



#### SEIZURE FIRST AID



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**LEARN MORE AND GET A DOWNLOADABLE VERSION OF THIS ACTION PLAN AT:**



[childneurologyfoundation.org/sudep](http://childneurologyfoundation.org/sudep)



[dannydid.org](http://dannydid.org)



[epilepsy.com/sudep-institute](http://epilepsy.com/sudep-institute)

# Taking seizures into the summer

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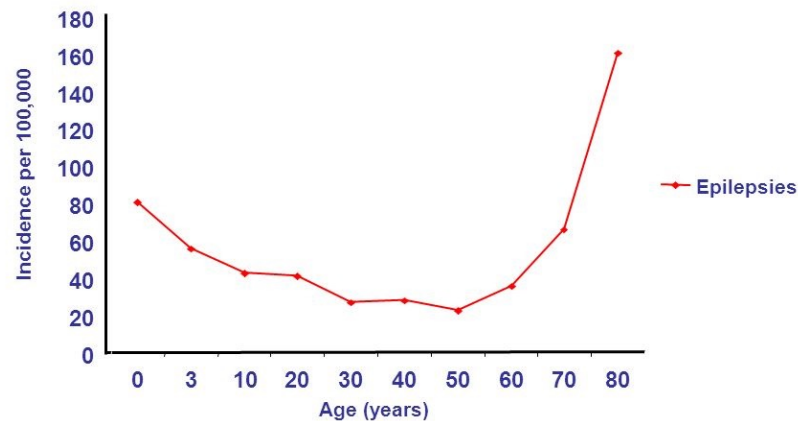
STRONG EPILEPSY CENTER



# Epilepsy is common, especially in kids

- ▶ 1 in 26 people will experience a diagnosis of epilepsy in their lifetime
- ▶ Epilepsy commonly starts in childhood

## Epilepsy: Incidence according to age



Annegers JF. Dans: Treatment of Epilepsy: Principle and Practice, 2nd Ed. Baltimore, MD, Williams & Wilkins. 1997: 165-172

# Special considerations in summer

- ▶ Kids with DEE, and really epilepsy of all kinds, are at risk for dysautonomia (difficulty regulating temperature, heart rate, and blood pressure in different environmental settings)
  - ▶ This puts them at higher risk for overheating, getting too cold in pools or in the air conditioning, or having increased puffiness or secretions when over heated.
- ▶ **Tips for keeping the right temperature**
  - ▶ Modulate time in the sun (wear sunscreen when outside, use rash guards, consider covers on wheelchairs and strollers)
  - ▶ Watch for lethargy, increased seizures, skin color changes (getting pale or red) to trigger a body temp check
  - ▶ Consider cooling fans, spray bottles, cooling towels or cold vests to beat the heat
  - ▶ Watch for shivering/ skin color changes (getting pale or turning purple/blue) to get them out of pools/AC environments and warm them up
- ▶ In some states, there is additional supports for schools to be able to provide temperature regulation (air conditioners) for kids that need them- including air conditioned transport (bussing) if appropriate.
- ▶ **Polarized** sunglasses can help to reduce glare and photically-induced seizure in kids who are sensitive to bright or flashing lights
- ▶ Dehydration can also be a trigger for seizures – so check with their team about how to add extra water to feeds, free water flushes, or meals to reduce dehydration risk!
- ▶ If these things are important for your child, make sure that their school/program team know about them and have a plan!



Prepping for summer



## What are people worried about?

- ▶ Seizures cause brain damage.
- ▶ Someone might die during a seizure.
- ▶ They might do something wrong that could harm a child or put teachers/schools at a liability.
- ▶ Seizures interfere with learning.
- ▶ Seizures disrupt the school day for the child and others around them.
- ▶ Aggressive/Irritable behavior might really be a seizure.



## What is the reality?

- ▶ Most students with epilepsy can (and SHOULD) participate safely in all aspects of school, including school sports, gym, and other activities to the best of their abilities, with appropriate supervision and precautions.

# Combat fear with information and education by identifying needs and establishing a plan

- ▶ Students with epilepsy may:
  - ▶ need to go to the school nurse for medicines, or rest if they feel a seizure coming on or have experienced seizure activity during the school day
  - ▶ have side effects from medicine, causing them to be tired, moody, or less attentive
  - ▶ miss class time due to seizures, epilepsy work up, or doctor visits
  - ▶ have learning or behavior problems associated with their underlying diagnoses or medication side effects (or the psychosocial issues related to epilepsy)
  - ▶ need seating accommodations so teachers can watch for seizures
  - ▶ may benefit from having an aide with them in the classroom setting to help with seizure monitoring, safety and redirection
  - ▶ feel embarrassed about their condition and may benefit from psychosocial supports





## How do we meet these needs?

- ▶ Individualized Education plan
- ▶ 504 plan
- ▶ Seizure action plan



# What Can Parents Do?

- ▶ Talk with the school and share what happens when their child has a seizure.
- ▶ Work with your provider to make sure your student with epilepsy has a seizure action plan
- ▶ Make sure that the seizure action plan is part of their *IEP* or 504 education plan.
- ▶ Ensure that people who work with the child regularly are familiar with the plan and are prepared to respond in the event of an emergency.
- ▶ Most seizures are not life-threatening. But if one lasts longer than 3-5 minutes or the child seems to have trouble breathing, or isn't recovering from a seizure, ensure that people know to call 911 right away.
- ▶ Kids and teens who have had a seizure may be tired, disoriented, confused, or even combative and agitated for minutes to hours. Make sure people know how to handle those experiences.
- ▶ Make safety plans for students to have recovery spaces, to go to the school nurse to lie down or go home for the day.
- ▶ Does the student require extra time to make up any missed class work or assignments?

<https://kidshealth.org/en/parents/epilepsy-factsheet.html>

<https://kidshealth.org/CookChildrens/en/parents/504-teachers.html>



# Seizure Action Plan

- ▶ What are the components?
  - ▶ Who is the kid and what are their needs/characteristics?
  - ▶ What do seizures look like?
  - ▶ Are there triggers to be aware of or to avoid?
  - ▶ What do they need to do to keep a kid safe during the seizures?
  - ▶ When do they need to use a rescue medication? (how much rescue medication, and what are the rules for when it can be used?)
  - ▶ When do they need to call EMS/ send a child to the hospital?
  - ▶ What are the safety precautions associated with a specific child's epilepsy?

# Creating a Seizure Action Plan

- ▶ You are not ALONE!
- ▶ Great resources: <https://seizureactionplans.org/>
  - ▶ The Seizure Action Plan Coalition
  - ▶ Seizure action plan awareness week is in February each year!



# Who is the kid and what are their needs/characteristics



## Individualized Seizure ACTION Plan (I-SAP)

Date I-SAP 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-SAP 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 do seizures look like?

## What triggers should they be aware of/avoid?

### 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-SAP to one page only so it can be used in an emergency. Just brief facts only. Delete this gray text of suggestions when finished.



## Seizure Action Plan

Effective Date

**This student is being treated for a seizure disorder. The information below should assist you if a seizure occurs during school hours.**

Student's Name	Date of Birth	
Parent/Guardian	Phone	Cell
Other Emergency Contact	Phone	Cell
Treating Physician	Phone	
Significant Medical History		

#### Seizure Information

Seizure Type	Length	Frequency	Description

Seizure triggers or warning signs:

Student's response after a seizure:

# What do they need to do to keep a kid safe during the seizures?

## 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-SAP 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?

Seizure triggers or warning signs:

Student's response after a seizure:

### Basic First Aid: Care & Comfort

Please describe basic first aid procedures:

Does student need to leave the classroom after a seizure? ☐ Yes ☐ No

If YES, describe process for returning student to classroom:

### Emergency Response

A "seizure emergency" for this student is defined as:

#### Seizure Emergency Protocol

(Check all that apply and clarify below)

- ☐ Contact school nurse at \_\_\_\_\_
- ☐ Call 911 for transport to \_\_\_\_\_
- ☐ Notify parent or emergency contact
- ☐ Administer emergency medications as indicated below
- ☐ Notify doctor
- ☐ Other \_\_\_\_\_

### Basic Seizure First Aid

- Stay calm & track time
- Keep child safe
- Do not restrain
- Do not put anything in mouth
- Stay with child until fully conscious
- Record seizure in log

#### For tonic-clonic seizure:

- Protect head
- Keep airway open/watch breathing
- Turn child on side

#### A seizure is generally considered an emergency when:

- Convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- Student has repeated seizures without regaining consciousness
- Student is injured or has diabetes
- Student has a first-time seizure
- Student has breathing difficulties
- Student has a seizure in water

# When do they need to use a rescue medication/what dose/what rules? When do they need to call EMS?

## 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?

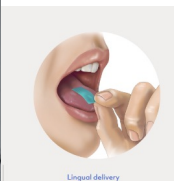
## When to call emergency services or go to the emergency department:

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)?

## Treatment Protocol During School Hours (include daily and emergency medications)

Emerg. Med. ✓	Medication	Dosage & Time of Day Given	Common Side Effects & Special Instructions

Does student have a Vagus Nerve Stimulator? ☐ Yes ☐ No If YES, describe magnet use:







# What are the safety precautions associated with a specific child's epilepsy?

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**Special Considerations and Precautions (regarding school activities, sports, trips, etc.)**

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Describe any special considerations or precautions:

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Physician Signature \_\_\_\_\_ Date \_\_\_\_\_

Parent/Guardian Signature \_\_\_\_\_ Date \_\_\_\_\_

DPC772

# Other considerations: Think about your audience!

Distributed by **Epilepsy Alliance America** epilepsyallianceamerica.org

## 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)

☐ Absc seizure (also called drop) ☐ Absence seizure (also called petit mal) ☐ Tonic seizure ☐ Clonic seizure ☐ Focal impaired awareness seizure (also called complex partial)

Describe: \_\_\_\_\_

### Care

#### Standard Care Needed

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

Time the seizure ☐ Keep person safe ☐ Don't restrict ☐ Stay with person ☐ Keep a record

#### Provide Rescue Treatment

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

☐ Rectum ☐ Nose ☐ Mouth ☐ Other: \_\_\_\_\_

Specific instructions: \_\_\_\_\_

#### Call for Emergency Help

If any of these happen, \_\_\_\_\_ Get help now

☐ Seizure longer than \_\_\_\_\_ minutes ☐ Unusual seizure ☐ Injury/Blue lips ☐ Other: \_\_\_\_\_

Call Healthcare Provider if: \_\_\_\_\_  
 Call for Emergency Help if: \_\_\_\_\_

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

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

☐ Absc seizure (also called drop) ☐ Absence seizure (also called petit mal) ☐ Tonic seizure ☐ Clonic seizure ☐ Focal impaired awareness seizure (also called complex partial)

Describe: \_\_\_\_\_

NOTES: \_\_\_\_\_

### Care

#### Standard Care Needed

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

Time the seizure ☐ Keep person safe ☐ Don't restrict ☐ Stay with person ☐ Keep a record

NOTES: \_\_\_\_\_

#### Provide Rescue Treatment

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

☐ Rectum ☐ Nose ☐ Mouth ☐ Other: \_\_\_\_\_

Specific instructions: \_\_\_\_\_

#### Call for Emergency Help

If any of these happen, \_\_\_\_\_ Get help now

☐ Seizure longer than \_\_\_\_\_ minutes ☐ Unusual seizure ☐ Injury/Blue lips ☐ Other: \_\_\_\_\_

Call Healthcare Provider if: \_\_\_\_\_  
 Call for Emergency Help if: \_\_\_\_\_

NOTES: \_\_\_\_\_

# Seizure Action Plans should be living documents.

- ▶ SAPs should be updated pretty regularly. Consider asking about updates with changes in
  - ▶ Seizure type
  - ▶ Seizure frequency
  - ▶ Seizure duration
  - ▶ Seizure medication type or dose
  - ▶ Rules of when to administer medications or to call for help
- ▶ Some schools/programs may have specific forms.
- ▶ You may need setting specific seizure action plans.



## Can my kid with epilepsy...

- ▶ Go to school (ABSOLUTELY! The Americans with Disabilities Act and the IDEA education law specifically address that kids with seizures can go to school)
- ▶ Go on field trips (Yes! That's what the Seizure Action Plan is for!)
- ▶ Swim? (Yes! To the best of their ability and... with appropriate supervision)

Questions?



THANK YOU!



GOLISANO  
CHILDREN'S HOSPITAL

