



Sjögren's Syndrome 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 Syndrome can be a debilitating, distressing and miserable condition.

- ◆ It affects approximately 0.1 - 0.4% of adults in the UK¹, with a mean age of 50 years.
- ◆ 90% of patients are women.

In Sjögren's Syndrome the secretory glands that produce saliva, tears, vaginal, and other secretions develop a form of inflammation. As a result of this, these glands stop working leading to dry eyes, dry mouth, dry skin, dry vagina and dryness of the gastrointestinal tract. These features, as well as being very uncomfortable and unpleasant, mean sufferers may have difficulty swallowing dry foods. Dryness of the large bowel can cause symptoms similar to irritable bowel syndrome (IBS).

The clinical presentation of Sjögren's Syndrome is variable, but typical symptoms include;

- ◆ Dry itchy, irritated eyes
- ◆ Joint pain and muscle aches
- ◆ Disabling fatigue
- ◆ Dry mouth and difficulty swallowing
- ◆ Low mood, irritability and impaired concentration

Sjögren's Syndrome is an autoimmune disease, a condition where the body's immune system starts attacking parts of the body instead of fighting infection. Sjögren's Syndrome affects women in their 40's and above, although up to 10% of cases occur in men and it is also seen in younger people. It affects one in 2000 women in the UK. Features such as muscle or joint aching and fatigue can be the most prominent symptoms.

Patients can develop both mental and physical fatigue and in some this is the most disabling symptom. In some where dryness is not a prominent feature the diagnosis may be delayed.

A number of studies have shown that the health-related quality of life of patients with Primary Sjögren's Syndrome is significantly decreased and is comparable with that of patients with conditions such as rheumatoid arthritis or systemic lupus erythematosus (SLE).

Sjögren's Syndrome can occur later in the course of other rheumatic conditions, such as rheumatoid arthritis, lupus or scleroderma, when it is known as Secondary Sjögren's Syndrome. Most patients with these conditions will already be under the care of a rheumatologist who will usually make the diagnosis of Sjögren's Syndrome.

Despite being a common disorder, Sjögren's Syndrome has not commanded a high profile and has been under-diagnosed and many patients have gone untreated. Serious complications occasionally occur including loss of teeth and damage or ulceration to the eye, which can affect vision. Some patients develop systemic complications such as neuropathies. Prompt diagnosis and treatment may prevent these complications from happening.

Systemic complications

These are some of the complications that can affect a sufferer:

- ◆ Arthritis
- ◆ Lung involvement
- ◆ Neurological involvement
- ◆ Raynaud's syndrome
- ◆ Kidney involvement
- ◆ MALT Lymphoma (40 times increased risk)

Barriers to diagnosis and therapy

These are some of the problems a sufferer can come across:

- ◆ Patients present to different specialties, due to their varied symptoms
- ◆ Often non-specific symptoms
- ◆ Long lead time before diagnosis
- ◆ Undiagnosed patients not receiving appropriate therapy

General advice

- ◆ Encourage regular dental review (6 monthly)
- ◆ Good dental hygiene (brushing, flossing, fluoride)
- ◆ Avoid excess sweet foods
- ◆ Avoid strong soaps (use aqueous creams and emollients)
- ◆ Avoid dry environments
- ◆ Avoid cigarette smoking and excess alcohol
- ◆ Receive information about self-help groups (e.g. Sjögren's UK)

Sjögren's UK

Sjögren's UK was founded in 1986, as a registered charity, to raise awareness of the disease and support research into its cause and treatment. It is a self-help organisation with more than 2300 members. Sjögren's UK is dedicated to providing mutual support and information to individuals affected by this disabling disease. We have regional support groups throughout the UK whose members include sufferers and supporters who work together in helping one another cope with the day-to-day challenges of this debilitating and distressing condition. Sjögren's UK also has a helpline, we distribute a variety of literature including an informative quarterly newsletter and we award research grants. There is currently no cure for Sjögren's Syndrome and the cause remains unknown.

Sjögren's UK aims and objectives are:

- ◆ Raise awareness of Sjögren's Syndrome
- ◆ Educate people about the condition
- ◆ Support research into its cause and treatment

Sjögren's UK activities include:

- ◆ Providing information, and support to those affected by the condition
- ◆ Distribute a variety of literature including an informative quarterly newsletter
- ◆ Operating a national helpline facility
- ◆ Hosting regular regional meetings throughout the UK

Sjögren's UK successes include:

- ◆ Having over 40 self help and support groups across the UK
- ◆ Giving grants to research projects associated with Sjögren's Syndrome
- ◆ Hosting an annual national Sjögren's Syndrome seminar for medical professionals and sufferers
- ◆ A constantly growing membership

For further information, please contact:

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Registered charity no. 1101571

References

¹S Bowman et al, Estimating the prevalence among Caucasian women of primary Sjögren's Syndrome in two general practices in Birmingham, UK Scandinavian Journal of Rheumatology 2004, Vol. 33, No. 1, Pages 39-43.