



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