

What is Sjögren's syndrome?

Sjögren's syndrome (pronounced 'showgren') is where the moisture-producing glands in the body become inflamed – especially in the eyes and mouth. Glands that help to lubricate the skin, bowel, vaginal and other areas can also be affected.

The symptoms are caused by the white blood cells (which are a part of the blood that fights infection) attacking the glands that produce saliva, tears and other secretions. This is the same process as in rheumatoid arthritis, where the immune system attacks the joints.

Sjögren's syndrome can be primary, whereby it develops by itself, or secondary, where it occurs in association with other autoimmune diseases such as rheumatoid arthritis. It occurs mostly in women between the ages of 40 and 60, with more than half a million people in the UK affected.

You will also find this factsheet helpful if you have dry eyes and mouth but don't have a diagnosis of Sjögren's.

REAL LIFE STORY

‘Several years after developing rheumatoid arthritis, my mouth became terribly dry and I had to start drinking a lot of water. I was tested for diabetes but that wasn't the cause. When my eyes started to become dry I explained all the symptoms as clearly as I could to my rheumatologist who said it sounded like Sjögren's syndrome.

After a while my salivary glands became painful and I had a constant deep ache in my face. For quite some time I was taking a new drug to stimulate the salivary glands. However, it worked too well and made me dribble, so I came off it. I use eye drops each day and drink quite a lot of water, although what works better for me is to have sweets to suck on. My sleep gets disturbed because my mouth gets so dry that I wake up and feel like I am gagging.

The pain has now faded to a dull ache in the background, but it does affect my mood at times and makes it hard to concentrate. I haven't been affected too much by a dry cough, although I do feel my body is getting dry inside. It is a really uncomfortable thing to live with, although for me it is not as bad as it was when it first developed. ’

How will it affect me?

Common symptoms are extremely dry eyes and mouth. Other symptoms can be a dry cough, difficulty swallowing, bowel discomfort, and joint inflammation and pain. Fatigue and aching joints/muscles are other main symptoms of Sjögren's syndrome.

Dry eyes can feel very sore and/or scratchy. This can be worse when reading, using a computer, watching TV or driving. They can sting, or feel generally achy and sore, and feel 'tight'.

A dry mouth and tongue can make it difficult to speak and swallow, and greatly increases the risk of tooth decay. Dryness in the mouth can interrupt your sleep. Rapid swelling or pain in your salivary glands should be investigated carefully.

Dryness in the vagina can cause discomfort and distress due to its impact on sexual relationships. Dryness in your nose and chest can cause a dry cough, and you may also experience stomach or bowel discomfort. Less common symptoms include dry skin and kidney problems.

How is it diagnosed?

The main tests for Sjögren's syndrome measure the amount of moisture produced in the eyes and mouth. A small piece of blotting paper is sometimes placed in an eye, or a small drop of dye is placed in it and the eye is examined with a special lamp. Salivary glands can be tested with scans or by having a dye injected into them. A very basic test involves spitting into a paper cup over a specific period of time. Blood tests can show two antibodies – Ro and La (or SSA and SSB) that are present in about 60 per cent of people with primary Sjögren's.

What is the outcome?

While there is no cure for Sjögren's syndrome, the right treatment can significantly improve your quality of life. Research has shown that where only the eyes and mouth are affected, the long-term outlook is that the disease is not likely to occur in other areas. When it is diagnosed early, long-term damage can be greatly reduced or prevented. However, there is a slightly increased risk of cancer of the lymph nodes.

What is the treatment?

A range of moisturisers is available on prescription.

- Tears: preservative-free tears lubricate the eyes and can be used frequently. Gel tears last longer than drops, and eye ointment lasts through the night. It is worth trying several types to find one that works best for you.
- Saliva: special 'dry mouth' toothpastes, mouth washes and gels can help to reduce dryness. There are some containing fluoride that help prevent tooth decay. Gels last longer than water based sprays. Both can be used as often as needed.
- Lubricants, moisturisers or oestrogen creams can help to relieve dryness in the vagina.
- A drug called pilocarpine (Salagen) can stimulate the glands that produce saliva and tears. It can take several weeks before symptoms improve. The main side effect is sweating.

- Disease-modifying anti-rheumatic drugs (DMARDs) like hydroxychloroquine can be used to treat swelling in the salivary glands and joint pain.
- Steroids and biologic drugs might be used to treat the underlying arthritis.

What can I do to help myself?

There is a lot you can do to alleviate the symptoms and prevent complications – particularly if the diagnosis is made early.

- Wash your eyes after waking up, during the day, and last thing at bedtime. Use cotton buds with eye drops to clean the lashes.
- Try 'moisture chamber' glasses that help to prevent your eyes from drying out.
- Don't use contact lenses.
- Do some exercise that you enjoy each day to help improve your energy levels.
- Adjust your routine to allow for more rest periods.
- Make sure you look after your teeth very carefully and visit the dentist/hygenist every six months.
- Use sugar-free mouth pastilles or lozenges to help stimulate your saliva glands.
- Minimise alcohol, tea and coffee because these dry out your mouth and throat.
- Keep lip moisturisers with you.
- Humidifiers and plants with large leaves in your home can help to reduce dryness.

Exercising may be difficult at first and make you feel tired. Just do a small amount to begin with and gradually build up – don't overdo it. Starting with 10 minutes a day can help.

Who will I see?

You may need to see a range of people, depending on the severity of your symptoms.

Sjögren's syndrome is not widely known and the wide range of symptoms mean a lot of things need to be ruled out first. However, it is important to have symptoms treated early to prevent eye, tooth and gum damage. You should be referred to a rheumatologist for primary Sjögren's. Your GP can refer you to an ophthalmologist (eye specialist) and to a rheumatologist. It's sensible to have an assessment by your dentist, dental hygenist and optician to get advice about caring for your teeth and eyes.

Is it hereditary?

The current understanding is that you can inherit a tendency to get an autoimmune disease but that it needs to be triggered by something – perhaps a virus or bacteria – to develop. The severity or pattern may be influenced by your genes, but there are likely to be other factors. It is uncommon for children to inherit the condition.

Where can I get more information and support?

Arthritis Care is the UK's largest charity working with and for all people who have arthritis.

We are here to help you make positive choices through our information, website, self-management training, and professional helpline. Call the free helpline for confidential support on 0808 800 4050 (10am-4pm weekdays) or email: Helpline@arthritiscare.org.uk

You can find support from others with arthritis by joining our online discussion forums.

We rely on donations to fund our vital work in supporting people living with arthritis. If you would like to make a contribution, please phone us on 020 7380 6540 or you can donate online.

www.arthritiscare.org.uk

Our factsheets are reviewed every 18 months. Please check our website for up to date information and reference sources or call 020 7380 6577.

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Contact us

For confidential information and support about treatments, available care and adapting your life, contact the Arthritis Care Helpline

Freephone: 0808 800 4050

10am-4pm (weekdays)

Email: Helplines@arthritiscare.org.uk

For information about Arthritis Care and the services we offer, contact us at: **www.arthritiscare.org.uk**

You can also talk to other people who are living with arthritis, through the discussion forums on our website.

Arthritis Care UK office and England regional services:

Tel: 020 7380 6500

Central England email: CentralEngland@arthritiscare.org.uk

North England email: NorthEngland@arthritiscare.org.uk

South England email: SouthEngland@arthritiscare.org.uk

Arthritis Care in Northern Ireland

Tel: 028 9078 2940

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Arthritis Care in Scotland

Tel: 0141 954 7776

Email: Scotland@arthritiscare.org.uk

Arthritis Care in Wales

Tel: 029 2044 4155

Email: Wales@arthritiscare.org.uk

Other organisations

British Sjögren's Syndrome Association (BSSA)

www.bssa.uk.net

Tel. 0121 455 6532

Email: office@bssa.uk.net