

School Guide for Students with Lupus

What is systematic lupus erythematosus (SLE), or lues?

SLE is the most common and most serious type of lupus. It is a chronic autoimmune disease, which means that the body's natural defense system (immune system) attacks its own tissues instead of attacking bacteria or viruses. This causes inflammation, resulting in swelling, pain, and tissue damage throughout the body. If the lupus becomes severe, problems with the kidneys, heart, lungs, nervous system, or blood cells. When the disease is more active or intense, it is called a flare or relapse. When lupus is in remission, the student may return to a virtually normal state of functioning. The exact cause of lupus is not known. Lupus is different for each individually who has it. The signs and symptoms experienced will depend on which body systems are affected by the disease.

Treatment Received:

The treatment for lupus is dependent on the severity of the disease. Some of the drugs have unwanted side effects, but are important in controlling the damage lupus often causes.

How can Lupus affect School Performance?

The symptoms of lupus vary widely with each individual and are often not visible to others. The effects of lupus are from manageable to life-threatening, and its course is sporadic. There are periods of wellness and flare. Lupus, as well as, side effects of the medications are characterized by the following:

- Facial rash on the cheeks and across the bridge of the nose
- Raised scaly rash on body
- Sun or light sensitivity
- Sores in the mouth, nose, or throat
- Hair loss (alopecia)
- Painful and swollen joints (arthritis)
- Extreme fatigue /weakness
- Migraine headaches
- Central Nervous System Issues (seizures, memory and concentration problems)
- Fever (of unknown origin)
- Fine motor impairment
- Gross motor limitations
- Kidney disease or failure
- Cognitive impairment
- Anxiety/depression
- Anemia
- Chest pain / shortness of breath
- White or blue fingers and toes due to cold or stress (Raynaud's phenomenon)

How can schools assist students with Lupus?

Academic:

- Start academic interventions right away under IDEA for Other Health Impairment or Section 504
- IEP should include PT/OT services
- Set up Homebound or Intermittent Homebound when the student will be out on several consecutive days
- Oral test during a “timed test” situation
- No grades or demerits for handwriting
- Use of computer or laptop for homework, essays, quizzes, and notes
- Provide a hard copy of notes prior to class or a tape recorder for note taking during class
- Provide memory aides (such as organizers or detailed schedule for assignments)
- Use teaching modules (such as repetition, visual aids, etc.)

Social/ Emotional

- Have a staff in-service for any staff involved with the student
- Provide counseling to address social and emotional distress
- Select a support person for any of the students concerns that may arise
- Frequent communication among student, school nurse, and medical team to monitor student’s needs

Physical

- Activities to tolerance, allow child to set own limits
- No contact sports (no activities that could stress joints or cause fatigue)
- If available, replace PE with swimming (in the presence of a responsible adult)
- Adaptive PE
- Use of elevators
- Extra time between classes (leave early or arrive late with no demerit)
- Provision of locker on each floor or in areas near assigned classroom
- Two sets of books (one at home and one distributed to appropriate lockers)
- Rest breaks to alleviate extreme fatigue
- Access to the nurse when needed
- Allow student to move during class period to reduce stiffness (handout or pick up papers, walk in the back of the room, etc.)
- Classroom seating away from windows and out of direct sunlight
- Application of sunscreen to all exposed body surfaces before going outside
- Modify school bus pick up for door to door transportation; or parking place close to school entrance
- PT and OT evaluations to plan for school accessibility and adaptation needs each semester and as needed
- Please accept a note from adult caregiver regarding the students status from the morning (increased pain or fatigue, and modify the students activities accordingly)
- Dietary restrictions (no added salt, and only sugar-free beverages)

Resources

www.mayoclinic.com

www.lupus.org

www.kidshealth.org

*Rheumatology Department at
Children's Medical Center Dallas*

School Services Department

Children's Health

Children's Medical Center

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