

Preventive Care Strategies: Living with Lupus

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Introduction

- * Lupus is a chronic autoimmune disease that can affect any part of the body (skin, joints, major organs)
- * Symptoms and signs of lupus tend to last for months → years and can sometimes come and go (flares)
- * The immune system is the key player in lupus
 - * Cannot tell the difference between “self” and “foreign” and creates antibodies which attack healthy tissue
 - * Chronic inflammation contributes to pain and organ damage over time

Introduction

- * Lupus can range from mild to life threatening
- * Patients with lupus are at higher risk for:
 - * Heart disease, stroke, heart attacks
 - * Osteoporosis (especially if you are taking prednisone)
 - * Certain infections
- * There is no way to prevent the development of lupus
- * With good medical care, most patients can lead a full and healthy life
- * My personal goal: to provide you with the tools and information to help you lead a long and happy life!

Objectives

- * Learn about ways to prevent lupus flares by protecting the skin
- * Learn about Raynaud's phenomenon and ways to prevent it
- * Discuss ways to decrease heart disease in patients with lupus
- * Discuss the important vaccines which are safe and recommended for patients with lupus
- * Learn about ways to improve bone health in patients with lupus
- * Discuss cancer risk in lupus patients and the current cancer screening recommendations
- * Discuss ways to have a healthy pregnancy in patients with lupus

Why does the skin matter?

- * Most people with lupus experience some sort of skin involvement during the course of their disease
- * There are three major types of skin involvement in lupus:
 - * Discoid lupus erythematosus (DLE)
 - * Scarring rash, typically over face/ears/scalp
 - * Subacute cutaneous lupus erythematosus (SCLE)
 - * Does not leave a scar, +++ photosensitive
 - * Acute cutaneous lupus erythematosus (ACLE)
 - * Malar rash = “butterfly rash”
- * Research has shown that exposure of the cells of the skin to UV light leads to DNA damage which can then lead to autoantibody formation and cause local and eventually systemic inflammation

Photosensitivity



Preventive Strategies: Skin

- * Avoid sun exposure (beaches, snow, lakes)
 - * Especially between 10AM and 3PM
- * Use sunscreen DAILY (whether it is cloudy or rainy)
 - * Apply 30-60min before going outside, reapply every 4-6hours
 - * Use sunscreen which is at least SPF30; higher SPF such as 70 and Helioplex is available for highly sensitive patients
- * Ultraviolet A vs. Ultraviolet B
 - * UVA = 95% of all UV radiation; less intense than UVB but can penetrate glass
 - * Typically leads to a tanning of the skin, affects cells called “keratinocytes” → a tan occurs from damage to the skin’s DNA and the skin darkens to prevent more DNA damage
 - * Tinted glass may be useful
 - * UVA can be produced from incandescent and halogen lamps
 - * UVB = “UV Bad”; plays a key role in the development of skin cancer
 - * Causes skin reddening and sunburn
 - * Does not significantly penetrate through glass
 - * UVB can be produced from uncovered fluorescent bulbs
- * Consider sun protective clothing (SPF30 or greater)
 - * www.sunprecautions.com
 - * www.sungrubbies.com

Preventive Strategies: Skin

- * Avoid medications that may cause photosensitivity
 - * Your doctor may avoid prescribing certain antibiotics, certain diuretic and blood pressure medications and other drugs which may worsen sun sensitivity
- * Quit smoking
 - * Research has shown that smoking increases the risk of skin involvement in lupus and may contribute to the development of more severe disease
 - * Smoking may also reduce the likelihood of the response of the skin lesions to medications like Plaquenil

What is Raynaud's phenomenon?

- * Definition: color changes (blue, white and red) that occur in fingers and, sometimes, toes after exposure to cold temperatures and with increased stress
- * Blood flow to the hands, fingers, toes is temporarily reduced
- * Can lead to finger swelling, color changes, numbness, pain, skin ulcers and rarely gangrene of the fingers and toes
- * Most common causes: Lupus, scleroderma, rheumatoid arthritis, Sjogren's syndrome
 - * Others: medications, smoking, disease of the arteries, injury

Raynaud's Phenomenon



Preventive Strategies: Raynaud's

- * Avoid cold exposure, especially sudden changes in temperature
 - * For example, walking into the frozen section of a grocery store
- * Keep the whole body warm (not just hands/feet)
 - * Thermal underwear, layered clothing, heat-conserving hat
 - * Put them on before you go outside
 - * Wear a coat with cuffs that fit snugly around your mittens or gloves to prevent cold air from reaching your hands
- * Keep the fingers and toes warm
 - * Winter gloves/mittens (sometimes 2 pair), chemical hand warmers, heavy wool stockings/socks
 - * Do not walk barefoot
- * Protect your nails and avoid injuries to your hands/feet
- * Avoid wearing things that decrease blood flow
 - * Tight wristbands, tight rings, tight shoes
- * Run your car heater for a few minutes before driving in cold weather

Preventive Strategies: Raynaud's

- * When taking food out of the refrigerator or freezer, wear gloves, mittens or oven mitts.
- * Some people find it helpful to wear mittens and socks to bed during winter.
- * Because air conditioning can trigger attacks, setting your air conditioner to a warmer temperature may help prevent attacks
- * Avoid potential triggers such as smoking, stress, certain medications
- * If you think you are having an attack:
 - * Put your hands in a warm place (armpits, under/between thighs), move to a warmer area, rub your hands together, place them under warm water (NOT hot water), move your arms around in a windmill pattern, massage your hands/toes, wiggle your fingers/toes
- * If your symptoms do not go away with these general measures, you may need prescription medication to help prevent these attacks

Let's talk about heart health...

- * Lupus can affect the cardiovascular system, which includes your heart and blood vessels
- * In fact, cardiovascular disease, not lupus itself, is the number one cause of death in people with lupus
 - * Therefore, it is very important that you take steps to maintain optimal heart health
- * Atherosclerosis occurs when cholesterol and other inflammatory substances build up along the inner lining of the arteries causing “plaque”
 - * Eventually, the plaque can become hard and prevent blood flow to various parts of the body, including the heart and brain leading to heart attacks and stroke

Cardiovascular disease in Lupus

- * Research has shown that being overweight and having high blood pressure are the two most important predictors of heart disease in lupus patients
 - * The risk of heart attack in women with lupus aged 35-44 is 50-times greater than that of women without lupus, and for everyone with lupus the risk is increased 7 to 9-fold
 - * 50% of people with lupus experience hypertension (high blood pressure), which is defined as a blood pressure of greater than 140/90 mmHg
 - * Goal blood pressure is around 120/80mmHg

Preventive Strategies: Heart

- * Do not smoke, since smoking increases the risk of cardiovascular disease and atherosclerosis
- * A low-fat, low-cholesterol diet is recommended
 - * Your doctor may start cholesterol lowering medication to help with this
- * Focus on eating whole grains, vegetables, and lean sources of protein
- * Limit your sodium (i.e., salt) intake, since sodium levels are directly linked to blood pressure
- * Try to exercise at least 30 minutes per day
 - * This goal can be difficult for people with lupus who have joint and muscle pain, fatigue, and other symptoms. However, engaging in low-impact daily activities such as walking, biking, yoga, Tai chi, and other forms of stretching may help to decrease some of this pain while also helping you to maintain a healthy weight and strong cardiovascular system

Infections, Vaccines and Lupus

- * When you have lupus, you are at increased risk for all kinds of infections
 - * The way lupus affects the immune system can sometimes limit the body's ability to fight off foreign invaders, such as bacteria and viruses
 - * People with lupus often take immunosuppressive medicines to control their overactive immune system and these medications decrease the body's ability to respond effectively to infection, leaving them at risk

Infections, Vaccines and Lupus

- * What types of infections are common in patients with lupus?
 - * Respiratory system: lungs → pneumonia, colds, flu
 - * Urinary system: kidneys/urinary tract → urinary tract infections
 - * Skin: bacterial skin infections
 - * Others: candida (yeast) infection, Herpes Zoster infection (shingles)
- * In patients with lupus, sometimes infections tend to last longer and can require a longer period of treatment with antibiotics

Preventive Strategies: Infection

- * Do your best to avoid anyone who has a cold or other contagious condition
- * During cold and flu season, wash your hands often to cut down transmission of infectious germs
- * Make sure you and the members of your family are up to date on recommended vaccines to prevent the spread and to help your immune system fight infection
 - * Best time to get your vaccines is BEFORE you start immunosuppressive medications

Vaccines and Lupus: Safety

- * Seasonal Flu Vaccine (Once a year)
 - * Flu shot = pieces of proteins from different strains of the flu virus which are NOT live (killed particles); vaccine changes composition frequently because of different strains and mutations throughout the country/world
 - * Cannot “give you the flu” but can cause a low grade immune response which includes low grade fever, muscle aches, injection site reactions
 - * FluMist spray = nasal spray, LIVE attenuated vaccine
 - * Not recommended for patients with lupus, anyone living with a person with lupus or any one taking immunosuppressive medications
- * Safety of the seasonal influenza vaccine (flu shot)
 - * Considered to be safe and effective for people with lupus
 - * Has not been shown to increase the risk of lupus flare

Vaccines and Lupus: Safety

- * Pneumococcal vaccine (Pneumonia shot)
 - * Pneumovax PPSV23
 - * Given once and then a booster 5 years later
 - * Prevents complications from infection with most common strains of *Streptococcus pneumoniae* bacteria
 - * Prevnar 13
 - * Given once, at least one year apart from the Pneumovax
 - * Used to be given only to children but recently the CDC started to recommend this vaccine for adults with conditions that suppress/alter the immune system
- * Safety of the pneumonia vaccines
 - * The pneumonia vaccines, like the flu vaccine, can cause some mild symptoms of local swelling and inflammation in the arm, low grade fever and body aches but are considered to be safe and effective
 - * Have not been shown to increase the risk of lupus flare

Vaccines and Lupus: Others

- * Herpes Zoster (Shingles) and Zostavax
 - * People with lupus are at higher risk of getting shingles, compared to those without lupus, and the effects of shingles can be painful and long lasting
 - * Not everyone with lupus should get this vaccine because it is a LIVE (but weakened) virus
 - * Who is eligible?
 - * If you are older than 50
 - * If your lupus is well controlled
 - * If you are on LOW doses of **immunosuppressive** medications such as prednisone, plaquenil, methotrexate, azathioprine
 - * Who should not get the vaccine?
 - * If you are having a lupus flare
 - * If you are on high doses of steroids, mycophenolate mofetil, cyclophosphamide, and any biologic or infusion medications
- * Talk to your doctor and ask them whether the Shingles vaccine is right for you.

Vaccines and Lupus: Others

- * The quadrivalent human papilloma virus (HPV) vaccine has also been shown to be safe and reasonably effective in patients with stable lupus, without increasing disease activity or flares
- * The Hepatitis B vaccine appears to be safe in patients with stable lupus
- * We do **not** immunize potentially immunosuppressed patients (including those treated with glucocorticoids alone at doses equivalent to ≥ 20 mg/day of prednisone for more than two weeks) with **live** vaccines (measles, mumps, rubella, varicella, yellow fever and smallpox)

Bone health and Lupus

- * Osteoporosis (bone thinning) occurs when the bones lose calcium and other minerals that help keep them strong and compact
 - * Can lead to fractures, bone pain, and shorter stature
 - * Everyone is at risk for osteoporosis as they age, women more so than men (after menopause)
 - * People with lupus are at increased risk for osteoporosis compared to people who do not have lupus
- * Fractures and osteoporosis in patients with lupus
 - * Not just from steroid use!
 - * Research shows that bone integrity is lost even in patients who have not been on high dose steroids over long periods of time → chronic inflammation from lupus itself can affect bone health

Diagnosing Osteoporosis: DEXA

A bone density scan is a low-dose x-ray which checks an area of the body such as the hip, hand or foot for signs of mineral loss and bone thinning



Bone health and Lupus

- * Osteoporosis vs. osteopenia
 - * Osteopenia is a condition in which bone mineral density is lower than normal and is considered by many doctors to be a precursor of osteoporosis
 - * Not everyone with osteopenia will go on to develop osteoporosis but these people should be monitored and treated with calcium and vitamin D supplementation

Bone health and Lupus

- * Vitamin D - an oil soluble vitamin with many functions
 - * It helps absorb dietary calcium and phosphorus from the intestines
 - * It helps decrease bone resorption/breakdown
 - * A low vitamin D is diagnosed with a blood test called '25-hydroxyvitamin D level or 25-OH Vitamin D'
 - * Normal level = greater than 30ng/mL
 - * Vitamin D insufficiency = 20-30ng/mL
 - * Vitamin D deficiency = less than 20ng/mL

Bone health and Lupus

- * Bisphosphonates
 - * Class of medications which help to slow the breakdown and removal of bone (resorption)
 - * Typically prescribed together with Calcium/D
 - * Most common bisphosphonates
 - * Alendronate (Fosamax) - weekly or daily pill
 - * Risedronate (Actonel) - weekly/daily/monthly pill
 - * Ibandronate (Boniva) - daily/monthly pill or IV injection every 3 months
 - * Zoledronic Acid (Reclast) - IV infusion, once a year

Preventive Strategies: Bone

- * Modification of lifestyle factors
 - * Eliminate cigarette smoking
 - * Limit alcohol consumption
 - * Maintain a weight-bearing exercise regimen
- * Work with your rheumatologist to limit steroid therapy to the lowest possible dose and duration
- * Supplement your diet with calcium and vitamin D
- * Have your bone mineral density test (DEXA) checked to see if you need additional medications such as bisphosphonates
- * If you are on chronic steroids, your rheumatologist may start you on a low dose bisphosphonate to prevent osteoporosis

Calcium and Vitamin D

- * How much do I need?
 - * Calcium = on average 1,200mg every day
 - * Vitamin D = on average 800-1000IUs every day
 - * If your Vitamin D level is very low you may need 8 to 12 weeks of high dose ergocalciferol 50,000IU
- * But Dr. Fradlis, I don't like taking calcium, it makes me constipated and the pills are really big!
 - * Try to increase your calcium intake from the diet
 - * Yogurt, milk, cheese, spinach, collard greens, salmon, tofu
 - * Milk and orange juice fortified with calcium/D
 - * Try the chewable chocolate calcium or gummies instead

Lupus and Cancer, what is my risk?

- * Lupus (as well as other autoimmune diseases) is linked to an increased risk in certain types of cancer
 - * Lymphoma
 - * Cervical cancer
- * Risk is greatest in the earlier stages of lupus
 - * Some connection to medications (azathioprine, mycophenolate mofetil) exists but research has shown that exposure to immunosuppressive therapy is not the ONLY link between lupus and cancer

Lupus and Lymphoma

- * Studies show an increased risk of both Hodgkin's and non-Hodgkin's lymphoma in lupus patients
 - * B-cells (lymphocytes) are overstimulated in lupus and this, in combination with an impaired immune system is believed to play a role in the development of lymphoma
- * People who also have Sjogren's syndrome (a condition which is common in people who have lupus) experience an even greater risk of developing lymphoma and are typically monitored for this by their rheumatologist

Lupus and Cervical Cancer

- * Certain studies have shown an elevated risk of cervical cancer and abnormal PAP tests in women with lupus
- * It is thought that women with lupus have a decreased ability to fight off HPV (human papilloma virus) which is the virus associated with cervical cancer
 - * The HPV vaccine (Gardasil) is recommended in young women with lupus to help decrease this risk

Lupus and Other Cancers

- * **Breast cancer and endometrial cancer**
 - * Some data show that women with lupus are at an increased risk for breast cancer and this is thought to be connected to estrogen levels which are increased in lupus patients
 - * There is also some new evidence that the risk of endometrial cancer is slightly increased in women with lupus
- * **Lung cancer**
 - * Lung cancer is about 1.4 times more common in lupus patients than the general population
 - * Much like in patients who do not have lupus, lung cancer is largely related to smoking (85%)

Lupus and Cancer

- * Despite the evidence that people with lupus are at an increased risk for cancer, studies show that lupus patients are actually *less* likely than the general population to undergo recommended cancer screening tests
 - * Difficulty with access to care
 - * Doctors not getting to address cancer risk because they are busy tackling symptoms of lupus

Preventive Strategies: Cancer

- * Recommended cancer screening
 - * Mammogram (yearly in women >40yo)
 - * Pap smear (every 3-5 years in women between 21-65yo)
 - * Colonoscopy (every 10 years beginning age 50)
- * Smoking cessation
- * Regular exercise/healthy diet
- * Tell your doctor if you are experiencing fevers (not explained by infection or a lupus flare), night sweats, unintentional weight loss

Lupus and Pregnancy

- * MYTH: Women with lupus should never become pregnant
- * FACT: Your chances for a successful pregnancy are excellent if you plan properly—when lupus symptoms are in remission—and your rheumatologist and specialists in maternal-fetal medicine monitor you closely

Lupus and Pregnancy

- * Certain factors can make you at higher risk for lupus flares and poor fetal outcome during your pregnancy:
 - * Pre-existing or present hypertension
 - * History or presence of kidney disease
 - * History of previous preeclampsia
 - * History of low platelets
 - * History of blood clots
 - * History or presence of antiphospholipid antibodies
- * All lupus pregnancies are considered “high risk”
 - * Even though many pregnancies do not have any complications

Lupus and Pregnancy

- * Risks of pregnancy in women with lupus are twofold: risk for the mother AND risk for the fetus
- * Risk of miscarriage is increased in women with lupus
 - * Later in the pregnancy (2nd and 3rd trimester) fetal losses are usually related to antiphospholipid antibody syndrome
 - * All patients should be screened for APL antibodies
 - * Patients with APL antibodies may be started on aspirin +/- heparin/lovenox during their pregnancy
- * Risk of preterm birth and intrauterine growth retardation is increased and related to pre-eclampsia and premature rupture of membranes
- * Risk of lupus flare during pregnancy has been reported in women who had active disease when they became pregnant

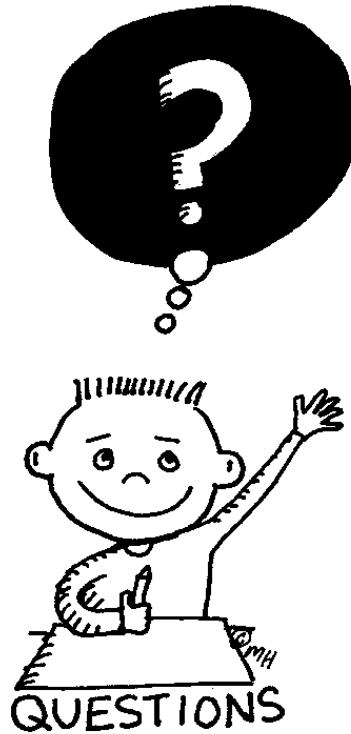
Lupus and Pregnancy

- * Important lab tests/studies during pregnancy
 - * Urinalysis - to check for protein in the urine
 - * Complete blood count, liver and kidney function tests
 - * Antiphospholipid antibody tests - to check for risk of miscarriage and blood clots
 - * Anti-SSA/Ro and anti-SSB/La antibodies - which are important in the development of fetal heart block and neonatal lupus and may lead to additional testing during the second trimester with fetal ECHO
 - * Anti-dsDNA antibodies
 - * Complement levels

Tips for a healthy pregnancy

- * The best time to become pregnant is when your lupus is under control or you are in remission
- * Talk to your doctor in advance - 3 to 6 months before you plan on becoming pregnant - because you may need to stop certain medications which may be harmful to the baby (ex. mycophenolate mofetil, cyclophosphamide, methotrexate)
 - * Plaquenil is generally safe in pregnancy and during lactation as is prednisone
 - * Azathioprine is an acceptable alternative to mycophenolate mofetil
- * See your rheumatologist frequently (every 1-2 months) for a check-up and labs/urine studies if needed
 - * The perinatologist and obstetrician will also see you regularly, follow their recommendations and report any symptoms to a doctor ASAP

Questions?



Thank you!

