



# What I Need to Know About How Lupus Is Diagnosed

Many challenges exist in confirming that a person has lupus. A lupus diagnosis is made by a careful review of current symptoms, laboratory test results, medical history, and the medical history of close family members. All of this information may be necessary for a doctor to make a diagnosis of lupus because laboratory tests alone cannot give a definite “yes” or “no” answer.

## What Is My Doctor Looking For?

A doctor who is considering the possibility of lupus will look for signs of inflammation, such as pain, heat, redness, and swelling. Inflammation can occur on the inside of your body, on the outside, or both.

## What Are the Common Symptoms of Lupus?

The American College of Rheumatology (ACR) developed a list of eleven common criteria to help physicians diagnose lupus. A person is considered to have lupus if they have at least four of the criteria on the list either at the present time or at some time in the past.

- **Malar Rash**-a rash over the cheeks and nose, often in the shape of a butterfly
- **Discoid Rash**-a rash that appears as red, raised, disk-shaped patches
- **Photosensitivity**-a reaction to the sun or light that causes a skin rash to appear or get worse
- **Oral Ulcers**-sores appearing in the mouth
- **Arthritis**-joint pain and swelling of two or more joints in which the bones around the joints do not become destroyed
- **Serositis**-inflammation of the lining around the lung (pleuritis) or inflammation of the lining around the heart that causes chest pain which is worse with deep breathing (pericarditis)
- **Kidney Disorder**-persistent protein or cellular casts in the urine
- **Neurological Disorder**-seizures or psychosis
- **Blood Disorder**-anemia (low red blood cell count), leucopenia (low white blood cell count), lymphopenia (low level of specific white blood cells), or thrombocytopenia (low platelet count).
- **Immunologic Disorder**-anti-*ODNA* or anti-*Sm* or positive test for antiphospholipid antibodies
- **Antinuclear Antibody (ANA)**

Other possible symptoms are fever (over 100 F), extreme fatigue, hair loss, fingers turning white and/or blue when cold (Raynaud’s phenomenon).

## What Laboratory Tests Will My Doctor Ask For?

A variety of laboratory tests are used to detect physical changes or conditions in your body that can occur with lupus. Each test result adds more information to the picture your doctor is forming of your illness.

**Routine Blood Tests** Usually your doctor will request a complete blood count (CBC). The complete blood count measures the levels of red blood cells, white blood cells, platelets, and serum. In cases of lupus, these blood tests may reveal low numbers.

**Urine Tests** Because your body’s waste is processed by your kidneys, testing a sample of urine can show any problems with the way your kidneys function. The most common urine tests look for *cell casts* (bits of cells that normally would be removed when your blood is filtered through the kidneys) and *proteinuria* (protein being spilled into your body because the kidneys are not filtering the waste properly). A collection of urine over a 24-hour period can also give important information.

**Antibodies** Antibodies that your body makes against its own normal cells and tissues play a large role in lupus. Many of these antibodies are found in a panel, or group, of tests ordered at the same time. The antibody test you will hear most about is the ANA test. This is not a specific test for lupus, however.

- **Antinuclear antibodies (ANA)** are antibodies that connect, or bind, to the nucleus-the “command center”-of the cell. This process damages, and can destroy the cells. The ANA blood test is a sensitive test for lupus, since these antibodies are found in 97% of people with the disease. A positive ANA test result does not always mean you have lupus. The ANA can be positive in people with other illnesses or positive in people with no illness. The ANA can also change from positive to negative, or negative to positive, in the same person.
- **Antibodies to double-stranded DNA (anti dsDNA)** are antibodies that attack the DNA-the genetic material-inside the cell nucleus. Anti-dsDNA antibodies are found in half the people with lupus, but lupus can still be present even if these antibodies are not seen.

- **Antibodies to histone**, a protein that surrounds the DNA molecule, are sometimes found in people with systemic lupus but are more often seen in people with drug-induced lupus. This form of lupus is caused by certain drugs, and usually goes away after the drug is stopped.
- **Antibodies to phospholipids (aPLs)** can cause narrowing of blood vessels, leading to blood clots in the legs or lungs, stroke, heart attack, or miscarriage. The most commonly measured aPLs are lupus anticoagulant, anticardiolipin antibody, and the anti-beta2 glycoprotein1. Phospholipids found in lupus are also found in syphilis, and the blood test cannot always tell the difference between the two diseases. Therefore, if you have lupus, a positive result to a syphilis test does not mean that you have or ever had syphilis.
- **Antibodies to Ro/SS-A and La/SS-B** (Ro and La are the names of proteins in the cell nucleus) are often found in people with Sjoren's syndrome, another autoimmune disease that often occurs with lupus. Anti-Ro antibodies in particular will also be found in people with a form of cutaneous (skin) lupus which causes a rash that is very sun-sensitive. It is especially important for your doctor to look for the presence of Ro and La antibodies if you are pregnant, as both autoantibodies can cross the placenta and can cause neonatal lupus in the fetus. Neonatal lupus is rare and not usually dangerous, but it can be serious in some cases.
- **Antibodies to Sm** target Sm proteins in the cell nucleus. Found in 30-40 percent of people with lupus, the presence of this autoantibody almost always means that you have lupus.
- **Antibodies to RNP** target ribonucleoproteins, which help to control chemical activities of the cells. Anti-RNP's are found in many autoimmune conditions and will be at very high levels in people whose symptoms combine features of several diseases, including lupus.

**Other Blood Tests** Some blood tests measure levels of proteins that are not antibodies. The levels of these proteins can alert your doctor to the presence of inflammation somewhere in your body.

- **Complement** is the name of a group of proteins in your blood that protect your body against infections. Complement proteins are used up by the inflammation caused by lupus, which is why people with active lupus often have low complement levels. The most common complement tests are CH50, C3, and C4.
- **C-reactive protein (CRP)** is a protein produced by the liver, and high levels of CRP in your blood may mean that you have inflammation due to lupus.
- **Erythrocyte sedimentation rate (ESR or "sed" rate)** measures the amount of protein that makes red blood cells clump together. The sed rate is usually high in people with active lupus, but it can also be high for other reasons, such as an infection.

**Blood Clotting Time Tests** The rate at which blood begins to clot is important. If it clots too easily, a blood clot (called a thrombus) can break free and travel through your body causing damage such as stroke or miscarriage. If blood does not clot quickly enough, you could be at risk for excessive bleeding if you are injured or having surgery.

- **Prothrombin time (PT)** test measure blood clotting and can show whether you may be at risk for not clotting quickly enough at the site of a wound.
- **Partial thromboplastin time (PTT)** test also measures how long it takes for you blood to begin to clot.
- **Modified Russell viper venom time (RVVT) platelet neutralization procedure (PNP) and kaolin clotting time (KCT)** are other, more sensitive blood clotting time tests.

**Tissue Biopsies** A biopsy involves removal of a small bit of tissue which is then examined under a microscope. Almost any tissue can be biopsied. The skin and kidney are the most common sites biopsied in someone who may have lupus. The results of the biopsy can show the amount of inflammation and any damage being done to your body.

## What Do All These Test Results Mean?

Understanding these tests and what the test results mean can be difficult. In many cases, it can take months or even years for doctors to put together all of the information that is required to make a firm diagnosis of lupus. It is important to have open and ongoing communication with your doctors so that the proper diagnosis, whether of lupus or some other condition, can be made as early and accurately as possible.

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