



COMMONWEALTH of VIRGINIA

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Office of Integrated Health Health & Safety Information

Part 1: Seizure Disorder and Epilepsy Health & Safety Alert - The Basics

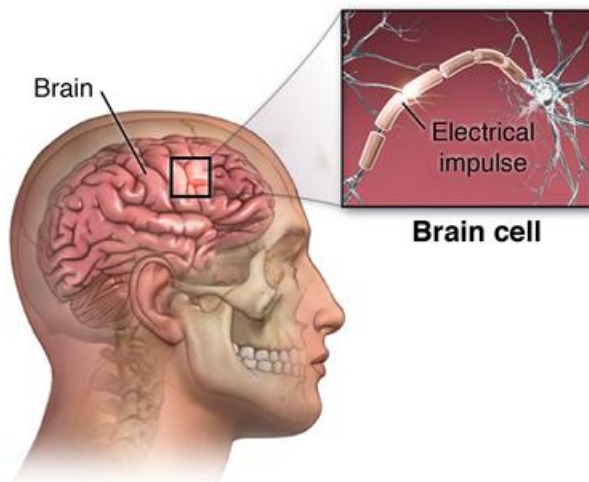
Introduction

A seizure disorder is a nervous system condition characterized by a change in the brain's electrical activity. A seizure is defined as a sudden uncontrolled rush of electrical energy in the brain (19) (5).

Changes in behavior, abnormal body movements, emotional changes, and the individual's level of consciousness can all be affected by seizure activity. There are several different types of seizures which range in symptoms and severity. The type of seizure an individual experiences is based on where in the brain it begins and how far it spreads throughout the brain tissue (19).

The average length of a seizure is between 30 seconds to two minutes. Seizures lasting longer than five minutes or occurring repeatedly are unlikely to end on their own. The seizure scenarios below require immediate emergency medical attention (24) (19) (23). If an individual is experiencing any of the following, **call 911**:

- An individual having a first seizure.
- An individual having a seizure lasting for more than five minutes.
- An individual having multiple seizures (3 or more) occurring one after another.
- Multiple seizures (3 or more) occurring within one hour.



A Single Seizure versus Epilepsy

Not every person who has a seizure has epilepsy. Having one seizure does not mean a person has epilepsy. **Epilepsy is a seizure disorder which causes repeated and/or random seizure activity.** Epilepsy is defined as experiencing two or more seizures within a 24-hour period that have no known cause or specific triggers (19). Epilepsy is not contagious. It cannot be spread from person to person (23).

The majority of individuals who suffer from a seizure disorder and/or epilepsy are able to live fairly normal lives with ongoing healthcare and medical management to balance and control seizure activity (5).

Prevalence of Epilepsy Among the General Population

Anyone can have a seizure or develop a seizure disorder such as epilepsy. Individuals from all cultures, age groups, and genders can experience seizures (23).

In 2021, the prevalence of epilepsy among the adult population in the U.S. was between 1 to 2%, approximately 2,865,000 adults, reported having seizure activity within a 12-month period or where being treated with anti-seizure medications (4) (17).

Lower social, economic, and educational levels has been connected to an increased occurrence of seizures disorders and epilepsy in individuals (14).

Possible Causes of Seizure Disorder or Epilepsy

In many cases the cause of a seizure disorder is unknown. More than half of all epilepsy diagnoses have no known cause. Any person can have a random seizure, which may or may not return. Some people with epilepsy have more than one type of seizure (19) (5). Any disturbance of normal cell activity in the brain can lead to a seizure (16) (14) (23).

Seizures can occur due to health issues such as:

- Traumatic brain injury (TBI).
- Abnormal brain development.
- Genetic factors.
- Sleep disorders.
- Injuries occurring during the neonatal period or during birth (25).
- Traumatic injury to the body (16) (14).

Several health conditions can cause seizure activity but may resolve after treatment. Some examples include:

- Electrolyte imbalances.
- Fever.

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- Brain tumors.
 - Alcohol withdrawal.
 - Heart attack (Myocardial Infarction).
 - Stroke.
 - Adverse drug reactions.
 - An oxygen deprived brain.
 - Abnormal blood vessel formations (arteriovenous malformations).
 - Bleeding, inflammation or swelling in the brain.
 - Infections such as meningitis, HIV-related infections, or viral encephalitis (23).

Seizure Types, Signs & Symptoms

Common seizure symptoms include:

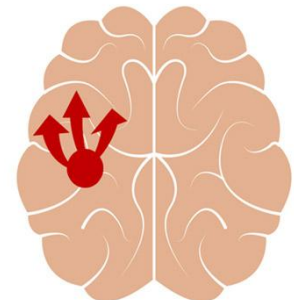
- Brief mental confusion.
- Brief staring off into space.
- Abnormal body movements.
- Loss of awareness or consciousness.
- Emotional changes (19).

Seizure signs and symptoms can vary greatly and may be mild to severe (19). Some individuals may have no clear pattern and may be difficult to diagnose. Some individuals experience multiple types of seizures (23).

Seizures are typically classified into two categories: generalized and focal (19) (5).

Focal Seizures

- Are classified into two basic categories:
 - Simple focal.
 - Complex focal.
- Typically begin on one side of the brain but can spread to both sides (19) (6) (23).
- Symptoms and seizure progression are similar with each occurrence.
- Can occur with or without a loss of consciousness.



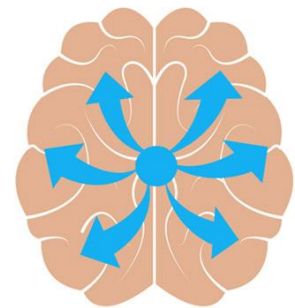
- May impact the individual's level of awareness to their surroundings sometimes causing a dream-like state or a feeling of déjà vu (a feeling something has happened before).
- May cause repetitive physical movements or behaviors (hand rubbing, mouth movements, repeating words, picking at clothes, walking in circles, etc.) (19) (6) (23).
- May change the individual's perception (the way things look, smell, feel, taste or sound).
- May cause weird sensations (tingling, dizziness, seeing lights flashing, etc.).
- May cause sudden swings (unexplained changes) in the person's emotional state (joy to sadness, happiness to sadness, happiness to anger, etc.).
- Can cause abnormal movements on one side of the body, or both.
- May cause auras (unusual sensations that warn of an impending seizure) (19) (6) (23).
- Symptoms of focal seizures can be confused with symptoms of sleep disorders such as narcolepsy (a disorder which affects the sleep-wake cycle), syncope (fainting/loss of consciousness), or mental illness.
- May require extensive testing to distinguish between focal seizures and/or another disorders (23).

Generalized Seizures

Generalized seizures start on both sides of the brain at the same time and involve all areas of the brain from the time they begin. Generalized seizures typically cause a loss of consciousness (19) (6) (23).

There are six main types of generalized seizures:

- Absence seizures.
 - Can cause staring off into space and/or a lapse of awareness.
 - Might cause subtle body movements such as eye blinking or lip smacking.
 - Last for about 5 to 10 seconds.
 - May occur in clusters and can happen hundreds of times a day.
 - May cause a brief loss of awareness (19) (6) (23).
- Tonic seizures.



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- Cause stiffening in the muscles.
 - Usually affects the muscles in the back, arms and legs.
 - May cause a loss of consciousness.
 - Can cause a fall with injury (19) (6) (23).
 - Clonic seizures.
 - Repeated jerking muscle movements.
 - Usually affect the neck, face, and arms on both sides of the body (19) (6).
 - Myoclonic seizures.
 - Sudden short jerks or twitches of the arms and legs.
 - Typically, there is no loss of consciousness (19) (6) (23).
 - Atonic seizures.
 - Also known as drop seizures.
 - Cause a complete loss of muscle control.
 - Can cause injury from suddenly falling down or dropping and hitting the head or other parts of the body (19) (6) (23).
 - Tonic-clonic seizures.
 - Cause muscle jerking or convulsive movements of the limbs or torso on both sides of the body.
 - Usually lasts a few minutes.
 - May cause confusion and tiredness afterwards.
 - May cause a fall with injury (19) (6) (23).
 - Secondary generalized, which begin with a focal seizure and then are followed by a generalized seizure (19) (6) (23).

Other Types of Seizures

- Febrile seizures are caused by high fever and typically occur in children.
 - Children who have febrile seizures are not normally prescribed antiseizure medications unless the child has a family history of epilepsy, show signs of nervous system impairment, experiences a long or complicated seizure or develops a repetitive pattern of febrile seizures.
 - The risk of subsequent non-febrile seizures is low unless one of these factors is present (23).
- A first seizure.

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- Are considered a medical emergency and require an immediate response to seek medical treatment by a healthcare professional as soon as possible.
 - Chances of a second seizure increase after the first seizure.
 - First seizure activity can have a specific cause or no cause, meaning the seizure can occur with or without any obvious triggering factors.
 - Unless the individual has suffered brain damage, is diagnosed with IDD or there is a family history of epilepsy or other cognitive brain abnormalities, most single seizures usually are not followed by additional seizures.
 - Medical conditions which can provoke a seizure include:
 - Very low or high blood sugar levels.
 - Changes in chemical levels in the blood (sodium, calcium, magnesium).
 - Eclampsia (Preeclampsia during pregnancy).
 - Impaired kidneys or liver function (23).

Seizure Disorder, Epilepsy and Individuals with Intellectual and Developmental Disabilities (IDD)

- As the severity of neurological, cognitive, and/or intellectual and developmental disability increases, so does the prevalence for a seizure disorders or epilepsy (18) (1) (9) (27).
- Making a reliable diagnoses of seizure disorder for an individual with IDD can be challenging due to the individual's communication limitations/barriers, their cognitive disability and their ability to be cooperative during testing (9).
- Seizure disorder and/or epilepsy signs and symptoms can present differently in individuals with IDD making diagnosis difficult.
- Sometimes seizure activity is wrongly labeled as “behavioral issues” and due to this goes undiagnosed (18) (9).
- Epilepsy usually begins in childhood among individuals with IDD (9).

Diagnostic Overshadowing

The tendency of health professionals to attribute all other problems to a primary diagnosis in patients with mental health issues or learning disabilities, thereby leaving other co-existing conditions undiagnosed and untreated.

Prevalence of Epilepsy Among Individuals with IDD

- Seizure disorder and epilepsy are more common among individuals with intellectual and developmental disabilities than the general population.
- Epilepsy is one of the most common secondary conditions in the IDD population (1) (9).
- A meta-analysis which reviewed 48 other research studies revealed the prevalence to be about 26% among individuals 19-49 years of age with IDD and 22% for individuals with IDD of all ages (27).
- Current estimates of epilepsy in individuals diagnosed with autism spectrum disorder (ASD) range from a low of 1.8% to a high of 60%, when all forms of epilepsy are included (4).

The Connection Between Genetic Syndromes and Epilepsy

- The same genetic syndrome is typically the cause of both the epilepsy and the intellectual or developmental disability (1) (9) (24).
- A mutation of the X-chromosome has been linked to more than half of all genetic epileptic syndromes affecting individuals with IDD (30).
- Individuals diagnosed with the following genetic syndromes typically experience seizure activity as part of their diagnosis:
 - Angelman syndrome (AS).
 - Börjeson-Forssman-Lehmann syndrome.
 - Christianson syndrome.
 - Fragile X syndrome (FXS).
 - Lennox-Gastaut.
 - Rett syndrome (RTT) (30) (18) (1).
 - SYNGAP1 (32).
 - Tuberous sclerosis complex (TSC) (30) (18) (1).
 - West syndrome (30) (18) (1).
- Individuals diagnosed with Lennox-Gastaut syndrome may experience several different types of seizures (30).
- Prevalence of epilepsy is approximately 12% among individuals with Down's syndrome (27), but many may not begin to experience epilepsy until they experience the onset of Alzheimer's as they age (24).

Common Epileptic Syndromes

There are hundreds of different types of epileptic syndromes which include seizures as a main symptom (16).

Some epileptic syndromes are genetically linked. Some epileptic syndromes are due to random mutations of DNA which are also known as “de novo gene changes”. Other epileptic syndromes have no known cause (23).

Epilepsy syndromes are usually defined by their symptoms or by which area of the brain they begin (23). Common epileptic syndromes include:

- Temporal lobe epilepsy (TLE)
- Absence epilepsy
- Frontal lobe epilepsy
- Neocortical epilepsy

Seizure Triggers

Triggers can produce seizure activity in an individual diagnosed with epilepsy. Some common seizure triggers are:

- Stressful situations and environments.
- Excessive alcohol use, or alcohol withdrawal.
- Dehydration.
- Missing meals.
- Exposure to toxins or poisons, such as lead, carbon monoxide, illicit drugs, and very large doses of some prescription medications.
- Hormonal changes associated with the menstrual cycle.
- Lack of sleep.
- Visual stimulation such as strobe lights, flashing or blinking lights and moving patterns (23). This includes in person occurrences, as well as visual displays on television, at the movie theater, computer screens, etc. (13).
- Hyponatremia (low sodium levels in the blood) can increase the risk of a seizure (28). Keep the individual well-hydrated, especially in the summer months.
- Fever, illness or vomiting can also trigger or increase seizure activity (23).

Seizure Auras

Some individuals will experience an aura before a seizure. An aura is something the individual feels immediately preceding a seizure and can function as a warning once identified. Auras have been described in the following ways (21):

- An unexpected feeling of fear or joy.
- A feeling that something has happened before, also known as Deja vu.
- An unexpected odor or taste.
- An unexpected sense of fear.
- A flip-flop feeling in the stomach.
- A tingling or numbing sensation.

The Postictal State

Is the period of time that directly follows the end of a seizure and can last for several minutes or several hours. After a seizure has ended, some individuals may experience the following (21):

- Headache.
- Confusion.
- Extreme tiredness.
- Extreme sleepiness.
- Muscle soreness.

Emergency Situations and Complications

Status epilepticus is a potentially life-threatening condition in which an individual either has an abnormally prolonged seizure (five minutes or more) or does not fully regain consciousness between recurring seizures (29) (23).

Individuals with IDD are more likely to experience status epilepticus than the general population (9) (24).

Status epilepticus may be convulsive (signs of a seizure can be visualized), or nonconvulsive (signs of a seizure cannot be visualized), which would require an electroencephalogram or EEG (23).

Nonconvulsive status epilepticus can sometimes go unnoticed by caregivers and may wrongly be assumed to be a long episode of confusion, agitation or loss of consciousness (23).

Another rare complication known to occur at higher rates in those individuals with IDD who experience uncontrolled seizures is Sudden Unexplained Death In Epilepsy (SUDEP). This is a medical emergency situation which requires an immediate response to 911 (24).

Both Status epilepticus and SUDEP are medical emergency situations requiring a call to 911 when an individual has either a prolonged seizure lasting for 5 minutes or more or when 3 seizures or more occur one right after another or within an hour. If treatment is not given immediately there is a risk of brain damage and death (24) (19).

Always Call 911 If:

- ✓ The individual is not conscious within 5 minutes of the seizure stopping.
- ✓ The individual's seizure activity lasts 5 or more minutes or a second seizure quickly follows.
- ✓ The individual appears to be injured.
- ✓ The individual is pregnant or has diabetes.
- ✓ You know (or believe it to be) the individual's first seizure.
- ✓ You are in doubt about any of the above and/or you are unsure what to do (23) (6).

The Fatal 7 and Risk of Injury for Individuals with IDD

Seizures are part of the Fatal 7 for individuals with IDD because of the increased risk of death and injury at the time the seizure occurs. Individuals who have a dual diagnosis of IDD and seizure disorder or epilepsy have a 2-3 times higher risk of injury requiring hospital admissions, urgent care and ER visits than those with IDD alone (9).

This may include injuries and accidents due to loss of consciousness while sitting, standing, walking, driving, crossing the street, bathing, swimming, cooking, etc.

Risk factors for falls in all settings may be worsened by age, impaired mobility, and behavioral issues (9). If the individual you are caring for has had falls due to seizures with injuries (especially head injuries), consult an occupational therapist (OT) or physical therapist (PT) to see if a helmet or other head gear may be an appropriate intervention.

Seizures can also create cumulative damage over a lifespan which can contribute to neurocognitive decline and numerous other health complications including shortened longevity (22).

Seizure Management Plans

There are many unique challenges for the individual diagnosed with IDD and seizure disorder and/or epilepsy in the community setting. Although some individuals might reside in a setting where there is ongoing nurse oversight, many do not. It is therefore important to have a physician-ordered seizure emergency management plan in place with clear guidelines for medication administration, including instructions on when to call 911 for emergency assistance (15).

It is important to address seizure management in all of the various settings/environments an individual's schedule normally entails which might include work, home, day program, school, college, overnight visits with family, community outings, etc.

Seizure management plans will also need to be incorporated into the person's Individual Service Plan (ISP), as well as their Individualized Education Plan (IEP) and/or their Individualized Healthcare Plan, if the individual is still attending school.

All caregivers in all settings should receive a copy of the individualized seizure management plan and be trained in all aspects of the plan. They should be able to demonstrate their understanding and confidence in delivering the physician-ordered plan of care to the individual whenever necessary (15).

A seizure management plan should include information on:

- The type of seizure.
- How long the seizures typically last.
- How often they occur.
- What happens during the seizure.
- How to respond to the seizure.
 - Such as staying calm and timing the seizure.
 - Keeping the individual safe by removing any harmful objects, protecting their head and not constraining the individual during the seizure.
 - Staying with the individual until the seizure is over.
 - Turning the individual onto their side during the seizure.
 - Using the magnet for the VNS.
- Specific instructions on when to call 911.
- Specific instructions on when to report changes to the primary care provider (PCP).

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- When and what to do for rescue measures if needed, such as the use of rectal diazepam if ordered.
 - How to care for the individual after the seizure has ended.
 - Any special instructions specific to the individual.
 - Current anti-seizure medications.
 - Known triggers.
 - Allergies.
 - Contact information for anyone who might need to be informed when a seizure emergency took place such as the PCP, a specialist, guardian, or authorized representative.
 - Signature of the prescribing physician (11).

An individualized seizure management plan should be reviewed and updated annually.

A copy of a sample seizure management plan can be found on the Epilepsy Foundation website at: <https://www.epilepsy.com/preparedness-safety/action-plans>

Caregiver Considerations

- Many individuals might have a history of a seizure disorder, but due to the success of some seizure medications, may not have had a seizure in some time. However, this does not mean that a seizure management plan should be abandoned. Refer to their physician for clarification and guidance.
- Maintain adherence to each individual's Medication Administration Record (MAR) to ensure an individual's seizure medications are administered correctly and per their physician's orders. If you are unsure what to do: ask questions and seek guidance.
- Certification on first-aid guidelines, CPR procedures, and airway obstruction clearance (i.e. Heimlich maneuver) is highly recommended for all caregivers.
- If an individual has a seizure, do not ever try to stop a seizure or restrain the individual in any way.
- If an individual is having a seizure, do try to protect their head, maintain their airway, and assist in lowering them to the floor in order to reduce the risk of bodily injury.
- Do not ever attempt to stick anything in an individual's mouth while they are having a seizure.

Download a generic seizure first aid safety poster from the Epilepsy Foundation (2020):
https://www.epilepsy.com/sites/default/files/atoms/files/SFA%20Flier_HQ_8.5x11_PDF.pdf

Seizure First Aid	
How to help someone having a seizure	
1	STAY with the person until they are awake and alert after the seizure. ✓ Time the seizure ✓ Remain calm ✓ Check for medical ID 
2	Keep the person SAFE. ✓ Move or guide away from harm 
3	Turn the person onto their SIDE if they are not awake and aware. ✓ Keep airway clear ✓ Loosen tight clothes around neck ✓ Put something small and soft under the head 
Call 911 if...	▶ Seizure lasts longer than 5 minutes ▶ Person does not return to their usual state ▶ Person is injured, pregnant, or sick ▶ Repeated seizures ▶ First time seizure ▶ Difficulty breathing ▶ Seizure occurs in water
Do NOT	✗ Do NOT restrain. ✗ Do NOT put any objects in their mouth. ✓ Rescue medicines can be given if prescribed by a health care professional
Learn more: epilepsy.com/firstaid	
 epilepsy.com	
24/7 Helpline: 1-800-332-1000	

Epilepsy Resources

For Students

- The Department of Education in Virginia has developed a guidance document entitled: *Guidelines for Seizure Management*, (Virginia Department of Education, 2010), which should be used to develop a student's Individualized Health Care Plan. The guidance document can be accessed here: <https://www.doe.virginia.gov/programs-services/student-services/specialized-student-support-services/school-health-services/school-health-guidance-resources>

Epilepsy Learning Portal:

- The Epilepsy Foundation has an online and on-demand Learning Portal with trainings about epilepsy and seizures. <https://learn.epilepsy.com/>
- The CDC also offers trainings for teachers, school personnel and law-enforcement officers (6). You can access those trainings here: <https://www.cdc.gov/epilepsy/groups/professionals.htm#school>
- The American Red Cross offers free mobile apps for all types of emergencies (including seizures) (2). You can access their mobile app site here: <https://www.redcross.org/get-help/how-to-prepare-for-emergencies/mobile-apps.html>

Part 1 - Seizure Disorders and Epilepsy Basics Health & Safety Alert.

Part 2 - Diagnosis and Treatment of Seizure Disorders and Epilepsy Health & Safety Alert.

Part 3 - Care Considerations and Seizure Disorders and Epilepsy Health & Safety Alert.

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To the best of the OIHSN Nursing Team's knowledge the information contained within this alert is current and accurate. If the reader discovers any broken or inactive hyperlinks, typographical errors, or out-of-date content please send email to communitynursing@dbhds.virginia.gov to include the title of the Health & Safety alert with specifics details of concern.