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Lupus

Q: What is lupus?

A: Lupus (LOO-puhss) is a chronic, autoimmune (aw-toh-ih-MYOON) disease that can damage any part of the body (skin, joints, and/or organs inside the body). Chronic means that the signs and symptoms tend to last longer than six weeks and often for many years. In lupus, something goes wrong with your immune system, which is the part of the body that fights off viruses, bacteria, and other germs (“foreign invaders,” like the flu). Normally our immune system produces proteins called antibodies that protect the body from these invaders. Autoimmune means your immune system cannot tell the difference between these foreign invaders and your body’s healthy tissues (“auto” means “self”). In lupus, your immune system creates autoantibodies (AW-toh-AN-teye-bah-deez), which attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body.

When people talk about “lupus,” they usually mean **systemic lupus erythematosus (ur-uh-thee-muh-TOH-suhss)**, or SLE. This is the most common type of lupus. Studies suggest that more than 16,000 new cases are reported annually across the country.

Although lupus can affect almost any organ system, the disease, for most people, affects only a few parts of the body. For example, one person with lupus may have swollen knees and fever. Another person may be tired all the time or have kidney trouble.

Someone else may have rashes.

Normally, lupus develops slowly, with symptoms that come and go. Women who get lupus most often develop symptoms and are diagnosed between the ages of 15 and 45. But the disease also can develop in childhood or later in life.

For most people, lupus is a mild disease. But for others, it may cause serious problems. Even if your lupus symptoms are mild, it is a serious disease that needs treatment. It can harm your organs and put your life at risk if untreated.

Although the term “lupus” commonly refers to SLE, this is only one type of the disease. There are other, less common types of lupus:

- **Discoid (DISS-koid) lupus erythematosus**, also called DLE, mainly affects the skin. A red rash may appear. Or, the skin on the face, scalp, or elsewhere may become scaly or change color. Sometimes DLE causes sores in the mouth or nose. A doctor will remove a small piece of the rash or sore and look at it under a microscope to tell if someone has DLE. If you have DLE, there is a small chance that you will later get SLE. There is no way to know if someone with DLE will get SLE.
- **Drug-induced lupus** is a lupus-like disease caused by certain prescription drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus, but only rarely will any major organs be affected. Symptoms can include: joint pain, muscle pain, and fever. Symptoms are mild for most people.



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Most of the time, the disease goes away when the medicine is stopped. More men get this type of lupus because the drugs with the highest risk of causing it are used to treat heart conditions that are more common in men; however, not everyone who takes these drugs will develop drug-induced lupus. The drugs most commonly connected with drug-induced lupus are procainamide (Pronestyl[®], Procanbid[®]) and hydralazine (Apresoline[®]; also, hydralazine is an ingredient in Apresazide[®] and Bidil[®]).

- **Neonatal lupus** is a rare condition that affects infants of women who have lupus and is caused by certain antibodies from the mother acting upon the infant in the womb. At birth, the infant may have a skin rash, liver problems, or low blood cell counts, but these symptoms disappear completely after several months with no lasting effects. Some infants with neonatal lupus can also have a serious heart defect. With proper testing, physicians can now identify most at-risk mothers, and the infant can be treated at or before birth. Most infants of mothers with lupus are entirely healthy.

Q: Who gets lupus?

A: Anyone can get lupus. But 9 out of 10 people who have lupus are women. African American women are three times more likely to get lupus than white women. Lupus is also more common in Hispanic/Latino, Asian, and Native American women. African Americans and Hispanics/

Latinos tend to get lupus at a younger age and have more symptoms, including kidney problems. Lupus also tends to be more severe in these ethnic groups. For example, African Americans with lupus have more problems with seizures and strokes. Hispanic/Latino patients have more heart problems. Scientists believe that genes play a role in how lupus affects these ethnic groups.

It is estimated that between 161,000 and 322,000 adults in the U.S. have SLE. Nine out of 10 people who have lupus are women. African American, Latino, Asian, and Native American women are at greater risk of getting lupus than white women.

Q: Why is lupus a concern for women?

A: Nine out of 10 people who have lupus are women. And lupus is most common in women of childbearing years. Having lupus increases your risk of developing other health problems that are common in women. It can also cause these diseases to occur earlier in life:

- **Heart disease.** When you have lupus you are at increased risk for the main type of heart disease, called coronary artery disease (CAD). This is partly because people with lupus have more CAD risk factors, which may include: high blood pressure (hypertension), high cholesterol levels, type 2 diabetes, and an inactive lifestyle due to fatigue, joint problems, and/or muscle pain. Heart disease is the number one killer of



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all women. But, women with lupus are 50 times more likely to have chest pain or a heart attack than other women of the same age.

- **Osteoporosis (OSS-tee-oh-puh-ROH-suhss).** Women with lupus have more bone loss and breaks than other women. This is thought to happen because some medicines used to treat lupus cause bone loss. Bone loss also may occur as a direct result of the disease. Also, pain and fatigue can keep women with lupus from exercising. Keeping active is an important way to keep bones healthy and strong.

Q: What causes lupus?

A: The cause of lupus is not known. More than one factor is likely to play a role in getting lupus. Researchers are looking at these factors:

- Genes (Lupus is probably caused by several genes acting together.)
- Environment (Sunlight, stress, certain medications, and viruses might trigger symptoms in people who are prone to getting lupus.)
- Hormones (Lupus is more common in women during childbearing years.)
- Problems with the immune system

You can't catch lupus from another person, and it isn't related to AIDS.

Q: What are the symptoms of lupus?

A: The signs of lupus differ from person to person. Some people have just a

few symptoms; others have more.

Lupus symptoms also tend to come and go. Lupus is a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better).

Common signs of lupus are:

- painful or swollen joints
- fever with no known cause
- feeling very tired
- skin rashes
- anemia (uh-NEE-me-uh) (too few red blood cells)
- trouble thinking, memory problems, confusion
- kidney problems with no known cause
- chest pain when taking a deep breath
- butterfly-shaped rash across the nose and cheeks
- sun or light sensitivity
- hair loss

Less common symptoms include:

- blood clots
- purple or pale fingers or toes from cold or stress
- seizures
- sores in the mouth or nose
- severe headache
- dizzy spells
- “seeing things”, not able to judge reality
- feeling sad
- strokes

Q: What are flares?



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A: The times when your symptoms worsen and you feel ill are called flares. Flares tend to come and go. You may have swelling and rashes one week and no symptoms at all the next. Even if you take medicine for lupus, you may find that some things trigger your symptoms to flare. You may find that your symptoms flare after you've been out in the sun or after a hard day at work. Common triggers include:

- overwork and not enough rest
- stress
- being out in the sun or exposed to fluorescent or halogen light
- infection
- injury
- stopping your lupus medicines
- certain medications

See *What can I do to control my lupus symptoms and prevent flares?*

Q: How can a doctor tell if I have lupus?

A: Lupus can be hard to diagnose. It's often mistaken for other diseases. Many people have lupus for awhile before they find out they have it. If you have symptoms, tell your doctor right away. No single test can tell if a person has lupus. But your doctor can find out if you have lupus in other ways, including:

1. Medical history. Telling your doctor about your symptoms and other problems you have had can help him or her understand your situation. Keep track of your symptoms by writing them down. See the symptom checklist on page 5.

2. Family history of lupus or other autoimmune diseases. Tell your doctor if lupus or other autoimmune diseases run in your family.
3. Complete physical exam. Your doctor will look for rashes and other signs that something is wrong.
4. Blood and urine tests. The antinuclear antibody (ANA) test can show if your immune system is more likely to produce the autoantibodies of lupus. Most people with lupus test positive for ANA. But, a positive ANA does not mean you have lupus. About 2 in 10 healthy people test positive for ANA. Positive tests also are seen in other conditions, such as thyroid disease, malaria, and other autoimmune diseases. That's why your doctor will use many tools—and maybe other tests—to tell if you have lupus.
5. Skin or kidney biopsy (BEYE-op-see). With a biopsy, doctors perform a minor surgery to remove a sample of tissue. The tissue is then looked at under a microscope. Skin and kidney tissue looked at in this way can show signs of an autoimmune disease.

Together, this information can provide clues to your disease. It also can help your doctor rule out other diseases that can be confused with lupus.

Q: How is lupus treated?

A: There is no known cure for lupus, but there are treatments. Your treatment will depend on your symptoms and needs. The goals of treatment are to:

- prevent flares

FREQUENTLY ASKED QUESTIONS



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- treat symptoms when they occur
- reduce organ damage and other problems

Your treatment might include using medicines to:

- reduce swelling and pain
- prevent or reduce flares
- calm the immune system
- reduce or prevent damage to the joints

- reduce or prevent organ damage

Drugs play an important role in treating lupus. Most likely, the drugs prescribed to you will change often during your treatment. Types of drugs commonly used to treat lupus include:

- **Nonsteroidal anti-inflammatory drugs (NSAIDs)**. NSAIDs are used to reduce pain and swelling in joints and muscles. They can help with mild lupus—when pain isn't

| Symptom Checklist | | | | | |
|---|---|----------------|----------------------------|-----------------------|--------------------------|
| Print out this table and use it to make notes to take to your doctor. Put a check mark beside the symptoms you have. Note when you have them. | | | | | |
| Symptom | ✓ | Where? | When did you first notice? | How often? | Recent dates? |
| Example: rash | ✓ | face and chest | 2 years ago | Once or twice a month | 9/17, 10/8, 10/23, 11/15 |
| Red rash or color change | | | | | |
| Painful or swollen joints | | | | | |
| Fever with no known cause | | | | | |
| Feeling very tired | | | | | |
| Trouble thinking, memory problems, confusion | | | | | |
| Chest pain with deep breathing | | | | | |
| Sensitivity to sun | | | | | |
| Unusual hair loss | | | | | |
| Pale or purple fingers or toes | | | | | |
| Other | | | | | |
| Sores in mouth or nose | | | | | |

Adapted from National Institute of Arthritis and Musculoskeletal and Skin Diseases



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too bad and vital organs are not affected. Aspirin, ibuprofen, and naproxen are some over-the-counter NSAIDs. You need a prescription for stronger NSAIDs. NSAIDs can cause stomach upset, heartburn, drowsiness, headache, fluid retention, and other side effects. NSAIDs also can cause problems in your blood, liver, and kidneys if overused.

- **Corticosteroids (KOR-tih-koh-STAIR-oyds).** Corticosteroids are hormones found in our bodies. Manmade versions are used to reduce swelling, tenderness, and pain in many parts of the body. In high doses, they can calm the immune system. Often, these drugs are called “steroids.” They are different than steroids used by some people who play sports or lift weights. Corticosteroids come as pills or liquids, creams to apply to the skin, and as a shot. Prednisone (PRED-nuh-sohn) is one drug commonly used to treat lupus. Lupus symptoms tend to respond very quickly to these powerful drugs. Once this has happened, your doctor will want to lower your dose slowly until you no longer need it. The longer a person uses corticosteroids, the harder it becomes to lower the dose. But stopping this medicine right away can harm your body. Make sure to use your medicine exactly as your doctor tells you to.

Corticosteroids can have many side effects, so your doctor will give you the lowest dose possible. Short-term side effects can include: a round or puffy face, acne, heartburn,

increased appetite, weight gain, and mood swings. These side effects typically stop when the drug is stopped. Long-term side effects can include: easy bruising, thinning skin and hair, weakened or damaged bones, high blood pressure, damage to the arteries, high blood sugar, infections, muscle weakness, and cataracts. Your doctor can prescribe medicines to take with corticosteroids to prevent some side effects, such as osteoporosis.

Never take vitamins or herbal supplements without talking to your doctor first. They might not mix well with medicines you use to treat lupus.

- **Antimalarial drugs.** Medicines used to prevent or treat malaria are used to treat joint pain, skin rashes, and mouth sores. Two common antimalarials are hydroxychloroquine (hey-DRÖK-see-KLÖR-uh-kween) (Plaquenil[®]) and chloroquine (KLÖR-uh-kween) phosphate (Aralen[®] phosphate). Side effects of antimalarials can include stomach upset, nausea, vomiting, diarrhea, headache, dizziness, blurred vision, trouble sleeping, and itching.
- **Immunosuppressive agents/ chemotherapy.** These agents are used in severe cases of lupus, when major organs are not working well and other treatments do not work. These drugs suppress the immune system to limit the damage to the organ. Examples are azathioprine (az-uh-THEYE-uh-preen) (Imuran[®]) and cyclophosphamide



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(seye-kluh-FOSS-fuh-myd) (Cytoxan[®]). These drugs can cause serious side effects including nausea, vomiting, hair loss, bladder problems, decreased fertility, and increased risk of cancer and infection.

You and your doctor should review your treatment plan often to be sure it is working. Tell your doctor about any side effects or if your medicines no longer help your symptoms. Tell your doctor if you have new symptoms. Never stop or change treatments without talking to your doctor first. Also, it is likely that you will need other drugs to treat conditions that are linked to your lupus—such as drugs to treat high blood pressure or osteoporosis.

Q: Will I need to see a special doctor for my lupus?

A: Depending on your symptoms and/or if your organs have been hurt by your lupus, you may need to see special kinds of doctors. Start by seeing your family doctor and a rheumatologist (ROOM-uh-TOL-uh-jist), a doctor who specializes in the diseases of joints and muscles such as lupus.

Your rheumatologist may ask that you also see:

- a clinical immunologist (im-yuh-NOL-uh-jist), a doctor who treats immune system disorders
- a nephrologist (nuh-FROL-uh-jist), a doctor who treats kidney diseases
- a hematologist (hee-muh-TOL-uh-jist), a doctor who treats blood disorders
- a dermatologist (dur-muh-TOL-

uh-jist), a doctor who treats skin problems and diseases

- a neurologist (noo-ROL-uh-jist), a doctor who treats problems with the nervous system
- a psychologist (seye-KOL-uh-jist)
- an occupational (ok-yuh-PAY-shuh-nul) therapist
- a social worker

Q: What can I do to control my lupus symptoms and prevent flares?

A: The best way to keep your lupus under control is by following your treatment plan and taking care of yourself. Take these steps:

- Learn how to tell that a flare is coming.
- See your doctors regularly.
- Maintain life balance by setting realistic goals and priorities.
- Limit the time you spend in the sun and in fluorescent and halogen light.
- Maintain a healthy diet.
- Develop coping skills to help limit stress.
- Get enough sleep and rest.
- Exercise moderately when possible.
- Develop a support system made up of people you trust and can go to for help.

Despite your best efforts to follow your treatment plan and take good care of yourself, there will be times when your lupus symptoms are worse. Being able to spot the warning signs of a flare can help you prevent the flare or make it less severe. Before a flare,



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your symptoms might get worse, or you might get new symptoms, such as:

- feeling more tired
- pain
- rash
- fever
- stomach ache
- severe headache

Contact your doctor right away if you suspect a flare is coming.

Q: Living with lupus can be hard. How can I cope?

A: Dealing with a long-lasting disease like lupus can be hard on the emotions. Concerns about your health and the effects of your lupus on your work and family life can be stressful. Changes in the way you look and other physical effects of lupus can be tough to handle. Your friends, family, and coworkers might not seem to understand how you feel. At times, you might feel sad or angry. Or, that you have no control over your life with lupus. But there are things you can do that will help you to cope and to keep a good outlook:

- **Pace yourself.** People with lupus have limited energy and must manage it wisely. Most women with lupus feel much better when they get enough rest and avoid taking on too much at home and at work. To do this, pay attention to your body. Slow down or stop before you're too tired. Learn to pace yourself. Spread out your work and other activities.
- **Reduce stress.** Exercising, finding ways to relax, and staying involved in social activities you enjoy will reduce stress and help you to cope.

- **Get support.** Be open about your feelings and needs with family members and close friends. Consider support groups or counseling. They can help you to see that you are not alone. Group members teach one another how to enjoy life with lupus.
- **Talk to your doctor.** The symptoms of lupus and some medications can bring on feelings of depression. Don't be afraid to talk to your doctor about these feelings.
- **Learn about lupus.** People who are well-informed and involved in their own care have less pain; make fewer visits to the doctor; feel better about themselves; and remain more active.

Q: I have lupus. Is it safe for me to become pregnant?

A: Women with lupus can safely become pregnant. If your disease is under control, pregnancy is unlikely to cause flares. But there are some important things you should know before you become pregnant:

- Your disease should be under control or in remission for 12 months before you get pregnant. Getting pregnant when your lupus is active could result in miscarriage, stillbirth, or other serious problems. Planning ahead is critical if you have lupus.
- Some women do develop flares during pregnancy. The flares happen most often in the first or second trimester or in the first few months after you have the baby. Most flares are mild and easily treated with proper medical care.



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- Preeclampsia (pree-ee-KLAMP-see-uh), or “toxemia”, is a serious condition that must be treated right away. Preeclampsia is a condition starting after 20 weeks of pregnancy that causes high blood pressure and problems with the kidneys and other organs. About 2 in 10 pregnant women with lupus get preeclampsia. If you get this, you might notice sudden weight gain, swelling of the hands and face, blurred vision, dizziness, or stomach pain. You might have to deliver your infant early.
- Although many women with lupus have normal pregnancies, all lupus pregnancies should be considered “high risk”. This means there are certain factors that make problems during pregnancy more likely for women with lupus. It doesn’t mean there will be problems.

Planning ahead and proper medical care are very important.

- Find an obstetrician (OB) who manages high-risk pregnancies and who can work closely with your regular doctor.
- Plan to have your baby at a hospital that can manage high-risk patients and provide the special care you and your baby may need.
- See your doctor often while you are pregnant.
- Talk to your doctor about which medicines are safe to use while pregnant.
- Develop a plan for help at home during your pregnancy and after your baby is born. Motherhood can be very tiring, and even more so for

women with lupus.

- Develop a birth control plan for after you have your baby. It would be unwise for you to become pregnant again soon after giving birth. It is possible to get pregnant before your period begins again or while you are breastfeeding.

Q: I am pregnant. How can I tell whether changes in my body are normal or signs of a flare?

A: It may be hard to tell the difference. You may have symptoms from being pregnant that you mistake for a flare. Here are some examples:

- Skin. While pregnant, you may have red palms and a rash. Lupus can also cause a rash.
- Joints. Lupus can cause pain and swelling in your joints. Pregnancy can cause aching in your joints.
- Lungs. Taking deep breaths can be hard if you have lupus. Pregnancy also can cause shortness of breath.

Fortunately, recent studies show that flares are uncommon and tend to be mild during pregnancy. Some women with lupus find their symptoms improve during pregnancy. Still, it’s important to report new symptoms to your doctor. This way, flares that do occur can be prevented or controlled.

Q: I am pregnant and have lupus. Will my baby be born healthy?

A: Babies born to women with lupus have no greater chance of birth defects or mental retardation than do babies born to women without lupus. About 3 in 100 babies born to mothers with lupus



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will have neonatal lupus. In most cases, this goes away after 3 to 6 months and does not come back.

During your pregnancy, your OB will regularly check the baby's heartbeat and growth with ultrasound (a machine that takes pictures of your baby's organs).

About 3 in 10 women with lupus will give birth too early. Although this can present a danger to the baby, most problems can be treated in a hospital that specializes in caring for premature newborns.

Q: Can I breastfeed if I have lupus?

A: Breastfeeding is possible for mothers with lupus. Some medicines can pass through your breast milk to your infant. Talk to your doctor about whether breastfeeding is safe if you are using any medicines to control your lupus. Breastfeeding also can be very tiring because breastfed babies eat more often than formula-fed babies. If the demands of breastfeeding become too much for you, think about breastfeeding only some of the time. Pumping breast milk to be used later also might help.

Q: What research is being done on lupus?

A: Lupus is the focus of intense research. Studies are looking at:

- the genes that play a role in lupus and in the immune system
- ways to change the immune system in people with lupus
- lupus in ethnic groups
- things in the environment that may cause lupus
- the role of hormones in lupus

- birth control pills and hormone therapy in women with lupus
- heart disease in people with lupus
- the causes of nervous system damage in people with lupus
- treatments for lupus

Clinical trials are medical research studies to see whether new treatments are safe and effective. These studies help doctors learn how people respond to medicines and other new or improved treatments. Patients and families can get information about these lupus trials at www.clinicaltrials.gov. ■



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For more information...

For more information on lupus, call the womenshealth.gov Call Center at 1-800-994-9662 or contact the following organizations:

National Heart, Lung, and Blood Institute

Phone number: (301) 592-8573
Internet address: www.nhlbi.nih.gov

National Institute of Arthritis and Musculoskeletal and Skin Diseases

Phone number: (877) 226-4267
Internet address: www.niams.nih.gov

National Institute of Neurological Disorders and Stroke

Phone number: (800) 352-9424
Internet address: www.ninds.nih.gov

National Kidney and Urologic Diseases Information Clearinghouse

Phone number: (800) 891-5390
Internet address: <http://kidney.niddk.nih.gov/>

National Library of Medicine's MedlinePlus

Internet address: www.nlm.nih.gov/medlineplus/lupus.html

Alliance for Lupus Research

Phone number(s): (212) 218-2840 or (800) 867-1743
Internet address: www.lupusresearch.org/

American Autoimmune Related Diseases Association

Phone number(s): (586) 776-3900 or (800) 598-4668 Literature Requests
Internet address: www.aarda.org

American College of Rheumatology

Phone number: (404) 633-3777
Internet address: www.rheumatology.org

Arthritis Foundation

Phone number: (800) 283-7800
Internet address: www.arthritis.org

Lupus Foundation of America

Phone number: (800) 558-0121
Internet address: www.lupus.org

S.L.E. Lupus Foundation

Phone numbers: (212) 685-4118, (800) 745-8787
Internet address: www.lupusny.org



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