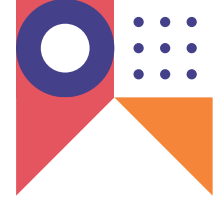


WELLNESS TIPS FOR LIVING WITH LUPUS





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A LOOK AT LUPUS THROUGHOUT THE LIFESPAN

Hormones regulate many of the body's functions and can have an impact on lupus symptoms and severity. Many women experience changes in their lupus symptoms that synchronize with their menstrual cycle, due to a female sex hormone called [estrogen](#). For example, symptoms may worsen before menstrual periods and during pregnancy, when estrogen levels are particularly high. While there is a correlation between estrogen levels and lupus symptom severity, this does not mean that estrogen or other hormones cause lupus.

A maternal-fetal medicine specialist is an obstetrician who has completed extra years of training to manage complicated and high-risk pregnancies – providing care for both mother and baby before, during, and shortly after pregnancy.

Talk to your health care provider about how hormones may be affecting your lupus symptoms throughout the different stages of your life.

Adolescence

 **1 in 5** people who have lupus develop it in childhood¹⁶

Although lupus is usually diagnosed in adults, lupus can develop in children and teenagers and is more common among girls than boys. There are a variety of medications available for treatment. Parents and families should work closely with their pediatric [rheumatologist](#) and focus on promoting a healthy lifestyle early and maintaining long-term health.

As an adolescent approaches the age of 18, it may be time to have a conversation with their pediatric care provider about transitioning to adult care. This transition can be challenging. Ask your current health care team to provide recommendations and/or referrals to adult-specialty providers in your local area. If you plan to move away for college or work, try to identify potential providers in the new area, and reach out to them ahead of time to see whether they are taking on new clients.

Pregnancy and Maternal Health Care

Women with lupus can safely get pregnant, have uneventful pregnancies, and deliver healthy babies. However, because lupus can cause certain pregnancy complications such as pre-eclampsia, increased blood clots, diabetes, and preterm delivery, it is important to find an obstetrician and a hospital with experience managing high-risk pregnancies. Women who are planning to have a family should have early conversations with their [rheumatologist](#) and OB/GYN about how their lupus and treatment plan may impact pregnancy.



Some considerations are:

- ▶ **Medication adjustments.** Discuss the risks and benefits of staying on or switching your current therapies before trying to conceive to ensure you are optimizing both your health and your future baby's health.
- ▶ **Symptoms and Flares.** The risk of flares does not increase with pregnancy, but flares can occur during pregnancy or immediately after birth.
- ▶ **Breastfeeding.** Most women with lupus are able to breastfeed their babies, but this depends on the type and dosage of medications you are using to treat your lupus.
- ▶ **Postpartum Period.** The fatigue experienced by new mothers can be elevated for women with lupus. Some women report having more severe symptoms or a flare after delivery, so it is helpful to plan ahead. Involve those in your support system to come up with a plan to help you care for your newborn and yourself post-delivery.

Menopause

As a woman gets older, her ovaries produce less estrogen and her menstrual cycle begins to change and eventually stops, resulting in menopause. The average

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3% of babies born to moms with lupus can have neonatal lupus. Your newborn may have a rash and abnormal blood counts, but this condition is usually temporary, disappearing after 6-8 months as the baby's immune system becomes more developed.¹⁷

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age of menopause for women in the United States is 51. Due to this eventual decline in estrogen, most women experience a decrease in lupus symptoms and flares after menopause.

Hormone replacement therapy may be used to treat menopausal symptoms by supplementing the estrogen that the body has stopped making. While this treatment has a chance of increasing risk for developing mild to moderate flares, it is also associated with significant improvement in menopausal symptoms and quality of life. Just like women in any other life stage, the most important aspect to treating postmenopausal lupus is tracking symptoms and talking to your health care providers about any changes in symptoms or flares.

ASSISTANCE AT SCHOOL FOR GIRLS WITH LUPUS

Due to the effects of lupus and lupus medications, children may experience joint stiffness, fatigue, pain, sensitivity to light, and trouble concentrating that can be challenging while at school. With proper treatment, a consistent routine, and adequate support, adolescents can be very successful in their educational pursuits.

Under the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA), K-12 public schools are required to create special accommodations for students with a disability. Lupus is an eligible condition for this accommodation, that if approved, allows students to participate in specialized education plans, such as a **504 Plan** and/or an **Individualized Education Plan** (IEP).

School Accommodations

Qualifying for lupus accommodations will likely involve having the student with lupus undergo an evaluation and provide a note from their health care provider(s). Once qualified, the student and their parents must collaborate with their providers and the **school faculty and staff**

(administrators, teachers, and nurse) to determine which accommodations should be put in place to best help the student succeed in their school environment.

Example accommodations at school might include:

- ▶ Modified physical education
- ▶ Extra time or short breaks during tests
- ▶ Help with note-taking, shared notes, or recordings of class to review again later
- ▶ Audio versions of textbooks
- ▶ Flexible deadlines for assignments
- ▶ Flexible scheduling of classes (e.g., certain subjects matching when the student is most alert)
- ▶ Regular access to a school social worker or counselor

The School Health Outreach Project (SHOP) provides resources for school-based health care providers to recognize lupus and support families and students living with lupus in their school setting.





WORKPLACE TIPS FOR WOMEN WITH LUPUS

Many women are actively working or in school during their lupus journey. Symptoms can be difficult to manage in the workplace setting, resulting in substantial absenteeism, as well as productivity losses when working (**presenteeism**) while experiencing disruptive symptoms or flares. Women in the workforce report challenges concentrating, fatigue, difficulty performing dexterous tasks, headaches, and reduced confidence. Maintaining a healthy lifestyle and a comfortable work environment can both help to reduce symptoms and mitigate their overall impact on your work-life productivity.

Up to \$20,000 – Average annual loss of productivity costs due to lupus¹⁵

There are personal steps you can take to improve your productivity; however, if it becomes an ongoing challenge to perform critical tasks at work or school, it may be appropriate to speak with your health care provider and the Human Resources (HR) manager at your job about seeking disability accommodations.

20% of Americans with work disability have lupus¹⁸

Americans with Disabilities Act (ADA)

The ADA protects the rights of individuals with disabilities by requiring employers to make reasonable accommodations to permit persons with disabilities to be employed. However, they are not required to give people with disabilities special considerations that they would otherwise not provide to all employees.

According to the ADA, a person has a disability if he/she has a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or is regarded as having an impairment.

ADA provisions only apply if the employer has been made aware of the employee's disability. You are not obligated to disclose your specific diagnosis to your employer. However, you should work with your health care provider to communicate your health challenges and your need for accommodations to your employer.

Workplace Accommodations

The Job Accommodation Network (JAN) conducted a national survey that included employers across industry sectors and sizes about the costs and benefits of implementing workplace accommodations for their employees:

56% of employers said the accommodations needed by their employees cost absolutely nothing¹⁹

82% of employers contacted JAN for information and solutions to retain or promote an employee¹⁹

Your employer is responsible for creating and maintaining a conducive and healthy work environment for all employees, including those with disabilities. If your working environment does not already have lupus-friendly accommodations or policies, do not be afraid to speak up and advocate for yourself (and other women) for the care and support you require.

Below are some examples of adjustments that may help improve your workplace (or school) environment and productivity:

Pain:

- Adjustable workstations
- Anti-fatigue mats
- Automatic door openers
- Ergonomic or pneumatic tools (chair with head support, stapler, hole punch, keyboard)

Decreased Stamina/Fatigue:

- Anti-fatigue mats
- Ergonomic equipment (chair, monitor riser, keyboard tray/rest)
- Multipurpose carts or vehicles to transport heavy items or travel far distances

Attentiveness/Concentration:

- Calendars or planners
- Flexible or alternative work/class schedule
- Full spectrum or natural lighting
- Modified break schedule

Headaches:

- Broad spectrum or natural lighting
- Anti-glare filters or alternative lighting
- Air cleaners and purifiers
- White noise or sound machines
- Odor control

Handling/Fingering:

- Speech recognition software
- Ergonomic or pneumatic equipment (electric stapler, scissors)
- Alternative keyboard or mouse
- Grip aids and gloves
- Writing aids
- Touchless faucets

Skin Rash or Sores:

- Alternative cleaning supplies
- Modified break schedule
- Odor control
- Touchless faucets
- Hands-free telephone accessories

Stress Intolerance:

- Modified break schedule
- White noise or sound machines
- Support animal

Suppressed Immune System:

- Disability awareness or etiquette training
- Physical distancing signage
- Hand protection
- Working remotely

Before meeting with your supervisor or HR, consider preparing a list of your symptoms, how they affect your ability to function at work, and treatments or actions you are taking to address them. You may also want to ask your health care provider for a letter describing your lupus symptoms. You can use the [Medical History Worksheet for Lupus](#) and [Lupus Care Journal](#) provided in the SWHR Living Well with Lupus Toolkit to help prepare for this conversation.

Productive conversations with your employer and institution about your lupus experience can help them to better understand and support your needs, and ultimately assist in determining what types of accommodations you or others might need going forward.

LIFESTYLE TIPS FOR WOMEN WITH LUPUS



Diet and Nutrition

Healthy eating and drinking behaviors can reduce inflammation and other issues associated with lupus. Keep healthy snacks in your desk or work bag so that you aren't skipping meals during a busy day. Think: fiber, fruits, veggies, and healthy fats (e.g., avocado, nuts, and fish). Make sure to drink plenty of water during the day, and reduce your caffeine and alcohol intake.

Infection Prevention

Practice good hand hygiene by washing your hands often and after touching high-traffic surfaces. Lupus patients are predisposed to pneumonia and bloodstream infections. Try to avoid people with colds or other contagious illnesses, and talk to your provider about the pneumonia, the annual flu, and other recommended vaccines. Remember to always be cautious with live vaccines that might negatively interact with your immunosuppressive medications.



Skin Protection

The sun gives off ultraviolet (UV) light that can trigger inflammatory responses in someone with lupus. Try to add sun-protective clothing to your wardrobe, like wide-brimmed hats, long sleeves, and cover-ups, especially for sunny days and during vacations in warm climates. Applying sunscreen with SPF 70 or higher also helps protect your skin from harmful UV rays. SPF protection can also be found in lotions, lipsticks and glosses, and makeup products.

Rest and Relaxation

Stress and anxiety can promote muscle tension and inflammation that can aggravate lupus symptoms and pain. Take mini breaks to stand or sit (depending on what you do all day) and keep your body limber. Maintain a regular sleep routine that allows enough hours of rest and avoid caffeine and nicotine close to bedtime. Schedule vacations or staycations during which you can recharge your body and mind.



Travel Readiness

Sometimes lupus symptoms can get worse due to changes in estrogen levels during a woman's monthly menstrual cycle. Try to schedule travel during the less symptomatic windows during your cycle, and make sure you pack enough medication to last the trip. Schedule enough time to rest and allow your body to recuperate after strenuous or high-intensity activities, and try to journal what you eat and drink that might be different from your normal regimen at home.

Community of Support

There are many opportunities for support in your journey with lupus. Find a confidant (or two or three) with whom you can share your experiences and concerns. They can help to hold you accountable for maintaining your health and wellness. You would be surprised how many individuals you already know that have also been impacted by a chronic or autoimmune disease like lupus and are willing to be in your circle of support. You can expand your circle by exploring local or virtual support groups — ask your doctor or search online for additional resources.



EMOTIONAL WELLNESS AND SEEKING SUPPORT FOR LUPUS

1.5x – women diagnosed with anxiety compared to men²⁰

2x – women diagnosed with depression compared to men²¹

Anxiety and depressive disorders are more common among people with chronic conditions, and studies show that having anxiety or depression can decrease your pain tolerance, making the symptoms from chronic disease feel worse. Anxiety and depression are also associated with increased fatigue, inflammation, and difficulty concentrating. With multiple medications to manage and challenges with completing daily tasks, it is understandable that women living with lupus might struggle to stay afloat, so it is imperative to take steps to interrupt the spiral of worsening symptoms.

Warning Signs

The first step in promoting mental wellness is recognizing if you are experiencing symptoms of anxiety or depression. Common symptoms may include:

- ▶ Fatigue
- ▶ Sleep disturbances
- ▶ Nausea or reduced appetite
- ▶ Dizziness
- ▶ Heart palpitations
- ▶ Panic attacks
- ▶ Chronic sweating
- ▶ Chills
- ▶ Irritability
- ▶ Trouble concentrating
- ▶ Feelings of sadness or hopelessness
- ▶ Loss of interest or pleasure in activities



Treatment and Coping Strategies

There are a variety of ways to address mental health concerns. Lifestyle habits such as eating well and exercising regularly are a great place to start, but if these alone are not enough there are other things to try, such as counseling and/or medications for anxiety and depression. Talk to your health care provider about your options, including whether a referral to a mental health professional would be helpful.

Seeking Support

Sometimes it can be hard to ask for help, especially if it feels like you are losing some of the independence you had before lupus. Letting others support you and your health can make adjusting to a lupus diagnosis easier – both physically and emotionally.

Caring for someone with lupus?

Being a caregiver can be a job in itself. If you are feeling overwhelmed, seek out resources and support for your own health and well-being.

- ▶ **Consider** sharing with your family and friends how your symptoms affect your day-to-day life and suggest areas where they may be able to help make things easier for you.
- ▶ **Consult** a trained professional (e.g., psychologist, counselor, licensed therapist) who may be able to offer you specific tools and coping strategies for handling tough moments and support your mental and physical wellness over the long term.
- ▶ **Connect** with other women who have lupus and know what it is like to live with a chronic health condition. Every support group is different, so you may have to explore a few before finding one that fits your personality and needs.

See the [Lupus Support Groups and Organizations](#) section of the SWHR Lupus Toolkit for a list of additional resources on seeking support.

Depression is **1.7x** more prevalent in women with lupus²²