



# Office of Ombudsman for Mental Health and Developmental Disabilities



## Seizure Alert

This Medical Alert is based on the work of the Medical Review Subcommittee and should be posted prominently. The Office of Ombudsman for Mental Health and Developmental Disabilities works to improve the services provided to people with disabilities by communicating important information found in the Medical Review Subcommittee's reviews of deaths and serious injuries. Thank you for promptly reporting deaths and serious injuries. You are helping us to meet our mission.

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### Overview

Because many of the serious injuries and deaths reported to the Office of Ombudsman for Mental Health and Mental Retardation involve seizures, the Medical Review Subcommittee (MRS) has developed this Seizure Alert. This Alert will focus on the care of people with a history of seizures who live in community settings. Topics covered will include general information about medications, seizure recognition, first aid, and precautions you can take to reduce the incidence of injury when a seizure occurs.

Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. It also is called a seizure disorder. When a person has two or more unprovoked seizures, they are considered to have epilepsy. An episode of abnormal electrical activity in the brain or a seizure can be detected with an EEG (electroencephalogram). In addition, behavioral changes also can occur with seizures. The term "seizure" is often used interchangeably with "convulsion." In addition to epilepsy, medical conditions such as diabetes, brain infection, heat exhaustion, pregnancy, poisoning, low blood sugar, high fever, tumors, low oxygen levels, electrolyte imbalance, vascular disease, drug or alcohol withdrawal, illicit drug use, head injury and others can cause seizures. For most people, epilepsy is not a life-threatening disorder. Yet people with seizures can die from accidents, from status epilepticus (non-stop seizures), and from a condition known as Sudden Unexplained Death in Epilepsy. Thirty-five percent of people with epilepsy report at least one injury from a seizure. Fractures from falls are the most frequent serious injuries reported to this Office. Burns and near-drownings much less frequently occur. Drownings occur most often in the bathtub or outdoor pool and usually happen when the client is unsupervised. Burns most often result from stovetop cooking or smoking.

### Medications and Seizure Disorders

While epilepsy may be treated today with surgery, a special diet, or an implanted device to stimulate the vagus nerve (VNS therapy), the most common treatment is drug therapy with anticonvulsant or antiepileptic drugs. Medications do not cure epilepsy, but they can help make it possible for many people to live normal, active lives completely free of seizures. Other people may continue to have some seizures but usually not as often. Seizure preventing drugs won't work properly until they reach a certain level in the body and that level has to be maintained. It is important to follow the healthcare provider's instructions.

Your client's healthcare provider will monitor your client's blood levels of the medication and will order blood studies to make sure your client stays healthy.

Your client's healthcare provider will expect you, as a caregiver, to give the medications to your client as prescribed (5 rights – right *dose/amount* of the right *medication* to the right *client* at the right *time* by the right *route*), to watch your client for possible side effects of the medication, and to record information (see the list of observations to record listed under "Seizure Recognition") about any seizures your client has, so the healthcare provider will know if the medication is working as expected.

All anti-seizure medications have some side effects. Mild side effects include: fatigue, dizziness, weight gain, loss of bone density, skin rashes, loss of coordination, speech problems. More severe but rare side effects include: depression, suicidal thoughts and behaviors, severe rash and inflammation of certain organs such as the pancreas or liver.

To achieve the best seizure control: take medications exactly as prescribed, call the prescriber before switching to a generic version or taking other prescriptions medications, over-the-counter drugs or herbal remedies, never stop taking medications without talking to the prescriber, and notify the prescriber immediately if there are new or increased feelings of depression, suicidal thoughts or unusual changes in mood and behavior. Drug interactions may increase or decrease the effect of the medications on the body. For example, some antiepileptic drugs and birth control pills may interact, making the birth control pills less effective. Women with epilepsy who are considering using birth control pills should discuss this possibility with their doctors.

For every medication prescribed for your client, ask the client's healthcare provider to give you a list of side effects to watch for.

## **Seizure Recognition**

Symptoms of seizures vary depending on the type of seizure. In most cases, a person with epilepsy will tend to have the same type of seizure each time. A person may have warning symptoms such as fear or anxiety, nausea, vertigo (dizziness) or visual symptoms (flashing bright light, wavy lines before the eyes). Signs of possible seizure activity include:

- Involuntary jerking of an arm or leg or other body parts.
- Eye deviation (blinking, twitching, eye rolling, eye fluttering).
- Inappropriate movements of the mouth or face accompanied by a blank expression (lip smacking, chewing, swallowing, yawning, spitting).
- Nodding, turning, or dropping of head.
- Sudden loss of muscle tone and/or falling.
- Aimless, dazed behavior, including walking or repetitive movements that seem inappropriate to the environment.
- Brief black out followed by period of confusion
- Changes in behavior such as picking at one's clothing
- Grunting and snorting
- Drooling or frothing at the mouth
- Mood changes such as sudden anger, unexplainable fear, panic, joy, laughter
- Tasting a bitter or metallic flavor
- Teeth clenching
- Temporary halt in breathing

It is possible for people to lose control of their bowel or bladder during a seizure. Shallow breathing or breathing that is stopped for a short time may make the skin and lips turn a bluish color. During a seizure, a client may make unusual sounds like a cry, moaning, barking, humming, snoring, whistling, repetitive words, etc. After a seizure, the client may be confused for a time. The confusion may last longer than the seizure did.

When a seizure occurs, it is usually helpful to the client's healthcare provider to record the following observations:

- Did the person have an aura (a peculiar sensation – feeling, odors, colors/patterns/lights – noticed by the client before a seizure)?
- When and how often do the seizures occur?
- Did the client lose consciousness?

- What body parts were involved?
- How long did the seizure last?
- Did the client lose bowel or bladder control or stop breathing?

## **First Aid**

An uncomplicated seizure in someone who is known to have epilepsy is not a medical emergency. Greater care needs to be taken with clients of the Office of Ombudsman for Mental Health and Developmental Disabilities, because there are often other complicating medical conditions present. The following recommendations are from several sources for care for a client in during a seizure:

- Lower the client to the ground
- Move objects that may cause injury away from the client (for example, furniture or sharp/hard objects).
- Time the seizure
- Remove eye glasses and loosen ties or anything around the neck that may make breathing difficult.
- Provide privacy.
- Protect the client's head from injury by putting something flat and soft under the head (like a folded jacket or towel).
- Turn the client onto the side (to prevent aspiration - the breathing in of saliva or vomit).
- Do not put any hard object in the mouth or try to hold the tongue. (It can't be swallowed.)
- Don't try to give liquids during or just after a seizure.
- Do not hold the person down or try to stop their movements.
- Do not attempt artificial respiration unless breathing does not return after muscle jerks stop.
- Stay with the person until the seizure ends naturally
- Be calm and reassuring; provide emotional support.

An ambulance should be called if any of the following happen:

- If the seizure happened in water.
- If there is no medical ID, and no way of knowing whether the seizure is caused by a known seizure disorder.
- If the person is pregnant, injured, has diabetes or heart disease.
- If the seizure continues for more than five minutes.
- If a second seizure starts soon after the first has ended (*unless a specific treatment plan has been developed by the healthcare provider for the client with a known seizure disorder*).
- If consciousness does not start to return after the shaking has stopped.
- If the person appears to be in pain or recovery is unusual in some way
- The person becomes aggressive

Prolonged or clustered seizures sometimes develop into non-stop seizures, a condition called status epilepticus. **Status epilepticus is a medical emergency. Call 911.**

## **Safety Precautions**

The Epilepsy Foundation has an excellent website with helpful information about living with a seizure disorder. Only bathroom and kitchen safety are covered in this Alert. More information about safer houses, workplaces, transportation, recreation, and children is available at <http://www.epilepsyfoundation.org/> .

Along with its Summer Alerts, the Office of Ombudsman for Mental Health and Mental Retardation distributes a Water Safety Alert. Please refer to it for more detailed water safety recommendations. **For people with a history of seizures, it is important to make sure that they never swim alone and are never on a boat or near water without wearing a flotation device or life jacket.**

## **Bathroom Safety – Preventing Falls, Drownings, and Burns:**

- Install doors are so they open outwards - so that if someone falls against the door, it can still be opened
- Put extra padding under bathroom carpeting
- Hang an “Occupied” sign on the outside handle of the bathroom door instead of locking it.
- Regularly check that the bathroom drain works properly before bathing or showering.
- For people who fall frequently during seizures, use a shower or tub seat with a safety strap.
- Keep water levels low in the tub. If clients have seizure disorders that are not well-controlled, **do not leave them unattended.**
- Consider using a hand-held shower nozzle while seated in a tub or shower
- Set water temperatures low (less than 120 degrees Fahrenheit) to prevent scalding.
- Avoid using electrical appliances such as hair dryers or electric razors in the bathroom or near water.

## **Kitchen Safety – Preventing Spills, Cuts, and Burns:**

- Slide containers of hot food along the counter instead of picking them up or use a cart when taking hot foods or liquids from one room to another.
- Use plastic dishes and cups with lids.
- Use a microwave oven for cooking.
- When using the stove, use the back burners as much as possible.
- Remove burner controls from gas or electric stoves when not in use.
- Use long, heavy-duty oven mitts or holders when reaching into a hot oven.
- Wear rubber gloves when handling knives or washing dishes and glassware in the sink.
- Use plastic rather than glass containers as much as possible.
- Do not allow vulnerable clients to cook without supervision.

## **Could this happen to one of your clients? Case Studies**

#1. A 32-year-old woman, with major depressive disorder, mild mental retardation, and a seizure disorder, died in an adult foster care (AFC) home. A week before her death, she had been discharged from the hospital after an eight day stay. During her hospitalization, she had received significant changes to her prescriptions for anticonvulsant medications. Her situation was complicated by the question of whether she was having pseudo seizures. Two days before her death, her case manager and adult foster care provider had consulted about concerns regarding the client’s actions. These actions included drooling, periods of eating poorly, and times when she went outside without clothing adequate for the season. The night before her death she had fallen out of bed and was helped back to bed. On the morning of her death, she was again found on the floor in a sleeping/drooling state. The foster care provider called the client’s physician but only reached voice mail. The provider then called the case manager. The case manager suggested calling 911. Shortly thereafter, the provider went to administer medications and found the client unresponsive, not breathing, and with clenched jaws. 911 then was called. The client was pronounced dead at the home. The death was reported to the medical examiner, and an autopsy was performed. Her manner of death was natural, and her immediate cause of death was attributed to probable seizure disorder. Following its investigation, the licensing agency found that the foster care provider on duty did not obtain medical care for the Vulnerable Adult (VA), and the allegation was substantiated as to neglect of the VA. The MRS noted in its review of the case that the significance of the client’s medication change was likely unrecognized by the AFC staff. The MRS also noted that gaps in service to clients occur when minimally trained residential staff are expected to provide a medical model of care.

#2. This 25-year-old man, with organic brain disease, borderline personality disorder, and Type I diabetes mellitus, died in his community hospital, nine days after he had been found unresponsive in the waived

group home in which he had lived. The facility nurse was called and performed a blood glucose check, which was 16 [dangerously low]. 911 was called, and the client was transported to his community hospital. When staff at his community hospital were unable to stop his seizures, he was transferred to a regional hospital. He was placed on a ventilator and never recovered. The client had been working with a diabetes specialist and diabetes educator, so it was important for recommendations and doctor's orders to be communicated to staff. In the documentation provided by the facility, there appeared to have been a specific instruction to test the client's blood sugar at 2:00 AM weekly and when the 10 PM check was less than 100. This instruction did not appear on the client's medication record and so was not readily available to the group home staff who provided care for the client. Following its review, the MRS recommended that all specific medical instructions made for the care of a client be written in the form of "doctor's orders" and be reflected on the Medication Administration Record, so that staff have ready access to the information. **The MRS recommended that whenever a client is found unresponsive, 911 should be called immediately.** While a facility policy may direct staff to call the nurse or to notify supervisory staff of an incident, **always call 911 first for unresponsive clients.**

## References:

Centers for Disease Control and Prevention. <http://www.cdc.gov/Epilepsy/>

Epilepsy Foundation website – <http://www.epilepsyfoundation.org/>

Epilepsy. <http://www.mayoclinic.com/health/epilepsy/DS00342>

Federal Drug Administration. <http://www.fda.gov/Drugs/ResourcesForYou/Consumers/default.htm>

Tucker et al (2000). *Patient Care Standards: Collaborative Planning and Nursing Interventions*. (7<sup>th</sup> ed.). Mosby Publishing.

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