Points To Remember About Sjögren’s Syndrome

- Sjögren’s syndrome is a disease that affects the glands that make moisture. It most often causes dryness in the mouth and eyes.
- The main symptoms of Sjögren’s syndrome are dry eyes and dry mouth.
- Sjögren’s syndrome is an autoimmune disease. In Sjögren’s syndrome, your immune system attacks the glands that make tears and saliva (spit).
- Doctors diagnose Sjögren’s using a medical history, physical exam, certain eye and mouth tests, and blood tests.
- Treatment differs for each person and depends on what parts of your body are affected and focuses on getting rid of symptoms.
- Living with Sjögren’s syndrome can be easier by taking good care of your eyes and mouth, by protecting your voice, and understanding what medicines cause dryness.

What is Sjögren’s syndrome?

Sjögren’s syndrome is a disease that affects the glands that make moisture. It most often causes dryness in the mouth and eyes. It can also lead to dryness in other places that need moisture, such as the nose, throat, and skin.

Sjögren’s syndrome is also a rheumatic disease, which affect:

- Joints.
- Tendons.
The signs and symptoms of rheumatic diseases can include:

- Redness or heat.
- Swelling.
- Pain.
- Loss of function.

**Primary Versus Secondary Sjögren’s Syndrome**

Doctors have two categories for Sjögren’s syndrome:

- Primary form: Occurs if you do not have other rheumatic diseases.
- Secondary form: Occurs if you already have another rheumatic disease, such as rheumatoid arthritis or systemic lupus erythematosus, scleroderma, or polymyositis.

**Who gets Sjögren’s syndrome?**

Most people with Sjögren’s syndrome are women. It can occur at any age and in any race. But it is rare in children and most often shows up after age 40.

**What are the symptoms of Sjögren’s syndrome?**

The main symptoms are:

- Dry eyes. Your eyes may burn or itch or feel like they have sand in them. Sometimes Sjögren’s syndrome can cause blurry vision or sensitivity to bright light, especially fluorescent lighting.
- Dry mouth. Your mouth may feel chalky or like it is full of cotton.
- You may have trouble:
  - Swallowing.
  - Speaking.
  - Tasting.
• Because you lack the protective effects of saliva, you may develop more dental decay (cavities) and mouth infections.

Sjögren’s syndrome also can affect other parts of the body, including:

• Skin.
• Joints.
• Lungs.
• Kidneys.
• Blood vessels.
• Digestive organs.
• Nerves.

Symptoms can include:

• Dry skin.
• Skin rashes.
• Chronic dry cough.
• Thyroid problems.
• Joint and muscle pain.
• Vaginal dryness.
• Numbness and tingling in the arms and legs.
• Fatigue or feeling very tired.

People with dry mouth can easily get mouth infections. Tell your doctor if you have any of these symptoms in your mouth:

• White patches.
• Red patches.
• Burning areas.

**What causes Sjögren’s syndrome?**

Sjögren’s syndrome is an autoimmune disease. The immune system is supposed to fight disease by killing off harmful viruses and bacteria. But with autoimmune diseases, your immune system attacks parts of your own body by mistake.

In Sjögren’s syndrome, your immune system attacks the glands that make tears
and saliva (spit). The damage keeps these glands from working right and causes dry eyes and dry mouth.

Doctors don’t know the exact cause of Sjögren’s syndrome. They think it may be caused by a combination of two things:

- Genes.
- Exposure to something like a virus or bacteria.

Is there a test for Sjögren’s syndrome?

Doctors diagnose Sjögren’s using:

- Medical history.
- Physical exam.
- Certain eye and mouth tests.
- Blood tests.

Doctors may also order:

- A urine test.
- A chest x-ray.

How is Sjögren’s syndrome treated?

Treatment differs for each person and depends on what parts of your body are affected. Treatment will focus on getting rid of symptoms and may include:

- Medicines for joint or muscle pain (such as aspirin and ibuprofen).
- Medicines that help you make more saliva.
- Medicines that suppress inflammation (such as corticosteroids).
- Medicines that suppress the immune system.

Treatment for dry eyes may include:

- Eye drops that come in different thicknesses. You may have to try a few to find the right one.
- Eye ointments. These are thicker than eye drops. They protect the eyes and
keep them wet for several hours. They can blur your vision, so you may want to use them while you sleep.

- Medicines to reduce inflammation in the eye.
- A chemical that wets the surface of the eye and keeps the natural tears from drying out so fast. It comes in a small pellet that you put in your lower eyelid. When you add eye drops, the pellet melts. This forms a film over your own tears and traps the moisture.
- Surgery to shut the tear ducts that drain tears from the eye.

Treatment for dry mouth may include:

- Chewing gum or sucking on hard candy helps your glands make more saliva. Use sugar-free gum and candy.
- Sipping water or a sugar-free drink often to keep your mouth wet.
- Using oil or petroleum-based lip balm or lipstick to help dry, cracked lips feel better.
- Using a saliva substitute prescribed by a doctor to make the mouth feel wet.
- Using medicine to help your mouth make more saliva.

**Who treats Sjögren’s syndrome?**

Because the symptoms of Sjögren’s syndrome develop gradually and are similar to those of many other diseases, getting a diagnosis can take time. A person could see a number of doctors, any of whom could diagnose the disease and be involved in its treatment. These might include:

- A rheumatologist, a doctor who specializes in diseases of the joints, muscles, and bones.
- A primary care physician.
- An internist.
- An ophthalmologist, a doctor who specializes in the care of the eyes.
- An otolaryngologist, a doctor who specializes in caring for ears, nose, and throat.

Usually a rheumatologist will coordinate treatment among a number of specialists.
Living with Sjögren’s syndrome

Living with Sjögren’s syndrome can be easier by following some tips for:

- Eye care.
- Mouth care.
- Protecting your voice.
- Understanding medicines that cause dryness.

General Tips for Eye Care

- Don’t use eye drops that irritate your eyes. If one brand or prescription bothers you, try another. Eye drops that do not contain preservatives are usually essential for long-term use.
- Practice blinking. You tend to blink less when reading or using the computer. Remember to blink 5 to 6 times a minute.
- Protect your eyes from drafts, breezes, and wind.
- Put humidifiers in the rooms where you spend the most time, including the bedroom, or install a humidifier in your heating and air conditioning unit.
- Don’t smoke, and stay out of smoky rooms.
- Apply mascara only to the tips of your lashes so it doesn’t get in your eyes. If you use eyeliner or eye shadow, put it only on the skin above your lashes, not on the sensitive skin under your lashes, close to your eyes. Avoid facial creams on the lower lid skin at bedtime if you are awakening with eye irritation.
- Ask your doctor whether any medications that you are taking contribute to dryness. If they do, ask how the dryness can be reduced.

Importance of Mouth Care

Natural saliva contains substances that help get rid of bacteria that can cause cavities and mouth infections. Good oral hygiene or mouth care is extremely important when you have dry mouth. Here’s what you can do to prevent cavities and infections:

- Visit a dentist regularly, at least twice a year, to have your teeth examined and cleaned.
- Rinse your mouth with water several times a day. Don’t use mouthwash that
contains alcohol, because alcohol is drying.
• Use toothpaste that contains fluoride to gently brush your teeth, gums, and
tongue after each meal and before bedtime. Non-foaming toothpaste is less
drying.
• Floss your teeth every day.
• Avoid sugar between meals. That means choosing sugar-free gum, candy, and
soda. If you do eat or drink sugary foods, brush your teeth immediately
afterward.
• See a dentist right away if you notice anything unusual or have continuous
burning or other oral symptoms.
• Ask your dentist whether you need to take fluoride supplements, use a fluoride
gel at night, or have a varnish put on your teeth to protect the enamel.

Protect Your Voice
You can develop hoarseness if their vocal cords become inflamed or become
irritated from throat dryness or coughing. To prevent further strain on your vocal
cords, try not to clear your throat before speaking. Clearing your throat is hard on
the vocal cords. To avoid irritating your vocal cords:

• Sip water.
• Chew sugar-free gum.
• Suck on sugar-free candy.
• Make an “h” sound, hum, or laugh to gently bring the vocal cords together.

Medicines and Dryness
Some medicines can cause eye and mouth dryness. If you are taking one of the
drugs listed below, talk to your doctor about adjusting the dose or finding a different
medicine. Don’t stop taking any medicine without asking your doctor. These can
include medicines that you take for:

• Allergies and colds (antihistamines and decongestants).
• Getting rid of extra fluids in your body (diuretics).
• Diarrhea.
• High blood pressure.

Some type of medicines that can cause dryness include:
• Antipsychotic medicines.
• Tranquilizers.
• Antidepressants.

Other medical problems related to Sjögren’s syndrome

A small number of people with Sjögren’s syndrome may develop lymphoma. A form of cancer, lymphoma can affect the salivary glands, lymph nodes, the gastrointestinal tract, or the lungs. If you have enlargement of a salivary gland, you should contact your doctor. Other symptoms may include the following:

• Unexplained fever.
• Night sweats.
• Constant fatigue.
• Unexplained weight loss.
• Itchy skin.
• Reddened patches on the skin.

Many of these can be symptoms of other problems, including Sjögren’s syndrome itself. Nevertheless, it is important to see your doctor if you have any of these symptoms.

For more info

U.S. Food and Drug Administration
Toll free: 888-INFO-FDA (888-463-6332)
Website: https://www.fda.gov

Drugs@FDA at https://www.accessdata.fda.gov/scripts/cder/daf Drugs@FDA is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics
Website: https://www.cdc.gov/nchs
National Eye Institute
Website: https://www.nei.nih.gov

National Institute of Dental and Craniofacial Research (NIDCR)
Website: https://www.nidcr.nih.gov

NIDCR Sjögren’s Syndrome Clinic
Website: https://www.nidcr.nih.gov/Research/NIDCRLaboratories/MolecularPhysiology/SjogrensSyndrome/

National Institute of Neurological Disorders and Stroke
Website: https://www.ninds.nih.gov

American Academy of Dermatology
Website: https://www.aad.org

American Academy of Ophthalmology
Website: http://www.aao.org

American Association for Dental Research and International Association for Dental Research
Website: http://www.iadr.org

American College of Rheumatology
Website: https://www.rheumatology.org

American Dental Association
Website: https://www.ada.org

American Autoimmune Related Diseases Association, Inc.
Website: https://www.aarda.org

Arthritis Foundation
Website: https://www.arthritis.org

Lupus Foundation of America
Website: https://www.lupus.org
The Myositis Association
Website: https://www.myositis.org

National Organization for Rare Disorders
Website: https://www.rarediseases.org

Scleroderma Foundation
Website: https://www.scleroderma.org

Scleroderma Research Foundation
Website: https://www.srfcure.org

Sjögren’s Syndrome Foundation, Inc.
Website: https://www.sjogrens.org

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