Students with Lupus: Guidance for School Healthcare Professionals

Signs, Symptoms, & Possible Recommended Treatments

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American College of Rheumatology
Empowering Rheumatology Professionals

the lupus initiative
Eliminating Health Disparities in Lupus

https://thelupusinitiative.org

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The following guidelines outline management of signs and symptoms of Childhood-onset Systemic Lupus Erythematosus (cSLE) in the school setting.

Request that the student and caregiver provide an updated, individualized care plan from the student's pediatric rheumatologist, and pediatrician, at the beginning of each school year.

Mild to Moderate Symptoms of Lupus

Notify the caregiver if the student experiences mild to moderate symptoms.

If the student presents frequently to the health office, inform the caregiver and recommend follow-up with the pediatrician, and pediatric rheumatologist.

Joint Pain/Joint Swelling

1. Allow the student to rest for approximately 30 minutes.
2. Apply heat or cold therapy based on student preference and care plan guidance.
3. Administer prescribed analgesic medication per healthcare professional orders (see Medical Authorization Form).
4. Resume activities as tolerated.
5. Provide accommodations as needed, including extra time between classes, elevator access, flexibility with handwriting requirements, and use of assistive technology (keyboard, dictation, occupational therapy supports). Permit movement during class to reduce stiffness.

Rash

1. Ensure daily application of broad-spectrum sunscreen (SPF 50 or higher that blocks UVA and UVB) with reapplication before outdoor activities.
2. Permit use of a wide-brimmed hat or cap during outdoor activities.
3. Seat student away from direct sunlight or window exposure when possible.

High Blood Pressure

1. Measure blood pressure if the student reports headache, dizziness, or palpitations.
2. If blood pressure exceeds parameters specified in the care plan, allow the student to rest for 30 minutes and recheck.
3. Confirm timing of last anti-hypertensive medication dose, if applicable.
4. If blood pressure remains elevated, contact the parent/guardian and/or healthcare provider for further instructions.

https://www.nhlbi.nih.gov/files/docs/guidelines/child_tbl.pdf

Headaches

1. Allow the student to rest for approximately 30 minutes.
2. Encourage hydration (e.g., one full glass of water).
3. Administer prescribed analgesic medication if symptoms persist and per healthcare professional orders.
4. If headache persists despite rest, hydration, and medication, advise the caregiver to contact the student's pediatrician, and rheumatologist.

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Mild to Moderate Symptoms of Lupus continued...

Fever

Contact the caregiver for pickup if temperature exceeds 100.5°F (38°C) and recommend medical evaluation.

Fatigue

1. Allow the student to rest for approximately 30 minutes.
2. Upon return to activity, provide modifications as needed (e.g., walking instead of running).

Color Change to Fingers/Toes (Raynaud's)

1. If color changes occur, initiate prompt warming of affected digits.
2. Use warming techniques such as warm (not hot) water, warm packs, gloves, or placing hands in pockets.

Mild Mental Changes

1. Decreased concentration, cognitive slowing, or fatigue may occur due to active disease or medication side effects.
2. Monitor and report concerns to the caregiver.

Additional Symptoms

Follow the individualized care plan for any additional symptoms identified by the healthcare professional student, or caregiver

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Severe Symptoms of cSLE

For all severe symptoms, follow emergency protocols as indicated, and notify the caregiver and recommend they contact their pediatrics and rheumatology offices.

Chest Pain/ Difficulty Breathing

1. Allow the student to rest.
2. Assess vital signs: blood pressure, heart rate, respiratory rate, temperature, and oxygen saturation.
3. If symptoms persist, follow the emergency care plan, including activating EMS (911) as indicated.

Seizures

1. Activate emergency medical services (call 911)
2. Remain calm and document seizure onset time
3. Protect the student from injury. Support the head. Do not place objects in the mouth. Maintain airway patency and monitor breathing. Do not restrain movements.
4. If no suspected spinal injury, position student on their side (recovery position).
5. Remain with the student until fully alert and EMS arrives.

Note: Seizures are not common in students with cSLE. If the student experiences a seizure, it is a medical emergency. Contact 911/emergency medical services and the family.

Epilepsy Foundation - Seizure Action Plans.
https://www.epilepsy.com/preparedness-safety/actionplans

Confusion/ Memory Loss/ Disorientation

1. Notify the caregiver of the change in mental status.
2. Maintain student safety and supervision.
3. For new-onset altered mental status, activate EMS (911) for immediate medical evaluation.

Severe Headaches with Neck Stiffness and/or Fever

1. Assess vital signs: blood pressure, heart rate, respiratory rate, temperature, and oxygen saturation.
2. Administer acetaminophen per healthcare professional order.
3. Notify the caregiver.
4. New-onset severe headache with neck stiffness and/or fever requires immediate medical evaluation. Activate EMS (911).

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Severe Symptoms continued...

Concern for Stroke / Change in Mental Status

1. If stroke is suspected, use the F.A.S.T. acronym to recognize warning signs
   - Face. Does the face droop on one side when the person tries to smile?
   - Arms. Is one arm lower when the person tries to raise both arms?
   - Speech. Can the person repeat a simple sentence? Is speech slurred or hard to understand?
   - Time. During a stroke every minute counts.

   Other signs and symptoms of a stroke, which come on suddenly, include:
   - Weakness or numbness on one side of the body, including either leg,
   - Dimness, blurring or loss of vision, particularly in one eye,
   - Severe headache — a bolt out of the blue — with no apparent cause, or
   - Unexplained dizziness, unsteadiness or a sudden fall, especially if accompanied by any of the other signs or symptoms.

   American Stroke Association. https://www.stroke.org/en/about-stroke/stroke-symptoms
2. Activate EMS (911) immediately and ensure transport to the nearest emergency department.
3. Maintain safety and minimize movement to reduce fall risk.

Additional Symptoms

Follow the individualized care plan and contact the caregiver and healthcare professionals (rheumatologist and pediatrician) as appropriate.

SLE and its treatments may cause physical changes (e.g., alopecia, scarring, weight changes, cushingoid appearance, visible rashes, striae). These changes may contribute to psychosocial concerns, including depression, bullying, or social isolation. If concerns arise, discuss with the caregiver and notify the healthcare provider as appropriate.

For all severe symptoms, follow emergency protocols as indicated, and notify the caregiver and recommend they contact their pediatrics and rheumatology offices.

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