

Experiences of people living with Sjögren's syndrome in Gloucestershire

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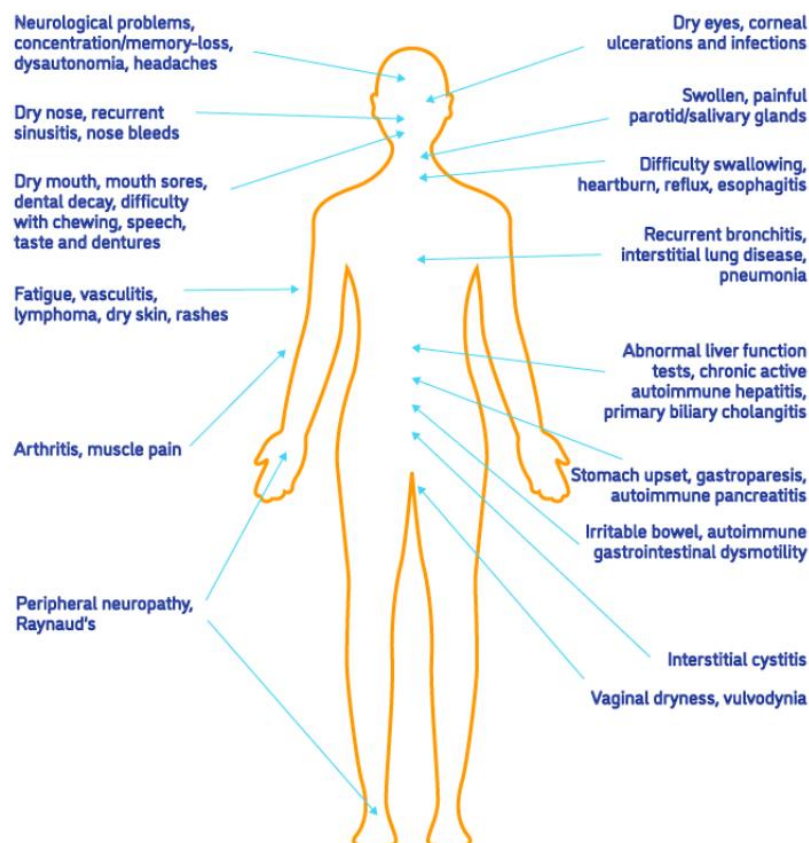
In January 2026, Healthwatch Gloucestershire were kindly invited to attend a peer support group in Cheltenham with people diagnosed with Sjögren's syndrome to raise awareness of the condition and to highlight the difficulties they have experienced in accessing care and treatment locally. This is the only group offering this kind of support to people with Sjögren's in Gloucestershire. The coordinator of the group is a volunteer who receives some support from Sjögren's UK, based in Birmingham, to be able to facilitate these sessions.

What is Sjögren's?

Sjögren's syndrome (also known as Sjögren's disease) is a condition where the glands that produce fluid, such as tears and spit (saliva), stop working properly. It can affect daily life, but treatments can help ease the symptoms. There are lots of possible symptoms of Sjögren's syndrome and the condition affects people differently. It affects approximately 0.6% of adults in the UK, with an average age of 50 years. 90% of people diagnosed with Sjögren's syndrome are women.

There's currently no cure for Sjögren's syndrome, but there are treatments that can help manage the symptoms. The type of treatment will depend on the symptoms someone has and how they affect them.

Image below from Sjögren's UK website: www.sjogrenuk.org/about-sjogrens/



Sjögren's UK say:

"Sjögren's (SHOW-grins) is the UK's second most common autoimmune rheumatic disease, yet the condition remains under recognised and frequently under treated. It does not command a high profile within the medical profession, and the general public is largely unaware of the problems faced by sufferers.

In reality, Sjögren's can be a debilitating, distressing and miserable condition."

What people diagnosed with Sjögren's told us about accessing health and care

5 women attended the group and shared their experiences with us. There are more who attend the group on a regular basis who unfortunately were unable to make it on the day we visited. Below is a summary of the key themes drawn out of their experiences:

1. Delays and challenges in diagnosis

- Many participants experienced significant delays in diagnosis, ranging from 2 to 4 years.
- Concerns were raised about 10-minute GP appointments where only one condition/ symptom can be discussed. Patients need to be treated holistically by looking at symptoms together to achieve a diagnosis.
- A widely held perception amongst health professionals that the condition is "only dry eyes and dry mouth," can lead to wrong or delayed diagnoses, and underestimate its systemic impact. A lack of these natural 'barriers and a reduction in effective microbiome means patients have poor immunity. Symptom flare-ups and untreated symptoms can lead to significant long term and systemic health impacts.
- Blood tests were often negative initially, contributing to missed or delayed diagnoses. A negative blood test often resulted in people being discharged from services despite continuing to report worsening symptoms.
- Several members were told their symptoms were psychological or anxiety-related and were discharged without further investigation. Other people's symptoms were blamed on the menopause.
- Symptoms can be triggered by other significant changes in health however this can also lead to the condition being 'masked'. For example, one person's

symptoms became apparent following a fall, and another person's during pregnancy.

- New GP protocol does not include Sjögren's syndrome.

2. Lack of awareness among healthcare professionals in Gloucestershire

- Limited knowledge of Sjögren's among GPs, nurses, and junior doctors was frequently mentioned by the group. Some group members eventually sought private diagnosis due to lack of progress within the NHS in Gloucestershire.
- Those who had been diagnosed in Gloucestershire raised concerns that the Doctors were reducing their hours or retiring soon.
- Group members feel forced to travel to Swindon Hospital for their healthcare needs as they have a Sjögren's specialist based there. However, this could be inaccessible for many people if they do not drive or live in rural areas. This also has time and financial implications.
- There are concerns that many more people may be living with Sjögren's in Gloucestershire, but they are undiagnosed due to lack of awareness.
- Dentists and opticians were sometimes the first to notice signs suggestive of Sjögren's.

3. Lack of access to specialist care in Gloucestershire

- Concerns were raised about the lack of access to A&E consultants familiar with Sjögren's in Gloucestershire. One example given was a member having a large red rash on her face diagnosed as being Eczema in the Emergency Department, but when she was able to visit her consultant in Swindon, she discovered it was a very serious case of photosensitivity – a side effect of taking hydroxychloroquine.
- Patients reported the need to attend multiple hospital departments before being properly assessed, which was described as exhausting and frustrating.
- No consistent follow-up after initial consultations was reported by several participants.

4. Treatment-related issues

- Some Gloucestershire GPs were reluctant to prescribe medications such as ciclosporine through Shared Care Agreements with consultants from Great Western Hospital. Group members often had to travel long distances to obtain prescribed treatments, e.g. Swindon.
- Different patients find different brands of medications, e.g. eye-drops, more or less effective. Group members had all experienced changes being made to medications without being informed by their GP or pharmacy.
- Complications related to receiving the wrong treatment, including gastrointestinal problems and abrasions on eyes, were mentioned.
- Drug budget limitations were mentioned in impacting on treatment availability and efficacy.

5. Impact on daily life and mental health

- Sjögren's was described as affecting the whole body "from head to toe."
- Severe pain (fingers, legs), fatigue, swallowing difficulties, and lack of saliva significantly affected quality of life.
- Basic daily activities, such as showering and dressing, were sometimes very difficult.
- The condition had a major impact on relationships, employment, time, finances, and mental health.
- Several participants reported being misdiagnosed with anxiety before receiving a correct diagnosis.
- Being a carer for someone with mental health difficulties added an additional burden.

6. Emotional experience and need for support

- Many participants described feelings of desperation, loss of hope, and fear before diagnosis.
- There was a strong sense that patients need better guidance and a clear pathway of care.
- Peer and community support were seen as essential.
- Participants expressed a desire to prevent others from experiencing the same level of suffering.
- It was noted that younger patients may experience additional challenges and feel less heard.

Recommendations

- Healthwatch Gloucestershire to support with raising awareness of Sjögren's and how it affects people amongst Health and Care professionals and the public through publishing this report and publicising it using social media channels and engagement opportunities.
- Ensure that GPs have the tools to recognise signs and symptoms of Sjögren's at the earliest opportunity, and to identify appropriate pathways for support and treatment, e.g. reviewing information available on G-care.
- NHS Gloucestershire (ICB) to review pathways for patients diagnosed with Sjögren's.
- NHS Gloucestershire and GP practices to raise awareness of Jess's Rule with patients. Jess's Rule is a 2025 primary care initiative to encourage GPs teams to rethink a diagnosis if a patient presents three times with the same symptoms or concerns, particularly if symptoms unexpectedly persist, escalate, or remain unexplained. Under Jess's Rule, listening carefully to the patient's concerns and taking note of each symptom remain crucial, recognising that patients are experts about what feels normal for their body. Joint decision-making between the clinician and patient remains key in this process. More information can be found here: www.england.nhs.uk/long-read/jesss-rule-three-strikes-and-we-rethink/
- At the point that people receive a diagnosis of Sjögren's, they should be referred to Sjögren's UK who can provide information about the condition itself and information on the peer support group in Cheltenham. This could include having leaflets/ posters in GP surgeries and hospital waiting rooms.
- NHS Gloucestershire to review the availability of certain medications through Shared Care Agreement, such as Cyclosporine, within Gloucestershire to reduce the need for people with Sjögren's to travel out of county.
- Members said they found it helpful for them to keep a diary to list symptoms and log flare ups and impacts on daily life so this can be given to the doctor in appointments.
- Both dentists and opticians should be included as part of multi-disciplinary teams for people with Sjögren's as they are often the first people to identify Sjögren's symptoms.

Provider response

Gloucestershire Integrated Care Board



Dr Becky Parish, Associate Director, Engagement and Experience

Thank you to Healthwatch Gloucestershire (HWG) for raising awareness of Sjögren's Syndrome and how it affects people with NHS Gloucestershire ICB.

The ICB has taken the opportunity to discuss this report with primary and secondary care NHS colleagues as well as members of the medicines team within the ICB to develop a combined response to the recommendations related to feedback from people diagnosed with Sjögren's syndrome. We welcome the insight presented in this report and offer the following comments:

All consultants within the Gloucestershire Hospitals NHS Foundation Trust (GHT) rheumatology department are familiar with the diagnosis and management of Sjogren's Syndrome and routinely provide care for patients with this condition. GHT specialists frequently receive both referrals and Advice and Guidance queries from primary care about patients with sicca/ dryness symptoms and a concern about possible underlying Sjogren's Syndrome. This indicates that there is an awareness of this condition amongst primary care colleagues. G-Care, the online information resource for GP practices in Gloucestershire, includes references to Sjogren's Syndrome in several places relating to its potential association with other clinical conditions. Currently there is no dedicated G-Care link for Sjogren's Syndrome. However, this is something that the ICB can explore further with system partners.

Consultant rheumatologists working in Gloucestershire routinely diagnose and manage Sjögren's and are working to strengthen specialist input and develop a more structured local pathway. This includes closer collaboration with ophthalmology and oral medicine, particularly given the current limited access to basic diagnostic tools such as Schirmer's testing within rheumatology outpatient settings. The establishment of a joint clinic with ophthalmology in the near future is also underway.

For more complex or diagnostically uncertain cases, patients are currently referred outside the region for investigations due to the need for specialist histopathology expertise and experienced interpretation. Gloucestershire is fortunate to have access to national centres relatively close to our county borders, including those in Birmingham and Swindon, which provide valuable support and advice in selected complex cases. However, the Trust recognises the burden this can place on patients and are exploring opportunities to develop this capability locally over time.

Management options remain limited in Sjögren's disease. However, patients with more complex disease may be considered for clinical trials. These are typically accessed through specialist centres outside the region, which can present

additional challenges, reflecting the limited number of tertiary centres available nationally. GHT is also organising an educational session with a national expert to support the Gloucestershire team's awareness and to explore emerging developments in management.

Overall, while there is ongoing work to improve services, this remains an evolving area, and further progress is needed to improve access to specialist services locally.

With respect to awareness raising of Jess's Rule, the ICB can confirm that information was shared at the time of its publication in September 2025 in the Primary Care Bulletin: 'What's new this week'; which provides regular information for GPs, Practice Managers and Locum GPs. The article included a link to a letter about the introduction of Jess's Rule sent to Integrated Care Boards' and community trusts' medical directors, clinical directors and chief executive officers from the Secretary of State for Health and Social Care and NHS England's National Medical Director.

Finally, with respect to the availability of certain medications through a Shared Care arrangement between secondary and primary care such as Ciclosporin eye drops (Ikervis® and from October 2025, Cequa®). This medication is classified as "amber" in Gloucestershire, meaning it has been agreed as suitable for Primary Care GPs to prescribe in line with a Shared Care Guideline (SCG). However, as with all SCGs it is a Primary Care practice/GP decision as to whether they wish to prescribe or not.

One option open to patients would be to contact the secondary care provider to ask for their prescription to be sent to a community pharmacy near to the patient's home rather than the one linked to the secondary care specialist hospital. Alternatively, the secondary care provider during their consultation could give the patient a prescription (or a number of prescriptions to last for a longer period) to take away and hand to their preferred community pharmacy in Gloucestershire. If this is a service they offer, their local pharmacy may be prepared to deliver to patient's home.



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