Mental Health and Emotional Issues in Adolescents with Epilepsy

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Michigan Alliance for Families
information, support, and education

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END EPILEPSY TOGETHER

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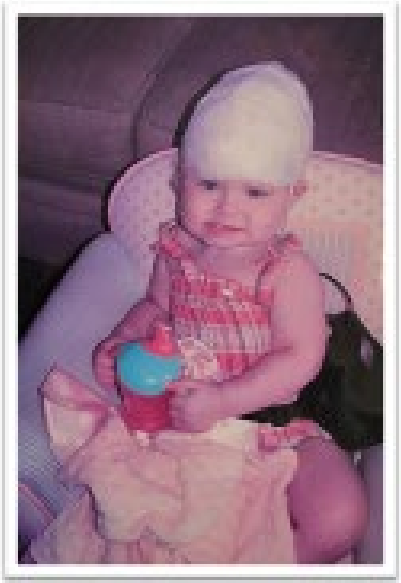


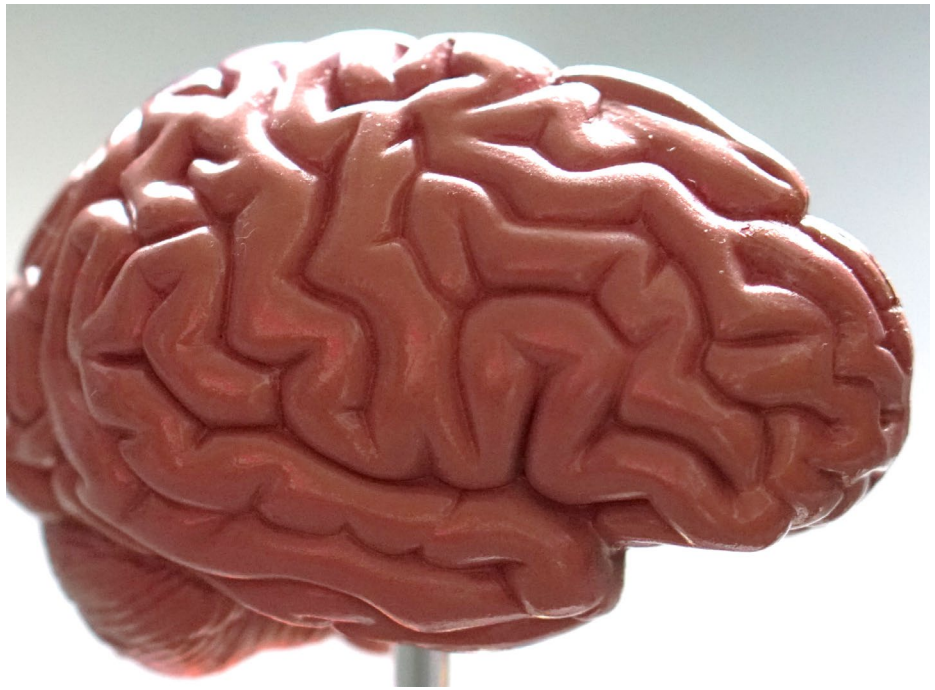
Mission of the Epilepsy Foundation

To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

Purpose

How to effectively support mental and emotional Health in students with epilepsy by:

- Understanding Epilepsy and Seizures
- Understanding Mental Health and Emotion Issues
- Supporting Positive Outcomes



The Brain, Seizures and Epilepsy

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How Common Is Epilepsy

- Prevalence of active epilepsy
  - ~3 million in U.S with epilepsy (self report)[1-3]
  - 65 million worldwide
  - 108,900 in Michigan (13,600 of whom are children)
  - 1.2% in U.S. have active epilepsy (1.4% of veterans[4])
- Cumulative incidence of epilepsy increases with age
  - Risk of developing epilepsy increases from 1% by age 20 to 3% by age 75-80[5]
  - 1 in 10 people will have a seizure in their lifetime
- ***1 in 26 people will develop epilepsy during their lifetime[5]***

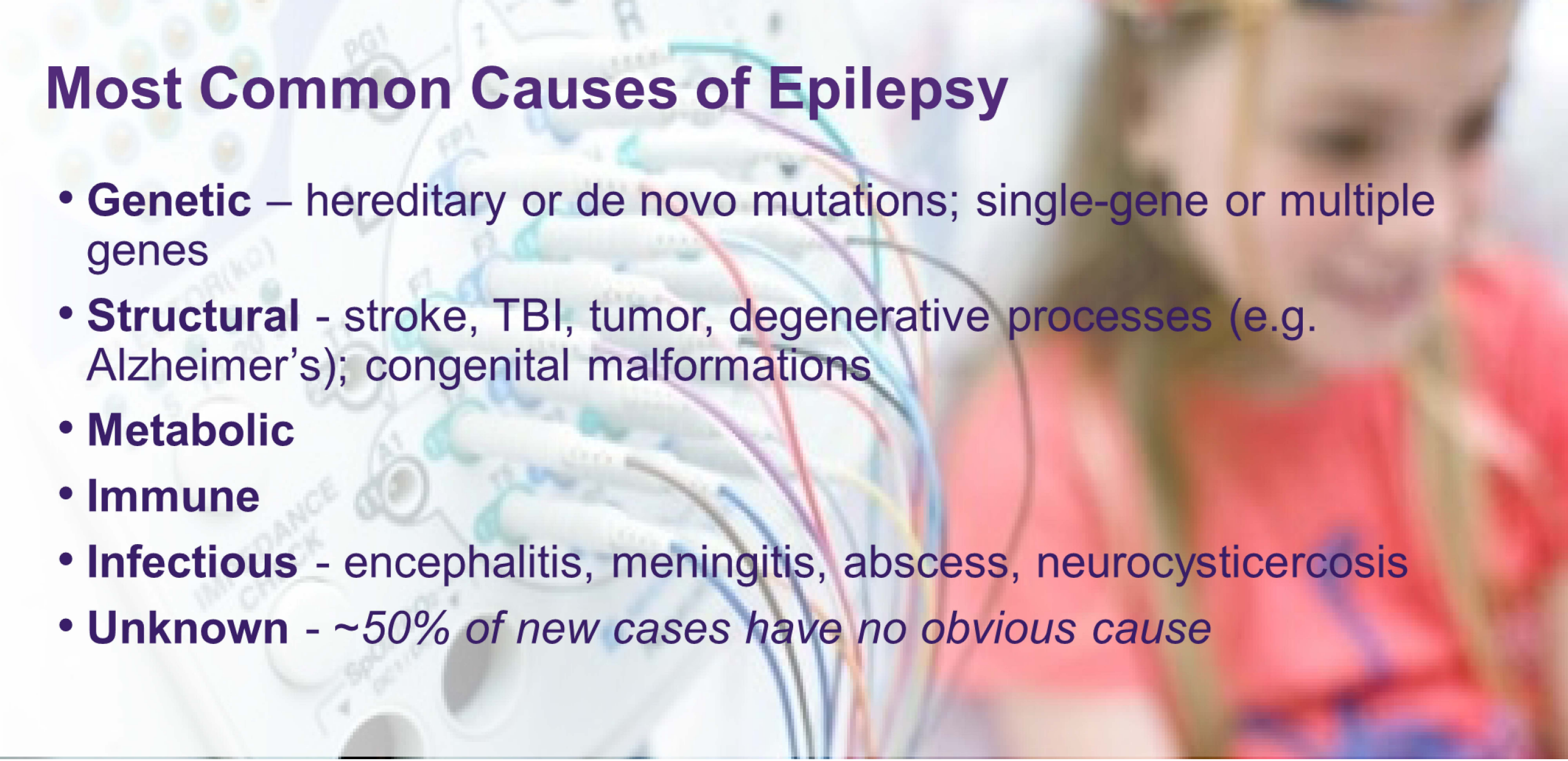
Epilepsy – What Is It?

- Not a single entity, but a family neurological disorders featuring recurrent, unprovoked seizures
- Defined as:
  - 2 or more unprovoked seizures > 24 hours part,
  - 1 seizure with risk of recurrent seizures, OR
  - Diagnosis of an epilepsy syndrome

- The term “epilepsy” = “seizure disorder”, but seizures are not always due to epilepsy

Most Common Causes of Epilepsy

- **Genetic** – hereditary or de novo mutations; single-gene or multiple genes
- **Structural** - stroke, TBI, tumor, degenerative processes (e.g. Alzheimer's); congenital malformations
- **Metabolic**
- **Immune**
- **Infectious** - encephalitis, meningitis, abscess, neurocysticercosis
- **Unknown** - *~50% of new cases have no obvious cause*



Key Points of Epilepsy

•Epilepsy increases a child's risk of developing mental health and behavioral problems by a factor of five. Between 30 and 50 percent of children with epilepsy will develop a behavioral or mental health problem.

•The types of behavioral problems associated with epilepsy include attention deficit, hyperactivity, anxiety, depression, aggression, autism spectrum disorder, and more.

•Early identification and treatment of behavioral problems provides the best possible outcome. Experts recommend that ALL people diagnosed with epilepsy be screened for mental health and behavioral problems.

Comorbidities

- Neurologic (TBI, stroke, MS, CP, migraine, Alzheimer's)
- Somatic (osteoporosis, sleep disorders)
- Mental health (depression, anxiety, PNES)
- Cognitive disorders (memory & attention problems, intellectual disability, dementia, autism)

Common Cognitive Functions Impacted by Epilepsy

Memory – most common complaint among people with epilepsy; typically short-term memory is most affected; often exacerbated by seizures; can impact med adherence and seizure reporting

Attention – medication for ADHD can be effective and safe

Executive Function – includes working memory, planning, decision making, organization, etc.

Processing Speed – drowsiness is most common side effect of antiseizure meds

Language – word-finding difficulty most common

Learning – specific learning disabilities related to location of seizure focus

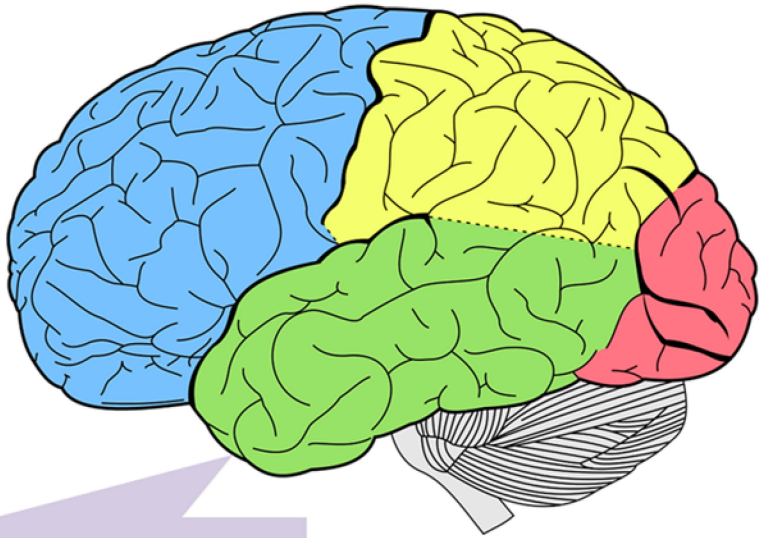
Cognitive challenges may persist in people with full seizure control or whose epilepsy has resolved (i.e. seizure free off medication for 5 years)

Seizures: What Are They?

A seizure is…

- A temporary disturbance in the electrical activity of the brain that causes changes in movement, sensation, awareness, behavior, or other bodily functions

- Can be manifestation or symptom of many medical problems
  - Provoked seizures
  - Unprovoked seizures



What a seizure looks like depends on the area of brain involved.

Seizure Types

And How they are Classified

Focal Onset Seizures

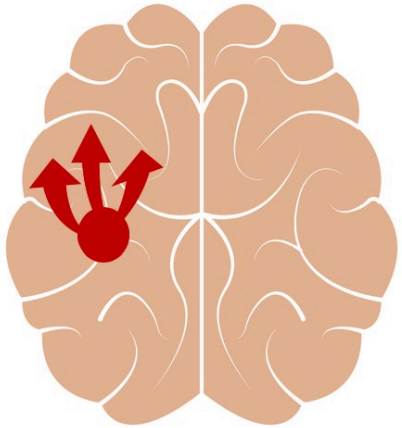
- Involve only part of the brain
- Common types – focal aware and focal impaired awareness

Generalized Onset Seizures

- Involve both sides of the brain
- Common types – absence and tonic-clonic

Unknown

- Where it starts is unknown



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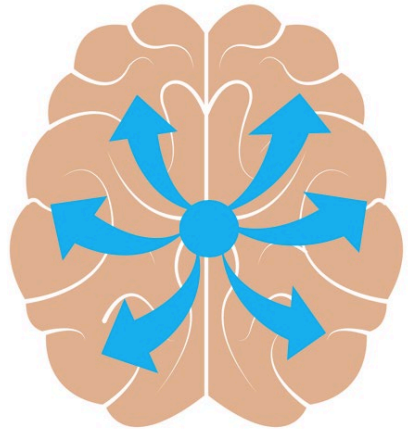
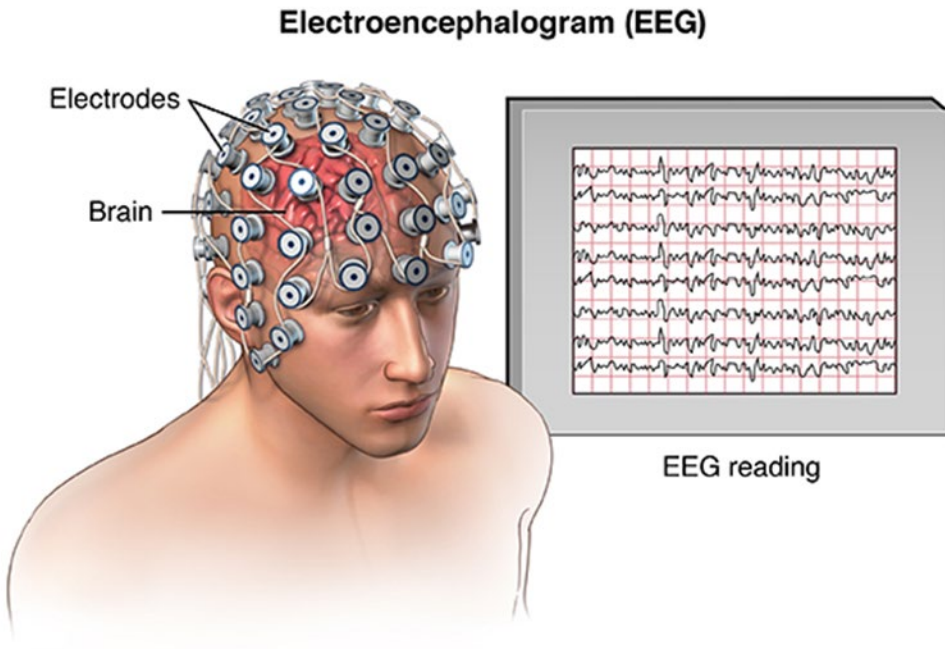


GENERALIZED

Functional Seizures or Psychogenic Nonepileptic Seizures (PNES)

- Behavioral events that resemble seizures
- Epileptic seizures are caused by sudden abnormal electrical discharges in the brain
- Epileptic seizures have characteristic EEG changes durin the seizure
- EEG testing shows no electrical disturbance associated with typical events during a psychogenic nonepileptic event
- PNES are caused by stressful psychological experiences or emotional trauma



Is PNES a Rare Disorder?

- PNES are the most common condition misdiagnosed as epilepsy
- 1 in 5 patients sent to Comprehensive Epilepsy Centers for difficult seizures is found to have PNES instead of epileptic seizures
- 40% of patients admitted to the EMU, are discharged with a diagnosis of PNES
- Patients can have both epileptic and nonepileptic seizures (approx. 5-10%)

Difference between Epileptic Seizures & PNES

- Epileptic seizures occur whether or not anyone else is present. PNES are usually (although not always) witnessed
- Epileptic seizures are stereotypic. PNES may involve erratic, non-repetitive movements
- Seizure related injuries, such as broken bones, are more typical of epileptic seizures
- Epileptic seizures tend to be brief, lasting a minute or less. The longer a spell goes on, the more possible it is to be PNES

Difference between Epileptic Seizures & PNES

(continued)

- Deliberate behaviors that seem to have a purpose (e.g. moving something to avoid injury) are more likely to be PNES
- Unusual posturing, side-to-side shaking of the head, banging the head against the wall, may occur during PNES
- A cry or shriek in the middle or at the end of the seizure is more likely to be PNES, as are the motor movements that come and go, that alternately affect the left and right side of the body.

Risks & Fears Related to Seizures

- Physical injury
- Difficulty breathing
- Drowning
- Prolonged Seizure Activity
- Seizure emergencies
- Early death
  - Accidents or drowning
  - Breathing or heart problems
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Suicide

Seizure Triggers

Missed Medicines
Missing doses of seizure medicine is the most common cause of breakthrough seizures.

Lack of Sleep
If you have epilepsy, lack of "good sleep" may make it more likely for you to have a seizure.

Stress
Stress is an expected and unavoidable part of life. This includes excitement, both positive and negative.

Alcohol & Recreational Drugs
Alcohol may interfere with certain anti-seizure medications. The effects and risks of recreational drugs vary greatly.

Hormones
The brain contains many nerve cells that are directly affected by estrogen and progesterone, the main sex hormones in women.

Sensitivity to Light
About 3% of PWE: exposure to flashing lights at certain intensities or to certain visual patterns can trigger seizures.

Other Illnesses
Head colds, lung infections or sinus infections (caused by viruses or bacteria) can often lead to a change in seizures.

Nutritional Deficiencies
Low levels of sugar, mineral's sodium, calcium and magnesium can alter the electrical activity of brain cells and cause seizures.

Over the Counter Medication
This is especially true for medicines to treat colds, allergies, and sleep problems.

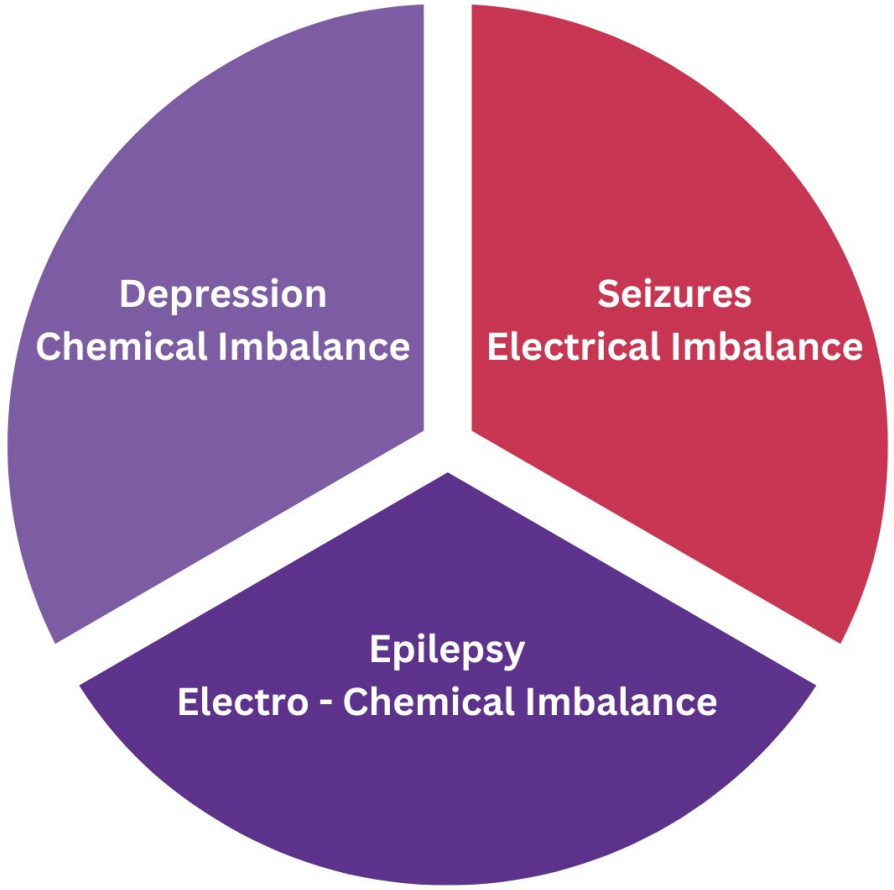
Prevalence of Learning Problems

- 50% of children with epilepsy (CWE) have school-related difficulties
- 25% of CWE have a learning disability
- Risk of learning problems 3x higher than general population
- Epilepsy Foundation of MI Needs Assessment:
  - 64% of CWE experienced school performance problems related to epilepsy

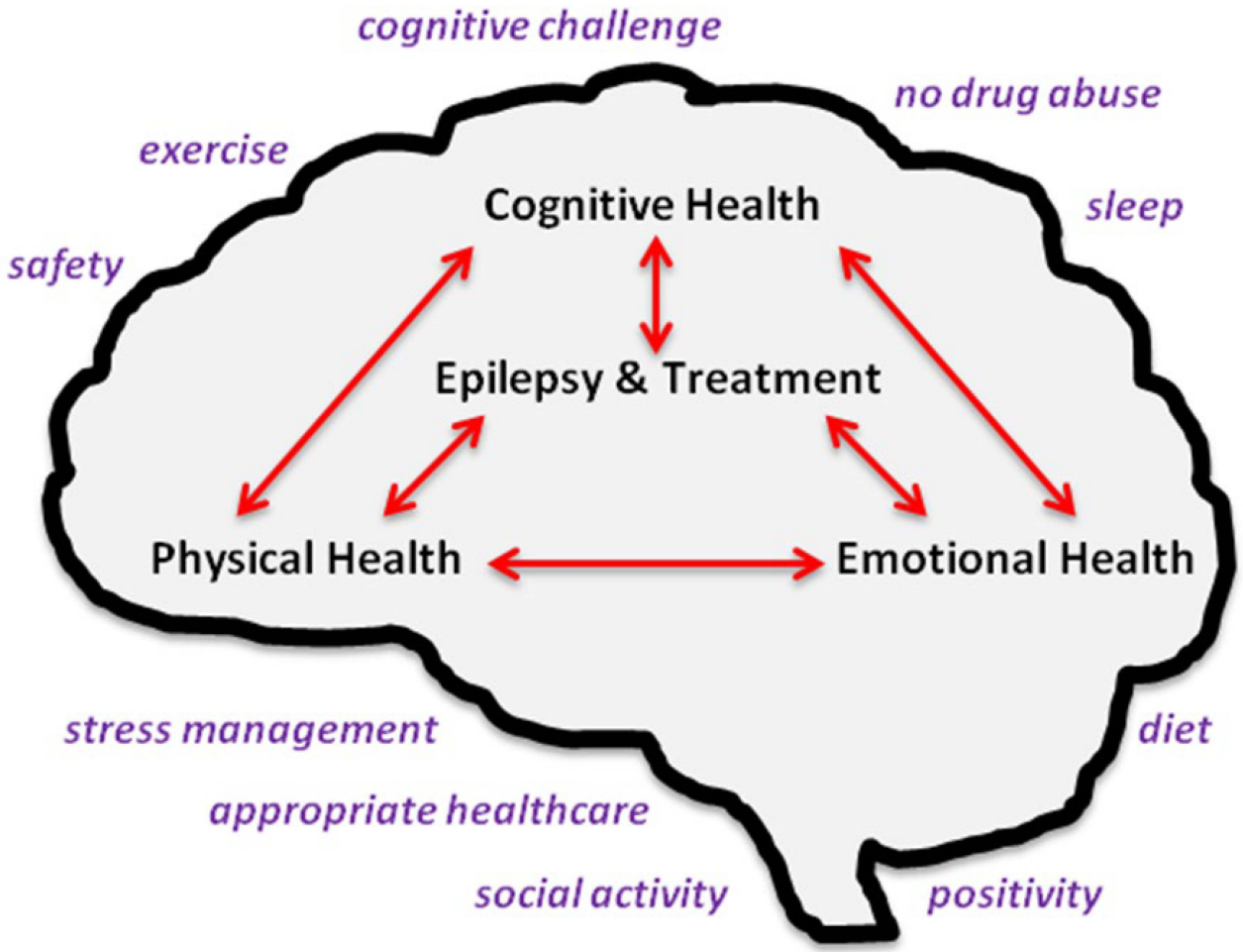
Epilepsy and Mental Health

CONNECTION BETWEEN EPILEPSY AND PSYCHOLOGICAL CONDITIONS

- Epilepsy was once considered as a mental illness.
- In some demographics and cultures, epilepsy is still considered and named under different stereotypes.



CONNECTION BETWEEN EPILEPSY AND PSYCHOLOGICAL CONDITIONS



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Mental Health & Epilepsy: Contributing Factors

Factors that negatively impact mental health		Factors that improve mental health

• Genetic factors
• Structural changes to brain
• Medication side effects
• Seizures
• Stress
• Sleep disorders
• Cognitive impairment
• Unpredictability
• Social isolation
• Activity restriction
• Loss of independence
• External locus of control
• Stigma
	MENTAL HEALTH	• Screening/early detection
		• Appropriate epilepsy care
		• Appropriate mental health care
		• Healthy behaviors
		  • Sleep
		  • Diet
		  • Exercise
		  • Stress management
		• Self-management skills
		• Meaning & purpose
		• Social support and activity
		• Addressing social determinants of health

CONNECTION BETWEEN EPILEPSY AND PSYCHOLOGICAL CONDITIONS

- The underlying cause(s) of depression and anxiety in people with epilepsy differ from person to person. The connection between epilepsy and mental health issues may be related to:
- Depression which existed prior to a diagnosis of epilepsy.
- Seizure activity, particularly where seizures lead to feelings of sadness or negative thoughts.
- Depression and/or anxiety may develop after a diagnosis of epilepsy, as this can be a life changing event and lead to feelings of sadness, grief, lowered self-esteem and fear of having a seizure.
- Depression and/or anxiety may develop as a result of living with epilepsy, and can be as a result of feeling socially isolated, and/or feeling stigmatized.

Prevalence of Psychiatric Disorders in Youth with Epilepsy

Recent study[1] screened 119 children with epilepsy (ages 9-18), excluding those who had been diagnosed with depression, anxiety, or suicidality.

- 30% screened positive for anxiety
- 40% screened positive for depression
- 11% tested positive for suicidality

Recent study of 107 transition-aged adolescents with epilepsy[2]...

- 56% showed signs of mental illness
- Mental health was a significant predictor of QOL; more so than many seizure- or epilepsy-related variables

[1]Dagar A et al. American Epilepsy Society, 2020. Abstract 913294
[2]Healy et. al. Epilepsy & Behavior 2020;112.

MENTAL, BEHAVIORAL, & EMOTIONAL HEALTH ISSUES IN EPILEPSY

Facts about student 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 contributes to peer-rejection, avoidance of age appropriate activity, social isolation
- Low Self esteem = Low Academic Performance

Epilepsy's Impact on Self-Sufficiency and Community Participation

- **Education** – school performance can be affected by cognitive impairment and psychosocial impact; missed school; inadequate training on seizure response among school personnel; reluctance to administer rescue medications; unnecessary restrictions
- **Transportation** – must be seizure-free for 6-months to drive in MI; public transportation options generally inadequate; huge impact on employability and community participation
- **Employment** – unemployment and underemployment; discrimination; transportation barriers

Common Issues to Address: Stress

In addition to it's central role in depression and anxiety disorders, stress is also a common seizure trigger, so effective management of stress is likely to lead not only to improved mental health but possibly reduced seizures as well.

Relaxation techniques – helpful for both chronic and acute stress

- Progressive Muscle Relaxation
- Deep breathing exercises
- Mindfulness meditations
- Yoga, music, art, exercise, pleasurable activities, etc.

Practice, Practice, Practice!

Common Issues to Address: Executive Function

In addition to memory dysfunction, executive function disorders are common in PWE

Difficulty with planning

Lack of organization

Difficulty with decision making

Impulsivity

Trouble initiating tasks

Exacerbation of existing problems

Creation of new problems

Anxiety, Depression, Self-blame

psychotherapeutic interventions

psychotherapeutic interventions

psychotherapeutic interventions

Common Issues to Address: Social Challenges

A variety of social and interpersonal challenges can both contribute to anxiety and depression AND act as barriers to accessing care.

- **Social Isolation** – fear of seizures, social anxiety, and lack of transportation
- **Limited Social Skills** – lack off opportunity to practice social skills; comorbid neurological conditions that impact social skills (e.g. autism, TBI, ADHD, ID)
- **Stigma -** They are embedder in our language and more deeply in our unconscious belief system
- **Discrimination –** Being set aside, unable to make dissections on your own.
- **Unpredictability –** Not being able to live as freely as you would like.

Strategies for Support and Available Services

Strategies for Support

Mental & Emotional Health

- Promote school and community awareness programs and support activities
- Define and maintain anti-bullying and anti-harassment, anti-discrimination policies, & enforce ADA laws. Request information from school to better understand their policies.
- Mandatory school, workplace and community education programs on epilepsy and first aide (no panic, no fear = no stigma)
- Maintain Student 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.)

Support & Services

- Monitoring for changes in behavior and mood, with early intervention requesting a 504, with testing for IEP, possible neuropsychiatric independent evaluation
- Social work and school psychologist consult. Possible creation of behavioral intervention plan
- Disability Manifestation Determination review to prevent unfair discipline or suspension
- 1:1 ParaPro request, change in placement or schooling accommodations
- Constant contact with teachers and school staff with changes in student's meds and seizure activity/daily behavior log

Support & Services (Continued)

- **Mental Health** – develop a working collaborative relationship (someone student can talk with), convey a caring attitude, avoid negative techniques such as punishment, sarcasm, avoid criticism and create a positive learning environment. Give extra time on assignments and tests, break down assignments into smaller sections, pair up with a student willing to help. Assist with organization, setting up schedules, study habits.
- **Emotional support** includes encouraging student to use anxiety-reducing techniques, allow self-calming objects, breaks, encourage open door with social worker when feeling anxious. Consider classroom setup and routines. Assign student a designated “buddy” for out of class opportunities. Allow preferential grouping for field trips. Allow break pass (with buddy) as needed, create a plan for catching up after absence or illness to decrease anxiety.

Support & Services (Continued)

- **Memory** – develop a working collaborative relationship (buddy system, small workgroups, 1:1 aide or ParaPro), convey a caring attitude, avoid negative techniques such as punishment, sarcasm, avoid criticism and create a positive learning environment. Give extra time on assignments and tests, break down assignments into smaller sections, pair up with a student willing to help. Assist with organization, setting up schedules, study habits. Accommodations to build self-esteem, socialization skills.
- Understand and incorporate accommodations for educational performance affected by memory, organization, slower processing skills, etc. that can occur (pre-, inter-, and post-ictal seizure effects)

Support & Services – Additional Accommodations

- Give advance notice of planned substitute, changes in routine, and time before upcoming transitions.
- Ensure all substitute staff are aware of students IEP, 504, Seizure Action Plan
- Give instructions clearly, write down expectations.
- Provide the student with a signal if unable to clearly communicate needs without interruption to classmates.
- Let students share their story, if desired.
- Limit attention activities or provide individual opportunities for presentations, reading aloud, etc.
- Provide extended time on tests, different location, supports as needed.
- Encourage brain breaks, talk through behavior problems and monitor student's emotional state or frustration one-on-one.

Strategies for Support: Mindfulness-based Therapies

Mindfulness-based therapies…

- include dialectical-behavioral therapy, acceptance and commitment therapy, mindfulness-based stress reduction, and others
- allow patients to notice unpleasant experiences and accept them without judgment
- increase sense of control over behaviors and prevent automatic PNES response

Small study by Baslet et al[1] (49 patients recruited; 26 completed):

- 50% seizure free by end of treatment period (12-session manualized MBT program)
- 70% reduced seizure frequency of at least 50%

[1]Baslet G et al. Epilepsy & Behavior. 2020;103(Pt A):106534.

Strategies for Support: Cognitive Behavioral Therapy

CBT…

- can help manage underlying depression and anxiety disorders that contribute to PNES
- can help identify appropriate responses to emotional triggers, maladaptive thoughts, and avoidance behaviors
- has most reliable body of evidence to support its effectiveness

Small RCT by LaFrance et al. (34 patients)[1]

- CBT: 51% reduction in seizures
- CBT + sertraline: 59% reduction in seizures
- sertraline only: 27% reduction in seizures
- TAU: 34% reduction in seizures

CBT groups also had depression & anxiety and QOL

[1]LaFrance WC et al. JAMA Psychiatry. 2014;71:997–1005.

Strategies for Support: Prolonged Exposure Therapy

PE therapy…

- appropriate for those with PNES and PTSD (39% of people with PNES)
- allows patient to process past trauma in a safe context and learn that avoidance through PNES is not effective
- imaginal exposure (retelling of memory) and in vivo (confronting trauma-related situations in everyday life)

Small study by Myers et al[1] (18 patients started, 16 completed):

- 81% were seizure free by end of treatment period (12 to 15 90-minute sessions)
- Remainder reported reduced seizure frequency

[1]Myers L et al. Epilepsy & Behavior. 2017;66:86–92.

Strategies for Support: Psychodynamic Therapy

Psychodynamic therapies…

- make patients aware of events or physical/emotional cues that trigger seizures, and encourage verbal expression of these emotions
- reduce the unconscious repression of negative emotions that results in seizures

Small study by Barry et al[1] (12 patients started; 7 completed 32-week program):

- 57% seizure free by end of treatment period
- 86% experienced decline in seizure frequency

[1]Barry JJ et al. Epilepsy & Behavior. 2008;13(4):624-9.

Additional Support Services

E·SMART

Epilepsy Self-Management, Advocacy, & Resilience for Teens

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- Camp (for students with epilepsy)
- Psychoeducational and Support Groups
- Case Management, CMH, CSHCS
- Play Therapy / Art Therapy
- Educational Supports (IDEA, 504), School social work,
- Behavioral Management, OT, ST, PT
- Health Agencies (Michigan Alliance for Families, EFM, Disability Advocates, A Kid Again, The Arc, 211, etc.)

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Inclusion Opportunities

- Talk with student
- No mimicking or posting of person during a seizure
- Intervene consistently
- Educate students, classrooms and school groups (assemblies, fundraisers, etc.)
- Encourage *peer support*
- Support Abilities Campaign
- Support Special Observance Days (Purple Day for Epilepsy)
- Involve the parents or caregivers

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Epilepsy Foundation School Resources

- *Seizure Training for School Personnel*
- Take Charge Epilepsy Education Series
- Videos on Seizure First Aid, Rescue Therapies, and Seizure Action Plans
- Brochures, videos, pamphlets, fact sheets, posters
- Available at:
  - epilepsy.com
  - epilepsymichigan.org
  - Youtube (https://www.youtube.com/c/EpilepsyFoundationNational/videos)

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Information on…

- how/when to seek epilepsy specialty care
- diagnosis & prognosis
- treatment options
- possible comorbidities
- self-management
- psychosocial & cognitive impact
- impact on school & employment available resources

Services include:

- Toll-free Here for You Helpline
- Annual Conferences
- Monthly Learn & Share Conference Calls
- Parent & Young Adult Support Groups
- Individual Advocacy
- Public Policy Advocacy
- Camp Discovery
- Public/Professional Awareness Training
- E-SMART program for teens

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Questions?

Case Study if time allows.

Thank You for all you do!

GET INFORMATION: epilepsy.com

epilepsymichigan.org

24/7 Helpline: 1-800-332-1000

Here for You Helpline (MI) 1-800-377-6226

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