications that work quickly to calm down the overactive immune system. They may be given through the veins (intravenous) in severe disease, or as oral tablets. Steroid creams may be given in patients with rashes. Steroids may also be given through injections into a swollen joint to reduce inflammation in a more directed manner.
- **Immunosuppressants** may be given to reduce the need for long-term steroids for patients with more severe organ involvement. These are medications given in the form of tablets (e.g. mycophenolate mofetil, mycophenolic sodium, azathioprine, ciclosporin, tacrolimus, methotrexate, Hydroxychloroquine) or intravenous infusions through the veins (e.g. cyclophosphamide). The choice of immunosuppressants depends on the affected parts of the body and severity of involvement. Blood tests monitoring is usually required while on these medications.
- **Biologic medications** are newer targeted medications that are usually given through intravenous infusions (e.g. rituximab).

Higher dose of medications is usually required during disease flares and doses will be reduced when the disease is controlled. Your treatment plan will be tailored to your symptoms and preferences.

What should I do if I have Sjögren's syndrome?

Many patients with Sjögren's syndrome can live active lives with the right treatment and support.

Some recommended lifestyle changes are listed below:

- Stay hydrated – sip water often, especially when eating or talking.
- Use eye drops and saliva substitutes regularly as prescribed.
- Avoid smoking.
- Avoid dry environments – use a humidifier at home.
- Maintain good oral hygiene – brush, floss, and see your dentist regularly
- Eat a balanced diet. Avoid raw and partially cooked food to reduce risks of infections, especially if you are on steroids or immunosuppressants.
- Attend regular medical check-ups to monitor your health. Participate actively in your care and ask questions during your clinic consultations.
- Take your medications as prescribed, even when you feel well to avoid disease flares.

Notes:

NUHS Rheumatology Cluster

National University Hospital

5 Lower Kent Ridge Road, Singapore 119074

OneNUHS Hotline: (65) 6908 2222

OneNUHS General Enquiries: contactus@nuhs.edu.sg

OneNUHS Appointments: appointment@nuhs.edu.sg

www.nuh.com.sg

Ng Teng Fong General Hospital and Jurong Community Hospital

1 Jurong East Street 21, Singapore 609606

OneNUHS Hotline: (65) 6908 2222

OneNUHS General Enquiries: contactus@nuhs.edu.sg

OneNUHS Appointments: appointment@nuhs.edu.sg

www.ntfgh.com.sg

www.jch.com.sg

Alexandra Hospital

378 Alexandra Road, Singapore 159964

OneNUHS Hotline: (65) 6908 2222

OneNUHS General Enquiries: contactus@nuhs.edu.sg

OneNUHS Appointments: appointment@nuhs.edu.sg

www.ah.com.sg

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Information is correct at time of printing [March] [2026] and subject to revision without prior notice.