

The Moisture Seekers

Sjögren's Syndrome Foundation



www.sjogrens.org

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 SjogrensSyndromeFoundation

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Living with Sjögren's

by Darlene F. Cross, MS, LMFT

A patient has an illness, but a person has a life. For some of us, including many if not most Sjögren's patients, keeping a healthy balance between the two can be a demanding and relentless job. Realistically working to understand what we are each similarly and uniquely facing is the first step to managing the challenges, instead of letting the challenges manage us.

Logically much of our attention is focused on the medical aspects of our illness, from the scavenger hunt of finding good answers, to putting together an effective healthcare team, to executing the treatment plan. The medical costs of illness are tangible, measurable, often helpful and sometimes not. What seems to get lost all too often is what is not tangible or easily measured, namely the emotional expense of living with chronic illness. While emotions did not cause the illness, they have a lot to say about how we live with it.

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You Don't Look Sick! How Do you Respond to this Comment?

by Janet Church, Entrepreneur, tech-industry veteran,
Sjögren's patient and Chair-elect of the SSF Board of Directors

We've all heard it... *You don't look sick.* When you live with an autoimmune disease, this comment is common. How do you react and then respond?

There are times when I'm happy to hear this comment and times when I'm displeased. I do have a prepared response for this

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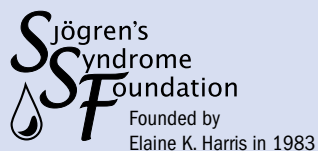
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Losses from Chronic Illness

Time spent in waiting rooms and medical appointments is time lost forever. Gone is the money used for treatments and drugs that may or may not help. How did you lose your identity as a person to instead become your diagnosis, your date of birth, or the last four digits of your Social Security number? Do you find yourself getting excited during times when you feel better only to become discouraged when the improvement is lost once again? As you think through your own history and your own losses, how much did you think about the experiences you had compared to how you felt about them?

Losses can be primary as with a diagnosed illness, or they can be secondary as with losses that occur as the result of the primary loss. For example, a primary loss may be an illness that includes debilitating musculoskeletal pain that makes sitting for long periods of time problematic. A secondary loss in this situation would occur if a job or career requires sitting, but the illness makes it necessary to now work less, maybe have less income, or even be forced to give up a needed and valued job or career. Another example would be an illness with crippling fatigue that demands frequent and long periods of rest. A secondary loss in this case would occur if a love of travel is curtailed with fewer and shorter trips, trips compromised in favor of naps over sightseeing, or no trips at all. Understanding loss from this perspective helps to provide clarity as to why the task of dealing with losses caused by illness is so difficult—the illness is never the only loss.

Losses from Sjögren’s

Sjögren’s has a way of standing out in the crowd of autoimmune diseases as the mystery guest at the family reunion. It’s hard enough to live with a chronic illness, but having one that many people have never heard of makes Sjögren’s even more difficult. Say you have Lupus and hear the groan of condolences and war stories of other Lupus patients; say you have Sjögren’s and wait for the confused reaction, and maybe well-intentioned wishes that you feel better soon. How frustrating to have different doctors contradict one another on diagnosis, as can happen too often for Sjögren’s patients. Even recommendations from vitamins to medications to diet vary, with my all-time favorite of being told to eat more blueberries.

Sjögren’s is a family affair, affecting everyone in the house. How do you explain to your loved ones who may be struggling to understand what is happening, when sometimes even we don’t understand it ourselves? How do they explain it to people around them? The patient is not

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You Stood Up!

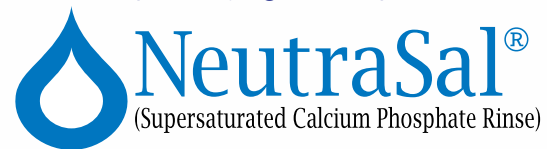
SSF Members Stand Up Around the Country

As we enter into the fall and gear up for a new year of events, the Sjögren's Syndrome Foundation would like to thank everyone who stepped up by attending, volunteering or donating to one of our events over this past year! The Foundation's success is a direct result from you, our amazing volunteers and supporters. Thank you for being a part of our journey to transform Sjögren's and develop new therapeutics to treat this debilitating disease.

The SSF 2017 – 2018 National Event Calendar will be released shortly, but below is a look back at last year's SSF National Events:

- Cycle for Sjögren's – Chico, CA
- Comedy Night – Harrisburg, PA
- Vermont Trail Run – Burlington, VT
- Team Sjögren's Denver – Denver, CO
- Northern Virginia Sip for Sjögren's – Herndon, VA
- Houston Walkabout – Houston, TX
- Los Angeles Sjögren's Education Lunch – Beverly Hills, CA
- Phoenix Walkabout – Phoenix, AZ
- National Patient Conference and Walkabout – Cherry Hill, NJ
- Team Sjögren's Nashville – Nashville, TN
- Tastefully Georgia – Atlanta, GA
- Philadelphia Walkabout – Philadelphia, PA
- Northeast Ohio Walkabout – Parma, OH
- New York City Sip for Sjögren's – New York, NY
- Dallas Walkabout – Dallas, TX
- Denver Walkabout – Denver, CO
- Greater Washington Walkabout – Bethesda, MD
- Raleigh-Durham Sip for Sjögren's – Raleigh, NC

Thank you to our National Walkabout & Sip for Sjögren's Sponsor





And a special thank you to everyone who achieved our "Sjögren's Star" status by raising over \$1,000 for an SSF Walkabout! View our Sjögren's Stars on www.sjogrens.org.

“You Don’t Look Sick” continued from page 1 ▼

statement, but it doesn’t always fit my emotional or intellectual needs at the time. I hear the comment often enough (and I know you do as well) that I thought it a worthy topic to explore. My hope is that this article gives you ideas to help you craft your best response for any situation.

I believe there are a number of factors to consider when determining the best response to *You Don’t Look Sick*. Consider your:

1. Personality
2. Disease activity level
3. Emotional status
4. Time since diagnosis
5. Relationship to the person

Each time someone tells you that you don’t look sick, you need to examine your answers to all of these questions and ask yourself the ultimate question: *Why do I care?*

Why do I care?

The degree to which I care about the comment depends on how I’m feeling and who is saying: You don’t look sick.

As the Chair-Elect of the Sjögren’s Syndrome Foundation (SSF) a key reason I care is that I see it as an opportunity to educate people. Often times people are making the statement in awe — as if they can’t believe I can be so ill and still look pretty good. That’s an opportunity to educate.

As a Sjögren’s patient, I need to step through factors 2, 3 and 5 listed above in order to answer the question, “why do I care?” and then give the best response. Since I’m well versed in my personality and I’ve been diagnosed a long time, I don’t need to consider factors 1 and 4.

When I’m pleased to hear, You don’t Look Sick

Much of the time, I am so thankful that I don’t look like I feel. In my industry (technology) my age is already an issue, so looking as well as possible is important to my livelihood. I also value taking care of myself and being presentable. Being presentable to others gives them the impression that I’m handling my life well, which adds to my desire to appear competent and capable. So the fact that I don’t look like I feel helps me actually feel better!

When I’m unhappy to hear, You Don’t Look Sick

The first few years of my diagnosis, it hurt my feelings when friends would make this comment. Did they not believe me that I’m ill? Even some friends who have known me a long time could not understand a disease that couldn’t be cured and yet didn’t quickly progress to kill you (like cancer). When I hear the comment now, it is usually by new friends or acquaintances and it only hurts when I’m feeling very ill. I have learned to recognize that this feeling has more to do with my own sadness of having to deal with Sjögren’s than the other person’s comment.

There are also times when I simply don’t care when someone makes a statement. This is usually when a random person hears I’m ill, makes a comment, and I decide that a response simply isn’t worth my time. The comment is then out of my head in two seconds. We use enough energy taking care of ourselves, so why waste it when no impact can be made?

Factors to Craft your Response

I believe people have different reactions at any given time depending on the factors below. The trick is to craft a response that makes you feel good and that allows the other person to clearly hear you and feel good about receiving the information.

Your Personality

My nature is to be analytical and calm, with an ability to easily see another person’s perspective. If you’re into Myers-Briggs, I’m an ENTP (“THE DEBATER” personality). So it works well for me to consider the other person’s reason for making the comment and calmly offer a response. I am then available to discuss their questions, should they have any. But this is in line with my personality.

I have a friend with a few autoimmune diseases and her personality is all fire. She tends to approach people more aggressively and ask them how they would feel if they had an invisible disease and received that comment. She is happy to discuss specifics, but I imagine that her approach may close down the conversation. However, she feels good standing up for herself and the other person realizes their comment felt hurtful to her (and may to other people with an invisible disease). Her goal is to show the person that the comment is hurtful.

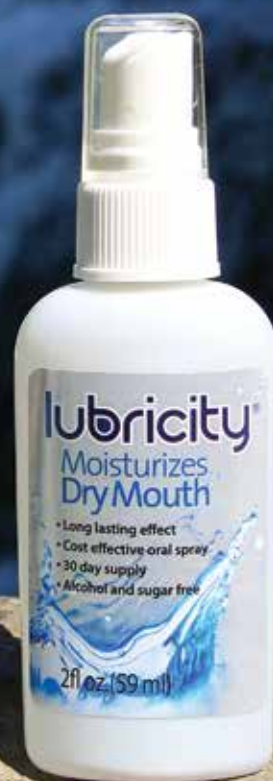
Our go-to responses to you don’t look sick are polar opposite. But our personality drives the approach.

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“Living with Sjögren’s” *continued from page 2 ▼*

the only one affected when plans must be altered or cancelled, or plans go on with a vital member of the family sadly absent.

Instead of giving falsely positive reports to protect the feelings of others, tell the truth about how you are doing and what you need. Honesty offers the potential to replace feelings of loneliness and helplessness for both the patient and loved ones, with a greater understanding, more empathy, and a sense of being a real team together—for better and for worse.

Quality of Life

I was at the doctor’s office for my regular visit going through the usual check-in procedures when the nurse asked me the dreaded question I knew was coming, “What is your level of pain today?” What was different this day from all the others? Had I been asked that same annoying question just one time too many? I’m sure I wasn’t her favorite patient of the day as I asked her exactly what she wanted me to describe since different places have different levels of pain and some have none. Out of my frustration I declared, “It’s the wrong question! The question should be, ‘what is your quality of life today?’”

While the level of pain question may be helpful to doctors, and even required by some insurance companies, it may not be so helpful to the patient. Focusing on, arguably, the most negative aspect of illness may leave the patient feeling more helpless, more powerless, maybe with no good solution in sight. On the contrary, we all know what our quality of life is. We know what makes it good or bad or what makes it

better or worse. When we can identify what is interfering with a good quality of life, it’s possible to begin to design a plan to diminish or remove obstacles within our power and build on the things that do work.

What is your quality of life today? If today is a good day, take notice of what makes it good and plan to do more. If today is not a very good day, what is getting in your way and is there something you can do to make it better, even if only a little bit? If something is causing you to have a poor quality of life right now, finding something that helps can allow you to regain some sense of power and hope in your own life. It can be as simple as buying a new book to read, calling a friend for a chat, coloring a picture with a child you love, or getting out of the house for your favorite ice cream.

Thriving Instead of Surviving

It is possible to live a successful life while dealing with chronic illness, but it doesn’t happen by accident or luck and no one does it alone. Here are some ideas that have helped others and may help you too, or spark some fresh ideas that you may not have considered before.

- Surround yourself with people you love and who love you. These are people who just make you feel better to be around them, people who listen, people who make you laugh. You feel energized just from being around them, so be around them often. Include quiet time for yourself when you need to recharge. Don’t forget to include the Sjögren’s Syndrome Foundation (SSF) crew as part of your support team.

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Dry Mouth Can Damage Your Teeth

Dry mouth creates an oral environment that favors bad bacteria which convert sugars from food into acids that can damage your teeth.

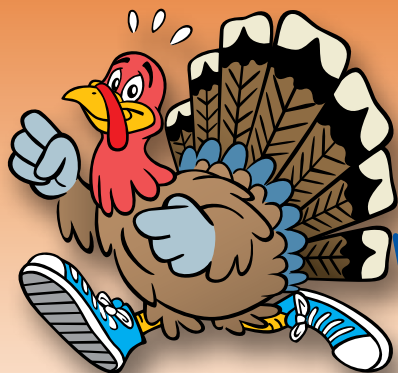
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A Single Kit Includes: \$35

- SSF Awareness Bracelet
- Team Sjögren's T-shirt, with Turkey Trot logo on the front!
- Certificate of Participation
- "What is Sjögren's?" Brochure
- SSF Reusable Shopping Bag
- 1 SSF Pin



A Two-Person Kit Includes: \$75

- 2 SSF Awareness Bracelets
- 2 Team Sjögren's T-shirts, with Turkey Trot logo on the front!
- 2 Certificates of Participation
- 2 "What is Sjögren's?" Brochures
- 2 SSF Reusable Shopping Bags
- 2 SSF Hats
- 2 SSF Pins

This Thanksgiving, we hope you will consider participating in your community Turkey Trot as a member of Team Sjögren's!

What a great way to start your day of giving thanks – by purchasing a Team Sjögren's Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren's and helping raise crucial funds for Sjögren's research.

We hope you consider creating your own Turkey Trot by asking family and friends to join you for a morning walk on Thanksgiving in your neighborhood while wearing your Team Sjögren's T-shirts! You can also find a local Turkey Trot by visiting www.active.com or in your local newspaper.

Order your Team Sjögren's Turkey Kit by calling 800-475-6473 or online at www.sjogrens.org. Additional T-shirts can be added to a Kit by calling the SSF office.

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Exp. Date _____ Security Code _____ Signature _____



“You Don’t Look Sick” continued from page 6 ▼

Your Disease Activity Level

I have Sjögren’s and sometimes I’m doing well and sometimes not so well. When I am more ill and hear the comment, I may wonder if the person doesn’t believe that I’m ill. Do they think that I am playing a victim role or using a “fake” excuse to get out of something? (I despise the idea that someone might consider me a victim). When I am very ill, I am also emotionally weaker, so these questions arise. These questions also arise if the comment is delivered with a tone that suggests disbelief.

When I’m feeling well, the comment tends to come from people who are curious and I launch into some education about Sjögren’s.

Do you notice a difference in your response depending on your disease level?

Your Emotional Status

Above I made a comment about being emotionally weaker when I’m in a relapse. But it is also worth considering the other emotional challenges in life when your disease is not acting up. When I’m feeling challenged emotionally, this comment feels like an additional emotional burden because of the underlying meaning it may have. Of course, our interpretation of the meaning behind the comment has a great deal to do with our own emotional status.

Recognizing my emotional status is more of a touch point for me as most of the time I tend to be “in my head.”

Time Since Diagnosis

If you have been diagnosed for less than three years, hearing you don’t look sick holds a bit more power than if you’ve been diagnosed for longer. So be sure to consider this in the formulation of your answers. Early on, your family members and close friends may make the statement and it’s an opportunity to educate them. Once they understand more, then they will make the comment less.

Your Relationship to Person

Is the person commenting a friend, a co-worker or an acquaintance? Some hold greater meaning such as family and close friends. Here are a few comments about different relationships.

Family: It’s important to remember that our family loves us and that they also hate that we are ill. They are also in a grieving process because they lost “the person they know and love.” Even though we are sick, I think we need to have empathy for their loss as well.

After diagnosis, it takes time to educate family about what your disease is and how you react to it. It is also important for them to know how you prefer to receive support and how you can give them support.

Friend: Frankly, some friends are able to make this journey with us and some are not. Be clear about who you can depend on and whom you can enjoy activities and conversations. Once you are clear on the friends you can depend on, then you need to dive deeper into your questions. Why are they asking? If a dependable friend is making a comment, they may need more education about the disease. Or perhaps they miss how the friendship used to be and you can mourn together.

Several years ago, I had asked one of my friends why she stated, You don’t look sick. We had a quality discussion about how I had been so Sjögren’s-focused that I had not been interested enough in her life. This was about two years after my diagnosis and helped snap me out of my self-focused grieving.

Casual Acquaintance: I simply choose to educate or ignore the comments depending on my energy and the impact I may have. If it is worthwhile, it is always beneficial to educate people.

My go-to response

I do have a response I use most often when people tell me, You don’t look sick. I deliver this statement with humor: “Thank God! You wouldn’t want to see that!”

In one quick, light-hearted answer, I believe I have educated the person that:

- A. I know I don’t look sick, but I truly am
- B. I am grateful that I don’t look as bad as I feel
- C. If they could see how bad I feel, it might make them uncomfortable!

I then can gauge their reaction and see if it is an opportunity to educate them on Sjögren’s. Perhaps with a bit of education they can show more empathy for those of us struggling daily with an autoimmune disease (or two, or four).



For more ideas from Janet about managing your daily life living with an autoimmune disease, visit her blog *Sjögren’s Life* at www.sjogrenslife.com. ■

in memoriam

In Memory of Abby Swanson

Juliette and Andreas
Kevin P. Ryan, DDS
Jill and Chris Hagan and Family

In Memory of Ann Martire

Debbie and Anthony Tampone

In Memory of Betty Billings

Alex, Aundia, Helen, Natalie,
Theresa, Zoe

In Memory of Cora Pavur

The Darryl Berger, Sr. Family

In Memory of Eileen Legg Wilkinson

Domenic and Terri Nepote

In Memory of Eve Black

Ana Jeftenic

In Memory of Ivan Hametz

Ellen and Jerry Reibstein

In Memory of Jack Wilder Beam, infant son of Chad and Elizabeth Beam

John McCarthy

In Memory of Jeff Coleman

Ellen and Jerry Reibstein

In Memory of Joan Clark

Anne Ferguson

In Memory of Kay Pavur

Joanne Jordan

In Memory of Mildred (Millie) Hill

ExpressJet Airlines-MX Division

In Memory of Randall Pineau

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in honor

In Honor of Angela Catalano, on the occasion of her 94th Birthday

Jeanine Catalano

In Honor of Dona Frosio, for her long-time dedication and outstanding service to the chapter community

SSF San Diego-Imperial Counties Chapter

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Wade and Kelly Malone

Charles T. Huddleston

In Honor of Larry Levin, on the occasion of his Birthday

Hannah and David Kaplan

In Honor of Lorna Simms-Carter

John Simms

 Team
Sjögren's

Viva Las Vegas!



Walk or Run with Team Sjögren's in Las Vegas!

Take a gamble and sign up to join our Team Sjögren's Training program for the Rock 'n' Roll series Las Vegas half marathon and 10K. Follow our program and we will prepare you to WALK or RUN in either the half marathon or 10K event on Sunday, November 12th in Las Vegas!

The SSF has only 25 reserved spots for the Las Vegas event and we hope you'll be one of them! By taking part, you will get to enjoy the "Strip at Night" as we participate alongside 20,000 other walkers/runners from all over the world! The half marathon and 10K courses take you up and down the Las Vegas Strip during an early evening race. You will be cheered on by bands along the route, as well as cheerleaders and spectators to support your effort.

As a Team Sjögren's member, you will not only receive world-class training from our team trainer, but also leadership and mentorship from past runners and staff. The SSF staff will help guide you through the entire process and ensure you are ready to complete either the 6.2 or 13.1 mile course. Our team is always full of walkers and runners – so don't fret if you aren't a runner – Team Sjögren's was designed for you! Our plan takes people from the couch to the starting line... so take a bet on yourself and join us!

In addition, you will be raising awareness for Sjögren's, as well as, helping raise crucial funds for Sjögren's research and education. So try your luck and plan to be with us on November 12th. If you don't feel you can walk or run in this event, do what so many other patients have done and recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them walk or run in your honor.

We bet you can do it! Take a chance and join Team Sjögren's!

To learn more about Team Sjögren's, contact Steven Taylor at 800-475-6473 or staylor@sjogrens.org.

“Living with Sjögren’s” *continued from page 8 ▼*

- Find the best doctors and don’t settle for less. When coping with illnesses that involve multiple symptoms, it takes multiple doctors. Having a treatment team working together for you is not only invaluable, it is critical.
- Cognitive-Behavioral Therapy (CBT) has proven beneficial for many years in helping people cope with serious illnesses and surrounding life circumstances. Consider finding a licensed and skilled professional to help you and to provide a safe place to talk openly about whatever you need and want to talk about without fear of repercussions. Good therapy can help with coping skills, provide non-judgmental support, and encourage positive aspects of life while honestly facing the not-so-positive. You may also be surprised to find yourself having a good laugh or two with someone who sees you as a person and not just an illness.
- Consider creating a Quality of Life journal. (The Foundation suggests partnering this journal with the SSF “Tracking your Symptoms” worksheet) Track how you are doing, write down ideas you come across that you think you may want to try. Write down chal-

lenges you want to overcome. Set goals and assign a timeline and keep track of your progress. Make certain to give yourself credit for the things you do rather than focusing on what you don’t.

- There are some great drugs with awesome side effects, and they may be available to you right now for free! They come in the form of heartfelt hugs, belly laughs, healthy love life, oceans, and at my house shaggy sheepdogs. Things that make us happy and release feel-good chemicals in our brains without a single visit to the drug store or warning label needed. Take frequent doses and don’t worry about risks of excessive use.
- Include the SSF and its crew as part of your support team. They are working diligently to make a difference on your behalf and others like you. Reach out to them and they will reach back.

About the Author:

Darlene Cross is a Licensed Marriage & Family Therapist in private practice near Las Vegas, NV. She is the author of A New Normal: Learning to Live with Grief and Loss, Second Edition (2017), and Reinventing Normal: How Choice and Change Shape Our Lives (2013). She is a mother, a grandmother and a patient. ■

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Tracking Your Sjögren's Symptoms

Date: _____

Additional notes about daily activities/results:

Sleeping Notes

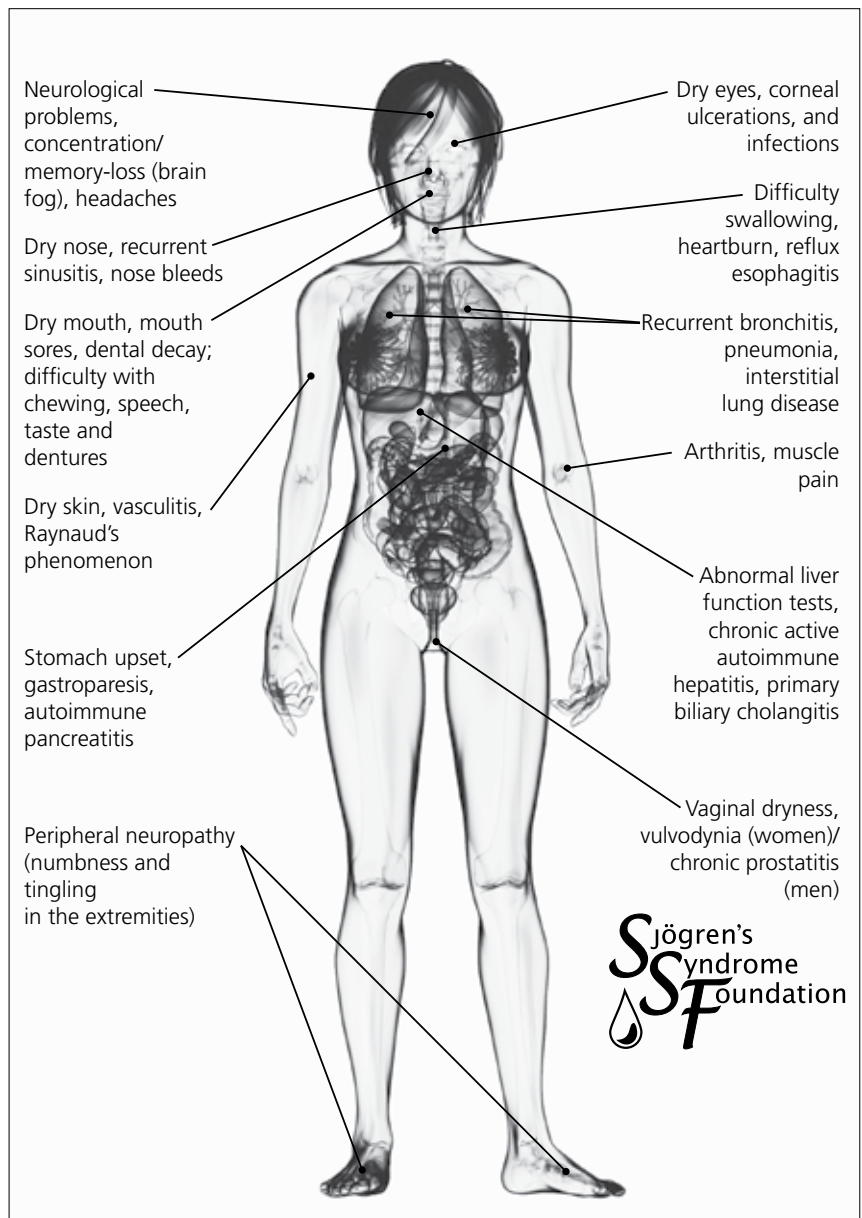
Bed Time: _____

Hours of Sleep: _____

Times Getting up for Medication: _____

Activity Notes

Work Sheet



Symptom	Morning	Afternoon	Evening
Fatigue Level			
Joint Pain			
Dry Eyes			
Dry Mouth			

Key: **N**= None, **S**= Slight, **M**= Moderate, **SE**= Severe, **I**= Intense

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10 TIPS FOR FAMILY CAREGIVERS



Seek support from other caregivers. You are not alone!



Take care of your own health so that you can be strong enough to take care of your loved one.



Accept offers of help and suggest specific things people can do to help you.



Learn how to communicate effectively with doctors.

1



Be open to new technologies that can help you care for your loved one.

2



Watch out for signs of depression and don't delay getting professional help when you need it.

3



Caregiving is hard work so take respite breaks often.

4

7



Organize medical information so it's up to date and easy to find.

6



Make sure legal documents are in order.

5



Give yourself credit for doing the best you can in one of the toughest jobs there is!

8

9

10



CaregiverAction.org



The Moisture Seekers
Sjögren's Syndrome Foundation Inc.
6707 Democracy Blvd., Ste 325
Bethesda, MD 20817
Phone: 800-475-6473
Fax: 301-530-4415

If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

IT'S TIME

United Way • Combined Federal Campaign • State Payroll Deduction

Remember, the Foundation has received the:



Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren's Syndrome Foundation when choosing where to allocate your donation. **(CFC #10603)**

If we are not listed on the contribution form, you usually may write in the Sjögren's Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren's Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren's Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 and ask for Elizabeth Trocchio.

Just think – every dollar counts.

Last year alone – thanks to those who chose to give through their employer's payroll campaign – the Sjögren's Syndrome Foundation was able to increase its Research and Awareness commitments.