

Article Level: Advanced

A Desert Within: Living with Sjogren's Syndrome

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Introduction

Imagine your eyes are filled with sand. Imagine your mouth is so dry that your gums stick to your teeth. Imagine not being able to sweat--which you need to do to survive. Imagine spending a lifetime like this.

People with Sjogren's syndrome don't have to imagine: They know how all this feels. Two to 4 million Americans are thought to suffer from this condition.

"One look at a Sjogren's patient tells you how miserable they are."

Sjogren's syndrome makes the body attack its own immune system. It strikes at all ages and in both sexes but most often in women in their early 40s.

Sjogren's can appear on its own, but often it shows up in patients who also have rheumatoid arthritis and lupus. But whether it strikes along with another condition or not, patients who have it experience a dramatic life change. And as yet, there is no cure.

Symptoms of Sjogren's syndrome include

- Dry, itchy, painful eyes (sometimes with excessive tearing at first).
- Dry nose and mouth.
- Excessive thirst.
- Vaginal dryness.
- Fatigue and aching.

According to Dr. Richard Brasington, associate professor of medicine and director of clinical rheumatology at Washington University School of Medicine in St. Louis, people with Sjogren's have a deficiency of tears, saliva, and digestive enzymes because their glands can't make these fluids any more.

Brasington says the most common symptom when the disease begins is dry eyes and mouth. "This usually comes on slowly and remains chronic. People come in describing a sandy or scratchy feeling in their eyes and a very dry mouth. One look at a Sjogren's patient tells you how miserable they are."

Managing the Dry Spells

Joy Breslow, 46, of Philadelphia, has lupus and says her Sjogren's started 12 years ago. "My eyes hurt so bad, so I finally went to my eye doctor and he diagnosed me." Dry gums and tongue are another problem with this condition. "My mouth is so dry it's hard to swallow," Breslow says, "so I carry a bottle of water 24 hours a day."

Products are available that can help Sjogren's sufferers manage the constant dryness. Special mouthwashes, toothpastes, sugarless gum, and certain prescription medications can help stimulate saliva, and artificial tears can be used to moisten itchy, painful eyes.

Dr. Steven Birney, professor of medicine and chief of the rheumatology department at Temple University Hospital in

Philadelphia, says people with dry eyes need to constantly put moisturizing drops in them during the day and use an ointment at night to keep the insides of their lids lubricated.

Some experts also use a treatment called *punctal plugs* for advanced cases of dry eyes. Each eye, says Brasington, has a puncta, which is like a bathtub drain. Plugging this up to prevent moisture from getting out helps keep the eyes moist. First a plastic plug is used, according to Brasington, and if that works, the doctor will go ahead and cauterize (burn) the "drain" to keep it closed permanently.

Added Complications

Besides having dry eyes and a dry mouth, Sjogren's sufferers also can't sweat. If you can't sweat, you overheat. "Turning on the air-conditioning makes it worse because it dries me out," says Alice Penderghest, 50, of Hatboro, Pennsylvania, who also suffers Sjogren's-related joint problems. "I go to the pool because the water soothes my joints and makes me semi-pain-free."

Since Sjogren's affects the sense of taste and smell, most foods lose their appeal. Penderghest says, "The brain says you're eating mashed potatoes, but everything tastes like paper. The sense of smell is gone unless the food is very pungent. And you can't eat spicy food."

As if all these problems weren't enough to contend with, Sjogren's can also open the door for other diseases. "People with Sjogren's are exuberant autoantibody producers," Birney says. "They make all kinds of curious antibodies which may or may not be part of the disease." When the body turns its immune system on itself, there can be many complications.

Penderghest was diagnosed with Sjogren's 9 years ago and now suffers from spondylosis in her lower spine, fibromyalgia, neuropathy, interstitial cystitis, and gastroparesis. Treating these conditions is a juggling act: Taking medication for one sometimes adversely affects the others.

"The brain says you're eating mashed potatoes, but [with Sjogren's] everything tastes like paper."

According to Birney, Sjogren's patients also tend to have a higher than normal rate of lymphoma, so they need to be closely monitored. But fortunately, he says, "That's the only life-threatening complication of having this particular condition."

Because Sjogren's is not a life-threatening disease, doctors prefer not to use strong immunosuppressant drugs to treat it, unless it has affected vital organs. Usually an antimalarial drug like Plaquenil (hydroxychloroquine) will be used instead.

Where to Get Help

Through the Sjogren's Syndrome Foundation and Web site you can find out about the newest over-the-counter and prescription medications and products to help you if you have the disease. You will also find resources for information on all aspects of living with your condition.

The Sjogren's Syndrome Foundation
366 N. Broadway
Jericho, NY 11753
Phone: (516) 933-6365
Information Requests: (800) 475-6473 or <http://www.sjogrens.org/>.

Two publications may also be of help:

- *The Moisture Seekers Newsletter*
- *The New Sjogren's Syndrome Handbook*

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Reviewed by:



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