



Dear Friend,

We have put together some useful information for you.

Whether you are wondering if you have lupus or are newly diagnosed, **we want you to know we're your partner every step of the way.**

At the Lupus Foundation of America, we work with lupus medical experts to provide resources, programs, and services that help people with lupus and their doctors manage the disease. Our health educators are available to answer your questions and provide support. Call 1-800-558-0121 or visit Lupus.org/HealthEducator to talk with an educator in English or Spanish.

In addition to the enclosed materials, the resources below can help you learn more and connect with others.

CONNECT, GET SUPPORT, GET ANSWERS

The **National Resource Center on Lupus** is an online collection of up-to-date resources on all things lupus, available at Lupus.org/Resources.

LupusConnect™ is an online community where thousands of people with lupus and their loved ones can talk with others, share experiences, and find support. Join at Lupus.org/Resources/LupusConnect.

Take Charge is an email series that helps newly diagnosed and longtime lupus warriors learn ways to manage their health and wellness. Sign up at Lupus.org/Take-Charge.

SELF: Strategies to Embrace Living with Lupus Fearlessly is a free, online program that offers tips, tools, trackers, resources and support to help you manage your lupus. Get started at Lupus.org/Self.

ADVOCACY, ACTION, AND EMPOWERMENT

Become a Lupus Advocate. Our lupus advocates play a critical role in helping us elevate the disease on the national health care agenda. There are many ways you can partner with us to make a difference, including sharing your story and becoming an e-advocate. Learn more at Lupus.org/Advocate/Advocate-with-Us.

Fundraise to support the fight against lupus. You can make a difference while doing something you love through *Make Your Mark™* – our national fundraising program that helps you create your own unique event. Learn more at Lupus.org/MakeYourMark.

Help us accelerate research. Speed is the key. We support and fund research that shows the most promise to improve the lives of people with lupus now while helping develop better treatments and a cure. Join our efforts to advance research by making a donation at Lupus.org/Give/Ways-to-Give.

Enroll in RAY: Research Accelerated by You. RAY is a lupus data platform where people with lupus and caregivers provide information about their lupus experience to help researchers accelerate the development of new treatments and improve disease outcomes. Your participation can brighten the future of lupus research. Learn more at Lupus.org/RAY.

On behalf of the health educators at the Lupus Foundation of America, welcome!



Connecting with Your Local Chapter/Region

The [Lupus Foundation of America National Network](#) consists of chapters, regional offices, and support groups in communities throughout the United States. With the help of informed volunteers and committed supporters, we:

- Conduct activities to increase awareness of lupus.
- Provide educational programs, support groups and services.
- Rally support for those who are affected by lupus and advocate on their behalf.
- Raise money to support research and education programs so everyone affected by lupus can have an improved quality of life.

Our local chapters and regions offer events and resources unique to their communities; find out more at lupus.org/get-local.

We also have both in person and virtual support groups. Find local support at lupus.org/resources/find-support-near-you.

Not sure which chapter or regional office to contact? Get in touch with our national office by email at info@lupus.org or phone at (202) 349-1155 or (800) 558-0121.



Wondering if it is **Lupus?**

Lupus is a serious disease that causes your body to attack itself.

Lupus is a disease that affects the immune system, which protects the body from germs and infections. In a person with lupus, the immune system can't tell the difference between these germs and the body's healthy tissues and organs. So, the body attacks itself.

Lupus can affect nearly every part of the body. If you have lupus, you may have some symptoms that are visible and others that are not. Lupus symptoms vary from person to person, can come and go, and can change over time.

Common lupus symptoms:



Feeling very tired all the time, even when you've had enough sleep



Pain and swelling in your joints or muscles



A butterfly-shaped red rash on your nose and cheeks



Feeling sick or getting a rash after being in the sun



Fingers or toes that turn white or blue in the cold or when you feel stressed



A low-grade fever

Getting an early, accurate lupus diagnosis can reduce its long-term effects.

How do doctors diagnose lupus?

There is not just one test doctors can use to tell if you have lupus. Doctors must consider many different sources of information. Your doctor will look at:

- Your symptoms
- Your medical history
- Results from lab tests such as the ANA or AVISE® test (other tests may include anti-dsDNA or anti-Sm)

What is an ANA test and how does it work?

Doctors may use an ANA test to determine if a person has a certain type of antibody, called antinuclear antibodies (ANA), in their blood. The immune system normally creates antibodies (proteins) to fight germs and infections. Sometimes, the immune system mistakes healthy cells as foreign invaders and makes antinuclear antibodies that attack the healthy cells. Scientists have found that a majority of people with lupus (up to 98%) have antinuclear antibodies in their blood.

The ANA test is not specific for lupus and can sometimes show a positive test result when it's detecting different types of antibodies in the blood. Therefore, if you have a positive ANA test result, it doesn't necessarily mean you have lupus. It can, however, be an important clue for your doctor to look more closely for signs of lupus. After hearing more about your symptoms, your doctor may recommend more tests to help determine if you have lupus.

For more information on the ANA test, visit [Lupus.org/Resources](https://lupus.org/Resources).

What is AVISE® testing?

New, advanced tests like the AVISE Connective Tissue Disease (CTD) test can help diagnose lupus as well as other conditions. AVISE Lupus and AVISE SLE Monitor are specialized blood tests that help doctors identify lupus disease activity in the blood. When combined with a doctor's medical assessment, AVISE tests can provide the information needed to help you get on the path to better health. The Lupus Foundation of America contributed to the research that led to the development of the AVISE Lupus test.

For more information on AVISE testing, visit AviseTest.com.

Talking with your doctor about all of your symptoms and getting the right lab tests are important steps to arriving at an accurate diagnosis.

The Lupus Foundation of America is your partner, helping you find resources and getting the support you need. As the national organization devoted to solving the mysteries of lupus, the Foundation advances medical research and provides caring support to those who are living with the brutal impact of lupus.

RESOURCES INCLUDE

National Resource Center on Lupus - A collection of up-to-date resources and information on lupus. You will find a questionnaire to see if your symptoms could be related to lupus, a guide for talking with your doctor, additional information on how lupus is diagnosed, a lupus symptom tracker and more. Lupus.org/Resources

National Health Educator Network - Our health education experts are available to answer questions and provide helpful information, resources and support to those with questions about lupus. Call 1-800-558-0121 or visit Lupus.org/HealthEducator to get help in English and Spanish.

LupusConnect™ Online Community - An online community where members engage with others like them to share experiences and find emotional support. Lupus.org/LupusConnect

E-newsletter - Sign up to receive our monthly e-newsletter that includes the latest research, news and articles about living with lupus.

Social Media - For daily updates on news and information on lupus, follow us here:

[Facebook](https://www.facebook.com/LupusFoundationofAmerica) LupusFoundationofAmerica [Twitter](https://twitter.com/LupusOrg) LupusOrg [Instagram](https://www.instagram.com/LupusOrg) @LupusOrg [YouTube](https://www.youtube.com/LupusFoundation) LupusFoundation

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Understanding Lupus

If you've been diagnosed with lupus, you probably have a lot of questions about the disease and how it may affect your life. Lupus affects different people in different ways. For some, lupus can be mild — for others, it can be life-threatening.

Right now, there's no cure for lupus. The good news is that with the support of your doctors and loved ones, you can learn to manage it. Learning as much as you can about lupus is an important first step.

| What is lupus?

Lupus is a chronic (long-term) disease that can cause inflammation (swelling) and pain in any part of your body. It's an autoimmune disease, meaning that your immune system attacks healthy tissue (tissue is what our organs are made of). Lupus most commonly affects the skin, joints, and internal organs — like your kidneys or lungs.

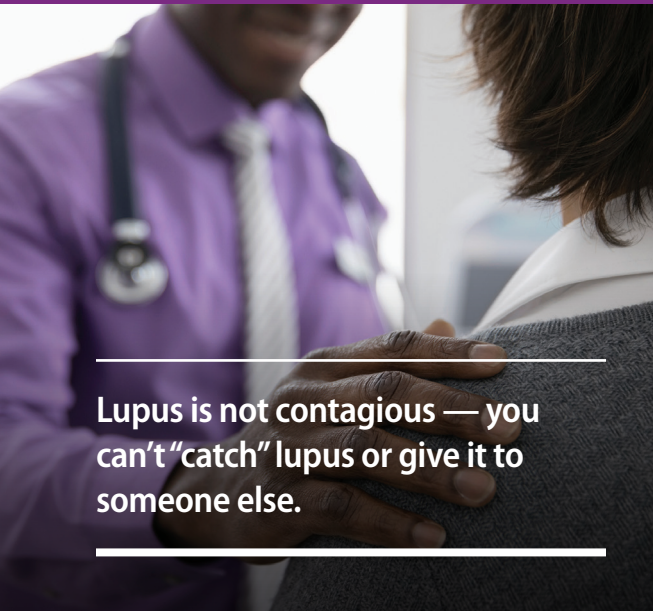
The immune system is the part of the body that fights off bacteria and viruses to help you stay healthy.

| Who is at risk for developing lupus?

In the United States, at least 1.5 million people have lupus — and about 16,000 new cases of lupus are reported each year. People of all ages, genders, and racial or ethnic groups can develop lupus. But certain people are at higher risk than others, including:

- Women ages 15 to 44
- Certain racial or ethnic groups — including people who are African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
- People who have a family member with lupus or another autoimmune disease

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Lupus is not contagious — you can't "catch" lupus or give it to someone else.

What causes lupus?

No one knows what causes lupus. Lupus and other autoimmune diseases do run in families. Experts also think it may develop in response to certain hormones (including estrogen) or environmental triggers. An environmental trigger is something outside the body that can bring on symptoms of lupus — or make them worse.

Some common triggers of lupus symptoms include:

- ✓ Ultraviolet rays from the sun or fluorescent lights
- ✓ Certain antibiotic drugs
- ✓ Having an infection
- ✓ Exhaustion (feeling very tired)
- ✓ Stress to the body, like getting hurt or having surgery
- ✓ Emotional stress, like being very busy or having problems at home

What are the symptoms of lupus?

Because lupus can affect so many different parts of the body, it can cause a lot of different symptoms. Keep in mind that these symptoms may come and go.

Symptoms of lupus may include:

- Fatigue (feeling tired often)
- Painful or swollen joints
- Swelling in the hands, feet, or around the eyes
- Headaches
- Low-grade fevers
- Sensitivity to sunlight or fluorescent light
- Chest pain when breathing deeply

People with lupus may also have problems with the skin and hair, including:

- A butterfly-shaped rash on the cheeks and nose
- Hair loss
- Sores in the mouth or nose

Lupus may also cause problems with the blood and blood vessels, like:

- Blood clots
- Low numbers of red blood cells (anemia)
- Fingers and toes turning white or blue and feeling numb when a person is cold or stressed (Raynaud's phenomenon)

What kinds of doctors treat lupus?

Most people who have lupus will see a **rheumatologist**. Rheumatologists are specialists who diagnose and treat diseases in the joints or muscles. But because lupus can cause problems anywhere in the body, you may have other types of doctors on your treatment team — for example, a:

- **Dermatologist** (for your skin)
- **Nephrologist** (for your kidneys)
- **Cardiologist** (for your heart)

Other types of lupus

When people talk about lupus, they're usually talking about systemic lupus. But there are other types — including **cutaneous lupus**, **drug-induced lupus**, and **neonatal lupus**. To learn more, check out this resource:

Resources.Lupus.org/Entry/Types-of-Lupus



Diagnosing Lupus

Diagnosing lupus can be challenging. There isn't just 1 test that can give doctors a "yes" or "no" answer. Sometimes, it can take months — or even years — before your doctor has all the information needed to make a lupus diagnosis.

If your doctor thinks you could have lupus, she'll ask you to answer questions about your symptoms, your medical history, and your family medical history. You may also get different kinds of tests. Making a lupus diagnosis is kind of like putting together a puzzle — each answer or test result is like a puzzle piece. When enough of the pieces fit together, your doctor may diagnose you with lupus.

Here's what you need to know about diagnosing lupus.

| What are the symptoms of lupus?

Because lupus can cause inflammation (swelling) in many different parts of the body, it can cause a lot of different symptoms. Symptoms may come and go — and they can change. Many people with lupus don't have all the symptoms.

Your doctor will ask about symptoms like:

- Fatigue (feeling tired often)
- Painful or swollen joints
- Swelling in the hands, feet, or around the eyes
- Headache
- Low-grade fever
- Sensitivity to sunlight or fluorescent light
- Chest pain when breathing deeply

People with lupus may also have problems with the skin and hair, including:

- A butterfly-shaped rash on the cheeks and nose
- Hair loss
- Sores in the mouth or nose

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| What questions will my doctor ask?



If your doctor thinks you might have lupus, he'll usually start by asking you questions about your symptoms.

For example:

- ☐ What symptoms are you having?
- ☐ When did your symptoms start?
- ☐ How often do you have these symptoms?
- ☐ Does anything make your symptoms better or worse?
- ☐ Are your symptoms constant or do they come and go?
- ☐ Do your symptoms get worse at a certain time of day?
- ☐ Do your symptoms get in the way of your daily routine?



It can be helpful to think through the answers to these questions ahead of time —

try writing down your answers and taking them with you to your appointment.

Your doctor may also ask you if anyone in your family has had lupus — or another autoimmune disease (where the immune system attacks healthy tissue). That's because people who have a family member with an autoimmune disease may be more likely to develop lupus.

Lupus may also cause problems with the blood and blood vessels, like:

- Blood clots
- Low numbers of red blood cells (anemia)
- Fingers and toes turning white or blue and going numb when a person is cold or stressed (Raynaud's phenomenon)

Keep in mind that different kinds of health care professionals — like nurses, physical therapists, or primary care doctors — may play a role in helping to diagnose lupus.

| What types of tests could my doctor give me?

Your doctor might give you different lab tests to help find out if you have lupus. While no single test can diagnose lupus, tests help doctors check for changes in your body that could be caused by lupus.

Blood tests

Blood tests can help doctors see things like how your immune system is working, or if there are signs of inflammation (swelling) in your body.

Your doctor may give you blood tests like:

- A complete blood count (CBC) to measure the numbers of red blood cells, white blood cells, and platelets (cells that help blood clot) in your blood
- Antibodies tests to find out if your immune system is attacking your body
- Blood clotting time tests to see if you have clotting problems that could be from lupus
- Complement tests to check for signs of inflammation

Urine tests

Urine (pee) tests can help your doctor see if there are any problems with your kidneys. Your doctor may test your urine just once — or many times to check for changes.

Biopsies

Your doctor may remove a small piece of tissue (what our organs are made of) from different parts of your body — like your skin. Then your doctor can check tissue to see if there are any signs of inflammation and damage.

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For more information on the diagnosing lupus, please visit the **National Resource Center on Lupus** at:

Resources.Lupus.org/Collections/Diagnosing-Lupus



Treating Lupus

If you've been diagnosed with lupus, you're probably wondering how it's treated. One of the most important things to know about treating lupus is that it's a team effort. You and your treatment team will work together to find the combination of medicines that's right for you. Your treatment plan may depend on things like your age, your lifestyle, and how healthy you are.

While there's no cure for lupus right now, having the right treatment plan can help:

- Control your symptoms — like joint pain, inflammation (swelling), and feeling tired
- Keep your immune system from attacking your body
- Protect your organs from damage

Treating lupus can be difficult. It can take months — or even years — to find the right treatment plan for you. The good news is there are medicines that can help you feel better.

| What medicines can treat lupus?

Because lupus can cause a lot of different symptoms, there are many different kinds of medicines that can treat it. A doctor will need to prescribe some of them — others are available over the counter.

The most common medicines used to treat lupus include:

- **Anti-inflammatories** to help with inflammation and pain
- **Antimalarials** to protect skin from rashes and UV light
- **Biologics** to help your immune system work correctly
- **Anticoagulants** to help prevent blood clots
- **Immunosuppressives** to help keep your immune system from attacking your body
- **Steroids** to help with inflammation

The immune system is the part of the body that fights off bacteria and viruses to help you stay healthy.

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What about alternative medicines?

If you're thinking of trying alternative treatments — like herbal medicines — always talk with your doctors first. Some alternative treatments might not be safe to take with certain medicines, and some could make your symptoms worse. Very few alternative medicines have been tested in people with lupus.

Keep in mind that any medicine you take for lupus can have side effects, and some medicines could put you at risk for life-threatening infections. Talk with your doctors about what changes to watch for with the medicines you're taking. And tell your treatment team right away if you have any side effects.

What do I ask the doctor?

It's normal to have a lot of questions when you and your doctors are working together to develop your treatment plan.

Here are some ideas for questions to ask about your medicines:

- ✓ What is the name of this medicine?
- ✓ How will this medicine help me?
- ✓ Is it okay to take the generic version instead of the brand name?
- ✓ How much do I need to take and when?
- ✓ What are the possible side effects?
- ✓ When will this medicine start to work?
- ✓ Is it safe to take with my other medicines?

Work with your doctors to find a treatment plan that's right for you

You may have to try many different medicines before you find a combination that works for you — and that can mean a lot of back and forth with your treatment team. Playing an active role in your health care can help you and your doctors find the right medicines for you faster.

Keep in mind that people with lupus usually see more than 1 doctor for treatment. That means it's especially important to keep everyone on your treatment team updated.

Remember, treating lupus is a team effort — so check in with your doctor often. In time, you and your doctor can find a treatment plan that's right for you.



Here are some things you can do to play an active role in your treatment:

- ✓ Use a journal to keep track of your medicines, the doses you're taking, and any side effects you notice
- ✓ Let your treatment team know if you're having side effects or if your symptoms change after starting a new medicine
- ✓ Share any concerns you have about your treatment with your doctors
- ✓ Write down questions about your treatment for the doctor ahead of time and take them to your appointments
- ✓ Ask a friend or family member to go with you to appointments for support — they can also help you keep track of your questions and information about your treatment

For more information on treating lupus, please visit the **National Resource Center on Lupus** at:

Resources.Lupus.org/Topics/Treatment-Options

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Coping with **Lupus**

Having lupus can make everyday life challenging. When your lupus is active, symptoms like joint stiffness, pain, fatigue, confusion, or depression can make simple tasks difficult — and sometimes impossible. Since these symptoms aren't visible, the people around you may have trouble understanding how you feel.

It's important not to ignore the limitations that come with this disease. However, there are steps you can take to stay involved with work, relationships, and the activities you care about. Start by following these strategies to help you lighten the burden of your illness and maintain a fulfilling life.

| Learn how to explain lupus to others

It's important for family and friends to understand lupus so they know how they can help. But since lupus has so many different symptoms that come and go — which may range from manageable to life-threatening — it can be hard to describe.

You may want to start by explaining what lupus is not:

- Lupus is not contagious — you can't "catch" it from someone or "give" it to someone
- Lupus is not like or related to cancer
- Lupus is not like or related to HIV or AIDS

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Take time for yourself



While it's important to learn as much as you can about lupus, it's also important to take a break from focusing on your disease when you need to. Living well with lupus often involves making some changes within your family, your profession, and your social circle. But even though lupus may affect many different areas of your life, it's important to remember that this disease does not define you. Taking time to do activities you enjoy will help you reconnect with yourself.



Then, you can talk about what lupus is:

- Lupus is an autoimmune disease — the immune system attacks your own healthy tissues because it mistakenly sees them as foreign invaders
- Lupus is a chronic disease — people who develop lupus will have lupus for the rest of their lives
- Lupus has many different symptoms and affects each person differently

Explain that lupus is unpredictable. Symptoms can appear, disappear, and change. Knowing this may help other people understand your ups and downs, and also the changes that you may have to make in your life.

| Make adjustments as a family

Good communication is important for helping your family adjust to a lupus diagnosis. You'll want to make sure you share details of your lupus symptoms and treatment with your family — keeping them informed can lessen their concerns. It'll also help them understand why you may sometimes say “no” to activities.

These tips can also help your family adjust:

- Maintain a manageable schedule with time for breaks
- Reassign household responsibilities as needed
- Ask friends or extended family members to help around the house when possible
- If you have children, talk to them about your lupus and how it may affect life at home



| Manage work with lupus

Many people with lupus can continue to work, although they may need to make changes in their work environment. Depending on what your lupus symptoms are like and what kind of job you have, you may be able to work with your employer to make adjustments so you can stick with your current career.

Use these tips:

- Make small changes to your workstation — like getting a more comfortable desk chair (sometimes called ergonomic chairs)
- Request a different or more flexible work schedule — for example, you could work from home on certain days or start your workday later
- Get help from a vocational rehabilitation counselor (job coach for people with disabilities) to find work that's more manageable

If the physical or mental demands of your job become overwhelming, you might benefit from changing jobs or switching to part-time hours. In some cases, not working at all may be the best choice for your health. You can learn about disability benefits from your company's human resources office or from the Social Security Administration (SSA).

If you're concerned about what will happen if you tell your employer you have lupus, remember that people with long-term health problems like lupus are protected by the Americans with Disabilities Act (ADA). The ADA says that employers will offer accommodations to help a person to meet the requirements for their job.



To do well in the classroom while keeping your lupus in check, make sure you:

- ✓ Don't overload your schedule — try to leave time for relaxation
- ✓ Communicate with the school about your lupus — make sure you register with the school accessibility office and consider telling roommates, your academic advisor, professors, and staff at the student health center about your lupus
- ✓ Learn about financial assistance opportunities — you might be eligible for federal financial aid and a number of scholarship programs
- ✓ Think about accommodations you might need — if you expect to miss class sometimes or think you may need extra time on tests, make sure you talk to your professors or other staff members

Manage school with lupus

Many people who have lupus are successful at school while preparing to pursue their dreams. School at any level can be demanding, so you'll want to make sure you're prepared to balance tests and homework with the need to take care of your health.

Find the support you need

Staying connected socially can help you put lupus in perspective and build a support system. Make sure you spend time doing activities you enjoy with other people, and identify family members and friends you can turn to when you need to talk to someone.

In addition to sharing with your family and friends, there are other ways you can find support:

- Individual therapy can help you cope with issues like depression and anxiety
- Couples therapy can help you and your partner communicate as you both adjust to your diagnosis
- An online support group can help you engage with other people affected by lupus and learn tips from people dealing with similar experiences

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For more information about coping with lupus, please visit the **National Resource Center on Lupus** at:

Resources.Lupus.org



Living with **Lupus**

If you've been diagnosed with lupus, you may need to make some changes to your daily routines to help manage your symptoms. Living with lupus can be difficult, and it's normal to feel overwhelmed — especially at first.

The good news is there's a lot you can do to stay on top of your health and manage your symptoms. Start by learning some steps you can take to develop healthy habits.

| Make your treatment plan work for you

One of the most important tools you have to manage lupus is yourself — your effort, your attention, and your awareness of your body.

Remember to:

- Follow instructions from your doctors
- Take your medicines as prescribed
- Keep a medical diary to record your symptoms, medicines, and side effects
- Talk with your doctor about your questions and concerns — especially if you need help with side effects
- Pay attention to how you feel, and share what you notice with your doctors
- Tell your doctor right away if your symptoms change or get worse

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| Eat healthy and be physically active

Healthy living is good for everyone — but for people with lupus, it's especially important. Good nutrition and physical activity can help you feel better.

Use these tips to help you eat healthy and be active:

- Eat lots of fruits, vegetables, and whole grains
- Choose healthy protein foods — like lean meats, poultry, and seafood
- For bone health, eat foods with lots of calcium — like spinach and dairy
- For heart health, eat foods with Omega-3 fatty acids — like salmon and walnuts
- Try walking, swimming, or biking — these low-impact activities help your bones and muscles without hurting your joints
- Try gentle yoga to relieve stress and loosen tight muscles — ask your treatment team what kind of yoga is best for you

Always check with your doctors before taking any herbs, vitamins, or dietary supplements — they can affect the medicines used to treat lupus or make your condition worse.

| Manage fatigue

Most people with lupus have fatigue (feel tired often).

Try these tips to beat fatigue:

- Get enough sleep — aim for at least 7 hours each night
- Take breaks during the day to rest and recover — there's no shame in needing a nap
- Make changes to your daily routine when you need to



Manage stress

For many people with lupus, stress can trigger your symptoms — or make them worse.

Use these tips to manage everyday stress:

- Plan ahead for how you're going to use your time — decide what's most important and do that task first
- Ask for help when you need it
- Make time for fun, relaxing activities
- Try not to sweat it if you don't get everything done or have to cancel plans — remember, your health comes first

Manage pain

Most people with lupus have joint pain, muscle pain, or headaches. Always check with your doctors before trying new ways to manage your pain.

Smoking can trigger lupus symptoms and make them worse. If you smoke, make a plan to quit.

Manage lupus fog

Many people with lupus have “lupus fog” (feelings of confusion and memory loss).



Try these ideas to clear the fog:

- ✓ Focus on 1 task at a time
- ✓ When someone tells you their name or an important piece of information, try repeating it out loud and writing it down
- ✓ Before a doctor's appointment, write down your questions — and bring your medical diary so you can tell the doctor about your symptoms and side effects
- ✓ Keep a calendar to record appointments and reminders



| Protect yourself from ultraviolet (UV) light

Most people with lupus are sensitive to UV light — and it can trigger lupus symptoms.

Follow these tips to stay protected:

- ✓ Use sunscreen with SPF 30 or higher that blocks both UVA and UVB rays
- ✓ Wear long sleeves, pants, and wide-brimmed hats made of fabrics that protect you from the sun
- ✓ Plan outdoor activities for early in the morning or later in the evening

People with lupus can be sensitive to indoor lighting. If indoor light bothers you, try putting light shields over fluorescent bulbs. You can also buy light bulbs that send out low amounts of UV radiation, like LED lights.

Here are some ideas to try:

- Use heat or cold packs
- Talk with your treatment team about taking over-the-counter pain medicines
- Try relaxation techniques — like meditation, breathing exercises, or gentle yoga
- Consider trying healing techniques — ask your treatment team about acupuncture, acupressure, or biofeedback

If you have lupus, it's a good idea to get certain vaccines — but you may not be able to get others. Always check with your doctors before you get vaccines or allergy shots.

| Protect yourself from infections

Lupus increases your risk of infections.

Use these tips to protect yourself:

- Wash your hands often
- Clean and protect any cuts or wounds
- Avoid people with colds or other illnesses you could catch
- Talk with your doctors about taking antibiotics before procedures
- Tell a doctor right away if a cut becomes red, painful, or swollen
- Tell a doctor right away if you have a fever over 100 °F

| Get help living with lupus

Don't be afraid to get professional help if lupus interferes with your life.

Here are some types of professionals who can help with the physical symptoms of lupus:

- Cognitive therapists can help with lupus fog
- Occupational therapists can make your work space and tasks more manageable
- Physical therapists can help with joint problems and improve your strength

You may need to make some changes in your life because of lupus. But you can learn to live with your symptoms — and keep doing the things you want to do.

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For more information on living with lupus, please visit
the **National Resource Center on Lupus** at:

Resources.Lupus.org/Collections/Living-With-Lupus

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HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

Instructions: Knowing how to explain your lupus to others is an important skill to have in your toolbox. Mix and match answers to commonly asked questions about lupus and add your own responses to create your 30-second “About Lupus” speech. Sample speeches are provided at the end.

Q: WHAT IS LUPUS?

EXAMPLES

- Lupus is an autoimmune disease. That means my immune system is overactive and is causing inflammation and damage throughout my body.
- For me, lupus has affected: [list your organ systems affected].
- Lupus is also a disease of flares, when symptoms become active. Sometimes I know when a flare is coming, but sometimes it catches me by surprise.
- When I’m having a flare, it helps me to get extra rest, so sometimes I must change or cancel plans, or miss work.

ADD YOUR RESPONSE HERE

Q. IS LUPUS A KIND OF ARTHRITIS? OR IS IT LIKE HIV/AIDS OR LIKE CANCER?

EXAMPLES

- Lupus is an autoimmune disease. That means my immune system is overactive and is causing inflammation and damage throughout my body.
- Lupus is not a form of arthritis, but the joint pain and swelling of arthritis are also common symptoms of lupus.
- Lupus is not like or related to HIV/AIDS. In these illnesses, the immune system isn’t working correctly. The difference is that, with HIV/AIDS, the immune system is under-active; and in lupus, the immune system is overactive.

ADD YOUR RESPONSE HERE

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

- Lupus is not like or related to cancer. In lupus, your immune system attacks healthy tissue (tissue is what our organs are made of). In cancer, some of the body’s cells begin to divide without stopping and spread into surrounding tissues.

Q: IS THERE A CURE?

EXAMPLES

- No, lupus is a chronic illness, which means it’s long-term.
- Right now, there’s no cure for lupus, but I hope that there will be one in my lifetime!
- No, not yet. That’s why I must take good care of myself and learn how to manage it.

ADD YOUR RESPONSE HERE

Q: WHO GETS LUPUS?

EXAMPLES

- People of all ages, genders, and racial and ethnic groups can develop lupus.
- In the United States, certain people are at higher risk for developing lupus than others, including:
 - Women ages 15 to 44
 - Certain racial and ethnic groups—including people who are African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
 - People who have a family member with lupus or another autoimmune disease

ADD YOUR RESPONSE HERE

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your "About Lupus" Speech

Q: HOW/WHEN WERE YOU DIAGNOSED?

EXAMPLES

- I was diagnosed [give the date], but now that I know more about lupus, I think I've had symptoms since [fill in details].
- Diagnosing lupus can be hard because the symptoms are seen in many other illnesses. For example, I had [fill in your first known lupus symptom(s)], which could also have meant I had [different illness with similar symptom(s)].
- It took [number of months or years] and seeing [how many] different doctors before I had the right diagnosis.

ADD YOUR RESPONSE HERE

Q: HOW DID YOU GET LUPUS? IS IT CONTAGIOUS?

EXAMPLES

- Lupus is not contagious, not even through sexual contact.
- You can't "catch" lupus from someone or "give" lupus to someone.
- No one knows what causes lupus.
- Lupus and other autoimmune diseases do run in families.
- Experts think lupus may develop in response to certain hormones or environmental triggers (like sun exposure, having an infection, and stress).
- I think what triggers lupus to become active or worse in me is/are [list possible trigger(s)].

ADD YOUR RESPONSE HERE

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

Q: CAN LUPUS BE PREVENTED?

EXAMPLES

- Right now, there’s no way to prevent the onset of lupus.
- There are a few known risk factors, but none of them can be prevented. They are: gender, age, ethnicity, and heredity.

ADD YOUR RESPONSE HERE

Q: HOW IS LUPUS TREATED?

EXAMPLES

- The goal of my treatment plan is to help me control my symptoms, keep my immune system from attacking my body, and protect my organs from damage.
- Since there are very few drugs specifically developed for lupus, medications originally developed for other conditions are used to treat lupus.
- Right now, I’m taking [list your medications here]. Sometimes I need to take additional medications to treat the side effects of these drugs, so I also take [list additional medications].
- Treating lupus can be difficult. It can take months – or even years – to find the right treatment plan.
- Lifestyle adjustments can really help people with lupus, especially getting enough rest and having the support of family and friends. The things that help me most are [list the top two or three].
- It’s important for me to avoid things that trigger the disease to become active, especially too much sun exposure, stress, infections, and smoking.

ADD YOUR RESPONSE HERE

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

Q: CAN YOU DIE FROM LUPUS?

EXAMPLES

- Yes, lupus can be fatal. The leading causes of death are serious infections, heart attacks and related cardiovascular diseases, and kidney failure.
- Most people will live a normal lifespan if they follow their treatment plan and make any lifestyle changes that keep lupus from becoming active.

ADD YOUR RESPONSE HERE

Q: HOW DOES LUPUS MAKE YOU FEEL?

EXAMPLES

- Lupus has many different symptoms. It affects each person differently. The symptoms that affect me most are [list symptoms that most affect you].
- It’s hard to describe how much effort it takes for me to function every day because of the extreme fatigue, pain, memory loss, and medication side effects that I experience. [Or use your own examples].
- The worst thing for me is that lupus is so unpredictable. When I suddenly have a flare, it can be frustrating. [Or use your own examples].

ADD YOUR RESPONSE HERE

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

Q: ARE YOU SURE YOU REALLY HAVE A DISEASE? YOU DON'T LOOK SICK.

EXAMPLES

- My doctor has offered to explain my condition to my family members and friends. I'd really like it if you'd come with me to my next appointment.
- I just wish I felt as good as I look!
- It's strange, isn't it, that I can be so sick on the inside and still look OK on the outside, but that's lupus.

ADD YOUR RESPONSE HERE

Q: WHY DON'T YOU TRY ALTERNATIVE TREATMENTS, LIKE [FILL IN THE BLANK]?

EXAMPLES

- I've worked with my doctor on a treatment plan, and I want to give it a chance.
- My doctor explained that herbal supplements and other unproven therapies can be dangerous when taken along with my prescribed medications, and could make my lupus worse.

ADD YOUR RESPONSE HERE

Q: WHY DON'T YOU CHANGE YOUR DIET TO [FILL IN THE BLANK]?

EXAMPLES

- There's been a lot of research done on this topic and currently there's no “special” diet for people with lupus. The recommended diet for me is the same one recommended for the general population.
- My current diet meets with my doctor's approval, so I'm going to stick with it.

ADD YOUR RESPONSE HERE

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

EXAMPLE SPEECHES

EXAMPLE 1

Lupus is an autoimmune disease. That means my immune system is overactive and is causing inflammation and damage throughout my body. It's also a chronic illness, which means it's long-term. I was diagnosed last month, but now that I know more about lupus, I think I've had symptoms since I was a teenager. So far, lupus has affected my kidneys most of all. Right now, I'm taking corticosteroids and an antimalarial and infusions of a chemotherapy drug, all to keep my immune system from causing further damage. (31 seconds)

EXAMPLE 2

Lupus has so many different symptoms and it affects each person differently. The worst things for me are the joint pain and how tired I feel. It's hard to describe how much effort it takes me to function day-to-day. One of the most important things about living with lupus is to avoid things that trigger disease flares, like too much sun exposure and infections. I'm pretty good about those things, but lupus can flare without warning, and when I have a flare, it makes me feel really frustrated. Having the support of family and friends is so important. Right now, the things that help me most are my husband and kids pitching in to do the housework and switching to working part-time until I feel better. (33 seconds)

ADD YOUR SPEECH HERE

I am newly diagnosed...

What should I ask my rheumatologist?

INSTRUCTIONS:

This form is intended to remind you of some important questions that you may want to ask your rheumatologist if you are newly diagnosed and/or learning more about lupus. You can print or download this form and bring it to the doctor's office with you, for easy reference. You may want to ask these questions over the course of several visits. Feel free to mark up the form as you see fit, highlighting the questions you would like to ask and marking your notes below the questions your rheumatologist has answered. Please keep in mind that not all of these questions will apply to you and some questions may not be answered by your physician.

What symptoms should I expect as a part of this disease?

Under what circumstances should I notify my doctor or go to the emergency room?

Will other tests need to be done in the near future? How will my lupus be monitored?

What medications will I need to take? And what are the side effects?

How long before I start to see relief or know the medications are working?

How long will I be on these medications?

Will this disease affect my organs? And, if so, how do I prevent further damage?

Is lupus a fatal disease?

Which vaccines are safe for me to take?

What are some trusted websites where I can find more information? And do you recommend any good resources in which I can find material to help those around me understand?

Other questions you may want to ask now, or at a future visit:

MEDICATIONS

Will any of these medications interact with other medications that I am currently taking?

Will any of these medications affect other conditions that I may have?

Are there alternative therapies?

LIFESTYLE

Do I need to avoid the sun?

What should I use for sun protection?

What can I do to manage my fatigue?

Will I need to limit any of my normal day activities (e.g. exercise)?

Are there any exercises that may help?

Should I tell my employer that I have lupus?

(If it's difficult to work full or part-time) Will I need to apply for disability?

(If you smoke) How do I quit?

DIET/SUPPLEMENTS

Is there a diet I need to follow or certain foods I need to avoid?

Should I take vitamins or other dietary supplements?

FAMILY PLANNING

Will I have trouble getting pregnant?

Will my children develop lupus?

NOTES

LUPUS CHECKLIST

If you have systemic lupus erythematosus (lupus), every symptom matters.

With lupus, it is important to discuss all of your symptoms — even the ones you might not associate with lupus. Please complete the Lupus Checklist below and discuss these symptoms with your rheumatologist at each appointment.

SYMPTOMS	I have had this symptom since my last doctor visit	I have had this symptom for: ____ hr/days/weeks	This is the first time I have had this symptom
<i>Example: Skin rash</i>	<input checked="" type="checkbox"/>	3 weeks	<input type="checkbox"/>
Heart			
Chest pain	<input type="checkbox"/>	_____	<input type="checkbox"/>
Difficulty breathing	<input type="checkbox"/>	_____	<input type="checkbox"/>
Rapid and/or irregular heartbeat	<input type="checkbox"/>	_____	<input type="checkbox"/>
Lung			
Pain in the chest when deep breathing	<input type="checkbox"/>	_____	<input type="checkbox"/>
Eye			
Dry eyes	<input type="checkbox"/>	_____	<input type="checkbox"/>
Eye redness	<input type="checkbox"/>	_____	<input type="checkbox"/>
Some loss of vision	<input type="checkbox"/>	_____	<input type="checkbox"/>
Blood			
Bleeding and/or bruising easily	<input type="checkbox"/>	_____	<input type="checkbox"/>
Infections	<input type="checkbox"/>	_____	<input type="checkbox"/>
Muscles & Bones			
Muscle weakness	<input type="checkbox"/>	_____	<input type="checkbox"/>
Stiffness in joints	<input type="checkbox"/>	_____	<input type="checkbox"/>
Aching muscles	<input type="checkbox"/>	_____	<input type="checkbox"/>
Skin			
Skin rashes	<input type="checkbox"/>	_____	<input type="checkbox"/>
Sensitivity to sun or light	<input type="checkbox"/>	_____	<input type="checkbox"/>
Mouth or nose sores	<input type="checkbox"/>	_____	<input type="checkbox"/>
Hair loss	<input type="checkbox"/>	_____	<input type="checkbox"/>
Brain			
Seizures	<input type="checkbox"/>	_____	<input type="checkbox"/>
Headache and/or dizziness	<input type="checkbox"/>	_____	<input type="checkbox"/>
Memory problems or confusion	<input type="checkbox"/>	_____	<input type="checkbox"/>
Sad thoughts	<input type="checkbox"/>	_____	<input type="checkbox"/>
Weakness/numbness on one side (for example, one arm weak or numb)	<input type="checkbox"/>	_____	<input type="checkbox"/>
Kidney			
Swelling of legs and/or feet	<input type="checkbox"/>	_____	<input type="checkbox"/>
Frothy and/or bloody urine	<input type="checkbox"/>	_____	<input type="checkbox"/>
General			
Fatigue	<input type="checkbox"/>	_____	<input type="checkbox"/>
Fevers	<input type="checkbox"/>	_____	<input type="checkbox"/>
Weight change	<input type="checkbox"/>	_____	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	_____	<input type="checkbox"/>
Other			
Other 1: _____	<input type="checkbox"/>	_____	<input type="checkbox"/>
Other 2: _____	<input type="checkbox"/>	_____	<input type="checkbox"/>



This checklist is neither a diagnostic tool nor a complete list of all possible lupus symptoms. Be sure to talk to your doctor about all of your symptoms.

TALK TO YOUR RHEUMATOLOGIST ABOUT YOUR LUPUS SYMPTOMS.

This checklist can help you at your next appointment.

Step 1: Complete the checklist.

Step 2: Use the notes space below to prepare for each appointment. Regular appointments are often brief so it's important to write down any questions you may have for your rheumatologist ahead of time. Keeping questions brief and focused can help you make the most of your time together.

Step 3: Consider bringing a close friend or family member along with you to your appointment to support you and act as an extra set of ears. Give that person the job of writing down the information and answers to your questions that your doctor provides.

Step 4: At each appointment, discuss any changes in your health (even the ones you don't think are related to your lupus) with your rheumatologist, as some symptoms may indicate organ damage.

If you have more than one doctor, make sure they are all aware what the others are recommending to help ensure there are no conflicts in your health management. Consider bringing copies of your most recent appointment notes to each doctor visit.

Help your doctor help you. Use this checklist to capture your lupus symptoms and bring it to each appointment.

