Family Education and Support

Supported by HRSA MCHB Cooperative Agreement Number U23MC26252
Key Topics

- First Aid
- Seizure safety
  - Water
  - Sports
  - Physical activity
- Driving
- Familial Psychosocial Needs in Treating Pediatric Epilepsy
Role of the Primary Care Team

- Create a seizure safety plan and to know the basics about how to partner with families to choose and administer a rescue medication if needed

- Know the basic common sense instructions for safety while the seizures are not controlled - with caveats that the advice might feel restrictive so to find positives
Role of the Primary Care Team

• Know state law for driving with epilepsy

• Know a couple of resources such as Epilepsy Foundation or Parent-2-Parent to give as information and support

• Be aware that kids with epilepsy might be at increased risk for mental health and learning disorders. Address as a priority during the first visit and explore more at future visits
First Aid When Someone is Having a Seizure

• Stay calm and stay with the person until the seizure is over
  • Pay attention to the time of the seizure
  • Discuss importance on not relying on “estimate of time”
  • Noting time seizure stopped

• Prevent injury by removing nearby objects
  • Especially sharp objects and objects that may fall on to the individual.
  • Wandering/confused patients should be guided away from harm (e.g. traffic)

Source: http://www.epilepsy.com/start-here/seizure-first-aid
First Aid When Someone is Having a Seizure

• Be sure the person is comfortable
  • Sit the person down in a safe place or guide to the floor if falling
  • Support the head to keep it from hitting the floor
  • If lying down, turn the person to the side with the mouth pointing toward the ground

• Be supportive
  • Keep onlookers away
  • Once they are able to communicate, explain in simple terms what happened
  • Offer to stay with the person or call someone to be with them.

Source: http://www.epilepsy.com/start-here/seizure-first-aid
DO NOT...

• Restrain the person
  • Stopping the person’s movements won’t stop the seizure and can cause injuries
  • If they are restrained when they are confused, they may react aggressively
  • If a person tries to walk around, let them walk in a safe, enclosed area if possible

• Insert anything in the person’s mouth
  • Do not put any object in the mouth: explain that one can’t swallow his/her tongue during a seizure
  • Do not give water, pills, or food until fully alert
    • Oral dissolving clonazepam/buccal or intranasal midazolam or benzodiazepine intensol solution is ok if prescribed

Source: http://www.epilepsy.com/start-here/seizure-first-aid
Call Emergency Medical Services If...

- The seizure lasts over 5 minutes- (Keep in mind that seizures often have a post-ictal phase that may be different from baseline activity)
- Seizures occur back-to-back without recovery between
- Seizures occur closer together than usual for the person
- Breathing becomes difficult or the person is choking
- The seizure occurs in water
- Injuries may have occurred
- The person asks for medical help
- First time seizure in a public place, with no one to help

Source: http://www.epilepsy.com/start-here/seizure-first-aid
Seizure Safety

• Epilepsy can be a challenge for maintaining independence, participating fully in activities, and social interactions
• Public safety vs. psychosocial impact
• Parents report disability due to restrictions in 83% of children with active epilepsy
• ↑ perceived disability when a doctor recommends restrictions.
  • Your words matter!

Joshi & Shellhaas, 2014
Seizure Safety

• Cognitively normal children with epilepsy have the same rate of injuries as children without epilepsy

• Risk factors for injury:
  • Generalized-onset seizures (due to falling, especially atonic seizures)
  • ↑ seizure burden
  • ADHD (increased impulsivity)
  • Intellectual disability
    • Often more difficult and severe epilepsy

Seizure-related injuries

• 500 children with epilepsy (133 “complicated” abnormal neurologic examination or IQ < 80) retrospective analysis, injuries serious enough to require medical attention
  • When comparing children with epilepsy (n= 210) with sibling controls (n=210)
    • 57% of kids with epilepsy sustained injury, compared to 50% of sibling controls. (p=0.17)
    • Of those with epilepsy 17% of injuries were attributed to seizures
    • 9% required hospitalization or surgery
    • 25% fractures, 22% head injuries, 8% dental injuries, 8% burns/scalds
    • Controls had similar numbers of injuries as uncomplicated epilepsy patients, but less often head injuries.

Seizure-related injuries

- 500 children with epilepsy (133 “complicated” abnormal neurologic examination or IQ <80) retrospective analysis, injuries serious enough to require medical attention
  - When comparing children with complicated (n=133) vs. uncomplicated (n=368) epilepsy
    - 27% of complicated epilepsy patients experienced a seizure related injury
    - Compared to 14% of uncomplicated patients. (P < 0.01)

Seizure-related injuries

- 122 children with newly diagnosed epilepsy (before treatment) and any type of injury
  - 9% had a seizure-related injury
    - 92% soft tissue injuries
    - 75% dental injuries
    - No submersion, fractures, concussions
  - 73% of injuries were with GTC seizures

Seizure-related injuries

- 25 children with epilepsy, otherwise normal
  - 14% sustained at least one seizure-related injury in their lifetime
  - No difference in age-matched nonepileptic peers
    - Trend toward increased number of bicycle accidents and head injuries (did not reach statistical significance)
  - Patients with ADHD had higher injury rate (epileptic or not)
  - One absence epilepsy patient had aspiration injury as a result of water being thrown in her face during a seizure

Source: Kirsch R, Wirrell E. Do cognitively normal children with epilepsy have a higher rate of injury than their nonepileptic peers? J Child Neurol 2001;16:100-104.
Seizure-Related Injuries

• 951 children and adults with epilepsy, 904 matched controls
  • Prospective study
  • 21% of patients and 14% of controls had an accident (P < 0.0001)
    • 24% were seizure-related
    • Location of accident: Domestic > street > work
    • Epilepsy patients had higher rates of hospitalization and medical action required for their accidents
    • Generalized convulsions more often resulted in concussion
    • Active epilepsy and at least monthly seizures is associated with an increased risk of accidents
    • When seizure-related accidents are removed, statistical significance is lost

Seizure-Related Injuries

- 33 patients in residential care given protective helmets
  - 14,751 seizures occurred
  - 59 injuries (risk 4/1000 seizures)
  - Scalp and facial bruises most common (50%)
    - No intracranial injuries, 3% dental injuries
  - Helmets were worn in 46% of accidents
    - 68% sustained facial or scalp injury, 48% needing medical attention
  - Helmets not worn in 41% of accidents
    - 57% sustained facial or scalp injury, 36% needing medical attention

- Conclusion: Helmets need to be better designed!

Seizure-Related

• 198 children with newly diagnosed, untreated epilepsy
  • 25 (12%) had an injury, none died
  • 4 (2%) required medical attention
  • 15 at home, 6 at school, 4 outside
• Seizure type
  • Tonic-clonic 17
  • Focal (Complex Partial) 4
  • Myoclonic 1
  • Uncertain 3
  • Absence 0

Seizure-Related

• 83% of parents of 122 children with epilepsy report that their child was disabled by restrictions suggested/imposed by physicians in order to prevent seizure-related injuries.

  • Most restrictions were:
    • Swimming
    • Bicycling
    • Staying overnight with friends

Prevention of Complications:

**HEAT SOURCES**

- People with uncontrolled seizures must be careful around all heat sources
- Microwave cooking is safest
- Cook on a back burner; electric safer than flame
- Set the maximum hot water temperature in the house to 110 degrees Fahrenheit
- Put guards on open fireplaces, wood stoves, and radiators
- Don’t smoke or use matches when alone

Prevention of complications:

**HEIGHTS**

- If seizures are not controlled, avoid working on ladders or unprotected heights
- Use a safety harness if feasible
- Be cautious with stairs if seizures not controlled
- Keep common household items on all floors of the house to avoid having to use the stairs as often

Prevention of complications:

**EQUIPMENT AND POWER TOOLS**

- Use safety guards on equipment for cutting, chopping, and drilling
- Make sure equipment (lawn mowers, etc.) have automatic stop switches
- As with anybody, use caution and protective gear

Prevention of complications:

**SAFETY PROOF THE ENVIRONMENT**

- Arrange the home, work, study places to be safe
  - Pad sharp corners, avoid glass tables
  - Use non-slip carpet
  - Avoid throw rugs
  - Put barriers in front of fireplaces or hot stoves
- For those who wander during the seizure....
  - Special caution to heights, rails, bodies of water
  - Shut the door when home alone
  - Be sure a neighbor or friend has a key to get in to check on the person
- For those with frequent falls
  - Wear a protective helmet

Prevention of complications:

**MOMS WITH EPILEPSY**

- Carrying the baby can be hazardous for those who fall with seizures
  - Use a small stroller
- Change the baby on the floor
- Do not bathe the baby in a tub when alone
- Have an enclosed safe play area
- Avoid co-sleeping

Safety: Water

• Relative risk ~ 14 for drowning
  • 96 for drowning in a bath; 23 for a pool

• Bathe & swim only with direct supervision (LIFEJACKETS)
  • Designate a specific supervisor in the pool.
  • Specify hot tubs, inflatable pools, wading pools, etc

• Showers are preferred
  • Unlock the bathroom door
  • Regulate the hot water temperature

Joshi & Shellhaas, 2014
Sports

• YES!!! Encourage patients to participate!
• Contact sports are **not** precluded
  • There is no evidence they induce seizures.

• Swimming and water sports, harnessed rock climbing, horseback riding, and gymnastics
  • Safe with appropriate supervision

• Free climbing, sky-diving, hang-gliding, and scuba diving
  • Not safe

*Source: Joshi & Shellhaas, 2014 www.epilepsy.com/epilepsy/safety_sports*
Bicycles

• Helmets are a **must !!!**
• Also applies to roller blades, inline skates, scooters, anything with wheels
• Ask “what is the color of your helmet?”

Joshi & Shellhaas, 2014
Driving

- **Driving is not permitted when seizures are not controlled**
- State laws differ as to when an individual with epilepsy can drive.
- Know your state’s laws about:
  - Driving with epilepsy
  - Physician reporting (PA, CA, DL, NV, NJ, OR)
  - Good resource: www.epilepsyfoundation.org
- If a parent of child with epilepsy has epilepsy, check if the parent is driving

Joshi & Shellhaas, 2014
Safety: Other Precautions

- Clothing irons
- Hairdryers and curling irons
- Camp fires
- BBQs
- Playground equipment

Joshi & Shellhaas, 2014
Seizure Management Plan

• All caregivers should have the person’s seizure management plan and be trained in the first aid measures used during/after a seizure.

• The plan should include:
  • Seizure description
  • Rescue medication
  • VNS activation

Source: The Epilepsy Foundation website

https://www.epilepsy.com/get-help/managing-your-epilepsy
Seizure Management Plan

• Seizure type(s) described
  • Warning signs
  • Seizure semiology
  • Typical seizure duration, what defines an emergency

• Rescue medication
  • Length of seizure
  • More than certain number of seizures in certain time

• VNS activation parameters
• INCLUDE LINK TO http://www.epilepsynorcal.org/docs/Seizure-Action-Plan_v1.pdf