



Sjögren's Syndrome

What are the aims of this Information Leaflet?

This leaflet has been written to help you understand Sjögren's Syndrome. It provides general information on Sjögren's Syndrome, including how it is diagnosed and managed and potential complications of the condition. Additional sources of information have been included if you wish to find out more about Sjögren's Syndrome.

What is Sjögren's syndrome?

Sjögren's Syndrome is a chronic (long term) autoimmune disease which affects the salivary and tear glands causing dryness of the mouth and eyes. In some people it can also affect other areas of the body such as the joints. It is a non-transmissible condition, which means that you have not caught it and you can't give it to anyone else. It is estimated that half a million people in the UK have Sjögren's syndrome, and it most commonly affects women aged 40– 60. Only about 1 in 10 Sjögren's patients are men.

What causes Sjögren's Syndrome?

Sjögren's Syndrome is an autoimmune disorder. This means that the immune system mistakenly damages your own healthy body tissue by producing antibodies against tear and salivary glands, affecting their function. The exact cause is



unknown. However, research suggests that a combination of several factors such as genetic factors, environmental triggers and hormonal influences may play a role.

Is Sjögren's Syndrome hereditary?

Sjögren's Syndrome is not thought to be hereditary.

What are the symptoms of Sjögren's Syndrome?

The most common symptoms of Sjögren's Syndrome are:

- Dry mouth causing
 - Difficulty in talking, and swallowing certain foods due to lack of saliva
 - Altered taste
 - Dental decay and gum inflammation (gingivitis)
 - Recurrent candidal infections (oral thrush infections) affecting the mouth and the corners of the lips.
- Dry, sore irritable or gritty eyes
- Swollen salivary glands, particularly the parotid glands around the ears and the submandibular glands under the jaw (swelling may be recurrent or persistent)
- Dryness elsewhere e.g. skin, digestive tract, genitals or air passages
- Tiredness (fatigue)
- Joint pains or general aching of the body



What does Sjögren's Syndrome look like?

Some patients have no visible signs. Others have swollen salivary glands, particularly the parotid glands around the ears and the submandibular glands under the lower jaw. Inside the mouth, the tongue often looks very dry and saliva is absent. The eyes can look red due to irritation from dryness.

How is Sjogren's syndrome diagnosed?

There is no one test for Sjögren's Syndrome. Diagnosis is based on a combination of your symptoms and by the results of clinical examination and various tests. Typically the following tests will be carried out:

- Saliva flow tests
- Tests for eye dryness
- Blood tests to look for antibodies
- Ultrasound scans of the major salivary glands
- Biopsy of the minor salivary glands which are easily accessible inside the lower lip. (A biopsy involves removal of a small piece of tissue while the lip is numb; this is then examined under a microscope).

The diagnosis of Sjögren's Syndrome is made, if after the results of tests, you meet the criteria laid out by the American College of Rheumatology & European League Against Rheumatism.



Can Sjögren's Syndrome be cured and what is the outlook?

There is no cure for Sjögren's Syndrome yet, however treatment is aimed at easing your symptoms. You're unlikely to be disabled by Sjögren's syndrome, although the symptoms can be uncomfortable and long lasting.

What treatment is available for Sjögren's Syndrome?

Treatments available for dry mouth:

- To stimulate saliva:
 - Use sugar-free chewing gum and sugar free sweets.
 - Pastilles to help stimulate saliva flow are available directly from a pharmacist but can also be prescribed.
 - A tablet called Pilocarpine has been shown to be useful in stimulating saliva production, but it is not suitable for everybody as it has some side effects and cannot be used if you have certain medical conditions.
- To replace saliva:
 - Salivary substitutes in the form of sprays, liquids and gels are available directly from a pharmacist but can also be prescribed.
- Antifungal (anti-thrush) treatments in the form of liquids, gels or tablets may be prescribed if recurrent fungal infections are a problem.

Treatments for dry eyes:



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- Dry eyes usually respond to artificial tears and gels and ointments which can be used as often as needed.

Treatment for fatigue and/or joint pains and other symptoms:

- Hydroxychloroquine which is an anti-malarial drug is sometimes prescribed to help symptoms of tiredness and joint pains if present.
- For those patients with severe symptoms or vasculitis (inflammation of blood vessels) treatment with new biological drugs is available through specialist centres.

Some patients with Sjögren's Syndrome have an increased risk of developing cancers of the lymphatic system known as lymphoma. The lymphomas of salivary glands can present as swellings in the glands or are found on an ultrasound scan. They are usually low grade and respond well to treatment.

What can I do?

- Keep your mouth moist with regular sips of water sips or salivary substitutes.
Keep water to hand
- Gentle daily massage of the glands may help to increase saliva.
- Choose wet foods or drink water while eating.
- Eat a diet low in sugar, avoid acidic fizzy drinks and use a tooth paste with a high concentration fluoride toothpaste or daily fluoride mouth rinse to protect your teeth from decay.



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- Maintain good oral hygiene and visit the hygienist regularly to prevent gum disease.
 - Oral dryness may make fungal infections (thrush) more likely. If you wear dentures remove these at night and soak them in a suitable denture cleaner.
 - Continue to visit your dentist for routine care even if you are seen in a specialist centre.
 - Keep your eyes moist with eye drops and ointments, as advised by your specialist.
 - Visit the optician regularly so that your eyes can be checked for signs of corneal damage.
 - The use of a humidifier may help to improve nasal dryness.
 - If you have problems with genital dryness, please discuss treatment options with your doctor.
 - Contact your specialist or dentist if you notice any new swellings in your glands.
 - If you intend to become pregnant, please contact your doctor. Women with Sjögren's syndrome have a small risk of passing on antibodies which cause heart block (slowing of the heart) in the foetus. You and your baby will need to be monitored throughout your pregnancy.



Where can I find out more information on Sjögren's Syndrome?

Sjögren's Syndrome Foundation. (www.sjogrens.org)

British Sjögren's Syndrome Association - (www.bssa.uk.net)

Arthritis Research UK - (www.arthritisresearchuk.org)

This leaflet has been prepared by the British and Irish Society for Oral Medicine (BISOM). It is reviewed periodically to reflect relevant advances and improved understanding. Not all the information will be relevant to all patients. For individual advice please see your Oral Medicine specialist. The BISOM is not responsible for information on web sites where links are provided.

This leaflet is available online at www.bisom.org.uk

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