

Fatigue & Sjögren's

CAUSES OF FATIGUE IN SJÖGREN'S

- Treatable medical problems your doctor can test via blood tests; or medicines that cause fatigue can be stopped
- Systemic Inflammation from the disease itself
- Other common causes of fatigue that you can learn to identify and improve

A PRACTICAL APPROACH TO IMPROVE ENERGY LEVELS IN SJÖGREN'S BASED ON THE CAUSES ABOVE

1. Work with your doctor to consider trying treatments for Sjögren's targeting the immune system (*see List A*)
2. Ask your doctor if the medical tests listed in List B have been checked and treated if abnormal
3. Ask your doctor if any of your medications could be causing fatigue (See list C)
4. Work on Sleep Hygiene. Sit down and read the included list. Use a yellow highlighter and highlight everything you are not doing regularly. Pick one or two things to work on at a time. Over time, slowly try to incorporate everything in your lifestyle. Inadequate sleep is one of the most common problems we see in Sjögren's and is a major cause for making fatigue worse.
5. Take the "Self-Tests" for obstructive sleep apnea, depression, anxiety disorder, and fibromyalgia (included in this handout). If any of these are positive, show your results to your doctor and ask if there is the possibility of your having that problem or not. If so, ask for treatment. In the case of sleep apnea, ask your doctor if a sleep study is warranted.
6. Decrease stress in your life. Sit down and read the stress reduction list in this handout. Just as above, pick one or two things to work on, then slowly add on additional good habits over time. Many of these overlap with the sleep hygiene list, so it is a good idea to first choose those items that overlap with each other to work on first.
7. Join the CRESTA Fatigue Clinic's Facebook group "CRESTA Fatigue Clinic Health Champions"
8. Learn to accept fatigue as a part of your life and learn how to cope with it by doing the things in the last list of this handout. Hopefully, the severity and frequency of your fatigue will improve over time as you work on the above recommendations. Keep in mind "The Spoon Theory" (you only have so many spoonfuls of energy to use daily).

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A. MEDICATIONS TARGETING THE IMMUNE SYSTEM OF SJÖGREN'S THAT COULD POTENTIALLY HELP WITH FATIGUE

- **Plaquenil** (hydroxychloroquine)
 - Note: If you take Plaquenil, it is important to get 2 of the following eye tests done yearly, make sure your eye doctor is doing the correct tests (don't just assume they are being done)
 - VF 10-2 (preferable)
 - SD-OCT (preferable)
 - FAF (less preferable than the above two tests)
 - Mf-ERG (the most specific test, but hard to find)
 - IF you have Asian ancestry, you need 3 tests yearly, 2 of the above (hopefully both VF 10-2 plus SD-OCT test) plus a VF 24-2 or a VF 30-2 test
- **Benlysta** (belimumab)
 - For patients with lupus overlap
 - Best in patients with low C3 or C4 complement levels or high anti-dsDNA levels
- **Rituxan** (rituximab)
 - FDA indicated for rheumatoid arthritis
 - 2016 Guidelines state that it can also be considered in patient with:
 - Systemic symptoms that do not respond to usual treatments (Plaquenil, steroids, methotrexate, azathioprine)
 - Severe dry eyes not responding to Xiidra or Restasis
 - Severe dry mouth not responding to Salagen (pilocarpine) or Evoxac (cevimeline)

B. TESTS LOOKING FOR POTENTIALLY TREATABLE CAUSES OF FATIGUE IN SJÖGREN'S

- **BLOOD TESTS:**
 - **Blood counts: Hemoglobin (Hb, Hgb), hematocrit (Hct):** (low levels = anemia). Sjögren's patients are at increased risk for developing anemia due to inflammation.
 - **Thyroid tests: TSH** (elevated level = hypothyroidism or underactive thyroid condition; low level = hyperthyroidism, overactive thyroid). Sjögren's patients may have an increased risk for developing autoimmune thyroid conditions.
 - **Vitamin B-12** (low levels can cause fatigue and muscle weakness)
 - **Vitamin D** (low levels have been associated with fatigue and muscle weakness)
 - **ALT, AST** (elevated levels can be due to liver or muscle problems)
 - **Muscle enzymes: CPK** (very high levels can be seen in muscle inflammation, myositis; note... slightly elevated levels can be seen in African Americans and can be considered normal)
 - **Potassium (K)** (low potassium can cause muscle weakness)
 - **HCO₃** (plasma bicarbonate level): Low levels may be a clue to having interstitial nephritis (kidney inflammation from Sjögren's syndrome)

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- **Glucose and HbA1C** (elevated levels may indicate diabetes)
- **Serum creatinine (sCr, Cr, creat):** elevated level may indicate decreased kidney function
- **Calcium (Ca)** (elevated levels can cause weakness and fatigue)
- **HIV**
- **Hepatitis C (especially if you were born between 1945 and 1965)**
- **Celiac disease (IgA endomysial antibody, IgA gliadin antibody, IgA tissue transglutaminase antibody)**
- **CHEST X-RAY and/or CT scan** if clinically indicated (to look for scarring in the lungs, interstitial lung disease)
- **ECHOCARDIOGRAM AND PULMONARY FUNCTION TESTS** (screening tests for pulmonary hypertension, but this is rare in primary Sjögren's)

C. DRUGS THAT CAN CAUSE FATIGUE/WEAKNESS *(Not an exhaustive list)*

- Sleep medicines
- Pain medicines
 - Lyrica, gabapentin
 - Tramadol (a special note about tramadol ... it can also disrupt the sleep cycle if taken before bed, causing disrupted sleep and therefore fatigue the next day; in this situation, try taking the last dose before 5PM; it can also cause fatigue when taken in the day time as a direct side effect)
 - Opioid medications (also called narcotics) such as hydrocodone, oxycodone, etc. Have similar effects as tramadol above
- Antidepressants
- Benzodiazepines (used for anxiety disorder, such as Valium, diazepam, and lorazepam)
- Anti-psychotic medicines (used to treat bipolar disorder, schizophrenia, etc)
- Blood pressure medicines
- Cholesterol lowering medicines, especially statins
- Antihistamines (especially Benadryl, diphenhydramine)
- Alcohol abuse
- Antibiotics
- Illicit drugs (cocaine, marijuana, crack, Ecstasy, methamphetamine, etc)

SLEEP HYGIENE TECHNIQUES

- Use a humidifier in your bedroom (or have one installed in your central air): This is an absolute necessity for everyone who has Sjögren's and fatigue or trouble sleeping
- Use lubricating gel in eyes before going to bed (e.g. Refresh Liquigel, Systane Lubricant Eye Gel, and GenTeal Lubricant Gel)
- Wear moisturizing goggles to bed (e.g. TranquilEyes Hydrating Goggles, Moisture Goggles, Tranquileyes-Thermoeyes, EyeSeals)
- Use artificial saliva before bed; keep on your nightstand in case needed in middle of night
- Use a good moisturizer on skin before going to bed every night (decreases itchy skin in the middle of the night)

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- Maintain a regular sleep schedule; get up and go to bed the same time daily even on non-workdays and holidays
- Reduce stress in your life.
- Get exposure to light first thing in the morning to normalize your biological clock.
- Consider using a non-UV source of light exposure such as the Philips goLITE or the Miroco Light Therapy Lamp.
- Exercise daily; mornings and afternoons are best. Do not exercise right before bedtime.
 - Most professional medical groups recommend 150 minutes of moderate aerobic exercise weekly
 - If you do not know how to exercise safely and effectively with your particular medical situation, ask your doctor for a physical therapy referral to be evaluated and to have an exercise regimen designed specifically for you
 - Repeat this mantra whenever you feel too tired (or lazy) to exercise:
 - **“Exercise is as important to living as eating and sleeping”**
- Avoid naps late in the afternoon or evening.
- Finish eating two to three hours before bed; a light snack is fine, but avoid foods containing sugar as it can stimulate the mind and interfere with falling asleep.
- Limit fluids before bed to keep from getting up to urinate throughout the night.
- Avoid caffeine six hours before bed.
- Do not smoke; if you do, do not smoke for two hours before bed; nicotine is a stimulant.
- Avoid alcohol two to five hours before bed; alcohol disrupts the sleep cycle.
- Avoid medicines that are stimulating (ask your doctor).
- Avoid stimulating mind activities for a few hours before bed (reading technical articles, listing tasks to do, troubleshooting, paying bills, etc.).
- Have a hot bath one to two hours before bed; it raises your body temperature and you will get sleepy as your temperature decreases again afterward.
- Keep indoor lighting low for a few hours before bed.
- Establish a regular, relaxing bedtime regimen (aroma therapy, drink warm milk, read, listen to soft music, meditate, pray, do relaxation/breathing exercises).
- Ensure your sleeping environment is quiet and comfortable (comfortable mattress and pillows; white noise like a fan; pleasant, light smells).
- If pets ever wake you, keep them outside of the bedroom.
- Use the bedroom only for sleep and sex; never eat, read, or watch TV in bed.
- Never keep a TV, computer, or work materials in your bedroom.
- Go to bed only when sleepy.
- If you cannot go to sleep within fifteen to twenty minutes in bed, go to another room and read something boring under low light, meditate, pray, listen to soft music, or do relaxation/breathing exercises until sleepy.
- If you have dry mouth problems, use a mouth lubricant such as Biotene Mouth Spray before you go to bed.

“STOP” QUESTIONNAIRE FOR OBSTRUCTIVE SLEEP APNEA

(If you answer “yes” to three or more of the following, then you should have a sleep study done

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to make sure you do not have obstructive sleep apnea.

- Do you **S**nore loudly (louder than talking or loud enough for people to hear through closed doors)?
- Do you often feel **T**ired, fatigued, or sleepy during the daytime?
- Have you ever had anyone **O**bserve you stop breathing while you sleep?
- Are you being treated, or have you received treatment for high blood **P**ressure?

DEPRESSION SCREENING TEST: PHQ-9 Depression Questionnaire

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Over the last two weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3
Trouble falling or staying asleep, or sleeping too much	0	1	2	3
Feeling tired or having little energy	0	1	2	3
Poor appetite or overeating	0	1	2	3
Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	0	1	2	3
Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
Moving or speaking so slowly that other people could have noticed. Or the opposite, being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
Total _____ =	—	+__	+__	+__

Circle the corresponding number score to the right of each list of columns.

Add up the circled numbers in each column, then total these results.

Score of 5-9 = suggests mild depression

Score of ≥ 10 suggests major depression

ANXIETY DISORDER SCREENING TEST

GAD-7 Test for Anxiety

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Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious, or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Worrying too much about different things	0	1	2	3
Having trouble relaxing	0	1	2	3
Being so restless that it is hard to sit still	0	1	2	3
Becoming easily annoyed or irritable	0	1	2	3
Feeling afraid as if something awful might happen	0	1	2	3
Total score = ____	—	+__	+__	+__

Circle the appropriate number to the right of each list of problems.

Add up each column of numbers; then add up the total of each column to get your total score.

If you score 5 points or higher, you may have an anxiety disorder.

FIBROMYALGIA DIAGNOSTIC CRITERIA

Take this survey if you have had any of these symptoms for three months or longer.

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I. **Pain Score:** Circle each **body part** where you have had had pain in the past week:

- | | | |
|---------------------------------------------------|----------------------------------------------------|----------------------------------|
| <input type="radio"/> Left shoulder region | <input type="radio"/> Right shoulder region | <input type="radio"/> Chest |
| <input type="radio"/> Left upper arm | <input type="radio"/> Right upper arm | <input type="radio"/> Abdomen |
| <input type="radio"/> Left lower arm | <input type="radio"/> Right lower arm | <input type="radio"/> Upper back |
| <input type="radio"/> Left buttock or side of hip | <input type="radio"/> Right buttock or side of hip | <input type="radio"/> Lower back |
| <input type="radio"/> Left upper leg | <input type="radio"/> Right upper leg | <input type="radio"/> Neck |
| <input type="radio"/> Left lower leg | <input type="radio"/> Right lower leg | |
| <input type="radio"/> Left jaw | <input type="radio"/> Right jaw | |

Each area circled is 1 point. Add up each circled area for your Pain Score.

Total points for part I Pain Score = _____

II. **Symptom Score:** For each of the following three **symptoms** (a, b, and c), circle the number corresponding to how much it bothers you.

Scoring method for Symptom Score

For a, b, and c, use this scale:

- 0 = You have not had this problem at all.
- 1 = The problem is very mild and comes and goes.
- 2 = It causes considerable problems, or is often present at a moderate severity.
- 3 = The problem is severe, constant, or life-disturbing.

- | | |
|----------------------------------------------------------------------------|---------|
| a. How fatigued and tired are you? | 0 1 2 3 |
| b. Do you feel like you did not get a good night's sleep when you wake up? | 0 1 2 3 |
| c. Do you have difficulty remembering things or concentrating? | 0 1 2 3 |

For d, use this scale:

- 0 = no problems
- 1 = few problems
- 2 = a moderate number of problems
- 3 = a large number of problems

- | | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|
| d. How many problems (like pain, fatigue, weakness, drowsiness, difficulty thinking, insomnia, headaches, stomach upset, diarrhea, constipation, numbness, feeling too hot or cold, etc.) do you have? | 0 1 2 3 |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|

Add up each number for a, b, c, and d for Symptom Score total points

Total points for Symptom Score = _____

You may have fibromyalgia if:

- Your pain score is ≥ 7 and your problem score is ≥ 5
- Or your pain score is 3 – 6 and your problem score is ≥ 9

STRESS REDUCTION TECHNIQUES

- Learn to say “no” to increased amounts of work and duties.
- When you have children, it is even more important to learn to say “no” to additional

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- activities other than what is immediately important for your family and your health
- Learn to ask for help in doing activities.
 - Proactively lighten your load.
 - Prioritize the important things in your life; cut out activities that are less important.
 - Do yoga and/or tai chi (setting aside time for yourself is important!)
 - Get biofeedback training from a professional to learn to decrease anxiety and stress.
 - Do deep breathing exercises and perform “mental imagery” exercises.
 - Practice Mindfulness.
 - Pray frequently.
 - Meditate.
 - Prepare well ahead of time for any major activity.
 - Learn to practice good time management.
 - Plan specifically for periods of rest and relaxation in your routine every day. Learn to say positive things to yourself and compliment yourself for doing things well.
 - Do not think negative things about yourself.
 - When running errands or going to appointments, get ready early and give yourself more time than you think you need; always plan on arriving early for any occasion.
 - Schedule appointments and errands during less busy times such as early Saturday mornings. This can decrease stress due to traffic, waiting in long lines, and the like.
 - Learn not to argue with others. Learning and accepting that everyone has different opinions or ways of doing things and that many conflicts are not particularly important is essential (or worth the stress and headache).
 - Learn to take a deep breath, relax, leave before an argument begins or before you say something you may regret.
 - Learn to live at or below your means. Too many people in America try to keep up with the “Joneses” or other family members and friends. Learning to stay out of debt can greatly decrease stress. ‘
 - Always ask yourself “is this something I truly need, or just something I want?” before you buy it.
 - Whenever you feel stressed, put it into perspective compared to the important things in life (health, family, religion). Learn to “not sweat the small stuff.
 - Exercise regularly.
 - Schedule in at least eight hours of planned sleep a night.
 - Get good quality sleep by abiding by ALL sleep hygiene techniques on previous page
 - Do not skip healthy, planned meals.
 - Avoid unhealthy foods such as sweets, carbohydrates, greasy foods, and “fast food.”
 - Consider counseling to learn better communication skills if you have difficulties with relationships.
 - If you have depression or anxiety disorder, get good treatment for it If you are not sure if you have depression or anxiety, take the self-tests on previous pages. If you score high on the tests, show your doctor to see if you may have depression or anxiety contributing to stress
 - Consider attending a Sjögren's or chronic illness support group

GENERAL FATIGUE MANAGEMENT STRATEGIES

- Join the Facebook group: CRESTA Fatigue Clinic health champions

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- Go on a low-calorie or low-carbohydrate diet to lose weight if you are overweight
- Consider trying an antidepressant if any depression symptoms exist (such as insomnia, difficulty concentrating, moodiness, loss of interest in doing activities, loss of libido or sexual interest, if you have decreased doing social activities, or if you have feelings of guilt or low self-worth)
- Learn your limits; pace yourself
- Educate family, friends, co-workers, and employers about your condition and how it affects you
- Learn to ask for help when you need it
- On bad fatigue days, do not do more than one important activity. You can try to do more on better days (Remember “The Spoon Theory” ... you only have so many spoons’ worth of energy to accomplish tasks each day)
- Listen to your body; take 20-30-minute planned rests every few hours
- Identify stressors in your life. Work with a mental health professional if needed
- Exercise regularly (consider something “fun” such as Wii Fit, dancing, etc.). Try to move every day.
- If you work, ask your employer for accommodations for your condition. If you need help with this, go to www.askjan.org for assistance and guidance

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