

# ABOUT SEIZURE EMERGENCIES

**Seizure clusters and status epilepticus are common in LGS and are seizure emergencies.**



## What is a Seizure Cluster?

The definition of a seizure cluster varies from one individual to another, but in general, the term refers to a group of seizures occurring over a number of hours in a way that differs from an individual's usual seizure pattern. For one patient, having three seizures over the course of two hours may represent a seizure cluster, while for another, a seizure cluster may be dozens of seizures over a few minutes. Adverse effects of seizure clusters include risk of injury from the seizures themselves, prolonged recovery time after seizures, and missed work, school, or social activities. Seizure clusters may progress into status epilepticus.

## What is a Status Epilepticus?

The official definition of status epilepticus has evolved over time, but the term generally refers to a prolonged seizure that may not stop on its own without intervention. The most recent definition presented by the International League Against Epilepsy identifies generalized convulsive (tonic-clonic) status epilepticus as a seizure lasting longer than five minutes, with an increased risk of brain injury if the seizure continues for too long. For other seizure types, such as focal or absence seizures, these time points may be more prolonged.

**The majority of seizures in individuals with LGS are short and terminate on their own in less than two to three minutes. However, if status epilepticus occurs, it is a medical emergency that may result in severe consequences if not treated rapidly.**



## What is a Non-Convulsive Status Epilepticus?

Non-convulsive status epilepticus (NCSE) is a prolonged seizure that looks like an altered mental state as opposed to the dramatic convulsions seen in generalized tonic-clonic status epilepticus. There are 2 main types of NCSE.

- In the first type of NCSE, patients are confused or behaving abnormally and appear to be having a non-stop absence (petit mal) seizure or a non-stop focal impaired awareness (complex partial) seizure.
- The second type of NCSE is subtle and occurs after a long generalized tonic-clonic seizure. The person will have continuous subtle motor jerks, especially of the face or hands, and this persists over time. Brain damage can occur if not treated in a timely manner.

## What Causes Seizure Clusters and Status Epilepticus?

People with intractable epilepsy (seizures that are not controlled by medication) are at higher risk for having seizure clusters or status epilepticus, but these episodes may also occur in people whose seizures are usually well controlled. Some common triggers for seizure clusters or status epilepticus include:

- Illness
- Missed antiseizure medication doses
- Sleep deprivation
- Stress
- Having a Developmental and Epileptic Encephalopathy (DEE), such as LGS
- Menstrual cycle

Seizure clusters or status epilepticus may also occur without an apparent trigger. Keeping a seizure diary may be helpful in identifying seizure patterns triggers.



**Request a New Family Welcome Kit**

Scan this QR code to learn more

**NEW TO LGS?  
YOU ARE NOT ALONE!**



None of the information herein constitutes medical advice, diagnosis, treatment, or recommendation. Always seek the advice of your doctor, or other qualified health professional, with any questions about or related to a medical condition.

**LGS FOUNDATION**  
LENNOX-GASTAUT SYNDROME

# TREATING SEIZURE EMERGENCIES

## How Can Seizure Clusters and Status Epilepticus Be Treated?

**Prompt treatment of seizure clusters and status epilepticus is important in limiting the duration of seizures and may prevent the need for more intensive treatment.**

Medications to treat seizure clusters or status epilepticus are often called emergency or rescue medications. Several rescue medications are now available for out-of-hospital treatment. All of these medications are part of the benzodiazepine group of drugs, which are regularly used to treat prolonged seizures in the hospital. While benzodiazepines used in the hospital are usually given intravenously (IV), they are available for out-of-hospital treatment and may be given orally, rectally, or nasally. All benzodiazepines have the same potential side effects, which include drowsiness, dizziness, and impaired coordination. At high doses, they may cause respiratory depression. People who are given these medications should be monitored closely.



### Oral Medications

Oral Medications used for seizure clusters include clonazepam, lorazepam, and diazepam. These medications may be swallowed or given by a gastrostomy tube, and some come in forms that can dissolve on the tongue. Absorption of medications given by mouth is slower than the other treatment options. It is important that a person be alert and responsive before administering oral medication to reduce the risk of aspiration. A person experiencing a seizure may also inadvertently bite down and injure someone trying to put something in his or her mouth, so do so with caution.



### Rectal Medications

Rectal Medication used for seizure clusters or status epilepticus is diazepam gel. Diazepam gel is provided as a needleless syringe and is administered into the rectum, where it is quickly absorbed into the bloodstream. It is often preferred for use in young children, as the method of administration is undesirable for many adolescents and adults.

CHECK OUT THIS  
VIDEO FROM  
ABOUT SEIZURE  
RESCUE  
MEDICATIONS



### Nasal Medications

Nasal Medications may be used to treat seizure clusters, but are not FDA-approved for the treatment of status epilepticus. These medications are sprays that are administered into the nose. There are currently two FDA-approved nasal medications: intranasal midazolam (Nayzilam<sup>®</sup>) and intranasal diazepam (Valtoco<sup>®</sup>). There are several potential benefits to nasal medications, including ease of usage, safety for the person administering the medication, and avoidance of potential embarrassment for adolescents and adults that may otherwise require rectal medication. However, nasal medications may not be a good option for everyone.

## When Should Rescue Medications Be Used For Seizure Clusters Or Status Epilepticus?

Every person with LGS and epilepsy should develop a Seizure Action Plan (SAP) with his or her medical provider that details the indications for use of a seizure rescue medication and which medication should be used. This plan should be implemented as soon as possible once a seizure cluster or status epilepticus (seizure greater than 5 minutes) is identified. The plan should be written down and be available for anyone who might be with the individual when they experience a seizure. For those known to have frequent seizure clusters or status epilepticus, a plan should also be available for emergency medical personnel. Most schools and daycare providers require a written Seizure Action Plan for all children with epilepsy that details the types of seizures they have, what should be done if they have a seizure, and when rescue medications should be given.

# SEIZURE ACTION PLAN (SAP)

## Create Yours Today!

- Work with your medical provider to determine when a seizure rescue medication should be used and which medication you will use.

The image shows a sample of the 'Acute Seizure Action Plan' form. It is a multi-section document with a purple border. At the top, it has fields for 'Name', 'Birth date', 'Today's date', 'Care partner phone numbers', 'Provider name/facility', and 'Provider phone numbers'. Below this is the 'Usual Seizure Pattern' section, which includes 'Triggers', 'Pattern of seizures', 'Allergies', and 'What the seizures normally look like (Check all that apply)'. It features several icons representing different seizure types: Absence seizure (also called drop), Absence seizure (also called petit mal), Tonic seizure, Clonic seizure, and Focal impaired awareness seizure (also called complex partial). The 'Care' section is titled 'Standard Care Needed' and includes instructions like 'Time the seizure', 'Keep person safe', 'Don't restrict', 'Stay with person', and 'Keep a record'. The 'Provide Rescue Treatment' section includes 'If this happens' and 'Specific instructions'. The 'Call for Emergency Help' section includes 'If any of these happen' and 'Get help now'. At the bottom, there is a 'Healthcare Provider Authorization' section with a signature line and a date field.

## Seizure Action Plan Template

Use this handy template to create your own SAP today!



***Don't forget to share this Plan with other caregivers!***

RESCUE MEDICATIONS  
VIDEO  
DEMONSTRATIONS



NEED A SAP FORM  
WITH MORE SPACE TO  
WRITE?



NEED ANOTHER COPY  
OF THIS PAGE



# Acute Seizure Action Plan

Name: _____	Birth date: _____	Today's date: _____
Care partner phone numbers: _____	Provider name/facility: _____	Provider phone numbers: _____



## Usual Seizure Pattern

**Triggers:** \_\_\_\_\_

**Pattern of seizures:** \_\_\_\_\_

**Allergies:** \_\_\_\_\_

**What the seizures normally look like (Check all that apply)**

<p>Head May Drop Loss of Muscle Control Slump or Fall Forward</p> <p><input type="checkbox"/> Atonic seizure (also called drop)</p>	<p>Occurs Through the Entire Brain Blank Stare</p> <p><input type="checkbox"/> Absence seizure (also called petit mal)</p>	<p>Blink Rapidly Roll Their Eyes Can Be Confused With Daydreaming</p> <p><input type="checkbox"/> Tonic seizure</p>	<p>Stiff Body Incontinence Back Arched Epileptic Cry</p> <p><input type="checkbox"/> Clonic seizure</p>	<p>Frothy Saliva Blinking Eyes Occurs in Specific Lobe of the Brain Blank Stare</p> <p><input type="checkbox"/> Focal impaired awareness seizure (also called complex partial)</p>	<p><b>Describe:</b> _____</p> <p>_____</p> <p>_____</p> <p>_____</p>
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**NOTES:** \_\_\_\_\_

## Care

**Standard Care Needed**

If this happens, \_\_\_\_\_ provide standard care

<p>Time the seizure</p> <p>NOTES: _____</p>	<p>Keep person safe</p> <p>NOTES: _____</p>	<p>Don't restrict</p> <p>NOTES: _____</p>	<p>Stay with person</p> <p>NOTES: _____</p>	<p>Keep a record</p> <p>NOTES: _____</p>
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**Provide Rescue Treatment**

If this happens, \_\_\_\_\_ provide standard care (above) **and** rescue treatment

<p><input type="checkbox"/> Rectum</p>	<p><input type="checkbox"/> Nose</p>	<p><input type="checkbox"/> Mouth</p>	<p><b>Specific Instructions:</b> _____</p> <p>_____</p> <p><input type="checkbox"/> Other: _____</p>
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**Call for Emergency Help**

If any of these happen,

<p><input type="checkbox"/> Seizure longer than _____ minutes</p>	<p><input type="checkbox"/> Unusual seizure</p>	<p><input type="checkbox"/> Injury/Blue lips</p>	<p><input type="checkbox"/> Other: _____</p> <p>_____</p> <p>_____</p> <p>_____</p>
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**Get help now**

<p>Call Healthcare Provider if: _____</p> <p>Call for Emergency Help if: _____</p>	
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**NOTES:** \_\_\_\_\_

## Healthcare Provider Authorization

Signature: \_\_\_\_\_ Provider Printed Name: \_\_\_\_\_ Date: \_\_\_\_\_ For use from: \_\_\_\_\_ to: \_\_\_\_\_

**Don't forget to share this with other caregivers!**

# Seizure First Aid

How to help someone having a seizure

**01**

## **STAY WITH THE PERSON UNTIL THEY ARE AWAKE AND ALERT AFTER THE SEIZURE**

- Remain calm and check for medical ID
- Time the seizure and write it down in your seizure log
- Video the seizure if want to share with the doctor

**02**

## **KEEP THE PERSON SAFE**

- Move them away from harm

**03**

## **TURN THE PERSON ONTO THEIR SIDE IF THEY ARE NOT AWAKE AND AWARE**

- Keep airway clear
- Loosen any tight clothes around their neck
- Put something small and soft under their head

**04**

## **CALL 911 IF...**

- Seizure lasts longer than 5 minutes
- Person does not return to their usual state
- Person is injured, pregnant, or sick
- First time seizure or repeated seizures
- Person has difficulty breathing
- The seizure occurs in water

**05**

## **DO NOT...**

- ✗ Restrain them
- ✗ Put any objects in their mouth
- ✓ Rescue meds can be given if prescribed by a health care professional

**BEFORE YOUR NEXT SEIZURE:**

CREATE A SEIZURE ACTION PLAN (SAP) WITH YOUR DOCTOR.  
SHARE YOUR SAP WITH ALL CAREGIVERS.

ON DEMAND SEIZURE  
FIRST AID TRAINING  
FOR EVERYONE YOU  
KNOW!



BE SURE TO COMPLETE REVERSE SIDE



Name: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Relationship: \_\_\_\_\_  
City: \_\_\_\_\_  
State: \_\_\_\_\_

In Case of Emergency, Please Notify:

# Emergency Medical Information

Street: \_\_\_\_\_  
City: \_\_\_\_\_  
State: \_\_\_\_\_  
Zip: \_\_\_\_\_  
Phone: \_\_\_\_\_



Name: \_\_\_\_\_  
Date Completed: \_\_\_\_\_  
Updated: \_\_\_\_\_

Keep Copies of this Card Handy for Paramedics and Hospital Staff

FOLD HERE - PLACE ON REFRIGERATOR - FOLD HERE

## Current Medical Information

Name of Doctor: \_\_\_\_\_ Phone #: \_\_\_\_\_

Name of Doctor: \_\_\_\_\_ Phone #: \_\_\_\_\_

Currently Being Treated For:

## Current Medications:

Medication	Dosage	Taken How Often? (Frequency)	Taken to treat what condition?	Located where in your home?

\* Attach & date a separate page for additional medications or to record updates.

Allergies to Medications: \_\_\_\_\_

Pharmacy Name: \_\_\_\_\_ Phone: \_\_\_\_\_



## Basic Information

Name: \_\_\_\_\_

Male: \_\_\_\_\_ Female: \_\_\_\_\_ Height: \_\_\_\_\_ Weight: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Marital Status: \_\_\_\_\_

Hair Color: \_\_\_\_\_ Eye Color: \_\_\_\_\_ Blood Type: \_\_\_\_\_ Religion: \_\_\_\_\_

Primary Language Spoken: \_\_\_\_\_ Other Language(s): \_\_\_\_\_

\_\_\_\_\_ Glasses \_\_\_\_\_ Contact Lenses \_\_\_\_\_ False Teeth/Bridge

Hearing Aid: \_\_\_\_\_ Left \_\_\_\_\_ Right Deaf: \_\_\_\_\_ Left \_\_\_\_\_ Right

Blind: \_\_\_\_\_ Left \_\_\_\_\_ Right Artificial Eye: \_\_\_\_\_ Left \_\_\_\_\_ Right

Artificial Limbs or Prosthetic Devices: \_\_\_\_\_

Pacemaker Model #: \_\_\_\_\_ Defibrillator Model #: \_\_\_\_\_

Identifying Marks (i.e., birthmarks, tattoos, etc.): \_\_\_\_\_

Normal Blood Pressure: \_\_\_\_\_ / \_\_\_\_\_ Smoker? \_\_\_\_\_

## Medical History

Check Conditions that you have been treated for:

<input type="checkbox"/> Allergies	<input type="checkbox"/> Blood Pressure	<input type="checkbox"/> Epilepsy	<input type="checkbox"/> Insulin	<input type="checkbox"/> Stroke
<input type="checkbox"/> Anemia	<input type="checkbox"/> Cancer	<input type="checkbox"/> Glaucoma	<input type="checkbox"/> Jaundice	<input type="checkbox"/> Tuberculosis
<input type="checkbox"/> Arthritis	<input type="checkbox"/> Dementia	<input type="checkbox"/> Hay Fever	<input type="checkbox"/> Parkinson's Disease	
<input type="checkbox"/> Asthma	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Heart Condition	<input type="checkbox"/> Sinus	

## Hospital Information

Hospital Preference: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_

Last Hospitalization: \_\_\_\_\_ Hospital: \_\_\_\_\_ Date: \_\_\_\_\_ Treated For: \_\_\_\_\_

\_\_\_\_\_ Living Will If yes, location of Living Will: \_\_\_\_\_

\_\_\_\_\_ Do Not Resuscitate (DNR) Order Location of DNR: \_\_\_\_\_ Organ Donor: \_\_\_\_\_

## Medical Insurance Coverage

Medicare #: \_\_\_\_\_ Medicaid #: \_\_\_\_\_

Other Policy #: \_\_\_\_\_

**Need Another Copy? Download at [www.MedicalCareAlert.com/EMS](http://www.MedicalCareAlert.com/EMS)  
or call Customer Service 1-877-913-3680**



**Keep Copies of this Card Handy for Paramedics and Hospital Staff**

# MORE IMPORTANT INFO ABOUT SEIZURES

## Seizure Types

We at the LGS Foundation believe it is important for families living with LGS to be able to recognize different seizure types. However, there is a lack of detailed, accurate information on the internet as to what seizure types may look like. This brought us to create this video library of what seizures may look like. Thank you to the families who shared these heartbreaking videos with us so we may educate others. And thank you to the physicians who have reviewed these videos to help us best determine the seizure types represented.

### Seizure Type Videos



## Seizure Safety

Safety Is A Constant Concern For Those With LGS

Children and adults with LGS have frequent seizures and are at high risk of injury. Furthermore, they may not have the ability to sense danger, may wander off from their home or school, and may place themselves in potentially dangerous situations if not properly supervised. Always consider potential safety issues ahead of time to keep the person with LGS safe.

### More on Seizure Safety



## Keeping an Online Seizure Diary

Keep a seizure diary where you record seizures along with other relevant information, such as dietary changes, the timing of medication intake of both anticonvulsants and other drugs, the amount and quality of sleep, etc. This is a useful tool when working with your neurologist and may assist in identifying seizure triggers. Seizure Tracker is an online tool that is free and easy to use and allows you to print reports and graphs that can be shared with medical professionals.

**Seizure Tracker®**  
be aware. track it.



GET THE SEIZURE  
TRACKER APP



## Seizure Detection Devices

While no device has been proven to prevent epilepsy-related mortality (including SUDEP), the Danny Did Foundation (DDF) is devoted to seeking out seizure detection and seizure prediction devices - as well as other technologies - that are designed to enable intervention by a caregiver. Intervention is believed to reduce the risks that accompany epilepsy. Check out the latest from our friends at Danny Did. LGS Foundation and Danny Did also partner to provide grants to families to get seizure detection devices.



DANNY DID  
FOUNDATION  
HAS GREAT INFO  
& GRANTS



## Durable Medical Equipment

Those with LGS often need medical equipment or supplies. These include seizure safety helmets, manual or power wheelchairs, assistive communications devices, special beds, special seating, gait trainers, standers, lifts, etc. Insurance often covers some or all of the costs for these medically necessary items. See some useful links below:



**About Medical  
Equipment & Supplies**



**Daily Living  
Aids\***



**Special Needs  
Equipment\***



**Danmar Products  
Helmets\***

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# IMPORTANT INFO ABOUT SUDEP

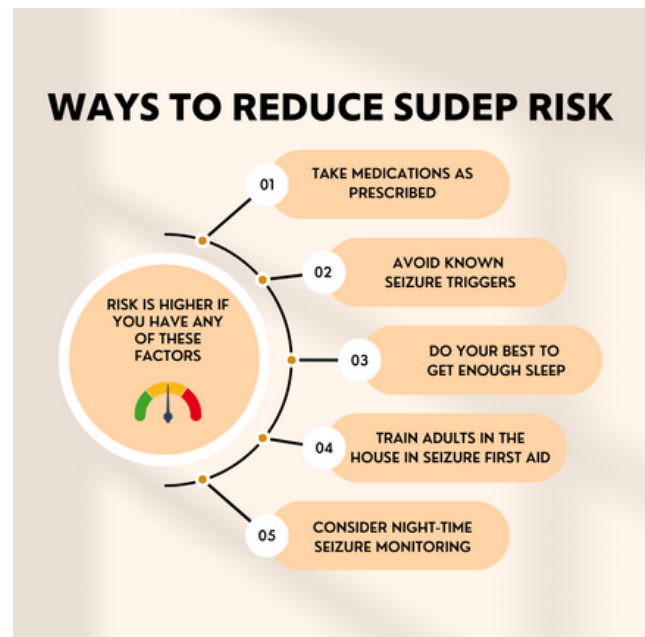
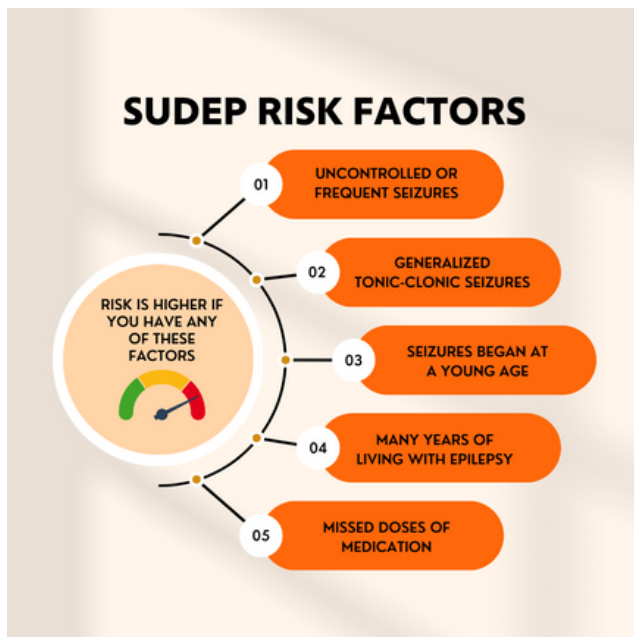
## Learn About Sudden Unexpected Death in Epilepsy (SUDEP)

While this information may be frightening for a family to read, the LGS Foundation is committed to making sure that families have the knowledge they need to do what they can to prevent complications and death from seizures. There may be some things families can do to avoid situations and modify risks. The LGS Foundation recommends that families of those diagnosed with LGS be given information about SUDEP from their physician and ways to reduce the risk. People with LGS are 14x more likely to die prematurely. SUDEP is a major cause.

Mortality due to epilepsy is a significant concern for the families of those with LGS. Seizures can sometimes be fatal for a number of reasons. Some children with LGS may lose their lives due to accidents, status epilepticus, or illness. Another concern for our community is SUDEP or Sudden Unexpected Death in Epilepsy. It is defined as the “Sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicologic or anatomic cause for death.” (Nashef, 1997).

There are several risk factors for SUDEP, and research suggests there are ways to reduce the risk.

**Get More Info  
on SUDEP**



<https://www.cdc.gov/epilepsy/about/sudep>



**5 Things You Should  
Know About SUDEP**



**Video: Mortality  
& SUDEP in LGS**



**Why is it important  
to talk about SUDEP?**



**Partners Against  
Mortality in Epilepsy**



**North American  
SUDEP Registry**

**For Our Bereaved Families  
We Are Here For You**



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