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SJÖGREN'S SYNDROME

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What Is Sjögren's Syndrome?

Sjögren's (SHOW-grins) syndrome is an autoimmune disease--that is, a disease in which the immune system turns against the body's own cells. In Sjögren's syndrome, the immune system targets moisture-producing glands and causes dryness in the mouth and eyes. Other parts of the body can be affected as well, resulting in a wide range of possible symptoms.

Normally, the immune system works to protect us from disease by destroying harmful invading organisms like viruses and bacteria. In the case of Sjögren's syndrome, disease-fighting cells attack the glands that produce tears and saliva (the lacrimal and salivary glands).

Damage to these glands keeps them from working properly and causes dry eyes and dry mouth. In technical terms, dry eyes are called keratoconjunctivitis sicca, or KCS, and dry mouth is called xerostomia. Your doctor may use these terms when talking to you about Sjögren's syndrome.

The disease can affect other glands too, such as those in the stomach, pancreas, and intestines, and can cause dryness in other places that need moisture, such as the nose, throat, airways, and skin.

You might hear Sjögren's syndrome called a rheumatic disease. A rheumatic disease causes inflammation in joints, muscles, skin, or other body tissue, and Sjögren's can do that. The many forms of arthritis, which often involve inflammation in the joints, among other problems, are examples of rheumatic diseases.

Sjögren's is also considered a disorder of connective tissue, which is the framework of the body that supports organs and tissues (joints, muscles, and skin).

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703-931-9100

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703-573-8080

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703-430-4400

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703-858-3170

Primary versus Secondary Sjögren's Syndrome

Sjögren's syndrome is classified as either primary or secondary disease. Primary Sjögren's occurs by itself, and secondary Sjögren's occurs with another disease. Both are systemic disorders, although the symptoms in primary are more restricted.

In primary Sjögren's syndrome, the doctor can trace the symptoms to problems with the tear and saliva glands. People with primary disease are more likely to have certain antibodies (substances that help fight a particular disease) circulating in their blood than people with secondary disease. These antibodies are called SS-A and SS-B. People with primary Sjögren's are more likely to have antinuclear antibodies (ANAs) in their blood. ANAs are autoantibodies, which are directed against the body.

In secondary Sjögren's syndrome, the person had an autoimmune disease like rheumatoid arthritis or lupus before Sjögren's developed. People with this type tend to have more health problems because they have two diseases, and they are also less likely to have the antibodies associated with primary Sjögren's.

What Are the Symptoms of Sjögren's Syndrome?

The main symptoms are:

- **Dry eyes**--Your eyes may be red and burn and itch. People say it feels like they have sand in their eyes. Also, your vision may be blurry, and bright light, especially fluorescent lighting, might bother you.
- **Dry mouth**--Dry mouth feels like a mouth full of cotton. It's difficult to swallow, speak, and taste. Your sense of smell can change, and you may develop a dry cough. Also, because you lack the protective effects of saliva, dry mouth increases your chances of developing cavities and mouth infections. Both primary and secondary Sjögren's syndrome can affect other parts of the body as well, including the skin, joints, lungs, kidneys, blood vessels, and nervous system, and cause symptoms such as

- **Dry skin**
- **Skin rashes**
- **Thyroid problems**
- **Joint and muscle pain**
- **Pneumonia**
- **Vaginal dryness**
- **Numbness and tingling in the extremities**

When Sjögren's affects other parts of the body, the condition is called extraglandular involvement because the problems extend beyond the tear and salivary glands. These problems are described in more detail later.

Finally, Sjögren's can cause extreme fatigue that can seriously interfere with daily life.

What Causes Dryness in Sjögren's Syndrome?

In the autoimmune attack that causes Sjögren's, disease-fighting cells called lymphocytes target the glands that produce moisture--primarily the lacrimal (tear) and salivary (saliva) glands. Although no one knows exactly how damage occurs, damaged glands can no longer produce tears and saliva, and eye and mouth dryness result. When the skin, sinuses, airways, and vaginal tissues are affected, dryness occurs in those places, too.

Who Gets Sjögren's Syndrome?

Experts believe 1 to 4 million people have the disease. Most--90 percent---are women. It can occur at any age, but it usually is diagnosed after age 40 and can affect people of all races and ethnic backgrounds. It's rare in children, but it can occur.

What Causes Sjögren's Syndrome?

Researchers think Sjögren's syndrome is caused by a combination of genetic and environmental factors. Several different genes appear to be involved, but scientists are not certain exactly which ones are linked to the disease since different genes seem to play a role in different people. For example, there is one gene that predisposes Caucasians to the disease. Other genes are linked to Sjögren's in people of Japanese, Chinese, and African American descent. Simply having one of these genes will not cause a person to develop the disease, however. Some sort of trigger must activate the immune system.

Scientists think that the trigger may be a viral or bacterial infection. It might work like this: A person who has a Sjögren's-associated gene gets a viral infection. The virus stimulates the immune system to act, but the gene alters the attack, sending fighter cells (lymphocytes) to the eye and mouth glands. Once there, the lymphocytes attack healthy cells, causing the inflammation that damages the glands and keeps them from working properly. These fighter cells are supposed to die after their attack in a natural process called apoptosis, but in people with Sjögren's syndrome, they continue to attack, causing further damage. Scientists think that resistance to apoptosis may be genetic.

The possibility that the endocrine and nervous systems play a role is also under investigation.

How Is Sjögren's Syndrome Diagnosed?

The doctor will first take a detailed medical history, which includes asking questions about general health, symptoms, family medical history, alcohol consumption, smoking, or use of drugs or medications. The doctor will also do a complete physical exam to check for other signs of Sjögren's.

You may have some tests, too. First, the doctor will want to check your eyes and mouth to see whether Sjögren's is causing your symptoms and how severe the problem is. Then, the doctor may do other tests to see whether the disease is elsewhere in the body as well.

Common eye and mouth tests are:

Schirmer test--This test measures tears to see how the lacrimal gland is working. It can be done in two ways: In Schirmer I, the doctor puts thin paper strips under the lower eyelids and measures the amount of wetness on the paper after 5 minutes. People with Sjögren's usually produce less than 8 millimeters of tears. The Schirmer II test is similar, but the doctor uses a cotton swab to stimulate a tear reflex inside the nose.

Staining with vital dyes (rose bengal or lissamine green)--The tests show how much damage dryness has done to the surface of the eye. The doctor puts a drop of a liquid containing a dye into the lower eye lid. These drops stain on the surface of the eye, highlighting any areas of injury.

Slit lamp examination--This test shows how severe the dryness is and whether the outside of the eye is inflamed. An ophthalmologist (eye specialist) uses equipment that magnifies to carefully examine the eye.

Mouth exam--The doctor will look in the mouth for signs of dryness and to see whether any of the major salivary glands are swollen. Signs of dryness include a dry, sticky mouth; cavities; thick saliva, or none at all; a smooth look to the tongue; redness in the mouth; dry, cracked lips; and sores at the corners of the

mouth. The doctor might also try to get a sample of saliva to see how much the glands are producing and to check its quality.

Salivary gland biopsy of the lip--This test is the best way to find out whether dry mouth is caused by Sjögren's syndrome. The doctor removes tiny minor salivary glands from the inside of the lower lip and examines them under the microscope. If the glands contain lymphocytes in a particular pattern, the test is positive for Sjögren's syndrome.

Because there are many causes of dry eyes and dry mouth, the doctor will take other possible causes into account. Generally, you are considered to have definite Sjögren's if you have dry eyes, dry mouth, and a positive lip biopsy. But the doctor may decide to do additional tests to see whether other parts of the body are affected. These tests may include

Routine blood tests--The doctor will take blood samples to check blood count and blood sugar level, and to see how the liver and kidneys are working.

Immunological tests--These blood tests check for antibodies commonly found in the blood of people with Sjögren's syndrome. For example: Antithyroid antibodies are created when antibodies migrate out of the salivary glands into the thyroid gland. Antithyroid antibodies cause thyroiditis (inflammation of the thyroid), a common problem in people with Sjögren's.

Immunoglobulins and gamma globulins are antibodies that everyone has in their blood, but people with Sjögren's usually have too many of them.

Rheumatoid factors (RFs) are found in the blood of people with rheumatoid arthritis, as well as in people with Sjögren's. Substances known as cryoglobulins may be detected; these indicate risk of lymphoma.

Similarly, the presence of antinuclear antibodies (ANAs) can indicate an autoimmune disorder, including Sjögren's.

Sjögren's antibodies, called SS-A (or SS-Ro) and SS-B (or SS-La), are specific antinuclear antibodies common in people with Sjögren's. However, you can have Sjögren's without having these ANAs.

Chest x ray--Sjögren's can cause inflammation in the lungs, so the doctor may want to take an x ray to check them.

Urinalysis--The doctor will probably test a sample of your urine to see how well the kidneys are working.

What Type of Doctor Diagnoses and Treats Sjögren's Syndrome?

Because the symptoms of Sjögren's are similar to those of many other diseases, getting a diagnosis can take time--in fact, the average time from first symptom to diagnosis ranges from 2 to 8 years. During those years, depending on the symptoms, a person might see a number of doctors, any of whom may diagnose the disease and be involved in treatment. Usually, a rheumatologist (a doctor who specializes in diseases of the joints, muscles, and bones) will coordinate treatment among a number of specialists. Other doctors who may be involved include:

- Allergist
- Dentist
- Dermatologist (skin specialist)
- Gastroenterologist (digestive disease specialist)

- Gynecologist (women's reproductive health specialist)
- Neurologist (nerve and brain specialist)
- Ophthalmologist (eye specialist)
- Otolaryngologist (ear, nose, and throat specialist)
- Pulmonologist (lung specialist)
- Urologist

How Is Sjögren's Syndrome Treated?

Treatment is different for each person, depending on what parts of the body are affected. But in all cases, the doctor will help relieve your symptoms, especially dryness. For example, you can use artificial tears to help with dry eyes and saliva stimulants and mouth lubricants for dry mouth. Treatment for dryness is described in more detail below.

If you have extraglandular involvement, your doctor--or the appropriate specialist--will also treat those problems. Treatment may include nonsteroidal anti-inflammatory drugs for joint or muscle pain, saliva- and mucus-stimulating drugs for nose and throat dryness, and corticosteroids or drugs that suppress the immune system for lung, kidney, blood vessel, or nervous system problems. Hydroxychloroquine, methotrexate, and cyclophosphamide are examples of such immunosuppressants (drugs that suppress the immune system).

What Can I Do About Dry Eyes?

Artificial tears can help. They come in different thicknesses, so you may have to experiment to find the right one. Some drops contain preservatives that might irritate your eyes. Drops without preservatives don't usually bother the eyes. Nonpreserved tears typically come in single-dose packages to prevent contamination with bacteria.

At night, an eye ointment might provide more relief. Ointments are thicker than artificial tears and moisturize and protect the eye for several hours. They may blur your vision, which is why some people prefer to use them while they sleep.

Hydroxypropyl methylcellulose (Lacriserts*) is a chemical that lubricates the surface of the eye and slows the evaporation of natural tears. It comes in a small pellet that you put in your lower eyelid. When you add artificial tears, the pellet dissolves and forms a film over your own tears that traps the moisture.

Another alternative is surgery to close the tear ducts that drain tears from the eye. The surgery is called punctal occlusion. For a temporary closure, the doctor inserts collagen or silicone plugs into the ducts. Collagen plugs eventually dissolve, and silicone plugs are "permanent" until they are removed or fall out. For a longer lasting effect, the doctor can use a laser or cautery to seal the ducts.

* Brand names included in this booklet are provided as examples only, and their inclusion does not mean that these products are endorsed by the National Institutes of Health or any other Government agency. Also, if a particular brand name is not mentioned, this does not mean or imply that the product is unsatisfactory.

General Tips for Eye Care

- Don't use artificial tears that irritate your eyes--try another brand or preparation.
- Nonpreserved drops may be more comfortable.
- Blink several times a minute while reading or working on the computer.
- Protect your eyes from drafts, breezes, and wind.

- Put a humidifier 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.
- Ask your doctor whether any of your medications contribute to dryness and, if so, how to reduce that effect.

What Can I Do About Dry Mouth?

If your salivary glands still produce some saliva, you can stimulate them to make more by chewing gum or sucking on hard candy. However, gum and candy must be sugar free because dry mouth makes you extremely prone to cavities. Take sips of water or another sugar free drink often throughout the day to wet your mouth, especially when you are eating or talking. Note that you should take sips of water--drinking large amounts of liquid throughout the day will not make your mouth any less dry. It will only make you urinate more often and may strip your mouth of mucus, causing even more dryness. You can soothe dry, cracked lips by using oil- or petroleum-based lip balm or lipstick. If your mouth hurts, the doctor may give you medicine in a mouth rinse, ointment, or gel to apply to the sore areas to control pain and inflammation.

If you produce very little saliva or none at all, your doctor might recommend a saliva substitute. These products mimic some of the properties of saliva, which means they make the mouth feel wet, and if they contain fluoride, they can help prevent cavities. Gel-based saliva substitutes tend to give the longest relief, but all saliva products are limited since you eventually swallow them.

At least two drugs that stimulate the salivary glands to produce saliva are available. These are pilocarpine and cevimeline. The effects last for a few hours, and you can take them three or four times a day. However, they are not suitable for everyone, so talk to your doctor about whether they might help you.

People with dry mouth can easily get mouth infections. Candidiasis, a fungal mouth infection, is one of the most commonly seen in people with Sjögren's. It most often shows up as white patches inside the mouth that you can scrape off, or as red, burning areas in the mouth. Candidiasis is treated with antifungal drugs. Various viruses and bacteria can also cause infections; they're treated with the appropriate antiviral or antibiotic medicines.

The Importance of Oral Hygiene

Natural saliva contains substances that rid the mouth of the bacteria that cause cavities and mouth infections, so good oral hygiene is extremely important when you have dry mouth. Here's what you can do to prevent cavities and infections:

- Visit a dentist at least three times 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 fluoride toothpaste 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. That means choosing sugar-free gum, candy, and soda. If you do eat or drink sugary foods, brush your teeth immediately afterward.
- Look at your mouth every day to check for redness or sores. See a dentist right away if you notice anything unusual or have any mouth pain or bleeding.
- Ask your dentist whether you need to take fluoride supplements, use a fluoride gel at night, or have a protective varnish put on your teeth to protect the enamel.

What Other Parts of the Body Are Involved in Sjögren's Syndrome?

The autoimmune response that causes dry eyes and mouth can cause inflammation throughout the body. People with Sjögren's often have skin, lung, kidney, and nerve problems, as well as disorders of the digestive system and connective tissue. Following are examples of extraglandular problems.

Skin Problems

About half of the people who have Sjögren's have dry skin. Some experience only itching, but it can be severe. Others develop cracked, split skin that can easily become infected. Infection is a risk for people with itchy skin, too, particularly if they scratch vigorously. The skin may darken in infected areas, but it returns to normal when the infection clears up and the scratching stops.

To treat dry skin, apply heavy moisturizing creams and ointments three or four times a day to trap moisture in the skin. Lotions, which are lighter than creams and ointments, aren't recommended because they evaporate quickly and can contribute to dry skin. Also, doctors suggest that you take only a short shower (less than 5 minutes), use a moisturizing soap, pat your skin almost dry, and then cover it with a cream or ointment. If you take baths, it's a good idea to soak for 10 to 15 minutes to give your skin time to absorb moisture. Having a humidifier in the bedroom can help hydrate your skin, too. If these steps don't help the itching, your doctor might recommend that you use a skin cream or ointment containing steroids.

Some patients who have Sjögren's, particularly those who have lupus, are sensitive to sunlight and can get painful burns from even a little sun exposure, such as through a window. So, if you're sensitive to sunlight, you need to wear sunscreen (at least SPF 15) whenever you go outdoors and try to avoid being in the sun for long periods of time.

Vaginal Dryness

Vaginal dryness is common in women with Sjögren's syndrome. Painful intercourse is the most common complaint. A vaginal moisturizer helps retain moisture, and a vaginal lubricant can make intercourse more comfortable. Vaginal moisturizers attract liquid to the dry tissues and are designed for regular use. Vaginal lubricants should be used only for intercourse--they don't moisturize. Oil-based lubricants, such as petroleum jelly, trap moisture and can cause sores and hinder the vagina's natural cleaning process. A water-soluble lubricant is better.

Regular skin creams and ointments relieve dry skin on the outer surface of the vagina (the vulva).

Lung Problems

Dry mouth can cause lung problems. For example, aspiration pneumonia can happen when a person breathes in food instead of swallowing it (dry mouth can keep you from swallowing food properly), and the food gets stuck in the lungs. Pneumonia can also develop when bacteria in the mouth migrate into the lungs and cause infection, or when bacteria get into the lungs and coughing doesn't remove them. (Some people with Sjögren's don't produce enough mucus in the lungs to remove bacteria, and others are too weak to be able to cough.) Pneumonia is treated with various antibiotics, depending on the person and the type of infection. It is important to get treatment for pneumonia to prevent lung abscess (a hole in the lung caused by severe infection).

People with Sjögren's also tend to have lung problems caused by inflammation, such as bronchitis (affecting the bronchial tubes), tracheobronchitis (affecting the windpipe and bronchial tubes), and laryngotracheobronchitis (affecting the voice box, windpipe, and bronchial tubes). Depending on your condition, the doctor may recommend using a humidifier, taking medicines to open the bronchial tubes, or

taking corticosteroids to relieve inflammation. Pleurisy is inflammation of the lining of the lungs and is treated with corticosteroids and nonsteroidal anti-inflammatory drugs.

Protect Your Voice

People with Sjögren's can develop hoarseness if their vocal cords become inflamed as part of the disease or become irritated from throat dryness or coughing. To prevent further strain on your vocal cords, try not to clear your throat before speaking. Instead, take a sip of water, chew gum, or suck on candy. Or else make an "h" sound, hum, or laugh to gently bring the vocal cords together so you can get sound out. Clearing your throat does the same thing, but it's hard on the vocal cords, and you want to avoid irritating them further.

Kidney Problems

The kidneys filter waste products from the blood and remove them from the body through urine. The most common kidney problem in people with Sjögren's is interstitial nephritis, or inflammation of the tissue around the kidney's filters, which can occur even before dry eyes and dry mouth. Inflammation of the filters themselves, called glomerulonephritis, is less common. Some people develop renal tubular acidosis, which means they can't get rid of certain acids through urine. The amount of potassium in their blood drops, causing an imbalance in blood chemicals that can affect the heart, muscles, and nerves.

Often, doctors do not treat these problems unless they start to affect kidney function or cause other health problems. However, they keep a close eye on the problem through regular exams, and will prescribe medicines called alkaline agents to balance blood chemicals when necessary. Corticosteroids or immunosuppressants are used to treat more severe cases.

Nerve Problems

People with Sjögren's syndrome can have nerve problems. When they do, the problem usually involves the peripheral nervous system (PNS), which contains the nerves that control sensation and movement. Involvement of the PNS is increasingly being recognized. Carpal tunnel syndrome, peripheral neuropathy, and cranial neuropathy are examples of peripheral nervous system disorders that occur in people with Sjögren's. In carpal tunnel syndrome, inflamed tissue in the forearm presses against the median nerve, causing pain, numbness, tingling, and sometimes muscle weakness in the thumb and index and middle fingers. In peripheral neuropathy, an immune attack damages nerves in the legs or arms, causing the same symptoms there. (Sometimes nerves are damaged because inflamed blood vessels cut off their blood supply.) In cranial neuropathy, nerve damage causes face pain; loss of feeling in the face, tongue, eyes, ears, or throat; and loss of taste and smell.

Nerve problems are treated with medicines to control pain and, if necessary, with steroids or other drugs to control inflammation.

Digestive Problems

Inflammation in the esophagus, stomach, pancreas, and liver can cause problems like painful swallowing, heartburn, abdominal pain and swelling, loss of appetite, diarrhea, and weight loss. It can also cause hepatitis (inflammation of the liver) and cirrhosis (hardening of the liver). Sjögren's is closely linked to a liver disease called primary biliary cirrhosis (PBC), which causes itching, fatigue, and, eventually, cirrhosis. Many patients with PBC have Sjögren's.

Treatment varies, depending on the problem, but may include pain medicine, anti-inflammatory drugs, steroids, and immunosuppressants.

Connective Tissue Disorders

Connective tissue is the framework of the body that supports organs and tissues. Examples are joints, muscles, bones, skin, blood vessel walls, and the lining of internal organs. Many connective tissue disorders are autoimmune diseases, and several are common among people with Sjögren's:

Polymyositis is an inflammation of the muscles that causes weakness and pain, difficulty moving, and, in some cases, problems breathing and swallowing. If the skin is inflamed too, it's called dermatomyositis. The disease is treated with corticosteroids and immunosuppressants.

Raynaud's phenomenon, blood vessels in the hands, arms, feet, and legs constrict (narrow) when exposed to cold. The result is pain, tingling, and numbness. When vessels constrict, fingers turn white. Shortly after that, they turn blue because of blood that remained in the tissue pools. When new blood rushes in, the fingers turn red. The problem is treated with medicines that dilate blood vessels. Raynaud's phenomenon usually occurs before dryness of the eyes or mouth.

Rheumatoid arthritis (RA) is severe inflammation of the joints that can eventually deform the surrounding bones (fingers, hands, knees, etc.). RA can also damage muscles, blood vessels, and major organs. Treatment depends on the severity of the pain and swelling and which body parts are involved. It may include physical therapy, aspirin, rest, nonsteroidal anti-inflammatory agents, steroids, or immunosuppressants.

Scleroderma causes the body to accumulate too much collagen, a protein commonly found in the skin. The result is thick, tight skin and damage to muscles, joints, and internal organs such as the esophagus, intestines, lungs, heart, kidneys, and blood vessels. Treatment is aimed at relieving pain and includes drugs, skin softeners, and physical therapy.

Systemic lupus erythematosus (SLE) causes joint and muscle pain, weakness, skin rashes, and, in more severe cases, heart, lung, kidney, and nervous system problems. As with RA, treatment for SLE depends on the symptoms and may include aspirin, rest, steroids, and anti-inflammatory and other drugs, as well as dialysis and high blood pressure medicine.

Vasculitis is an inflammation of the blood vessels, which then become scarred and too narrow for blood to get through to reach the organs. In people with Sjögren's, vasculitis tends to occur in those who also have Raynaud's phenomenon and lung and liver problems.

Autoimmune thyroid disorders are common with Sjögren's. They can appear as either the overactive thyroid of Graves' disease or the underactive thyroid of Hashimoto's. Nearly half of the people with autoimmune thyroid disorder also have Sjögren's, and many people with Sjögren's show evidence of thyroid disease.

Does Sjögren's Syndrome Cause Lymphoma?

About 5 percent of people with Sjögren's develop cancer of the lymph nodes, or lymphoma. The most common symptom of lymphoma is a painless swelling of the lymph nodes in the neck, underarm, or groin. In Sjögren's syndrome, when lymphoma develops it often involves the salivary glands. Persistent enlargement of the salivary glands should be investigated further. Other symptoms may include the following:

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

These symptoms are not sure signs of lymphoma. They may be caused by other, less serious conditions, such as the flu or an infection. If you have these symptoms, see a doctor so that any illness can be diagnosed and treated as early as possible.

If you're worried that you might develop lymphoma, talk to your doctor to learn more about the disease, symptoms to watch for, any special medical care you might need, and what you can do to relieve your worry.

Medicines and Dryness

Certain drugs can contribute to eye and mouth dryness. If you take any of the drugs listed below, ask your doctor whether they could be causing symptoms. However, don't stop taking them without asking your doctor--he or she may already have adjusted the dose to help protect you against drying side effects or chosen a drug that's least likely to cause dryness.

Drugs that can cause dryness include

- Antihistamines
- Decongestants
- Diuretics
- Some anti-diarrhea drugs
- Some anti-psychotic drugs
- Tranquilizers
- Some blood pressure medicines
- Antidepressants

What Research Is Being Done on Sjögren's Syndrome?

Through basic research on the immune system, autoimmunity, genetics, and connective tissue diseases, researchers continue to learn more about Sjögren's syndrome. As they get a better understanding of the genes involved and which environmental factors trigger disease and how, they'll be able to develop more effective treatments. For example, gene therapy studies suggest that we may someday be able to insert molecules into salivary glands that will control inflammation and prevent their destruction. Other research focuses on how the immune and hormonal systems work in people who have Sjögren's and on the natural history of the disease (learning how it affects people by following those who have it).

Researchers are also looking into the use of the salivary stimulant pilocarpine for dry eyes. Other researchers are testing immune modulating drugs to treat the glandular inflammation. A drug called cevimeline has recently been approved for treating dry mouth. Work on developing an artificial salivary gland is in progress.

The National Institute of Dental and Craniofacial Research is conducting several studies on Sjögren's syndrome designed to help scientists better understand, manage, and treat the disease. Some focus on the disease's natural history, while others test potential new treatments. Talk to your doctor if you'd like more information about these clinical trials.

Where Can People Find More Information About Sjögren's Syndrome?

The following organizations have information relevant to Sjögren's syndrome:

Professional Groups

American Academy of Dermatology

930 N. Meacham Road

Schaumburg, IL 60173
Phone: 847-330-0230 or 888-462-3376 (free of charge)
www.aad.org

American Academy of Ophthalmology
P.O. Box 7424
San Francisco, CA 94120
Phone: 415-561-8500
Fax: 415-561-8567
www.eyenet.org

American Association for Dental Research
1619 Duke Street
Alexandria, VA 22314
Phone: 703-548-0066
Fax: 703-548-1883
www.iadr.com

American College of Rheumatology
1800 Century Place, Suite 250
Atlanta, GA 30345
Phone: 404-633-3777
Fax: 404-633-1870
E-mail: acr@rheumatology.org
www.rheumatology.org

American Dental Association
Department of Public Information and Education
211 East Chicago Avenue
Chicago, IL 60611
Phone: 312-440-2500
Fax: 312-440-2800
E-mail: publicinfo@ada.org
www.ada.org
Government Agencies

National Eye Institute
National Institutes of Health
2020 Vision Place
Bethesda, MD 20892-3655
Phone: 301-496-5248
www.nei.nih.gov

National Institute of Allergy and Infectious Diseases
National Institutes of Health
Building 31, Room 7A-50
31 Center Drive, MSC 2520
Bethesda, MD 20892
Phone: 301-496-5717
Fax: 301-402-0120
www.niaid.nih.gov

National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675
Phone: 301-495-4484 or
877-22-NIAMS (226-4267) (free of charge)
TTY: 301-565-2966
Fax: 301-718-6366
www.nih.gov/niams

National Institute of Dental and Craniofacial Research
National Institutes of Health
45 Center Drive, MSC 6400
Building 45, Room 4AS-25
Bethesda, MD 20892-6400
Phone: 301-496-4261
E-mail: nidrinfo@od31.nidr.nih.gov
www.nidcr.nih.gov
National Institute of Dental and Craniofacial Research
National Institutes of Health
Sjögren's Syndrome Clinic
10 Center Drive, MSC 1190
Building 10, Room 1N113
Bethesda, MD 20892-1190
Phone: 301-435-8528

National Institute of Neurological Disorders and Stroke
National Institutes of Health
Office of Communications and Public Liaison
P.O. Box 5801
Bethesda, MD 20824
Phone: 800-352-9424 (free of charge)
www.ninds.nih.gov
Consumer and Patient Groups

American Autoimmune Related Diseases Association, Inc.
22100 Gratiot Avenue
E. Detroit, MI 48021
Phone: 810-776-3900
E-mail: aarda@aol.com
www.aarda.org

Arthritis Foundation
1330 West Peachtree Street
Atlanta, GA 30309
Phone: 800-283-7800 (free of charge) or

call your local chapter (listed in the telephone directory)
www.arthritis.org

Fax: 602-516-0111
E-mail: NSSA@aol.com

Lupus Foundation of America
1300 Pickard Drive
Rockville, MD 20850
Phone: 301-670-9292
Fax: 301-670-9486
www.lupus.org

Scleroderma Foundation
89 Newbury Street, Suite 201
Danvers, MA 01923
Help Line: 800-722-HOPE (722-4673) (free of charge)
Phone: 978-750-4499
Fax: 978-750-9902
E-mail: sfinfo@scleroderma.org
www.scleroderma.org

Myositis Foundation of America
755 Cantrell Avenue, Suite C
Harrisonburg, VA 22801
Phone: 540-433-7686
Fax: 540-432-0206
E-mail: maa@myositis.org
www.myositis.org
National Organization for Rare Disorders
100 Route 37, P.O. Box 8923
New Fairfield, CT 06812-8923
Phone: 203-746-6518 or 800-999-6673 (free of charge)
TDD: 203-746-6927
E-mail: orphan@nord-rdb.com
www.rarediseases.org

Scleroderma Research Foundation
2320 Bath Street, Suite 315
Santa Barbara, CA 93105
Phone: 805-563-9133 or
800-441-CURE (411-2873) (free of charge)
Fax: 805-563-2402
E-mail: srfcure@srfcure.org
www.srfcure.org

National Sjögren's Syndrome Association
5815 North Black Canyon Highway, Suite 103
Phoenix, AZ 85015
Phone: 602-433-9844 or 800-395-6772 (free of charge)

Sjögren's Syndrome Foundation
366 North Broadway
Jerhico, NY 11753
Phone: 516-933-6365 or 800-475-6473 (free of charge)
Fax: 516-933-6368
E-mail: ssf@sjogrens.org
www.sjogrens.org

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