

Newly Diagnosed Patient Guide

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Introduction

Lupus LA is a healthcare non-profit that promotes lupus research, awareness, and education, and serves the needs of people with lupus and their families in the Greater Los Angeles Area. Committed to the hope and demonstrated promise of innovated science, Lupus LA partners with the Lupus Research Institute (LRI) to fund novel lupus research that will prevent, treat and cure the complex disease.

Lupus LA was founded in 2000 by Daniel Wallace, MD, a renowned physician and author and attending physician in the division on Rheumatology at Cedars-Sinai Medical Center and a clinical professor of medicine at UCLA's David Geffen School of Medicine. Under his guidance, Lupus LA offers monthly support groups, peer support, patient navigation, referral services, education programs and workshops throughout the Greater Los Angeles Area.

This guide was created with the goal of helping people recently diagnosed with lupus understand the disease better, as well as helping them properly advocate for themselves. Once you have read through this guide, please consider calling us and setting up a one-on-one appointment with our patient services staff. We know that a lupus diagnosis can be frightening and overwhelming, but please know that you are not alone. The staff at Lupus LA is more than happy to help you with whatever you may need.

Best regards,

Katherine McMahon Program Manager

Lupus LA 8383 Wilshire Blvd., Suite 232 Beverly Hills, CA 90211 T: 310-657-LOOP (5667) F: 310-860-9966 Email: info@lupusla.org Whether it has taken one month or five years to get a diagnosis, you now know that you have lupus. In order to be sure that you are getting the best care possible, you need to learn about this disease.

What is lupus?

Systemic lupus erythematous (S.L.E.), commonly called lupus, is a chronic autoimmune disorder that can affect virtually any organ of the body. In lupus, the body's immune system, which normally functions to protect against foreign invaders, becomes hyperactive, forming antibodies that attack normal tissues and organs, including the skin, joints, kidneys, brain, heart, lungs, and blood. Lupus is characterized by periods of illness, called flares, and periods of wellness, or remission.

Types of Lupus

The term "lupus" usually refers to "systemic lupus erythematous" (S.L.E.), but there are in fact other types of lupus, this is only one type of lupus. Other types of lupus are cutaneous or "skin" lupus erythematous, which mainly affects the skin—not the rest of the body.

Unlike systemic lupus, cutaneous lupus does not threaten the health of other organs and tissues in the body. And although it's clearly a concern, it's not that common for cutaneous lupus to turn into systemic lupus. A type of cutaneous lupus called "discoid" lupus involves potentially scarring sores with inflammation, typically on the face, scalp, and ears. These lesions can scar.

"Drug-induced lupus" is triggered by the use of certain medicines. It usually goes away once the triggering medicines are stopped. Symptoms of this form of lupus are often relatively mild.

What are lupus symptoms?

Although no two cases of lupus are alike, there are symptoms—things that a person with lupus feels or experiences as opposed to a doctor testing for—that many with the disease notice.

- Achy joints (arthralgia)
- Fever over 100 degrees
- Swollen and painful joints (arthritis)
- Prolonged fatigue
- Skin rashes
- Anemia

- Swollen ankles
- Chest pain upon deep breathing
- Butterfly-shaped rash across cheeks and nose
- Sensitivity to sun
- Unusual hair loss

• Abnormal blood clotting problems

- Mouth ulcers (often painless, at roof of mouth)
- Pale or purple fingers from cold or stress
- Seizures

The above symptoms are particularly important when several occur together. No two lupus patients have identical symptoms and complaints.

Who Gets Lupus?

Ninety percent of people diagnosed with lupus are women, and the onset of the disease usually occurs between the ages of 15 and 44. Lupus is also a leading cause of kidney disease, stroke, and premature cardiovascular disease in women of childbearing age. Lupus is more common among African American, Latino, Asian, and Native American women. Men and children are also diagnosed with lupus.

Diagnosis:

No single lab test can determine whether an individual has lupus. Many physicians use the American College of Rheumatology's "Eleven Criteria of Lupus" (see below) to help diagnose lupus and distinguish it from other diseases. The criteria include symptoms as well as specific laboratory tests which provide information about a person's immune system. In most cases, an individual should have four or more of these symptoms to suspect lupus.

The "Eleven Criteria of Lupus"

- 1. Malar rash: butterfly-shaped rash across cheeks and nose
- 2. Discoid (skin) rash: raised red patches
- 3. Photosensitivity: skin rash as a result of reaction to sunlight
- 4. Mouth or nose ulcers: usually painless
- 5. Nonerosive Arthritis (bones around joints do not get destroyed): in 2 or more joints with tenderness, swelling, or effusion
- 6. Cardio-pulmonary involvement: inflammation of the lining around the heart (pericarditis) and/or lungs (pleuritis)
- 7. Neurologic disorder: seizures and/or psychosis/cognitive dysfunction
- 8. Renal (kidney) disorder: excessive protein in the urine, or cellular casts in the urine
- 9. Hematologic (blood) disorder: low red blood cell count (hemolytic anemia), low white blood cell count (leukopenia), or low platelet count (thrombocytopenia)
- 10. Immunologic disorder: antibodies to double stranded DNA, antibodies to Sm, positive antiphospholipid antibody such as anticardiolipin, or false positive syphilis test (VDRL)
- 11. Antinuclear antibodies (ANA): positive test in absence of drugs known to induce it

Blood Tests Used to Diagnose and Monitor Lupus

Lupus is chronic and complex, and is often difficult to diagnose. There is no single laboratory test that can determine if a person has lupus. To complicate matters, many symptoms of lupus are similar to those of other diseases, and can come and go over weeks and months. It can often take years for a diagnosis to be made.

To diagnose lupus, a doctor should be able to find physical or laboratory evidence of the condition, such as swelling of joints, protein in the urine, fluid around the lungs or heart, or a skin biopsy (test of a sample) that shows evidence of the disease. The doctor also will look at a person's medical history and special tests to rule out other diseases.

Antinuclear antibody (ANA)

The ANA test is positive in more than 95% of individuals with systemic lupus, and is used to determine if autoantibodies to cell nuclei are present in the blood. At this time, the ANA test is the most sensitive diagnostic test available for confirming the diagnosis of systemic lupus; however, **it is NOT a lupus test**. If three or more clinical features, such as skin, joint, kidney, lung, heart, blood or central nervous system findings are present, a positive ANA test may confirm the disease. However, it is important to understand that a positive ANA test **does not** automatically mean you have lupus. If you have several symptoms and a positive ANA test, further testing can be done to make a more definite diagnosis.

Antibodies to DNA (Anti-DNA antibody test)

Anti DNA antibodies are present in about 60-80% of individuals with active systemic lupus. This test is used to determine if there are antibodies to the genetic material in the cell (the protein that makes up the body's genetic code). The test is highly specific for systemic lupus and not found in individuals with other rheumatic diseases. It is also associated with a greater risk of lupus nephritis. If the ANA test is positive, the tests for anti-Sm and anti-RNP are helpful in the diagnoses of various rheumatic diseases. These two tests are most helpful when ordered together.

Antibodies to the Sm antigen (Anti-Smith antibody) (Anti-Sm antibody) Anti-Sm is present in about 30% of individuals with lupus. It is used to

determine if there are antibodies to Sm, and which are ribonucleoproteins found in the cell nucleus. This test is highly specific for systemic lupus and rarely found with other rheumatic diseases. It is often used to confirm a diagnosis of lupus.

Antibodies to RNP (ribonucleoprotein)

Anti RNP antibodies are found in many connective tissue diseases. Anti-RNP will be positive whenever anti-Sm is detected, but can be detected in some individuals with lupus in the absence of anti-Sm. When present in very high levels, RNP antibodies can suggest mixed connective tissue disease (MCTD), a condition with symptoms like those of systemic lupus.

Antibodies to Ro/SS-A and Antibodies to La/SS-B

Anti-Ro is found in about 30% of individuals with systemic lupus and is also found with Sjögren's syndrome. It is also associated with photosensitivity. Anti-La is found in about 15% of individuals with systemic lupus. Both of these are almost always found in babies who are born with neonatal lupus.

Antibodies to histones (DNA packaging proteins) are usually found in people with drug-induced lupus (DIL), but may also be found in those with systemic lupus.

Antibodies to Jo-1 are associated with polymyositis.

Antibodies to PM-Scl are associated with cases of polymyositis that also have features of scleroderma.

Antibodies to Scl-70 are found in people with a generalized form of scleroderma.

Antibodies to the centromere (a structure involved in cell division) are found in individuals with a limited form of scleroderma which tends to have a chronic course.

Antiphospholipid Antibodies

The most widely measured antiphospholipid antibodies are the lupus anticoagulant and the anticardiolipin antibody.

Anticardiolipin Antibody (ACA)

Measured in an ELISA (Enzyme-Linked Immunosorbent Assay) test. There are 3 classes of anticardiolipin that are usually tested: IgG, IgM and IgA. IgG is the most commonly detected, and is usually the most significant for lupus.

Lupus Anticoagulant (APL)

Present in about 30–40% of people with lupus. A positive APL plus the presence of arterial and venous thrombosis (blood clots) is called Antiphospholipid Antibody Syndrome, or APLS. APLS affects about 10–15% of individuals with lupus. This syndrome also occurs in individuals without lupus.

Complement

Serum (blood) complement is a group of blood proteins that cause immune responses and inflammation. Complement activity is measured to determine if complement is involved in the development of a number of diseases, including systemic lupus. It is also used to monitor the severity of a disease or to determine if medical treatment is working. There are nine major complement proteins, which are labeled C1 through C9. If the total blood complement level is low, or the C3 or C4 values are low and the person also has a positive ANA, some weight can be added to the diagnosis of lupus. These component levels may also be watched as an indicator of disease activity. Low C3 and C4 levels in people with a positive ANA may mean the presence of active disease, especially kidney involvement.

C-reactive protein (CRP) binding and erythrocyte sedimentation rate (ESR)

These levels frequently rise with generalized inflammation. The levels may increase in individuals with active lupus and decrease with corticosteroid or NSAID use.

Biopsy or tissue sample

Examination of tissue samples (biopsy) can further support the diagnosis of lupus and also helps to evaluate organ damage. The most common biopsy sites are the skin and kidney. The procedure involves removing a small amount of tissue, which is then examined under a microscope. The doctor can use the biopsy to identify the amount of inflammation and/or damage to the tissue.

Chemistry panel

Chemistry panels help determine a person's general health status. They are also used to evaluate the body's electrolyte balance and/or the status of body organs. In individuals with lupus, the tests may reveal muscle or kidney involvement or abnormalities of liver function. The Comprehensive Metabolic Panel (CMP) usually includes 14 tests and the Basic Metabolic Panel (BMP) usually contains 8 tests, all of which are found in the CMP.

Syphilis test (VDRL or RPR)

This test may be falsely positive in individuals with lupus.

Complete blood count (CBC)

• Red blood count (RBC)

About 40% of individuals with systemic lupus will have a decrease in their RBCs (anemia), which may be caused by chronic inflammation, iron deficiency, GI bleeding, medications or autoantibody formation to RBCs.

- White blood count (WBC) About 15–20% of individuals with systemic lupus have a decrease in WBCs (leukopenia).
- *Platelets* About 25–35% of individuals with lupus have a low platelet count (thrombocytopenia).

Treatment:

Since lupus is highly individualized, and no two cases are exactly alike, the treatment also varies depending on the symptoms and needs of the patient. Creams are often prescribed for a rash. For more serious problems, anti-inflammatory drugs, anti-malarials, and steroids, such as cortisone, are used to treat lupus. Cytotoxic chemotherapies similar to those given in the treatment of cancer are also used to suppress the immune system in lupus patients.

Medicines Commonly Used for Lupus in 2011

- *NSAIDS, nonsteroidal anti-inflammatory drugs,* are used to relieve achy joints and arthritis in mild lupus when pain is limited and organs are not affected.
- *Antimalarial drugs*, such as hydroxycholorquine, are often prescribed for arthritis or skin problems.
- *Corticosteroids*, such as prednisone, are used for major organ involvement. The dosage prescribed will depend on the type of organ involvement, symptoms, and blood-test results.
- *Immunosuppressive agents*, such as azathioprine (Imuran), methotrexate, cyclophosphamide, cyclosporine and mycophenolate mofetil (CellCept), are potent drugs that help control the overactive but misdirected immune system in lupus patients. They help limit damage to major organs and are closely monitored to counter the potentially serious side effects and complications.
- *Biologics* are genetically engineered medication made from a living organism, such as a virus, gene or protein, and then used to treat a problem occurring in a different organism, such as a humans. Because the biologics block triggers of inflammation, they are used to treat autoimmune forms of arthritis, such as rheumatoid arthritis (RA), juvenile idiopathic arthritis (JIA), ankylosing spondylitis or psoriasis/psoriatic arthritis. Benlysta (belimumab) is a new drug that was developed specifically to treat systemic lupus. It works by calming down the hyperactive immune system of lupus by inhibiting a protein called "B lymphocyte stimulator (BLyS)" believed to increase inflammatory reactions that attack and damage the body's own healthy tissues.

Importance for Early Diagnosis:

Once a lupus diagnosis is established, patients are assessed for damage to major organs (central nervous system, kidneys, heart, or lungs). Treatment depends on the activity and extent of the disease, and can range from over the counter pain relievers and anti-inflammatories to prescription medication, therapy, dietary changes, and lifestyle changes such as staying out of the sun, wearing sunblock, and avoiding stress.

Specialists:

A lupus patient should needs to have a rheumatologist to manage their lupus. If there is any other organ involvement, the patient should have a team of specialists working with their rheumatologist. It may be wise to ask each patient if they are seeing:

- Nephrologist
- Cardiologist
- Neurologist
- Pulmonologist

- Hematologist
- Psychologist, psychiatrist, social worker, etc.

Ways to Manage Lupus:

- During a flare: get plenty of rest.
- When in remission: exercise to increase joint flexibility and muscle strength.
- If you are sensitive to sun: use sunscreen and sun-protective clothing, and avoid the sun.
- If rashes persist: check with your doctor about using a cortisone cream.
- Relieve stress: support groups, counseling, talking with friends, family, and doctors can be helpful.
- For fever over 100 degrees F: call your doctor.
- Get regular checkups: these usually include blood and urine tests.
- Ask questions: when in doubt, call your doctor.
- Report any side effects or new symptoms promptly: help your doctor know when a change in therapy might be needed.

Due to the variety of symptoms experienced by the patient, several professionals may be involved in working with the patient at any one time. This multidisciplinary team functions in a variety of ways, with a focus on improving rheumatology care, education, and research.

Why use a team?

Because rheumatic diseases are often complex and affect many aspects of the patient's life, effective management requires the coordinated efforts of a diverse group of professionals. With the patient as its central focus, the role of the multidisciplinary team is to assess and manage the patient's symptoms and their effects on physical, psychological, and social functioning. The priorities of treatment are determined with the patient, resulting in a treatment plan that will lead to the best control of the disease and its symptoms and improve patient functioning.

Who are the members of the lupus team?

The role of the patient on this team is to identify the problems, fully participate in developing the treatment plan, and evaluate the outcomes of the plan on an ongoing basis. Additional members of the team may include any of the following:

- Advanced Practice Nurses
- Case Managers
- Dietitians
- Health Educators
- Internists
- Nurses
- Occupational Therapists
- Orthopedic Surgeons
- Psychiatrists
- Primary Care Physicians

- Physician Assistants
- Physical Therapists
- Psychologists
- Rheumatologist
- Social Workers
- Vocational Rehabilitation Counselors
- Other Health Care Professionals

The various team members may be involved in treatment, education, and/or research. Each member has unique skills that complement those of the others; and, together, they are responsible for creating an individualized, cost-effective treatment plan. The following papers attempt to give an overview of the role of some of these team members in the management of rheumatic disease.

Rheumatologists and Rheumatology Health Professionals

A rheumatologist is an internist or pediatrician who is qualified by additional training and experience in the diagnosis and treatment of arthritis and other diseases of the joints, muscles and bones. Many rheumatologists conduct research to determine the cause and better treatments for these disabling and sometimes fatal diseases.

Your rheumatologist may ask that you also see:

- A clinical immunologist (im-yoo-NOL-oh-jist), a doctor who treats immune system disorders
- A nephrologist (ne-FROL-oh-jist), a doctor who treats kidney diseases
- A hematologist (hee-muh-TOL-oh-jist), a doctor who treats blood disorders
- A dermatologist (dur-muh-TOL-oh-jist), a doctor who treats skin problems and diseases
- A neurologist (noo-ROL-oh-jist), a doctor who treats problems with the nervous system
- A cardiologist (kar-dee-OL-oh-jist), a doctor who specializes in the heart and blood vessels
- An endocrinologist (EN-doh-kri-NOL-oh-jist), a doctor who specializes in problems with the glands and hormones
- A psychologist (seye-KOL-uh-jist) or psychiatrist (seye-KEYE-uh-trist), doctors who treat anxiety and depression
- An occupational (ok-yuh-PAY-shuh-nul) therapist
- A social worker

Because lupus is a complex disease whose course can vary so much from person to person, it's important to work with knowledgeable doctors and other health professionals. Equally is building your own knowledge about your disease, symptoms, treatments and non-medical needs.

For the first few visits with your rheumatologist, you may be overwhelmed. It is completely understandable. The following pages contain forms for you to fill out and bring to your appointments. By filling out these forms, you will gain a better understanding of your disease and can be an active partner in your treatment. Sharing this information with your doctors will give them more information than they might have at the time of your appointment, especially if you are seeing someone new. This information will also help cut down on errors due to missing information and reduce costs by eliminating duplicative tests, immunizations, and prescriptions.

- Your Support Team Who makes up your support team? Does it include specific family members, friends or neighbors? Will you attend a local support group? Will you see a therapist?
- Your Medical Team Who are the players on your medical team? Remember to include all of your doctors and medical professionals. What is the field of specialty of each doctor? Why do you see them?
- Your Disease(s) What is your family's medical history? What is your official diagnosis (es)? What are your symptoms and triggers? Do you have other health issues not related to lupus such as high cholesterol?
- Your Treatments What do you do to treat your illness (es)? Do you take medications? If so, do you know what each medication is supposed to treat? Do you know how much of each medication you need to take per day and why? Are you required to partake in any physical therapy? Do you see a therapist?
- Your Plan What are your treatment plans? Do you have health-related goals? What steps will you take to ensure that you reach these goals? Who from your lupus network is needed to help you reach those goals? What do you need from them?

My Personal Information

My Name is:		
I prefer to be called:		
My Address is:		
My Home Phone Number is:		
My Cell Phone Number is:		
My Date of Birth is:		
My Age (as of today) is:		
My Next of Kin is:		
Next of Kin Address:		
I do /do not want you to	Please Call	Please Do NOT Call
in the case of an emergency:		

My Support Team

My Main Caregiver is:		
His /Her Phone Number is:		
His /Her Address is:		
My Main Caregiver is allowed to hear private information about my condition and treatment.	YES	NO
My Next of Kin (if different from above) is:		
His /Her Phone Number is:		
Next of Kin Address:		
My Next of Kin is allowed to hear private information about my condition and treatment.	YES	NO
Other Support Team Member Name:		
Other Support Team Member Phone Number is:		
This support team member is allowed to hear private information about my condition and treatment.	YES	NO
Other Support Team Member		
Name:		
Other Support Team Member Phone Number is:		
This support team member is allowed to hear private information about my condition and treatment.	YES	NO

Family Medical History

Knowing about the health of your immediate family will be helpful in the diagnostic and treatment phase. If you do not know the answer to these questions, please ask your family members to share. If that is not possible, write down any details you might have.

	~	x	?	Who has this health issue? Please provide any details you know.
Lupus				
Rheumatoid Arthritis				
Fibromyalgia				
Raynaud's Syndrome				
Sjögrens Syndrome				
High Blood Pressure				
Diabetes				
Asthma				
Cancer				
Mental Illness				

More information

My Health History

	~	Comments
General Health		
Blood Pressure		
Diabetes		
Mental Health		
Asthma		
Lupus		
Fibromyalgia		
Sjogren's Syndrome		
Raynaud's Syndrome		
Rheumatoid Arthritis		
Other		
Notes:		·

	2015	2016	2017	2018
Height				
Weight				
BMI				
Blood pressure				
Pulse				
Urinalysis				
Medication review				
Cardiac risk assessment				
Blood tests				
Continence assessment				
Skin care				
Eye test / Eye care				
Hearing test / Ear care				
Dental / Mouth care				
Podiatry / Foot care				
Mobility				
Health promotion	2015	2016	2017	2018
Diet / Advice				
Exercise / Advice				
Smoking / Alcohol / Drug /Advice				
Immunizations				
Notes:	1	1	1	1

My Disease

I was diagnosed on:	
The symptoms that	
led to my diagnosis	
were:	

As of today:	Yes	No
My lupus is stable		
I have a care plan in place		
I take my medications as prescribed		

Date of Last Appointment

Special information about my lupus

What are my flare triggers? (sunlight, fatigue, eating certain foods, etc.)

During a flare I have these symptoms: (nausea, headaches, butterfly rash, etc.)

To manage the flare, I will:

(call my doctor, be sure to get extra sleep, use a cane to help me walk, etc.)

My Medical Team

Current as of:			
Specialty	Name of Doctor	Address	Phone Number
Internal Medicine			
Rheumatology			

During my appointments I need:	✓	Comments
My caregiver to stay with me		
A longer appointment		
Help with physical examinations		
Help with blood pressure checks		
Help to have a blood test taken		
Help to have an injection		
Help to get weighed		
Additional Information:		

My Treatments

I prefer to /can only take my medication in

		Which medications?
1000 1000 1000 1000 1000 1000 1000 100	Tablets	
	Liquid	
	Other	

	YES	NO
I need blood tests to check my medications.		
If YES, which medications and how often?		

Lam allergic to some medications	
If VEC which medications?	
IT TES, WHICH INCUCATIONS?	

I need support to take my medications properly:

My Medications

Name of medication	I take this medication for:	How I take my medication:	How much medication do I take?	When do I take my medication?
Plaquenil	Lupus	With food	300mg (one and one-half pills)	One time a day in the morning

My Supplements

Name of supplement	I take this supplement for:	How I take my supplement:	How much of the supplement do I take?	When do I take my supplement?
Vitamin D	Bone Density	With food	One 500mg pill	Twice a day –at breakfast and dinner

My Plan

When you're learning about something new, especially a new diagnosis, it's easy to feel overwhelmed by the sheer amount of information available. The aim of this plan is to help you focus on what is relevant. It's important to understand that health and well-being comes from the combination of your lifestyle factors, and not just one aspect of it – lifestyle factors are all inter-linked. This means that to improve one aspect of your overall well-being, you need to focus on emotional well-being, nutrition, exercise/fitness and life balance.

My Emotional Well-Being

Information about my current emotional and mental well-being:

My goals for my emotional and mental well-being include:

Steps I will take to achieve these goals include:

I need support to achieve these goals from:

My Nutrition Goals

The food I eat needs to be:-		
Vegetarian	Vegan	
Low Fat	Low Sugar	
Gluten free	Other e.g. diabetic	
Thickened food		
Soft food	Food cut up for me	

My Nutrition Goals:

Things I will do to achieve my nutrition goals:

To meet my nutrition goals, I need this support:

My Exercise/Fitness Plan

	Yes	No
I like to keep active		
My Exercise and Fitness Goals include:		

Things I will do to keep active

To keep active I need this support:

Life Balance Goals

	Yes	No
I currently keep a good balance between my obligations and things I do		
for my own enjoyment.		
My Life Balance goals include:		

Things I will do to better manage my life balance.

To better balance my life I need this support:

My Responsibilities

Now that you have a diagnosis, you should begin to take some responsibility for your role in the task of feeling well. You and your network are part of a team. Here are some steps you can take to ensure you are doing all that you can to contribute to the efforts of restoring your health.

- Write down your symptoms, including when you first noticed them and how often they occur. Consider using the symptom log in the appendix of this guide.
- Write down key personal information, including any recent changes or major stressors in your life.
- Make a list of your key medical information, including any other conditions for which you're being treated and the names of any medications, vitamins or supplements you're taking. Your doctor will also want to know if you have any family history of lupus or other autoimmune disorders.
- Take a family member or friend along, if possible. Sometimes it can be difficult to soak up all the information provided to you during an appointment. Someone who accompanies you may remember something that you missed or forgot.
- Write down questions to ask your doctor. Creating your list of questions in advance can help you make the most of your time with your doctor.ⁱ

Questions to Ask My Doctor

As a member of your Support and Medical Team, you should have a strong understanding of what you need to do as well as for what each medication and procedure are intended. One great way to gain more understanding is to ask questions about every part of your care. Below you will find a list of general health questions as well as questions related to your lupus treatment plan.

General Questions:

- 1. What do you think is causing my problem?
- 2. Is there more than one condition (disease) that could be causing my problem?
- 3. What tests will you do to diagnose the problem and which of the conditions is present?
- 4. How good are the tests for diagnosing the problem and the conditions?
- 5. How safe are the tests?
- 6. What is the likely course of this condition? What is the long-term outlook with and without treatment?
- 7. What are my treatment options? How effective is each treatment option?
- 8. What are the benefits versus risks of each treatment option?
- 9. If my symptoms worsen, what should I do on my own? When should I contact you?
- 10. Are you aware of each of the medications that I am taking? Can they adversely interact with the medications you are prescribing for me?
- 11. Should we monitor for side effects of the medications that you are prescribing or for their interactions with other medications I am taking?

Questions about your Lupus Treatment Plan:

- 1. Could any medications I'm taking be triggering my lupus symptoms?
- 2. Could another condition be causing my lupus symptoms?
- 3. Has the disease already damaged my kidneys or other organs?
- 4. Should I have a bone density test?
- 5. Should I be taking calcium or other supplements?
- 6. What are the possible side effects of my lupus drugs?
- 7. How long will I need to take these lupus drugs?
- 8. Is it safe for me to become pregnant if I have lupus? Are my lupus medications safe to take while I'm pregnant?
- 9. How often should I have checkups?
- 10. What lifestyle changes do you recommend?

Questions My Doctor May Ask Me

Your doctor is likely to ask you a number of questions. Being ready to answer them may reserve time to go over any points you want to spend more time on. Your doctor may ask:

- What are your symptoms? What part of your body is affected?
- When did you first notice these symptoms?
- Have your symptoms changed over time?
- Do your symptoms seem to come and go?
- Have you noticed anything that seems to trigger your symptoms?
- Do your symptoms include extreme fatigue?
- Have you had pain, stiffness or swelling in your joints?
- Does sun exposure cause you to develop skin rashes?
- Do your fingers or toes turn cold, pale or purple from cold or stress?
- Do your symptoms include chest pain with deep breathing?
- Have you experienced shortness of breath?
- Have you had an unexplained fever?
- Do your symptoms include any problems with memory or concentration?
- How often do you feel anxious or depressed?
- How much do your symptoms limit your ability to function at school, work or in personal relationships?
- Have you been diagnosed with any other medical conditions?
- Are you taking any medications, including over-the-counter and prescription drugs as well as vitamins and supplements?
- Have any first-degree relatives such as a parent or sibling had lupus or another autoimmune disease?
- Are you pregnant or do you plan to become pregnant?
- What you can do in the meantime?

Glossary of Terms

Understanding what goes on during a lupus flare, and even during a remission, is no small feat. Here is a glossary of commonly used phrases in immunology. Use it in conjunction with the National Institute of Allergy and Infectious Diseases' highly accessible 2003 brochure, **Understanding the Immune System: How it Works**.

adrenal gland – a gland located on each kidney that secretes hormones regulating metabolism, sexual function, water balance, and stress.

allergen – any substance that causes an allergy.

allergy – a harmful response of the immune system to normally harmless substances.

antibodies – molecules (also called immunoglobulins) produced by a B cell in response to an antigen. When an antibody attaches to an antigen, it helps the body destroy or inactivate the antigen.

antigen – a substance or molecule that is recognized by the immune system. The molecule can be from foreign material such as bacteria or viruses.

antiserum – a serum rich in antibodies against a particular microbe.

appendix – lymphoid organ in the intestine.

autoantibodies – antibodies that react against a person's own tissue.

autoimmune disease – disease that results when the immune system mistakenly attacks the body's own tissues. Examples include multiple sclerosis, type I diabetes, rheumatoid arthritis, and systemic lupus erythematosus.

B cells – small white blood cells crucia to the immune defenses. Also know as B lymphocytes, they come from bone marrow and develop into blood cells called plasma cells, which are the source of antibodies.

bacteria – microscopic organisms composed of a single cell. Some cause disease.

basophils – white blood cells that contribute to inflammatory reactions. Along with mast cells, basophils are responsible for the symptoms of allergy.

biological response modifiers – substances, either natural or synthesized, that boost, direct, or restore normal immune defenses. They include interferons, interleukins, thymus hormones, and monoclonal antibodies.

blood vessels – arteries, veins, and capillaries that carry blood to and from the heart and body tissues.

bone marrow – soft tissue located in the cavities of the bones. Bone marrow is the source of all blood cells.

chemokines – certain proteins that stimulate both specific and general immune cells and help coordinate immune responses and inflammation.

clone – a group of genetically identical cells or organisms descended from a single common ancestor; or, to reproduce identical copies.

complement – a complex series of blood proteins whose action 'complements' the work of antibodies. Complement destroys bacteria, produces inflammation, and regulates immune reactions.

complement cascade – a precise sequence of events, usually triggered by antigenantibody complexes, in which each component of the complement system is activated in turn.

cytokines – powerful chemical substances secreted by cells that enable the body's cells to communicate with one another. Cytokines include lymphokines produced by lymphocytes and monokines produced by monocytes and macrophages.

cytotoxic T lymphocytes (CTLs) – a subset of T cells that carry the CD8 marker and can destroy body cells infected by viruses or transformed by cancer.

DNA (deoxyribonucleic acid) – a long molecule found in the cell nucleus; it carries the cell's genetic information.**enzyme** – a protein produced by living cells that promotes the chemical processes of life without itself being altered.

eosinophils – white blood cells that contain granules filled with chemicals damaging to parasites, and enzymes that affect inflammatory reactions.

epithelial cells – cells making up the epithelium, the covering for internal and external body surfaces.

fungi – members of a class of relatively primitive vegetable organisms. They include mushrooms, yeasts, rusts, molds, and smuts.

genes – units of genetic material (DNA) inherited from a parent. Genes carry the directions a cell uses to perform a specific function. **graft rejection** – an immune response against transplanted tissue.

g**raft-versus host disease (GVHD)** – a life-threatening reaction in which transplanted cells attack the tissues of the recipient.

granules – membrane-bound organelles within cells where proteins are stored before secretion.

granulocytes – phagocytic white blood cells filled with granules organisms. Neutrophils, eosinophils, basophils, and mast cells are examples of granulocytes.

growth factors – chemicals secreted by cells that stimulate proliferation of or changes in the physical properties of other cells.

helper T cells (Th cells) – a subset of T cells that carry the CD4 surface marker and are essential for turning on antibody production, activating cytotoxic T cells, and initiating many other immune functions.

HIV (human immunodeficiency virus) – the virus that causes AIDS.

immune response – reaction of the immune system to foreign substances.

immunoglobulins – a family of large protein molecules, also known as antibodies, produced by B cells.

immunosuppressive – capable of reducing immune responses.

inflammatory response – redness, warmth, and swelling produced in response to infection, as the result of increased blood flow and an influx of immune cells and secretions.

interferons – proteins produced by cells that stimulate anti-virus immune responses or alter the physical properties of immune cells.

interleukins – a major group of lymphokines and monokines.

leukocytes – all white blood cells.

lymph – a transparent, slightly yellow fluid that carries lymphocytes, bathes the body tissues, and drains into the lymphatic vessels.

lymph nodes – small bean-shaped organs of the immune system, distributed widely throughout the body and linked by lymphatic vessels. Lymph nodes are garrisons of B, T, and other immune cells.

lymphatic vessels – a bodywide network of channels, similar to the blood vessels, which transport lymph to the immune organs and into the bloodstream.

lymphocytes – small white blood cells produced in the lymphoid organs and paramount in the immune defenses. B cells and T cells are lymphocytes.

lymphoid organs – the organs of the immune system, where lymphocytes develop and congregate. They include the bone marrow, thymus, lymph nodes, spleen, and various other clusters of lymphoid tissue. Blood vessels and lymphatic vessels are also lymphoid organs.

lymphokines – powerful chemical substances secreted by lymphocytes. These molecules help direct and regulate the immune responses.

macrophage – a large and versatile immune cell that devours invading pathogens and other intruders. Macrophages stimulate other immune cells by presenting them with small pieces of the invaders.

major histocompatibility complex (MHC) – a group of genes that controls several aspects of the immune response. MHC genes code for 'self' markers on all body cells.

mast cell – a granulocyte found in tissue. The contents of mast cells, along with those of basophils, are responsible for the symptoms of allergy.

memory cells – a subset of T cells and B cells that have been exposed to antigens and can then respond more readily when the immune system encounters those same antigens again.

microbes – microscopic living organisms, including bacteria, viruses, fungi, and protozoa.

microorganisms – microscopic organisms, including bacteria, virus, fungi, plants, and parasites.

molecule – the smallest amount of a specific chemical substance. Large molecules such as proteins, fats, carbohydrates, and nucleic acids are the building blocks of a cell, and a gene determines how each molecule is produced.

monoclonal antibodies – antibodies produced by a single cell or its identical progeny, specific for a given antigen. As tools for binding to specific protein molecules, they are invaluable in research, medicine, and industry.

monocytes – large phagocytic white blood cells which, when entering tissue, develop into macrophages.

monokines – powerful chemical substances secreted by monocytes and macrophages. These molecules help direct and regulate the immune responses.

natural killer (NK) cells – large granule-containing lymphocytes that recognize and kill cells lacking self-antigens. Their target recognition molecules are different from T cells.

neutrophil – white blood cell that is an abundant and important phagocyte.

organisms – individual living things.

parasites – plants or animals that live, grow, and feed on or within another living organism.

passive immunity – immunity resulting from the transfer of antibodies or antiserum produced by another individual.

pathogen – a disease-causing organism.

phagocytes – large white blood cells that contribute to the immune defenses by ingesting microbes or other cells and foreign particles.

phagocytosis – process by which one cell engulfs another cell or large particle.

plasma cells – large antibody-producing cells that develop from B cells.

platelet – cellular fragment critical for blood clotting and sealing off wounds.

serum – the clear liquid that separates from the blood when it is allowed to clot. This fluid contains the antibodies that were present in the whole blood.

spleen – a lymphoid organ in the abdominal cavity that is an important center for immune system activities.

stem cells – immature cells from which all cells derive. The bone marrow is rich in stem cells, which become specialized blood cells.

T cells – small white blood cells (also known as T lymphocytes) that recognize antigen fragments bound to cell surfaces by specialized antibody-like receptors. "T" stands for thymus, where T cells acquire their receptors.

T lymphocytes – see T cells.

thymus – a primary lymphoid organ, high in the chest, where T lymphocytes proliferate and mature.

tissue typing – see histocompatibility testing.

tissues – groups of similar cells joined to perform the same function.

tolerance – a state of immune nonresponsiveness to a particular antigen or group of antigens.

tonsils and adenoids – prominent oval masses of lymphoid tissues on either side of the throat.

toxins – agents produced in plants and bacteria, normally very damaging to cells.

vaccines – preparations that stimulate an immune response that can prevent an infection or create resistance to an infection. They do not cause disease.

viruses – microorganisms composed of a piece of genetic material — RNA or DNA — surrounded by a protein coat. Viruses can reproduce only in living cells.

Source: <u>Understanding the Immune System: How It Works</u>. U.S. Department of Health and Human Services & The National Institutes of Health (National Institute of Allergy and Infectious Diseases, National Cancer Institute). NIH Publication No. 03-5423. September, 2003, pages 47-57.

Monthly Symptom Tracker

Month/Year:																			Ζ	.dd:	Mil(4 P	fod:	Moc	lerat	e S	: Set	/ere		
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Swelling																														
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Chest Pain																														
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Lupus Impact Tracker

The Lupus Impact Tracker was developed to help y	ou communi	<u>Na</u> cate effectiv	urne vely with yo	urdoctoral	Date bout your lup	bus
To complete the form, read each statement and cin experience. Select only one response for each state your lupus.	:le the num ement. Be so	ber in the r ure to ans	esponse bo wer the qu	ox that best estions in	describes yo the context	our of
Complete the Lupus Impact Tracker once every <u>4 w</u> one completed form for each month since your last	r <u>eeks,</u> and sl appointmen	hare the res t.	ults with yo	our doctor. E	}e sure to bri	ing
During the past 4 weeks, how <u>often</u> did you experience the following <u>due to your lupus?</u>	None of the time	A little of the time	Some of the time	Most of the time	All of the time	
1. I woke up feeling worn out	0	1	2	з	4	
2. I felt pain and aching in my body	0	1	2	3	4	
3. I was unable to perform my usual activities for long periods of time because of pain or fatigue	0	1	2	3	4	
4. I was limited in fulfilling family responsibilities because of my physical health	0	1	2	3	4	
5. My lupus interfered with my ability to plan activities and schedule events	0	1	2	3	4	
6. I was anxious	0	1	2	3	4	
7. I was depressed	0	1	2	3	4	
8. I experienced difficulty concentrating	0	1	2	3	4	
9. I was self -conscious about my appearance	0	1	2	3	4	
10. My lupus medication(s) caused bothersome side effects	0	1	2	3	4	
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How to score: 1. Add your responses in each column and write the r 2. Add the column subtotals along the bottom row to box to the right. 3. To determine your Lupus Impact score, refer to the right. 2 3 4 5 6 7 6 9 10 11 12 13 14 15 16 17 14 5 6 75 10 12 13 14 15 16 17 14 5 6 75 10 125 15 175 20 22.5 25 27.6 30 32.5 36 37.6 40 42.5 4 type: mpact score is	number in th achieve you chart below 8 19 20 21 5 47.5 50 52.5	ne box at th ir total. Plac v. 22 23 24 2 55 575 60 62	e bottom o ce that num 5 26 27 28 25 65 67.5 70	f each colur ber in the 29 30 31 3 72.5 75 77.5 a	nn. 2 33 34 35 5 80 82.5 85 87.5	36 37 38 90 92.5 95
How to use the score: The lower your Lupus Impact score, the less impact lu the score with your doctor to help discuss the impact	ipus is havir Iupus mav I	ng on your l be having o	ife. Share n vour life.	Lupus Imj	pact Score is:	

Lupus LA Support Groups



Lupus LA Adult Support Groups

Lupus LA's monthly support groups are here to help you learn more about lupus and how to live well with lupus. Please come join us at one of the following groups!

Irvine Support Group

First Monday of the month From 7:00 PM to 9:00 PM University United Methodist Church 18422 Culver Drive, Irvine, CA 92612

Spanish-Language Support Group

Primer Jueves del mes De 7:00 PM a 8:30 PM Clinica Oscar Romero, Sala 35 2032 Marengo St., Los Angeles, CA 90033 (En frente del hospital general de USC)

UCLA Support Group

First Tuesday of the month From 6:30 PM to 8:00 PM Rheumatology - Rehabilitation Center Building 3rd Floor - Library 1000 Veteran Ave, Los Angeles, CA 90024

Howse Foundation & Lupus LA Support Group Second Saturday of the month From 10:30 AM to 12:00 PM Olive Branch Diagnostic Imaging Women's Health Center 10722 Arrow Route Suite 520 Rancho Cucamonga, CA 91730

Loom 4 Lupus Support Group

Second Saturday of the month From 9:30 AM to 11:30 AM Kaiser Permanente, Educational Outreach Program 4141 Maine Ave., Baldwin Park, CA 91706

Alhambra Support Group

Third Tuesday of the month From 6:30 PM to 8:00 PM Alhambra Civic Center Library, 2nd floor Conference Rm. 101 S. First Street, Alhambra, CA 91801

Sherman Oaks Support Group

Second Tuesday of the month From 6:30 PM to 8:00 PM Circle of Care Conference Room, Sherman Oaks Hospital 4929 Van Nuys Blvd, Sherman Oaks, CA 91403

Long Beach Support Group Fourth Tuesday of the month From 6:30 PM to 8:00 PM

Miller Children's Hospital Long Beach Children's Hospital Pavilion Conference Room B 2801 Atlantic Ave, Long Beach, CA 90806

The support groups are free, confidential, and open to the public. For more information about the Lupus LA support groups, please contact **(310) 657-5667** and/or <u>kmcmahon@lupusla.org</u>. Please visit our website, <u>www.lupusla.org</u>, for more information about our programs and events.

Additional Resources

American College of Rheumatology http://www.rheumatology.org/

Los Angeles Homeless Services Authority: http://www.lahsa.org/

Job Accommodation Network http://www.jan.wvu.edu/media/Lupus.html

Lupus Clinical Trials: http://www.lupustrials.org/

Lupus Research Institute: http://www.lupusresearchinstitute.org/

Lupus LA www.lupusla.org

Medi-Cal http://www.dhcs.ca.gov/services/medi-cal

Medicare and Prescription Help: http://www.ssa.gov/prescriptionhelp/

National Institute of Arthritis and Musculoskeletal and Skin Disease: http://www.niams.nih.gov/default.asp

The Office of Women's Health: http://www.womenshealth.gov/owh/

Legal Aid Society of Los Angeles: http://www.lafla.org/index.php

Patient Assistance Programs http://www.freemedicineprogram.org/

http://www.pparx.org/

http://www.healthwellfoundation.org/

Social Security Disability:

http://www.ssa.gov/pubs/10029.html

Supplemental Social Security Income (SSI)

http://www.ssa.gov/ssi/text-understanding-ssi.htm

Society for Women's Health Research:

http://www.womenshealthresearch.org

Sjögrens Foundation http://www.sjogrens.org/

American Red Cross www.Redcross.org

ⁱ http://www.mayoclinic.com/health/lupus/DS00115/DSECTION=preparing-for-your-appointment