



DOCTOR DISCUSSION GUIDE

Managing Lupus

Lupus can be a difficult illness, but with the right treatment and management strategies, people with this disease can live full lives. Asking the right questions during your conversation will help you know what to expect and how to better navigate your condition. Familiarize yourself with these common terms before your appointment to help facilitate your discussion.

Vocabulary to Know

Your doctor might mention these common terms. Here's what they mean.

Autoimmune Disease	In autoimmune disease, your body attacks itself. The immune system works to destroy healthy tissues in the body because it mistakes them for dangerous invaders, such as a virus or bacteria.
Elevated Erythrocyte Sedimentation Rate (sed rate or ESR)	A blood test that helps diagnose lupus and many other conditions. The lab measures how quickly red blood cells settle to the bottom of a container. Healthy cells settle slowly, and more rapidly settling ones can indicate inflammation. However, it doesn't indicate whether the inflammation comes from chronic disease, infection, or injury. Thus, it's only part of a diagnostic process.
Antinuclear Antibody (ANA) Test	Antibodies are proteins in the immune system that attack foreign invaders, or—in the case of autoimmune disease—your own cells. In that case, they're called autoantibodies. Antinuclear antibodies are a type of autoantibodies that attack the nucleus of your cells. An ANA blood test, therefore, can indicate the presence of some autoimmune diseases. At least 97 percent of people with lupus have a positive ANA test.
Flare/Relapse & Remission	Many, but not all, cases of lupus have symptoms that come and go. Periods of increased symptoms are called flares or relapses. Periods of no symptoms or milder symptoms are called remissions. Often, flares are triggered by predictable things, such as hormonal fluctuations or stressful events. Other times, a flare may strike with no obvious causes.
Malar Rash	Also called a butterfly rash, the malar rash is a common symptom of lupus. It includes redness or rash across your cheeks and nose that is shaped like a butterfly.
Photosensitivity	An abnormal skin reaction to ultraviolet light, which leads to especially fast burning or blistering of the skin. This is a common symptom of lupus.
Disease-Modifying Antirheumatic Drug (DMARD)	Drugs used to slow down the progression of tissue damage in lupus. They're not a class of drugs, but a term for numerous, unrelated drugs used to fight this disease.
Biologic Agents	A biologic agent is made from living organism or products of living organisms. They can be used to prevent, diagnose, or treat certain diseases.
Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)	Medications that reduce pain, inflammation, and fever. The most common ones are the over-the-counter drugs ibuprofen (Motrin, Advil), naproxen (Aleve), and aspirin.



Questions to Ask

These questions will help you start a conversation with your doctor about how to best manage your lupus.

About Symptoms

- Will my symptoms get worse?
- Are my symptoms typical of lupus?
- What's the typical progression of this disease?

About Causes & Risk Factors

- Can you pinpoint why I got this?
- Will my kids get it? How can I lower their risk?

About Diagnosis

- How long will the diagnostic process take?
- How certain is the diagnosis?
- Which type of lupus do I have?

About Treatment

- What type of drug should I try?
- How soon should I see results?
- What if I get side effects?
- What if the drug doesn't work?
- Can supplements and/or complementary treatments help?

About Coping

- How do I deal with depression?
- Should I see a therapist to adjust to living with a chronic illness?
- Do you know of any good support groups in the area?

About Living With Lupus

- What kinds of activities should I do?
- What kinds of activities should I avoid?
- Should I stop working?
- What positive changes can I make to my diet?
