



<b>Name</b>	<b>DOB</b>
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## Head Injury and LBSL

- HEAD INJURY** – Patients with LBSL are particularly vulnerable to severe consequences from head injury, including significant changes in motor and cognitive functioning. This can occur with relatively minor head injuries that would be unlikely to cause these symptoms in the general population. Fever after head trauma has also been reported in the literature.
- SEIZURES:** There is a higher prevalence of seizures in LBSL patients vs. the general population

## Signs and Symptoms – From Acute Concussion Evaluation ACE (ED v.1.4) – CDC Heads Up toolkit

Early Signs	Cognitive	Physical	Sleep
Loss of consciousness	Feeling mentally foggy	Headache*	Drowsiness
Appeared dazed/stunned	Feeling slowed down	Nausea	Sleeping less than usual
Confused about events	Difficulty concentrating	Vomiting	Sleeping more than usual*
Answers questions slowly	Difficulty remembering	Balance Problems*	Trouble falling asleep
Repeats questions		Dizziness	
Forgetful	Emotional	Visual Problems	* These signs/symptoms are commonly reported in patients with LBSL, and/or may first be observed following a head injury.
Amnesia (events before)	Irritability	Fatigue*	
Amnesia (event after)	Sadness	Sensitivity to light	
Seizures*	More emotional	Sensitivity to noise	
	Nervousness	Numbness/tingling*	

## Recommended Actions Outside of the Hospital Setting

### Home

- Call neurologist: \_\_\_\_\_
- If the person is not exhibiting symptoms, have someone else drive them to the closest hospital Emergency Department. If asymptomatic, they can travel to a hospital where the patient has an existing relationship.  
**IMPORTANT:** someone with a possible head injury should not drive themselves to the hospital
- If the person is showing signs or symptoms of a head injury, call 911 for transportation to the closest hospital. Alert EMS personnel if the patient has an existing relationship at a particular hospital.

### School / Camp / Sports

- If available, seek immediate assessment by on-site healthcare provider (nurse, certified athletic trainer, paramedic, etc.). Non-medical staff should not be tasked with providing assessments.
- Call parents / caregivers / emergency contact immediately.
- Recommend thorough neurological evaluation with possible imaging at the Emergency Department.
- If caregivers can't be reached, call 911 for ambulance transportation to closest Emergency Department.



### Recommended Assessments at the Hospital

- Neurological Assessment:** Recommend thorough neurological assessment, including mental status exam appropriate for age and baseline ability (note several signs/symptoms of head injuries overlap with LBSL). Pay close attention for any changes in mental status and/or episodes suspicious for **seizures**.
- Imaging:** Low threshold to obtain head CT depending on injury circumstance. Any abnormality on head CT should be followed up with MRI w/wo contrast. When available, perform comparison study with baseline MRI.
- Precipitating factors:** Diligently investigate cause of head injury. If caused by fall, investigate precipitating factors such as dehydration, fasting, fever, temperature dysregulation, and/or medication reaction.
- Vitals:** Patient vitals (especially body temperature), lab results, etc. may be *out of reference range*. Inquire about *baseline*, and trust patients/parents as experts on their own “normal” values.
- Pharmaceutical consideration:** LBSL patients may be taking custom prescription “*mito cocktails*” (high potency antioxidants and amino acids) to support metabolic needs. Consult with pharmacy as indicated for contraindications and/or need for additional lab work. IV fluids should contain dextrose and electrolytes. Note: despite theoretical concerns raised by some clinicians, expert metabolic consultants advise that Lactated Ringers is acceptable for use in the LBSL population.

### Recommended Management

- EXTENDED OBSERVATION**, frequently assessing for cognitive or physical changes from baseline.
- AVOID COMPLICATIONS** from aggravating conditions while patient is in care. Prevent whenever feasible; otherwise treat quickly and aggressively:
  - Infection
  - Fever
  - Dehydration
  - Fasting
  - Overheating
  - Hypothermia

### Follow Up

- CARE TEAM:** Patients should be counseled to follow up with their primary care provider and neurologist.
- FURTHER ASSESSMENT:** Consider neuropsychological evaluation and testing.
- PROTRACTED RECOVERY:** Patient recovery may be longer than expected. Plan for extended impact.

### Healthcare provider signature

Provider name:	Date:
Signature:	Contact number:

These guidelines were developed by [Melody Kisor, MS](#) (Bioethicist) and [Beth McGinn](#) from [Cure LBSL](#), in close consultation with: [Dr. Amena Smith Fine, MD PhD](#) (Neurologist) and [Dr. S. Ali Fatemi, MD MBA](#) (Neurologist) from Kennedy Krieger Institute; [Dr. Kayla Kendric, MD](#) (Emergency Medicine) from Kaiser Permanente; and [Dr. Mark Korson, MD](#) (Biochemical Geneticist) from VMP Genetics.

These guidelines are intended to educate and inform, but should never be used to replace clinical judgement. Whenever possible, collaborate with patient’s specialty care team and/or your referral network to determine optimal treatment plan.