Understanding Epilepsy to Promote Correct Diagnosis in Childhood and Effective Early Intervention

Epilepsy Facts...
- Approximately 2.2 million Americans have epilepsy
- Epilepsy is the most common neurological condition in children and the fourth most common in adults after Alzheimer’s, stroke and migraines
- Approximately 1 in 10 people will have a seizure in their lifetime and 1 in 26 people will develop epilepsy
- Over 60,000 people in our service area

Epilepsy is...
- NOT contagious
- NOT a mental illness
- NOT a mental impairment
- NOT a single disease

Conditions that might be confused with epilepsy...
- One time seizure
- Febrile Seizure
- Non-epileptic events
- Narcolepsy
- Tourette’s Syndrome
- Eclampsia
- Migraines
- Sleep disorders
- Cardiac disorders
- TIA – Transient Ischemia Attacks
- Drug or alcohol withdrawal
- Congenital health problem, like down’s syndrome, stroke or Alzheimer’s
- Schizophrenia
- Bipolar
- Depression
- Borderline personality disorder
- Multiple personality
- ADD or ADHD
- Hypochondria
- Breath holding spells
- Fainting episodes
- Daydreaming

Epilepsy is...
- A neurological disorder of the brain characterized by the tendency to have recurring seizures
- May also be called a Seizure Disorder
What happens to the brain during a seizure?
- Sudden electrical activity in the brain
- Most seizures are either focal (partial) or generalized
- Where the activity occurs in the brain will determine how the seizure will look

Possible Causes of Epilepsy
- Head trauma
- Brain tumor and stroke
- Infection and maternal injury
- Abnormal brain development
- Some forms are genetic

In 70% of the epilepsy cases – there is no known cause

Possible Seizure Triggers
- Failure to take medications
- Lack of sleep
- Stress / Anxiety
- Dehydration
- Photosensitivity – strobe lights
- Menstrual cycle / hormonal changes
- Environmental

Seizure Classification
Focal Onset Seizures (partial)
- Involves only part of brain
- May or may not have change in awareness
- Symptoms relate to the part of brain effected

Generalized Seizures
- Involves whole brain
- Convulsions, staring, muscle spasms, and falls
- Most common are absence & tonic-clonic

Focal Seizures w/o change in awareness (Simple partial seizures)
- Uncontrollable shaking movements of hand, arm or legs
- Sensory Seizures – may see flashing lights in peripheral vision, hear bells ringing, etc.
- Seizure usually lasts between 1 and 2 minutes – no impairment of consciousness
- May be considered an aura
- No immediate action is needed other than reassurance and emotional support
- A medical evaluation is recommended

A medical evaluation is recommended
Focal Seizures with change in awareness (Complex partial seizures)

- Most common seizure type
- Unaware of surroundings and unable to respond
- Repetitive, purposeless movements such as lip smacking, hand wringing, or wandering - actions seem unusual
- Seizure usually lasts approximately three minutes

Appropriate Response for Complex Partial Seizures

- Stay calm
- Track time
- Do not restrain
- Gently direct away from hazards
- Remain with the individual until they have gained full awareness

Absence Seizures (formerly petit mal)

- Usual onset between 4 and 12 years of age
- Characterized by brief staring – can be confused with “daydreaming”
- Starts and ends abruptly - can happen several times a day
- Quickly returns to complete awareness
- Appropriate response includes documentation

Generalized Tonic Clonic (formerly grand mal)

- NOT the most common type
- Completely unconscious – loss of control
- Characterized by a sudden fall
- May cry out or make some types of noise
- Onset of uncontrolled jerking or shaking of muscles
- May have irregular breathing
- Lasts 5 minutes or less

Appropriate Response for Generalized Tonic Clonic Seizures

- Stay calm
- Protect their head
- Turn on side to prevent choking *
- Track time
- Check for Seizure Disorder ID
- Move objects out of the way

* Do NOT put anything in the person's mouth.

Convulsive Seizure in a Wheelchair

- Don’t remove from wheelchair unless absolutely necessary
- Secure wheelchair to prevent movement
- Fasten seatbelt loosely to prevent student from falling from wheelchair
- Protect and support head
- Ensure breathing is unobstructed and allow secretions to flow from mouth
- Pad wheelchair to prevent injuries to limbs
- Follow relevant seizure first aid protocol
Convulsive Seizure on a School Bus

- Safely pull over and stop bus
- Place student on their side across the seat facing away from the seat back or in aisle
- Follow standard seizure response protocol
- Continue to destination or follow school policy

Call 911 if the person...
- Is injured
- Has diabetes or is pregnant
- Does not resume normal breathing or breathing stops
- Has a 1st time seizure
- Has a seizure in water
- Situation escalates

Also call 911 if:
- STATUS EPILEPTICUS
  - There is more than 5 minutes of continuous seizure activity
  - Two or more consecutive seizures (cluster) without complete recovery

Convulsive Seizure in the Water

- Support head so that both the mouth and nose are always above the water
- Remove the student from the water as soon as it can be done safely
- If the student is not breathing, begin rescue breathing
- Always transport the student to the emergency room, even if they appear fully recovered

Appropriate Response for Generalized Tonic Clonic Seizures

- Remain with them until they have gained full awareness
- If seizure lasts more than 5 minutes, call EMS
- Recovery period– post ictal state
  - Not included in timing of the seizure

Treatment Options

- Medication
- Brain surgery
- Medical Devices
- Diet
- Social and psychological support
Medications
- Medications are often the first line of treatment
- Approximately 60% of people achieve seizure control after the 1st year
- 15% achieve control at a later date
- 25% continue to have seizures despite treatment
- Currently there are over 30 different medications

Common Side Effects of Medication
- Lethargy
- Weight gain / weight loss
- Cognitive, concentration, memory difficulties
- Hyperactivity
- Emotional and/or behavioral changes
- May go away after first several weeks

Rescue Medications
- Used in emergency situations to stop a seizure that will not stop on its own
- State/school district regulations often govern use in school
- There are various emergency medications available
- It can be administered a few different ways
  - rectal
  - buccal
  - nasal

Brain Surgery Options
- Lobectomy
  - Partial Seizures
  - Hope for result of seizure free
- Corpus Callosotomy
  - Generalized Seizures
  - Never seizure free, less frequent/intense seizures
- Visualase
  - MRI guided laser ablation
  - Minimally invasive
  - For tumors, tubers - MRI visible lesions

Medical Device Options
- RNS (NeuroPace)
  - Responsive Neurostimulator System
  - Need to know localization of epileptic brain tissue
  - Remote monitor
Special Diets

- Ketogenic Diet
  - Burns fat instead of glucose (fasting induced)
  - Gets 80% of calories from fat
  - Gets 20% from carbohydrates and proteins
  - Must be strictly managed and maintained daily
  - 1/3 become seizure free or almost seizure free
  - 1/3 improve but still have some seizures
  - 1/3 do not respond or find it too hard to comply
- There are other various diets that may used in conjunction with other treatment options

Alternative Therapies

- Seizure Assist Dogs
  - Help people during and after a seizure
  - May be trained to get help
  - May wear a backpack with pockets that can hold medicine and medical alert information in case the person is unable to communicate

Medical Cannabis - Minnesota

- Patient registry process for monitoring and evaluating
- Established a medical cannabis task force
- July 1, 2015 medical cannabis became available to registered patients
- Need personalized service? Our 24/7 helpline is available at 800.779.0777, ext. 2310 during business hours or 800.332.1000 (en Espanol) 866.748.8008 (after hours)

Social and Psychological Support

- It is important for the person with epilepsy to take care of their whole self, including their social well-being, mental health, family relationships, employment issues, and spiritual needs
- Living with a chronic condition like epilepsy can be quite stressful on oneself as well as one’s support system
- Team approach - may include a psychologist or social worker

Safety Issues with Epilepsy

- Safety at home
- Safety at work
- Driving
- SUDEP
The Impact on Learning & Behavior

- Seizures may cause short-term memory problems
- After a seizure, coursework may have to be re-taught
- Medications may cause drowsiness, inattention, concentration difficulties and behavior changes
- Students with epilepsy are more likely to suffer from low self-esteem
- School difficulties are not always epilepsy related

Tips for Supporting Students with Epilepsy

- Stay calm during seizure episodes
- Be supportive
- Have a copy of the child's seizure action plan
- Discuss seizure action plan in the child's IEP
- Know child's medications and their possible side effects
- Encourage positive peer interaction
- Communicate with the parents

Possible Impact of Epilepsy

- Depression, Anger, Anxiety, Fear
- Cognitive Problems
- Developmental Delays
- Relationships
- Financial Costs
- School/Employment
- Driving
- Recreational Activities

What Does EFMN DO?

Bemidji Connect
Sanford Bemidji Medical Center Conference Room
May 10 & November 8 5:30-7:30 PM
Join us for a time to connect with individuals and families affected by epilepsy for a potluck style dinner. After dinner, children's activities will be available while the adults enjoy conversation.

RSVP @ 218.624.1330
Or lpeterson@efmn.org
Family Potluck Picnic
Tuesday, July 19 5:30-7:30 pm
Diamond Point in Bemidji

Bring your own beverage and a dish to share for our family potluck picnic. If you have a lawn game, bring it as well! Want to learn how to get involved with Bemidji’s Rise Above Seizures Walk? Contact Tia Barthorpe at 218.335.2641 or docbart@paulbunyan.net to hear about her DIY fundraiser.

The Rise Above Seizures Walk helps raise awareness and funds to educate, empower, and connect people affected by epilepsy.

Please RSVP: 1.800.779.0777 or rsvp@efmn.org
Reach Us @ 218.624.1330
Or lpeterson@efmn.org

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Shining Star Event
SHINING STARS & STRIKES
Saturday, April 2 | 1-3 PM
Incline Bowling Station
601 W Superior Street in Duluth

Shining Stars and Strikes brings youth with epilepsy from across MN and ND together to bowl and meet others affected by seizures. Duluth, Fargo, Rochester, St. Cloud and Twin Cities are hosting this event simultaneously. Cost is $10/immediate family (includes food and bowling). RSVP by Friday, March 25.

Please RSVP: 1.800.779.0777 or rsvp@efmn.org
Reach Us @ 218.624.1330
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Make A Difference!
Help us educate, connect and empower those impacted by epilepsy!

- Visit us online at www.efmn.org/giving
- Participate in your employee giving campaign (United Way, Community Health Charities or Combined Federal Campaign)
- Attend EFMN events
- Donate your used clothing

efmn.org

The Epilepsy Foundation of Minnesota leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.

1.800.779.0777
www.efmn.org

Connect with us:
Facebook: Epilepsy-Foundation Minnesota
Twitter: @EpilepsyMN