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# After Diagnosis Navigation Toolkit

This toolkit aims to help individuals living with lupus manage their condition after diagnosis, including keeping up with doctors' appointments, tracking medications, and making lifestyle adjustments.



# You've Been Diagnosed—Now What?

When you're first diagnosed with lupus, you'll see your rheumatologist (a doctor who treats lupus) often. These visits help your doctor understand how lupus is affecting your body and make sure your treatment is working. As your symptoms become more stable, your visits may become less frequent.

## What Happens at These Appointments?

- **Checking Your Symptoms**  
Your doctor will ask about any pain, tiredness, rashes, or other symptoms you're experiencing.
- **Lab Tests**  
You'll likely have blood and urine tests to check how your body is handling lupus and your medications.
- **Adjusting Medications**  
If your treatment isn't working well or is causing side effects, your doctor may change the dose or try a different medication.
- **Seeing Other Doctors**  
Because lupus can affect different parts of your body, you may need to see other specialists, like a kidney doctor, skin doctor, or heart doctor.



## You Got This!

At first, it might feel like you're always at the doctor's office, but these visits are important to help you feel better and keep lupus from causing serious health problems. If you ever notice new or worse symptoms, don't wait for your next appointment—call your doctor right away!

# Tracking Medications

Managing lupus often means taking different medications to help control symptoms, reduce inflammation, and prevent flare-ups. Since lupus affects everyone differently, your doctor may adjust your medications over time to find what works best for you.

## Tips for Keeping Up with Your Medications



### Use Your Phone

- A notebook, smartphone app, or medication tracker can help you record what you take and when.
- Set alarms to remind you when to take your medicine.



### Set Up a Routine

- Take your medications at the same time every day to make it a habit.
- Use a pill organizer to sort your daily doses, especially if you take multiple medications.



### Keep a Symptom & Side Effect Journal

- Write down how you feel each day, including pain levels, fatigue, or any new symptoms.
- Track any side effects, like nausea, dizziness, or mood changes, and report them to your doctor.



### Plan for Refills

- Set calendar reminders to refill prescriptions before they run out.
- Ask your pharmacy about automatic refills or 90-day supplies to reduce trips to the pharmacy.



## Bring Your Medication List to Appointments

Be sure to keep an updated list of your medications, dosages, and any allergies and share this list with every doctor you see to avoid harmful drug interactions.

Taking lupus medications correctly is one of the most important ways to manage your condition. Keeping good records and sticking to a routine can help you feel more in control and get the best results from your treatment.

# Lifestyle Changes for Better Health

Living with lupus means making some changes to protect your health and prevent flare-ups. While there's no cure, healthy habits can make a big difference in how you feel and how well your treatment works. Here are some key lifestyle changes to consider:

## Here's what you can do:



### Get Enough Rest & Manage Fatigue

Take breaks when needed and don't push yourself too hard. Aim for 7–9 hours of sleep each night to help your body recover.



### Eat a Balanced, Anti-Inflammatory Diet

Some foods can help reduce inflammation, while others can make symptoms worse. Eat more fruits, vegetables, whole grains, and lean protein. Avoid processed foods, excessive salt and red meat, alcohol, and caffeine.



### Stay Active (But Don't Overdo It!)

Exercise can help with joint pain, stiffness, and fatigue. Low-impact activities like walking, swimming, or yoga are easier on your joints. Stretching and light strength training can help keep your muscles strong. Listen to your body—if you feel too tired or sore, rest instead of pushing through.

### Protect Yourself from the Sun

Many people with lupus are sensitive to sunlight, which can trigger flares and cause skin rashes. Wear sunscreen (SPF 50+), even on cloudy days. Wear hats, sunglasses, and long sleeves if you're outside for a long time.

### Manage Stress & Mental Health

Stress can make lupus symptoms worse, so finding ways to manage it is important. Try relaxation techniques like deep breathing, meditation, or journaling. Stay connected with supportive family, friends, or a lupus support group. Consider therapy or counseling to help with anxiety, depression, or the emotional impact of lupus.



## Making Lifestyle Changes One Step at a Time

Changing everything at once can feel overwhelming. Start small—maybe focusing on getting more sleep or improving your diet. Over time, these changes will help you feel better and stay healthier while living with lupus.

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