

Seizure Action Plan for LGS

Attention: This plan should be filled out with the epilepsy care team and shared with everyone who helps care for the person with LGS.

About Me and Communication

Name: _____

Date of birth: _____

Weight: _____ lbs

Primary diagnosis: Lennox-Gastaut syndrome (LGS)

Etiology (if known):

Structural Genetic Metabolic Infectious Unknown

Details:

Other health conditions (e.g., sleep apnea, aspiration risk, cardiac, respiratory):



About me and how to support me

- What helps me feel comfortable with new staff/caregivers:
Examples: topics I like, routines or items that calm me.

- Things I enjoy (topics, characters, activities):
Examples: favorite shows, music, hobbies.

- Things that scare or upset me:
Examples: noises, situations, physical touch that I dislike.

- My communication preferences:
How I show "yes/no," pain, distress, or that something is wrong; devices or augmentative and alternative communication (AAC) that I use.

Allergies/medication intolerances:


Behaviors easily confused with seizures

Baseline non-seizure features and behaviors that may look like seizures but do not typically represent epileptic seizures for this person when unchanged from baseline.

To be completed by the epilepsy care team. List behaviors that are commonly mistaken for seizures in this individual but have been determined by the team to be non-epileptic events when they match the person's usual pattern (for example, sudden increase in muscle tone related to pain or stress; stereotyped movements such as rocking or breath holding; non-epileptic events diagnosed by the neurology team, sometimes called functional seizures; or behavioral "flopping to the floor" when opposed to an activity).

Behavior/feature (e.g., rocking, pacing, vocalizations, baseline staring)

Frequency of occurrence



If any of the behaviors listed above change significantly from baseline (for example, last much longer, are more intense, or look very different), describe how staff should assess and respond for each behavior (responses may differ for each behavior):

Behavior 1 (from list above): _____

Staff response if this behavior changes from baseline:

Behavior 2 (from list above): _____

Staff response if this behavior changes from baseline:

Behavior 3 (from list above): _____

Staff response if this behavior changes from baseline:

Baseline Seizure Pattern (LGS)

Typical seizure types (check all that apply and describe):

Seizure pattern	Seizure description/ observable signs <small>(triggers, warning signs, awareness, motor and other symptoms)</small>	Usual length <small>(when within baseline)</small>	Usual frequency <small>(when within baseline)</small>	Routine response when this seizure matches baseline

**The epilepsy care team may also note the formal seizure type here (e.g., tonic, atonic), but the description should use words that families and staff recognize based on what they see.*

Baseline cognition and communication:

(How the person usually understands, communicates, and behaves when well.)

Typical recovery after seizures (postictal period):

(How long they usually take to wake up, common behaviors after seizures.)

Known triggers (e.g., missed medications, illness, sleep loss, flashing lights):

Daily Treatment

Daily antiseizure medicines

Medication	Dose (mg or mL)	Time(s) given	Notes

Other therapies:

Devices:

- Vagus nerve stimulation (VNS)
- Responsive neurostimulation (RNS)
- Deep brain stimulation (DBS)

Details:

Dietary therapy:

- Ketogenic Modified Atkins
- Other _____

Special instructions:

Step 1: General Seizure First Aid (All Settings)

For any seizure:

- Stay calm and start timing the event.
- Keep the person safe: quickly clear the area and protect the head once they are on the ground.
- If possible, gently roll onto side; keep airway clear and have nothing in the mouth.
- Do not restrain movements; do not give food or drink during a seizure.
- Stay with the person until they are back to their usual baseline.
- If the patient has a VNS device, swipe the magnet over the generator (chest area) when a seizure starts, following the neurologist's instructions.

Special instructions for this person (falls, aspiration risk, equipment, helmet, etc.):

Step 2: When Seizures Need Extra Help

Define what is an emergency for this patient:

Emergency seizure patterns (check and complete):

Any seizure lasting more than _____ minutes.

More than _____ drop/atonic seizures in _____ minutes.

_____ seizures in _____ hours without full recovery in between.

Seizure different from usual pattern: _____

Non-convulsive event lasting longer than _____ minutes with behavior change.

Other: _____

Patterns that are NOT an emergency for this person (if they match baseline and no injury occurs):
(Complete with the treating clinician.)

- Brief drop/tonic seizures lasting less than _____ seconds, up to _____ times per day.
-
- Brief staring/atypical absence spells lasting less than _____ seconds, up to _____ times per day.
-
- Other baseline events that do NOT require rescue medicine or 911: _____
-

“As-Needed” Treatments (Rescue Medications/Devices)

Treatment <small>(e.g., intranasal/rectal/buccal medicine, VNS magnet)</small>	Doses/steps	When to use	How to give/notes	Maximum times in 24h
.....
.....
.....
.....

When to Call 911/Emergency Medical Services

Call 911/EMS immediately if:

- A convulsive seizure lasts longer than 5 minutes.
- Seizures repeat without full recovery for 10 minutes, even after using rescue medication.
- Any of the emergency criteria listed in Step 2 are met and rescue therapy is not available or not working.
- There is concern about breathing, color change, or the person is not waking up or responding as they usually do after a seizure.
- The person is injured during a seizure (especially head injury from a drop attack), has fallen from height, or is bleeding.
- A seizure occurs in water or during a high-risk activity.
- You observe a seizure that is very different from the person's usual pattern.
- You are worried, unsure, or cannot reach a health care professional.

Additional instructions from treating clinician:

Call the epilepsy care provider if you notice any significant change in seizure frequency or type, if new seizure behaviors appear, or if recovery after seizures is different than usual.



Setting-Specific Instructions

Home/Group home/Residential program

- Supervision needs after a seizure (e.g., monitoring during sleep):

- How and where to document seizures/events in this setting (e.g., seizure log, electronic health record, paper form):

- Who to notify and in what order (e.g., on-call nurse, house supervisor, family, neurologist):

School/Day program/Workplace

- Who must be notified after a seizure: _____
- Activity restrictions/safety precautions (e.g., stairs, gym, swimming): _____

Support Team (important contacts)

Primary caregiver:	_____	Phone: _____
Secondary caregiver:	_____	Phone: _____
Neurologist/Epileptologist:	_____	Phone: _____
Primary care provider:	_____	Phone: _____
Residential/group home lead contact:	_____	Phone: _____
Preferred hospital/ED:	_____	Phone: _____
Pharmacy:	_____	Phone: _____
Other key support (behavioral health, school, day program, etc.):	_____	Phone: _____

Review and Signatures

Date completed: _____

Next review due: _____

Plan reviewed on:

(Review at least annually and whenever medications, seizure patterns, or living situations change, including before transition to adult care.)

Health care professional
name and signature:

Parent/Guardian/Adult
patient signature:

Make copies of this plan for home, school, workplace, group home, and any setting where the person receives care. Provide it to all caregivers (teachers, nurses, aides, residential staff), and update them whenever the plan changes.