Sjögren's India

For Living Well with Sjögren's syndrome

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Sjögren's Syndrome

Sjögren's syndrome (SS) (pronounced SHOW-grins) is a serious, under-recognized autoimmune condition.

SS is a chronic, connective tissue disease in which white blood cells attack and destroy the moisture-producing glands. Although the hallmark symptoms are dry eyes and dry mouth, Sjögren's syndrome may also cause dryness of other organs.

It may also involve the kidneys, gastro intestinal system, blood vessels, lung, liver, pancreas and the central nervous system. Many patients experience debilitating fatigue and joint pains.

Every patient may experience different symptoms at different times with waxing and waning intensity.

No two patients exhibit the same set of symptoms. Nine out of ten patients are women.

Reaching Out.....

DOC TALK : Dr. Sapan Pandya M.D. D.M. (Rheumatology and Immunology)

Clinical research for Sjögren's syndrome: A summary (2009-10)

- The **EULAR Sjögren's syndrome Task Force** compared the **applicability of 3 disease activity indices** for SS i.e. the ESSDAI (EULAR Sjögren's syndrome disease activity index), SSDAI (Sjögren's syndrome DAI) and SCAI (Sjögren's systemic clinical activity index) on 96 patient profiles and found similarity in patients with improved disease activity. In subjects with stable disease activity the ESSDAI more accurately showed no improvement.
- **Avouac J and colleagues** from France reported from their cohort of over 1000 subjects (including Italian cohort) the **overlap of another autoimmune disease in patients of Systemic Sclerosis especially Sjögren's syndrome (12%)** made the disease milder – they were more often limited scleroderma with ANA positivity and lesser digital ulcers.
- **The Sjögren's International Collaborative Clinical Alliance Research Groups** from the University of California, San Francisco has devised **a new Ocular Staining Score (OSS)** using the

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- Schirmer's test (unanesthetised), tear break-up time, ocular surface staining (lissamine green fluorescein) and external eye examination on slit lamp and in the 1208 subjects from the SICCA registry, found strong correlation of OSS > or equal to 3 scores with salivary gland lymphocytic focus score >1 and other phenotypic features . They also found a large group of Kerato Conjunctivitis Sicca subjects without Sjögrens' syndrome in whom the pathogenesis may differ.

- **Yoon KC and colleagues** from Korea reported significantly raised levels of the **chemokines CXCL 9, 10, 11 and CXCR 3** in dry eyes especially of Sjögren's syndrome subjects when compared to controls. CXCL 11 levels also correlated with tear film and ocular surface parameters.

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May I Ask?

What kind of doctors treats Sjögren's?

Rheumatologists have primary responsibility for managing Sjögren's syndrome. Ophthalmologists, dentists and other specialists also can treat symptoms related to Sjögren's.

What treatments are available?

Over the counter products for relieving dry eyes and dry mouth are available. Prescription drugs are available for systemic symptoms, depending on the nature and severity of the condition.

What else can be done?

High quality professional dental and eye care are extremely important. Lifestyle changes and use of protective gear such as wrap around goggles help in relieving symptoms. Often, patients learn useful tips from one another in patient support groups.

Will I die from Sjögren's syndrome?

Sjögren's syndrome is serious but generally not fatal if complications are diagnosed and treated early. In one study the incidence of lymphoma (cancer of the lymph glands) was 44 times higher in people with Sjögren's syndrome than in the general population. Sjögren's syndrome patients must be monitored carefully for development of related autoimmune diseases, lymphoma, and other complications.

Voices

Dr. Ramani Atkuri (M.D.)

Ganiyari, MP

"I believe that a better orientation regarding the multi-organ manifestations of this condition among multi-disciplinary specialists, general practitioners and care-givers will enable a greater understanding and better management of Sjögren's syndrome."

Living well with Sjögren's Syndrome…

A doctor by training with a specialization in public health, I have been working in rural and tribal parts of central India for the past twenty years. My work involves attending to patients, training nurses, birth attendants and health workers dealing with issues related to women's health. I have been married to a doctor for the past twenty years.

Becoming ill

My work required me to walk long distances up and down mountainous regions and through forested areas in order to reach remote villages. I often had to sleep over in villages during my field visits. Having worked as a doctor in UNICEF for over a decade, I had always led a physically active life.

In 1998, I began feeling really unwell… I started finding it difficult to accomplish what I had earlier been doing with ease. At 35 I felt extremely tired all the time! My exhaustion and joint pains made even cycling home from work (merely a kilometer away) in the evenings and climbing up a single flight of stairs seem like a major challenge. I had no energy to go to the market or entertain visitors at home during the week. I had to manage all additional chores only on Sundays when I could rest frequently during the day. My eyes became red, dry and painful. My life seemed to be defined by the limits set by my fatigue… By 2004, I was barely functional.

Why did I feel so totally drained out all the time? I began to feel very depressed as I couldn't understand what was wrong with me. I was fast losing hope about ever getting better…

Difficult Diagnosis

Although both I and my husband are doctors, we had not suspected that I could have Sjögren's Syndrome (SS). We had briefly learnt about SS while studying medicine, but had no idea about the multi-system manifestations and the different ways in which SS affects every patient. I was aware only of the hallmark symptoms of dry eyes, dry mouth and joint pains. I learnt about the debilitating fatigue, the dryness in all the moisture producing glands, the pain

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caused by hands and feet turning blue with cold (Raynaud's phenomenon), the excruciatingly painful neuralgia and the depression - only when I experienced these symptoms myself. Till then I was completely unaware of just how SS would change the quality of my life!

After being miserable and ill for over five years, my Ophthalmologist referred me to a Rheumatologist who put me through some specialized diagnostic tests and procedures. While most tests were normal, a lip biopsy finally confirmed that I suffered from Sjögren's syndrome (SS)! I was so relieved to find that I had not been imagining all my symptoms and my fatigue.

Learning to Live Well...

"WHY ME?" I questioned, over and over again… I refused to accept this 'new' me, who was so different from what I knew myself to be… I was very angry at not being able to do what I wanted to. I felt extremely embarrassed when I had to tell someone that I could not do something because I could not cope physically.

Fortunately, I overcame this bitter phase with the help of medicines and lifestyle changes. The medication helped me in deal with the muscle and joint pains, relieved the dryness to some extent and most importantly reduced the level of fatigue. The insertion of punctual plugs in my tear glands helps me retain moisture longer and the artificial tears help lubricate

I needed antidepressants for a year initially. These helped me accept my illness and start thinking positively again.

Lessons I Learnt

- By accepting my limitations and changing my expectations from myself, I realized that I could still contribute meaningfully to society - maybe in a different way.
- SS affects the whole family. My husband too had to struggle to understand and accept the limitations posed by my chronic illness.
- Although difficult, I have learnt to say 'No' without feeling guilty, when my body does not permit.
- Spacing out activities, taking short breaks periodically and keeping my hands and feet warm has helped me live a near normal life again.
- I have learnt to understand my illness better. A few times during the year when the illness worsens I take more rest.

I look forward to the good days. I know I am fortunate. I have been diagnosed, am being treated and have learnt to Live Well again.

Dr. Ramani Atkuri works with Jan Swasthya Sahyog (JSS) which provides low cost health care to tribal and scheduled caste populations in Bilaspur, Chhattisgarh (MP).

Sjögren's India: What we do

Sjögren's India (SI), managed by patient volunteers, is dedicated to enabling patients and their families to 'Live Well with Sjögren's Syndrome (SS)'. SI works for empowering patients through education creating better public awareness and providing a forum for interaction with healthcare professionals. Support in terms of counseling, lifestyle management tips etc. is extended to patients/families through personal/ group, telephonic and virtual interaction.

Your Doctor is your FRIEND

Sjögren's India
For Living Well with Sjögren's syndrome

- **Gune SE and group** from Turkey used **Tc-99 scintigraphy** in 27 subjects of SS (16 early and 11 advanced) and 10 controls and found significant difference in parotid and submandibular function. Submandibular glands were more frequently affected and there was an asymmetrical uptake in the parotid glands in the early stages. Thyroid uptakes were similar in two groups and controls. There was no correlation with ocular features. They therefore recommend the use of scintigraphy to evaluate salivary gland function and severity.

- In the treatment strategies, Cankaya H and co. from Turkey reported improvement in unstimulated salivary flow rate (SFR) in 30 subjects with SS after using **hydroxychloroquine** 400mg per day for 30 weeks. There was however no improvement in the stimulated SFR or other objective and subjective measures.

- **Virkki LM and group** from Finland used **Dehydroepiandrosterone (DHEA)** 50mg/day and placebo in a multicenter, investigator based, randomized controlled trial in 107 subjects with SS for fatigue (subjects with low DHEA levels) and found no benefit in any of the measures of fatigue (general, mental, physical, reduced motivation, VAS). They hypothesize this could be due to lack of intracrine tissue specific conversion of DHEA to active metabolite.

- **Meijer et al** from Netherlands, in a double blind randomized placebo controlled trial reported the results of **rituximab** in 36 subjects over 48 weeks and showed significant improvements in stimulated whole salivary flow rates, B cell and rheumatoid factor levels, subjective measures of sicca and fatigue and extraglandular manifestations. Compared to baseline values, there was significant improvement in stimulated whole salivary flow rates, unstimulated whole SFR, lacrimal gland function, fatigue and sicca symptoms. They concluded rituximab is safe and effective in SS.

Send us

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Your queries
Your story at

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