

# LIVING WELL WITH LUPUS:



A Toolkit for Women



Society for  
Women's Health  
Research

## About SWHR

The Society for Women's Health Research (SWHR) is a national nonprofit and thought leader dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education. Founded in 1990 by a group of physicians, medical researchers, and health advocates, SWHR is making women's health mainstream by addressing unmet needs and research gaps in women's health. Thanks to SWHR's efforts, women are now routinely included in most major medical research studies and more scientists are considering sex as a biological variable in their research. Visit [www.swhr.org](http://www.swhr.org) for more information.

## SWHR's Lupus Program

SWHR Science Programs identify research gaps and address unmet needs in diseases and conditions that exclusively affect women or that disproportionately or differently affect women. The Lupus Program was launched in 2022 to address the impact of lupus on women's health across the lifespan. The program engages researchers, health care providers, patients, advocates, and health care policy decision-makers to explore strategies to address knowledge gaps, unmet patient needs, and relevant policies that present barriers to equitable and quality care for women living with lupus.

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SWHR extends our sincere thanks to  
the following sponsors for their support  
of this educational work.





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# UNDERSTANDING LUPUS



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## AUTOIMMUNE DISEASES AND WOMEN'S HEALTH

### Autoimmune and Immune-mediated Inflammatory Diseases

The body's immune system keeps you healthy by recognizing any microscopic foreign material that enters your body, such as pollen, bacteria, or a virus. It then produces proteins called **antibodies** to target these foreign materials that could make you sick if they remain in the body. Once the resulting infection is controlled, this immune response stops and your health should begin to restore.

Sometimes your immune system mistakenly cannot tell the difference between the foreign material and your own cells. It malfunctions or wrongly attacks the body's healthy cells and tissues, often resulting in an inappropriate or excessive immune response. This activity can lead to the development of an **immune-mediated inflammatory disease (IMID)** that can cause inflammation and internal damage to almost any part of the body – from your joints and skin to your lungs and kidneys. **Autoimmune diseases** are a subset of IMIDs for which the antibody responsible for the abnormal immune response has been identified.

 **15-20 million** Americans have an autoimmune disease<sup>1</sup>

### Disease Prevalence and Impacts on Women

Autoimmune diseases are much more common in women than men. They can be challenging to diagnose because their symptoms can seem unrelated and mimic other conditions. They can also be difficult to treat, especially if the cause of the disease is not fully understood.

 **4 out of 5** people diagnosed with an autoimmune disease are women<sup>2</sup>

Some common autoimmune conditions that are more prevalent in women include:

- ▶ Alopecia areata
- ▶ Lupus
- ▶ Multiple sclerosis
- ▶ Psoriasis
- ▶ Psoriatic arthritis
- ▶ Rheumatoid arthritis
- ▶ Sjogren's syndrome
- ▶ Thyroid diseases

Understanding your risk of developing an autoimmune disease or IMID, recognizing early symptoms, and communicating frequently with your health care providers can help them to diagnose a condition early and help you to receive the care you need to feel your best.

## WHAT IS LUPUS?

Lupus is a chronic autoimmune disease where the body attacks its own tissues, creating widespread inflammation and symptoms throughout the body. This inflammation often results in organ tissue damage – most commonly in the joints, skin, brain, heart, lungs, kidneys, and blood vessels.

**90%** of Americans with lupus are women ages 15-44<sup>3</sup>

**50%** of Americans report knowing someone personally who has lupus<sup>4</sup>

## Types of Lupus

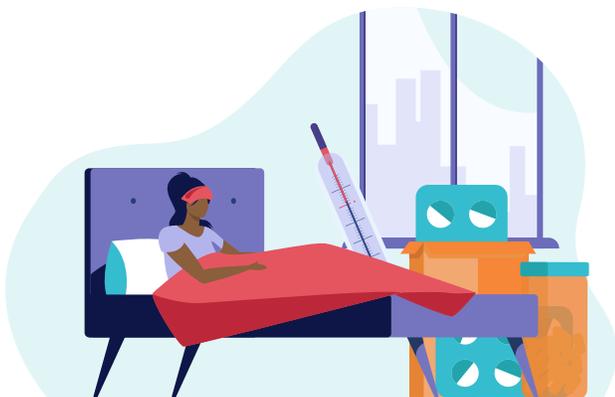
Lupus can take a number of forms, including:

- ▶ **Systemic lupus erythematosus (SLE)** – the most common type of lupus; symptoms can occur throughout the body, commonly affecting the kidneys, heart, hair, joints, and skin
- ▶ **Cutaneous lupus erythematosus (CLE)** – lupus that primarily affects the skin
- ▶ **Drug-induced lupus** – a temporary form of lupus due to reactions from certain medications
- ▶ **Neonatal lupus** – a rare form of lupus that can occur in infants of a mother with SLE

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**Some women may have incomplete systemic lupus erythematosus (iSLE); they experience some of the symptoms of lupus, without meeting the full criteria for SLE. Up to 55% of iSLE patients progress to established SLE.<sup>5</sup>**

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## Causes and Risk Factors

With many autoimmune diseases like lupus, it is not clear why the immune system mistakenly attacks healthy cells and tissues; however, it is likely that environmental and genetic factors play a role.

Risk factors for developing lupus:

- ▶ Sex and Age: women between the ages of 15 and 44 years old
- ▶ Race: African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
- ▶ Family history of lupus or autoimmune disease
- ▶ Existing diagnosis for another autoimmune disease or IMID

African American and Hispanic women are **3-4 times more likely** to develop lupus than white women<sup>6</sup>

Women of color tend to develop lupus at a younger age, experience more serious complications, and have higher mortality rates. The LUMINA study found that African American lupus patients have more active disease with organ system involvement and lower levels of social support compared with their white counterparts.

## Common Symptoms

Symptoms of lupus are often a result of inflammation in the body. They may come and go, and they differ from person to person. The most common lupus symptoms include:

- ▶ Fatigue
- ▶ Pain or swelling in the joints
- ▶ A butterfly-shaped rash on the cheeks and nose
- ▶ Swelling in the hands and feet, or around the eyes
- ▶ Headaches
- ▶ Hair loss
- ▶ Sores in the mouth or nose
- ▶ Low-grade fevers
- ▶ Sensitivity to sunlight or fluorescent light
- ▶ Chest pain when breathing deeply
- ▶ Discoloration of fingers and toes when cold
- ▶ Brain fog



## LUPUS TRIGGERS AND FLARES

Even women with well-managed lupus experience periods of time when their symptoms become worse, known as symptom **flares**. Many women find there are a specific set of factors (triggers) - both in the body and the environment - that tend to cause their lupus to flare. Some examples of **triggers** include:

- ▶ **Estrogen** hormone levels
- ▶ High stress (emotionally or physically)
- ▶ Exhaustion
- ▶ Infection or injury
- ▶ Changes in lupus medications
- ▶ Exposure to the sun or ultraviolet light (photosensitivity)
- ▶ Certain medications (e.g., hormone therapy or medications that increase light sensitivity)

Every woman with lupus is different, and various triggers may not affect all people with lupus in the same way. Similarly, the symptoms that come with a lupus flare are unique to each individual.

Because flares can be unpredictable and spread out, it is common for women with lupus to go back and forth between extended times where symptoms are significant and times where disease activity is low. With an appropriate treatment regimen and symptom management, it is sometimes possible to have low enough disease activity that your lupus reaches **remission**.

Tracking potential triggers and flares can help you determine which triggers you need to avoid (if possible) and develop strategies to address them when they arise. Relevant tracking and health applications are in the **Resources for Women Living with Lupus** section of the SWHR Living Well with Lupus Toolkit.

# DIAGNOSING AND TREATING LUPUS



# DIAGNOSING AND TREATING LUPUS



## JOURNEY TO DIAGNOSIS

Since lupus symptoms are similar to those of other **rheumatic diseases**, such as fibromyalgia or rheumatoid arthritis, and symptoms can come and go, it can be difficult for health care providers to come to a lupus diagnosis quickly. Your primary care provider might refer you to a **rheumatologist** that specializes in inflammatory diseases to better assess your symptoms. There is no single diagnostic test for lupus, so diagnosis often relies on a process of elimination and meeting multiple criteria to indicate **SLE**. This process can take time and a number of appointments with your health care provider(s).

**76%** of lupus patients had early symptoms misdiagnosed<sup>7</sup>

**The ANA test is not specific for lupus. While many women with lupus test positive for ANA, up to 15% of healthy individuals test positive and are not diagnosed with lupus or any other autoimmune disease.<sup>9</sup>**

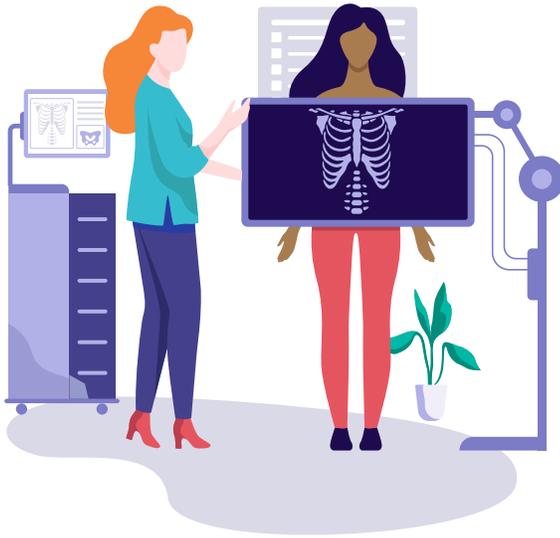
**4+ providers** seen before an accurate lupus diagnosis<sup>8</sup>

## Lupus Evaluation Process

Your health care provider will likely consider a number of factors when evaluating the possibility of lupus, including your medical and family history, relevant risk factors, and past and current symptoms. They may also conduct a physical exam to assess symptoms, such as skin, hair, or joint issues.

Additional tests along the diagnostic journey might include:

- ▶ **Blood tests** to assess immune activity and kidney or liver function
  - **Antinuclear antibody (ANA) test** determines if certain antibodies are present in your bloodstream. If the test comes back positive, this indicates that the immune system is active; however, **it does not mean you have lupus.**



- **Anti-dsDNA antibody test** measures immune activity as a follow-up test to a positive ANA test. Anti-dsDNA in the blood is often high just before or during a flare, making this a strong positive indicator of lupus.
- **Serum complement test** measures certain protein levels (C3 and C4) that are commonly used to monitor lupus activity.
- **Extractable nuclear antigen (ENA) panels** tests for a set of additional antibodies for proteins (e.g., Ro/SSA, La/SSB, Sm, and RNP) associated with lupus activity and other rheumatic conditions.
- **Anti-phospholipid antibody tests** look for certain proteins associated with blood clots due to their common occurrence in individuals with lupus.

- ▶ **Urine tests** to assess lupus activity or damage in the kidneys
- ▶ **Biopsies** of tissue samples to assess inflammation or damage in the kidneys, skin, or other organs
- ▶ **Imaging tests** to assess the lungs (chest x-ray), heart health (echocardiogram), and other specific organs as needed

### Delays in Diagnosis

An untimely diagnosis can have long term impacts on your health and well-being, but it is important to note that getting to a lupus diagnosis is a journey that will likely need time, patience, and support from others. Remain an active participant in your diagnosis journey by asking questions or seeking a second opinion if you feel that your concerns are not being addressed properly. Being informed about the signs and symptoms of lupus can also help guide conversations with your provider(s) and get you to a diagnosis sooner.

 **Up to 4 years** – average time from symptom onset to diagnosis<sup>10</sup>

For more tips, see the [Talking to Your Health Care Provider](#) section of the SWHR Living Well with Lupus Toolkit.



## TREATMENT OPTIONS FOR LUPUS

There is no cure for lupus, but there are several medical and lifestyle approaches that can prevent progression of disease, improve symptoms, and in some cases, achieve [remission](#). Treatment approaches vary depending on the type and severity of disease. Talk to your health care provider(s) about which treatment options would be appropriate for you.

**2 out of 3** lupus patients list chronic pain as the most difficult aspect of lupus<sup>11</sup>

### Medications

- ▶ **Anti-malarial pills** to treat disease activity and reduce the risk of flares
- ▶ **Nonsteroidal anti-inflammatory drugs (NSAIDs)** to relieve pain and reduce inflammation, swelling, and fever, except in patients that have significant kidney disease
- ▶ **Corticosteroids** (pill or injection) to reduce inflammation
- ▶ **Immunosuppressants** (pill or infusion) to reduce immune activity
- ▶ **Biologic agents** (injection) to inhibit specific immune cells from causing damage, reducing symptoms

### Complementary and Alternative Medicine

While complementary and alternative medicine (CAM) approaches cannot address the causes of lupus symptoms, they may offer some symptom relief. Research supporting CAM approaches to lupus

treatment is limited, so be sure to talk to your health care provider before trying new approaches to your symptom management.

- ▶ **Acupuncture** to ease muscle pain and fatigue associated with lupus
- ▶ **Dehydroepiandrosterone (DHEA)** supplements to help reduce lupus flares
- ▶ **Fish or krill oil** supplements contain omega-3 fatty acids that may be beneficial for people with lupus
- ▶ **Physical and/or Occupational Therapy** to help with pain relief and increased flexibility and mobility
- ▶ **Yoga** to help with stress management and pain relief

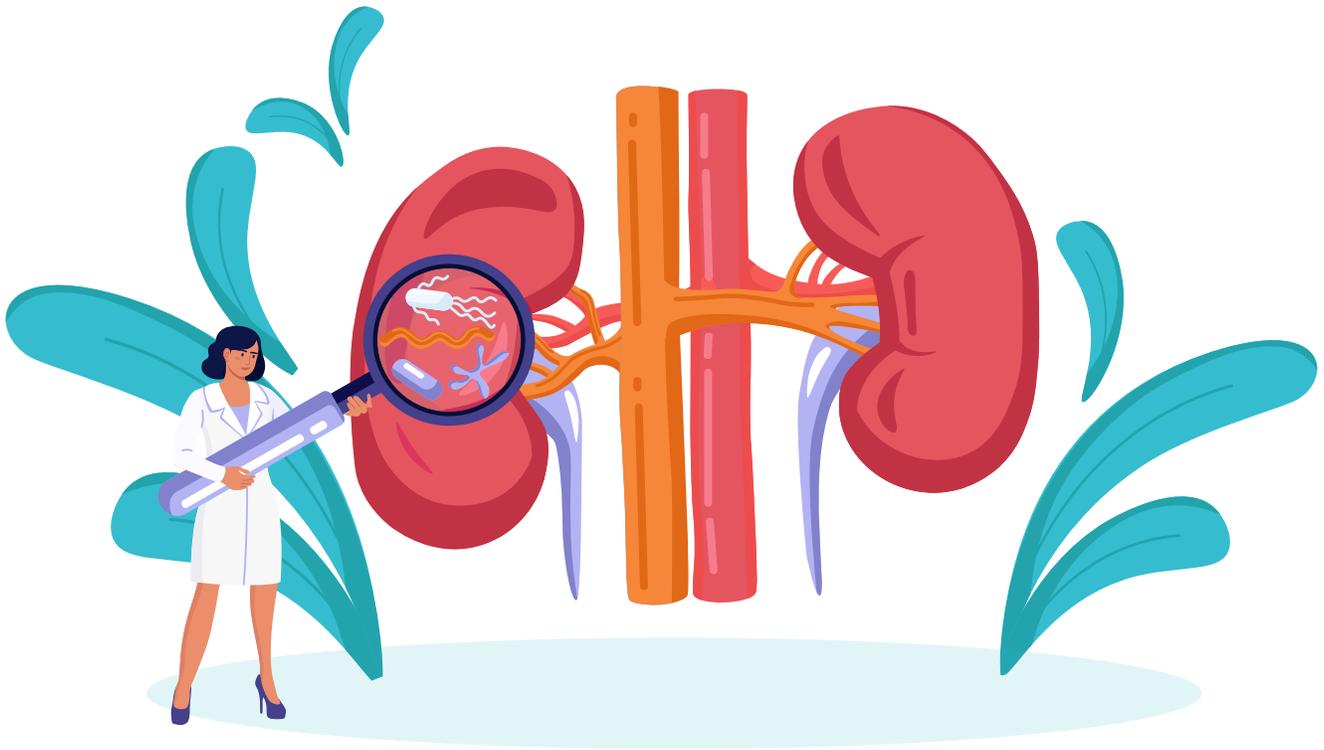
### Lifestyle Approaches

There are a number of steps you can take at home to help manage your symptoms and flares. Consider:

- ▶ Regular movement or physical activity
- ▶ Healthy diet and weight maintenance – talk to your provider about dietary choices that may be beneficial (e.g., anti-inflammatory diet, kidney-friendly diet)
- ▶ Sun protection
- ▶ Heat and cold therapy to ease swelling and pain in the joints
- ▶ Stress management and meditation techniques
- ▶ Quitting or avoiding smoking
- ▶ Reduced alcohol intake

For more information about lifestyle approaches to manage lupus symptoms, visit the [Lifestyle Tips for Women with Lupus](#) section of the SWHR Living Well with Lupus Toolkit.





## COMMON IMPACTS OF LUPUS IN WOMEN

Because lupus can affect many organs throughout the body, women with lupus are more likely to develop complications and other health conditions that co-occur with lupus.

Many of the impacts from lupus are due to autoimmune-related inflammation in the organs. Other impacts can be a result of lupus medications that, for example, may increase the risk for infection, thinning bones, high blood pressure, or diabetes.

Some conditions that may develop in women with lupus include:

- ▶ Anxiety
- ▶ Cardiovascular damage (e.g., early risk of heart attack, stroke, blood clots, hardening of the arteries)
- ▶ Depression
- ▶ Diabetes

- ▶ High blood pressure
- ▶ Osteoporosis (brittle bones)
- ▶ Thyroid dysfunction

 **1 in 3** lupus patients suffer from multiple autoimmune diseases<sup>12</sup>

Be sure to communicate any new diagnoses or changes in symptoms with your health care provider(s), as there may be ways to manage your symptoms more comprehensively.

### Lupus Nephritis

**Lupus nephritis** is kidney inflammation that occurs when lupus autoantibodies harm structures in the kidneys that are important for filtering out toxins and waste for the body. Lupus nephritis is one of the most common health complications caused by lupus and can lead to its own set of related diseases, such as chronic kidney disease and kidney failure.



## DECIDING ON A TREATMENT PLAN

Things to consider when deciding your lupus care plan:

- ▶ Your age
- ▶ Lifestyle and activity levels
- ▶ Symptom management
- ▶ Family planning goals
- ▶ Treatment efficacy and side effects
- ▶ Other health risk factors and conditions
- ▶ Health insurance coverage

Your treatment plan will likely incorporate a combination of approaches, and it may change over time. You should discuss with your health care providers which treatments will address the disease itself and which will address your symptoms, as well as your personal needs and goals for treatment, both now and in the future.

Some other key topics to discuss include:

- ▶ How long you should wait before you can expect to experience positive results from your treatment
- ▶ Side effects of any medications and/or therapies and how to handle them
- ▶ Recommended resources to help you understand your financial options for paying for treatments

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**If you experience health complications as a result of your lupus medications, talk to your health care provider about whether modifications to your treatment plan would be beneficial.**

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Ask your providers to outline what a follow-up plan for monitoring your health looks like – recovery time for any procedures, which specialists to consult, and how often to schedule a visit.

**5 out of 10** adults with lupus will develop lupus nephritis<sup>13</sup>

If you develop symptoms that indicate kidney issues, such as blood in your urine, foamy urine, high blood pressure, or swelling in your hands, ankles, or feet, be sure to alert your health care providers. Medications that reduce inflammation in the kidneys and suppress your immune system can help manage the risk of further kidney damage.

**10-30%** of people who have lupus nephritis develop kidney failure<sup>13</sup>



# MANAGING YOUR LUPUS CARE





# MANAGING YOUR LUPUS CARE

## UNDERSTANDING CHRONIC DISEASE MANAGEMENT

Lupus is a chronic condition that you will have to manage throughout your life. It might be overwhelming to learn there is no cure for your disease, but with the right treatment regimen and lifestyle approaches, it is possible to reach low enough disease activity that your lupus could potentially achieve [remission](#). Changes will eventually become routine and feel less disruptive over time. Some tips for managing chronic disease are below.

 **22%** of patients reported sustained clinical remission after 5 years, while on treatment<sup>14</sup>

**Even if your lupus activity and symptoms are said to be in remission, you may still need medication to maintain low disease activity. Consider discussing with your lupus care provider how to adjust your medication(s) to a minimum dosage that can maintain decreased lupus activity without flares.**



**Keep a record or journal of your treatment activities** and how each affects your symptoms and health, so that it is readily available when you talk with your health care providers.

- ▶ For more information, see the [Lupus Care Journal](#) in the SWHR Living Well with Lupus Toolkit.



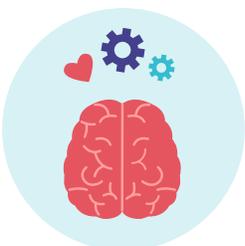
**Know that flares are common.** While it can be frustrating and disruptive to experience a symptom flare, you can come up with a plan for how to manage them when they occur. This might include rest, additional self-care activities, or connecting with your health care provider.

- ▶ For more information, see the [Lifestyle Tips for Women with Lupus](#) section of the SWHR Living Well with Lupus Toolkit.



**Include others.** Connect with friends, family, peer support groups, patient navigators, or others that can help you as you adjust to life with a chronic condition.

- ▶ For more information, see the [Lupus Support Groups and Organizations](#) section of the SWHR Living Well with Lupus Toolkit.



**Seek support for your mental health and wellness.** It is common for individuals with chronic health conditions to experience anxiety or depression. It is important to recognize this and to seek professional help if you need it.

- ▶ For more information, see the [Emotional Wellness and Seeking Support for Lupus](#) section of the SWHR Living Well with Lupus Toolkit.

## SELF-MANAGEMENT AND LUPUS

**Self-management** is a disease management approach designed to provide health education and enhance social support, especially among individuals with chronic diseases. Evidence has shown that self-management skills are effective for improving your physical, mental, and emotional health.

Four key components of self-management that can be applied to lupus are:

- ▶ **Management of Physical Symptoms.** Trust your body and recognize warning signs of lupus flares and worsening kidney disease, and track new and existing symptoms and their progress.
- ▶ **Medication Decision Making.** Work with your health care providers to choose the best medication for your situation, take your medication consistently and correctly, and track and discuss side effects with your providers.
- ▶ **Communication with Health Care Team.** Prepare in advance for your medical appointments, give detailed information about what you are feeling and experiencing, and ask questions until you and your provider both have a clear understanding of what is going on. If you are considering planning for a family, speak to your doctor early and often about your reproductive health and how your medications might impact your fertility or pregnancy.
- ▶ **Lifestyle Management.** Make healthy food choices, reduce stress when you can, promote social and emotional wellness, and look for opportunities to be active.

## TALKING TO YOUR HEALTH CARE PROVIDER

Recognizing the risks and symptoms of lupus will help you know when it is necessary to seek care. If you are currently experiencing symptoms and think you may have lupus, do not wait for them to become severe before seeing your health care provider.

### Preparing for a Visit

To help your provider better understand your symptoms and experience, give specific examples and details about your pain or discomfort. For example, list activities that your symptoms prohibit you from doing and use descriptive words to convey what kind of pain you feel (e.g., dull, aching, sharp, stabbing). You should also discuss remedies you have tried to manage your symptoms.

**Do not hesitate to seek out a second opinion if you want another perspective on your diagnosis and/or treatment options.**

For your appointments, consider bringing the following:

- ▶ Your history of symptoms (e.g., when they started, duration, triggers, coping and management strategies)
- ▶ A record of relevant tests, treatments, and surgeries you have completed
- ▶ A list of your current medications and past diagnoses for any medical conditions
- ▶ Names and contact information for other health care professionals who provide you with care
- ▶ A support person (spouse, family member, or friend) who can help you take notes and advocate for you



## Questions to Ask Your Health Care Provider

Compiling a list of questions before visiting your provider may help you feel more prepared to discuss your experience and plans for symptom management. Questions may vary depending on your type of lupus and the severity of your symptoms. Below are some example questions you may consider asking.



### Initial Consultations:

- ▶ I am experiencing [*joint pain/swelling/hair loss/sensitivity to light*]. How can I know if what I am experiencing is lupus?
- ▶ What other conditions cause similar symptoms?
- ▶ Could any of my current medications make my lupus worse? (Have a list of medications and doses prepared to share with your provider.)
- ▶ Which medical treatment option(s) do you recommend that I try first? Why?
- ▶ What alternative treatments (e.g., acupuncture, yoga, diet) might be worth trying?
- ▶ Are there any helpful strategies or practices I can do at home to assist with managing my symptoms and flares?
- ▶ Can you provide me with additional resources to learn more about lupus?

### Ongoing Management and Care:

- ▶ With my current treatment, how long can I expect it to take before I experience some symptom relief?
- ▶ Are there side effects I should watch for? What should I do if I experience any of these side effects?
- ▶ How will lupus affect my long-term health?

- ▶ Do I have an elevated risk for another condition like heart disease or osteoporosis? Is there a screening test or preventive steps we should pursue?
- ▶ Can you recommend resources that can help me talk to my family, friends, or employer about having a chronic health condition like lupus?
- ▶ My lupus is impacting my ability to perform important activities (Provide specific examples). Are there accommodations or disability support that you can suggest for my employer or school?
- ▶ Should I seek a physical or occupational therapy assessment for work/school accommodations or to help me address my mobility concerns?
- ▶ Does lupus affect fertility or pregnancy? If so, how?
- ▶ Are there medications that I won't be able to take during pregnancy and/or breastfeeding?
- ▶ Is participation in a clinical trial an option for me?

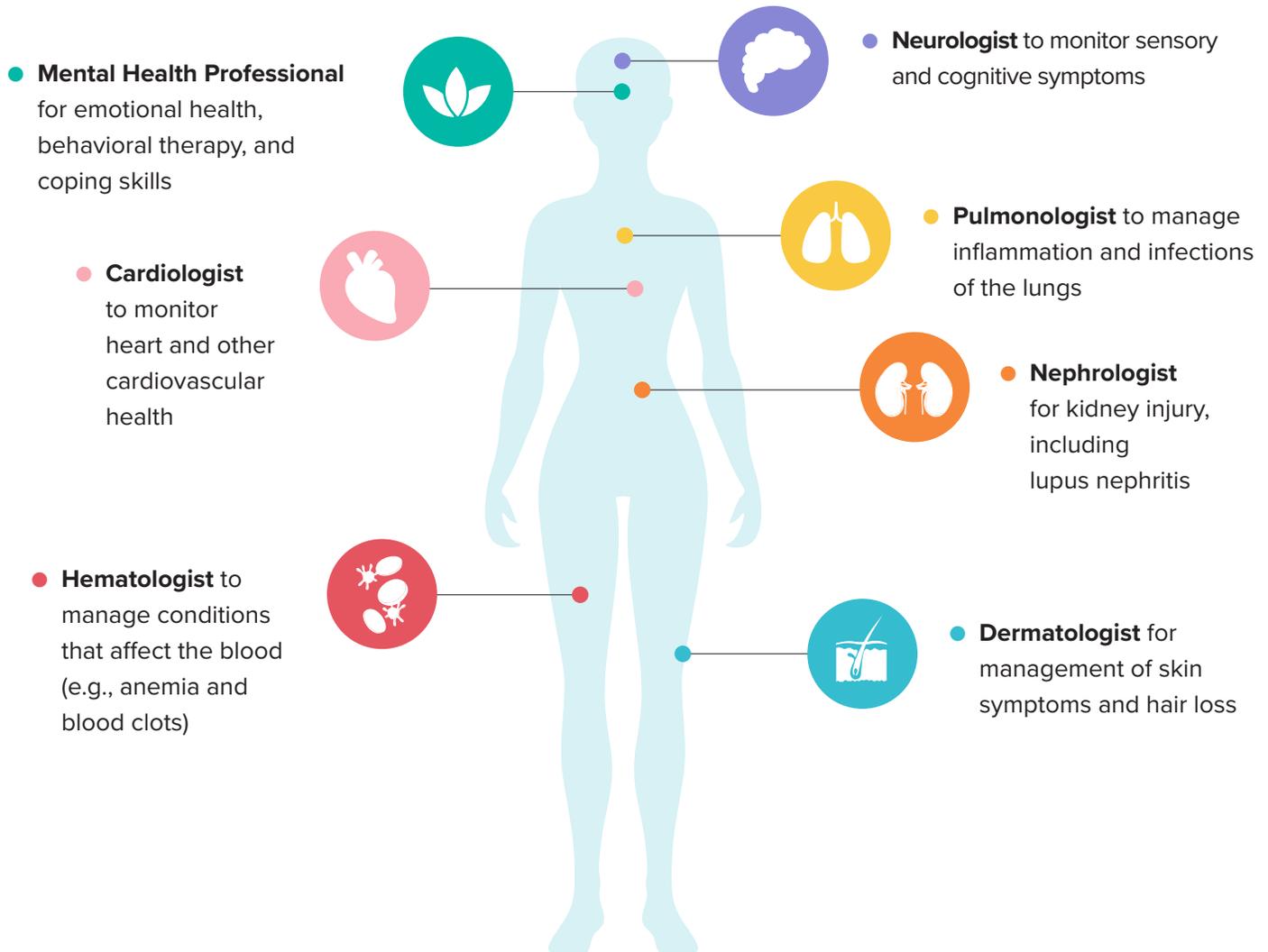
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**Inclusion of women across all stages of life, including adolescents, pregnant and lactating populations, and menopausal women, in clinical trials is important for developing treatment options that improve outcomes for women.**

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## COORDINATING YOUR LUPUS CARE TEAM

A **rheumatologist** is a doctor of internal medicine or pediatrics who specializes in diseases of the joints, muscles, and bones. A good primary care physician and rheumatologist are essential to your lupus care. Depending on the nature of your disease, other health care providers that they might consult as part of your multidisciplinary care team are:



### Additional support might be sought by:

- ▶ **Pain Specialist** for severe pain management
- ▶ **Physical or Occupational Therapist** for joint rehabilitation, strengthening, and pain management
- ▶ **Maternal-fetal Medicine Specialist** for maternal and infant health during pregnancy



## NAVIGATING INSURANCE COVERAGE

 **\$33,223** – Average annual direct health care costs for a person with lupus<sup>15</sup>

Lupus requires life-long monitoring and treatment. You may need to work with your health care providers and insurance company to minimize the financial burden of your care. Here are some tips on how to effectively communicate with your health insurance provider.

### Talking with Your Insurance Company

#### ***Know the details of your insurance policies.***

Coverage for chronic diseases can sometimes be confusing, and many individuals will have a variety of providers in both primary and specialty care.

Request a copy of your insurance policies for explanations about:

- ▶ Services covered (in and out of network)
- ▶ Referral processes to see various health care professionals
- ▶ Prior authorization processes to receive services or medications
- ▶ Premium payment amounts
- ▶ Policy expiration date

#### ***Understand the financial aspects of your policy.***

Insurance plans rarely cover 100% of health care costs, requiring patients to pay a portion of the costs. The main types of out-of-pocket costs are:

- ▶ **Deductible** – a preset amount you must pay annually before your insurance coverage fully kicks in
- ▶ **Copayment** – a preset, flat fee you must pay for each doctor's visit, and for prescriptions, tests, etc.; these payments do not count towards your annual deductible
- ▶ **Coinsurance** – an amount (often a percentage) you must continue to pay for visits and services after the deductible has been reached

#### ***Be aware of special coverage requirements.***

Some insurance companies have [prior authorization](#) requirements that must be met before they will cover a specific medication, treatment, or procedure.

- ▶ Some plans may require a specialist to evaluate you before you can receive certain medications.
- ▶ Some plans may require medications to be prescribed in a specified order and with certain outcomes (e.g., [step therapy](#)).

**Step therapy (also known as "fail first") is a policy implemented by an insurance company that requires a patient to try and "fail" a lower-cost treatment before a clinician can prescribe a newer or more expensive treatment option. This policy often delays preferred treatments and can result in unnecessary disease progression.**

In most cases, your doctor's office will be responsible for submitting the prior authorization request. You may have to work with the office staff to ensure the necessary forms are completed accurately and submitted quickly. Talk with your health care providers to determine if the required treatments in a step therapy plan could have negative consequences on your disease progression. If so, work with their office to appeal the step therapy requirement as soon as possible.

For additional help navigating the insurance process, some insurance companies offer the support of a case manager that you may be able to request. When available, this is typically a free resource provided by the insurance company.

## Filing Claims & Appeals

There are a variety of reasons your insurance company might deny your claim for your lupus care, such as:

- ▶ The benefit is not offered under your health plan
- ▶ The requested service or treatment is deemed "not medically necessary"
- ▶ The requested service or treatment is considered "experimental" or "investigative"
- ▶ The health care provider is not in your plan's approved network
- ▶ The requested treatment is not on your plan's formulary (list of approved drugs)

Your insurance company must notify you to explain why your claim was denied in writing. This has to be completed within certain timeframes, depending on the circumstance. Typically, these timeframes are:

- ▶ **15 days** for prior authorization of a treatment
- ▶ **30 days** for medical services already received
- ▶ **72 hours** for urgent care cases

If your insurance company denies your claim for your lupus care, **you have the right to appeal the decision.**

Insurers are required to tell you how you can dispute their decisions and how they can be referred to and reviewed by a third party. **If you decide to appeal, it is important to take action immediately.** Carefully review your insurance policy to understand what it covers and to outline your argument as to why your insurer should honor your appeal.



**Patient navigators, also referred to as patient advocates, are people who help guide patients through the health care system. Patient navigators may be able to offer a wide variety of services, including setting up doctor's appointments, communicating with insurance companies, and providing social support while individuals navigate complex medical conditions and care.**

## Additional Resources

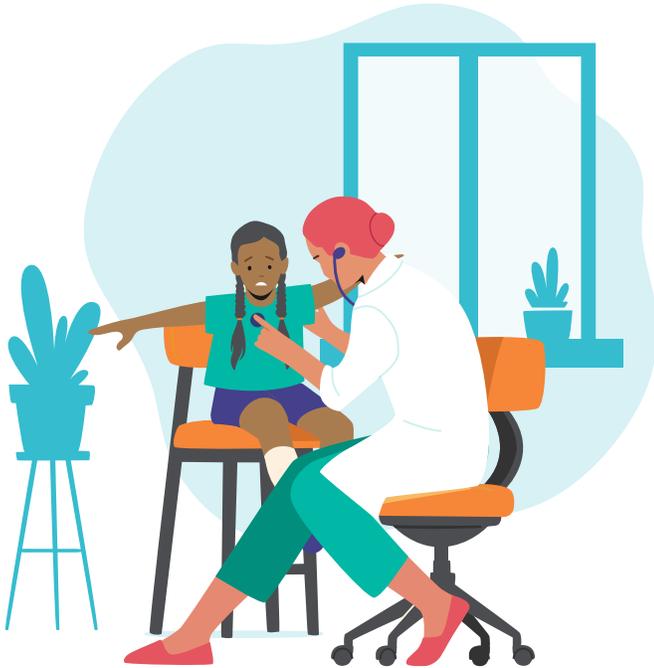
- ▶ **Employer** – If you receive health insurance coverage through your employer, contact the human resources department. They may have dedicated case managers who can assist with your appeal or connect you with potential state-run external review processes.
- ▶ **State** – Many states offer administrative help with difficult claims. If you need help filing an internal appeal or external review, contact your state's **Consumer Assistance Program**. States also offer free health benefits counseling services for Medicare beneficiaries and their families or caregivers, such as the **State Health Insurance Assistance Program (SHIP)**.
- ▶ **Federal** – Contact the U.S. Department of Labor **Employee Benefits Security Administration** for more information about employer-sponsored benefits.

# WELLNESS TIPS FOR LIVING WITH LUPUS





## WELLNESS TIPS FOR LIVING WITH LUPUS



### 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 childhood<sup>16</sup>

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.<sup>17</sup>**

.....

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 lupus<sup>15</sup>

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 lupus<sup>18</sup>

## 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 nothing<sup>19</sup>

**82%** of employers contacted JAN for information and solutions to retain or promote an employee<sup>19</sup>

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 men<sup>20</sup>

**2x** – women diagnosed with depression compared to men<sup>21</sup>

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 lupus<sup>22</sup>

# RESOURCES FOR WOMEN LIVING WITH LUPUS





# RESOURCES FOR WOMEN LIVING WITH LUPUS

## GLOSSARY

**Antibody** – A protein made by the immune system in response to a foreign substance, such as bacteria or viruses, entering the body

**Antinuclear antibody (ANA) test** – A blood test that determines whether certain antibodies that attack the body's own tissues are present in the cell's nucleus

**Autoimmune disease** – A disease in which the immune system mistakenly attacks its own body, including healthy tissues

**Cutaneous lupus erythematosus (CLE)** – A type of lupus that attacks the skin

**Estrogen** – A sex hormone primarily made in the ovaries that is responsible for the development and regulation of the female reproductive system and secondary sex characteristics

**Flare** – A measurable increase in lupus disease activity, resulting in new or worse symptoms

**Immune-mediated inflammatory disease (IMID)** – An inflammatory disease where the causes and mechanisms of action may not be fully understood, but the immune system is involved

**Lupus nephritis** – A type of kidney disease that results from damage caused by inflammation in the kidneys in people with systemic lupus erythematosus

**Presenteeism** – The loss in productivity when an employee is not fully functioning in the workplace because of an illness, injury, or other condition

**Prior authorization** – A process used by some health insurance companies that requires the review and approval of a specific procedure, service, or drug

before it is prescribed; also known as precertification or prior approval

**Remission** – A level of disease activity and symptom improvement that no longer interferes with a patient's behavior or regular activities for an extended period of time; for lupus, it takes at least 6 months to establish this designation, requires continued monitoring by a physician, and may or may not include medication

**Rheumatic disease** – Often grouped under the term "arthritis," a type of autoimmune or inflammatory disease that cause your immune system to attack your joints, muscles, bones, and organs

**Rheumatologist** – A doctor of internal medicine or pediatrics who specializes in diseases of the joints, muscles, and bones

**Self-management** – A person's continuous engagement in his/her healthcare to understand the illness, participate in the determination of a treatment plan, understand and adhere to the treatment plan, and feel empowered to discuss ongoing symptoms and challenges with their healthcare team

**Step therapy** – A practice used by health insurance companies to begin treatment for a medical condition with the most cost-effective drug therapy and then progress "step-wise" to other more costly or risky therapies, only if necessary. This approach is intended to control the costs and risks posed by prescription drugs

**Systemic lupus erythematosus (SLE)** – A type of lupus that can affect the entire body, including joints, skin, kidneys, blood cells, brain, heart, and lungs

**Trigger** – Conditions in the environment or body that cause disease symptoms to worsen or flare

## LUPUS SUPPORT GROUPS AND ORGANIZATIONS

### Health Apps

#### *Medication and Pain Management*

- **Flaredown:** <http://flaredown.com>
- **LupusMinder:** <https://www.hss.edu/lupusminder.asp>
- **Medisafe:** <https://www.medisafeapp.com>

#### *Meditation*

- **Calm:** <https://www.calm.com>
- **Headspace:** <https://www.headspace.com>
- **Insight Timer:** <https://insighttimer.com>

There are many health apps to choose from. The Federal Trade Commission provides [guidance to consumers](#) on how to select and use health apps while reducing privacy risks.

### Lupus Education and Support Organizations

- **Autoimmune Association:** <https://autoimmune.org/disease-information/lupus>
- **Looms for Lupus:** <https://looms4lupus.org>
- **Lupus and Allied Diseases Association:** <https://www.ladainc.org>
- **LupusCorner:** <https://lupuscorner.com>
- **Lupus Foundation of America:** <https://www.lupus.org>
- **Lupus Research Alliance:** <https://www.lupusresearch.org>
- **The Lupus Initiative Self-Management Tools:** <https://selfcare.thelupusinitiative.org>

### Finding a Provider

- **American College of Rheumatology:** <https://my.rheumatology.org/find-a-rheumatologist>
- **Lupus Foundation of America:** <https://www.lupus.org/resources/finding-a-new-doctor>
- **Mental Health America:** <https://www.mhanational.org/finding-therapy>

### Health Insurance and Financial Resources

- **Consumer Assistance Program:** <https://www.cms.gov/ccio/resources/consumer-assistance-grants#statelisting>
- **Employee Benefits Security Administration:** <https://www.dol.gov/agencies/ebsa/about-ebsa/ask-a-question/ask-ebsa>
- **State Health Insurance Assistance Program (SHIP):** <https://www.shiphelp.org>

### Other Resources

- **ACR School Health Outreach Project (SHOP):** <https://thelupusinitiative.org/healthcare-providers/schoolnurses/>
- **American Chronic Pain Association:** <https://www.theacpa.org>
- **Americans with Disabilities Act (ADA):** <https://www.ada.gov>
- **Job Accommodation Network:** <https://askjan.org/disabilities/Lupus.cfm>
- **LFA Teenagers Resource Guide:** <https://www.lupus.org/resources/lupus-and-teenagers>
- **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIH/NIAMS):** <https://www.niams.nih.gov/health-topics/lupus>

## SELECT REFERENCES

### In-text Citations

1. Roberts MH, Erdei E. Comparative United States Autoimmune Disease Rates for 2010–2016 by Sex, Geographic Region, and Race. *Autoimmun Rev*. 2020;19(1):102423.
2. Angum F, Khan T, Kaler J, Siddiqui L, Hussain A. The Prevalence of Autoimmune Disorders in Women: A Narrative Review. *Cureus*. 2020 May 13;12(5):e8094.
3. Pons-Estel GJ, Alarcón GS, Scofield L, Reinlib L, Cooper GS. Understanding the Epidemiology and Progression of Systemic Lupus Erythematosus. *Semin Arthritis Rheum*. 2010 Feb;39(4):257-268.
4. Lupus Awareness Survey for the Lupus Foundation of America (2019) [Executive Summary]. Washington, DC. Published 25 June 2019. <https://www.lupus.org/news/2019-lupus-awareness-survey-summary>. Accessed 1 July 2022.
5. Lambers WM, Westra J, Jonkman MF, Bootsma H, de Leeuw K. Incomplete Systemic Lupus Erythematosus: What Remains After Application of American College of Rheumatology and Systemic Lupus International Collaborating Clinics Criteria? *Arthritis Care Res (Hoboken)*. 2020 May;72(5):607-614.
6. Broadway-Duren JB, Cesario SK. The Lived Experiences of Women Seeking a Diagnosis of Systemic Lupus Erythematosus. *J Nurse Pract*. 2022 May;18(5):534-538
7. Sloan M, Harwood R, Sutton S, et al. Medically Explained Symptoms: A Mixed Methods Study of Diagnostic, Symptom and Support Experiences of Patients with Lupus and Related Systemic Autoimmune Diseases. *Rheumatol Adv Pract*. 2020 Feb 26;4(1):rkaa006.
8. Al Sawah S, Daly R, Foster S, et al. SAT0423 Understanding Delay in Diagnosis, Access to Care and Satisfaction with Care in Lupus: Findings from a Cross-Sectional Online Survey in the United States. *Ann Rheum Dis*. 2015;74:812.
9. Antinuclear Antibodies. American College heumatology. <https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Antinuclear-Antibodies-ANA>. Accessed 29 June 2022.
10. Kernder A, Richter JG, Fischer-Betz R, et al. Delayed Diagnosis Adversely Affects Outcome in Systemic Lupus Erythematosus: Cross Sectional Analysis of the LuLa Cohort. *Lupus*. 2021 Mar;30(3):431-438.
11. Daly R, Al Sawah S, Foster S, et al. FRI0420 Health Related Quality of Life in Lupus Differs by How Patients Perceive their Health and How Often They Experience Flares: Findings from a Cross-Sectional Online Survey in the United States. *Ann Rheum Dis*. 2015;74:578-579.
12. McDonagh JE, Isenberg DA. Development of Additional Autoimmune Diseases in a Population of Patients with Systemic Lupus Erythematosus. *Ann Rheum Dis*. 2000 Mar;59(3):230-232.
13. Ortega LM, Schultz DR, Lenz O, Pardo V, Contreras GN. Review: Lupus Nephritis: Pathologic Features, Epidemiology and a Guide to Therapeutic Decisions. *Lupus*. 2010;19(5):557–574.
14. Tani C, Vagelli R, Stagnaro C, Carli L, Mosca M. Remission and Low Disease Activity in Systemic Lupus Erythematosus: An Achievable Goal Even with Fewer Steroids? Real-life Data from a Monocentric Cohort. *Lupus Sci Med*. 2018 Feb 27;5(1):e000234.
15. Carter EE, Barr SG, Clarke AE. The Global Burden of SLE: Prevalence, Health Disparities and Socioeconomic Impact. *Nat Rev Rheumatol*. 2016 Oct;12(10):605-620.
16. Kamphuis S, Silverman ED. Prevalence and Burden of Pediatric-onset Systemic Lupus Erythematosus. *Nat Rev Rheumatol*. 2010 Sep;6(9):538-546.
17. Diaz-Frias J, Badri T. Neonatal Lupus Erythematosus. [Updated 27 Jun 2022]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-.
18. Agarwal N, Kumar V. Burden of Lupus on Work: Issues in the Employment of Individuals with Lupus. *Work*. 2016 Oct 17;55(2):429-439.
19. Lupus. Job Accommodation Network. <https://askjan.org/disabilities/Lupus.cfm>. Accessed 28 June 2022.
20. National Institute of Mental Health. Any Anxiety Disorder. <https://www.nimh.nih.gov/health/statistics/any-anxiety-disorder>. Accessed 22 June 2022.
21. Brody DJ, Pratt LA, Hughes JP. Prevalence of Depression Among Adults Aged 20 and Over: United States, 2013-2016. *NCHS Data Brief*. 2018 Feb;(303):1-8.
22. Roberts AL, Kubzansky LD, Malspeis S, Feldman CH, Costenbader KH. Association of Depression With Risk of Incident Systemic Lupus Erythematosus in Women Assessed Across 2 Decades. *JAMA Psychiatry*. 2018 Dec 1;75(12):1225-1233.

### Additional References

- Alarcón GS, Friedman AW, Straaton KV, et al. Systemic Lupus Erythematosus in Three Ethnic Groups: III. A Comparison of Characteristics Early in the Natural History of the LUMINA Cohort. Lupus in Minority populations: NAture vs. Nurture. *Lupus*. 1999;8(3):197-209.
- Erton B, Dwivaedi AP, Erkan D. 10 Things Women Who Have Lupus Should Know About Pregnancy. Updated 29 March 2022. [https://www.hss.edu/conditions\\_lupus-pregnancy-points-optimize-outcome.asp#time](https://www.hss.edu/conditions_lupus-pregnancy-points-optimize-outcome.asp#time). Accessed 30 June 2022.
- Greco CM, Kao AH, Maksimowicz-McKinnon K, et al. Acupuncture for Systemic Lupus Erythematosus: A Pilot RCT Feasibility and Safety Study. *Lupus*. 2008 Dec;17(12):1108-1116.
- Greco CM, Nakajima C, Manzi S. Updated Review of Complementary and Alternative Medicine Treatments for Systemic Lupus Erythematosus. *Curr Rheumatol Rep*. 2013 Nov;15(11):378.
- Khafagy AM, Stewart KI, Christianson MS, et al. Effect of Menopause Hormone Therapy on Disease Progression in Systemic Lupus Erythematosus: A Systematic Review. *Maturitas*. 2015 Jun;81(2):276-281.
- Lupus Foundation of America. Assistance at school for Children with Lupus. <https://www.lupus.org/resources/assistance-at-school-for-children-with-lupus>. Accessed 30 June 2022.
- Sammaritano LR, Bermas BL, Chakravarty EE, et al. 2020 American College of Rheumatology Guideline for the Management of Reproductive Health in Rheumatic and Musculoskeletal Diseases. *Arthritis Rheumatol*. 2020 Apr;72(4):529-556.
- Self-Management Tools for People Living with Lupus. The Lupus Initiative. <https://selfcare.thelupusinitiative.org> Accessed 3 Aug 2022.

## MEDICAL HISTORY WORKSHEET FOR LUPUS

First day of your last period: \_\_\_\_\_ Today's Date: \_\_\_\_\_

Are you:  Perimenopausal  Postmenopausal  I don't know

Reproductive history (*pregnancies, child births, infertility, etc.*): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Your typical vitals: Weight: \_\_\_\_\_ lbs. Temperature: \_\_\_\_\_°F Blood pressure: \_\_\_\_\_/\_\_\_\_\_

Your primary symptoms of lupus: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Known triggers (if any): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Describe your last flare (*When did it start? How long did it last? What symptoms were most debilitating?*):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Have you received any previous diagnoses for autoimmune diseases?  No  Yes

Disease(s) & Date(s): \_\_\_\_\_  
\_\_\_\_\_

Family history of lupus or undiagnosed symptoms: \_\_\_\_\_  
\_\_\_\_\_

Relevant past procedures, tests, and treatments:

Procedure/Test/Treatment	Date	Notes (provider, results, etc.)
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Current medications (include prescription and any over-the-counter meds you take regularly):

Medication	Dose & Frequency	Notable Side Effects
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Your health care professional team:

Name	Specialty	Contact Info	Date of Last Visit
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Keeping a journal allows you to share a more complete picture of your experience with your health care providers. It can also help you to identify triggers, patterns in your flares, and effective ways to manage your symptoms.

This journal allows you to keep track of your lupus symptoms and relevant details, such as when they occur, duration, severity, effects on your ability to function, and your treatment actions and results. With a better understanding of your lupus experience, you and your health care providers can design and/or adjust a care plan tailored to your needs.

**Examples of Symptoms:**

- Fatigue
- Pain or swelling in the joints
- Swelling in the hands, feet, or around the eyes
- Headaches
- Butterfly-shaped rash on the cheeks and nose
- Hair loss
- Sores in the mouth or nose
- Low-grade fevers
- Sensitivity to sunlight or fluorescent light
- Chest pain when breathing deeply

**Examples of Triggers:**

- Estrogen levels (e.g., a certain time in your menstrual cycle)
- High stress (emotionally or physically)
- Exhaustion
- Infection or injury
- Exposure to ultraviolet light
- Change in medication(s)

**Symptoms Severity Rating:**



**Functional Ability Rating:**



**Relief Rating:**



**Notes** (including identification of possible triggers and why):

Month & Year: \_\_\_\_\_

Day	Symptom(s)	Duration	Severity [1-10]	Ability to Function [0-10]	Medication/ Treatment [Name, Dose]	Relief [0-10]	Flare Day? [Y/N]
01							
02							
03							
04							
05							
06							
07							
08							
09							
10							
11							
12							
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