The Moisture Seekers

Sjögren's Syndrome Foundation

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Caring for Others – and Yourself – While Living on the Edge

by Sarah Schafer, MD

Unexpected crises are an inevitable part of life. When a chronic illness of your own forces you to measure every action, how is it possible to deal with the sudden illness of a loved one? How do you manage to keep going when the careful routines of daily life are disrupted? No matter what your intentions, the reality is that even one long day may cause an illness flare that can put you out of commission for weeks or even months.

Recently I managed to navigate a family health crisis without suffering a serious flare of my autoimmune disease, Sjögren's syndrome. My father fell ill in June 2011 and died three weeks later. Because I am a physician, he

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Take Charge!
You are More than Your Disorder – Nine Easy Steps to Taking Control of Sjögren's

by Ruth Fremes, MA & Nancy Carteron, MD, FACR

Coming off a plane after a particularly harrowing flight through snow and ice this past winter, I was partnered with a very noisy and critical gentleman. He hadn't a good word to say about anything. Our flight had been held up because of stormy weather and he was certain the pilot was just being lazy, the cabin stewards were "snowing" us, his bags would end up in Bogota or even further, and he'd never get home.

Why, I thought, doesn't he just say thanks to the pilots, air traffic controllers and stewards for getting him home in one piece? Why not tell them

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previously had chosen me to be his primary health advocate. I felt particularly responsible to see that he received the best care possible, spending four days at the hospital and participating in difficult medical decisions. I also had the stress of unexpected travel, which is challenging at the best of times due to severe daily fatigue and back pain. Below I will share some helpful strategies based on my experience from living for more than a decade with this illness. These strategies allowed me to be a part of my father's last days without causing serious harm to my own health.

My practical wisdom boils down to four concepts:

1. *Plan ahead: Know that difficult things will happen in life.*
2. *Stack the deck: Support yourself as much as possible.*
3. *Self-compassion: Don't add unnecessary stress. Be kind to yourself!*
4. *Accept your limits: Don't apologize.*

Plan ahead

There will always be things that you cannot plan or prepare for ahead of time. However, you can protect your precious energy supply by avoiding unnecessary tasks, such as last-minute pharmacy runs or grocery shopping for staples.

Food

1. Keep extra food, water and your favorite travel snacks in the house. Frozen homemade soups are especially helpful. When my father fell ill, I quickly packed my favorite food bars, oatmeal, and nuts from my cabinets.
2. Find healthy food on the run: Have ice and a cooler ready to go. I stopped at Trader Joe's on my six-hour drive down California, where I purchased pre-made salads, fruit and humus. This was a big improvement over hospital food.

Medical

1. Store phone numbers for your medical provider, advice nurse and pharmacy in your cell phone. I used all three unexpectedly during my recent trip.
2. Keep an updated medical packing list on your computer. Be sure to include items such as eye drops, skin care, etc.
3. If you have a complicated regimen with pillboxes, try to keep a 2-3 week supply of boxes filled and ready to go.
4. Consider the big guns: If you have tricks to pull out of your sleeve, now is the time!
   - If you are taking prednisone, ask your rheumatologist ahead of time if it

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I Stood Up . . .

A Community Stood Up

Caitlyn Van Heest, a 16-year-old high school junior at the Rockdale Magnet School for Science and Technology, who had earned numerous academic honors as well as varsity letters in track, cross country, soccer, swimming, and tennis, was sidelined by a mysterious illness. It began at the end of January 2011 when she experienced excruciating ear pain that spread across her face, into her jaw and down her neck. She was hospitalized on three separate occasions in Atlanta for a total of 30 days while doctors tried to determine the cause of her illness. In addition to severe trigeminal and glossal pharyngeal pain, Caitlyn lost feeling in her legs from mid-thigh down. She had symptoms of a severe cranial and peripheral polyneuropathy. When the doctors were unable to come up with a consistent diagnosis, Caitlyn was referred to Cincinnati Children's Hospital where she was hospitalized for five more days and eventually diagnosed with an extremely rare presentation of Sjögren's syndrome. Doctors called it a post-viral autoimmune inflammatory polyneuropathy. Caitlyn received IV steroids twice and IVIG and was discharged with a long list of medications.

When Caitlyn returned to Atlanta in April, some neighbors – parents of students that Caitlyn's mom teaches – decided to organize a run in Caitlyn's honor. A group of about 10 individuals worked feverishly to put together a one-mile fun run and a 5K Caitlyn's Challenge race in just six weeks time. The race course went through Caitlyn's neighborhood and Caitlyn rode in a golf cart along the course. Registration exceeded everyone's expectations; more than 200 people registered and raced on June 4, 2011, donating $1,500 to the Sjögren's Syndrome Foundation because a community had decided that they could do something to make a difference!

Since then Caitlyn's condition has improved significantly. Last week she was able to start driving again and didn't miss a day of school all week. That hadn't happened since January! Caitlyn plans to go to college in the fall. She intends to study either rheumatology or neurology. We are confident that her experiences during her illness will serve to make her a more compassionate and caring physician.

Sjögren's also impacts the lives of your friends and family members, and they often ask what they can do to help to make a difference. There are many ways that they can help by organizing an event or awareness raiser in your community! Encourage your loved ones to contact Sheriese DeFruscio at 301-530-4420 ext 212 or e-mail sdefruscio@sjogrens.org to learn more. ■

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is OK to raise your dose on your own in the event of an emergency. I often add 10 mg the day before and the day of my travel. This helps a great deal.

- If you have been prescribed stimulants such as Provigil® or Ritalin,® use them as needed.

Make friends and support networks a priority before you hit a crisis. Let people know ahead of time that you may ask for help at some point due to your health issues. I keep a bright-colored phone contact list posted on my refrigerator. It includes friends, neighbors and anyone who ever said, "let me know if you ever need anything."

It is a good idea to be as reciprocal as possible by giving a hand to others in ways that are congruent with your energy resources. On the other hand, don't offer your support and precious energy because you expect to "cash in" on your investment with specific people. Sometimes the people you least expect come through in a time of need, while others just disappear.

Support during a crisis. Ask for a "point person" to coordinate support if you anticipate a prolonged situation. Give this person your contact list and let him or her know what you might need, such as food, childcare, errands, rides, dog walking, etc. This makes it easier to ask for help because it eliminates the awkwardness of asking directly.

Stack the deck

Beef up your comfort /spend money as needed, especially when you are away from home.

- Consider paying for services that you would not normally spend money on. On my recent trip, I planned to call a taxi if I needed to go from the hotel to the hospital in the middle of the night. I did not feel safe driving, both due to fatigue and marginal night vision due to Sjögren's eye disease.
- Bring ear plugs/noise-canceling headphones.
- If you have an activity that is essential to maintaining health or controlling pain, make it a priority. Swimming is my best tool for combating stress, pain and the afternoon energy slump. I stayed at a hotel with a decent pool, even though it cost more than I would have preferred.

Self-compassion

Don't add unnecessary stress:

- Do what you can within your limits, and don't make a big deal out of it. Pace yourself realistically, prioritizing your contribution.
- Don't beat yourself up for not being able to do what a healthy person can do. State your limits firmly, without apology. If you spend a lot of time apologizing and explaining, it can backfire, and people may become resentful.
- Respect your need for extra rest. Except for the first day of touch-and-go with my father, I went back to the hotel to rest every afternoon.
- This is not the time for a self-improvement project. Eat healthy food and don't deprive yourself.
- Continue your long-term medications at a stable dose, unless this is medically contraindicated. This is not the time to wean off prednisone, pain medication, antidepressants, etc.

Accept your limits

Be honest with yourself and others. Accept that fatigue, pain and other symptoms will leave you with fewer physical resources to cope with the big things. This is simply the way it is.

Be realistic about your abilities:

Packing for my complicated medical needs took many hours. I could not do this and then drive for 6 hours the same day. It helped that I had discussed my inability to leave at a moment's notice with my siblings ahead of time. My brother stepped up to the plate and was able to drive to the hospital the day that my father fell ill.

Pay attention to your warning flags:

After five days away from home, I had two minor infections, and could feel my energy rapidly diminishing, despite my efforts at self-care. Even though I was reluctant to leave my father, I drove home once he was stabilized. I needed to rest. I was able to do a good job talking with him, his doctors, nurses and my siblings by telephone and e-mail.

Don't get broadsided by the inevitable painful situations:

1. Family strife: There is nothing like a crisis to stir up old family resentments. Let it go, and make calm statements such as: "right now, my priority is to deal with _____" (*fill in the blank*). You may need to repeat this like a mantra.
2. People may expect you to do more than you can give: Most people, including those who are close in our lives, have no clue how challenging chronic illness is, especially when we don't look sick. We are often expected to do "our fair share," or even worse, we can be asked to take on extra if we are not working in a paid job.

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For patients with Sjögren's syndrome

DRY-MOUTH SYMPTOMS DON'T HAVE TO BE SO DISTRACTING.

If you experience dry-mouth symptoms due to Sjögren's syndrome, then you already know how distracting these can be to your daily life. It might be time to ask about EVOXAC® (cevimeline HCl), a prescription treatment that works by stimulating the production of your body's own natural saliva.

Talk to your doctor to see if EVOXAC can help, or visit DiscoverEVOXAC.com.

Please see important information about EVOXAC below.

Important Safety Information

What is EVOXAC?

- EVOXAC (cevimeline HCl) is a prescription medicine used to treat symptoms of dry mouth in patients with Sjögren's syndrome.

Who Should Not Take EVOXAC?

- You should not take EVOXAC if you have uncontrolled asthma, allergies to EVOXAC or a condition affecting the contraction of your pupil such as narrow-angle (angle-closure) glaucoma or inflammation of the iris.

What should I tell my Healthcare Provider?

- Tell your healthcare provider if you have any of the following conditions:
  - History of heart disease;
  - Controlled asthma;
  - Chronic bronchitis;
  - Chronic obstructive pulmonary disease (COPD);
  - History of kidney stones;
  - History of gallbladder stones
- Tell your healthcare provider if you are trying to become pregnant, are already pregnant, or are breastfeeding.
- Tell your healthcare provider about all medications that you are taking, including those you take without a prescription. It is particularly important to tell your healthcare provider if you are taking any heart medications especially "beta-blockers".
- If you are older than 65, your healthcare provider may want to monitor you more closely.

General Precautions with EVOXAC

- When taking EVOXAC use caution when driving at night or performing other hazardous activities in reduced lighting because EVOXAC may cause blurred vision or changes in depth perception.
- If you sweat excessively while taking EVOXAC drink extra water and tell your health care provider, as dehydration may develop.
- The safety and effectiveness of EVOXAC in patients under 18 years of age have not been established.

What are some possible side effects of EVOXAC?

- In clinical trials, the most commonly reported side effects were excessive sweating, headache, nausea, sinus infection, upper respiratory infections, runny nose, and diarrhea.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.FDA.gov/medwatch, or call 1-800-FDA-1088.

Please visit www.EVOXAC.com for full Product Information for EVOXAC.

For patients having difficulty affording their Daiichi Sankyo medication, please call the Daiichi Sankyo Patient Assistance Program at 1-866-268-7327 for more information or visit www.dsi.com/news/patientassitance.html.

Please see a brief summary of Important Information for EVOXAC on the next page.

Evoxac® (cevimeline HCl) 30 mg Capsules

Brief Summary – See package insert for full Prescribing Information.

EVOXAC® Capsules

(cevimeline hydrochloride)

INDICATIONS AND USAGE
Cevimeline is indicated for the treatment of symptoms of dry mouth in patients with Sjögren's Syndrome.

CONTRAINDICATIONS
Cevimeline is contraindicated in patients with uncontrolled asthma, known hypersensitivity to cevimeline, and when miosis is undesirable, e.g., in acute iritis and in narrow-angle (angle-closure) glaucoma.

WARNINGS
Cardiovascular Disease:
Cevimeline can potentially alter cardiac conduction and/or heart rate. Patients with significant cardiovascular disease may potentially be unable to compensate for transient changes in hemodynamics or rhythm induced by EVOXAC®. EVOXAC® should be used with caution and under close medical supervision in patients with a history of cardiovascular disease evidenced by angina pectoris or myocardial infarction.

Pulmonary Disease:
Cevimeline can potentially increase airway resistance, bronchial smooth muscle tone, and bronchial secretions. Cevimeline should be administered with caution and with close medical supervision to patients with controlled asthma, chronic bronchitis, or chronic obstructive pulmonary disease.

Ocular:
Ophthalmic formulations of muscarinic agonists have been reported to cause visual blurring which may result in decreased visual acuity, especially at night and in patients with central lens changes, and to cause impairment of depth perception. Caution should be advised while driving at night or performing hazardous activities in reduced lighting.

PRECAUTIONS
General:
Cevimeline toxicity is characterized by an exaggeration of its parasympathomimetic effects. These may include: headache, visual disturbance, lacrimation, sweating, respiratory distress, gastrointestinal spasm, nausea, vomiting, diarrhea, atrioventricular block, tachycardia, bradycardia, hypotension, hypertension, shock, mental confusion, cardiac arrhythmia, and tremors.

Cevimeline should be administered with caution to patients with a history of nephrolithiasis or cholelithiasis. Contractions of the gallbladder or biliary smooth muscle could precipitate complications such as cholecystitis, cholangitis and biliary obstruction. An increase in the ureteral smooth muscle tone could theoretically precipitate renal colic or ureteral reflux in patients with nephrolithiasis.

Information for Patients: Patients should be informed that cevimeline may cause visual disturbances, especially at night, that could impair their ability to drive safely.

If a patient sweats excessively while taking cevimeline, dehydration may develop. The patient should drink extra water and consult a health care provider.

Drug Interactions:
Cevimeline should be administered with caution to patients taking beta adrenergic antagonists, because of the possibility of conduction disturbances. Drugs with parasympathomimetic effects administered concurrently with cevimeline can be expected to have additive effects. Cevimeline might interfere with desirable antimuscarinic effects of drugs used concomitantly.

Drugs which inhibit CYP2D6 and CYP3A3/4 also inhibit the metabolism of cevimeline. Cevimeline should be used with caution in individuals known or suspected to be deficient in CYP2D6 activity, based on previous experience, as they may be at a higher risk of adverse events. In an *in vitro* study, cytochrome P450 isozymes 1A2, 2A6, 2C9, 2C19, 2D6, 2E1, and 3A4 were not inhibited by exposure to cevimeline.

Carcinogenesis, Mutagenesis and Impairment of Fertility:
Lifetime carcinogenicity studies were conducted in CD-1 mice and F-344 rats. A statistically significant increase in the incidence of adenocarcinomas of the uterus was observed in female rats that received cevimeline at a dosage of 100 mg/kg/day (approximately 8 times the maximum human exposure based on comparison of AUC data). No other significant differences in tumor incidence were observed in either mice or rats.

Cevimeline exhibited no evidence of mutagenicity or clastogenicity in a battery of assays that included an Ames test, an *in vitro* chromosomal aberration study in mammalian cells, a mouse lymphoma study in L5178Y cells, or a micronucleus assay conducted *in vivo* in ICR mice.

Cevimeline did not adversely affect the reproductive performance or fertility of male Sprague-Dawley rats when administered for 63 days prior to mating and throughout the period of mating at dosages up to 45 mg/kg/day (approximately 5 times the maximum recommended dose for a 60 kg human following normalization of the data on the basis of body surface area estimates). Females that were treated with cevimeline at dosages up to 45 mg/kg/day from 14 days prior to mating through day seven of gestation exhibited a statistically significantly smaller number of implantations than did control animals.

Pregnancy:
Pregnancy Category C.
Cevimeline was associated with a reduction in the mean number of implantations when given to pregnant Sprague-Dawley rats from 14 days prior to mating through day seven of gestation at a dosage of 45 mg/kg/day (approximately 5 times the maximum recommended dose for a 60 kg human when compared on the basis of body surface area estimates). This effect may have been secondary to maternal toxicity. There are no adequate and well-controlled studies in pregnant women. Cevimeline should be used during pregnancy only if the potential benefit justifies the potential risk to the fetus.

Nursing Mothers:
It is not known whether this drug is secreted in human milk. Because many drugs are excreted in human milk, and because of the potential for serious adverse reactions in nursing infants from EVOXAC®, a decision should be made whether to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use:
Safety and effectiveness in pediatric patients have not been established.

Geriatric Use:
Although clinical studies of cevimeline included subjects over the age of 65, the numbers were not sufficient to determine whether they respond differently from younger subjects. Special care should be exercised when cevimeline treatment is initiated in an elderly patient, considering the greater frequency of decreased hepatic, renal, or cardiac function, and of concomitant disease or other drug therapy in the elderly.

ADVERSE REACTIONS
Cevimeline was administered to 1777 patients during clinical trials worldwide, including Sjögren's patients and patients with other conditions. In placebo-controlled Sjögren's studies in the U.S., 320 patients received cevimeline doses ranging from 15 mg tid to 60 mg tid, of whom 93% were women and 7% were men. Demographic distribution was 90% Caucasian, 5% Hispanic, 3% Black and 2% of other origin. In these studies, 14.6% of patients discontinued treatment with cevimeline due to adverse events.

The following adverse events associated with muscarinic agonism were observed in the clinical trials of cevimeline in Sjögren's syndrome patients:

Adverse Event	Cevimeline 30 mg (tid) n*=533	Placebo (tid) n=164
Excessive Sweating	18.7%	2.4%
Nausea	13.8%	7.9%
Rhinitis	11.2%	5.4%
Diarrhea	10.3%	10.3%
Excessive Salivation	2.2%	0.6%
Urinary Frequency	0.9%	1.8%
Asthenia	0.5%	0.0%
Flushing	0.3%	0.6%
Polyuria	0.1%	0.6%

*n is the total number of patients exposed to the dose at any time during the study.

In addition, the following adverse events (≥3% incidence) were reported in the Sjögren's clinical trials:

Adverse Event	Cevimeline 30 mg (tid) n*=533	Placebo (tid) n=164	Adverse Event	Cevimeline 30 mg (tid) n*=533	Placebo (tid) n=164
Headache	14.4%	20.1%	Conjunctivitis	4.3%	3.6%
Sinusitis	12.3%	10.9%	Dizziness	4.1%	7.3%
Upper Respiratory Tract Infection	11.4%	9.1%	Bronchitis	4.1%	1.2%
Dyspepsia	7.8%	8.5%	Arthralgia	3.7%	1.8%
Abdominal Pain	7.6%	6.7%	Surgical Intervention	3.3%	3.0%
Urinary Tract Infection	6.1%	3.0%	Fatigue	3.3%	1.2%
Coughing	6.1%	3.0%	Pain	3.3%	3.0%
Pharyngitis	5.2%	5.4%	Skeletal Pain	2.8%	1.8%
Vomiting	4.6%	2.4%	Insomnia	2.4%	1.2%
Injury	4.5%	2.4%	Hot Flushes	2.4%	0.0%
Back Pain	4.5%	4.2%	Rigors	1.3%	1.2%
Rash	4.3%	6.0%	Anxiety	1.3%	1.2%

*n is the total number of patients exposed to the dose at any time during the study.

The following events were reported in Sjögren's patients at incidences of <3% and ≥1%: constipation, tremor, abnormal vision, hypertonia, peripheral edema, chest pain, myalgia, fever, anorexia, eye pain, earache, dry mouth, vertigo, salivary gland pain, pruritus, influenza-like symptoms, eye infection, post-operative pain, vaginitis, skin disorder, depression, hiccup, hyporeflexia, infection, fungal infection, sialoadenitis, otitis media, erythematous rash, pneumonia, edema, salivary gland enlargement, allergy, gastroesophageal reflux, eye abnormality, migraine, tooth disorder, epistaxis, flatulence, toothache, ulcerative stomatitis, anemia, hypoesthesia, cystitis, leg cramps, abscess, eructation, moniliasis, palpitation, increased amylase, xerophthalmia, allergic reaction.

The following events were reported rarely in treated Sjögren's patients (<1%): Causal relation is unknown:

Body as a Whole Disorders: aggravated allergy, precordial chest pain, abnormal crying, hematoma, leg pain, edema, periorbital edema, activated pain trauma, pallor, changed sensation temperature, weight decrease, weight increase, choking, mouth edema, syncope, malaise, face edema, substernal chest pain

Cardiovascular Disorders: abnormal ECG, heart disorder, heart murmur, aggravated hypertension, hypotension, arrhythmia, extrasystoles, t wave inversion, tachycardia, supraventricular tachycardia, angina pectoris, myocardial infarction, pericarditis, pulmonary embolism, peripheral ischemia, superficial phlebitis, purpura, deep thrombophlebitis, vascular disorder, vasculitis, hypertension

Digestive Disorders: appendicitis, increased appetite, ulcerative colitis, diverticulitis, duodenitis, dysphagia, enterocolitis, gastric ulcer, gastritis, gastroenteritis, gastrointestinal hemorrhage, gingivitis, glossitis, rectum hemorrhage, hemorrhoids, ileus, irritable bowel syndrome, melena, mucositis, esophageal stricture, esophagitis, oral hemorrhage, peptic ulcer, periodontal destruction, rectal disorder, stomatitis, tenesmus, tongue discoloration, tongue disorder, geographic tongue, tongue ulceration, dental caries

Endocrine Disorders: increased glucocorticoids, goiter, hypothyroidism

Hematologic Disorders: thrombocytopenic purpura, thrombocythemia, thrombocytopenia, hypochromic anemia, eosinophilia, granulocytopenia, leucopenia, leukocytosis, cervical lymphadenopathy, lymphadenopathy

Liver and Biliary System Disorders: cholelithiasis, increased gamma-glutamyl transferase, increased hepatic enzymes, abnormal hepatic function, viral hepatitis, increased serum glutamate oxaloacetic transaminase (SGOT) (also called AST-aspartate aminotransferase), increased serum glutamate pyruvate transaminase (SGPT) (also called ALT-alanine aminotransferase)

Metabolic and Nutritional Disorders: dehydration, diabetes mellitus, hypercalcemia, hypercholesterolemia, hyperglycemia, hyperlipemia, hypertriglyceridemia, hyperuricemia, hypoglycemia, hypokalemia, hyponatremia, thirst

Musculoskeletal Disorders: arthritis, aggravated arthritis, arthropathy, femoral head avascular necrosis, bone disorder, bursitis, costochondritis, plantar fasciitis, muscle weakness, osteomyelitis, osteoporosis, synovitis, tendinitis, tenosynovitis

Neoplasms: basal cell carcinoma, squamous carcinoma

Nervous Disorders: carpal tunnel syndrome, coma, abnormal coordination, dysesthesia, dyskinesia, dysphonia, aggravated multiple sclerosis, involuntary muscle contractions, neuralgia, neuropathy, paresthesia, speech disorder, agitation, confusion, depersonalization, aggravated depression, abnormal dreaming, emotional lability, manic reaction, paroniria, somnolence, abnormal thinking, hyperkinesia, hallucination

Miscellaneous Disorders: fall, food poisoning, heat stroke, joint dislocation, post-operative hemorrhage

Resistance Mechanism Disorders: cellulitis, herpes simplex, herpes zoster, bacterial infection, viral infection, genital moniliasis, sepsis

Respiratory Disorders: asthma, bronchospasm, chronic obstructive airway disease, dyspnea, hemoptysis, laryngitis, nasal ulcer, pleural effusion, pleurisy, pulmonary congestion, pulmonary fibrosis, respiratory disorder

Rheumatologic Disorders: aggravated rheumatoid arthritis, lupus erythematosus rash, lupus erythematosus syndrome

Skin and Appendages Disorders: acne, alopecia, burn, dermatitis, contact dermatitis, lichenoid dermatitis, eczema, furunculosis, hyperkeratosis, lichen planus, nail discoloration, nail disorder, onychia, onychomycosis, paronychia, photosensitivity reaction, rosacea, scleroderma, seborrhea, skin discoloration, dry skin, skin exfoliation, skin hypertrophy, skin ulceration, urticaria, verruca, bullous eruption, cold clammy skin

Special Senses Disorders: deafness, decreased hearing, motion sickness, parosmia, taste perversion, blepharitis, cataract, corneal opacity, corneal ulceration, diplopia, glaucoma, anterior chamber eye hemorrhage, keratitis, keratoconjunctivitis, mydriasis, myopia, photopsia, retinal deposits, retinal disorder, scleritis, vitreous detachment, tinnitus

Urogenital Disorders: epididymitis, prostatic disorder, abnormal sexual function, amenorrhea, female breast neoplasm, malignant female breast neoplasm, female breast pain, positive cervical smear test, dysmenorrhea, endometrial disorder, intermenstrual bleeding, leukorrhea, menorrhagia, menstrual disorder, ovarian cyst, ovarian disorder, genital pruritus, uterine hemorrhage, vaginal hemorrhage, atrophic vaginitis, albuminuria, bladder discomfort, increased blood urea nitrogen, dysuria, hematuria, micturition disorder, nephrosis, nocturia, increased nonprotein nitrogen, pyelonephritis, renal calculus, abnormal renal function, renal pain, strangury, urethral disorder, abnormal urine, urinary incontinence, decreased urine flow, pyuria

In one subject with lupus erythematosus receiving concomitant multiple drug therapy, a highly elevated ALT level was noted after the fourth week of cevimeline therapy. In two other subjects receiving cevimeline in the clinical trials, very high AST levels were noted. The significance of these findings is unknown.

Additional adverse events (relationship unknown) which occurred in other clinical studies (patient population different from Sjögren's patients) are as follows:

cholinergic syndrome, blood pressure fluctuation, cardiomegaly, postural hypotension, aphasia, convulsions, abnormal gait, hyperesthesia, paralysis, abnormal sexual function, enlarged abdomen, change in bowel habits, gum hyperplasia, intestinal obstruction, bundle branch block, increased creatine phosphokinase, electrolyte abnormality, glycosuria, gout, hyperkalemia, hyperproteinemia, increased lactic dehydrogenase (LDH), increased alkaline phosphatase, failure to thrive, abnormal platelets, aggressive reaction, amnesia, apathy, delirium, delusion, dementia, illusion, impotence, neurosis, paranoid reaction, personality disorder, hyperhemoglobinemia, apnea, atelectasis, yawning, oliguria, urinary retention, distended vein, lymphocytosis

The following adverse reaction has been identified during post-approval use of EVOXAC®. Because post-marketing adverse reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Post-Marketing Adverse Events: *Liver and Biliary System Disorders:* cholecystitis

MANAGEMENT OF OVERDOSE
Management of the signs and symptoms of acute overdosage should be handled in a manner consistent with that indicated for other muscarinic agonists: general supportive measures should be instituted. If medically indicated, atropine, an anti-cholinergic agent, may be of value as an antidote for emergency use in patients who have had an overdose of cevimeline. If medically indicated, epinephrine may also be of value in the presence of severe cardiovascular depression or bronchoconstriction. It is not known if cevimeline is dialyzable.

℞ Only

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Sjögren's Syndrome Foundation Personal Support System

Listed below are ssf support group leaders and the city where meetings are held. International support groups are available throughout the world. Please contact our office for specific information.

ALABAMA		
Birmingham	Anne Rose	(205) 972-4261
ARIZONA		
Phoenix Area	Lois Peach	(480) 391-2522
ARKANSAS		
Little Rock	Karen Fulton	(501) 590-0171
CALIFORNIA		
Inland Empire/ San Gabriel Valley	Judy (Moffet) Whale	(909) 624-1809
	Susan Buller	(909) 944-1773
San Diego	Suzanne Davies	ssfsuzannedavies@gmail.com
	Dona Frosio	(619) 303-9004
San Francisco Bay Area	Nancy Crabbe	(650) 593-9022
	Claire Goodman	(925) 258-6666
West Hills	Rhoda Dennison	(818) 346-6694
COLORADO		
Denver/Englewood	Maurine Daniels	(303) 721-0241
Ft. Collins/Loveland	Eunice Krivonak	(970) 203-0147
CONNECTICUT		
Farmington	Mary Beth Walter	(860) 569-6933
FLORIDA		
Ft. Lauderdale	Georgie Littlefield	(954) 977-0775
Lady Lake	Karen M. Marshall	(352) 259-1309
Orlando/Lakeland	Joyce Tompkins	(863) 701-0512
Tallahassee	Kathleen Abrams	(850) 668-3586
GEORGIA		
Atlanta Area	Suzi Wixson	(770) 642-0323
HAWAII		
Ewa Beach	Melaca Cannella	(808) 383-1687
ILLINOIS		
Chicago Area	Heidi Shierry	(630) 279-9437 or (630) 853-6836
Plainfield	Audrey M. Grey-Lowry	(815) 436-5168
	April Flentge	(815) 886-4715
INDIANA		
Indianapolis	Diana Altom	(317) 356-2558
IOWA		
Dubuque	Paula Martens	(563) 542-5308
IDAHO		
Boise	Richard Bliss	(208) 816-3686
KANSAS		
Lenexa	Janet Nichols	(913) 492-9581
	Janine Bensman	(913) 897-2441
LOUISIANA		
Lafayette/Kaplan	Tonya Broussard	(337) 643-3565
MARYLAND		
Bel Air	Eva L. Plude	(410) 836-1040 or bigeva@qis.net
Frederick	Elizabeth E. Ward	(301) 663-3947
Montgomery County Area	Bonnie Schneider	(301) 774-4662
Prince George's and South Maryland	Barbara Straub	(301) 392-1388
MASSACHUSETTS		
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Sjögren's Syndrome Foundation

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Welcome to our newest support groups!

Tallahassee, Florida Support Group
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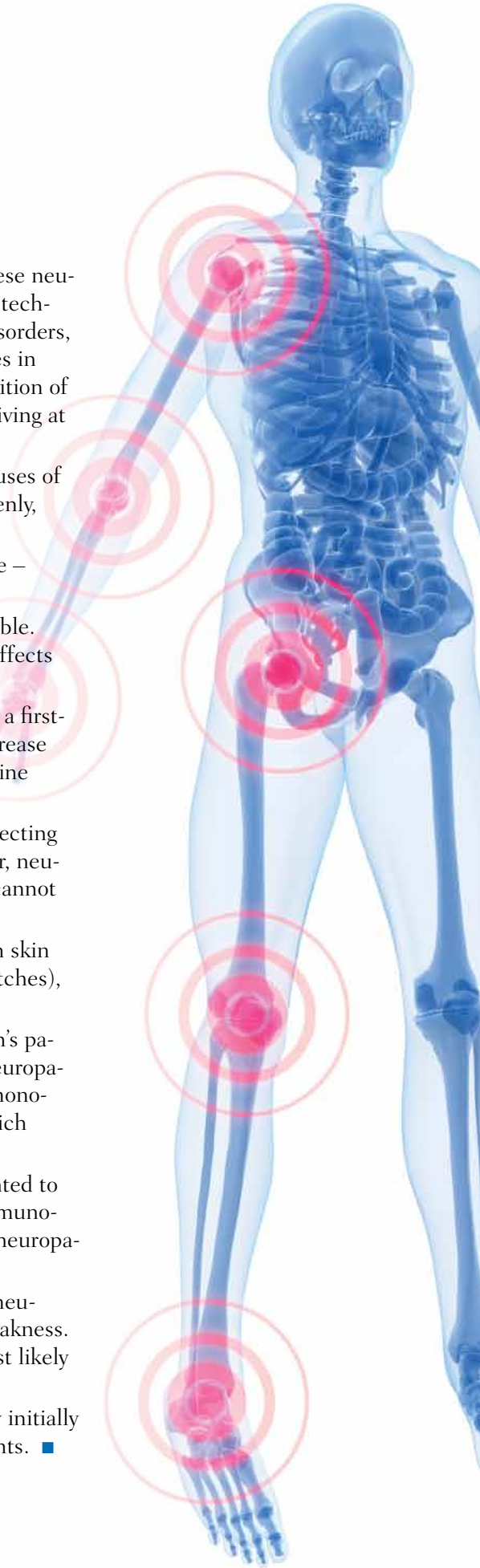
Melaca Cannella, Group Leader

Durham, North Carolina Support Group
Nancy Carter, Group Leader

Peripheral Neuropathy and Sjögren's

by Julius Birnbaum, MD.
A rheumatologist and neurologist, Dr. Birnbaum is Assistant Director of the Johns Hopkins Jerome L. Greene Sjögren's Syndrome, Baltimore, Maryland.



There are many different types of neuropathies in Sjögren's syndrome. These neuropathies can have different causes and may require different diagnostic techniques and different therapeutic strategies. Unlike other autoimmune disorders, in which the neuropathies predominantly cause weakness, the neuropathies in Sjögren's primarily affect sensation and also can cause severe pain. Recognition of unique patterns and causes of neuropathies in Sjögren's is important in arriving at appropriate therapies.

- Recognize that neuropathic pain is a chronic disease. Just as most causes of neuropathies and neuropathic pain in Sjögren's do not come on suddenly, reduction of neuropathic pain can take a while.
- Initial and predominant neuropathies in Sjögren's can occur anywhere – in the feet, thighs, hands, arms, torso and/or face.
- Many different symptomatic therapies for neuropathic pain are available. Both physician and patient awareness of potential benefits and side-effects can help tailor an appropriate approach.
- While the class of tricyclic anti-depressants (TCAs) often constitutes a first-line tier of therapy in other neuropathy syndromes, the TCAs can increase mouth and eye dryness and therefore are not routinely used as front-line therapies in most Sjögren's patients.
- Electrophysiologic tests may help in the diagnosis of neuropathies affecting larger nerves which are coated by an insulator called myelin. However, neuropathies affecting smaller-fiber nerves that lack this myelin coating cannot be detected with these tests.
- Special diagnostic tests, including the technique of superficial, punch skin biopsies (small biopsies of three millimeters and not requiring any stitches), can help in the diagnosis.
- A relatively rare neuropathy can cause significant weakness in Sjögren's patients. In contrast to other neuropathies which develop slowly, this neuropathy can present with very abrupt-onset of weakness. This so-called "mononeuritis multiplex" occurs because the blood-flow through vessels which nourishes nerves is suddenly compromised.
- In general, immunosuppressive medications are almost always warranted to treat "mononeuritis multiplex" neuropathy. In contrast, the role of immunosuppressives is not well-established in other neuropathies, including neuropathies that cause pain but are not associated with weakness.
- Sjögren's patients frequently wonder whether pain associated with a neuropathy means they are at an increased risk for more severe motor weakness. While there are exceptions, if weakness is not present at onset, it most likely will not occur.
- Neuropathic pain can be alleviated and assuaged, although there may initially be a "trial-and-error" process with different and perhaps multiple agents. ■

"Take Charge" continued from page 6 ▼

they had done an incredible job flying and landing in such snowy and windy conditions, because they had? He seemed incapable of saying anything positive. It reminded me of myself at a time when I looked at everything through gray-colored glasses – glasses that reflected my attitude towards the symptoms of Sjögren's. Nothing was ever "fine," really.

I wanted to change that – I wanted a positive view of my world. The negative ideation was simply adding to my burden, but I couldn't seem to get past it. A friend suggested I discuss this with her life coach, and after some resistance on my part, I actually called and booked an appointment. It was a good match. Together we assembled a list of "action points" that I could always call upon when I slipped into negative thoughts. These nine steps brought me back to my center and out of "the dumps." Now whenever I detect myself feeling negative or complaining, I turn to them. Perhaps they can help you as well.

Getting Ready

Find yourself a quiet place. Sit comfortably; focus on yourself; take your time to get comfortable – become aware of your presence in the room – and begin.

The Nine Easy Steps to Healing

- **Breathe in and hold it**. Become aware of holding your breath. Breathe. Continue ten times as you empty your mind of clutter.
- **Catch yourself in negative thinking**. Change direction to positive or neutral thoughts. Instead of focusing on how sick you are, think about and be grateful for the good times.
- **Identify people and situations that drain your energy**. Make a note to avoid them.
- **Tell yourself that you will do what you want and need to do, not what you should**.
- **Remind yourself to slow down**. Do everything slowly and purposefully.
- **Promise yourself that you will not take on other people's issues**. You can be compassionate at the same time as you are self-protective.
- **Check out your feelings about your healthcare professional**. Does he listen? Does she seem to care about you? If that relationship is unrewarding, perhaps you might think about a change.
- **Permit yourself to be mindful and graceful**. Complete each action before starting another. Don't multi-task.
- **Remember** – This has happened before and you have survived; you're going to be O.K.

The Doctor Comments

I am very enthusiastic about these nine steps. I have seen them work over and over again. Sometimes acceptance comes quickly; more often it takes longer. I try to encourage my Sjögren's patients to take the first step of silent, calm breathing, then moving through the nine steps. Often, through practice, a patient will begin to feel different – more positive and open.

At this stage I have observed flexibility to be important. If you have bundled appointments one on top of the other with little space for yourself, you could have locked yourself in a stress-producing folly. Allow space to surround you so if you are feeling the negative effects of a flare, you will have time to recover. If you have a flare and have the space to recover, you are less apt to push through and trigger a downward spiral.

As patients get to know themselves better, they can further fine-tune what works for them and what does not. Most discover nutrition, exercise of some sort, and good sleep are key to healing.

I also have observed that as patients engage again in the world around them, they continue on the healing pathway. Think about the healing effect of a pet, volunteering, connecting with friends with a sunny attitude, developing a spiritual journey, trying something NEW. These have worked for many.

Until you are far down the healing path, there is the risk of a quick spiral down when a flare occurs – much like going back to jail on the Monopoly Board. But when jail time is over, you can get back to where you were before, often quicker each time. No one's perfect; simply get right back on track and continue.

This is where adding a Coach* to your Healing Team can really add value. They often are able to just remind you what you now already know.

I have observed that in the later stages of healing development of a spirit of gratitude (there is always something to be thankful for) and service solidify the process.

At this point, people are often able to identify a "silver lining in the cloud" of Sjögren's. I've seen:

- A patient who was really there for a twin sister who lost her husband to lymphoma.
- A patient who was able to start her own business after working for a high-powered company that did not share her ideals.
- A patient who discovered a special artistic talent that never had time to develop.

continued page 12 ▼

In Memory of Amy D. Greaney
David & Jane Buck
Casey and Sandy Clark
Ray & Kay Costello
Madeline & Bernard Dauphin
Jeane & Charlie Fasullo
Jack & Kathy Foley
Alyssa Freedman
Friends at the Northeast-Suburban Area Office Westborough
Hadley Friends
Sally, Steven & Selma Hoffman
Sydney Hoffman and Stacy Dill
HY-Line Cruises, Security Department
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Brittany Jarvis & Jeff Burgdorff
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Trip Pilgrim
Hampton Pitts

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Scot & Tina Bauermeister
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Joseph Puglisi

In Honor of Carol Maleto
William & Mary Hilliker

In Honor of Catherine Shilstone's Birthday
Karen Markman

In Honor of Debbi Yarbrough
Hazel A. Luksa

In Honor of Dr. David & Linda Lehrman
Ted Pincus

In Honor of Elaine Montano
Christopher & Sean, Love & Support for Recent Diagnosis

In Honor of Flora Hurteau
Class of 2011, GEMS

In Honor of Gwen Ragan
Ted & Rhonda

In Honor of Janet Johnson's Birthday
Dr. Lisa Rae Mitchell and Thomas Anderson Sobieck

In Honor of Kelli Al-Mutawa
Pamela & Alvin Hare

In Honor of Leah Miller, "Happy Birthday!"
with love from Laura

In Honor of Robert I. Fox, MD
The Henry J. Fox Charitable Trust

In Honor of Sara Silverman's Birthday
Judy & Peter Salzer

In Honor of "Susanne Moliere and support of World Sjögren's Day"
John P. Moliere

In Honor of Tariq Al-Mutawa's 40th Birthday
Suzanne, Lawrence and Bryn Busta

"Take Charge" continued from page 10 ▼

- An architect who was able to design her own home.

These nine steps can help enhance your trip to healing. Your symptoms may continue to appear and surprise but the peaceful acceptance of your reality helps you gain control, once again, of your body.

**Coaches can wear varied "hats." They may be a good friend or a partner that agrees to encourage you on your journey. Professional coaches also come in several varieties. Some are therapists (MFT, PhD), some are chronic illness survivors themselves who help others take charge of their illness.*

Ruth Fremes, MA and Nancy Carteron, MD, FACR are co-authors of A Body Out of Balance *(Penguin 2003), and co-founders of web blog Sjögren's Forum (founded 2010). Ruth, author of nine books on health and nutrition, has consulted for University of California, the American Dietetic Association, and the National Cancer Institution, and was founder of the SSF Bay Area Sjögren's Support Group. Ruth currently resides in her hometown of Toronto, Canada. Nancy is a rheumatologist with a consultative practice specializing in autoimmune diseases, Associate Clinical Professor at University of California in San Francisco, and Sjögren's Syndrome Foundation Board Member, with training as an immunologist and virologist at Johns Hopkins. Nancy currently resides in San Francisco and Napa Valley. Ruth as patient and Nancy as physician are collaborating to facilitate increased awareness and rapid diagnosis and to develop healing strategies for those with and who may have Sjögren's. Their blog may be found at* Sjögrensforum.com. ■

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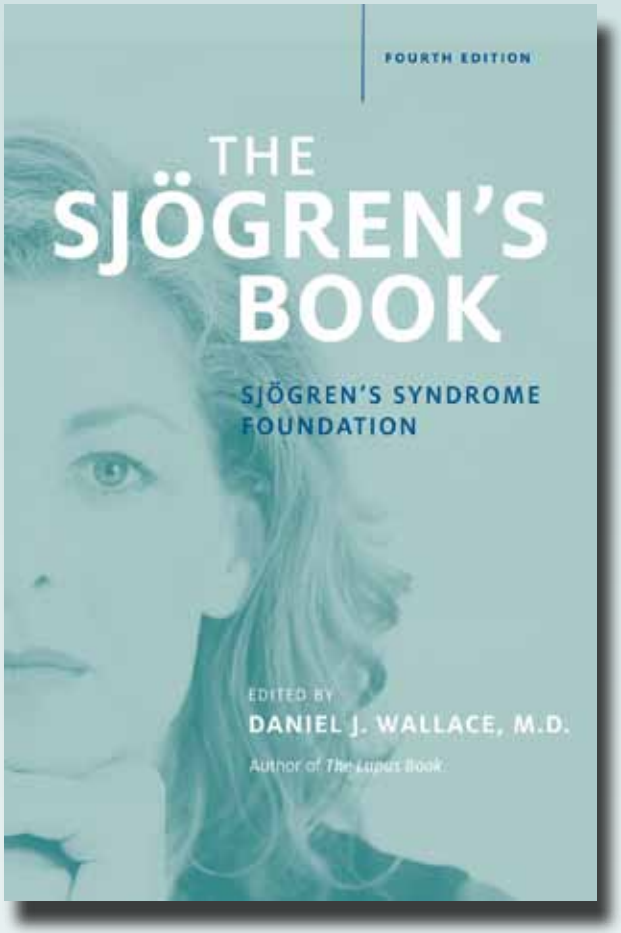
- **iGive.com** offers exclusive deals with over 700 brand-name stores you know and love, with a specified percentage of each purchase coming back to the SSF. Be sure to select "Sjögren's Syndrome Foundation" as your charity of choice. Whenever you return to iGive.com and log in, any shopping you do will benefit the SSF! It's that simple.

Just go to www.sjogrens.org/shopforsjogrens and start shopping!



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"Caring for Others" continued from page 4 ▼

I have learned the most effective approach, rather than repeatedly trying to educate and explain, is to say: "I can do X and Y. Then I need to rest." Keep your statement brief, unapologetic, and clear.

3. Don't waste your time on resenting those who don't support you. If people behave badly, and some of them will, set it aside for now and thank those who do help you. You can sort out your feelings and relationships once the crisis has passed.

Organization and compassion during a crisis are essential for people living with chronic illness such as Sjögren's syndrome. Creating strategies for support and self-care can help you get through difficult times. Even basic preparation ahead of time will pay huge dividends in terms of wear and tear on your health. ■

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Team Sjögren's

Nashville 2012

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"Charting the Course"

April 20-21, 2012
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As a Sjögren's patient, it's easy to feel confused or overwhelmed by the abundance of information available about the illness and how it affects your body. But here is your opportunity of "Charting the Course" for an educational journey to take control of your health and day-to-day living by learning from the best minds dealing with Sjögren's. This April, join fellow Sjögren's patients and their family members as well as healthcare professionals and other experts who specialize in Sjögren's at the 2012 SSF National Patient Conference in La Jolla, California.

SSF programs are the best Sjögren's patient education opportunities in the country. They have helped thousands gain a better understanding of Sjögren's and will help you, too. This two-day event will feature an array of presentations from the country's leading Sjögren's experts – physicians, dentists, eye care providers, and researchers – who will help you understand how to manage all key aspects of your disease. Presentation topics will include:

Overview of Sjögren's Syndrome
Sleep Disorders and Sjögren's
Dermatological Issues and Sjögren's
Gastrointestinal Issues of Sjögren's
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