

Guidance to Caring for Students with Lupus



AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals



Lupus Care Plan

This student is being treated for Systemic Lupus Erythematosus.
Please visit: <https://thelupusinitiative.org/> for more information regarding the diagnosis.

Student Name

DOB

Parent/Guardian Name

Cell

Rheumatology Physician Name

Physician phone #

Emergency Contact Name

Cell

Lupus Care Plan

Below are instructions for treatment of signs and symptoms of Systemic Lupus Erythematosus.

We strongly recommend that you request your student with lupus and his/her parents provide you with a Customized Care Plan from his/her Pediatric Rheumatologist at the beginning of each school year.

Mild to Moderate Symptoms:

Contact the student's parent if experiencing mild to moderate symptoms.

If the student is presenting frequently to your office, please inform the student's parents and encourage the student's parents to contact the physician's office directly.



Joint Pain/ Joint Swelling

1. Allow the student to rest for 30 minutes.
2. May apply heat or ice per student preference.
3. If joint pain persists, administer acetaminophen (Tylenol) as ordered (see Medical Release Form)
4. Resume physical activities as tolerated.
5. In general, please allow extra time between classes and elevator use if available. No demerits for hand-writing. Where possible, encourage the use of technology, such as keyboard, dictation or other OT support. Allow student to move around in class to reduce stiffness.

Note: The use of NSAIDs vary from student to student. Please consult with parent and rheumatologist to allow any pain medication use other than Tylenol as needed.



Rash

Student should be applying daily sunscreen with reapplication prior to outside activities. Allow wide-brimmed hat/baseball cap when outside. Seat away from windows in classroom.



High Blood Pressure

1. Check blood pressure if student is experiencing headaches, light-headedness, or palpitations.
2. If BP is higher than that recommended by the pediatric rheumatologist in the Student's Care Plan, allow student to rest x 30 minutes, then recheck.
3. If BP is still elevated after 30 minutes, contact family and rheumatologist. If student is taking blood pressure medications, please ask when the last dose was taken.
4. If BP is ever significantly above the recommended BP, please call 911 to transport to nearest ER.

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



Headaches

1. Allow the student to rest about 30 minutes.
2. Have student drink a full glass of water.
3. If headache persists, may give Tylenol as ordered.
4. If headaches persist despite rest, hydration and Tylenol, encourage the family to contact their student's rheumatologist.

Lupus Care Plan

Mild to Moderate Symptoms continued...



Fever

Contact parent to pick up student for fever > 100.5 F and instruct parent to have student evaluated by a medical professional.



Fatigue

1. Allow the student to rest x 30 minutes.
2. When returning to activities, consider modifications (i.e. walking instead of running).



Color Change to Fingers/Toes (Raynaud's)

1. Utilize hand/foot warming techniques, such as placing under warm water, using gloves or placing hands in pockets.
2. If there is color change, it is important to warm fingers/toes promptly.



Mild Mental Changes

Decreased ability to concentrate or fatigue may be noted due to active disease or side effects of certain medications.



Other (to be filled out by physician)

Lupus Care Plan

Severe Symptoms:

Contact the parent AND rheumatologist for all severe symptoms



Chest Pain/ Difficulty Breathing

1. Allow the student to rest.
2. Check vital signs including blood pressure, heart rate, respiratory rate, temperature and pulse oximetry.
3. If chest pain and/or difficulty breathing persist, contact 911 if needed and/or family to pick student up and have him/her evaluated by a medical professional.



Seizures

1. Call 911.
2. Stay calm and track starting time of seizure.
3. Keep student safe. Protect head. Do not put anything in student's mouth. Keep airway open and watch breathing. Do not restrain the student.
4. May turn the student on his/her side if no suspected neck or spinal injury.
5. Stay with the student until fully conscious and medical professionals arrive.

Note: Seizures are not common in students with lupus. If the student experiences a seizure, it is a medical emergency and the student should be transported to the nearest ER via EMS.

Epilepsy Foundation (2008). Seizure Action Plan. www.epilepsy.com



Confusion/ Memory Loss/ Disorientation

1. Contact parent and inform of the student's change in mental status.
2. Keep the student safe.
3. Student should be immediately evaluated in the nearest ER and/or by a medical professional.



Severe Headaches with Neck Stiffness and/or Fever

1. Check vital signs including blood pressure, heart rate, respiratory rate, temperature and pulse oximetry.
2. Administer Tylenol if ordered (See Medical Release Form) and contact parent to pick up the student.
3. Student should be immediately evaluated in the nearest ER and/or by a medical professional.



Lupus Care Plan

Severe Symptoms continued...



Concern for Stroke / Change in Mental Status

1. In the event of a possible stroke, use F.A.S.T. to help remember 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.
2. Call 911 immediately if you observe any of these signs. Have the student transported to nearest ER.
3. Keep the student safe and discourage mobility to prevent a fall.

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.

Mayo Clinic (2018, October 28). Stroke. www.mayoclinic.org/diseases-conditions/stroke



Other (to be filled out by physician)

Physician Printed Name

Date

Physician Signature

Physician Telephone

Lupus and treatment for lupus may also lead to changes in appearance, such as: hair loss, scarring, weight loss or weight gain, visible rashes, stretch marks. Changes in appearance may lead to depression, bullying, isolation, and other psychosocial issues. If the student is experiencing any of these, please discuss directly with the parent. You may also contact the physician's office.