

Individualized Seizure EMERGENCY Plan (I-SEP)

- *This I-SEP is a tool that may prepare caregivers for what to do if a seizure emergency occurs or is likely to occur. It was created by caregivers of children and adults with severe epilepsy.*
- *This I-SEP should be discussed and agreed upon with a Neurologist who understands seizure emergencies and rescue medication use. If your doctor does not understand this, you may want to seek a second option.*
- *This I-SEP, once filled out with your doctor, can be handed to emergency personnel to get the facts to them, in writing, as quickly as possible if needed.*
- *The below document is meant to be an interactive form where you can add or delete spaces in each section as needed. Read the suggested comments in gray and then delete them once you add your own loved one's information. It is suggested that you print your I-SEP and hang it on the wall for emergency use.*
- *For more information on this I-SEP see this webinar at [DEEP-Connections](#).*

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Date I-SEP filled out: _____ (review and update every 3 months with Neurologist as needed)

Info on the person with seizures:

Name:

Date of Birth:

Height:

Weight:

Parents/Guardians/Contacts:

Read these suggestions for filling out your I-SEP and then delete them as you go. As you type, add more lines to each box as needed by pressing enter.

Phone:

Diagnosis:

Include diagnosis and what baseline seizures look like (type, frequency, duration).

Drug Allergies:

Include all allergies here that are important to know in an emergency situation.

Current Medications/Diets/Devices/Treatments:

Include alternative therapies and treatments as well.

What to do in the event of a seizure emergency:

Before a seizure emergency occurs:

Briefly write here what to do to possibly prevent a seizure emergency. Use if the person with seizures experiences triggers that, based on experience, often lead to emergencies (e.g. unusual seizure patterns, onset of menstruation, fever, missed medication, etc). When should a parent/caregiver be called if not at home? The doctor should agree with this plan. Try to keep the whole I-SEP to one page only so it can be used in an emergency. Just brief facts only. Delete this gray text of suggestions when finished.

During a seizure emergency:

Briefly write here what to do if the seizures cluster or become convulsive or non-convulsive status epilepticus. The doctor should agree with this plan. When should rescue medications be given? Where are the rescue treatments? Knowing the prolonged seizures can cause brain damage, how soon should rescues be given? Who should give rescue meds (most rescue meds can be given by anyone who has read and understands the instructions)? Should the VNS magnet be used (if relevant)? What rescue medication(s) should be given (e.g. rectal, intranasal, etc.)? Can a second dose be given? If so, when and how? What if rescue meds fail?

After the seizure emergency has ended:

Briefly write here what to do after the emergency has ended. The doctor should agree with this plan. Was a rescue med given? If so, should heart rate and breathing be monitored and for how long? How should the person with seizures be positioned? How long are they likely to need to recover? How do you comfort the person with seizures and bystanders?

When to call emergency services or go to the emergency department:

Briefly write here when to call an ambulance or go to the emergency room. Who will go in the ambulance with the person with seizures? Where is the Go Bag (a bag for trips to the hospital)?

Neurologist Name/Signature:

Phone:

Insurance:

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Date I-SEP filled out: <u>8-12-20</u> (review and update every 3 months with Neurologist as needed)			
Info on the person with seizures:			
Name: Jane Smith	Date of Birth: 12-29-80	Height: 5 ft 3 in	Weight: 110 lb
Parents/Guardians/Contacts: Cindy Smith (Mom) - Call first Joe Smith (Dad) - Call second Jake Smith (Brother) - Call third		Phone: Mom Cell: xxx-xxx-xxxx Dad Cell: xxx-xxx-xxxx Jake's Cell: xxx-xxx-xxxx	
Diagnosis: Intractable epilepsy with intellectual disability, Lennox-Gastaut Syndrome (LGS) caused by mutation in the SUCK gene, cerebral palsy. Baseline seizure number is 2-4 tonic clonics (2-4 minutes long) every day before waking and 0-15 myoclonic seizures (1 second) throughout the day.			
Drug Allergies: Tegretol, Depakote, Sulfa, Red Dye, Potassium Supplements, Shellfish			
Current Medications/Diets/Devices/Treatments: Dilantin (brand name only) - 100 mg in the am/130 mg in the pm Clonazepam - 1 mg in the am/1mg in the pm Topomax (brand name only) - 200mg in the am/200 mg in the pm Rufinamide - 600mg in the am/800mg in the pm VNS - Implanted July 2012, 2.75mA output Ketogenic Diet - 4:1 ratio Vitamin D3 - 2000 IU am/1000 IU pm			
What to do in the event of a seizure emergency:			
<u>Before a seizure emergency occurs:</u> Menstruation may cause tonic clonic seizures and nonconvulsive status epilepticus (NCSE). She gets an extra 1mg of clonazepam the week of her period. Being too hot or too cold may cause NCSE. Fevers may cause NCSE. Likely to go into NCSE if she has a daytime tonic clonic or >15 myoclonics in a day. Be on alert.			
<u>During a seizure emergency:</u> <u>Tonic clonic >4 minutes:</u> Roll on side if has a tonic clonic. Give 20mg Diastat Rectal Gel if lasts >4min. Call parent. If doesn't stop within 2 min, call 911. Anyone who has been trained by Cindy (Mom) may give Diastat. Diastat located in her backpack. <u>Daytime tonic clonic that tapers off into NCSE:</u> If tonic clonic turns into eye flutters with motor twitching and staring that does not clearly end, she is in NCSE. 10 minutes from the start of the tonic clonic, give 20mg of Diastat Rectal Gel. Call parent. If does not completely stop in 20 minutes, give 10mg of Diastat. If does not stop, call 911 or take to ER.			

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After the seizure emergency has ended:

If Diasat is given, monitor breathing and heart rate for one hour to ensure they do not stop. Lay on side so if drools so saliva does not get into lungs. May need to sleep for several hours after. Comfort her by telling her you are there and stroking her hair. Assure bystanders understand she is okay and everything will be alright.

When to call emergency services or go to the emergency department:

Call 911 tonic clonic does not stop after Diastat given (give at 4min, should stop within 2min)
Take to ER for NCSE that doesn't stop after second dose of Diastat fails. (give at 10min, should stop within 20 min).

Hospital Go Bag is in home hall closet and school cubby.

Neurologist/Signature:

DOCTOR SIGNS HERE!!!

Dr. Cure Epilepsy

Phone: xxx-xxx-xxxx

Insurance: Bluecross

SAMPLE