

PATIENT INFORMATION · RHEUMATOLOGY

Sjögren's syndrome

far more than dry eyes and a dry mouth

Sjögren's syndrome is an autoimmune condition in which the immune system attacks the glands producing tears and saliva. The dryness is what gets named — but for most people the dominant symptoms are **fatigue and joint pain**, which is why it takes an average of several years to diagnose.

Seek prompt assessment if you have

- a **persistently swollen salivary gland**, particularly one-sided or hard
- **new lumps or swollen glands** lasting more than three weeks
- **unexplained weight loss, fever or night sweats**
- **severe eye pain** or sudden visual change
- **numbness, tingling or weakness**
- **breathlessness or a persistent dry cough**

Sjögren's carries a small but real increased risk of lymphoma, and persistent salivary gland swelling is the main warning sign. It should be examined rather than assumed to be part of the condition.

Symptoms

- **Dry, gritty eyes** — often described as sand under the lids, worse in wind, air conditioning and on screens
- **Dry mouth** — difficulty swallowing dry food, needing water to eat, altered taste, waking at night to sip
- **Profound fatigue** — the most disabling symptom for most people, and the least acknowledged
- **Joint and muscle pain**, and Raynaud's
- **Dry skin, nose and vagina**, causing painful sex
- **Salivary gland swelling**, particularly in front of the ears
- Recurrent dental decay, oral thrush and mouth ulcers
- Less commonly: nerve, lung, liver or kidney involvement

Diagnosis

- **Anti-Ro (SSA) and anti-La (SSB) antibodies** — the most useful blood tests, though a proportion of people are negative.
- **ANA and rheumatoid factor**, often positive; raised immunoglobulins and low complement.

- **Schirmer's test** measuring tear production, and salivary flow assessment.
- **Ultrasound of the salivary glands**, which is increasingly used and avoids biopsy in many cases.
- **Lip gland biopsy** where the diagnosis remains unclear.
- It commonly coexists with other autoimmune conditions, particularly thyroid disease, lupus and rheumatoid arthritis.

Protect your teeth from the start

Saliva neutralises acid and protects enamel. Without it, decay accelerates dramatically — people with Sjögren's can lose teeth in a few years having never had a filling before. **See a dentist every three to six months, use high-fluoride toothpaste (prescribed, 2800 or 5000ppm), avoid sipping fruit juice, fizzy drinks or sugary tea through the day, and use sugar-free gum or xylitol products to stimulate what saliva you have.** This is the single most valuable practical measure and it is frequently not mentioned at diagnosis.

Managing dryness

Eyes

- Preservative-free artificial tears, used regularly rather than when sore
- Thicker gel or ointment at night
- Warm compresses and lid hygiene for associated blepharitis
- Humidifier; avoid direct air conditioning and fans
- Punctal plugs, which retain your own tears, if drops are not enough

Mouth

- Frequent sips of water; carry a bottle
- Saliva substitutes, sprays and gels, particularly at night
- Sugar-free gum and lozenges to stimulate flow
- Avoid alcohol-containing mouthwashes, which dry further
- Prescription medicines to stimulate saliva, where suitable

Treating the rest

- **Hydroxychloroquine** for fatigue, joint pain and rashes — the most commonly used systemic treatment, with annual eye monitoring after five years.
- **Immunosuppressants or biologics** for organ involvement.
- **Vaginal moisturisers and local oestrogen** for dryness causing painful sex.
- **Pacing and exercise** for fatigue — unglamorous, and the evidence supports both.
- **Review medicines** that worsen dryness: antihistamines, some antidepressants, diuretics and bladder medicines.

If you are planning a pregnancy

Anti-Ro and anti-La antibodies can cross the placenta and, rarely, affect the baby's heart conduction — congenital heart block. This is uncommon, it is monitored for with extra fetal heart scans, and it is entirely manageable when known about in advance. **Tell us before conceiving, not after**, so the pregnancy can be planned with the right monitoring.

Why come to us. Sjögren's is usually diagnosed years late because the dryness is treated symptomatically and the fatigue attributed to something else. We take the **full autoimmune panel — anti-Ro, anti-La, ANA, rheumatoid factor, immunoglobulins, inflammatory markers and thyroid function — in-house** with results explained in one visit, and perform **salivary gland ultrasound on site**. We refer to rheumatology with the workup complete, and can arrange the dental and ophthalmology input that matters most day to day.

The full antibody panel and gland ultrasound on site

Results explained in one visit. Seven days a week.

Book an appointment

or call 020 7916 0029

Where to get help

Tower Bridge Hospital London

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WhatsApp **07903 284 189**

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Open 7 days, 9am–7pm

In an emergency

Call 999, or go to the Royal London Hospital Emergency Department, Whitechapel Road, London E1 1FR.

When we are closed and it is not an emergency

Call NHS 111 or visit 111.nhs.uk.

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Written and reviewed by Dr H Bolat, GP & Clinical Director Review date: 26 July 2026 Next review due: July 2028

Ref: TBH-PIL-244

This leaflet is based on current NHS, NICE CKS and British Society for Rheumatology guidance on Sjögren's syndrome. It is general information and does not replace advice from a clinician who has assessed you. If your symptoms change or you are worried, contact us on 020 7916 0029, call NHS 111, or call 999 in an emergency.

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