EPILEPSY FOUNDATION
Michigan

Epilepsy & Seizure Disorders In Children

Advocating for a Child with Epilepsy in the Health Care Community and Beyond

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Epilepsy: Prevalence

- Epilepsy is the third most common neurological disorder in the United States after Alzheimer's disease and stroke.
- 1 out of every 100 persons (1% of the population) in the United States has epilepsy.
- It is estimated that over 100,000 people in the state of Michigan have epilepsy.

Seizures and Epilepsy

- Epileptic Seizure:
  - Disturbance of electrical activity in the brain that causes temporary changes in consciousness, awareness, movement, feelings, or behavior
- Epilepsy:
  - General term for over 40 conditions, each characterized by recurrent unprovoked seizures
  - Epilepsy = “Seizure Disorder”

Causes of Epilepsy

- **Unknown Cause** (often involves genetic factors)– 69%
- **Stroke**– 13% (2% in children)
- **Congenital Malformations**– 5% (20% in children)
- **Traumatic Brain Injury**– 4%
- **Brain Tumor**– 4%
- **Infections** (meningitis/encephalitis)– 3%
- **Degenerative** (Alzheimer's, MS)– 2%
- **Birth Trauma** (e.g. hypoxia)
- **Poisoning** (e.g. lead poisoning, substance abuse, environmental toxins)

Conditions Associated with Epilepsy

- Intellectual Disability (25% have epilepsy)
- Cerebral Palsy (13% have epilepsy)
- CP and Intellectual Disability (40% have epilepsy)
- Autism (5- 38% have epilepsy)
- tuberous sclerosis, Rett syndrome, Sturge-Weber Syndrome, MS, lupus, and others

Non-Epileptic Seizures

- Psychogenic:
  - Related to psychological stress or trauma
  - Treatment generally involves psychotherapy
- Hypoglycemic (low blood sugar)
- Metabolic (e.g. electrolyte imbalance)
- Febrile (fever-related; most often in infants & young children)
- Drug-related
- Cardiovascular (fainting spell from low blood pressure, cardiac arrhythmias)

Seizure Categories

- Generalized:
  - Seizure affects both sides of the brain simultaneously
  - Examples: tonic-clonic (grand mal), absence, myoclonic, and drop seizures
- Partial:
  - Seizure starts in a specific part of the brain
  - Examples: simple and complex
  - Sometimes spread to whole brain becoming secondarily generalized

Tonic-Clonic Seizure (also known as Grand Mal)

- A sudden hoarse cry
- Loss of consciousness
- A fall
- Rigidity – tonic phase
- Convulsions (rhythmic jerking) – clonic phase
- Shallow breathing and drooling may occur
- Possible loss of bowel or bladder control
- Occasionally skin may turn pale or blue
- Generally lasts 1 to 3 minutes
- Often followed by confusion, headache, tiredness, soreness, speech difficulty

Absence Seizure (also known as petit mal)

- Most common in children
- Pause in activity with a blank stare – eye fluttering may occur
- Last no more than a few seconds
- Start and end abruptly
- No memory of time during seizure
- May be confused with: daydreaming, lack of attention
- Happens many times a day

Myoclonic Seizure

- One or more sudden, involuntary, brief, shock-like bodily jerks
- Frequently occur shortly after awakening
- Often associated with childhood epilepsy syndromes

Drop Seizure (tonic and atonic)

- Tonic:
  - Sudden or gradual stiffening of the muscles
  - Often cause falls
  - Usually regains consciousness promptly
- Atonic:
  - Sudden loss of muscle tone
  - Drop of head or fall to ground
  - Usually regains consciousness promptly

- With both types, individual may wear a helmet to prevent injury during falls

Simple Partial Seizure

- Consciousness *is not* impaired
- Involuntary movements (isolated twitching of arms, face, legs)
- Sensory symptoms (tingling, weakness, sounds, smells, tastes, visual distortions)
- Psychic symptoms (déjà vu, fear, anxiety, “a feeling they can’t explain”)
- Autonomic symptoms (increase in heart or breathing rate, sweating)
- Duration usually less than 1 minute
- May be confused with: acting out, mystical experience, mental illness, psychosomatic illness

Complex Partial Seizure

- Consciousness *is* impaired
- Blank stare/dazed look
- Automatisms (picking at clothing, chewing, lip smacking, hand wringing)
- Mumbling or repetitive speech
- Clumsy or disoriented movements
- Aimless walking
- Usually last 1 to 3 minutes
- Often followed by tiredness, confusion, or nausea – little or no memory of seizure
- May be confused with: behavior problems, substance abuse, or mental illness

Managing Seizures: Seizure Tracking

- Seizure Tracking Tools like ***My Epilepsy Diary*** and ***Seizure Tracker*** will be helpful
- Ask your child's neurologist about what type of information needs to be recorded
- Describe seizure type, symptoms, and duration
- Look for patterns (e.g. seizures associated with menstrual period, seizures occurring at a specific time of day, etc.)
- Make note of possible triggers
- Pay attention to common seizure warnings in your child

Auras (minutes prior) , prodromal signs (30 minutes to several hours prior) include memory or cognitive functioning change, speech difficulties, mood/behavioral changes, HA etc.

Seizure Triggers & Management

- **Missed medication (#1 reason)**
- **Stress/anxiety**
- **Sleep deprivation**
- Dehydration
- Growth spurts/Hormonal changes
- Illness
- Poor nutrition
- Hyperventilation
- Photosensitivity
- Drug/alcohol abuse; drug interactions

Avoidance of triggers involves teaching parents, and children. Preparing them for transition to adult epilepsy self-management

Managing Stress

- Stress can’t be avoided entirely, but it can be managed
- Try keeping a journal to identify stressors and how they affect your child
- Help your child with acceptable methods to use in identifying, avoiding, confronting, or coping with stressors
- Some stressors can’t be avoided. Learning relaxation techniques can help a child or teen cope with them
  - Deep breathing
  - Progressive Muscle Relaxation
  - Mindfulness Meditation
- If stress is persistent and interfering with daily functioning, seek professional help for your child to review AED regime for potential causes of behavioral or mood issues, assess for depression or ADHD and need for Pharmacological intervention, professional psycho-social evaluation and counseling

Healthy Sleep Habits

- Children to teenagers need anywhere fro 8.5 – 12 hours of sleep per night, Recent studies show that as children reach teen years, only15% get enough sleep each night.
- Even in people without epilepsy, sleep deprivation can lead to…
  - Problems with thinking and memory
  - Mood changes
  - Car accidents
  - Weight gain, hypertension, and lowered immune function
- Tips to improve sleep
  - **Regular sleep schedule**
  - No caffeine,, screen time, or exercise before bed
  - Check for nocturnal seizures or medication side effects
  - Get the child or adult tested for sleep apnea or other sleep disorders

First Aid for a Tonic-Clonic Seizure

- Remain calm
- Check your watch or a clock
- Cushion head
- Turn on side
- Loosen tight clothing; remove glasses
- Look for medical ID bracelet (i.e. encourage to purchase and wear)
- As seizure ends, help to reorient, and give time to rest if needed

Potentially Dangerous Responses to a Seizure

Do Not

- Put anything in the person's mouth
- Try to hold down or restrain the person
- Attempt to give oral medication
- Keep the person on their back, face up throughout convulsion
- Attempt to administer oxygen or CPR

When to Call 911

- If the seizure lasts for more than 5 minutes
- If the seizure stops and is followed by another seizure without the person fully regaining consciousness
- If this is the person's first seizure
- If the seizure takes place in water
- If the person is injured during the seizure (especially the head)
- If the person has diabetes or is pregnant
- If normal breathing or complexion does not return after the seizure has stopped (artificial respiration may need to be administered)

First Aid for Complex Partial Seizures

- Be reassuring, talk quietly and tell the person they are safe
- Explain what is happening to bystanders
- Look for medical ID tag
- Gently guide the person away from hazards
- If person is agitated, stay back
- Stay with person until fully reoriented

Epilepsy Treatment

- Medication
- Surgery
- Ketogenic Diet
- Vagus Nerve Stimulator

Treatments: Medication

Broad Spectrum AEDs (for Partial & Generalized)	AEDs Used Primarily for Partial Epilepsy	Specialized AEDs
<u>Older</u> valproic acid <u>Newer</u> lamotrigine leviteracetam topiramate zonisamide felbamate rufinamide ezogabine perampanel	<u>Older</u> carbamazepine phenytoin <u>Newer</u> oxcarbazepine pregabalin gabapentin tiagabine lacosamide eslicarbazepine	vigabatrin *(infantile spasms)* ACTH *(infantile spasms)* ethosuximide *(absence only)* phenobarbital (*neonatal & febrile seizures*) benzodiazepines*

*clobazam (Onfi), clonazepam, & clorazepate are useful for Lennox Gastaut, but tolerance, addiction, and side effects limit their use; lorazepam. midazolam, and diazepam are most often used for management of prolonged seizures

Medication Side Effects

- **Side effects common to all antiseizure meds:** drowsiness, unsteadiness, dizziness, blurry vision, stomach upset, memory/thinking problems, headaches, reduced resistance to colds
- **Weight Gain** – valproic acid, carbamazepine, pregabalin, gabapentin, clobazam
- **Weight Loss** – topiramate, zonisamide, felbamate
- **Cosmetic Problems** (e.g. gum overgrowth, hairiness, hair loss, skin problems) – phenytoin, valproic acid
- **Bone Loss** – carbamazepine, phenytoin, valproic acid, phenobarbital, topiramate
- **Low Blood Sodium** – oxcarbazepine, carbamazepine
- **Depression or Irritability** – more common with lacosamide, levetiracetam, phenobarbital, benzodiazepines (but can occur with any antiseizure med)
- **Sleep Disturbance** – benzodiazepines, phenobarbital, carbamazepine, phenytoin, valproic acid, levetiracetam, lamotrigine

Medication Side Effects

Warning signs of potentially serious side effects:

- Prolonged fever
- Rash
- Very sore throat
- Mouth ulcers
- Easy bruising
- Pinpoint bleeding
- Weakness
- Extreme fatigue
- Swollen glands
- Lack of appetite
- Increased seizures

Warning signs of toxicity:

- Lethargy
- Dizziness
- Slurred speech
- Balance problems
- Coordination problems
- Shakiness
- Confusion
- Double vision
- Stomach upset

Vagus Nerve Stimulation

Pacemaker-like device implanted under skin on chest wall

Leads connect to vagus nerve in the neck

Device is programmed to periodically stimulate the brain via the vagus nerve

Magnet can be used to activate or turn off the device

(DEMONSTRATION)

- Can be useful for partial (including multifocal) and generalized epilepsies
- Palliative treatment – very unlikely to result in seizure freedom
- 30 – 50% are responders (reduction in seizures of 50% or more); response often improves over time

Prognosis

- ~20 – 25% of cases - seizures do not respond to treatment
- ~20 – 25% of cases - improvement, but continued seizures
- ~50 – 60% of cases - complete seizure control
- ~75% will eventually enter remission
- Generalized epilepsies, those that start early in life, and those with no known cause typically have better prognosis

When to Consider Advanced Treatment Options- Epileptologist Referral

- Ask the pediatric neurologist about these previous treatment options (i.e. surgery, Neuro-stimulation, Diet etc.) & epileptologist referral if…

  …the child has tried 2 first-line medications (and one drug combination), and they are still having seizures and/or significant side effects

  … Advanced treatment options entail a referral to a Pediatric Epileptologist practicing within a Comprehensive Epilepsy Center (http://www.naec-epilepsy.org/spec_care/guidelines.htm)

Pediatric Epileptologist

Pediatric Epileptologist is-

- A physician who is Board Certified in Pediatric Neurology (i.e. a Pediatric Neurologist)
- Can also be Board Certified in Clinical Neurophysiology (EEG interpretation)
- Has done extensive fellowship (additional 1-2 years beyond residency) at an Academic Comprehensive Epilepsy Center (level 3-4) with concentration in Pediatric Epilepsy
- Sees only children with Epilepsy in their practice at established Epilepsy Centers
- Concurrently involved in Epilepsy Research and studies and member of academic society (AES, AAN etc.)

Advanced Care Remotely

- Defined as Pediatric Epilepsy Telemedicine Initiative
- Using video Conferencing technology parents and their child can be connected to a Pediatric epilepsy specialist
- Currently provides access to Pediatric Epileptologists involved in CYE Telemedicine at C.S. Mott Children's Hospital – UofM AA, Helen Devos Children's Hospital – GR
- Provides Access to Comprehensive Epilepsy Centers and services provided in those centers
- Payments covered by Michigan Medicaid and CSHCS
- For more information call MDHHS 517-241-5071

Epilepsy Management & Self-Management

- Epilepsy management is what **a parent of a child** and the **child with epilepsy (or transitioned adolescent)** can do to…
  - reduce the number of seizures experienced and their severity
  - cope with the effects of epilepsy on daily life and family life,
  - and reduce the impact of epilepsy on the PWE overall Physical and mental health.

- Support from friends and families can always help, but as a child gets older and grows into their teens and adulthood transitioning them to be more responsible for their own epilepsy self-management is vital.

Managing or Self -managing Epilepsy

Involves -

- Education on the type of epilepsy one has
- Knowing Seizure First Aid (teaching others)
- Seizure monitoring (www.seizuretracker.com)
- Medication regimen compliance & Side Effect monitoring
- Maintaining good sleep habits
- Learning seizure triggers and methods to avoid
- Handling lifestyle factors that may be affected (mood/depression , activity/transportation, self-esteem, school – social & academics, employment)
- Safety –Developing a Seizure Plan with Rescue med. Usage, medic alert bracelets, seizure alert monitors, seizure response dogs

A Parents Responsibility in Working With their Child's Healthcare Team

At appointments, be sure to provide…

- Details on seizures experienced since last appointment (including "minor" seizures or auras)
  - What happened before, during, and after each seizure
  - Possible patterns or triggers
- Other symptoms their child has had (e.g. side effects, trouble with memory or thinking, depression, anxiety)
- Any treatment changes (e.g. new meds, complementary treatments, medication switching by pharmacist, etc.)
- A request for a prescription refill, if necessary
- Any questions or concerns they have about their child's epilepsy, psycho social well being, school issues etc.

A Neurologists Responsibility in Working With A Parent or Child with Epilepsy

At appointments a child's neurologist should…

- Explain the reasons for tests and the meaning of any test results recently performed
- Tell the parent what s/he knows about their child's condition
  - what the suspected cause is
  - what type of seizures they have
  - what type of epilepsy it is
  - what they expect in that child's future
- Describe treatment options (including risks and benefits) and why a particular treatment is being recommended for their child
- Provide important information on prescribed medications
- Explain the health and safety risks associated with epilepsy and how to reduce those risks
- Answer any questions about their child's diagnosis and take a parent's concerns seriously and form a good doctor patient bond with that child

Health care team Responsibilities in Working With A Parent & Adolescent - Preparing for Transition

At appointments a pediatric neurologist, staff or case manager should…

- Gear teaching and care toward " transition" not just "transfer" explain the different approach of pediatric family care approach versus adult neurologist office self-management approach
- Conduct Regular transition reediness assessments (begins usually age 14) (i.e "GOT T RANSITION")
- Discuss parent and the adolescents goals of self -management
- Tell the adolescent what they need to know about his or her condition
  - What epilepsy is and type of epilepsy and seizures they have
  - What are the symptoms of his /or her seizures and basic seizure first aide to teach others
  - When is a seizure an emergency for him/her, and teaching others their seizure response plan
  - Teach them about their medications (epilepsy and non-epilepsy, brand /generic names, dosage they take, when and how to take, how to read their medication labels, expiration dates, refills left, pharmacy contact number and how to use automated refill
  - Adverse side effects to report, MD office number and how to use after hour service
  - Teaching goaled toward compliance, using med reminders, automatic refills, pill box, sell phone alarms, keep extra medications with you, rescue meds for traveling especially
  - Medical alert bracelet wearing and caring important medical, and insurance information on them, and ICE numbers
  - Keep a medical file at home
  - How to ask and obtain referrals from their Primary physician

- Describe treatment options (including risks and benefits) and why a particular treatment is being recommended for them
- Explain the health and safety risks associated with epilepsy and how to reduce those risks
- Answer any questions about their adolescent has about their diagnosis and take concerns seriously and form a good doctor patient bond with that adolescent as part of the decision making team
- Have parent release apron strings and allow adolescent to try, help and support as needed, monitor and report progress toward goals

Transition Intervention: "Six Core Elements for Health Care Transition"	
Pediatric Health	**Adult Health**
1. Transition Policy	1. Privacy and Consent Policy (adult-centered care)
2. Transitioning Youth Registry	2. Young Adult Patient Registry
3. Transition Preparation (use of transition readiness assessment)	3. Transition Preparation (continuation of transition readiness assessment)
4. Transition Planning (use of portable medical summary with transition action plan)	4. Transition Planning (continuation of transition action plan and updating of portable medical summary)
5. Transition and Transfer of Care (transition or transfer to adult model of care, transfer checklist, communication with adult provider, and, if needed, shared care with adult provider)	5. Transition and Transfer of Care (review of transfer of care package and consultation with pediatric provider as needed)
6. Transition Completion (documentation of transfer)	6. Transition Completion (documentation of transfer and initiation of care)

Transition Planning

www.gottransition.org

- [Pediatric Practice Name] is **committed** to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, **beginning at ages 12 to 14**, and their families to prepare for the change from a "**pediatric" model** of care where parents make most decisions to an **"adult" model of care** where youth take full responsibility for decision-making. This means that we will **spend time during the visit with the teen without the parent present** in order to assist them in **setting health priorities** and supporting them in becoming more **independent with their own health care.**
- At **age 18, youth legally become adults**. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. **Only with the young adult's consent will we be able to discuss any personal health information with family members**. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making. We will collaborate with youth and families regarding the age for **transferring to an adult provide**r and recommend that this transfer occur **before age 22.**

Sample Transition Policy

www.gottransition.com

- 1. Individual Transition Flow Sheet
- 2. Transition Readiness Assessments (Check lists for Child, & Parent/Caregiver))
- 3. Sample Plan of Care (Blank form)
- 4. Medical Summary and Emergency Care Plan (signed by youth, parent/caregiver, primary care provider, care coordinator)
- Sample transfer check list
- Sample Transfer of care letter
- Transition Feedback Survey (Youth & Parent/caregiver)

Transition Sample Forms

www.gottransition.org

Epilepsy Management

EPILEPSY FOUNDATION
Michigan

Getting the Most Out of Your Medical Appointments

Epilepsy and seizures can be unpredictable and frustrating. Seizures can affect one's life in many ways. In order to minimize the impact of epilepsy, it is important to maximize the effectiveness of medical appointments. The following are some tips to help you get the most out of the relatively brief interactions.

Tell Your Doctor About...

- ☐ seizures you've had since your last appointment (including any seizures "missed" at home)
  - How many?
  - How often?
  - What time of day?
  - How long they lasted?
  - What they were like?
  - Is there a pattern you've noticed?
- ☐ what happened before your seizures
  - Was there a warning?
  - Was there a trigger (e.g. missed dose, lack of sleep, stress)?
  - How are you taking your medication as prescribed?
- ☐ what happened after your seizures
  - What symptoms did you have (e.g. drowsiness, confusion, inability to talk, headache, depression, etc.)?
  - How long did those symptoms last?
- ☐ any other symptoms you've had
  - possible medication side effects
  - problems with memory, attention, thinking, or language
  - depression or anxiety
- ☐ any treatment changes
  - any new doctors you've had (including other neurologists you've visited (including emergency room doctors))
  - any supplements, any herbal or alternative treatments you are using (e.g. marijuana, ketogenic, herbal therapies, supplements, special diets, etc.)
  - any changes in the appearance, name, or labeling of the medication you receive from the pharmacist
  - any prescriptions the doctor did not fill

Rescue Medications and Usage

Used to stop prolonged or cluster seizures (i.e. Early intervention (to prevent progression of Status Epilepticus)

Proposed Definitions of Status Epilepticus:

- **Prolonged seizures** (**Early Status Epilepticus**): seizure length longer then 5 minutes (5-30 minutes), OR 2 or more seizures without returning to baseline
- **Established Status Epilepticus** : 30-60 minutes
- **Refractory Status Epilepticus**: Greater then 60 minutes

Types of Community Administered Rescue Meds

- Most common used rescue meds in community–Benzodiazepine classifications (fast- acting)
- Name of Benzos most commonly used as rescues = diazepam (Valium), clonazepam (Klonopin), lorazepam (Ativan), midazolam (Versed)
- Forms used dependent on type of seizures occurring, SE, onset desired patients ability to swallow, and client preference, availability, cost,

  non-licensed comfort level with off label usage

  (i.e. midazolam)
- prescribed forms – valium (PO, IR, IM), Klonopin (PO, OD-SL,buccal), Ativan (PO), midazolam (IN, buccal)
- DEMONSTRATION

Seizure Plans

EPILEPSY FOUNDATION Michigan

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:_____

Treating Physician:_____ Phone: _____

Significant medical history:_____

SEIZURE INFORMATION:

Seizure Type	*Length*	*Frequency*	*Description*

Seizure triggers or warning signs:_____

Student's reaction to 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

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 (grand mal) seizure:
- ✓ Protect head
- ✓ Keep airway open/watch breathing
- ✓ Turn child on side

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 when _____
for transport to _____
- ☐ Notify parent or emergency contact
- ☐ Notify doctor
- ☐ Administer emergency medications as indicated below
- ☐ Other_____

A Seizure is generally considered an Emergency when:
- ✓ A convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- ✓ Student has repeated seizures without regaining consciousness
- ✓ Student has a first time seizure
- ✓ Student is injured or has diabetes
- ✓ Student has breathing difficulties
- ✓ Student has a seizure in water

TREATMENT PROTOCOL DURING SCHOOL HOURS: (include daily and emergency medications)

Daily Medication	Dosage & Time of Day Given	Common Side Effects & Special Instructions

Emergency/Rescue Medication

_____

Does student have a **Vagus Nerve Stimulator (VNS)**? YES NO
If YES, Describe magnet use_____

SPECIAL CONSIDERATIONS & SAFETY PRECAUTIONS: *(regarding school activities, sports, trips, etc.)*

Physician Signature:_____ **Date:**_____

Parent Signature:_____ **Date:**_____

Epilepsy in School & Learning Problems

- 50% of children with epilepsy have school-related difficulties (Aldenkamp et al, 1990)
- 25% of children with epilepsy have a learning disability (Lhatoo et al., 2006)
- Risk of learning problems 3x higher

2008 Epilepsy Foundation of MI Needs Assessment:

64% of children experienced school performance problems related to epilepsy in past year; 80% experienced learning problems

Depression

- Increased rate of depression
  - Depression in children with epilepsy – 25%
  - Depression in general childhood population – 5%
- Decreases QOL, Increases suicide risk
- Stress associated with depression can increase seizure activity
- Parent, guardian or client may be reluctant to seek or follow treatment (i.e due to stigma, not liking mood stabilizers, transportation issues etc.)
- Antidepressants (SSRIs) can be safely administered

Risk Factors for Learning Problems

- frequent/poorly controlled seizures
- high number of lifetime tonic clonic seizures
- missed or unrecognized seizures
- status epilepticus
- early onset of seizures
- epilepsy caused by perinatal insult
- symptomatic epilepsy, and temporal lobe (particularly left) epilepsy

Contributing Factors

- Underlying brain injury/condition
- Medication side effects
- Effects before, during, & after seizures
- Interictal epileptiform discharges
- Long-term effects of repeated seizures
- Brain injury from status epilepticus
- Absenteeism
- Poor Sleep
- Psychosocial aspects of epilepsy

Contributing Factors:
Medication Side Effects

Common Cognitive Side Effects:

- impaired attention
- drowsiness
- slowed processing speed

Other side effects:

- slowed motor speed
- coordination problems
- hyperactivity
- mood changes (e.g. depression, irritability)

Contributing Factors:
Effects Before, During, & After Seizures

Before (*preictal*)

- Symptoms (headaches, anxiety, irritability)
- may be distracting & cause worry about possible impending seizure

During (*ictal*)

- impairment of consciousness leads to missed information (especially with unrecognized absence seizures)
- simple partial seizures (auras) can be distracting and may not be recognized or reported

Contributing Factors:
Effects Before, During, & After Seizures

After (*postictal*)

- confusion and sleepiness (most common)
- psychosis, depression, muscle soreness, headache, weakness, paralysis, blindness, loss of sensation, loss of speech
- duration of symptoms varies (from a few minutes to several days)
- teacher may assume student is back to normal despite persistence of postictal symptoms

Contributing Factors:

Interictal Epileptiform Discharges (IEDs)

- abnormal electrical activity in brain that occurs between seizures
- can have a impact on cognitive functions of alertness, cognitive speed, working memory
- may have cumulative effects that can impact stable functions of IQ, executive functioning

Contributing Factors:
Absenteeism

- Could be due to frequent medical appointments and/or seizures
- Make sure school is not sending child home unnecessarily; most of the time child can return to class after seizure (after a brief rest if needed)
- get all homework, handouts, and lesson notes during absences
- consider tutors, after-school work, or even summer school to help student catch up

Cognitive Problems Associated with Epilepsy

- Most common problems relate to …

  memory

  attention

  cognitive speed

- Specific learning problems related to seizure focus

Strategies for Improving School Performance

- Begins with improving epilepsy care
- Receive treatment at an Epilepsy Center (level 3 or level 4)
- Evaluation and Continued Treatment by a Pediatric Epileptologist versus Pediatric Neurologist
- Goal tx goal “no seizures – no side effects”

Client, Parent & Physician Strategies for Improving Epilepsy Management: Medical

- adjust or change meds to reduce side effects
- adjust treatment to improve seizure control
- ask about adjunct treatments that reduce IEDs and/or minimize progressive epileptogenesis and neuronal damage
- seek new treatments and specialized care if still having seizures or intolerable side effects after 2-3 medication trials (i.e. epileptologists, level 3-4 center, CYE telemedicine)
- evaluate mental health and adjustment/mal-adjustment to living with epilepsy
- treat conditions associated with epilepsy (e.g. ADHD, anxiety disorder, depression)

Parents, Physician & Teachers Strategies for Improving School Performance – Mental Health

Facts about children epilepsy-

- Those who have a seizure in class risk decreased self-esteem and increased anxiety
- May perceive their disorder and its characteristics worse then others do
- Risk feelings of loss of control & learned helplessness(due to seizure unpredictability)
- Poor self-esteem contribute to peer-rejection, avoidance of age appropriate activity, social isolation
- Low Self esteem = Low Academic Performance

Epilepsy & Psychiatric Comorbidities

- 21-61% (3-4 x) more likely to develop psychological or behavioral dysfunction versus general public (6.6%)
- 1 in 4 children with epilepsy develop depression
- Depression Prone = those experiencing actual or perceived stigma (bullying), feelings of loss of control, have negative attitudes towards epilepsy themselves, needing polytherapy (more then 1 AED)
- Overprotective parents and school personnel = Poor interpersonal adjustment poor transition to adulthood
- Get mental health professional help for parent and child when S&S occur

Parents, Physician & Client Strategies for Improving Psychosocial Adjustment – Mental Health

- Promote school and community awareness programs and support activities
- Define and maintain anti-bullying and anti- harassment, anti-discrimination policies, & enforce ADA laws, assist client in constant monitoring for and intervention when prone to these incidences and what to do.
- Mandatory school, workplace and community education programs on epilepsy and first aide (no panic, no fear = no stigma)
- Maintain Student/client privacy (ask what they want, disclosure when they are ready, but wear a Med ID)
- Assess for signs and symptoms of maladjustment and get early intervention
- Involve in activities to promote positive self-esteem & adjustment (EFM camp, Teen group, etc.)

Strategies for Improving School Performance: Evaluation & Accommodation

- Request a medical management meeting and 504 plan creation (epilepsy is a disability under the ADA – Civil right)
- Request evaluation for SE services (categories usually OHI, can be specific Leaning Disability, TBI, emotional disturbance, intellectual disability, multiple disabilities)
- Test results show disability does not significantly impact learning, build up the accommodations on the 504 and request independent neuro-psych evaluation (epileptologist referral to Neuropsychologist)

Strategies for Improving School Performance: Evaluation & Accommodation

What to Include in IEP/504 evaluation & Plan-

- Be sure to include any test results and recommendations from outside sources (e.g. neuropsychologists, neurologist, independent assessors, etc.)
- Make sure information is well organized and has a cover sheet or table of contents
- Any information not included in main IEP document can be included in Parent Addendum and/or Child Profile as an attachment

Strategies for Improving School Performance: What to Include in IEP/504 Plan

Info on Learning Needs

- Present level of academic achievement and functional performance
- Statement of annual measurable goals and short term objectives including how those goals will be measured objectively and how the parents will be informed of their child's progress
- Supplementary aids and related services to be provided, including statement of health needs
- Participation with non-disabled students

STRATEGIES FOR IMPROVING SCHOOL PERFORMANCE:

What to Include in IEP/504 Plan

Info on Learning Needs *(cont.)*

- Participation and plan for state and district wide tests
- Where and when services will be provided
- Transition plan, if applicable
- Discussion of child's strengths, results of testing or evaluations, parent input
- Info on existing or potential behavioral or emotional problems that require management

Strategies for Improving School Performance: 504/IEP Services & Accommodations

Basic Accommodations

- testing accommodations (e.g. notes, extra time)
- written notes or recording of spoken lessons
- minimizing visual or auditory distractions
- repetition of information after seizures
- changing schedule so that less challenging classes take place during periods of lower functioning (i.e. math etc.)

Strategies for Improving School Performance: 504/IEP Services & Accommodations

- full-time or part-time aid/parapro
- access to a resource room
- speech/language therapy
- training to address specific learning disabilities
- Tutors
- Extended school year to keep the pace
- cognitive rehabilitation
- psychological counseling

ACCOMMODATIONS FOR SPECIFIC MEMORY DEFICITS IN EPILEPSY

- Thru proper assessment determine specific memory deficit (i.e. short term)
- Frequent repetition of materials and redirection, cueing
- Extra time for assignments & exams, non-timed assessments to measure performance
- Break tasks down to simpler steps, provide several brief tests instead of one long exam
- Use recognition format (multiple choice)for tests rather then recall (fill ins etc.)
- Test for understanding rather the facts memorization

ACCOMMODATIONS FOR SPECIFIC LANGUAGE DEFICITS IN EPILEPSY

Expressive aphasia and word finding deficits can occur with epilepsy

- Allow extended time for verbal responses
- Limit oral exams and /or presentations when afflicted
- Slow the pace of or allow recording of verbal material and instructions
- Provide written directions
- Pair students with classmates to help clarify (i.e. team assignments)
- Use examples with visual guidance

MEDICAL MANAGEMENT:

What to Include in 504 Plan /IEP/ or work accommodation plan

Info on Seizure Management

- seizure types experienced (descriptions of typical symptoms, frequency and duration)
- pre & postictal symptoms
- seizure triggers and how to avoid them
- medications, dosage, side effects, designated persons responsible for administration of medications
- VNS, Ketogenic/ Modified Atkins instruction
- mandatory epilepsy awareness training needed for all school staff/administrators/ bus drivers and students to dispel myths, misconceptions, eliminate fear and promote acceptance & inclusion. In the workplace mandatory training for supervisors, security, HR, and coworkers

MEDICAL:

What to Include in IEP/504 Plan/ Accommodation Work Plan/ Heath Plan

Info on Seizure Management

- level and type of supervision needed for specific activities, or client self-restriction (e.g. swimming, bathroom/shower use, etc.)
- restrictions (e.g. dietary, activity, etc.)
- monitoring and reporting seizures, side effects, learning problems, etc. (teacher's and parents' responsibilities, client self management responsibility)
- plans for dealing with absences (work or school)

MEDICAL ACCOMMODATIONS:

What to Include in IEP/504 Plan/ Workplace Seizure Plan

Info on Seizure Management

Seizure response protocol (Seizure Plan)

- first aid (what's done & who does it), 911 when?
- mandatory in-service on emergency rescue medication (i.e. Diastat, Ativan, Klonopin, Midazolam) administration and/or VNS stimulation for school or co-worker personnel designated to administer - after care requirements (rest if they desire and allow to return to previous activity-work, school etc.) Honor requests for when client feels the need to go home without penalty at work or school
- reporting to parents (when, what, how) or support partners (if client desires)
- plan handling bystanders to maintain privacy

Advocacy Tips

- make sure school doesn't rely solely on IQ tests
- be aware of transient impairment during assessment/testing so they can be taken into account and/or assessment can be rescheduled
- intermittent nature of epilepsy may lead teachers (or employers) to suspect malingering, withhold needed services (accommodations), or underestimate what student (client) is capable of (all could apply to workplace or community involvement). Educate, Educate, Educate

QUESTIONS FOR SCHOOL ADMINISTRATION

Access to axillary services –

- Have a school nurse or district nurse? Hours she works, responsibilities, contact number, does she handle staff education on epilepsy and how much time is she given (suggest EFA online course) No nurse who is designated to handle medical issues? Who designates?
- Policies on medication administration (teachers, axillary staff, bus drivers), forms needed, permissions, scripts, med forms.
- 4 hour medication administration classes (state suggested) does your staff take them
- Access to monitored post-seizure recovery area, or do they always want the parent to take them home.

QUESTIONS FOR SCHOOL ADMINISTRATORS

- Full time Social worker? Open door accommodation for counseling, case management of IEP/504
- School Psychologist and their background in disability understanding?
- Access to a Behavioral specialist, creation of behavioral plan and management if needed?
- Director of Special Education, Student services, responsibilities, contact #
- Other Axillary services (OT, PT, ST, transportation) contracted thru who?
- Transition, & work programs to age 25?

QUESTIONS FOR SCHOOL ADMINISTRATORS

- Attendance Policies? Methods to accommodate child's absences without penalty
- Home bound or hospitalized students accommodations and school staff responsibility in keeping child up with program, how to request? (plan ahead in cases of VEEG, Surgery)
- Suspension policies, acceptations for mental health issues?
- Bullying prevention methods, investigation methods, counseling for perpetrators and victims

- Seizure Action Plans
- Medication list
- Questionnaire For Parent
- Seizure observation record
- Getting the Best out of your medical Care
- Seizure First Aid Posters
- American Epilepsy Society Article

Review Handouts

Helpful Links – Section 504, IDEA and Education

- www.wrightslaw.com/advoc/articles/504_IDEA_Rosenfeld.html
- www2.ed.gov/print/about/offices/list/ocr/504faq.html
- www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html
- www.michigan.gov/documents/mde/May09-ProceduralSafeguardsNotice_278611_7.pdf
- www.epilepsynorcal.org/docs/Education_DayCare.pdf
- www.mpas.org/AdvocacyServices.asp?TOPIC=10026
- www.mpas.org/Article.asp?TOPIC=10692

Who to turn to for Help & Education - EPILEPSY FOUNDATION OF MICHIGAN

Programs & Services

- Camp Discovery (age 8-17, adult volunteers
- Education & Consultation
- Individual Advocacy(school, employment, legal)
- Public education (schools, Bus drivers, classmates, police, EMS, Employers)
- Learn & Share conference calls
- Wellness & Epilepsy Conference
- Social Programs (support groups, forums, art therapy, teen programs, depression groups)

www.epilepsymichigan.org **800-377-6226**