

Seizures and Epilepsy for IASN

LET'S USE OUR BRAINS TO
END EPILEPSY

EndEpilepsy.org

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Understanding Seizures and Epilepsy



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SEIZURES AND THE BRAIN

- The brain contains billions of nerve cells called **neurons** that communicate with each other by **sending and receiving electrical impulses**
- A **seizure** occurs when there is **abnormal and excessive electrical activity** that temporarily interrupts normal brain function



EVERY brain has
the potential
to seize

DEFINITION OF EPILEPSY

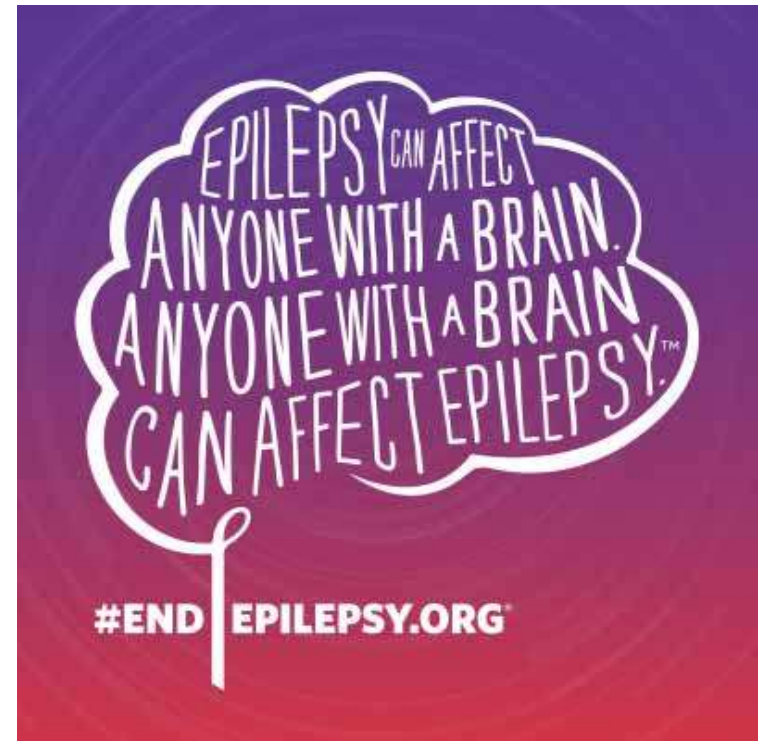
Epilepsy refers to a condition in which a person has a risk of recurrent seizures.

- A person is **diagnosed with epilepsy** if he/she has two unprovoked seizures or one unprovoked seizure with the likelihood of more.



THE SPECTRUM OF EPILEPSY

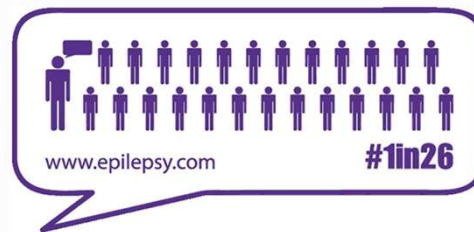
- **ANYONE** can be affected by epilepsy
 - Affects all ages, races and socioeconomic groups
 - **Children younger than age 2 years** and **adults older than 65** are more likely to be diagnosed with epilepsy



EPILEPSY BY THE NUMBERS

65 million
people:
worldwide
living with
epilepsy

470,000 children: have
active epilepsy in the US



For 60% of newly
diagnosed cases of
epilepsy the cause is
unknown

1 in 26 people in the US will be diagnosed
with epilepsy during their lifetime

3 million
adults: have
active epilepsy
in the US

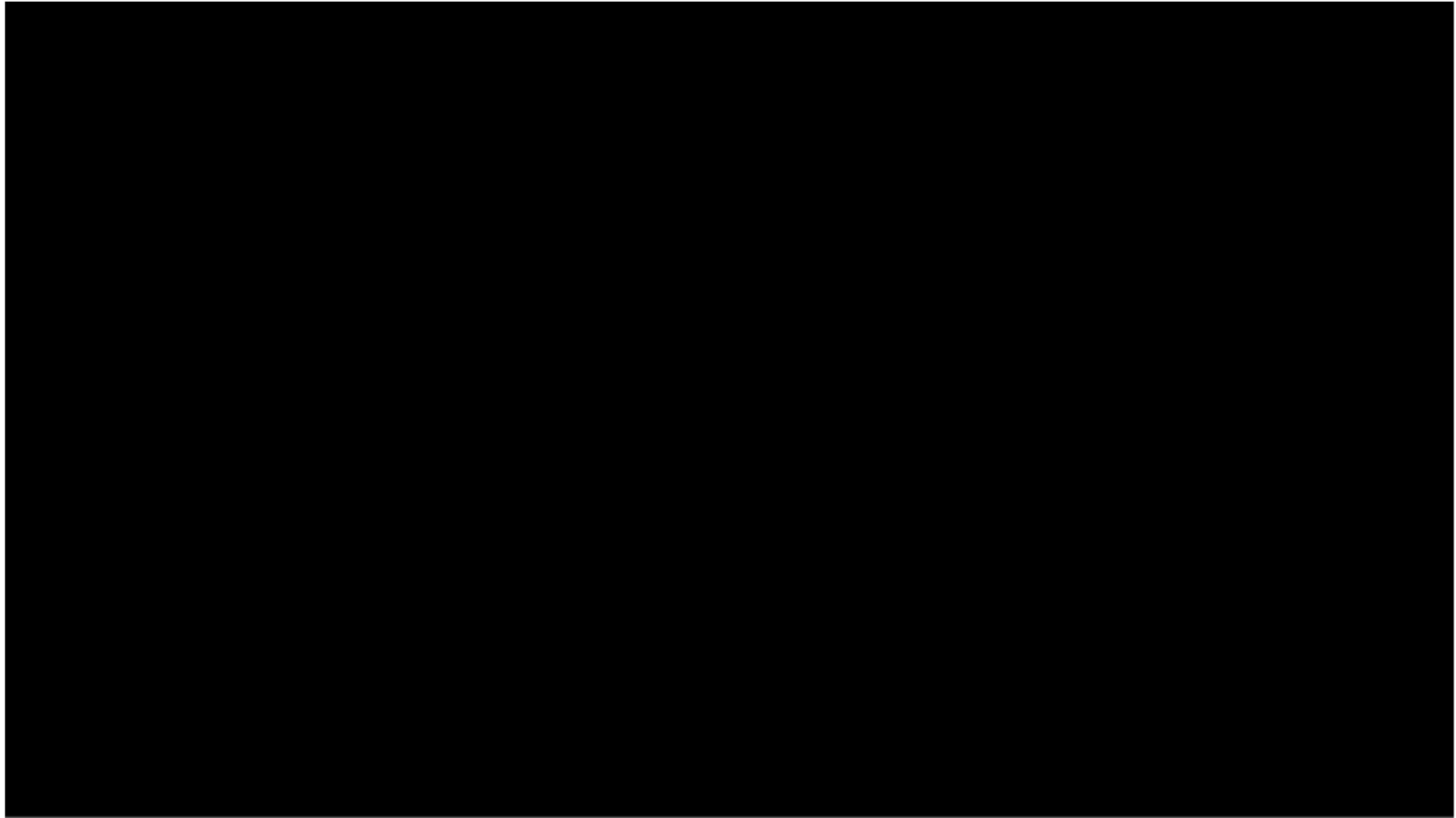
150,000 new cases of
epilepsy are diagnosed
each year in the US

1 in 10 people in the world
will experience a seizure
during their lifetime

EPILEPSY : CAUSES

- When the cause of epilepsy is known, the four most common causes are:
 1. Head Trauma
 2. Stroke
 3. Brain Tumor
 4. Brain infection
- Other causes include: metabolic, genetic, congenital malformations, immune diseases, unknown
- Advances in brain imaging and whole genomic sequencing will help more people better understand the cause of their epilepsy

Epilepsy is **more common** than Cerebral Palsy, Parkinson's Disease, and Multiple Sclerosis combined



SEIZURE TYPES

- ***Generalized Onset Seizures***
 - Involve both sides of the brain
 - Common types include absence and tonic-clonic
 - Symptoms may include convulsions, staring, muscle spasms and falls

GENERALIZED ONSET TONIC-CLONIC

- A sudden, hoarse cry; Loss of consciousness
- A fall; Shallow breathing & drooling may occur
- Convulsions (stiffening of arms and legs [tonic] followed by rhythmic jerking [clonic])
- Possible loss of bowel or bladder control
- Occasionally skin, nails, lips may turn blue
- Generally lasts 1 to 3 minutes
- Usually followed by confusion, headache, tiredness, soreness, speech difficulty



SEIZURE TYPES CONTINUED

- ***Focal Onset Seizures***
 - Involve only part of the brain
 - Common types include focal aware and focal impaired awareness
 - Symptoms relate to the part of the brain affected

GENERALIZED ONSET ABSENCE SEIZURES

- Pause in activity with blank stare
- Brief lapse of awareness
- Possible chewing or blinking motion
- Usually lasts 1 to 10 seconds
- May occur many times a day
- May be confused with:
 - Daydreaming
 - Lack of attention
 - ADD



FOCAL IMPAIRED AWARENESS SEIZURES

- Awareness impaired/inability to respond
- Often begins with blank dazed stare
- Clumsy or disoriented movements, aimless walking, picking things up, nonsensical speech or lip smacking
- Often lasts 1 to 3 minutes
- Often followed by tiredness, headache or nausea
- May become combative if restrained
- May be confused with: drunkenness, drug abuse, aggressive behavior



SEIZURE FIRST AID

STAY with the person and start timing the seizure. Remain ***calm*** and check for medical ID.



Keep the person **SAFE**.

Move or guide away from ***harmful objects***.

Turn the person onto their **SIDE** if they are not awake and aware. ***Don't block airway***, put something small and soft under the head, loosen tight clothes around the neck.

SEIZURE FIRST AID



Do **NOT** put ***anything*** in their mouth.

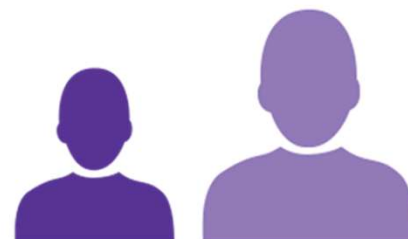
Don't give water, pills or food until the person is awake.

Do **NOT** *restrain*.



STAY with them until they are awake and alert after the seizure.

Most seizures end in a few minutes.



SEIZURE FIRST AID

CALL 911:

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

What is SUDEP?

- Sudden Unexpected Death in Epilepsy (SUDEP) is said to occur when a person with epilepsy dies unexpectedly and was previously in their usual state of health.
- The death is not known to be related to an accident or seizure emergency such as status epilepticus.
- Each year, about 1 out of 1,000 adults and 1 out of 4,500 children with epilepsy die from SUDEP.
- It occurs more frequently in people with epilepsy whose seizures are poorly controlled.



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**SEIZURE
OBSERVATIONS
AND TRIGGERS**



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TIPS FOR SEIZURE OBSERVATION

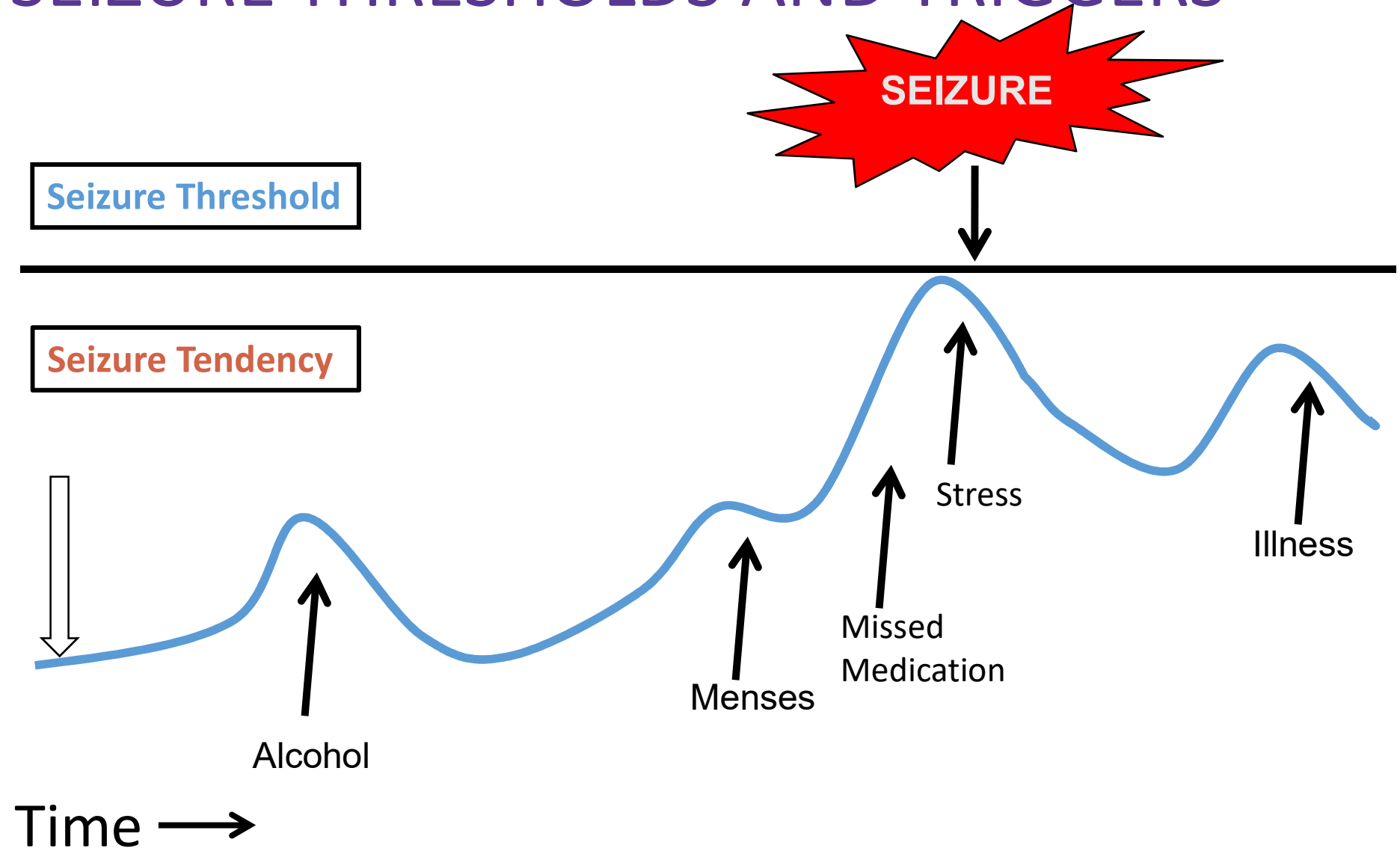
- What happens during each part of seizure:
 - Before, during and after
- Look for changes in:
 - Awareness, ability to talk and understand, remember, think clearly
 - Changes in senses, movement, muscle tone, facial expression, mood, and more
- How long it lasts:
 - Length of seizure and time it takes to return to usual state or activity



WHAT IS A SEIZURE TRIGGER?

- Seizures may occur in patterns.
- Something that makes a seizure more likely is called a seizure trigger
- Common seizure triggers:
 - Not taking medicine consistently
 - Not getting enough sleep or poor quality sleep
 - Stress
 - Alcohol
 - Menstruation, other hormonal changes
 - Not eating well
 - Flashing lights or patterns

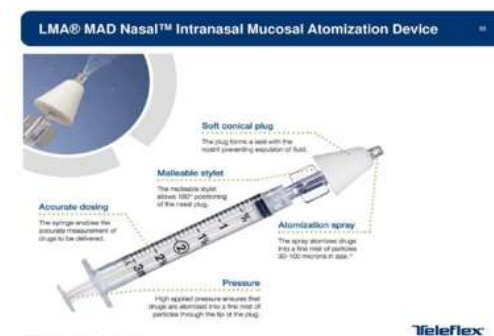
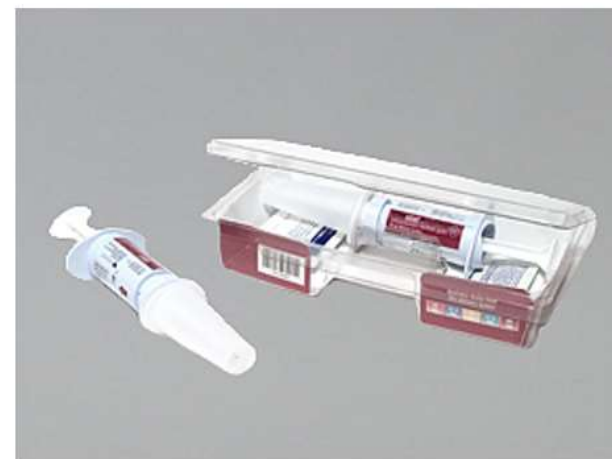
SEIZURE THRESHOLDS AND TRIGGERS



RESCUE THERAPIES

WHAT ARE THEY?

- Used “as needed” to stop seizures that are different or longer than usual or happen in a different pattern.
- Prescribed by health care provider, can be given by non-medical people outside of the hospital. Must be given *exactly* as prescribed.
- Does NOT take the place of usual seizure medicines.



Treatments of Status Epilepticus and Cluster Seizures

For people with seizures who experience status epilepticus (prolonged or recurrent seizures), getting the earliest possible treatment is important. The availability of treatments before emergency medical services (EMS) arrive or before being treated in an emergency room, is currently limited, but crucial.

When considering early treatments for status epilepticus, which can be given by family members or bystanders, the medication used needs to be effective at stopping seizures, and the delivery method needs to be easy to use, reliable, and able to quickly get the drug into the blood stream and brain.

Until recently, only the rectal form of [diazepam \(Diastat\)](#) was FDA approved for at-home treatment of cluster seizures. Though this is widely available, the route of administration is problematic in many circumstances.

Nayzilam (midazolam) Nasal Spray Approved for Seizure Clusters

- Nayzilam is a rescue therapy for acute (immediate, short-term) treatment of intermittent, stereotypic episodes of frequent seizure activity. This means that the medicine can be used to treat seizure clusters, bouts of increased seizures, or acute repetitive seizures (ARS).
- It can be given by a non-medical person outside of a hospital setting – when a person needs it!
- It's a nasal spray that can be given easily by the person with epilepsy between seizures. Or it can be given by someone else to a person during a seizure.
- Nayzilam (midazolam) is from a group of drugs called benzodiazepines. It is very good at stopping seizures quickly when used intermittently or “as needed” for specific situations.
- It is NOT approved as a seizure medicine to be used on a daily basis. And, it should not take the place of a person's usual seizure medication.

IF SEIZURES ARE NOT CONTROLLED AFTER 2 MEDICINES – ADDITIONAL OPTIONS

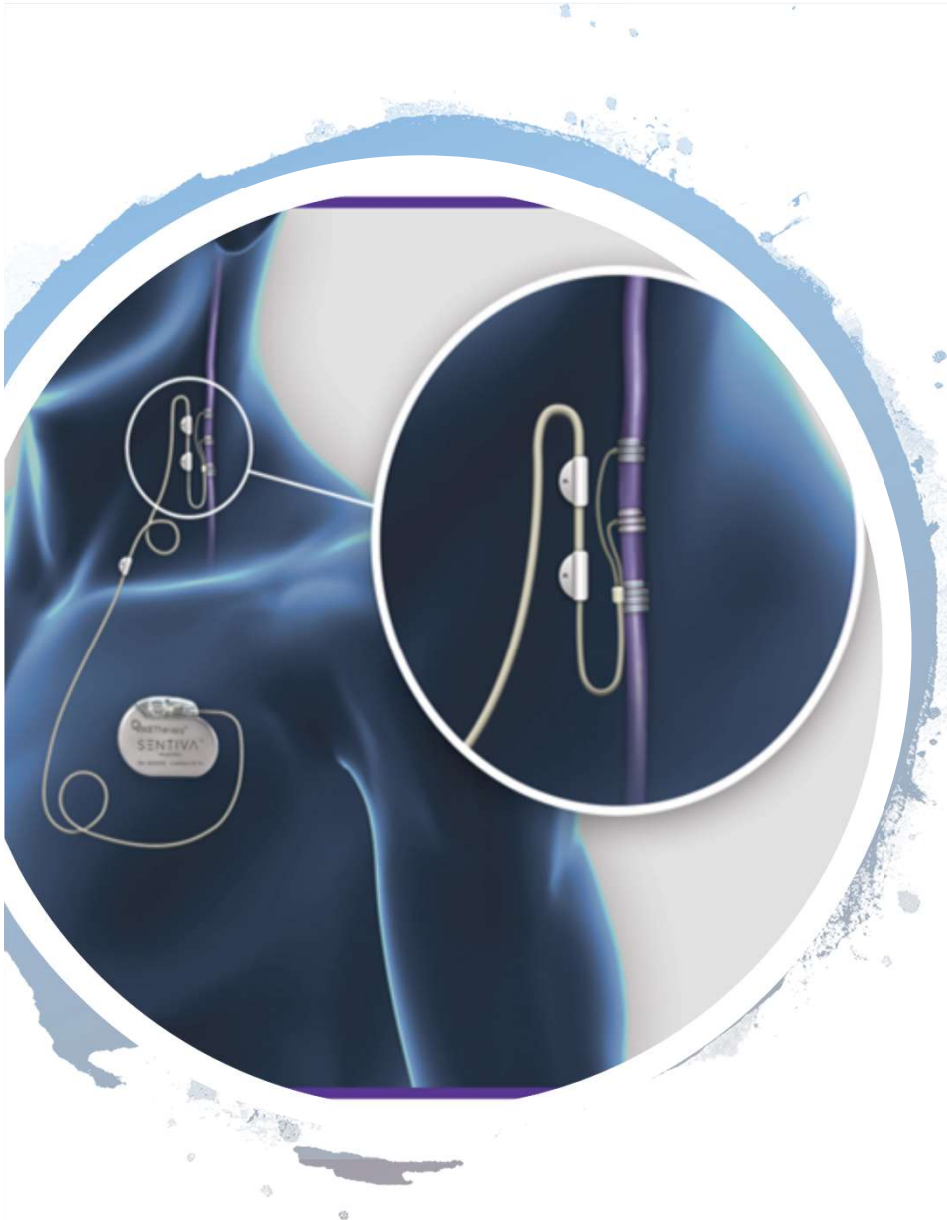
- Surgery
- Devices
- Dietary Therapy

SURGERY FOR EPILEPSY

- An option for some people if seizure medicines don't work and other therapies aren't appropriate
- Surgery may be possible if:
 - Seizures come from one area of the brain
 - Area is safe to remove without harming key areas of brain function (speech, movement, vision)
- Post surgery adjustment period

VAGAL NERVE STIMULATOR (VNS)

- Device implanted under the skin in the chest with wires that attach to the vagus nerve in the neck
- Delivers intermittent electrical stimulation to the vagus nerve in the neck that sends impulses to the brain
- Used primarily to treat focal seizures when medications don't work
- Magnet should be part of seizure first aid – swiping it over generator in student's chest can send an extra burst of stimulation – may help stop or lessen seizure
- Student will still take anti-seizure medication



DIETARY THERAPIES

Ketogenic, Modified Atkins, Low Glycemic Diets

- Burning fat for energy has an anti-seizure effect
- Used primarily to treat seizures in children but also works in adults
- Ketogenic diet includes high fat content, no sugar, low carbohydrate and adequate protein intake
- Requires strong family, school and caregiver commitment – *no cheating allowed*
- It is a medical treatment and requires medical supervision - *not a fad diet*



Medical Cannabis and CBD

- Medical cannabis and/or CBD must be used under the close supervision of your treating physician or prescribing provider.
- If an individual unilaterally, without the consultation or supervision of their treating physician, introduces medical cannabis and/or CBD to their treatment plan, they could be at a greater risk of breakthrough seizures, side effects, or other complications.
- Medical cannabis and CBD are not without side effects and may affect the efficacy of other medications taken.
 - The most common side effects - sleepiness, sedation and lethargy, elevated liver enzymes, decreased appetite, diarrhea, rash, fatigue, malaise and weakness, and insomnia.
 - There is also the risk of liver injury, generally mild, but which raises the possibility of rare, but more severe injury. This was seen more often when CBD was combined with valproic acid (Valproate, Depakote™).
 - CBD can significantly interact with a number of other medications including some taken for seizures

Medical Cannabis and CBD Continued

- While there have been some instances in which individuals were able to wean off certain medications under medical supervision while taking CBD, it is not true for every individual and should not be done without the guidance and supervision a physician. Anticonvulsant medications, including Epidiolex® and CBD, are not one-size-fits-all.
- Not all CBD products are the same. Many products claiming to have CBD also have other chemicals, bacteria, or mold.
- Further, there is no consistency within these products, which may cause seizures and/or side effects to change from month to month.

Medical Cannabis and CBD Continued

- Because of the lack of robust oversight in the commercial-grade CBD space, the FDA has found that some products were making unsubstantiated medical claims or did not contain the amount of CBD they claimed to contain, including, at times, containing no CBD at all.
- Epidiolex[®] is currently the only FDA approved CBD product, , a purified (>98% CBD) plant-based formulation that is oil-based, for the treatment of seizures associated with two rare and severe forms of epilepsy, Lennox-Gastaut syndrome and Dravet syndrome.



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**SEIZURE SAFE
SCHOOLS
LEGISLATION**



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Seizure Safe Schools

- Indiana was the second state to pass seizure school legislation
- The law take effect July 1st, 2020
- It requires all new staff and all recertifying staff to take appropriate seizure recognition and first aid training
- The Epilepsy Foundation provides free in person training for school personnel state wide
- Online training is also available
- New updated training is now available through the National Epilepsy Foundation

Seizure Action Plans

- It is the responsibility of the family to alert the school of a seizure action plan
- The law requires a school to use each individual's seizure action plan to respond to each student's seizure
- It also ensures that whatever medication that the family's medical team directs is made available to the student
- A teacher cannot be made to give a medication they are uncomfortable with, but a school must work out a way to make sure a student has access to needed medication
- The Epilepsy Foundation of Indiana is working with the Department of Education and the Indiana School Nurses Association to help the training and implementation go as smoothly as possible

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EPILEPSY FOUNDATION RESOURCES



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Epilepsy Foundation Resources

- Statewide
- Free Resources / Materials – families, schools, offices...
- Free trainings
- Monthly Facebook Live events
- Kids Crew
- Support Groups
- Connection to resources
- Monthly Newsletter
- Social Media

Toll Free Helpline: 1-800-332-1000

24 hours a day, 7 days a week

English & Spanish

epilepsy.com

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QUESTIONS
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THANK
YOU



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