Fatigue and Systemic Lupus Erythematosus (SLE)

CAUSES OF FATIGUE IN SLE

Systemic Inflammation from the disease itself

Other treatable medical problems your doctor can test via blood tests

Other common causes of fatigue that you can learn to identify and improve

A PRACTICAL APPROACH TO IMPROVE ENERGY LEVELS IN SLE BASED ON THE CAUSES ABOVE

1. Work with your doctor to consider trying treatments for SLE targeting the immune system (List A) if you are not in remission. Hydroxychloroquine, quinacrine, and Benlysta (belimumab) have the best medical evidence of their helping out with lupus fatigue.

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 life style. Inadequate sleep is one of the most common problems we see in SLE 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 you having that particular 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 list. 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. 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.”

A. MEDICATIONS TARGETING THE IMMUNE SYSTEM OF SYSTEMIC LUPUS THAT COULD POTENTIALLY HELP WITH FATIGUE

- Plaquenil (hydroxychloroquine)
- Quinacrine (available from Village Apothecary Green in Bethesda MD and Akina pharmacy in Chantilly VA, and ComCare in Bowie MD)
- Benlysta (belimumab)
- Steroids (prednisone, methylprednisolone) … but we do not want to use these very often
- Methotrexate
- Imuran (azathioprine)
- Arava (leflunomide)
- CellCept (mycophenolate mofetil)
- Rituxan (rituximab)
- Orencia (abatacept)
- Actemra (tocilizumab)
- Potential future therapies (interferon antagonists)
B. **TESTS LOOKING FOR POTENTIALLY TREATABLE CAUSES OF FATIGUE IN SLE**

- **BLOOD TESTS:**
  - **Hemoglobin (Hb, Hgb), hematocrit (Hct):** (low levels = anemia). Lupus patients are at increased risk for developing anemia due to inflammation.
  - **TSH** (elevated level = hypothyroidism or underactive thyroid condition; low level = hyperthyroidism, overactive thyroid). Lupus 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)
  - **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)
  - **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)

- **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)

C. **DRUGS THAT CAN CAUSE FATIGUE/WEAKNESS** (This isn’t 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
- Anti-histamines (especially Benadryl, diphenhydramine)
- Alcohol (especially when drunk before bed; it disrupts the sleep cycle)
- Illicit drugs (cocaine, marijuana, crack, Ecstasy, methamphetamine, etc)
SLEEP HYGIENE TECHNIQUES

• Reduce stress in your life.
• Get exposure to light first thing in the morning to set your biological clock. Use a non-ultraviolet light source of light exposure such as the Philips goLITE (Remember that UV light makes lupus worse, so you want a non-UV source such as the goLITE).
• Exercise daily; mornings and afternoons are best. Don’t exercise right before bedtime.
• 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, don’t 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, trouble-shooting, 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 can’t 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 dryness problems, do the following (dryness can cause sleep problems):
  - Use a humidifier in your bedroom (or have one installed in your central air)
  - 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 some on your night stand in case needed in middle of the night
  - If you have dry mouth problems, use a mouth lubricant such as Biotene Mouth Spray before you go to bed.
  - Use a good moisturizer on skin before going to bed every night (decreases itchy skin in the middle of the night)
  - Maintain a regular sleep schedule; get up and go to bed the same time daily even on non-work days and holidays.
“STOP” QUESTIONAIRRE FOR OBSTRUCTIVE SLEEP APNEA (If you answer “yes” to two or more of the following, then you should have a sleep study done 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

<table>
<thead>
<tr>
<th>Over the last two weeks, how often have you been bothered by any of the following problems?</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling bad about yourself, or that you are a failure, or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>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</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total _____ =</td>
<td>__</td>
<td>+__</td>
<td>+__</td>
<td>+__</td>
</tr>
</tbody>
</table>

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**

Over the last two weeks, how often have you been bothered by the following problems?

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nervous, anxious, or on edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Not being able to stop or control worrying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Worrying too much about different things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having trouble relaxing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being so restless that it is hard to sit still</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Becoming easily annoyed or irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling afraid as if something awful might happen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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 anxiety disorder.
FIBROMYALGIA DIAGNOSTIC CRITERIA

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

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

- ○ Left shoulder region
- ○ Right shoulder region
- ○ Left upper arm
- ○ Right upper arm
- ○ Left lower arm
- ○ Right lower arm
- ○ Left buttock or side of hip
- ○ Right buttock or side of hip
- ○ Left upper leg
- ○ Right upper leg
- ○ Left lower leg
- ○ Right lower leg
- ○ Left jaw
- ○ Right jaw
- ○ Chest
- ○ Abdomen
- ○ Upper back
- ○ Lower back
- ○ Neck

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 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. Declutter your life.
-- Prioritize the important things in your life; cut out activities that are less important.
-- Do yoga and/or tai chi.
-- Get biofeedback training from a professional to learn to decrease anxiety and stress.
-- Do deep breathing exercises and perform “mental imagery” exercises.
-- 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 very important is essential (not 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 the 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 Lupus Foundation support groups to learn techniques in dealing with lupus, stress, and relationships
GENERAL FATIGUE MANAGEMENT STRATEGIES

- Go on a low-calorie or low-carbohydrate diet to lose weight if you are overweight (studies show that forced weight loss improves energy levels in lupus)
• 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.). Make an effort 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


The best to you, your life, and your health!

Donald E. Thomas, Jr., MD
Author of “The Lupus Encyclopedia: A Comprehensive Guide for Patients and Families”
Arthritis and Pain Associates of PG County
301-345-5600
www.arthritispainpg.com
www.facebook.com/LupusEncyclopedia
www.twitter.com @lupuscyclopedia