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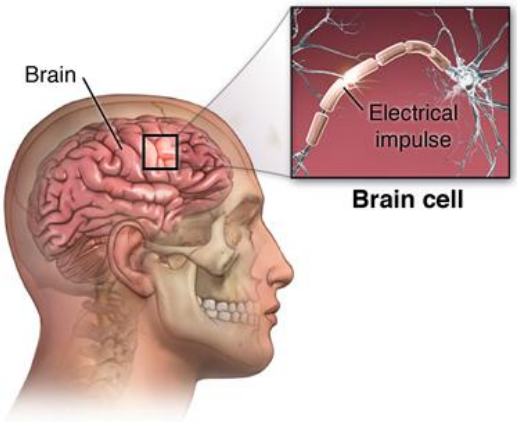
Office of Integrated Health
Health & Safety Information

Part 2: Seizure Disorder and Epilepsy Health & Safety Alert - Diagnosing and Treating

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 (33) (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 (33).

The average length of a seizure is between 30 seconds and two minutes. The seizure scenarios below require immediate emergency medical attention (33) (35). If an individual is experiencing any of the following, call 911:

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

Not every person who has a seizure has epilepsy. Epilepsy is a seizure disorder that 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 (33).

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

Prevalence

Anyone can have a seizure or develop a seizure disorder such as epilepsy. Individuals from all cultures, age groups, and genders can experience seizures (35).

Lower social, economic, and educational levels have been connected to an increased occurrence of seizure disorders and epilepsy in individuals (22).

Approximately 1 in every 3 individuals with mild to moderate IDD are diagnosed with epilepsy or a seizure disorder. Approximately 1 in 5 individuals diagnosed with epilepsy also have some form of learning disability (41) (18).

Current estimates for epilepsy in individuals diagnosed with autism spectrum disorder (ASD) vary within research studies, finding between 1.8 to 60% of individuals diagnosed with ASD having some form of epilepsy (4).

Possible Causes of Seizures and/or Epilepsy

In many cases, the cause of a seizure is unknown. More than half of all epilepsy diagnoses have no known cause. Depending on what a person might be experiencing at any given time, they could have a seizure. Any disturbance of normal cell activity in the brain can lead to a seizure (26) (22) (35).

Seizures can occur due to health issues such as:

- Traumatic brain injury (TBI).
- Abnormal brain development.
- Genetic factors.
- Sleep disorders.
- Traumatic injury to the body (26) (22).

Diagnosing Seizure Disorder and Epilepsy

Diagnostic testing is usually attempted after an individual has had two or more unprovoked seizures separated by at least 24 hours. The primary goal of all diagnostic procedures is to help medical specialists find effective treatment for the individual (35).

Diagnosing and treating seizure disorder and/or epilepsy in an individual with IDD requires a neurologist. A neurologist is a medical professional who specializes in the functions of the brain. The specialist may request medical records and conduct interviews with caregivers in order to piece together the individual's medical history from birth forward if possible.

The neurologist will conduct a physical assessment of the individual (i.e., history and physical) and will order tests to identify where in the brain the seizure activity is starting. The tests will focus on classifying the type of seizures the individual is experiencing (33).

A neurologist is a physician whose specialty is in diagnosing and treating diseases of the brain, spinal cord and nerves (8).

An epileptologist is a neurologist who specializes in epilepsy and has completed an additional one or two years of subspecialty training in epilepsy care (11).

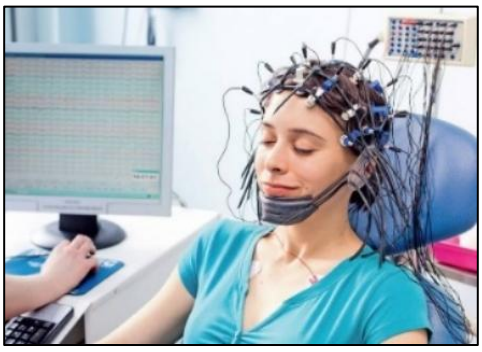
A neurologist needs to know if an individual has any history of head injury because head trauma can significantly increase the risk of developing epilepsy or experiencing seizures, particularly if the injury was severe.

- Caregivers can help the specialist with the diagnostic process by sharing information about:
  - When the seizures started and how they have progressed or changed over time.
  - Verbal or documented eyewitness accounts from caregivers, family members, and friends who may have witnessed prior seizure episodes (13).
  - Any past history of head injuries. A history of head trauma can significantly increase the risk of seizure disorder or epilepsy, especially if the head injury was severe (21).
  - Any past history of birth trauma.

    A difficult birth can be a significant risk factor for developing epilepsy due to potential brain injuries that may have occurred during delivery, such as oxygen deprivation or intracranial bleeding, which can lead to seizures later in life. A detailed birth history and any information about the pregnancy (especially if it was a difficult one) can provide helpful information during a neurological assessment (21).
  - Apgar scores. A low Apgar score is considered a risk factor for developing seizures in newborns, particularly when the score is low at the 5-minute mark. A low Apgar score may indicate perinatal asphyxia (lack of oxygen), which can increase the likelihood of seizures and other neurological complications (19).
  - Any genetic diagnoses (35).
  - Any known brain abnormalities (35).

  - Any history of infections, stroke, brain tumors, or sepsis (35).
- Documentation of a seizure should include the following details:
  - The date, time, place and duration of the individual's seizures.
  - Any patterns caregivers have noticed relating to seizure activity.
  - Whether the individual loses consciousness or not during the seizure.
  - A description of any abnormal body movements that occurred during the seizure.
  - Any warning signs or events which directly preceded the seizure.
  - How the individual felt after the seizure.
  - Any triggers caregivers have noticed.
  - Any family history relating to seizure disorder and/or epilepsy (41).
- Video recording of the individual having a seizure is a helpful tool specialists can use during the diagnostic process. Agency support staff members must obtain permission from the individual or legal guardian before videotaping an individual experiencing a seizure (13).
- Lab work, both urine and blood tests, are required to identify metabolic abnormalities such as abnormal amino acids, long-chain fatty acid levels, drug intoxication (recreational or prescribed), hypoglycemia, hyponatremia or infections that may be triggering seizures (43).

  They can also be used to detect vitamin B-6 deficiencies (pyridoxine deficiency), which can cause seizures. Lab work is used as part of the general clinical assessment of the individual's health. Research dictates that over 50% of "first seizures" have some type of acute symptomatic cause (43).
- Electroencephalography (EEG) can be done by placing electrodes on the scalp (33). The electrodes obtain a recording of the brain's electrical activity and determine where in the brain the seizure is beginning. This information can help specialists determine the seizure type and epilepsy syndrome (13). An EEG is a painless procedure.



- Stereo electroencephalography (SEEG) is an invasive type of EEG monitoring. If a typical EEG test does not reveal where the individual's seizures are beginning, surgically placed electrodes may need to be placed. The surgeon may place electrodes on the surface of the brain or deeper

inside the brain to be able to trace the exact cells causing the seizures. After the electrodes are placed the individual stays in the hospital to be monitored by a special epilepsy team to develop a targeted treatment plan (7).

- Video EEG includes video monitoring to record the seizures and their impact on the body, as they occur. Antiseizure medications will need to be reduced or stopped so seizures will occur during the testing. This type of testing will require hospital admission for monitoring of the individual. Correlating the changes in the EEG with the individual's body movements will help to pinpoint the area of the brain where their seizures are starting. Video EEG can also be done with surgically placed electrodes (24).
- Computed Tomography (CT) is a type of imaging that uses X-ray technology to create detailed images of the body. The CT machine then uses the x-rays to create cross-sectional images (called slices) of the bones, blood vessels, and soft tissues inside the body. CT scan images are much more detailed than regular X-rays (30).
- Magnetic Resonance Imaging (MRI) can be used to identify abnormalities in the brain (33). An MRI is a type of diagnostic test that creates detailed images using magnets and radio waves to produce images on a computer screen. MRI images can show organs, bones, muscles, and blood vessels. MRIs are considered very safe because they do not use radiation (23).
- Positron emission tomography (PET) scan is a specialized imaging device that measures brain function when the individual is seizure-free (29).
- Single-photon emission computerized tomography (SPECT) scan is a testing procedure that measures blood flow in the brain during a seizure. Typically, blood flow is higher in the region of the brain where seizures occur. The individual will be admitted to the hospital while having this test (31).

Treating Seizure Disorder and Epilepsy

Treatment for seizure disorder and epilepsy aims to help an individual become seizure-free with minimal adverse side effects and to live as normal a life as possible (18).

There are three main options to assist individuals with the management of seizure activity:

- Anti-seizure medications
- Vagus nerve stimulation (VNS)
- Resective surgery to remove the brain tissue causing the seizures (18).

Anti-seizure Medications

Antiepileptic drugs are the main resource used in controlling seizure activity (18).

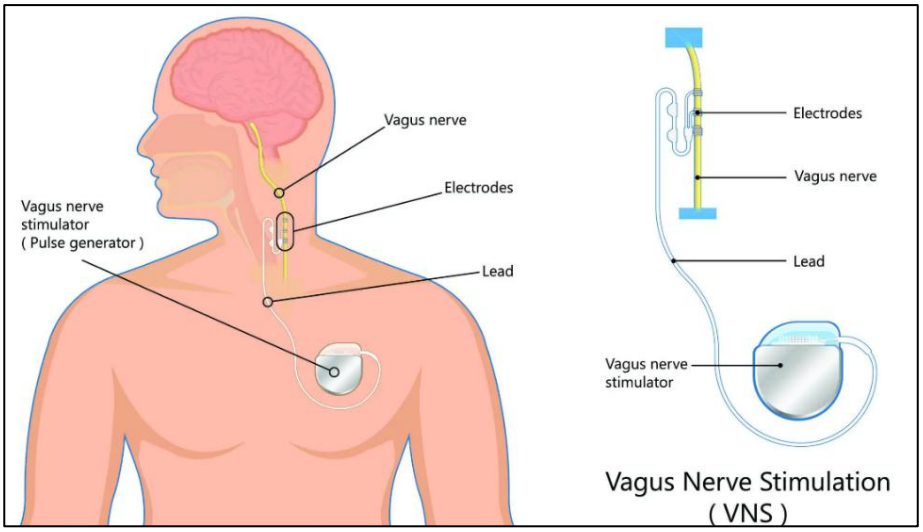
- Medications are successful in managing some seizure types better than others (41).
- Some individuals with IDD require more than one type of anti-seizure drug to manage their seizures, leading to increased polypharmacy (33).
- Individuals with IDD may not be able to communicate their discomfort to caregivers when they are experiencing side effects due to antiepileptic drugs (41).
- Adverse drug side effects are common with antiepileptic drugs, especially for individuals with IDD, including increased sleepiness, confusion, disorientation, difficulty with gait, and a change in mental state, which requires the need for close monitoring by caregivers (41) (18).
- Seizure disorder and epilepsy in some individuals with IDD are resistant to medication treatment, leading to higher rates of preventable death (28) (4).
- It can be very dangerous to stop antiepileptic drugs all at once, which can lead to a serious medical emergency, status epilepticus. Antiepileptic drugs require a tapering off when discontinuing the medication and should only be done by a healthcare professional (41).
- The main differences between the older and newer anti-seizure medications are how the drug interacts with other medications within the body during metabolism (41).
- Some older anti-seizure medications are:
  - Phenobarbital
  - Primidone
  - Carbamazepine
  - Valproic acid
  - Several benzodiazepines such as diazepam and clonazepam (41).
- Some newer anti-seizure drugs are:
  - Gabapentin
  - Lamotrigine
  - Topiramate
  - Vigabatrin

- Keppra
- Trileptal
- Lyrica
- Vimpat (41).

Vagus Nerve Stimulator (VNS)

When antiepileptic drugs are not controlling an individual's seizure activity, an individual's primary care provider (PCP), or neurologist may suggest the use of a vagus nerve stimulator (VNS), which interrupts the electrical impulses in the brain cells during a seizure (13).

- The VNS is sometimes referred to as the "pacemaker for the brain".
- A VNS is an implanted device under the skin on the left side of the chest. which emits mild electrical pulses to the brainstem through the Vagus nerve in the neck (13).
- A VNS comes with a hand-held magnet that can be swiped over the pulse generator in the chest to send extra stimulation to disrupt brain cell activity (9).
- The VNS electrical pulse intensity, frequency, duration, and on/off pauses can vary depending on the treatment set by the prescribing physician (13).
- A VNS doesn't cure epilepsy; it doesn't completely stop seizure activity; the individual will probably need to continue to take antiseizure medications.
- The objective of a VNS is to reduce the number, length, and severity of seizures (9).



- Regular assessment of an individual's VNS by the prescribing physician is required to verify the device is working properly and the pulse generator remains in place, along with checking battery life.
- VNS battery life varies between 1 and 15 years. The pulse generator is replaced when the battery life ends (9).
- Side effects from VNS can range from mild to serious. When caring for an individual with a VNS, all support staff members and caregivers should be educated and trained on how to recognize side effects and when to contact the prescribing physician for assistance (9).

Additional Dietary Treatments

Some physicians might recommend a keto diet for individuals with epilepsy in addition to medication. A typical keto diet consists of 70% to 80% fats, 20% proteins, and 5% to 10% carbohydrates. Both the low-sugar component and the high-fat element are thought to alter brain activity, reducing seizures (10).

Types of Epilepsy Surgery

- Resective brain surgery is a procedure that removes brain tissue to treat epilepsy or other conditions. It is the most common surgery for epilepsy when two or more anti-seizure medications have proven to be ineffective in reducing seizure activity. Resective surgery removes the part of the brain cells that are found through testing to be causing the seizures (31).
- The surgery can involve removing a small amount of brain tissue or a larger part of the brain, such as a lobe or hemisphere. The goal is to reduce or stop seizures. Resective brain surgery can also treat brain injuries or tumors. Typically, resective surgery is recommended for younger individuals (13) (32).
- During the procedure, a neurosurgeon:
  - Shaves the patient's head
  - Gives the patient general anesthesia
  - Creates a small window in the skull to access the brain
  - Removes the affected brain tissue
  - Sets the skull bone back in place and closes the skin
- Risks of resective brain surgery include:
  - Blood clots in the brain
  - Infection of the brain or surgical incision
  - Swelling in the brain
  - Increased risk of seizures or stroke

  - Temporary or permanent problems with thinking, seeing, speech, and memory

- Laser interstitial thermal therapy (LITT) is a less invasive procedure than resective brain surgery. LITT uses a laser to pinpoint and destroy a small portion of brain tissue. Magnetic resonance imaging (MRI) is used to help guide the surgeon's laser (36) (31).
- Deep brain stimulation is a procedure that involves implanting electrodes deep inside the brain. A pacemaker-like device is placed under the skin in the chest area. A wire connects this device to the electrodes in the brain. The electrodes send electrical impulses to disrupt seizure-causing activity. Like LITT, this procedure is guided by MRI (31).
- Corpus callosotomy is a surgery that completely or partially removes part of the brain connecting nerves on the right and left sides of the brain. This area is called the corpus callosum. This procedure is performed most often on children who experience irregular brain activity that spreads from one side of the brain to the other (31).
- Hemispherectomy is a procedure that removes one side of the brain, called a hemisphere. A hemisphere is part of the cerebral cortex, the folded gray matter of the brain. This surgery is usually performed on children who have seizures that start in different areas within one brain hemisphere. These types of seizures usually result from a condition present at birth or diagnosed in early infancy (31).
- Functional hemispherectomy is a procedure mostly performed on children to remove the connecting nerves between brain matter without removing actual pieces of the brain (31).

Seizure Management Plans

There are many unique challenges for the individual diagnosed with IDD and seizure disorder and/or epilepsy in the community. 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 (25).

It is important to address seizure management in all of the various settings/environments an individual's routine includes, 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 (25).

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).
- 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 takes place, such as the PCP, a specialist, guardian, or authorized representative.
- Signature of the prescribing physician (15).

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

IDD Individuals and Risk of Injury

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 (13).

The risk of concussion is elevated in individuals with epilepsy and IDD. While helmets are often recommended for individuals with recurring seizure-related falls, their effectiveness has not been proven (13).

Risk factors for falls in all settings may be worsened by age, impaired mobility, and behavioral issues (13). If the individual you are caring for has had falls with injuries, especially head injuries, consult an OT or PT to inquire if a helmet or other headgear may be an appropriate intervention.

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 a seizure management plan should be abandoned. Refer to their physician for clarification and guidance.
- Maintain adherence to the individual's Medication Administration Record (MAR) to ensure their 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 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 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.
- Caregivers should be aware of seizure triggers such as flashing/strobe lights. This includes flashing or strobing lights on television, at the movies, and on computer screens (20).
- Dehydration and low sodium (hyponatremia) can increase the risk of seizure activity (39). Attempt to keep the individual well-hydrated, especially in the summer months.

- Fever or illness, stress, and lack of sleep can increase seizure activity (35).

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

Types of Seizure Alert Devices

Seizure alert devices are used to detect seizure activity in real time. When there is a need to detect convulsive seizures for safety purposes, seizure detection devices (SDDs) can be used to provide a more accurate seizure count and can alert caregivers of a seizure to ensure prompt attention. The five different types of seizure alert devices include:

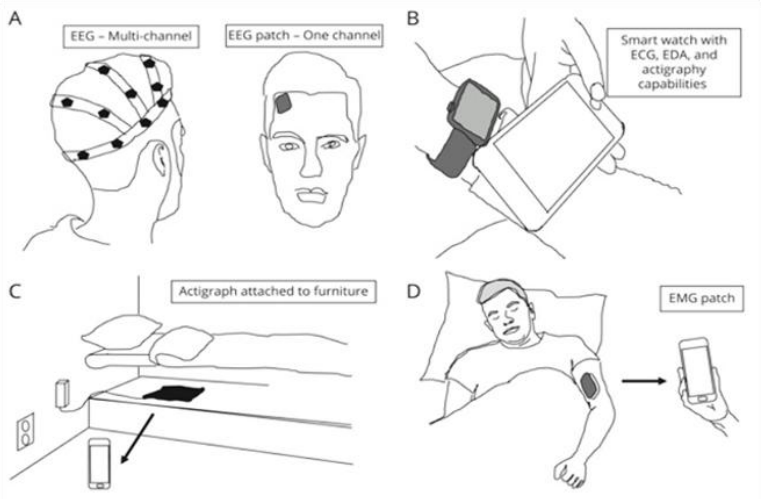
A. A wearable electroencephalography (EEG), which is the gold standard for seizure detection, current devices on the market may not be suitable for extended at-home monitoring (3).

B. Heart rate detection (HR) can be an effective method for detecting and potentially intervening on both convulsive and nonconvulsive seizures (3).

C. Electrodermal activity (EDA) is one of the most effective in detecting convulsive seizures when combined with a motion detection device. Several of these devices currently available can send an alert to a caregiver or support staff member when seizure activity is occurring in real time (3).

D. Motion detection pads are successful at detecting convulsive generalized tonic-clonic seizure activity when paired with the EDA or EMG. The downside of using only a motion detection device is it will also detect other movements made by an individual (3).

E. Electromyography (EMG) can be reliable at identifying the distinct pattern of a tonic-clonic seizure but cannot, on its own, detect seizures without a motor component (3).



List of Some Assistive Technology Devices for Epilepsy

- Bracelets for epilepsy: Divoti Sport ID Medical Alert Bracelet, Epilepsy Alert Medical Bracelet
- Mattress devices for epilepsy: Emfit Movement Monitor, MP5v2 Bed Movement Monitor for Seizures
- Cameras for epilepsy: SAMi-3 Camera, Sense-U Baby Breathing Monitor
- Anti-suffocation pillows for epilepsy: Breathe-zy Anti Suffocation Pillow, Sleep-Safe Anti Suffocation Pillow
- Watches for epilepsy: SOS Smartwatch, SeizAlarm: Seizure Detection (34).

Service Dogs

Seizure alert dogs are trained service animals who can help individuals when they have a seizure. Service dogs can be trained to summon help when an individual is having a seizure. They can also help to keep individuals safe if they are trained to wake the individual up when they become unconscious (17).

Safety Tips for Wheelchair Users

- If an individual who has a manual wheelchair and is having a seizure, engage the brakes to prevent the wheelchair from moving/rolling.
- If an individual who has a motorized wheelchair is having a seizure: turn the power off to stop the chair from moving/rolling.
- For all wheelchair users: let them remain seated in the wheelchair during the seizure (unless they have a seizure care plan which says they should be moved). Moving them could possibly lead to injuries for both you and them.
- If they have a seatbelt or harness on, leave it fastened.
- If they don't have a seatbelt or harness, try to provide support so they don't fall out of their wheelchair (manual or motorized).
- Cushion the individual's head if possible. A headrest can be helpful. The wheelchair (especially if it is a manual or non-motorized type), might offer the individual some protection from head injuries (14).

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Epilepsy 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 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

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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.