

*March 2016 Evergreen Annual Conference:
Creating Hope & Healing for Youth & Families*

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



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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



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Epilepsy is...

- NOT contagious
- NOT a mental illness
- NOT a mental impairment
- NOT a single disease



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Conditions that might be confused with epilepsy...

- One time seizure
- Febrile Seizure
- Non-epileptic events
- Narcolepsy
- Tourette's Syndrome
- Migraines
- Sleep disorders
- Cardiac disorders
- TIAs -- Transient Ischemia Attacks
- Drug or alcohol withdrawal
- Eclampsia
- congenital health problem, like down's syndrome, stroke or Alzheimer's



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Conditions that might be confused with epilepsy...

- Schizophrenia
- Bipolar
- Depression
- Borderline personality disorder
- Multiple personality disorder
- Daydreaming
- ADD or ADHD
- Hypochondria
- Breath holding spells
- Fainting episodes



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Epilepsy is...

- A neurological disorder of the brain characterized by the tendency to have recurring seizures
- May also be called a Seizure Disorder



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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



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Possible Causes of Epilepsy

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



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



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Possible Seizure Triggers

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



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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



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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



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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



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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



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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



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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



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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.



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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



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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



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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



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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



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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



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Also call 911 if:

STATUS EPILEPTICUS

There is more than 5 minutes
of continuous seizure activity

OR

Two or more consecutive seizures
(cluster) without complete recovery



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Treatment Options

- Medication
- Brain surgery
- Medical Devices
- Diet
- Social and psychological support



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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



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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



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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



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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



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Medical Device Options



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Medical Device Options

- RNS (NeuroPace)
 - Responsive Neurostimulator System
 - Need to know localization of epileptic brain tissue
 - Remote monitor



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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 be used in conjunction with other treatment options**



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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



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Alternative Therapies

- **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)**



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How does it work?

1. Receive certification from physician
2. Enroll in registry program
3. After registry verification eligible to receive at distribution facilities
4. Patients must agree to continue treatment and provide ongoing reports
5. Visit efmn.org/cannabis to get latest information and learn how the process works.



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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



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Safety Issues with Epilepsy

- Safety at home
- Safety at work
- Driving
- SUDEP



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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



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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



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Possible Impact of Epilepsy

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



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What Does EFMN DO?



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What Does EFMN DO?



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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

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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 Lisa @ 218.624.1330
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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
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Help raise epilepsy awareness across MN & eastern ND through creative expression. Submissions welcome for all programs!

Epilogues

This writing program is open to anyone affected by epilepsy. An Epilogues compilation is published annually.

Brainstorms

This [art collection](#) features over 150 pieces and the collection travels throughout MN and eastern ND. Artwork must be mailed or dropped off at EFMN. For information about hosting a Brainstorms Artwork Exhibit, contact Diane Senjem at 651.287.2312 or dsenjem@efmn.org

Cadenzas

This program is for creative minds that enjoy the stage. Submissions are accepted in the form of YouTube, multimedia or live performance at the annual Creative Arts Program Showcase. Save the date for the 2015 Creative Arts Program Showcase on Sunday, November 8 in Minneapolis.

<http://www.epilepsyfoundationmn.org/programs/adults/creative-arts/>



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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



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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

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