Pharmacy Alternatives
by PharMerica




# Seizures and Epilepsy in Individuals with I/DD

## A Comprehensive Guide for Care Teams

## What are seizures?

A seizure is generally defined as “a sudden burst of electrical activity in the brain.” When a seizure happens, neurons in the brain fire at up to four times their normal rate. This interrupts normal brain function, triggering changes in behavior, sensation, and/or awareness. Epilepsy is the term for a neurologic disorder characterized by recurring seizures. The underlying causes may be genetic, structural, infectious, metabolic, immune-related, or unknown.

**There are two main categories of seizures based on where abnormal electrical activity begins:**

**Focal seizures**

Starts on one side of the brain and can result in changes to awareness, behavior, or sensation. This type of seizure can cause mild or severe symptoms, depending on how it spreads across the brain.

**Generalized seizures**

Electrical activity originates on both sides of the brain at the same time and affects both sides of the body. These can also begin as focal onset seizures that quickly spread to both sides of the brain.

## What can trigger a seizure?

People with epilepsy may have individual triggers that increase the likelihood of having a seizure. A person can also experience a seizure because of an acute medical condition or other temporary cause without having epilepsy, such as:

| | | |
|---|---|---|
| Stress (both physical and emotional) | High fever | Brain infection |
| Illness | Lack of sleep (including poor or disrupted sleep) | Low blood sodium (hyponatremia) |
| Brain injury | Heavy alcohol use or alcohol withdrawal | Certain medications or illicit drugs ɓʁ!  lower the seizure threshold in some individuals |
| Missed doses of prescribed antiseizure medications | Menstrual cycle or other hormonal changes | |

Flashing or flickering lights can also trigger seizures in individuals with photosensitive epilepsy. Additionally, some individuals may identify personal triggers, including specific foods or dietary patterns, although these vary considerably from person to person.

Seizures present a serious concern and challenge for people with intellectual and developmental disabilities (I/DD), as epilepsy affects almost half of individuals with cerebral palsy or other developmental disabilities. Individuals with I/DD and epilepsy may experience additional challenges related to medication management, safety, and utilization of healthcare services.

It is essential for caregivers and care teams to understand what may trigger seizures in this population, how to help prevent them, and how to manage them when they occur.

## Why are seizures dangerous?



Seizures are not just upsetting to experience or witness; they can be physically dangerous. A prolonged seizure—one lasting five minutes or more—constitutes a medical emergency and carries a high risk of brain damage or death.



People with epilepsy who have prolonged and/or uncontrolled seizures are at risk for Sudden Unexpected Death in Epilepsy (SUDEP), which is rare but nonetheless a serious concern. Prolonged or frequent seizures can also lead to memory or learning issues.



Falls are common during or after seizures, especially if no one is around to assist when the event occurs. Falls can result in injuries such as bruises, broken bones, or head trauma.



All these complications can increase hospitalizations and emergency room visits, negatively impact mental health and well-being, and limit an individual's independence and autonomy.

## What are the symptoms?

It is sometimes possible to anticipate when a seizure might occur.

**Warning signs include:**

- Sensory changes
  Unusual tastes, smells, or visual disturbances.
- Behavioral, emotional, or mood changes
  Sudden or unusual feelings of anxiety, fear, or irritability.
- Physical changes
  Muscle twitching, jerking movements, sudden stiffness, rhythmic head nodding, headache, nausea, lightheadedness, dizziness, or breathing problems.
- Cognitive changes
  Temporary confusion, staring into space, inability to speak or communicate clearly, or loss of consciousness.

Warning signs may appear days, hours, or minutes before a seizure occurs, and they vary from person to person.

**There are two primary phases of warning signs:**

- Prodrome phase
  Can occur hours or days before a seizure and involves general mood, cognitive, or physical changes.
- Aura phase
  Typically occurs immediately before or at the beginning of a focal seizure and involves localized symptoms such as tingling, numbness, visual changes, ringing or buzzing in the ears, and/or a sudden change in awareness.

If a family member, caregiver, or staff member recognizes a warning sign, they should follow the individualized epilepsy care plan and prioritize the person's safety by helping them transition to a safe position (such as lying down on the floor away from sharp objects) and staying with them until the danger passes.

William Mercer, MD, CMD, a West Virginia-based physician, noted that some individuals with epilepsy utilize seizure alert dogs. He explained: "They can sense when someone is going to have a seizure and signal them to get into a safe position on the ground or floor. This can be very useful, especially for those who live alone or are unassisted for long periods of time."

**Not everyone experiences warning signs, and some seizures occur without any noticeable warning.**

## How can seizures be managed and/or prevented?

An accurate diagnosis is key to ensuring the most appropriate, person-centered management strategy.

> Once someone is diagnosed with epilepsy, the goal is to prevent seizures, but that's not always fully possible. We try to set up anÁ individualized epilepsy care plan for each person.
>
> **- Dr. William Mercer**

**Preventing seizures involves various interventions, starting with lifestyle adjustments such as:**

- Getting adequate and consistent sleep
- Maintaining a balanced diet and regular exercise
- Avoiding smoking and excessive intake of caffeine
- Reducing stress
- Limiting or avoiding alcohol consumption

It is also important to promote safety interventions such as wearing seatbelts, using helmets during physical activities, and implementing fall-prevention measures, since brain injuries can cause or worsen seizures. Additionally, caregivers should help prevent infections and illnesses by keeping vaccinations up to date and practicing good hygiene, such as frequent handwashing.

Dr. Mercer stressed the importance of care planning and training caregivers and staff on proper seizure response: "There are several myths about what to do when someone has a seizure that can actually cause more harm than good. For instance, some people believe you can swallow your tongue during a seizure. You cannot, so never put anything in a person's mouth."

Instead, he recommended placing a soft towel, blanket, or folded shirt under their head, gently rolling them onto their side to keep their airway clear, and never restraining their movements, which can cause severe muscle or joint injury. "If the seizure lasts more than five minutes, call 911 immediately," he added. He also emphasized that not all seizures present with full-body shaking; mild seizures can easily be mistaken for someone simply "spacing out."

Antiseizure (ASM) medications are used to prevent and manage seizures and treat epilepsy. ASM selection must account for the specific seizure type, comorbidities, safety profile, necessary monitoring, and potential interactions with other medications. Some individuals may require treatment with multiple ASMs to achieve adequate seizure control.

**Examples of ASMs include**

- **Lamotrigine (Lamictal®):** Used for both focal and generalized seizures; common side effects include dizziness and nausea. If a rash occurs during treatment, notify prescriber immediately.
- **Levetiracetam (Keppra®):** Used for multiple types of seizures; generally well-tolerated but may cause fatigue or mood/behavioral changes.
- **Valproic acid (Depakote®):** Used for multiple types of seizures; side effects include weight gain, tremors, and liver toxicity. Laboratory monitoring is required based on the individual's clinical circumstances, including reproductive considerations.
- **Topiramate (Topamax®, Trokendi® XR):** Used for focalÁ and generalized seizures; may cause weight loss andÁ cognitive changes, such as difficulty concentrating.
- **Phenytoin (Dilantin®):** Used mainly for focal seizures;Á side effects include gum overgrowth (gingivalÁ hyperplasia) and dizziness. Laboratory monitoringÁs required based on the individual's clinicalÁ circumstances.
- **Benzodiazepines (e.g., lorazepam (Ativan®), diazepam (Diastat®)):** Often used as rescue medications forÁ acute seizure clusters or status epilepticus.

**Rescue medications should be administered only as prescribed and according to the individual's seizure care plan and applicable facility protocols. ASMs should not be stopped abruptly unless directed by the prescriber.**

## What is the pharmacist's role in managing and preventing seizures?

Pharmacists play a critical role in managing and preventing seizures, particularly because individuals with I/DD are often prescribed multiple medications.

> Pharmacists do a great job of identifying potential drug interactions and highlighting opportunities to reduce dosages or eliminate medications that are no longer necessary.
>
> **- Dr. William Mercer**

Demetra Antimisiaris, PharmD, BCGP, FASCP, associate professor emerita at the University of Louisville, added: "People with I/DD often face a 'perfect storm' for drug interactions and adverse events, even when care teams are doing everything right. This population carries a lifelong chronic disease burden and is frequently on complex, long-term medication regimens." She emphasized that pharmacists are uniquely positioned to review regimens, verify proper dosing, and prevent adverse drug events.

Because missed doses of antiseizure medications are a common trigger for a breakthrough seizure, medication adherence is essential to maintaining seizure control. Family members and caregivers must understand the risks associated with missed doses, recognize potential signs of adverse effects, maintain an accurate and up-to-date medication list, and collaborate with the individual to support consistent adherence. Pharmacists can assist by offering clear medication education, providing adherence tools, reviewing prescription and over-the-counter medication changes for potential interactions, and identifying and addressing medication-related safety concerns.

## What is person-centered seizure care?



Managing seizures in individuals with I/DD requires a collaborative, multidisciplinary team approach. Group homes and care facilities typically maintain evidence-based protocols that all staff are expected to follow.

Proper seizure prevention and management training are vital. For example, staff must understand individual health risks, such as aspiration risks for individuals with feeding tubes, recurrent infections that can lower the seizure threshold, and environmental hazards that increase fall risks.

Dr. Mercer noted the importance of establishing routine visual check-ins for individuals prone to seizures: “Make sure their home environment is as safe as possible and that known triggers are controlled. Are they eating well? How is their sleep quality? Have there been any recent falls or minor head bumps? Tracking this information helps keep the personÁsafe and healthy.”

Supporting individuals who experience seizures requires a person-centered philosophy that balances medical safety with personal independence and quality of life. While minimizing seizure risks is critical, it is equally important to respect preferences, choices, and personal goalso

## References


Becker DA, Wheless JW, Sirven J, Tatum WO, Rabinowicz AL, Carrazana E. **Treatment of Seizure Clusters in Epilepsy: A Narrative Review on Rescue Therapies.** Neurol Ther. 2023 Oct;12(5):1439-1455. doi: 10.1007/s40120-023-00515-3.

Beniczky S, Trinka E, Wirrell E, Singh MB, Blumenfeld H, Bogacz Fressola A, et al. **A practical guide to the updated seizure classification 2025.** Epileptic Disord. 2025; 27: 1087–1104.

**PharMerica** Did You Know: Anticonvulsants & I/DD

**PharMerica Did You Know: Seizures**



# KNOWLEDGE THAT BUILDS CONFIDENCE

Access educational resources, clinical guidance, and expert insights for I/DD professionals.

Behavioral Health - PharMerica

## LOOKING FOR ADDITIONAL SUPPORT?

Learn how PharMerica partners with providers to navigate complex medication needs with confidence.

**Scan to explore our services.**