

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.

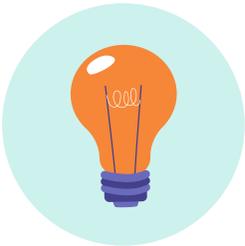
 **22%** of patients reported sustained clinical remission after 5 years, while on treatment¹⁴

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.



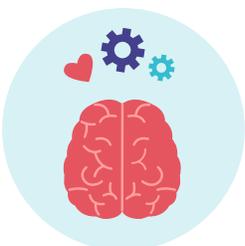
Know that flares are common. While it can be frustrating and disruptive to experience a symptom flare, you can come up with a plan for how to manage them when they occur. This might include rest, additional self-care activities, or connecting with your health care provider.

- ▶ 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?

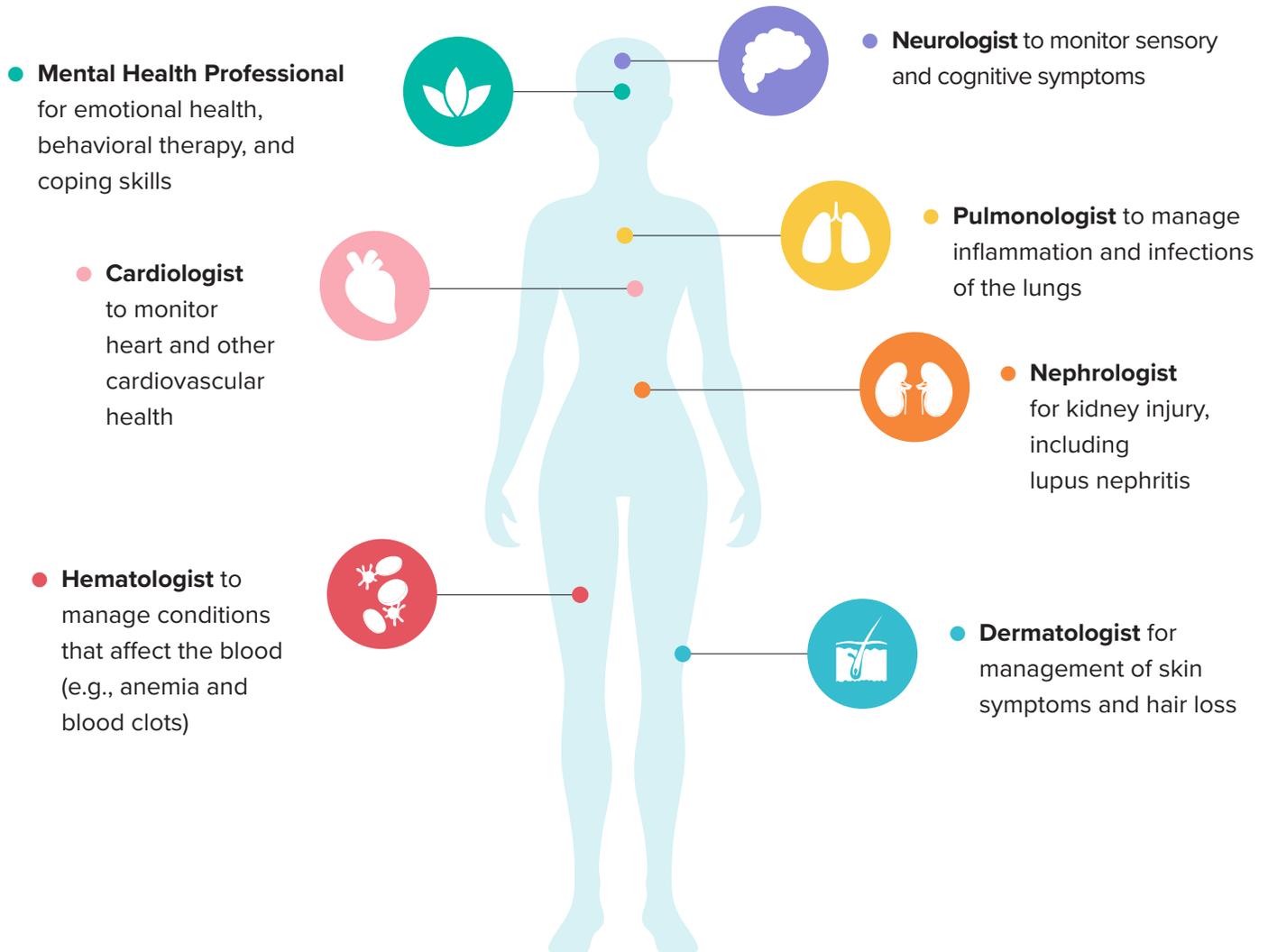
.....

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.

.....

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 lupus¹⁵

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.