

The Lupus Secrets

by Donald Thomas, MD

1. Avoid sulfa antibiotics (Septra and Bactrim); include them in your allergy list.
2. Keep a personal record of your labs, biopsy results, x-rays, and doctors' notes (especially those that established your diagnosis of SLE).
3. See a rheumatologist or other lupus specialist regularly, commonly every three months, even if you feel great. Kidney inflammation occurs in around 40% of SLE patients and doctors can identify it at early stages (by way of a urine sample) when it is easy to treat. It causes no symptoms until it becomes severe.
4. Take 81 mg of aspirin a day if you are at increased risk for heart attacks or strokes or if you are positive for antiphospholipid antibodies (check with your doctor first).
5. Get eight hours of quality sleep a day. (Get a list of sleep hygiene recommendations from your doctor if sleep is a problem).
6. Tell your doctor if you feel depressed or down in the dumps, especially if you have thoughts about hurting yourself.
7. If you have problems with dryness, ask your doctor if you could have Sjogren's syndrome along with your lupus. Treatment is important and available.
8. Keep blood pressure consistently < 140/90 mm/Hg; or < 130/80 mm/Hg if you have had a heart attack or stroke, or have chronic kidney disease.
9. Keep cholesterol normal (check with your doctor).
10. Do not smoke cigarettes. Smoking causes lupus to be more active, keeps hydroxychloroquine from working, increases strokes and heart attacks (which are the most common causes of death in lupus patients), increases the risk for lung cancer (which occurs more commonly in lupus patients), and causes broken bones from osteoporosis.
11. If you are unable to stop smoking on your own, go to www.smokefree.gov or call 1-800-QUIT-NOW.
12. Exercise regularly. If you are uncertain how to exercise safely with your medical condition, ask your doctor for a physical therapy referral to learn how.
13. Maintain normal weight. If you have trouble, ask your doctor for recommendations.
14. If you get a fever, call/see your primary care doctor ASAP in order to make sure you do not have an infection.
15. Get an influenza vaccination yearly in the fall.
16. Get the Pneumovax and Prevnar PCV-13 pneumonia vaccines if you are on medicines that lower your immune system.
17. Keep up to date on all vaccinations to prevent infections (ask your doctors).
18. Have screening tests done regularly for cancers (e.g., breast, cervical, colon, prostate, etc.).
19. Consider getting the human papilloma virus vaccine (Gardasil) series to prevent HPV-associated cancers if you are less than 26 years old.
20. Get adequate calcium (ask your doctor how much).
21. If you are on any stomach acid-lowering medicines, consider taking calcium citrate, which may be better absorbed than other forms.

22. Get adequate vitamin D. If you are vitamin D deficient, take vitamin D supplements for the rest of your life.
23. If you take steroids (such as prednisone) regularly, make sure you are taking a medicine to prevent osteoporosis if it is appropriate; check with your doctor.
24. If you take steroids regularly, consider wearing a medical alert bracelet.
25. Learn to take your medications regularly.
26. Take a completed medication list or a bag of all your medicines to every doctor's visit.
27. Take Plaquenil (hydroxychloroquine) regularly as one of your medications if prescribed by your doctor.
28. Make sure to see your eye doctor regularly for eye exams on your hydroxychloroquine.
29. Insist that the eye doctor performs 2 of the following 4 tests every year (if he or she doesn't have the proper equipment, see a different doctor): VF 10-2, SD-OCT, mfERG, FAF
30. Use an Amsler grid monthly when taking Plaquenil (hydroxychloroquine) or chloroquine. You can get one from your eye doctor, or download one from www.amslergrid.org.
31. Use sunscreen every day and regularly avoid UV light.
32. Avoid alfalfa and mung bean sprouts, which can cause lupus to get worse.
33. Eat a well-balanced diet with plenty of fruits and vegetables.
34. Include fish, walnuts, and flax seed rich in omega-3 fatty acids in your diet. These may decrease inflammation in lupus.
35. Learn how to decrease stress in your life. (Stress can make lupus worse).
36. Do not take Echinacea (supplement promoted to treat colds) as it can worsen lupus.
37. Consider taking DHEA to help your lupus if approved by your rheumatologist.
38. Do not get pregnant until cleared by your rheumatologist.
39. If you are anti-SSA or anti-SSB positive and get pregnant, alert your OB/GYN so you can get fetal heart monitoring beginning at sixteen to eighteen weeks of pregnancy.
40. If you get pregnant, see your rheumatologist more often to monitor your lupus closely.
41. Ensure your work environment is conducive for your SLE. If you feel that you need work accommodations for your condition, learn more from the Job Accommodation Network at www.askjan.org and 800-526-7234.
42. Continue to educate yourself about lupus; consider joining a lupus educational organization such as The Lupus Foundation of America at www.lupus.org or 800-558-0121.
43. Read a good educational book about lupus such as
 - a. "The Lupus Encyclopedia: A guide for patients families" by Donald Thomas, MD (On sale now at www.amazon.com; or call Johns Hopkins Press at 1-800-537-5487 to order directly and give the code "HNAF" to get 30% off)
 - b. "The Lupus Book" by Daniel Wallace, MD (available at www.amazon.com)
44. Consider joining a lupus support group (via Lupus Foundation)
45. If you are on Facebook, go to www.facebook.com/LupusEncyclopedia to learn more about lupus (make sure to click "like" in order to get access to new posts)
46. Every day tell yourself it is going to be a good day, that there is a lot in your power to do well, and remember that knowledge is power.