

# ASKING QUESTIONS AND FINDING ANSWERS:

## A GUIDE TO PREPARING FOR YOUR APPOINTMENT

**About 1.5 million people in the United States have lupus. Yet, more than half of Americans know nothing about the disease.<sup>1</sup>**

Have you experienced joint pain, severe tiredness, a butterfly-shaped rash, hair loss or light sensitivity for more than a few weeks?<sup>2,3</sup> If so, your symptoms indicate it's time to talk with your provider about lupus.

Lupus is a life-long autoimmune disease caused by the immune system attacking healthy cells or tissues like it would a virus. Symptoms of lupus may affect the entire body.<sup>4</sup>

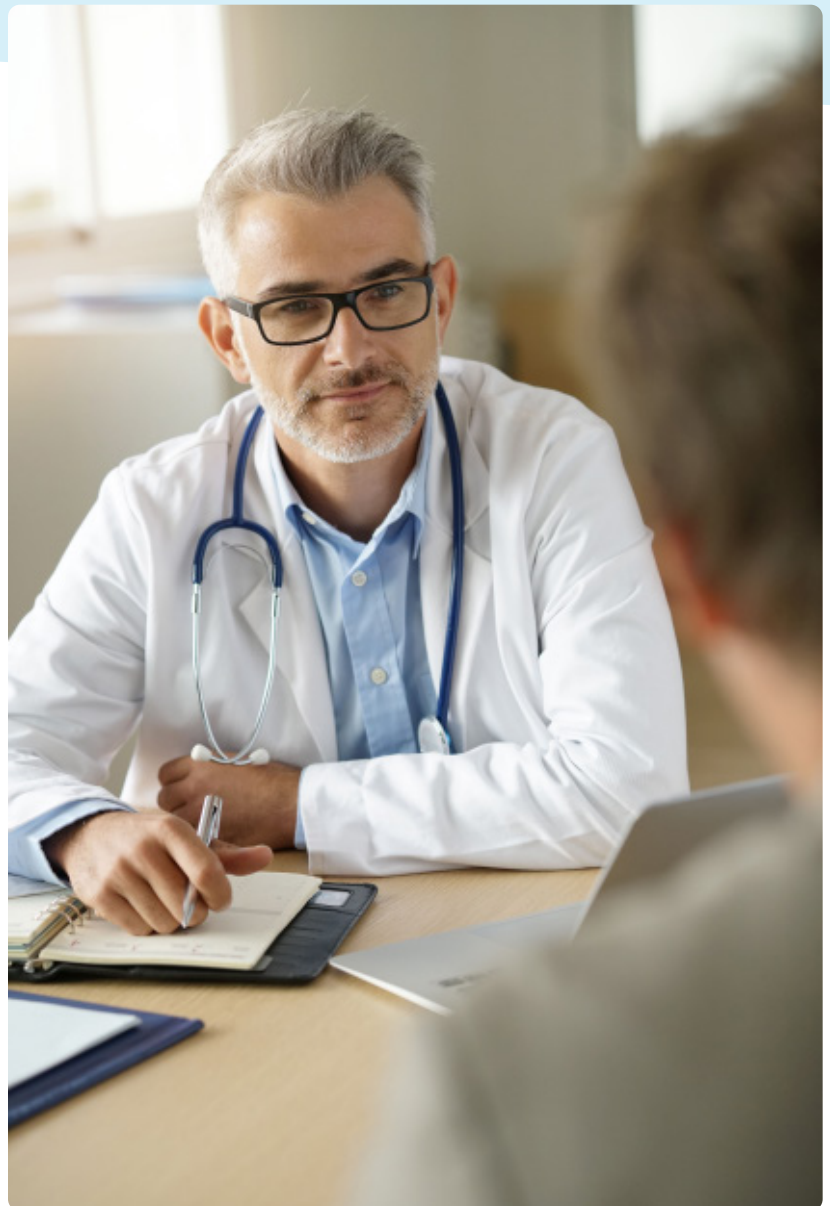
### STARTING THE PROCESS

The first step in finding out if you have lupus is scheduling an appointment with your primary care provider to discuss your symptoms and concerns. After your appointment, they may order tests or refer you to a doctor called a rheumatologist who specializes in autoimmune diseases.

Unlike many other conditions, there isn't a definitive test for lupus. This can make diagnosis challenging. Because lupus may mimic other health conditions and symptoms typically come and go, it takes an average of almost six years after first noticing symptoms to be diagnosed.<sup>1</sup>

However, recognizing the symptoms of lupus early on and knowing the process of getting diagnosed may help you get answers sooner.

**Advanced diagnostic lab tests such as the AVISE CTD [lupus test](#) may give your provider the information needed to make a diagnosis more efficiently.**





Make sure to list every symptom and give as many details as possible, even if a symptom doesn't bother you as much as others, doesn't seem very important or feels embarrassing. These details often make a big difference as your provider determines your diagnosis.<sup>6</sup>

## IT'S ALL ABOUT YOU

**Preliminary questions help your provider rule out other conditions and determine which diagnostic tests you need.**

Before ordering diagnostic tests, your provider will ask you questions about your symptoms to learn more about what you're experiencing and how it's affecting your life.<sup>5</sup>

You can also expect questions about personal and family medical history, such as:

- Are you taking any medications, including herbal supplements, over-the-counter medications or vitamins?
- Are you allergic to any medications?
- Has anyone in your family been diagnosed with lupus or another autoimmune disorder?
- Have you been diagnosed with another medical condition?

Your provider will ask you to describe [symptoms](#) you're having or have had in the past.

- Are your symptoms worse at a particular time of day or after a certain activity?
- Do any of your symptoms affect your day-to-day responsibilities at home, school or work?
- Do you always have symptoms, or do they come and go?
- How frequently do you have each symptom?
- Is there anything that worsens or improves your symptoms?
- When did you start having symptoms?

**Complete and download this [lupus symptoms checklist](#) to help you prepare. The [AVISE CTD conversation guide](#) is also available to help you communicate with your provider.**

## ASKING QUESTIONS ABOUT THE DIAGNOSTIC PROCESS

**Before you can address living with lupus, you need to get the correct diagnosis.**

When you're facing a possible diagnosis of lupus, it can be easy to get lost in worries about the future.

You probably have many questions about living a life with lupus:

- Are there long-term effects of lupus I should be aware of?
- How can I best manage lupus while doing what I need and want to do?
- What are my treatment options?
- What results can I expect from treatment?

### ONE STEP AT A TIME

Feeling prepared for your appointment can help keep you calm. Write down questions you have about the next steps in the diagnostic process and the support you may need while waiting for a diagnosis.

- Are there activities, foods or medications I should avoid while I wait for a diagnosis?
- Could there be another cause for my symptoms?
- How much can I expect to learn from testing?
- Should I ask for accommodations at work or take a leave of absence?
- What might happen if I wait to undergo testing?
- Which tests will be the most helpful for me?



**Your provider likely already knows about the newest advances in testing for lupus, such as the innovative [AVISE CTD lupus test](#). If not, providers can visit [www.avisetest.com/provider](http://www.avisetest.com/provider) to learn more about the test's accuracy and benefits and how it may fit your needs.**

## GETTING READY

Being able to share as much information as possible can help your provider come to an accurate diagnosis.

### A FEW DAYS OR WEEKS BEFORE YOUR APPOINTMENT

Track how you feel each day. In a journal or log book, note:

- Every symptom you have, including mental and physical health symptoms
- Whether and how each symptom interferes with your daily routine
- How severe each symptom is
- The day and time you notice each symptom and how long it lasts

If you take your vital signs, such as temperature or blood pressure, record those in your log book too. Our [lupus symptoms checklist](#) can be a helpful starting point.

Ask any previous providers to send your medical records to your provider in advance. It may take several days to sign releases and have the records sent.

If you are unable to have your medical records sent, gather copies of what you have, including lab test results and imaging reports, to bring with you to your appointment.

Make a list or take a picture of the medications you take, including all herbal supplements, over-the-counter medications and vitamins. Record the dosages, when you take them, how long you've taken them, side effects and any medication allergies.

Write a brief medical history that includes other diagnoses, significant injuries, hospitalizations, surgeries and vaccinations and when they happened. Approximate dates are OK.<sup>2</sup> List close family members' medical conditions, as well.

Take time to learn about lupus and its diagnosis, and make a list of questions to ask your provider.



## ON THE DAY OF YOUR APPOINTMENT

Follow any instructions you received from your provider.

Wear a short-sleeved shirt or layered shirts that can be removed easily for blood tests. In case your provider orders same-day imaging tests, avoid wearing makeup, nail polish and clothing with wire, metal fasteners, metal fibers or other metal particles. Tell your provider if you have any metal inside your body from previous injuries or surgeries. During certain imaging tests, metal in or next to your body may cause injury.<sup>7</sup>

It's often helpful to have a friend or family member come with you to your appointment. They can ask questions you may not think to ask, take notes and offer emotional support. After the appointment, they may also help you remember what the doctor said.

### Don't forget to bring these essentials to your appointment:



Checkbook, credit card, or FSA or HSA card to cover any co-pays



Copies of medical records that weren't already sent to your provider



Insurance card(s)



Personal and family medical history information, including a list of all medications



Photo ID



Questions for your provider



Symptoms log book

Consider bringing information about tests you'd like to know more about, including details about the AVISE CTD [lupus test](#).



# THE BASICS OF LUPUS TESTING

If your provider believes you may have lupus, they will order tests to get a clearer picture of how your body functions to rule out other conditions.<sup>2, 8</sup>

Common tests used to diagnose lupus include<sup>9, 10</sup>:

- A complete blood count test, which measures your red blood cells, white blood cells and platelet levels
- Antibody tests, which are blood tests that look for specific proteins that fight viruses or other foreign materials in the body. One of the most common lupus antibody tests is an antinuclear antibody (ANA) test.
- Blood clotting time tests, which check for a higher risk of blood clots or excessive bleeding
- Imaging tests, such as MRI and CT scans, that can detect damage or inflammation
- Tissue biopsies, usually taken from the kidneys or skin, that test for inflammation or lupus-related damage
- Urine tests to see if your kidneys are removing waste from the body as they should

Your provider may also have you take some tests more than once over the course of a few days, weeks or months to track changes.<sup>11</sup>

**If common tests are inconclusive or you've had a positive ANA test but don't have a diagnosis yet, ask your provider if an AVISE CTD advanced diagnostic lupus test could help them make a diagnosis.**



About 97% of people with lupus have a positive ANA test.<sup>11</sup> However, other health conditions may cause a positive ANA test result, and healthy individuals may also test positive. The AVISE CTD lupus blood test can provide additional information to help differentiate between autoimmune diseases.

## KNOW WHAT LIES AHEAD

**Your first appointment to discuss a potential lupus diagnosis can be stressful. However, you should never leave an appointment confused about your next steps.**

If something isn't clear, take the time to ask for more details. You can also ask for a copy of the information in writing.<sup>6</sup>

### BEFORE YOU LEAVE

Double check instructions for new medications or changes to your current medications.<sup>2, 6</sup>

Confirm recommendations for changes to diet, exercise or sleep.<sup>6</sup> Let your provider know if you don't think the new recommendations will fit your energy level, lifestyle or schedule. Your provider may be able to suggest alternatives.

Write down the name and contact information of the person who will help guide you through the rest of the diagnostic process. This may be your provider, a nurse or a patient navigator.

### TAKE THE NEXT STEPS

Get a list of which tests have been ordered and ask<sup>2, 6</sup>:

- How do I schedule these tests?
- Are there special instructions for these tests?
- Where do I go for testing?
- How soon can I expect results?
- When do I schedule a follow-up appointment with my provider?

Continue to track your symptoms. Keeping a record will help prepare you for the next appointment. It will also be a valuable tool for your provider throughout the diagnostic process.<sup>2</sup>

**Learn more about how the advanced patented technology of the AVISE CTD test can provide results you and your provider can trust.**

## References

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