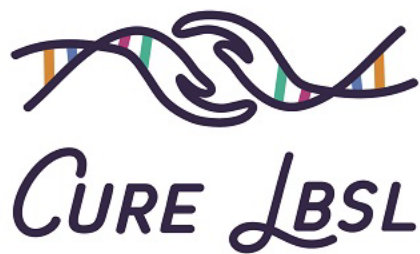


School Needs and Accommodations for Students with LBSL



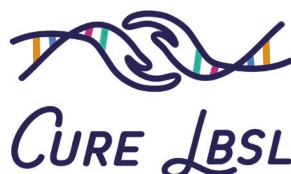
About this Document

Leukoencephalopathy with Brain Stem and Spinal Cord Involvement and Lactate Elevation (LBSL) is a complicated neurological and metabolic condition, requiring careful planning for the school-aged child or young adult. The goal of this document is to help families and educators create the best possible plans to help students with LBSL thrive in school.

While each individual is unique, many students with LBSL have similar needs at school. Cure LBSL has created a list of common needs and accommodations to assist school teams with planning and creating strong plans, including:

- Health and medical action plans
- Emergency action plans
- Building accessibility plans
- Transportation plans
- Special education plans (IEP/504)

For more information about LBSL, or to request hardcopies of this document or other patient advocacy resources, please visit www.curelbsl.org.



About LBSL

Leukoencephalopathy with Brain Stem and Spinal Cord Involvement and Lactate Elevation (LBSL) is an ultra-rare, progressive, genetic condition. LBSL is both a mitochondrial disorder (affecting energy to the cells), and a form of leukodystrophy (a disorder affecting the white matter of the brain, the spinal cord, and/or peripheral nerves).

Common concerns include:

- Mobility, coordination, & balance challenges
- Energy depletion
- Vulnerable to complications from dehydration, fasting, and overheating
- Serious harm from head injuries
- Higher risk of complications from infections

When setting up accommodations for students with LBSL, it is important to not only cover current needs, but anticipate needs that may arise due to the progressive and variable nature of the disorder. Factors such as illness, sleep disturbance/exhaustion, and/or environmental temperature can greatly influence the student's day to day ability to function at school. Think beyond "present levels of performance" to create the most inclusive and adaptive plans!

Mobility, Coordination, & Balance

In LBSL, the brain and spinal cord are affected to varying degrees, which can make walking and staying balanced a challenge. Fine motor and gross motor coordination may be difficult, and for some kids, there is a higher risk of falling.

Some kids with LBSL are able to walk on their own, although often slower and for shorter distances than their peers. Other kids use assistive devices such as orthotics, canes, walkers, or wheelchairs.

Schools can help by:

- reducing tripping hazards
- seating student at easily accessible seat / desk / table
- making the classroom easy to navigate
- limiting the need to travel long distances in the building
- allowing extra time for transitions
- collaborating with OT & PT specialists
- planning for emergencies (including evacuations)

Energy Depletion

In people with LBSL, the mitochondria aren't able to produce full power, so they are very prone to energy depletion.

Schools can help by:

- reducing non-essential or excessive demands on their energy reserves.
- helping the student find a safe and private place to rest as needed during the day.
- being flexible with workload and assignment deadlines.

Overheating, Dehydration, and Fasting

People with LBSL are often particularly sensitive to the heat. They also are also very vulnerable to complications if they don't have enough water or high-energy food.

Schools can help by:

- keeping students inside when it's too hot outside
- allowing students to keep a full water bottle with them at all times
- offering high-energy snacks at regular intervals and after periods of high exertion (families will provide snacks and instructions).

Head Injury Prevention

One of the most important things you can do is help students with LBSL prevent head injuries.

Schools can help by:

- Having student avoid activities that have a high risk of head injury like contact sports.
- Having student wear a protective helmet or be given extra space for movement during higher risk activities.
- Making sure to always report ANY head injury to the family and/or health clinic staff right away.
- Creating a strong health action plan to make sure everyone knows what to do in case of a head injury.

Infection Risk

People with LBSL are extra vulnerable to harm from fevers and infection. In addition to the health risks, students can quickly fall behind in school from repeated or extended absences.

Schools can help by reduce the infection risk by:

- Encouraging best practices like handwashing, mask-wearing, good ventilation, and disinfecting surfaces.
- Cohorting students into lower-risk groups.
- Reporting any signs of fever or illness.
- Telling families about any known or suspected exposures to people with infectious illnesses.

Plans to Consider for Students with LBSL

- Health Action Plans
 - General Medical
 - Medication
 - Mental Health
 - Infection Prevention
 - Head Injury
 - Seizure
 - Asthma
 - Allergy
- Emergency Plans
- Building Access Plan
- Transportation Plan
- Special Education Plans
 - 504
 - IEP
 - Related Services
 - OT/PT
 - Speech
 - Assistive Technology
 - Transition
 - Self-Advocacy
- General Academic Plans
 - Athletics / PE
 - Substitute Teacher
 - Assignments
 - Attendance
 - Field Trips

***Not all students will require all types of plans**

Planning Considerations

Health Action Plans

- What are the likely medical needs at school? Is there an action plan for all of them?
- Who is responsible for health services? Mental health care?
- How does the student access medications or other care?
- What forms need to be filled out? How often? Signed by who?

Emergency Plans

- Building evacuation – What is the route? Are there any obstacles?
- Fire alarms (unplanned) - Is there a designated evacuation area?
- Fire drills – Can the student get advance notice and/or a head start?
- Wheelchair evacuation – Is there a stair chair? Do staff members know its location and operating instructions?
- Bus evacuation / safety drills – Do they need to be modified? How often are they practiced?
- Aide or buddy system – Is there a staff member assigned to assist the student? Which student(s) have been identified? Have they been consulted (and permission given by their parents) for this role? Is there a backup plan?
- Lockdown/Shelter-in-place- Does the school have 72-hours worth of medications, supplies, and high-energy food? Are there other special needs to be considered (i.e. toileting needs)?

Planning Considerations

Building Access Plans

- Where are the accessible entrances/exits in the building? Are they always open and available?
- Does the student have access to an elevator? Do they need a key? Can they have a buddy to go with them?
- Is there always an unlocked bathroom available on each floor of the building (preferably near classroom)?
- What classroom modifications need to be addressed?

Transportation Plans

- What are the child's daily transportation needs?
 - School Bus / Van
 - Family vehicle
 - Public transportation
- Who is responsible for planning and coordinating field trip transportation?
- Does the family have access to accessible parking spots and entrances at school?
- Is there an assigned aide and/or buddy to help?
- Does the plan include wheelchair accessibility if needed? (may be used intermittently)
- What are the infection prevention plans for the bus or shared vehicle (i.e. distance from other students)
- Do the bus safety drills and evacuation plans have to be modified? Who will assist?

Planning Considerations

Athletics/PE Plan

- How can the curriculum be modified to avoid contact sports, running, etc.?
- Are there meaningful alternative activities?
- What plans are in place to avoid head injuries? (i.e. helmet)
- How can student access water and high energy snacks?
- What are the infection prevention practices? (i.e. no shared water bottles, disinfected equipment, etc.)

Substitute Teacher Plan

- Where is a written plan for substitute teachers located? Do the administrators have a copy?
- Is the substitute aware of needs and accommodations?
- Is there another staff member who is familiar with child's needs?
- Is there a plan to notify the families of scheduled or long-term teacher absences?

Assignments

- Who will make sure student knows what was missed if they leave class early / arrive late / need to rest?
- How can student catch up on missed assignments during absences?
- Who can help if it gets overwhelming?
- Can assignments be reduced without affecting learning?
- Can student dictate or type instead of handwriting?
- What assistive technology might be helpful?

Planning Considerations

Attendance Plan

- What is the plan if the student has an extended absence due to illness or quarantine after exposure?
- Are there any in-school services available that can reduce the need for the student to be pulled out for private appointments?
- Would a reduced schedule be appropriate? $\frac{3}{4}$ day? $\frac{1}{2}$ day?
- Is it possible to limit high-demand classes in the later part of the day?
- Are there hybrid learning options?
- What are the home schooling options?

Field Trips

- How will student navigate the site? Is it fully accessible?
- Will they need an aide or a buddy?
- Who will monitor energy needs? Is there a place to rest?
- What is the plan to avoid overheating, dehydration, and/or fasting?
- Are there any special transportation needs?
- What supplies or medications are needed?
- What emergency medical care is available on/near field trip site?

Related Services

LBSL is a degenerative condition with complex neurological and metabolic needs. In the medical setting, it is common to have a multidisciplinary team work together to form a comprehensive care plan. For school success, please consider consulting with school-based experts from a wide variety of disciplines, including:

- Rehabilitation
 - Physical Therapy (PT)
 - Occupational Therapy (OT)
 - Speech Therapy (SLP)

- Health & Wellness
 - School Health
 - Counseling Services
 - Social Work
 - Therapeutic Recreation

- Access Specialists
 - Assistive Technology
 - Transportation

List of 504 Accommodations By Area of Disability

The following section includes a list of common accommodations to consider based on area of disability, including:

- Mobility & Balance
- Fine & Gross Motor
- Head Injury Risk
- Energy Depletion
- Infection Risk
- Other Considerations

Important reminders:

- Every child is unique!
- Not all students with LBSL will require these common accommodations.
- Some students will require additional accommodations for related or unrelated disabling conditions, such as ADHD, severe allergies, seizure disorders, etc.
- LBSL is progressive, so accommodations must be adaptable and revisited frequently.
- Events such as illness or head injury can dramatically alter student needs and performance at school.

Mobility & Balance

- Transitions during the day**
 - Minimize need for movement
 - Give warnings
 - Allow extra time
 - Priority in movement (going first or last)
 - Early release from class / allow late arrival
- Seating**
 - Preferential seating in classroom
 - Preferential seating in large assemblies
- Assistance**
 - Buddy system: pair student with a peer
 - 1:1 aide
 - Escort between classes
 - Specified person to oversee transition
 - Assistance with carrying lunch tray, books, etc.
- Transportation**
 - Special transportation
- Athletics / PE / Recess**
 - Modification of non-academic tasks (e.g., lunch or recess)
 - Adaptive physical education
 - Modified activity level for recess
- Building Accessibility**
 - Use of ramps
 - Elevator access
 - Restroom adaptations
 - Simple route-finding maps & cues

Fine & Gross Motor

- Seating and posture**
 - Encourage the student to use and maintain appropriate posture during a task requiring writing
 - Offer seat pads, sit-upon balls, etc
 - Preferential seating
- Modify workload**
 - Reduce volume of writing and copying
 - Reduce the number of items on a page or assign fewer items
 - Provide additional time to complete written tasks
 - Use a closure procedure on worksheets
 - Offer alternatives for completing assignments
 - Typed instead of written
 - Permit the student to respond orally rather than in writing
 - Use a scribe to whom the student can dictate responses
- Computers/Keyboarding**
 - Provide opportunities for the student to learn keyboarding and word processing skills
 - Teach shortcuts on computers
 - Accessibility options on computer
- Assistive Technology (high tech & low tech)**
 - Demonstrate & encourage use of technology
 - Consult with OT/PT for special pens, pencils, calculators, fidgety toys, large print books, audio, pencil grips, slant boards, etc.
 - Use grid paper for the student to complete math computation problems
 - Allow use of preferred writing implement
 - Provide wide-lined paper with a baseline and dotted midline

Fine & Gross Motor

- Notetaking and copying work**
 - Limit notetaking and copying tasks
 - Don't require work at the board in front of the class
 - When copying from text, provide a magnified text copy
 - When copying from the board, provide seating close to the board
- Organization**
 - At the outset of a task requiring writing, assist the student to organize work on the page
 - Provide sufficient visual markers on a page to prompt a student where to write and organize responses
 - Provide and support electronic organizers
- Advocacy & Self Esteem**
 - Set up opportunities for child to self-advocate
 - Avoid using jokes, sarcasm and bringing unwanted attention to the student
- Transitions**
 - Minimize transitions between assignments or classroom tasks
- Monitoring Progress**
 - Monitor performance at a high rate and provide prompts when necessary to assist the student
 - Daily check-in with child
 - Monthly, weekly or bi-weekly phone or in person conferences with parents
- Adapted curriculum**
 - Adaptive PE
 - Modified graduation requirements based on mobility

Head Injury Risk

Reduce risk of head injury

- Remind student to wear helmet
- Education sessions for peers to help them understand disability
- Substitute teachers: Letting the child or family know when a substitute will be in the classroom and school educates substitute on head injury protocol
- If advised by the student's doctor, allow students to participate in modified physical education classes, or exempt them from class, if needed
- Having student avoid activities that have a high risk of head injury like contact sports.
- Having student wear a protective helmet or be given extra space for movement during higher risk activities.
- Making sure to always report ANY head injury to the family and/or health clinic staff right away.
- Creating a strong health action plan to make sure everyone knows what to do in case of a head injury.

Response to head injury

- Have head injury protocols in place
- Train teachers and staff to respond quickly
- Have health professional (i.e. nurse or athletic trainer) conduct a head injury assessment as soon as possible.
- Contact parents immediately

Energy Depletion

Encourage rest

- Schedule frequent breaks (do not make student have to ask)
- Allow additional breaks as requested
- Offer opportunities for comfortable rest (i.e. lie down in office)
- Provide a quiet workplace to avoid sensory overload

Modify schedule or school day

- Implement a modified schedule or creative programming
- Schedule arranged for high cognitive demand tasks to be followed by less stressful coursework
- Permit students to attend school in shorter periods rather than a full day
- Modify length of school day
- Provide system for transition
- Allow students to participate in modified physical education classes, or exempt them from class, if needed
- Consider hybrid school options
- Consider homeschool options

Energy Depletion

Modify workload

- Reduce quantity of work required, in favor of quality
- Modify assignments to only include essential content
- Allow student to hand in all assignments late, as pre-determined
- Set reasonable time limits for homework
- Offer alternatives for completing assignments
- Break down longer assignments
- Provide graphic organizers
- Help child learn organizational and time management skills

Modify tests

- Testing in the morning only
- If 2+ exams are scheduled on the same day, reschedule for another day
- Administer long examinations in a series of shorter segments with breaks allowed between sections
- Use a scribe or oral testing for open ended and/or essay formats
- Tests are taken in a separate, quiet environment

Limit writing and carrying materials

- Record class lectures
- Use a scribe for notes
- Provide a study guide
- Provide video/audio recordings
- Provide teacher notes or peer notes
- Provide notes and/or outlines with key concepts or terms highlighted
- Provide extra set of textbooks (1 set for home, 1 for school)

Infection Risk

- Infection Prevention Education**
 - Educate student – when and how to clean hands, use cleaning supplies, etc.
 - Educate teachers – safe storage and use of supplies, cohorting of students in classroom, etc.
 - Educate peers – how they can help with hand hygiene, masks, staying home when sick, etc.
 - Educate families – critical need to keep sick kids home
- Hand Hygiene**
 - Allow frequent access to handwashing
 - Personal access to hand sanitizer (if age appropriate)
 - Encourage good hand hygiene for teachers and classmates
- Cleaning and Disinfecting Surfaces**
 - Have separate work areas with complete sets of supplies
 - Allow student to keep personal supplies to wipe work areas
 - Schedule a daily time to clean and organize the workspace
 - Regularly disinfect high-touch areas of classroom
 - Determine who provides and restocks supplies
 - Ensure that supplies are safe to be used in areas cleaned with other products (i.e. by nightly custodial staff)
- Ventilation / Indoor Air Quality**
 - Portable HEPA filter (or equivalent) in classroom
 - Preferential seating near source of clean air (open window, classroom door, HEPA filter)
 - Avoid seating child near bathroom or trash cans

Infection Risk

Limit the Number of Close Contacts

- Cohort / Cluster to reduce the number of close contacts
 - Seat next to same group of children as often as possible
 - Seat near people student already has close contact with outside of classroom (i.e. friends/family, lunch or recess buddies, carpool group, club members, etc.)
- Seat near children at lower risk of spreading infections
 - Classmates with higher immunity
 - Fully vaccinated
 - Fully recovered from infectious illness
 - Not immunocompromised
 - Classmates with strong infection prevention practice
 - Consistently and correctly wearing masks
 - Good hand hygiene
 - Good respiratory etiquette
 - Classmates who are well
 - Avoid seating near symptomatic children (even those with “just allergies”)
- Request / require all students and staff in classroom wear masks during respiratory outbreaks

Recovery

- Illness can be severe and prolonged for individuals with LBSL
- Create flexible and thoughtful plans for returning to school after extended absence due to illness
- Student may not have enough energy for school and homework
- Be proactive as missed work can spike anxious feelings

Other Considerations

Mental health and wellness

- Avoid placing student in high pressure situations (e.g., short time frames, extensive volume of work; highly competitive)
- Allow access to counselor
- Identify one adult at school to seek help from when feeling anxious
- Provide clear, concise instructions that are at child's ability
- Use a special sign or signal between teacher and student to facilitate nonverbal communication
- Set up buddy system for unstructured times

Field trips

- Create clear and thoughtful fieldtrip plans in advance (include safety and transportation considerations)
- Thoroughly prepare the child in advance for field trips, or other changes, regardless of how minimal
- Preferential group (teacher or adult child knows well) for field trips

Substitute teachers

- Letting the child or family know when a substitute will be in the classroom
- School educates substitute on head injury protocol, infection prevention needs, and other accommodations

Sample 504 Plan for Student with LBSL

Description of educational strategies

Writing and typing are taxing. Takes long time to do best work.

Description of Student and the Disabling Condition

Child has been diagnosed with Leukoencephalopathy, with brainstem and spinal cord involvement with lactate elevation. (LBSL). Leukoencephalopathy refers to abnormalities in the white matter of the brain, which are tissues containing nerve cell fibers (axons) that transmit nerve impulses. Those with LBSL typically have abnormal muscle stiffness and difficulty with coordinating fine and gross motor movements. Younger individuals with LBSL may start to lose the ability to sense the position of their limbs and/or experience sensation problems. This typically starts in the lower extremities.

Because of their condition, it is imperative that staff members promptly communicate with parents if any illness is present. Depending upon the illness, this may be a trigger for further medical complications. In addition, Child's head must be protected during activities where Child may be susceptible to tripping, falling, or losing their balance. A minor head injury, coupled with her current medical condition, could be extremely serious. Prolonged exposure to heat or developing a fever can also have profound impact on Child's balance and movement.

Sample 504 Plan for Student with LBSL

Meet physical needs

- Child will have transfer chair assistance on field trips or outside classroom activities.
- Child will receive quarterly consultative checks from the district physical therapist. Optional electric wheelchair practice with the district Physical Therapist per Child's request.

Meet safety needs

- School staff will develop a plan for fire drills and evacuation emergencies and communicate that plan with Child and her parents, prior to drills.

Meet academic needs

- Teachers will reduce , when possible, the number of practice items on classwork and homework in order to reduce Child's overall workload.
- When needed Child should be able to use writing assistive technologies such as, speech to text and Co-Writer.
- Child will be allowed extra time to complete bigger projects and assignments

Meet assessment needs

- Child will be allowed an alternate setting to complete the State exam.
- Child should also be given extra time and a separate setting for classroom assessments.

References & Links

- **LBSL**
 - **Cure LBSL Foundation**
<http://www.curelbsl.org>
 - **NORD**
<https://rarediseases.org/rare-diseases/leukoencephalopathy-brain-stem-spinal-cord-involvement-lactate-elevation/>
- **Mitochondrial Disorders**
 - **MitoAction School Advocacy**
<https://www.mitoaction.org/school-education>
- **Leukodystrophy Care Guides**
 - **Family Neurological Companion**
<https://www.huntershope.org/wp-content/uploads/2020/10/FamilyCompanionNeuroFINALDRAFT6.29.pdf>
 - **Living with Leukodystrophy**
<https://www.thecalliopejoyfoundation.org/product-page/ebook-living-with-leukodystrophy-free-download>
- **Advocacy**
 - **Advocating for Your Child With a Rare Disease At School**
https://globalgenes.org/wp-content/uploads/2019/01/GG_toolkit_educational-advocacy_web-hyperlinked.pdf
 - **Self Advocacy for Children and Teens**
<https://www.imdetermined.org>

References & Links

- **Special Education Advocacy**
 - <https://www.wrightslaw.com/advoc.htm>
- **How to Prepare for an IEP Eligibility Meeting**
 - <https://www.understood.org/en/articles/what-to-expect-at-an-iep-eligibility-meeting>
- **Assistive Technology**
 - <https://www.wrightslaw.com/info/atech.index.htm>
- **Emergency Planning for Students with Disabilities**
 - https://www.ssdmo.org/cool_tools/inclusive/Resources/emergency_plan.pdf
- **Seizure Action Plans**
 - <https://www.epilepsy.com/preparedness-safety/action-plans>
- **Asthma Action Plan**
 - <https://www.aafa.org/asthma-treatment-action-plan/>
- **Allergy Action Plans**
 - <https://www.foodallergy.org/living-food-allergies/food-allergy-essentials/food-allergy-anaphylaxis-emergency-care-plan>
- **Head Injury Action Plans**
 - <https://www.cdc.gov/headsup/schools/index.html>

LBSL School Accommodations

was created by the Cure LBSL
patient advocacy organization.

For more information or additional resources, please
visit www.curelbsl.org

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Customize Your Plans

Please use the following pages to customize your school-year plans. There are blank pages at the end for any additional needs your child may have.

You can print out the slides and combine with other school documents in a binder to help stay organized.

Share extra copies with your child's teacher(s) and the special education team.

These documents can be edited in Microsoft PowerPoint or Adobe Acrobat. You can even record yourself or your child narrating the presentation and save it as a video file!

You can also just print and fill in information by hand.

Need help? If you need any assistance with customizing the document (including translation services), please reach out for assistance.

Melody Kisor, MS

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Contact Information

School special education case carrier:

School 504 case carrier:

School LEA:

School counselor:

School clinic:

District compliance officer:

Director of special education:

State office of disability rights:

US office of disability rights:

Planning Notes

The background is a teal color with a repeating pattern of white line-art icons representing various school supplies and subjects. These include calculators, pencils, pens, paper airplanes, backpacks, globes, and numbers. The central text is contained within a white rounded rectangle.

Safety Needs & Accommodations

The background is a teal color with a repeating pattern of white line-art icons representing various school supplies and subjects. These include calculators, pencils, pens, paper airplanes, backpacks, globes, and numbers like '2' and '3'.

Physical Needs & Accommodations

The background is a teal color with a repeating pattern of white line-art icons representing various school supplies and subjects, such as calculators, pencils, books, globes, and laboratory glassware.

Assessment Needs & Accommodations



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