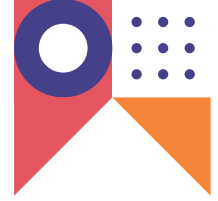


# DIAGNOSING AND TREATING LUPUS




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## 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>**

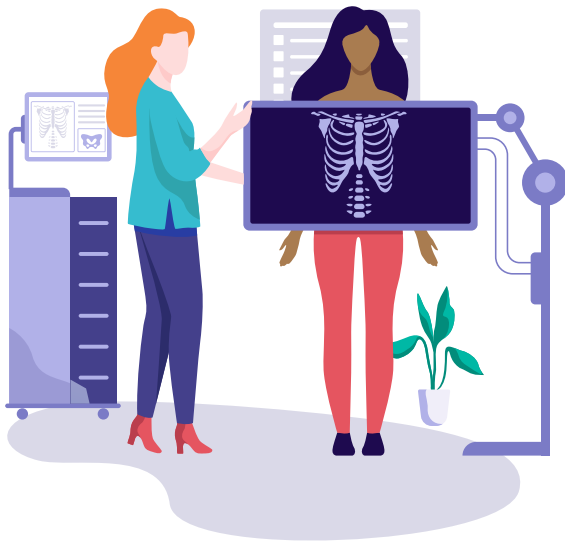
 **4+ providers** seen before an accurate lupus diagnosis<sup>8</sup>

## 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

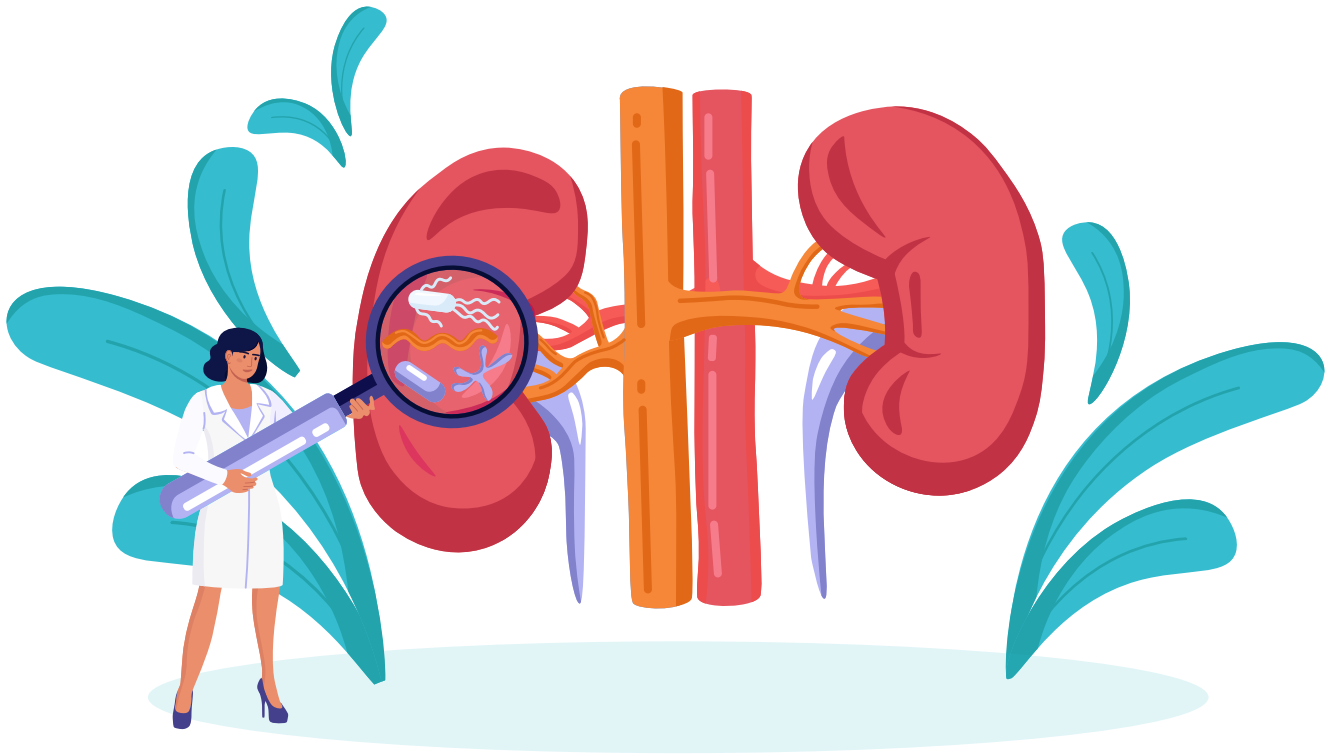
### Lifestyle Approaches

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>

