SCHOOL SURVIVAL GUIDE FOR TEENS WITH LUPUS
Lupus can be a lot to deal with on top of the demands of middle and high school. But there’s a lot you can do to take charge of your health and manage your symptoms at school.

USE THESE TIPS TO HELP YOU KEEP YOUR SCHOOL DAYS FUN, PRODUCTIVE, AND HEALTHY!
It’s a good idea to have a plan for managing your lupus symptoms at school. To do well in the classroom while keeping your lupus in check, make sure you:

- Keep a health care kit at school with a hat, sunscreen, your medicines (in case you forgot to take them), a water bottle, your insurance card, and your doctor’s contact information.
- Don’t overload your schedule — try to leave time for rest and relaxation.
- Have a quiet place at school to lie down and recharge. Ask a teacher or the school nurse for suggestions.

After I was diagnosed, I started using lotion with SPF 30 because the sun has been shown to make lupus worse.

—CAROLINE DALL, AGE 17
STAY ON TOP OF YOUR MEDS

Having lupus means taking your medications on a regular schedule. It’s especially important if you’re feeling well — that means the medicines are working! If you skip doses, your lupus symptoms will get worse. New symptoms could start, too.

Keep pills organized in a container with separate compartments for each day of the week. Take them at the same time each day — you’ll find it’s much easier to remember to take them once they’re part of your daily routine. And if you have to take any meds during the school day, have your parents set up a plan with the school nurse.

— LYDIA SUNDBERG, AGE 14

“Have a routine every day, such as taking your meds in the morning before you start checking Instagram, or before you plug in your phone at night. This will make you less likely to forget, and make you feel better and have more energy at school.” — LYDIA SUNDBERG, AGE 14
You don’t need to be embarrassed about having lupus. And if you feel ill, you’ll need to get help. Lupus can flare without warning, and ignoring symptoms can be dangerous. Plus, medicine side effects may need medical attention. Listen to what your body’s telling you, and if you’re feeling like something isn’t right or has changed, speak up.

Don’t ignore your mental and emotional health, either. Mental health is just as important as physical health! If you find yourself crying often, feeling hopeless or helpless, or losing interest in school and hobbies, talk to someone you trust. You’ll find that when you have a few people at school you can talk to about what’s going on, it relieves some of the pressure. And your parents and doctors need to know about anything that’s bothering you too.
Stress is a normal part of life. But stress can trigger lupus flares, so you’ll want to know how to manage your reactions to stressful situations at school.

You hold the key to keeping stress in check. Start by anticipating what might cause stress, then think about how to get control of those situations. For example, if you’re worried about finishing a project on time when you’ve been sick, take charge of your situation by asking your teacher for more time. If you need notes from a class you missed, ask a classmate. Another way to lower stress is to stay organized — use your phone to remind you about assignment deadlines, medical appointments, and when to take medications.
Always have a 504/medical plan in place. If you don’t know how to get one, ask a counselor or the principal at your school. This helps if you miss a few days and need to turn in work late.

—MADDIE (MADISEN) STREICH, AGE 16

Finding what you need and how to ask for it is called self-advocacy. Because lupus is a complex disease, there’s likely something you’d like to change at school that could help you. Maybe your classes are so far apart that you arrive late. Or maybe your assigned seat is in the full sun.

You can talk with your doctor and your parents about what kinds of adjustments or assistance at school might help. Your parents may decide to request that a plan be put in place at your school that tells teachers and other staff how to support you. For example, if you need to take medication during the day, the school nurse can write up an Individualized Health Care Plan. Or if you need changes to the classroom setup or a different kind of instruction, your parents can work with the school to develop a 504 plan or an Individualized Education Plan (IEP).
Having lupus can sometimes make you feel isolated and alone — especially if you miss a lot of school and social events because you’re out sick. Look for ways to stay connected with your classmates and school community.

- Lots of schools have Facebook pages or other social media groups you can join, as well as live-streamed events.
- Schools may also offer courses via YouTube.
- Don’t forget social media tools for video conferencing!

Staying connected using your favorite social media can help keep you engaged and informed about what’s going on at school while you’re away.

— SITARA LEWIS, AGE 18
Homework. Exams. Sports and music practice. Screen time. Hanging out with friends. Who has time to sleep? When you get busy, you might be tempted to sleep less. But lupus makes a lot of demands on your body, and sleep is critical if you want to avoid flares.

A good night’s sleep will also help you have the energy to excel in school, spend time with friends, and do activities you enjoy. Be honest with other people, though. If you don’t feel like going out, tell your friends the truth, and offer to have them over when you’re feeling better.

Bottom line: No matter how packed your schedule gets, keep sleep at the top of your to-do list.
LEARN TO JUGGLE PRIORITIES

Having lupus is all about learning to balance activities with rest – learning when to say, “No, not today” and “Yes, I’m on it.” The key is to organize your commitments. Find the most organized person you know and ask for tips. Keep your daily schedule on your phone or in a datebook, and make sure taking your medicines is part of your daily routine. Schedule 9 or more hours of sleep every night. Get ahead in classwork, so if you feel sick, you’re ahead of the game.

There’ll be times when you really want to go on that school trip or out with friends. But if you’re stressed or dealing with more intense lupus symptoms than usual, you’re better off staying home. Your teachers and friends will understand that you need to protect your health most of all.

“Don’t over-exert yourself every day — you could crash and burn and not be able to do stuff you need to do.”
— MADDIE (MADISEN) STREICH, AGE 16
Having lupus is bound to cause some changes for you. For example, the disease and medicine side effects can affect your mood, your memory, and your ability to think clearly. If you find that schoolwork seems harder, or that your concentration isn’t very good, talk to your parents. They can contact the school about providing adjustments or assistance that can help you learn.

You may also experience changes in your appearance due to lupus or medicine side effects. Some will be temporary, some may leave scars. But no matter what happens, remember: You have lupus, but lupus doesn’t define you.

“Lupus isn’t your life. Yeah it’s a portion and maybe even a big portion of it, but it’s not who YOU are. Just always remember that you are strong and you just keep doing you!”

— MADDIE (MADISEN) STREICH, AGE 16
Never give up your dreams and goals because of lupus — just figure out how to reach them a different way. For example, if fatigue and joint pain make it hard to play your favorite sport, switch to a different sport or take on another role for a while. Why is that important? Because staying active can improve many symptoms of lupus. Keeping up with your favorite hobbies is also a good idea.

Not only will your skills boost your self-esteem, but you’ll also have something you love to take your mind off of lupus. And sometimes, dreams become careers. So dream big!