TOP 10 ACTION ITEMS FOR COLLEGE-BOUND TEENS WITH LUPUS

If you’re heading to college away from home, there are a few things you’ll need to prepare for beyond choosing your classes and moving into your dorm. Living away from home for the first time means more responsibility — especially when it comes to your health. Add these 10 action items to your “Must Do” list to make sure your first year is the best it can be.

1. **Understand your health insurance.**

For people with lupus, having insurance is very important. But health insurance can be confusing. Many students heading to college are covered under their parents’ insurance, but that may not be true for you. You need to understand your insurance options, how your insurance works, and how to get the care you need.

**STEPS TO TAKE**

**Understand your health insurance.**

You need to know the basics of your health insurance.

- Is your insurance through your parent’s employer, the state insurance exchange, or Medicaid?
- Does your school offer health insurance? If you’re uninsured or are otherwise considering buying the school’s insurance, make sure you understand it before you buy it.
- What’s the name of the insurance company that handles your health insurance plan? If you have a health insurance card, this information will be on the card.
- How do you find doctors in the plan’s network?
- Will you need a doctor’s referral to see a specialist?

**Understand what you’ll have to pay out of pocket.**

What will you have to pay out of your own pocket for your insurance and medical care?

- **Premiums:** The premium is the amount that must be paid every month for your health insurance plan. Will you have to pay the premiums for your insurance? If you’re covered under your parent’s insurance, that parent pays the premium.
- **Copayments or coinsurance:** These are the amounts you pay for each service you receive. If the amount you pay is a set dollar figure, say $20, it is called a copayment or copay. If the amount is a percentage of the cost of the service, say 20%, it is called coinsurance.
- **Deductible:** This is the amount you will have to pay before your health insurance starts paying for care.
- **Out-of-pocket maximum:** This is the amount you pay for covered services in a year before your insurance pays 100% for those services.
If your health insurance is through Medicaid, that coverage ends when you turn 19. You will need to buy your own insurance at that point. Start shopping around for insurance early — you’ll have to file paperwork, and the processing takes time.

2 Find a rheumatologist in the city or town where you’ll be living.

You’ll want to make sure you continue getting regular medical follow-ups, including lab work and physical exams. Once you’ve found a rheumatologist in the area, you’ll be able to start scheduling your own doctor appointments, managing your prescriptions and refills, and deciding when to go to the school clinic for treatment. Taking over your health care also means dealing with health insurance and paperwork.

☑️ STEPS TO TAKE

Ask for recommendations for a rheumatologist who has experience with lupus.
Ask your current rheumatologist to help you find a rheumatologist where you’ll be living who can monitor your health. Make sure the doctor takes your health insurance — call the office to make certain.

Schedule your first appointment.
Call the new rheumatologist’s office at least three months in advance to schedule your first appointment. Tell the office scheduler that it’s an introductory appointment so they give the doctor more time with you.

Forward your medical history.
Ask your current rheumatologist to send your medical records and a medical summary to the new rheumatologist. Ask for a second copy to be sent to you, and a third copy to the college health center.

Confirm your records have arrived.
Call the new doctor’s office a few weeks before your appointment to make sure the paperwork has arrived.

Keep in touch with your home doctor.
Ask your current rheumatologist if they would like to see you when you’re at home during school holidays and breaks.

3 Arrange a way to get your prescribed medications.

Your medications help to control lupus symptoms. It’s never a good idea to stop — or start — taking any medications without prior planning. Don’t change your medications without talking to your doctor.

☑️ STEPS TO TAKE

Find out whether there’s a pharmacy in the student health center.
Check to see if the student health center has a pharmacy that can fill your prescriptions. If so, ask your current pharmacy to transfer your prescriptions there. Your current rheumatologist can also transfer your prescriptions.
Find out which local pharmacies deliver to campus.
Some pharmacies may have a delivery service that will meet you at a pre-arranged location on campus.

Look into switching to a mail order pharmacy.
There are prescription mail order services that will deliver to your campus mailbox. Make sure you arrange for a text or phone message to alert you when the package is on the way and its expected arrival date. Filling your regular prescriptions by mail order may cost less, and it will usually allow you to fill a prescription for 90 days instead of refilling it monthly.

Set reminders so you don’t miss a refill.
Set an alert on your smartphone or other device to remind you when it’s time for refills. You can also set up a reminder with most pharmacies.

Update your emergency contact information card.

You’ll want the people taking care of you to know that you have lupus, which medications you’re taking, the name of your insurance company, and your emergency contacts. There may also be health information that emergency responders should know.

☑️ STEPS TO TAKE

Carry an emergency contact wallet card.
If you don’t have an emergency contact card in your wallet or on your smartphone, use a free service online to create one. When it’s completed, scan it and add it to your smartphone. Print out a copy for your wallet, too.

Make sure the right people have your emergency info.
Make sure your parents, the resident adviser (RA) at your dorm, and your rheumatologist have copies of the card. It’s also a good idea to have this card on file at the student health center.

Complete an authorization form that allows your medical information to be released to your designated personal representatives.

Federal law states that when you turn 18, no one can look at your medical information without your permission. An “Authorization to Release Medical Information” form allows you to list which individuals can see your medical records, lab test results, and other medical information.

☑️ STEPS TO TAKE

Ask your rheumatologist for a form to authorize release of your medical information.
Complete the form (don’t forget to sign and date it), scan it, and add it to your smartphone.

Take a signed copy to each doctor’s office, and give a signed copy to others you designate.
Give copies to everyone who you’ve listed on the form — for example, your parents and your RA. It’s also a good idea to have this form on file at the campus health center.
People with lupus are more likely to have heart, lung, kidney, brain, and blood complications. Infections are more common, too. When you know the warning signs of these complications, you can alert your rheumatologist and any other health care providers.

**STEPS TO TAKE**

**Be aware.**
Ask your rheumatologist for the most important warning signs of lupus-related health problems, as well as what you should do if you suspect a problem.

**Keep a symptoms diary.**
Keep a record of your health. A daily or weekly "self check-up" will help you catch any issues before they turn into problems. You can set a reminder on your phone so you don’t forget.

**Know your medication side effects.**
Know the most common side effects of your medications — especially anything new — so you can tell the difference between a side effect and any new symptoms related to your lupus. Tell your doctor about side effects and symptoms.

Lupus is an unpredictable disease — sometimes you may feel fine, and other times, your symptoms might suddenly worsen, or flare. The sooner you recognize the signs of a flare, the sooner you’ll be able to get help and prevent damage to your organs.

**STEPS TO TAKE**

**Learn your triggers.**
Think about the last time you had a flare. What was going on in your life when it happened? Can you think of an event or activity that might have caused it?

**Avoid common triggers.**
Lupus flares can be triggered by different kinds of stress, including not getting enough sleep, not eating well, feeling overwhelmed, too much sun exposure, smoking, and abusing alcohol or drugs.

**Stay on your meds.**
Sometimes people stop taking their medications because they’re feeling better, or because they hate the side effects. But stopping those medications can cause your lupus to flare. If you have questions about a medication, make sure you ask your doctor.

**Consider your triggers when making plans.**
Keep your flare triggers in mind as you plan activities. This will help you avoid missing class or other commitments, or having to take stronger medication.
Ask for help.
If you’re having trouble avoiding your lupus flare triggers, ask your rheumatologist for advice.

Register with the student accessibility office on campus.

Besides causing physical complications, lupus can also affect how your brain functions. Sometimes it can cause difficulty processing information, concentrating, or remembering. Whatever kind of help you need, the best place to start is the student accessibility office.

**STEPS TO TAKE**

Reach out.
Find out if there’s time for you to stop by this office during your orientation. That way, you won’t have to scramble to register if you have a need during the semester.

Explain any limitations you experience.
Be prepared to discuss the ways that lupus affects or could affect your ability to accomplish your coursework or get to your classes. Examples might be a building with stairs that are hard for you to climb, or you might need extra time for assignments because it can take you longer to put your thoughts into words.

Keep staff updated.
If your contact information or class schedule changes, let the accessibility office know.

Think about ways to make your schedule manageable.

College life is often hectic, especially if you’re juggling a job, extracurricular commitments, and social activities along with all your classes. But overextending yourself is the surest way to bring on a lupus flare.

**STEPS TO TAKE**

Work out a course load you can handle.
Make an appointment to talk to your academic adviser about a class load that will allow you to have downtime while still fulfilling graduation requirements.

Schedule classes around your energy level.
Whenever possible, take your hardest classes at the time of day when you usually feel your best. Ask classmates to share notes with you in case you’re absent.

Build in downtime.
Look at your daily routine, and try to make sure you’ve included time to rest each day.

Lupus doesn’t mean you can’t be social!
Movie nights with friends, dating, attending sports events, and other social activities can help you balance class work and fun.
Take care of your body.
Think about the best way you can consistently eat healthy foods, and look for ways to fit in daily exercise. Above all, make it a priority to get enough sleep every night.

Know who to talk to if you need emotional support.

Your first year of college can be one of the best times of your life, but it may also be one of the most challenging times. It’s easy to get overwhelmed, especially if your lupus flares and you can’t work as hard as you’d like to. If you start feeling frustrated or depressed and the feelings don’t go away, ask for help.

Steps to take

Pick the right people.
Whether you need moral support or just want to vent, think about people you can turn to. Your support network may include your parents and other relatives, friends, a mentor, and your health care providers. You can also talk to your college adviser, professors, and staff at the accessibility office. Every staff member at your college is there for one purpose — to help you succeed. They expect students to need help and reach out, and they will typically do everything they can to provide support.

Stay connected.
Keep in touch with your family and friends through social media, texts, and emails. Let them know you’re thinking of them and you’re glad they’re part of your support network. Or, you can try LupusConnect™, a new online community for individuals with lupus and their loved ones. Join at LupusConnect.inspire.com.

Learn where to look for professional counseling.
If you’d prefer to talk to a therapist, ask who would be available at the campus health center. You can also search for a mental health professional who’s in your health insurance network. Most insurance will pay a portion of the cost of counseling sessions.

We’re here to help.
The Lupus Foundation of America has trained health educators who are available to answer questions and provide support. Call 1.888.558.0121 or visit Lupus.org/healtheducator to speak to a health educator in English or Spanish. There also may be a lupus support group near you. To learn more about how you can participate in events, programs, and support opportunities, visit Resources.Lupus.org/local-support.
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- Find a rheumatologist in the city or town where you’ll be living.
- Arrange a way to get your medications.
- Update your emergency contact information card.
- Complete the “Authorization to Release Medical Information” form.
- Know the early warning signs of infection, blood clots, heart or kidney disease, and other lupus-related complications.
- Be alert to the triggers that can lead to a lupus flare.
- Register with the student accessibility office on campus.
- Make your schedule manageable.
- Know who to talk to if you need emotional support.