

# Sjögren's Syndrome Self-Help

*Tips for more  
comfortable living.*

Sjögren's  
Syndrome  
SF  
Foundation



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Tips for more comfortable living

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Sjögren's Syndrome Foundation

*Dedicated to all Sjögren's Syndrome Foundation members especially Elaine Harris, our founder.*

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*Steven Taylor*



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## INTRODUCTION

The Sjögren's Syndrome Foundation is proud to provide the Sjögren's Syndrome Self-Help booklet. This is the third edition of this helpful publication, updated to include the latest tips.

I encourage you to use this booklet as a first step in expanding your knowledge about how to live with Sjögren's syndrome. As you will see over the next few pages, numerous tips, suggestions and ideas for everyday life are outlined.

The Foundation understands the challenges of living with Sjögren's syndrome and that is why we continue to focus on providing resources that will help patients live with their disease. We have over 75 support groups in the United States, offer three patient conferences a year and continue to support life-changing research.

I would like to thank Dona Frosio, author of the Sjögren's Syndrome Self-Help booklet, and our publications committee for once again putting together a wonderful resource. For a listing of the Foundation's additional programs and services, please visit [www.sjogrens.org](http://www.sjogrens.org).

As the only national organization focused on Sjogren's syndrome research, education and awareness, the Sjogren's Syndrome Foundation is dedicated to helping make a difference for all Sjögren's patients.

*Steven Taylor  
Chief Executive Officer  
Sjögren's Syndrome Foundation*

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## PREFACE TO THE THIRD EDITION

After many years of dealing with lupus, I suddenly found myself facing a new diagnosis of Sjögren's syndrome.

I had read extensively on lupus and had come across "Sjögren's" occasionally in the lupus literature. This still hadn't prepared me for all the new challenges that Sjögren's would bring my way.

Several years ago I started gathering information by reading, searching the internet, attending support group meetings and speaking with others who were successfully coping with Sjögren's syndrome. Then my doctor asked me to write down the things that I found helpful so that he could share these with his other patients. The result was this little booklet.

In no way is this booklet meant to replace the advice of your physician. I merely offer some ideas and products that have helped me. The Sjögren's Syndrome Foundation (SSF) has prepared a comprehensive list of products frequently used by people with Sjögren's syndrome and I encourage you to review that.

In addition, I also refer you to *The New Sjögren's Syndrome Handbook* and *The Sjögren's Syndrome Survival Guide* for more in-depth information on the many aspects of Sjögren's syndrome.

So enjoy this third edition of the *Sjögren's Syndrome Self-Help!*

*Dona Frosio*



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## EYES

As you all know, dry eyes are common among Sjögren's patients. Living with them on a daily basis can be a struggle and that is why I wanted to share with you some things I have learned along the way.

### **drops and treatments**

Many brands of eye drops are available, as you can see when you visit any pharmacy or grocery store. I recommend that you check with your eye care provider who can suggest a particular brand for your severity of dry eye. He might also give you samples to try so that you don't have to waste money purchasing all different types. I warn you that it may take trying several products until you find one that works best for you.

The two basic kinds of drops are bottled drops that contain a preservative and preservative-free drops that come in single dose vials. Additionally, there are drops and gels that have a preservative that disappears when it comes in contact with your eye. Check with your eye care provider about what type is best for you but most patients are told to use preservative-free drops.

Remember that ointments and gels tend to blur your vision and are usually reserved for overnight use. Some people find great success using them before bed and others choose to use regular drops before going to sleep and again if they wake during the night.

Another product on the market is Lacriserts®, small dissolvable cellulose pellets that fit into your lower eyelids. I have found them extremely helpful as they freed me from using drops for most of the day. I encourage you to talk to your eye care provider about them since they require a prescription.

The newest prescription product for dry eyes is Restasis®, cyclosporine eyedrops. Restasis® doesn't work immediately; it takes time to make a difference. I encourage you to stick to the treatment and work with your eye care provider, as he will monitor its success. The biggest complaint is

a burning sensation after application. This usually subsides after using the product for a period of time, so I encourage you to stick it out. I also have heard that keeping Restasis® in the refrigerator can help alleviate some of the burning. This also works with making over-the-counter eye drops feel even more soothing.

Finally, punctal plugs inserted into the tear ducts will keep moisture on your eye by preventing natural and artificial tears from draining down your nose. Most people with plugs love them and, if done properly, the plugs are comfortable.

### **glasses, goggles, etc.**

Most glasses will give some measure of protection from air currents that might irritate your eyes. Frames without separate nose pieces are better for keeping the air away from your eyes when you walk. Wrap-around sunglasses provide outdoor comfort and there are brands that fit against the face with foam such as Onion Goggles (available from stores that carry kitchen items) and Panoptx® windless eyewear, which keep out the wind and debris. Although expensive, they may be just what you need to enjoy being outdoors. Another alternative is safety glasses which I found at Home Depot for less than \$10.00. Swim goggles do a good job too although wearing them might not be the fashion statement some of us really like to make.

Moisture chamber glasses are another product that might offer the dry eye sufferer great relief. The glasses are made up by an optician who orders the clear panels from suppliers like EagleVision®. The panels are attached to your regular glasses and trap moisture like goggles. Since the glasses are made individually for each person, they take time and can be costly but those who have used them have found they work well.

Another product that can help protect eyes at night and during the day while napping or resting (since you cannot see through them) is Tranquileyes™, flexible nighttime goggle-like eye shields. Tranquileyes™ have a sponge insert that you can soak in water if you want before you put them on. They were designed to keep the moisture around your eye while you sleep.

Running a humidifier or vaporizer at night can help with not only nighttime eye dryness but also with mouth and nose dryness.

### **blepharitis**

Blepharitis is very common and many people with Sjögren's experience this condition. Your eye care provider can help you treat this condition and give you some tips as well. And treat it you should.

Blepharitis is a chronic inflammation of the eyelids which causes irritation, itching, and occasionally a red eye. Glands that make tenacious secretions are located along the base of the eyelids. In some patients with dry eyes, the tenacious secretions plug the openings of the gland. This can lead to low grade chronic inflammation and bacterial infection resulting in pain and swelling of the lower eyelids.

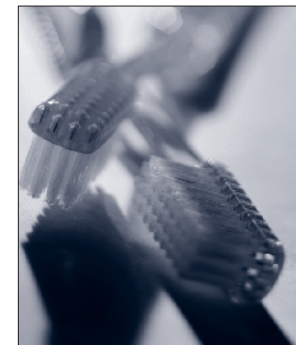
Blepharitis is common in patients with dry eyes and may be exacerbated by use of eye drops containing preservatives or extended wear of contact lenses. Also, use of excessive amounts of ocular lubricant can plug the glands and contribute to the problem.

Again, I encourage you to follow your eye care provider's advice. My ophthalmologist has prescribed a product to treat it and has also suggested using a little baby shampoo and a warm wash cloth on the eyes a few times a day. In addition, there are a few sterile eyelid cleansers and individually packaged eyelid scrubs on the market, so you may want to consider using them as well.

### **fish oil and other supplements**

First and foremost ALWAYS inform your care provider when adding any over-the-counter items to your diet. This includes vitamins!

Extensive discussion has taken place about adding fish oil and Omega 3's to the diet. Some research has shown an improvement in the quality of tears that people produce after using these products. You can find products on the market that include these items or you can add them to your diet by buying specific additional supplements. Check near the artificial tears in the store or look for specific products in the vitamin section.



### **M O U T H**

Dry mouth is a major symptom of Sjögren's syndrome. Living with dry mouth can be challenging and I have met many patients who use all

different types of treatment options, so I will do my best to list some of the most common in this section.

First, however, I must stress that good regular oral hygiene is a must! Most Sjögren's patients no longer produce sufficient quantities of protective saliva. Not only can that make our mouths feel dry, but also our teeth can be damaged. Most people don't realize the protective value of saliva. They think it's just moisturizing their mouth, when in reality it's helping to recoat their teeth with important minerals that will slow down cavities and infection. Without saliva, you have a higher chance of infections and quick moving cavities.

Second, I encourage you to ask your dentist to be your partner in preventing oral problems. Your dentist can instruct you how to brush and floss properly and remind you when you are due for checkups. He can also prescribe fluoride gel for you to use at home as well as instruct you how to stimulate saliva.

Some dentists will encourage you to chew sugar-free gum or suck on a sugar-free candy to stimulate saliva. Others will encourage you to sip water throughout the day. Remember not to over sip since you will wash away the good saliva you are producing and lose the benefits from that saliva. Some dentists will tell you not to drink bottled water as your tap water may contain the extra fluoride protection you need.

Also there are some great new products that include mouth moisturizers, gels, sprays and specialized mouth washes for dry mouth patients. I encourage you to try these products because they all have different benefits and I am confident you will find one that you will like. It may take some trial and error but rest assured, once you find a product, you'll be in love with it.

Prescription products which treat dry mouth by stimulating more saliva in patients with Sjogren's syndrome are Evoxac® (cevimeline HCl) and Salagen® tablets (pilocarpine). You can ask your dentist or rheumatologist about the benefits and side effects of each product. Many patients find great dry mouth help from them and some patients even find that they help stimulate tears.

Below are a few tips on how to survive your next dental visit. The list was developed by a fellow Sjögren's patient who also happens to be a Registered Dental Hygienist.

- *Carry your throat spray or favorite rescue moisturizer with you.*
- *Alert the dental personnel that your dry mouth necessitates some extra consideration.*
- *Take control of the suction so you use it only when you need it.*

- *Ask for a spritz of water to rinse your tongue when they rinse off the place they are working (at least my dry mouth patients really like this).*
- *Arrange for some little signal at the beginning of the appointment so you can let them know if you need to take a break.*
- *Bring sun glasses if the lights might bother your eyes and use your moisturizing drops right before they call you into the exam room.*
- *Get plenty of rest the night before to increase your ability to cope!*
- *Have more frequent dental hygiene visits.*

Finally, remind your rheumatologist about your dry mouth problems. He can review your list of medications to see if any of them are causing dry mouth side effects as well as consider other options to help with salivary function.



## N O S E

Nasal dryness varies from person to person. My stuffy, runny, dry nose bothered me most when I tried to sleep. If you have nasal problems, discuss them with your physician. While not everything that goes wrong in your body is Sjögren's related, some things are.

Saline spray is generally considered safe and gives a lot of relief, albeit for a short duration. There are many brands on the market, or your allergist may be able to give you instructions for making your own. There are also saline nasal gels which helped me clear up the nasal sores I used to get from dryness.

I found that nasal lavage gives me the longest lasting relief. I do it at least once a day, and my nosebleeds have stopped since I have been using this method. My allergist gave me instructions for lavage and they are included below.

Instead of using a bulb syringe, you may prefer using a sinus rinse

bottle such as NeilMed®. I use the bottle and make my own solution from the recipe below. Waterpik® also makes an attachment tip for sinus rinse. Don't forget that a humidifier not only relieves nasal discomfort but also may help with other dryness problems too.

Below is the salt water nose rinse method as supplied by Kaiser San Diego, Allergy Department:

### nasal irrigation with bulb syringe

Materials needed:

1. Soft vinyl bulb syringe 2 to 3 oz. capacity. Purchased for about \$3.
2. Salt water solution
  - 1 cup body temperature water (lukewarm)
  - ¼ teaspoon table salt
  - ¼ teaspoon baking soda

Directions for use:

1. Fill bulb with salt water.
2. Place face directly over a sink and look straight down at the sink.
3. Place tip of bulb just inside of one nostril and squeeze the bulb gently. The salt water will fill the nostril and then go through a hole in the back of the nose and run out of the other nostril. If you are facing directly down toward the sink the water will not run down your throat. Do not force the salt water. Stop if there is significant pain.
4. Repeat the procedure on the other nostril using remaining solution.
5. This procedure may be repeated as often as it is helpful (2 to 3 times a day).
6. If steroid nose sprays are also used, apply after rinsing.

## EARS

Of all the problems with dryness, itching ears has been the easiest to deal with. One drop of earwax remover or mineral oil stops my problem for a week at a time. However, I caution you to check with your physician to see if you have another problem such as an infection in addition to Sjögren's. It's always important to remember to share any symptoms you are having with your physician so that they can have a complete picture of your disease.



## SKIN

Sjögren's is a disease that produces dryness in many areas of our bodies. It is not surprising that we have very dry skin as well. Your dermatologist can be your best ally and may be able to give you samples of products to try. Here are some basic survival tips that may help:

- Use gloves when you are using strong soaps or chemicals to clean. One way to get in the habit is to keep a pair of gloves in several areas, i.e. kitchen, bathroom, garage.
- Terry robes will dry you gently.
- Use warm, not hot, water for bathing and use soap sparingly. Apply lotion as soon as possible to seal in moisture.
- Shampoo might be drying to the rest of your body in the shower.
- Use sunscreen when you are going to be outdoors. Consider investing in sun protective clothing or try using SunGuard® which can be washed into regular clothing in the washing machine.
- When getting out of the shower, let yourself dry naturally since the moisture from the water will be absorbed by your skin.

## VAGINA

Vaginal dryness can be caused by Sjögren's as well as by other conditions such as menopause. No matter what the cause, if you are experiencing it, talk to your gynecologist. He can help discuss various options with you and help you make a decision as to the best treatment. Often an over-the-counter lubricant such as K-Y® Jelly, Astroglide®, Replens® or Feminease® may be all you need.

Hormones are a controversial topic and it is a personal choice. You will have to weigh the pros and cons with your gynecologist. Don't be afraid to bring up the subject. You know what you are experiencing.



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## SALIVARY GLANDS

Your salivary glands are affected by Sjögren's syndrome. Sometimes they may hurt, especially the parotid glands located in the front of your ears. *The New Sjögren's Syndrome Handbook*, 2nd edition, page 187, had instructions for massage if a plug of mucus is the problem:

"Gently massage the area just below the bottom of the earlobe with the fleshy part of your index and middle fingers. Go forward toward the end of the jawbone, slightly downward and over the jawbone, and then up again toward the tip of the earlobe. This sometimes helps to dislodge a mucous plug in a duct, relieving the pain caused by a blockage."

I also get pain relief by using a warm rice bag. Just microwave a minute or two and apply to the face. You can buy these or make one. The one I made is about 6" wide by 15" long. A long tube sock will also work and will take about two cups of rice (plain, uncooked and not instant!) Great for sore joints and muscles too. Remember to test the temperature as every microwave is different.

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## PERIPHERAL NEUROPATHY

My burning, hurting, numb feet and hands have bothered me for years but it was only recently that I received the diagnosis of peripheral neuropathy (PN). I have attended support group meetings and learned some things to help deal with the discomfort. I think my experiences and suggestions (listed below), may be of value to you. I am not saying all the pain disappears, but you may be able to be a bit more comfortable. Treating the underlying disease, Sjögren's syndrome, will often lessen the problem of peripheral neuropathy too.

The biggest change I made was my shoes. I found that with shoes that accommodated thick fluffy socks I felt a lot less pain. My personal favourite is SAS® brand, Free Time with Thorlos® walking socks. Wearing socks all the time was really a new concept for me too. I thought wearing even 100% cotton light-weight socks at night would make my feet hotter, but they didn't and even made me more comfortable. Some people get relief from wearing tight socks. Mild support knee highs might be worth a try and I found these the most helpful.

If my feet are really hurting, I first try soaking them for a while in really cool water. I then try to talk my husband into massaging them for a few minutes before I go to bed since this seems to be my worst time of day.

Neutrogena® Foot Cream works well for massage and is really good for dry skin too. The massage often gives me several hours of relief. If anyone needs convincing, just read what the Mayo Clinic says, "A massage helps improve circulation, stimulates nerves and may temporarily relieve pain."

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## WELLNESS

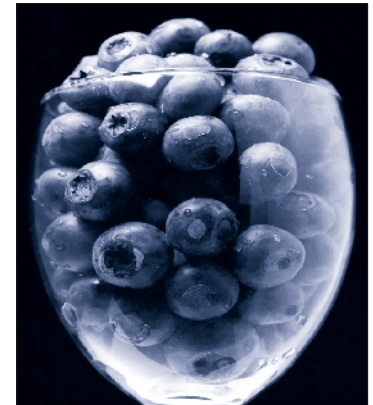
Now is the time to look at your overall health. Improve your lifestyle and ask your doctor to help with suggestions for improving the total you. Start practicing wellness behavior.

Every one of us can benefit from some form of exercise; even simple range of motion exercises will help. Videos and DVDs abound. The Arthritis Foundation offers P.A.C.E. classes at many different locations and many patients find great luck with water aerobics which are easy on your joints.

I love the gentle, stress-lowering exercise, Tai Chi. Yoga helps my back, breathing and general sense of well-being.

Remember: there is something for everyone. You'll be amazed at how much better exercise will make you feel, mentally as well as physically. Be sure to talk to your physician or consult with an exercise specialist to find out what is best for you.

Don't forget the importance of good nutrition for general health and wellness.




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## DIET

Your physician will tell you if you need a special diet. If not, most of us can safely follow the diet guidelines of The American Heart Association (<http://www.americanheart.org>) or The American Cancer Society (<http://www.cancer.org>).

Many patients have special dietary needs such as:

- *Avoiding spicy foods*
- *Choosing soft, smooth items*
- *Avoiding alcohol and wine*
- *Avoiding acidic juices, fruits and vegetables*

In a small number of cases, persons with Sjogren's are also diagnosed with celiac disease and must eat only gluten-free foods.

Check with your physician for other suggestions but also listen to your own body. Do what feels right. Not everyone has the same issues with food, so eat what you can tolerate and avoid those items you cannot.

Note: alcohol dries the mouth, and spicy foods and fruit acids tend to irritate those with dry mouth.

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## FOOD

Dryness can affect what we eat in many ways. Certain foods may irritate your mouth while other foods may need lots of liquid to make them go down.

Here are some ways to help with chewing and swallowing:

- *Moisten foods with mayonnaise, sauces, gravies, yogurts, or salad dressing. Try dipping dry foods into whatever you're drinking.*
- *Soften or thin foods with skim milk, broth, water, or melted margarine. Use your food processor or blender to finely chop or liquefy foods.*
- *Use a straw if it helps you swallow. Sip your drink while eating.*
- *Add soup with your sandwich.*
- *Add cucumbers to a sandwich to add moisture*

If it hurts to eat:

- *Try smooth, soft, creamy foods like soup, macaroni and cheese, mashed potatoes, casseroles, tender cooked vegetables, canned fruits, pudding, cheesecake, ice cream, and even tender cooked and simmered meats.*
- *Drink high-calorie, cold liquids such as milk shakes, instant breakfast drinks, or liquid nutritional supplements for both calories and ease in eating.*

- *Suck on fruit juice popsicles, ice chips, or other cold foods to help reduce the pain.*
- *AVOID salty, acidic, or spicy foods, or carbonated drinks that prolong pain.*
- *AVOID hot foods. Room temperature meals are easier to eat.*
- *AVOID hard, crunchy foods such as tough or crisp meats, dry snack foods, crusty bread, popcorn, or nuts since they can be irritating.*

When dining out, don't be shy about asking your waiter for help. Most will ask the cook if an item contains lots of pepper or other hot spices. (I always figure that deserves a larger tip.)

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## EMERGENCY FOOD

When it comes to food, the dry mouth of Sjogren's syndrome is not the only thing that many of us have to worry about. GERD, celiac disease, allergies and lactose intolerance, to name a few, can compound the problems of finding something you can eat when away from home. Here are some of my ideas about preparing for a day out, a trip or a quick errand.

When I travel I always carry some "emergency food." For example, I always carry instant oatmeal in its own container. This will take care of breakfast, lunch or dinner for me. Shelf stable soymilk completes my sumptuous feast. If there is any soymilk left over from the little 8 oz. container, I can store it in the little fridge in the room. You could also take oatmeal in the little packets but don't forget to pack a bowl. Something else that can be fixed easily is instant soup. There are many varieties that are mouth friendly and come in their own containers. Macaroni and cheese in the single serving size is doable if you use a little extra boiling water and let it sit longer. Here again, don't forget your bowl.

I also pack those little single servings of fruit such as applesauce. The pop-top, individual cans of fruit also make a great dessert. Pudding in individual serving containers is another nifty food to bring. Meal replacements in a can such as Ensure are good and certain protein bars are ok if I have something warm to wash them down with. Of course fresh fruit, like bananas, is nice and portable for the first day or so. Most airports seem to have some vendor that sells them and although pricey, I'm worth it.

I also get individual bags of baby carrots at a local grocery store near me. You could also peel and cut up your own and put them in plastic bags perhaps with some celery if you like that too. Refrigerate leftovers and

they should last several days. I make up my own trail mix using the fruits and nuts that I'm not allergic to. I carry some on the plane with me and pack the rest in my check-in bag.

For all the foods that require hot water, run a few pots of plain water through the coffee maker to clear out some of the old flavors. If you have the room in your baggage, a better solution is taking along a hotpot. This appliance is inexpensive, lightweight and packs easily. You can also fill it with supplies so space isn't wasted. A little immersion heater you put in a cup will also work. I bring my own tea bags with me so I really appreciate water not having coffee overtones.

I have mentioned all of my emergency foods but since your particular needs may differ, start looking at the grocery store with your travel plans in mind. I would rather enjoy my destination and not worry about finding something I can eat while there.



## SURGERY

Surgery is scary time for any of us, but when you have Sjögren's syndrome, there are some things you should know. I encourage you to share these pages with both your surgeon and the anesthesiologist to open a dialogue about surgery and your special needs. I also want to thank the Jefferson Rheumatology Associates for providing us with this great information.

### patient responsibility

- Before surgery, remind all of your doctors and nurses that you have Sjögren's syndrome, and share this information sheet with them.
- Give your providers a list of all medications you use, including non-prescription treatments such as eye and mouth lubricants, vitamin E, and anti-inflammatories (Advil®, Motrin®, etc.)

- Bring an adequate supply of your favorite tears, artificial saliva, and other treatments with you to the hospital or surgicenter on the day of your operation in case these cannot be provided to you.
- To ensure your safety and comfort, inform your providers of any arthritis-related problems, particularly those involving the neck, jaw, or back.
- Discontinue blood thinners such as vitamin E and aspirin at least two weeks before surgery; discontinue anti-inflammatories (e.g., Motrin®) at least 72 hours before surgery (unless instructed otherwise by your physician).
- Inform your healthcare providers if you suffer from Raynaud's phenomenon.

### medical provider information

- The most common postoperative problems in Sjögren's syndrome patients include corneal abrasions, sore throats, dysphagia, and flares of sicca symptoms.
- If indicated, patients using vitamin E regularly should discontinue this treatment two weeks prior to surgery as it may have an anticoagulant effect.
- Patients on chronic steroids should receive perioperative stress doses of steroids until clinically stable.
- On the day of surgery, patients should be instructed to continue their usual eye/oral care and medication regime. Eye drops should be ordered before and after surgery per the patient's routine. During surgery, the eyes should be lubricated every 30 minutes and taped gently, avoiding pressure.
- A humidifier should be added to the rebreathing system.
- Intubation may be difficult if the rheumatic disease involves the cervical spine or temporal mandibular joints. Endotracheal tubes and LMAs should be well lubricated and placed carefully. A dental guard may be necessary to protect carious teeth.

### special nursing information

- Before surgery, patients' eyes, mouth, skin, and mobility should be assessed. Continue routine oral and eye care.
- During surgery, observe careful movement and positioning of patients. Allow patients to transfer and position themselves if

possible. Keep the operating room warmer than usual due to patients' susceptibility to Raynaud's phenomenon.

- After surgery, humidified oxygen should be used. The status of patients' eyes and mouth should be assessed. Eye care should be resumed per the patient's routine. Patients should be allowed ice chips, liquids or artificial salivas as soon as possible.

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## BOOKS & PUBLICATIONS

I have found great information from reading books on Sjögren's syndrome and my various symptoms. In addition, I have purchased books to present to my physicians so that they can understand my disease. *The Sjögren's Syndrome Handbook* has been my greatest purchase and my physicians have found this book to be very helpful as well.

In addition, the Sjögren's Syndrome Foundation's monthly newsletter, *The Moisture Seekers*, has also been a great place to find information. This newsletter is full of helpful tips, articles from physicians as well as updated events and conferences held by the Foundation. Recently, the Foundation introduced a second newsletter called the *Sjögren's Quarterly* written for healthcare professionals and researchers on the latest information in Sjögren's syndrome. It is the only solely dedicated professional journal on Sjögren's syndrome but patients can obtain it as well.

Contact the Foundation to find out more about these two publications as well as for a listing of the books on Sjögren's syndrome and its various manifestations. You can more information at their website at [www.sjogrens.org](http://www.sjogrens.org) or by calling them at 800-475-6473.



Sjögren's Syndrome Foundation  
6707 Democracy Boulevard • Suite 325  
Bethesda, Maryland 20817

Phone: 301.530.4420 • Fax: 301.530.4415 • [www.sjogrens.org](http://www.sjogrens.org)