



Help Us Solve
The Cruel Mystery

LUPUS[®]
FOUNDATION OF AMERICA

HEALTH INSURANCE GUIDE

FOR PEOPLE WITH LUPUS



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INTRODUCTION

Health insurance is the main way that people pay for health care in the U.S. But there are so many types and complicated terms that it can be confusing to know where to start. This is especially true if you need specific care for your lupus or if you're helping someone with lupus navigate their care. **This guide is meant to help clear up some of that confusion by explaining what health insurance is and how getting the right health insurance can help with managing lupus.**

While everyone's experience with lupus is unique, taking the time to understand how health insurance works can help with getting the care you need.

Use this guide to learn about:

- Health insurance basics
- Lupus-specific considerations for health insurance
- How to advocate for yourself
- Other ways to pay for health care

Quick Reference - Important websites

This is a list of websites you can refer to if you need more information.

- [Lupus.org/resources](https://lupus.org/resources)
- [Lupus.org/health-educator](https://lupus.org/health-educator)
- [Healthcare.gov](https://healthcare.gov)
- [VA.gov/health-care](https://va.gov/health-care)
- [Medicare.gov](https://medicare.gov)
- [Medicaid.gov](https://medicaid.gov)

HEALTH INSURANCE BASICS

Health insurance is an agreement between you and a health insurance company that requires them to cover part of your medical costs. On your end, you have to make a regular payment to the health insurance company, called a **premium**. And depending on what kind of health insurance you have, you may have to pay a certain amount on your own before your coverage kicks in. This is called a **deductible**.

Health insurance can cover costs for:

- **Preventive care** — like health screenings, vaccinations, and regular check-ups
- **Specialty care** — like lupus-specific care and diagnostic tests
- **Prescriptions** — like any lupus medicines you take
- **Hospital care** — like surgery or visits to the emergency room

The type of plan you have will decide what services and costs your health insurance will cover. For example, after you've paid your deductible, your plan may have:

- **A copay.** This is a fixed amount you have to pay for a health care service that's covered by your plan. Your plan may have different copays for different services — but they'll stay the same as long as you have that plan.
- **Coinsurance.** This is the way you and your insurance split the cost of a health care service that's covered by your plan. With coinsurance,



you pay a percentage of the cost, and your insurance pays the rest.

- **An out-of-pocket maximum or limit.** This is the most you have to pay for health care services in 1 year. This includes your deductible, copays, and coinsurance. After you pay this amount, your insurance will pay all the costs for any more covered services you need for the rest of the year. This maximum doesn't count your premium or any costs you pay for services that your plan does not cover or that are out-of-network.

Insurance companies have contracts with certain doctors and health care organizations. These doctors and health care organizations are **in-network**. If an



Out-of-pocket maximum or limit doesn't count your premium or any costs you pay for services that your plan does not cover or that are out-of-network



insurance company doesn't have a contract with a doctor or organization, then they're **out-of-network**. You pay less for using in-network health care services — and what you pay can go toward your out-of-pocket maximum. To find out if a doctor or organization is in-network, call your insurance company or check your plan's directory of doctors online.

Why is health insurance important?

In the U.S., paying the total cost for health care is too expensive for most people. And people with a chronic condition, like lupus, may have high health care costs throughout their lives. These costs can come from things like seeing specialists, taking medicines, going to the hospital, or getting tests.

The good news is that health insurance can help pay for lupus-related health care and may even help pay for home health care services. This helps increase access to health care services by making them more affordable. It just takes some time to figure out what health insurance plans work for your health care needs and budget.

What are the different types of health insurance?

There are many different ways to get health insurance and different types of plans. But generally, health insurance falls into one of these categories:

- **Insurance through an employer.** Some jobs offer employer-sponsored insurance (ESI) as a benefit to their employees. Each employer has different options available — so you'll want to talk to your benefits representative at your job to find out more. And if you leave your job, you may be able to keep your ESI for a set period of time through COBRA. This is a federal law that helps you keep your coverage, but you'll have to pay more than you used to. Learn more about COBRA at [Healthcare.gov/unemployed/cobra-coverage](https://www.healthcare.gov/unemployed/cobra-coverage).
- **Marketplace insurance.** The U.S. government has set up a central website called the Health Insurance Marketplace where you can compare health insurance plans and get other resources to help pay for health care. You can also buy health insurance through the Marketplace. Learn more about the Marketplace at [Healthcare.gov/quick-guide](https://www.healthcare.gov/quick-guide).
- **Medicare.** This is a federal program (run by the U.S. government) that provides health insurance for people who are age 65 years and older or have disabilities — including people who may have disabilities from lupus. The State Health Insurance Assistance Program ([Shiphelp.org](https://www.shiphelp.org)) can help you get ready to enroll in Medicare. Learn more about Medicare at [Medicare.gov](https://www.Medicare.gov).
- **Medicaid.** This is a joint federal and state program, and each state sets its own guidelines for it. In most states, Medicaid is available for people and families with low incomes and



people with disabilities — including disabilities caused by lupus. Learn more about Medicaid at [Medicaid.gov](https://www.Medicaid.gov).

- **Tricare and U.S. Department of Veterans Affairs (VA).** These federal government programs provide insurance for military veterans, active-duty military personnel, and their families. Different Tricare plans are available depending on where a service member is located, when they served, and what role they're in now. Many military bases have patient advocates who can help with getting enrolled in a plan. Learn more about Tricare health insurance at [Tricare.mil/Plans/HealthPlans](https://www.Tricare.mil/Plans/HealthPlans) and VA health care at [VA.gov/health-care](https://www.VA.gov/health-care).

Some people have health insurance from more than 1 of these categories. For example, if your income is low and you're either age 65 or older or have certain kinds of disabilities, you may qualify for both Medicare and Medicaid (called dual eligibility). Being covered by more than 1 kind of health insurance can provide extra benefits, like monthly credits for everyday needs for some people who qualify for both Medicare and Medicaid.

How can I explore my insurance options?

If you have ESI, talk to your benefits representative at your job. They can help you figure out which of the plans your employer provides will work best for you.

- You can also go to [Healthcare.gov](https://www.Healthcare.gov). Even if you're not planning on buying Marketplace insurance, this website has useful information on comparing costs and finding other ways to make health care more affordable.



Our health education specialists are specially trained to provide people with lupus with:

- Free non-medical support
- Disease education and information
- Helpful resources — like tips on paying for care
- You can contact them online at [Lupus.org/resources/health-educator](https://www.Lupus.org/resources/health-educator) or call 1-800-558-0121 extension 136.

LUPUS-SPECIFIC CONSIDERATIONS FOR HEALTH INSURANCE

Living with lupus means you're likely to need many different health care services at different times — depending on how and when your symptoms affect you. Health insurance can help cover some of the services you need. **So it's important to know how to make the most of your insurance to keep your costs as low as possible.**

What types of insurance plans will work better for me?

Most people with lupus need insurance plans that cover both regular primary care visits and:

- Regular specialist appointments
- Diagnostics (tests and screenings)
- Medicines
- Hospital visits

If you take medicines for lupus, check the plan's **formulary** — or drug list — to make sure your insurance will cover your medicines. A formulary is a list of prescription medicines covered by an insurance plan. Different insurance plans cover different kinds of medicines. If your insurance plan doesn't cover your medicines, you may need to choose a different plan or get a prescription drug plan.

If you already have a health care team that works for you, sticking with them can help you manage



your lupus over time — even if you switch health insurance. When starting with a new insurance plan or getting insurance for the first time, you can ask your health care team if they take that plan. You can also call the insurance company or check the plan's directory of doctors online to find out.

- Don't be afraid to shop around! And look at all the costs that a plan has (see the "Yearly cost for sample health insurance plans" chart on page 9 for more details). If you're unsure about a term you come across while looking at plans, check the glossary of terms at [Healthcare.gov/glossary](https://www.healthcare.gov/glossary).

How can I estimate my costs?

Usually, you'll see the premium first because it's an upfront cost you have to pay to get insurance. But make sure to check what other costs you'll be responsible for — like the deductible and any copays. See the Health Insurance Basics section on page 5 to learn more about these costs.

See the Health Insurance Basics section on page 5 to learn more about deductibles and copay costs.

Here are some examples of how yearly costs might look for different plans:

YEARLY COST FOR SAMPLE HEALTH INSURANCE PLANS

	PLAN 1	PLAN 2	PLAN 3
Premium	\$1,000	\$2,000	\$3,000
Deductible	\$3,000	\$1,500	\$0
Specialist copay	\$0	\$0	\$600 (\$50 for each monthly visit)
TOTAL	\$4,000	\$3,500	\$3,600

At first glance, Plan 1 might look great because its yearly **premium** is lower than the other options. But the high deductible means you'll have to pay more out-of-pocket before your insurance kicks in and starts covering your health care services.

And Plan 3 might also seem like a good option because of the \$0 **deductible**. But if you see specialists a lot, the **copay** for each specialist visit might mean you'll pay more. It's important to plan out what health care services you'll probably need and compare them to what an insurance plan will cover — and how much you'll have to pay out-of-pocket before your insurance kicks in.

These example plans are very simple, to explore the basics of how to estimate costs. But remember that each plan is different, so figuring out your own costs may be more complex. For example, some plans put medicines into tiers and cover them differently depending on what tier they're in.

Make a list of the health care services and medicines you expect to use — and how often you think you'll

use them. Then look at your plan details to see how much your plan will cover and how much you'll need to pay. This can help you plan your costs for the upcoming year.

What insurance benefits can be useful for me?

Some insurance plans have benefits that are helpful for people with lupus. See if your plan offers:

- **Case management.** Employees from your insurance company can help coordinate your care with in-network providers.
- **Nurse lines.** You can call or use an online chat feature to speak to a nurse. Some nurse lines are open during specific hours, but others are open all the time. The nurses can answer basic health questions and address concerns you may have — like about medicines you're taking or any symptoms.
- **Telemedicine.** Sometimes known as telehealth, this service lets you access health care from home or another location that's convenient for you — using a phone or computer. This way you don't

have to travel to a doctor's office if you're not feeling well or don't have transportation.

- **Durable medical equipment (DME) coverage.**

Some plans cover medically necessary DME — like mobility aids (walkers and canes) or respiratory equipment that helps you breathe. If your doctor prescribes DME for you, check if your insurance covers it.

- **Home health care.** Home health staff can bring health care services right to you at home. For example, they can check what you're eating and drinking or check your blood pressure, heart rate, and breathing.



People with Medicare can get coverage for medicines through Medicare Part D, which has different plans you can choose from. Learn more at [Medicare.gov/drug-coverage-part-d](https://www.medicare.gov/drug-coverage-part-d).

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HOW TO ADVOCATE FOR YOURSELF

Health care costs can be high, even with insurance — and sometimes your plan may deny coverage for a certain service. But insurance companies can make mistakes. If you advocate for yourself with your insurance company, they may be willing to work with you to bring your costs down or make it easier to pay.

What if I'm not comfortable advocating for myself?

You have rights as a patient, like the right to ask your insurance company to explain costs or the right to get certain services. Take some time to know your rights — so you'll feel more confident about talking to your insurance company, your doctor, or any other people involved in your health care.

And keep in mind that you don't have to do it alone! When you need to advocate for yourself, ask for help from family and friends. Or find a patient advocate. Many hospitals have patient advocates who can help you understand your medical bills. They can also sit in on medical appointments to help you take notes and speak up for you when you're talking to a doctor. Get tips for finding a patient advocate by visiting [CMS.gov/medical-bill-rights/help/guides/patient-advocate](https://www.cms.gov/medical-bill-rights/help/guides/patient-advocate).

You can also see what support options you have through your state's Consumer Assistance Program. These programs can help people work through health insurance problems. Connect with your state's Consumer Assistance Program at [CMS.gov/CCIIO/Resources/Consumer-Assistance-Grants](https://www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants).



What are my rights?

If you find yourself unexpectedly needing emergency care or non-emergency care while visiting an in-network hospital, you're protected from surprise medical bills. The No Surprises Act is a law that protects people from unexpected medical bills. Thanks to this act, you have the right to request an estimate of your costs at the time of your visit — and you won't get any unexpected bills later.

There are also many health insurance rights and protections to make your insurance fairer and easier to understand. For example, most Health Insurance Marketplace plans have to provide free, preventive care and cover people with pre-existing conditions, like lupus, without charging you more. Learn more about your rights by going to [Healthcare.gov/health-care-law-protections/](https://www.healthcare.gov/health-care-law-protections/).

Make sure to always check your medical bills for accuracy — and ask your doctor to clarify any codes on your bill. If your insurance denies coverage for



a health care service you need, you always have the right to **file an appeal** asking them to cover it. Remember that your insurance must tell you why they denied you coverage and how you can reverse their decision.

How do I file an appeal?

To file an appeal, you'll need 2 main pieces of information from your insurance company: **the reason why they denied your claim and the company's process for appeals**. Call your insurance company and ask them for this information — they're required to give it to you. Keep in mind that each insurance plan or company handles appeals a little differently, so it's important to make sure you know what steps to follow and what forms or other information you need to send.

If your insurance denies your claim, be sure to file your appeal as soon as you can. For most insurance plans, you must do this within 6 months after your

claim was denied. But every plan is different, so it's important to check how long you have to file an appeal. You can find this information by reading your plan details or calling your insurance company.

Many appeals go through 2 stages:

- **First, you file an internal appeal.** In this stage, you fill out your insurance plan's forms and explain why you believe their decision was wrong. If your issue is urgent, they have to review your appeal quickly. And your insurance must provide their decision to approve or deny your appeal in writing.
- **If your insurance company denies your appeal, you can file for an external review.** An independent, third-party organization handles this process. They get the final say over your appeal decision, not your insurance company. The exact process you have to go through is different for each state.



If your insurance denies coverage for a health care service you need, you always have the right to file an appeal asking them to cover it. Remember that your insurance must tell you why they denied you coverage and how you can reverse their decision.

If your appeal is urgent, you may be able to file for both an internal appeal and an external review at the same time. Learn more about appeals — and your state’s external review process — by visiting [Healthcare.gov/appeal-insurance-company-decision/](https://www.healthcare.gov/appeal-insurance-company-decision/).

Whenever you call your insurance company about an appeal, be ready to advocate for yourself — stay focused on your goal for the call and make sure you get what you need. Most companies use an automated system, so listen carefully to the instructions and follow the prompts until you can speak to a representative. Once you get connected, remember to:

- **Be polite but firm.** Many insurance companies are looking to reduce costs on their end. Treating the representative you’re talking to with respect

and kindness can go a long way — but don’t let them talk you out of an appeal right away. If it seems like it’s hard to get information, keep asking questions. You can also ask to talk to a supervisor or call at a different time so you can speak to someone else.

- **Write down specific information.** Ask the representative to give you a definite reason for denying your coverage and clear, specific steps on how to start your appeal process. You can also ask for their name, contact information, and any reference information you need to easily follow up.
- **Get key information in writing.** Make sure the representative sends you next steps, summaries, and decision points in writing — through mail or email. This helps hold your insurance company accountable for what you talked about.

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OTHER WAYS TO PAY FOR HEALTH CARE

Health insurance is one of the best ways to pay for health care. But even if you have insurance, it may not pay for every service you need or cover the whole cost. The good news is that you have options that can help, no matter what your insurance status is.

How can I save on my medicines?

To lower the costs of your medicines, you can try:

- **Prescription assistance programs.**

Pharmaceutical companies that make medicines sometimes have programs that offer free or discounted prescriptions. Some companies call these patient assistance programs. Find out who makes your medicines and call or look online to see what they offer.

- **National and local organizations.** Many nonprofits, hospital systems, and other organizations have programs to connect patients with medicines and other health care services for free or at lower cost. Ask your health care team to share information about any programs they're familiar with. Or search online for "medication assistance program."

- **Discount pharmacies.** Some large retail stores with pharmacies carry generic versions of medicines — these are cheaper than name-brand medicines but work exactly the same way. Ask your doctor if you can switch to a generic version. You can also search online for "drug discount websites" to find the pharmacies near you that offer your medicines at the lowest cost.



- **Samples.** Ask your doctor if they have any samples of the medicines you need. Many pharmaceutical companies give doctors free samples to share with their patients — and you may be able to save on a few days' worth of medicine. But make sure you tell your pharmacist if you end up taking a new medicine. They can make sure it won't have any harmful interactions with other medicines you take.

How can I save on health care services?

Some nonprofit and charity organizations have their own health clinics. They may also organize health fairs in local communities. Health fairs can bring health care professionals to your community to provide routine preventive services like vaccines at low or no cost.



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Community health clinics provide high-quality health care — especially for people who don't have insurance or have limited insurance. They usually offer different ways to pay for services, like sliding fees (where the amount you pay depends on your income) and payment plans (where you pay over time instead of all at once).

Even if you have health insurance, you may be able to lower your costs by getting some services from a community health organization or clinic. To help find one in your area, try:

- Searching for Health Resources and Services Administration (HRSA) Health Centers at [Findahealthcenter.hrsa.gov](https://findahealthcenter.hrsa.gov).
- Talking to your state or local health department (find your health department at [CDC.gov/publichealthgateway/healthdirectories/index.html](https://www.cdc.gov/publichealthgateway/healthdirectories/index.html))

Are there government programs that can help me?

States offer health care assistance through Medicaid, and the federal government offers assistance through the Health Insurance Marketplace and Medicare. Learn more about these options in the Health Insurance Basics section on page 5.

Many states have medication or pharmaceutical assistance programs to help people get low-cost or free medicines. Often, you can get access to these



programs at rural or community health clinics — or you may be able to apply yourself. The requirements for these programs and the medicines they cover differ from state to state. Look online or contact your state or local health department to see if your state has a program and learn if you could qualify.

Where can I find more resources?

To explore more resources on paying for health care, go to [Lupus.org](https://www.lupus.org). There, you can find our:

- Financial assistance resources directory
- Expert Series podcast, including an episode on financing medical care
- Guide to reducing health care costs
- Information on prescription assistance programs



The Expert Series is a podcast where you can learn about lupus, including episodes on financing your medical care, access to care, medication management, and more. It's available on [Lupus.org](https://www.lupus.org).

Learn more about government programs in the Health Insurance Basics section on page 5.

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