

students with systemic lupus erythematosus

What is lupus?

Systemic Lupus Erythematosus (SLE), or lupus, is the most common and serious form of lupus. It is a chronic autoimmune disease, meaning the body's immune system mistakenly attacks its own tissues instead of fighting infections. This causes inflammation, which leads to swelling, pain, and damage throughout the body.

When lupus becomes more active, it's called a flare or relapse. During remission, students may return to near-normal functioning. Lupus affects each person differently, and symptoms vary depending on which body systems are involved. Severe cases can affect the kidneys, heart, lungs, nervous system, and blood cells.

Treatment

Treatment depends on how severe the disease is. Medications help control inflammation and prevent damage, but they may cause side effects. Managing lupus often requires ongoing medical care and adjustments to treatment.

How can lupus affect a student at school?

Lupus symptoms vary widely and are often not visible to others. The disease can range from manageable to life-threatening and tends to follow a cycle of flares and remission. Both lupus and its treatments can affect a student's ability to learn and participate in school. Children with lupus may struggle in the following areas:

- **Academic:** cognitive challenges, memory issues, trouble concentrating
- **Social/Emotional:** anxiety, depression, fear without a known cause
- **Physical:** facial rash, scaly rash on the body, sensitivity to sunlight, sores in the mouth, nose, or throat, hair loss, joint pain, extreme fatigue or weakness, migraine headaches, seizures, fine and gross motor difficulties, kidney disease or failure, anemia, chest pain or shortness of breath, Raynaud's phenomenon

How can schools support students with lupus?

Academic

- Start academic interventions under **Section 504** or **IDEA** (Other Health Impairment).
- Conduct **evaluations** for speech, OT/PT, vision/hearing, assistive technology, as needed.
- Offer **homebound** or **intermittent homebound** instruction for extended absences.
- Do not penalize **handwriting difficulties**; offer handwriting practice if needed.
- Allow **oral testing** or alternative response formats for lengthy writing tasks.
- Provide **assistive technology** (computer, tablet, word processor) for note-taking and writing.
- Provide **printed copies of notes**, highlighted materials, and recorded lessons.

- Use **visual aids** and memory supports like planners and checklists.
- Use **multi-sensory teaching methods** (visual, auditory, tactile) and repetition.

Social and Emotional

- Provide **counseling or emotional** support as needed.
- Provide **staff training** and share relevant information about the condition.
- Ensure the student has access to a trusted adult for support.

Physical

- Allow students to **set their own limits** for physical activity.
- Modify or excuse from **strenuous physical activities** or **contact sports**.
- Offer **adaptive PE** or alternatives (e.g., swimming).
- Allow **elevator access** if stairs pose a safety risk.
- Give **extra time** between classes without penalty.
- Assign **lockers near classrooms** or on each floor.
- Provide **two sets of textbooks** (one for home, one for school).
- Offer **rest breaks** during the day to manage fatigue.
- Ensure **access to the nurse's office** when needed.
- Allow **movement** during class to reduce stiffness (e.g., handing out papers, walking briefly).
- Seat student **away from windows and direct sunlight**.
- Remind student to **apply sunscreen** before going outside.
- Modify **transportation** for door-to-door pickup or assign a **parking space near the entrance**.
- Accept **notes from caregivers** about the student's morning condition and adjust activities accordingly.
- Follow **dietary restrictions** (e.g., no added salt, sugar-free beverages).

More Resources

- **Nemours Kids Health**
kidshealth.org
- **Lupus Foundation of America**
lupus.org

SCHOOL SERVICES

For more information, visit childrens.com/school-services