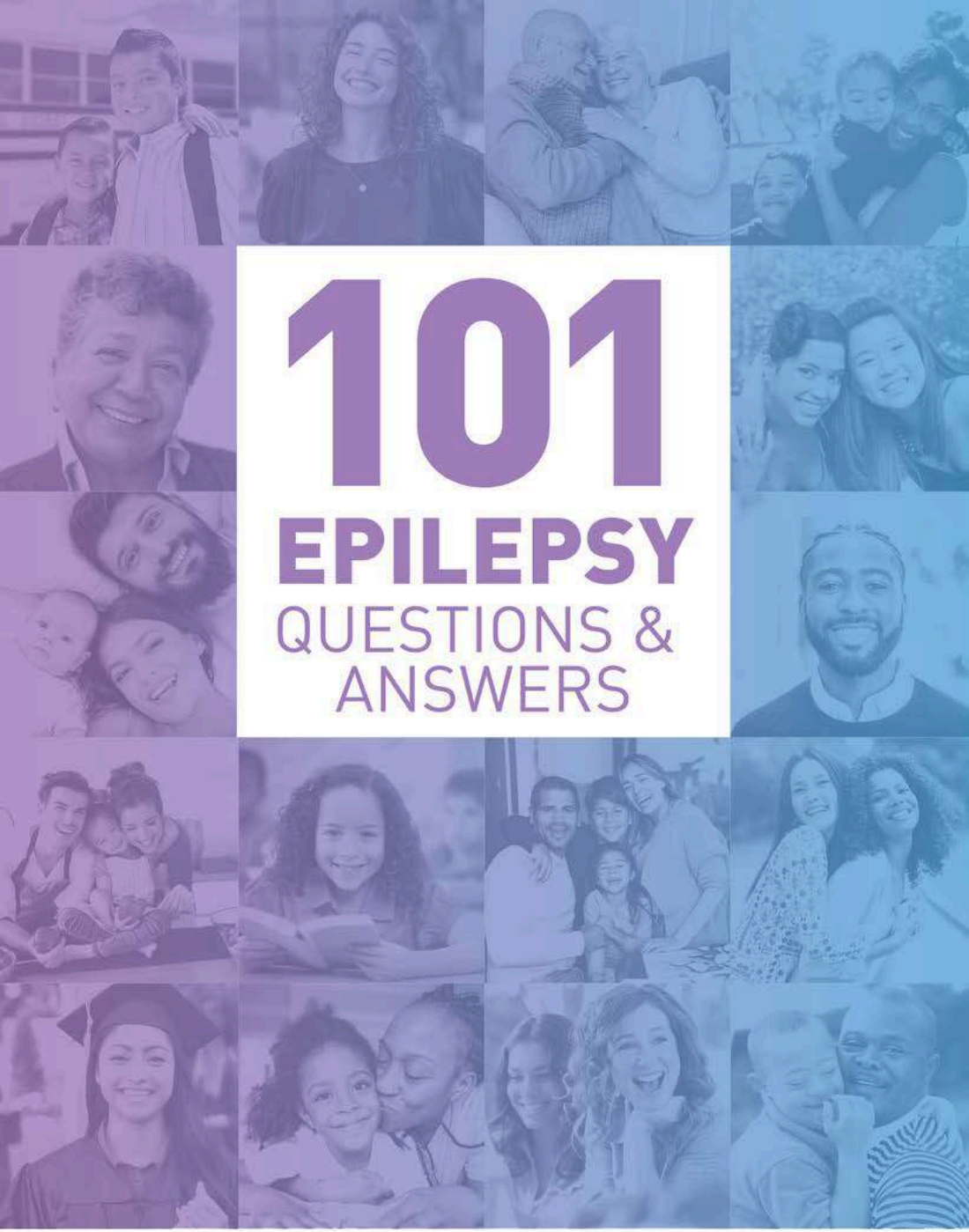

101 EPILEPSY QUESTIONS & ANSWERS

epilepsy ALLIANCE FLORIDA

THE POWER OF LOCAL

EPILEPSY ALLIANCE FLORIDA

Epilepsy Alliance Florida (EAFLA) is dedicated to supporting those impacted by epilepsy by confronting the spectrum of challenges created by seizures. The organization was established in 1971 as a not-for-profit 501(c)(3) and serves as the principal agency for epilepsy programs and services sponsored by the State of Florida. There are an estimated 426,000 Floridians who suffer from the condition. EAFLA is a proud member of the national Epilepsy Alliance America and serves as the lead advocate for the rights and needs of people with epilepsy and seizures at the local, county, state, and national levels.

1 in 26 people live with epilepsy. There is no cure. We are here to help. By supporting Epilepsy Alliance Florida, you are helping us further our mission: supporting those affected by epilepsy in local Florida communities. Will you join us in our fight against epilepsy?

Services include ongoing medical care, social services, case management, psychological services, support groups, a summer camp for children with epilepsy, prevention, and education for individuals, groups, or the community at large as well as advocacy for persons with epilepsy.

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The information contained in this pamphlet is not intended as a substitute for professional medical advice. A formal consult with the treating physician should be arranged for all medical concerns, care decisions, and treatment options.

GENERAL ISSUES

1 WHAT IS EPILEPSY?

Epilepsy is a chronic neurological disease characterized by recurrent, unprovoked seizures. A person is considered to have epilepsy if any of the following conditions are met: 1) a person has at least two unprovoked (or reflex) seizures that occur more than 24 hours apart; 2) a person has one unprovoked seizure and it is suspected that there is a minimum of a 60% likelihood of recurrence within the next ten years; and 3) a person is diagnosed as having epilepsy syndrome. Seizures and epilepsy are not the same entity, although a seizure is the principal clinical manifestation of epilepsy, the incidence of a single seizure does not necessitate an epilepsy diagnosis. A seizure is an event in the brain that causes abnormal changes in movement, behavior, perception, or consciousness. Epilepsy is the disease which involves recurrent, unprovoked seizures.

2 WHAT CAUSES EPILEPSY?

Epilepsy has many causes. In some people, the cause is evident, in others unclear, and in others, the cause remains unknown. The most common causes of epilepsy vary at different stages of the life span. 1) In childhood: issues that may occur during birth such as lack of oxygen and an intracranial bleed, inborn errors such as brain malformations and genetic mutations, and infections of the central nervous system. 2) In adulthood: head trauma commonly associated with an accident while in a motor vehicle, cycling, or performing some other outdoor activity and progressive brain diseases. 3) In the elderly: stroke, brain tumor, and Alzheimer's disease. Although this list includes a large variety of conditions which may lead to epilepsy, in approximately half of the individuals with epilepsy, the cause is unknown.

3 IS EPILEPSY AN INHERITED DISEASE?

Only some types of epilepsy are genetically determined, such as juvenile myoclonic epilepsy, most epilepsies are idiopathic, secondary to an unknown cause, or are secondary to one of the causes mentioned in the previous question. However, according to the Epilepsy Foundation, children of parents with epilepsy are at higher risk than the general population for developing seizures. Children whose father has epilepsy have a 2.4 percent incidence versus the 1-1.5 percent incidence of the general population. Children of mothers with epilepsy have a 4 percent incidence; the incidence is 6 to 12 percent in children who have both parents diagnosed with epilepsy.

4 WHAT AGE GROUPS ARE MOST AT RISK FOR EPILEPSY?

Epilepsy is the fourth most common chronic neurological disease and affects people of all ages, gender, and races. However, the elderly population is at the highest risk followed by the early childhood population. Middle age people are the least affected group by this disease. About 1 in 10 people will have a single unprovoked seizure in their lifetime and 1 in 26 people will develop epilepsy at some point in their lifetime but people with certain conditions will be at higher risk. The majority of these cases occur in the very young and in the older population. Currently, more than 3 million people are diagnosed with epilepsy in the USA. Epilepsy affects more than 65 million people worldwide.

5 WHAT CAUSES EPILEPTIC SEIZURES?

Epileptic seizures occur when bursts of abnormal electrical activity are generated in the brain. Normally, electrical energy is a function regulated by complex chemical changes carried out by brain cells called neurons. Neuronal misfiring results from an imbalance between excitatory and inhibitory neurons in response to abnormal chemical changes. This misfiring causes robust electrical activity to generate the seizure. The severity of the seizure is in direct proportion to the number of neurons affected; so that, the convulsion can be a focal event affecting only some parts of the body or a generalized convulsion affecting the whole brain and body.

6 WHAT FACTORS TRIGGER EPILEPTIC SEIZURES?

Knowing what triggers your seizures can help you recognize and avoid them; thus, you may lessen the chance of having seizures. Some commonly recognized triggering factors are: missing doses of the medicine or not taking the medicine as prescribed, fever, sleep deprivation, stress, over-exertion, consumption of excessive alcohol, and taking recreational drugs (for example cocaine). Hormonal changes, such as during the menstrual cycle, changes in sugar (glucose) level, dehydration, environmental factors such as high heat and humidity, flickering and strobe lights, some noises and colors, as well as specific time of day or night, among others, may also trigger seizures in people with epilepsy.

7 CAN PEOPLE OUTGROW EPILEPSY?

Yes. In many cases, especially the genetic types of epilepsy, children may simply outgrow the seizures as they go through adolescence and puberty. Seizures are unpredictable; they may continue to occur or decrease with time. Epilepsy is considered to be resolved for individuals who have remained seizure-free for the last 10 years with no seizure medicines for the last 5 years.

8 CAN SOMEONE WITH EPILEPSY OBTAIN AND MAINTAIN A DRIVER'S LICENSE?

In many cases, yes, the critical issue is seizure control. Florida, like the rest of the states in the U.S., has specific guidelines concerning driver's licensure for individuals with epilepsy. In Florida, applicants should be seizure free for at least 6 months and under medical supervision to be able to apply for a driver's license. However, if the individual has been seizure free for a period of two years, he or she can apply for a license even if not under medical supervision. For more information contact your local office of Driver Licenses or the Florida Department of Highway Safety and Motor Vehicles in Tallahassee at www.hsmv.state.fl.us/html/dlnew.html.

9 CAN SOMEONE WITH EPILEPSY PARTICIPATE IN SPORTS AND OTHER ACTIVITIES?

Most people with epilepsy want to participate in a wide variety of life's activities, including sports, exercise, and fitness programs. In most cases, they can participate in such programs depending on the degree of seizure control. High-risk activities (mountain climbing, skiing, sky diving, swimming alone, scuba diving) and contact sports (boxing, martial arts, football) and other hazardous high-risk

activities are not recommended for individuals with epilepsy. Always contact your doctor prior to beginning any physical sport or activity in which a brief lapse of consciousness would significantly increase the chance of injury. Keeping an active life and exercising is good therapy and fun for everyone but for people with epilepsy, the following safety tips could be helpful when exercising: take frequent breaks, stay cool, and save your greatest exertion for the coolest part of the day. Exercise on soft surfaces if you can. Avoid swimming alone. Wear head protection when playing contact sports.

10 DOES EPILEPSY AFFECT MENTAL ABILITY?

For most people with epilepsy, particularly those whose seizures are not very frequent or severe, epilepsy does not cause any serious compromise of memory, thinking, or cognitive functions. However, lapses of memory and cognitive impairments are two of the most common complaints of persons with epilepsy. They are usually most likely related to the seizure activity itself over a specific area of the brain regulating mental ability and/or side effects of the anticonvulsant drugs and not to a progressive decline of intellectual function. Individuals with uncontrolled, severe, prolonged, and very frequent seizure activity as well as frequent episodes of status epilepticus might have intellectual decline, memory problems, and cognitive and learning difficulties.

11 CAN PEOPLE DIE FROM EPILEPSY?

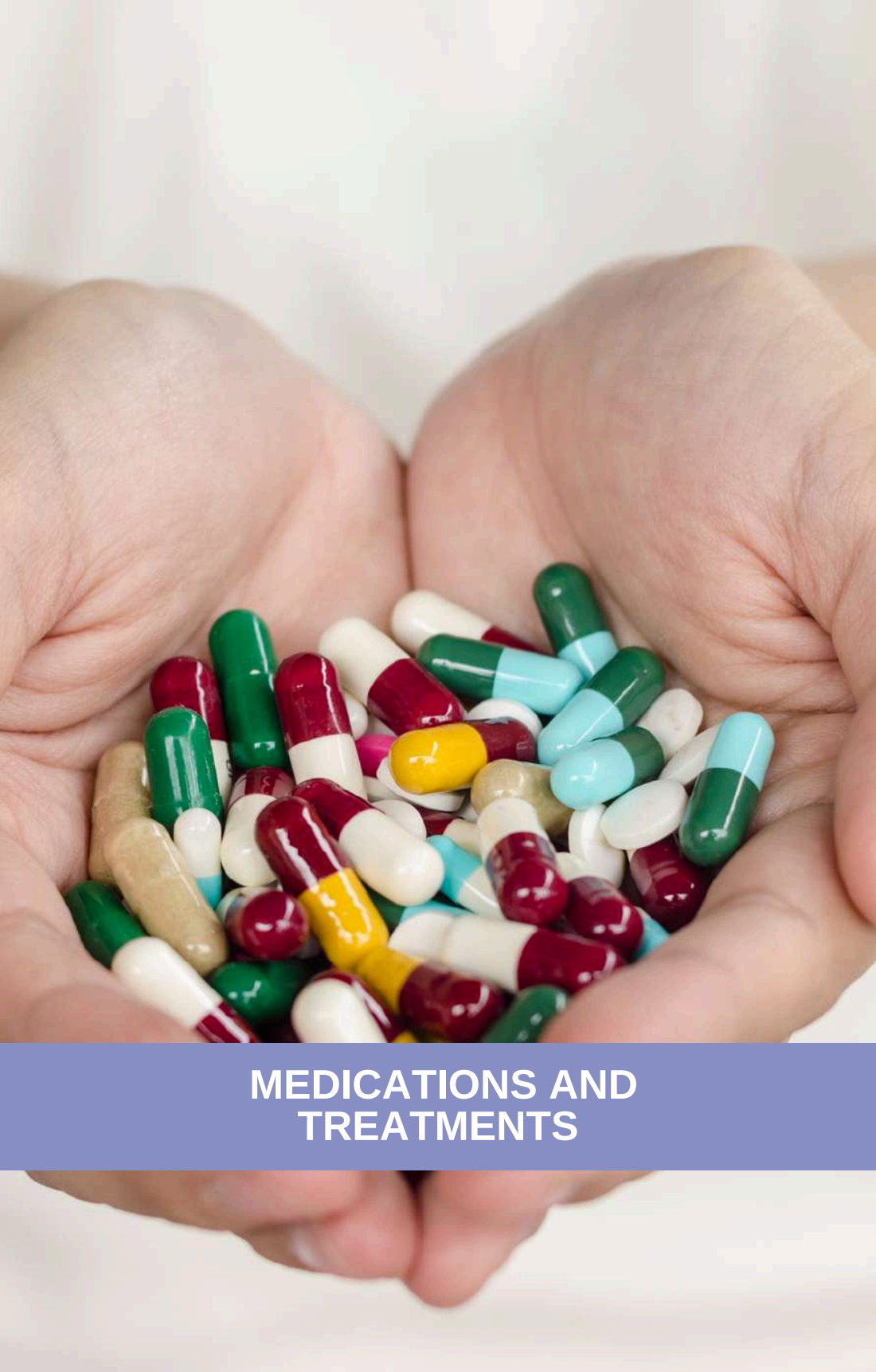
Most people with epilepsy live a full life span. However, there are potential factors associated with living with epilepsy and seizures that may increase the risk of early death. Prolonged seizure activity or seizures that happen quickly, one after another, must be considered life-threatening and 911 must be called. When the uninterrupted seizure activity lasts more than 5-10 minutes, this is called status epilepticus, it is a medical emergency and needs immediate medical attention. Some people with epilepsy may die suddenly and without explanation. This is called SUDEP which stands for Sudden Unexplained Death in Epilepsy. The risk of sudden death occurs more often among people with convulsive seizures, especially with uncontrolled generalized tonic-clonic epilepsy and complex partial seizures with secondary generalization.

12 ARE THERE ANY SAFETY PRECAUTIONS I SHOULD TAKE AT HOME IF MY SPOUSE OR CHILD HAS EPILEPSY?

Most people do not get hurt when they have a seizure but it can happen. There are many practical steps you can take to minimize your risk for injury in case of seizure, for example: 1) set the thermostat of the water heater low enough to prevent scalding or purchase a scald protection product; 2) pad sharp corners; 3) try a microwave oven for cooking; 4) select chairs with arms to prevent falling; 5) hang bathroom doors so they open outwards instead of inwards (so that if someone falls against the door, it can still be opened); 6) remove burner controls from gas or electric stoves when not in use; 7) consider Embrace or other sensor movement monitor device to be worn by the person or installed at home; 8) consider installing a closed circuit video monitoring system; and 9) do not allow the affected person to wander around alone over unprotected or elevated places where a brief lapse of consciousness may increase the risk of injury or death.

13 WHAT FAMOUS PEOPLE HAVE OR HAVE HAD EPILEPSY?

Many famous people throughout the ages have had epilepsy, including Alexander the Great, Julius Caesar, Socrates, Napoleon Bonaparte, Leonardo da Vinci, Vincent Van Gogh, Charles Dickens, Agatha Christie, Thomas Edison, Harriet Tubman, Alfred Nobel, Peter Tchaikovsky, Richard Burton, Margaux Hemingway, Danny Glover and many others.



MEDICATIONS AND TREATMENTS

14 WHAT IS A NEUROLOGIST

A neurologist is a specially trained physician who treats diseases and disorders of the nervous system. He or she sees patients who have Alzheimer's disease, stroke, movement disorders, neuromuscular diseases, memory disorders, brain infections, seizures, and epilepsy among others. An epileptologist is a neurologist who specializes in the treatment of epilepsy.

15 WHERE CAN A PERSON GET MEDICAL CARE FOR EPILEPSY?

Typically, medical care for epilepsy begins with a primary care physician. Many times, the primary care physician may then make a referral to a neurologist for more specialized care. For uninsured individuals in Florida, Epilepsy Alliance Florida may assist you to obtain neurological care by calling **1-877-553-7453.**
You can also get medical assistance at a number of community-based agencies, such as the County Public Health Department. In case of a medical emergency, dial 911 or the operator.

16 IS THERE ANY ONE-WAY OF DIAGNOSING EPILEPSY?

The diagnosis is initially suspected with the clinical seizure history and physical exam. There are a variety of tests available to confirm or rule out the diagnosis of epilepsy but basic testing consists of an electroencephalogram (EEG) and imaging of the brain if indicated via Magnetic Resonance Imaging (MRI) or Computerized Axial Tomography (CT scan). If these are inconclusive, other more sophisticated and complex studies can be done such as long-term Video-EEG monitoring, also known as video-EEG telemetry, Positron Emission Tomography (PET), Single Photon Emission Computed Tomography (SPECT), or functional MRI (fMRI). For the more difficult cases to diagnose or for evaluation of candidacy for brain surgery, deeper neurological evaluation and more specific diagnostic procedures can be done.

17 WHAT IS AN EEG?

The electroencephalogram or EEG is a very useful tool in the diagnosis of abnormal brain activity to confirm epileptic seizures but it is not a very sensitive diagnostic testing procedure. This device measures brain electrical activity through electrodes attached to the person's head. This painless procedure measures different patterns of electrical activity, normal and abnormal, in the whole brain. The EEG may indicate and confirm the person's type of epilepsy but a negative study does not rule out epilepsy. The EEG can provide supportive evidence for a person's epilepsy when coupled with their medical history. However, when a routine baseline EEG returns normally in a person with epilepsy, it may be necessary to perform other kinds of EEGs to confirm or rule out the diagnosis of epilepsy, particularly when seizures are not controllable with anticonvulsant drugs.

18 WHAT IS LONG-TERM VIDEO-EEG MONITORING?

Sometimes, when the EEG does not provide the supportive evidence or when the results are inconclusive, the epileptologist may request an evaluation with a long-term continuous EEG with simultaneous video recording known as Video-EEG telemetry monitoring also called Epilepsy Monitoring. This study consists of a simultaneous recording of both brain electrical activity (EEG recording) and the patient's behavior during a hospital admission lasting from 3-5 days or even more, sometimes up to two weeks, in order to capture typical epileptic events for diagnosis and treatment purposes. Having a correlation of the recorded behavior (video) and the EEG activity, the diagnosis of seizures or non-epileptic attacks can be made definitely in nearly all cases.

19 WHAT IS A MRI? A CT SCAN?

Magnetic Resonance Imaging (MRI) gives a detailed three-dimensional view or images of the brain. The sequential pictures obtained in an electro-magnetic field help to see through the skull and identify normal structures and diagnosis of solid structural abnormalities in the brain such as a tumor, congenital malformations, stroke, and other Computerized Tomography Scan (CT scan) using computer technology and X-Rays to make a computerized image of the brain, ideal to evaluate cystic lesions, bleeding, vascular structural abnormalities, and others. Both imaging procedures are very useful tools for an in depth neurological work-up to evaluate for brain structural abnormalities.

20 WHAT IS THE BEST TREATMENT FOR EPILEPSY?

There is no best treatment for epilepsy; however, medical treatment with a single drug that "is able to control the seizures at a minimum dose without causing side effects" is considered the ideal. There are, however, a number of modalities of treatment options available, including new medications, surgery, dietary therapies (Ketogenic Diet, Low Glycemic Index Therapy, and the Modified Atkins Diet), and implantable devices [Vagus Nerve Stimulation (VNS), Responsive Neurostimulation (NeuroPace), and deep brain stimulation]. Currently, new research is being conducted to develop innovative ways to inhibit and control seizures and cure epilepsy. One of these ways is the ongoing process of legalization of the use of medical marijuana in Florida. This movement began after further evidence emerged indicating that an ingredient of cannabis, cannabidiol (CBD), has helped in preventing some types of epileptic seizures. This data is not new, there have been reports dating from the 15th century documenting the use of medical marijuana to ease the symptoms of epilepsy. So far, (at the time of printing this document, January 2020), 40 states and the District of Columbia in the U.S. currently have laws legalizing in some form the use of medical marijuana to treat epilepsy and other medical conditions.

Data from: December 2019, https://disa.com/map-of-marijuana-legality-by-state

21 HOW DO MEDICATIONS WORK?

Anti-convulsant or anti-epileptic drugs work by either inhibiting or exciting the neuron to a normal level of chemical or electrical exchange by different mechanisms of action; this prevents unstable neurons from misfiring and leading to seizure activity. The medications do not cure epilepsy but help by maintaining the seizure threshold stable. Thus the seizures remain under control which enables individuals with epilepsy to regain their ability to live a productive life as normally and confidently as possible.

22 WHY DO I HAVE TO TAKE THE MEDICATION ON TIME?

Medication(s) must be taken regularly in order to maintain sufficient levels in the bloodstream so that they may control seizure activity and minimize side effects. If you do not take the medication(s) on time, drug levels may drop (sub-therapeutic) to the point where you do not have enough medication in your system to prevent seizures. Consequently, increased frequency of seizures will occur, status epilepticus may be precipitated, and the likelihood of SUDEP may be increased.

23 WHAT HAPPENS IF I MISS A DOSE?

It's quite common for people with epilepsy to miss a single dose once in a while. Often nothing bad happens but your chance of having a seizure may be increased. Missing one dose is more likely to cause seizures if you're scheduled to take your medicine only once a day. Then, if you miss a dose, you have missed a full day of medication. If you take your medicine two to four times a day, the risk of missing one full day of medication is less. If you miss several doses in a row, the risk of having a breakthrough seizure will be greater.

24 ARE THERE SIDE EFFECTS TO MEDICATIONS?

There are potential side effects from any medication including anti-epileptic medications. The effects vary a great deal from one individual to another. Common side effects are dizziness, drowsiness, fatigue, weakness, nausea, headaches, difficulty concentrating, unsteadiness, and blurry or double vision. Some major side effects include allergic reactions, anemia, liver failure, and psychiatric reactions, such as suicidal or homicidal ideation, among others. Please see next question for additional information.

25 WILL OTHER PRESCRIPTION MEDICATIONS OR OVER-THE-COUNTER (OTC) DRUGS HAVE AN EFFECT ON MY EPILEPSY MEDICATIONS OR VICE VERSA?

Co-administration of many medications, prescription or OTC drugs to treat other medical conditions, may have an effect on anti-epileptic medications or vice versa. Medications used to treat allergies, especially the antihistamines, anti-tuberculosis agents, hormonal preparations, some antipsychotic, and many other prescription and OTC drugs have been associated with either toxicity (severe side effects) or loss of seizure control. In the first case, the inhibitor delays the elimination of the anticonvulsant drug and its level rises to a toxic range in the blood causing severe side effects. In the latter case, the inducer accelerates the elimination of the anticonvulsant drug and consequently its concentration in the blood drops to a sub-therapeutic level leading to loss of seizure control. Always inform your physician or pharmacist about the medications you are currently taking before taking any new drugs.

26 HOW MANY ANTI-EPILEPTIC DRUGS (AEDS) ARE THERE AND WHICH ONE IS BEST FOR ME?

Since 1990, a number of AEDs have been approved by the Food and Drug Administration (FDA) and have been quickly introduced into the market. There are now more than 30 different medications available for controlling epileptic seizures. A formal consultation and follow up visits with your doctor are required to determine which medication is the best for you.

27 WHAT IS A THERAPEUTIC DRUG LEVEL?

A therapeutic drug level is the amount of medication generally required in the bloodstream for a particular medication to be effective with few or no side effects. Levels serve as guides to assist in treatment when they are required, e.g., to evaluate compliance with medical treatment, adjustment of medical treatment, determination of the therapeutic level that controls seizures or toxicity. Some newer drugs do not yet have established therapeutic ranges nor do they require blood level monitoring tests.

28 I AM TIRED OF TAKING MY EPILEPSY MEDICATION (AED). IS IT OKAY TO STOP TAKING IT COMPLETELY AD ABRUPTLY? IS IT OKAY TO BEGIN DECREASING THE DOSAGE OF MEDICATION?

Stopping anticonvulsant treatment abruptly, decreasing the dosage, or tapering off of your medication is not recommended unless you are following specific instructions from your doctor. The reason for taking the AED(s) is to maintain a drug level in your system that is able to control the seizure activity. Stopping or decreasing the dose of your medication may put you at increased risk for loss of control, exacerbation of seizure activity, or result in serious, prolonged, and possibly life-threatening consequences that may require hospitalization.

29 MY ANTI-EPILEPTIC MEDICATION IS CAUSING ME UNTOWARD SIDE EFFECTS. WHAT CAN I DO?

If you are experiencing notable or unwanted side effects due to your medication (such as nausea, rash, etc.), contact your physician and describe your symptoms. Occasionally, by adjusting the dosage, your side effects will decrease or diminish altogether. In other cases, alternative treatments may need to be considered if side effects are intolerable. Developing some severe adverse effects called idiosyncratic side effects such as severe allergic reaction (Stevens-Johnson Syndrome or Lyell's Syndrome), massive liver failure, aplastic anemia, and other life-threatening side effects usually require immediate replacement of the drug necessitating admission to the hospital.

30 IS IT ALL RIGHT TO SUBSTITUTE A GENERIC DRUG FOR A NAME-BRAND DRUG?

Many name-brand prescription drugs may be substituted with a generic drug at a cost savings that is passed on to the consumer. However, people with epilepsy should always talk to their physician before making such a change as generic medications may induce a change in seizure control or side effect profile (efficacy, safety, and tolerability).

31 CAN ALCOHOL OR RECREATIONAL DRUGS INTAKE AFFECT MY AED LEVELS OR CAUSE SEIZURES?

Yes, consuming alcohol may affect your AED levels and increase the risk for seizure activity. Drinking one or two alcoholic beverages does not cause meaningful changes in the blood AED levels or control of seizures. The problem begins following several drinks and/or consumption of recreational drugs. Crack and other forms of cocaine can cause seizures in people who have never had one before. Seizures can be provoked or made worse by the use of uppers such as amphetamines, downers such as barbiturates, benzodiazepines, heroin, LSD ("acid"), PCP ("angel dust"), "ecstasy," and certain painkillers. Although the real effects of all these drugs on epilepsy are not well known, they can bring on seizures by making the "user" forget to take the anticonvulsant medication or lose sleep. These drugs may also precipitate seizures as a consequence of withdrawal effects on the brain.

32 CAN EPILEPSY OR MY MEDICATIONS IMPACT OR AFFECT SEXUAL DRIVE?

Sexuality is an important and private aspect of life. People with epilepsy appear to have a higher incidence of sexual dysfunction than persons with other chronic neurologic conditions. However, when seizures are under control, people seem to have improved sexual desire and better performance. Studies indicate that seizure activity itself and/or certain anticonvulsant drugs may cause problems with reduced sexual desire and/or sexual arousal by affecting endocrine functions. If you experience sexual dysfunction, consult your physician.

33 WHY DO I HAVE TO HAVE PERIODIC BLOOD TESTS PERFORMED?

AEDs may be absorbed and metabolized at a different rate by each person. Doctors request a blood test to monitor the amount of medication circulating through a person's system, i.e., to measure how much medication is in the blood stream. For AEDs to work effectively, the medication has to be available throughout the day and in the proper amount for the optimum protection from seizures. Blood tests are also performed periodically for the monitoring of body functions that could be impaired by the continued, chronic use of the anticonvulsant drugs. Repeated, progressive, abnormal blood test results may lead to the consideration of a change in medication.

34 WHAT ROLE DOES SLEEP HAVE FOR EPILEPSY PATIENTS?

Persons with epilepsy should strive to maintain consistently good sleep patterns and rest. Sleep deprivation or irregular sleep patterns may trigger seizures in the great majority of people with epilepsy. In another group, their seizures are very closely related to their sleep, so that, they may occur only while sleeping, when falling asleep, or waking up. Finally, for a minor group of people with epilepsy, there may be no clear association between sleep and their seizures.

35 WHAT ROLE DOES NUTRITION PLAY IN THE TREATMENT OF EPILEPSY?

Good nutrition is important for everyone. It is important that persons with epilepsy taking AEDs follow proper nutrition. Proper nutrition allows medications to metabolize properly in the blood stream. Some AEDs may suppress appetite: topiramate, felbamate, primidone, rufinamide, zonisamide. Others increase appetite: valproic acid, divalproex sodium, vigabatrin, perampanel, pregabalin. Therefore, it is reasonable to try to eat regularly and eat a balanced diet at all times.

36 WHEN IS EPILEPSY TREATED BY SURGERY? IS IT SAFE?

Epilepsy surgery is an alternative treatment for some people whose seizures cannot be controlled by medications. However, epilepsy surgery is particularly helpful for people who have seizures originating from focal structural abnormalities in the brain such as benign tumors, stroke, and congenital malformations. Neurologists look at a number of criteria after extensive testing to evaluate if a candidate is eligible for epilepsy surgery. Usually a good candidate for surgery is a person whose seizures: 1) are not controlled and have not responded to at least two major anticonvulsant drugs, 2) frequency and or severity of seizures as well as side effects from the drugs interfere with daily activities, and 3) surgery can be performed safely. Surgery for epilepsy is a viable option today for about 30% of people with epilepsy with success rates ranging from 50% to 80% depending on the diagnosis of the lesion and complexity of the surgical technique employed. Consult your physician for more information.

37 WHAT IS WADA TEST?

The Wada test is used to assess language and memory functions in persons preparing to undergo surgery for seizures. Wada testing is used prior to epilepsy surgery for identification of the dominant speech hemisphere and memory dysfunction. The test is performed by three doctors, a neuro-radiologist, a neurologist/epileptologist, and a neuro-psychologist and it is a generally safe procedure with very few risks.

38 WHAT IS A VAGUS NERVE STIMULATOR (VNS)?

The Vagus Nerve Stimulator (VNS Therapy) is a surgical device designated to control seizures by sending regular micro-electrical signals to the brain via the vagus nerve. The device is sometimes referred to as a “pacemaker to the brain.” It is placed under the skin of the chest wall and a pin lead (wire) runs under the skin to the vagus nerve in the neck. Usually, about two weeks after surgical implantation, the neurologist sets the initial activation parameters of the device which are monitored and readjusted in subsequent medical visits. This device may reduce the frequency or severity of seizures in persons with epilepsy. VNS Therapy is now considered a viable and safe treatment option for both children and adults with epilepsy.

39 HOW DOES BIOFEEDBACK TREATMENT FOR EPILEPSY WORK?

Biofeedback is a self-training, mind-over-body technique that may help some people modify their seizures. By using biofeedback, a few persons with epilepsy may learn to “hear” or “see” certain bodily functions like pulse, body temperature, or muscle tension in order to shorten seizures or even prevent them from occurring by slowing one type of brain wave activity, while increasing another.

40 WHAT TYPE OF DIET IS USED TO TREAT EPILEPSY?

The ketogenic diet, a diet low in proteins and carbohydrates and high in fats, is sometimes used in certain childhood epilepsies, including absence, atonic, myoclonic seizures, infantile spasms, and Lennox-Gastaut Syndrome. The diet does have some short- term benefits of seizure response or control but most patients have difficulty with compliance. In rare cases, particularly for the children who have had poor seizure control with other methods, your physician may prescribe the ketogenic diet. The diet may change the body chemistry in ways that may have a positive effect on seizure control. A modified and less strict version of the ketogenic diet for both children and adults exists called the Modified Atkins Diet. These diets must be supervised by a physician or nutritionist.

41 CAN VITAMINS AND MINERALS HELP IN THE TREATMENT OF EPILEPSY?

Vitamins and minerals taken as dietary supplements can help with nutritional issues. The use of folic acid has been shown to reduce the potential for congenital malformations associated with the majority of anticonvulsant drugs. There is no conclusive proof that vitamins and minerals can help reduce the frequency of seizures.

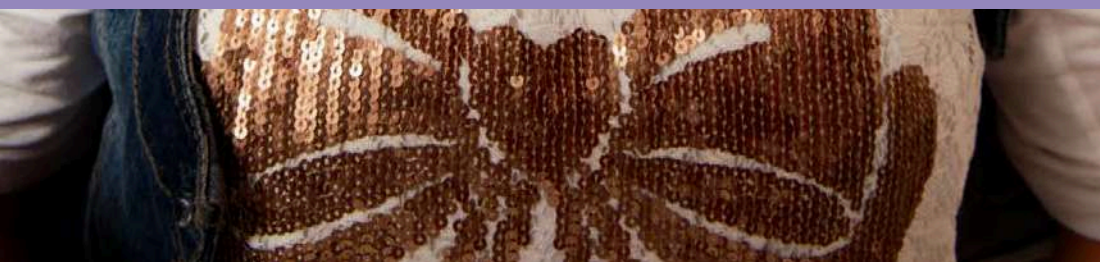
42 ARE METABOLIC ENHANCERS, PROTEIN SUPPLEMENTS AND DIETARY SUPPLEMENTS HARMFUL?

Some metabolic enhancers may interfere with proper utilization of medication for persons with epilepsy. Products claiming to be natural falsely imply that they are safe. If you are considering using herbal or synthetic supplements, talk to your doctor first.

43 CAN STRESS INCREASE THE FREQUENCY OF SEIZURES?

Although difficult to quantify, stress during activities of daily living appears to increase the frequency of seizures in some people with epilepsy. Physical or emotional stress causes the release of catecholamine or adrenaline hormones which increase the rate and force of contraction of the heart, blood pressure, and breathing rate. If you can identify stressful situations and avoid them or cope with them, you might reduce the chance of having a seizure. Stress alone does not cause epilepsy.

SEIZURE RECOGNITION AND FIRST AID



44 HOW DO PHYSICIANS DETERMINE WHAT TYPE OF SEIZURE I MAY HAVE?

The initial diagnosis of epilepsy is often based on information provided by the person with epilepsy, family, and friends describing events and behaviors before, during, and after seizures. During the medical consultation, the physician usually obtains a complete medical history, gives you a physical examination, and orders diagnostic tests such as EEGs, MRIs, CT scans, which will help with this diagnosis. If these tests are insufficient to confirm the diagnosis of epilepsy, other more specific tests may be performed to determine and classify seizure type.

45 WHAT IS THE DIFFERENCE BETWEEN AN EPILEPTIC AND NON-EPILEPTIC SEIZURE (NES)?

Epileptic seizures are seizures caused by abnormal electrical discharges of the brain. Typically, an EEG recording of the abnormal electrical activity of the brain will help with the diagnosis. Non-epileptic seizures are attacks mimicking epileptic seizures which are not accompanied by abnormal electrical discharges in the brain; therefore, they are not epileptic in nature and do not respond to anti-epileptic treatment.

46 WHAT ARE PSEUDOSEIZURES OR PSYCHOGENIC NON-EPILEPTIC SEIZURES (PNES)?

Pseudoseizures or psychogenic non-epileptic seizures (PNES) is the clinical term used to describe a psychiatric disorder that induces seizure-like episodes of non-epileptic origin resembling epileptic seizures. More often they are caused by a variety of traumatic experiences from the past such as rape, stress, and other emotional and psychiatric causes. PNES do not respond to conventional anticonvulsive treatment; they are treated with psychotherapy and anti-psychotic drugs.

47 WHAT KIND OF SEIZURES DO PEOPLE WITH EPILEPSY HAVE? (PLEASE SEE TABLE ON PAGE 18)

48 WHAT SHOULD YOU DO IF SOMEONE HAS AN EPILEPTIC SEIZURE?(PLEASE SEE TABLE ON PAGE 19)

49 DO SEIZURES HURT THE BRAIN?

Most types of epileptic seizures may momentarily incapacitate persons with epilepsy, particularly complex partial and generalized tonic-clonic seizures. There is no medical evidence that a single seizure permanently damages the brain. However, repeated episodes of status epilepticus or very frequent or prolonged seizures may cause progressive subtle brain damage leading to the decline of intellectual function.

50 WHAT IS STATUS EPILEPTICUS?

Status Epilepticus can be convulsive or non-convulsive. Convulsive status epilepticus consists of a prolonged seizure lasting 5 minutes or longer or a cluster of seizures occurring one after another, where the patient does not regain consciousness between seizures, lasting 30 minutes or longer. This is a life threatening medical emergency and 911 must be called at once (see answer to question #11). Non-convulsive status epilepticus is a term used to describe long or repeated absence or complex partial seizures. The person may be confused or not fully aware of surroundings but not unconscious like in a generalized tonic-clonic seizure. There is no consensus regarding the time-frame for when these seizures are called an emergency but when suspected, emergency medical treatment in a hospital setting is needed.

51 WHAT IS AN AURA?

An aura is the initial symptom of a seizure and is considered the initial event of a seizure. Some persons with epilepsy experience auras frequently and may describe them as a strange sensation or indescribable feeling just before the beginning of a typical complex partial or secondarily generalized seizure; others describe dizziness, numbness, nausea, a buzzing in the ear, a metallic taste, a stomach sensation, or strong emotions. In general, auras can be a change in feeling, sensation, perception, thought, or behavior that is similar in the same person each time a seizure happens. When the aura occurs alone without progressing to a more extended or complex event it is called a simple partial seizure. Auras typically occur from a few seconds to minutes in duration preceding the seizure.

52 WHAT ARE NEO-NATAL SEIZURES?

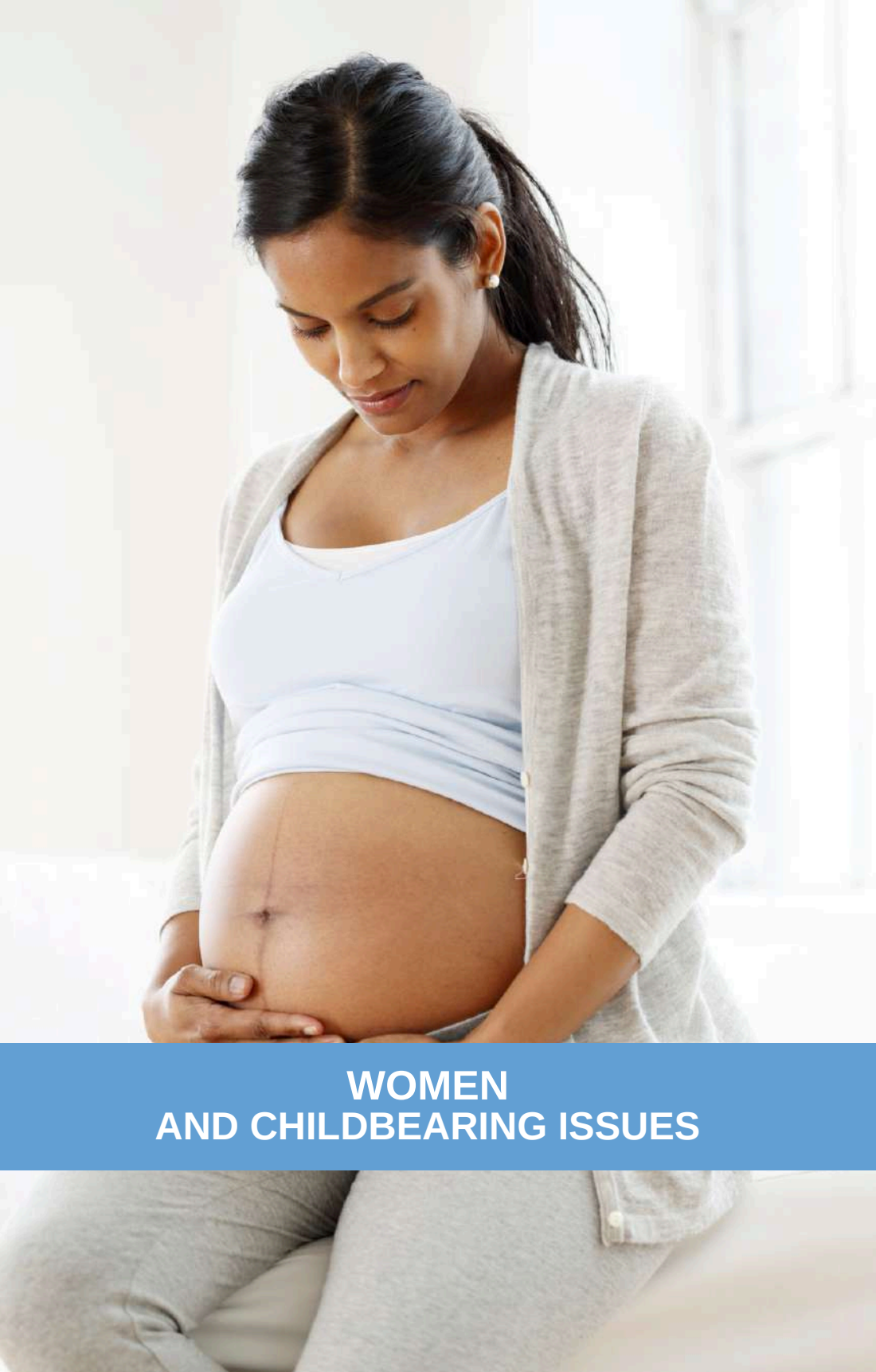
Neonatal seizures are seizures that occur during the first four weeks of an infant's life. Approximately 1% of all newborns will have neonatal seizures. Seizures in newborns are different from seizures that occur in older children and adults because the infant's brain is underdeveloped and still unable to carry out the coordinated response to a stimulus as seen in a developed brain. Thus, neonatal seizures are difficult to recognize even for experts and this often results in having appropriate treatment delayed.

53 WHAT IS NARCOLEPSY?

Narcolepsy, also known as hypnolepsy, is a chronic neurological disorder caused by disturbed regulation of the brain's ability to maintain sleep/wake cycles. It is characterized by sudden sleep attacks during the day and often disrupted nocturnal sleep, cataplexy, sleep paralysis, and visual/auditory hallucinations at the onset of sleep. Narcolepsy usually begins in adolescence or young adulthood. Persons with narcolepsy experience an uncontrollable desire to sleep, sometimes, many times in one day. Narcolepsy is unrelated to epilepsy.

Seizure Type	What It Looks Like
Generalized Tonic Clonic (Also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, blush skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue followed by return to full consciousness.
Absence (Also called Petit Mal)	A blank stare beginning and ending abruptly lasting only a few seconds, most common in children. May be accompanied by rapid blinking or some chewing movements of the mouth. The child or adult is unaware of what is going on during the seizure but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.
Simple Partial	Jerking may begin in one area of the body such as in the arm, leg, or face. Can't be stopped but the patient stays awake and alert. Jerking may proceed from one area of the body to another; seizure sometimes spreads to become a convulsive episode. Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment and may hear or see things that are not there or may feel unexplained fear, sadness, anger, or joy, may have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.
Complex Partial (Also called Psychomotor or Temporal Lobe)	Usually starts with a blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed, may mumble, and may be unresponsive. Actions appear clumsy, not directed. May pick at clothing, pick at objects, and try to take clothes off. May run, appear afraid, struggle, or flail at restraint. Once a pattern is established, same set of actions usually occur with each seizure. Lasts a few minutes but post-seizure confusion can last substantially longer. No memory of what happened during the seizure period.
Atonic Seizures (Also called Drop Attacks)	A child or adult suddenly collapses and falls. After 10 seconds or a minute he/she recovers, regains consciousness, and can stand and walk again.
Myoclonic Seizures	Sudden, brief, massive muscle jerks that may involve the whole body or parts of the body. May cause a person to spill what they were holding or to fall off a chair.
Infantile Spasms	These are quick, sudden movements that start between three months and two years of age. If a child is sitting up, the head will fall forward and the arms will flex forward. If lying down, the knees will be drawn up with the arms and head flexed forward as if the baby is reaching for support.

What It's Not	What To Do
• **Heart attack** • **Stroke** • **Unknown but life threatening emergency**	• Lookfor medical identification • Protect from nearby hazards and loosen shirt collars • Protect from head injury • Turn on side to keep airway clear unless injury exists • Reassure person as consciousness returns • If single seizure lasts less than 5 minutes, askif hospital evaluation is wanted
• **Daydreaming** • **Lack of attention** • **Deliberate ignoring of adult instructions**	• No first aid necessary, but if this is the first observation of a seizure, medical evaluation should be recommended
• **Acting out or bizarre behavior** • **Hysteria** • **Mental illness** • **Psychosomatic illness** • **Parapsychological or mystical experience.**	• No first aid necessary unless seizure becomes convulsive, then first as above • No immediate action needed other than reassurance and emotional support • Medical evaluation should be recommended
• **Drunkenness** • **Intoxication on drugs** • **Mental illness** • **Disorderly conduct**	• Speakcalmly and reassuringly to patient and others • Guide gently away from obvious hazards • Stay with the person until completely aware of the environment • Offer to help get the person home
• **Clumsiness** • **Normal childhood "stage"** • **In a child: lack of good walking skills** • **In an adult: drunkenness, acute illness**	• No first aid needed (unless injured during a fall) but the child should be given a thorough neurological evaluation
• **Clumsiness** • **Poor coordination**	• No first aid needed but the person should be given a thorough medical evaluation
• **Normal movements of the baby** • **Colic**	• No first aid but doctor needs to be consulted



WOMEN AND CHILDBEARING ISSUES

54 I HAVE EPILEPSY AND I WOULD LIKE TO RAISE A FAMILY. IS THIS A GOOD IDEA?

It is a good idea for women with epilepsy who want to raise a family to consult with their neurologist and OB/GYN for adjustment of medical treatment if needed and family planning prior to pregnancy. Pre-pregnancy counseling is always a good idea. The key for a happy ending for both, the mother and child, is to get proper care before, during and after pregnancy.

55 HOW SHOULD I PLAN BEFORE GETTING PREGNANT?

Because of the number of health issues involved, women with epilepsy should have coordinated health care at least 6 months prior to pregnancy. Pregnant women with epilepsy are generally considered high-risk pregnancies. Approximately 15% to 30% of women with epilepsy may have increased seizures during the first or third trimester of the pregnancy. The remaining women may experience better seizure control or experience no change of actual frequency of seizures at all during the whole pregnancy. It is important for pregnant women with epilepsy to see their physicians regularly during the pregnancy and three to four months postpartum at which time the newborn should also have a neurological evaluation to rule out any potential neurological problem.

56 IS IT TRUE THAT ANTI-EPILEPTIC MEDICATIONS MAY LESSEN THE EFFECTIVENESS OF MY BIRTH CONTROL PILL?

The effectiveness of birth control pills may indeed be impaired by certain AEDs. Phenobarbital, carbamazepine, phenytoin, felbamate, oxcarbazepine and perampanel can increase the risk of birth control pill failure leading to unintended or unwanted pregnancy. However, not every anti-convulsant drug interacts negatively with birth control pills. Your physician may recommend the appropriate oral contraceptive with lower estrogen content or suggest alternative birth control methods or may even change your AED.

57 IF THERE IS A HISTORY OF EPILEPSY IN OUR FAMILY, WHAT ARE THE CHANCES THAT MY CHILD WILL HAVE IT?

There are two issues here. First, if there is a history of non-heredity epilepsy in the family, the chances of the child having epilepsy is about the same as in the general public (about 1.5%). Second, if there is a history of hereditary epilepsy in the family of one parent, the chances rise to about 5%. If there is a history of hereditary epilepsy in both parents, the chances rise to about 10%. Again, pre-pregnancy genetic counseling is recommended to evaluate risks and outcomes.

58 I HAVE HEARD THAT ANTI-EPILEPTIC MEDICATIONS MAY CAUSE BIRTH DEFECTS. SHOULD I STOP TAKING MY MEDICATION DURING PREGNANCY? SHOULD I CHANGE MY MEDICATION?

The birth of a healthy baby without birth defects is a primary concern for all parents. The risk of congenital malformations or birth defects that cannot be prevented is about 2% to 3% in the general population and about 4% to 6% in women with epilepsy taking anticonvulsant drugs. Since almost all drugs have potential teratogenic effects (possible danger to a developing fetus), women with epilepsy taking AEDs must share their concerns with their neurologists and select an alternative therapy plan that may pose the least possible risks to their baby's development. Withdrawing medication during pregnancy can cause prolonged seizures. Stopping medication poses a greater risk than the effects of the drugs themselves. With careful planned conception, use of folic acid supplementation, a healthy and balanced diet, and other appropriate measures, more than 90%- 95% of women with epilepsy have normal babies.

59 CAN I BREAST FEED MY CHILD IF I AM TAKING ANTI-EPILEPTIC MEDICATION?

If you are planning on breast-feeding, it is important to discuss this with your doctor. Most infants do not suffer any harmful effects from traces of AEDs found in breast milk. Although some medications may be found in the mother's milk, breast-feeding is encouraged as long as it is not causing sedation or any other side effects to the baby.

60 DO WOMEN HAVE AN INCREASE IN SEIZURE ACTIVITY DURING THEIR MENSTRUAL CYCLE?

Some women are sensitive to endogenous hormonal changes and they experience increased frequency of seizures around the menstrual period due to normal fluctuation of sex hormone levels and water retention. It has been reported that estrogen has pro-convulsive properties and progesterone the opposite effect, anticonvulsive properties. Therefore, in sensitive women, seizures have a tendency to occur only or more often around the menstrual cycle precipitated or induced by the high concentration of estrogen. Conversely, frequency of seizures drops or simply seizures do not occur during the rest of the menstrual period, when the level of estrogen drops and the level of progesterone rises. When more than 50% to 60% of the seizures occur around the same week of the menstrual cycle, (before, during, or after menstruation), this pattern is known as catamenial epilepsy, regardless of seizure type.

CHILDHOOD AND YOUTH

61 WHAT IS THE FREQUENCY OF EPILEPSY IN CHILDREN?

1% of children have some type of epilepsy, that is, about 400,000 children under the age of 15 have epilepsy in the U.S. Most of them are able to control their seizures and lead normal lives. About 70% to 80% of reported cases of children with epilepsy will be completely seizure free with medication or will outgrow the disease after a few years.

62 ARE SEIZURES WITH FEVER RELATED TO EPILEPSY?

Febrile seizures (FS), or seizures occurring with a fever, are typically seen in early childhood, during the first two years of age. In fact, up to 4 - 5% of children ages 6 months to five years of age experience one or more febrile seizure. The vast majority of febrile seizures do not take place after age 5. There is a tendency for seizures with fever to run in families but in general, they are not related to epilepsy. FS may occur with childhood illnesses such as upper respiratory tract infection, measles, mumps, chickenpox, or following a vaccination.

63 DO SEIZURES IMPAIR THE LEARNING PROCESS?

Intelligence tests of people with epilepsy generally show a normal range of intelligence. However, there are some types of seizures that may impact negatively on the learning process and cause impaired attention and/or memory. The brain processes causing the seizure and side effects from some anticonvulsant drugs may also impair the learning process. Consult your physician for further evaluation/more information if you are experiencing any type of cognitive or learning difficulties.

64 ARE THERE EPILEPSY MEDICATIONS SPECIFICALLY DESIGNED FOR CHILDREN?

There is no epilepsy medication specifically designed for children. However, many AEDs, which are effective for adults with epilepsy, are equally effective for children. Dosages may differ and some medications are not recommended for newborns or infants due to medical reasons. Usually, these restrictions are listed in the warning box of the package insert of the medications. For more information, consult with your pediatric neurologist.

65 CAN MY CHILD TAKE GYMNASTICS, SWIMMING OR DANCE LESSONS?

Epilepsy should not preclude children or adults from taking part in most recreational activities and sports. Unless the child is having uncontrolled seizures, participating in any of these activities would add to the child's quality of life. No one should ever swim or participate in other water sports alone. Any activity where a brief lapse of consciousness would significantly increase the risk of injury should be considered with caution.

66 CAN MY CHILD BE INVOLVED IN CONTACT SPORTS?

Epilepsy should not prevent children from participating in sports but you should review the risks carefully before letting your child take up contact sports. Contact sports could put them in danger and risk of injury if they were suddenly unaware of what they're doing. Talk to your physician and inform the coaches about your child's condition.

67 SHOULD I TELL MY CHILD'S TEACHER ABOUT HIS/HER EPILEPSY?

Teachers should know if a student has epilepsy. It's important that you take time to discuss with teachers and school nurses how epilepsy affects your child. The more information you provide about your child's condition, the better the teacher/nurse will be attuned to your child's needs. Some parents may wish to conceal their child's condition particularly if the seizures are well-controlled. Most physicians would agree this would not be in the best interest of the child, therefore, reporting the child's condition regardless of seizure control is advised. If the child is seizure free and off of anticonvulsant drug treatment for at least one year, there is no need to report anything to the school.

68 WILL MY CHILD BE EXCLUDED FROM ANY SCHOOL ACTIVITIES BECAUSE HE OR SHE HAS SEIZURES?

Individuals with Disabilities Education Act, or IDEA, establishes the child's right to a free and appropriate education that is not above or below the child's need. Most children with epilepsy can be included in school activities such as drama, band, sports, field trips, cheerleading, chorus, service clubs, student government, and safety patrol even if their seizures are not totally controlled. Physical education supervision is important if the child has exercise-related seizures. The Rehabilitation Act of 1973, section 504, prohibits discrimination because of disability.

69 WHAT SHOULD I DO IF I FEEL MY CHILD IS BEING DISCRIMINATED AGAINST OR IS BEING EXCLUDED FROM SCHOOL ACTIVITIES BECAUSE OF EPILEPSY?

A good first measure is to meet with your child's teacher and/or nurse. If the problem cannot be resolved, meet with the school administrator. If the problem continues, contact your school board representative. Additional resources include the Florida Department of Education, the Epilepsy Alliance America, a parent advocacy group such as Parent to Parent, or the Advocacy Center for Persons with Disabilities in Tallahassee, Fl at 1-800-342-0823.

70 HOW CAN STUDENTS AND FACULTY LEARN MORE ABOUT EPILEPSY?

A number of resources for general information are available, such as, the American Epilepsy Society (AES) at www.aesnet.org, the National Association of Epilepsy Centers at www.naecepilepsy.org, the Epilepsy Institute at www.epilepsyinstitute.org, the Epilepsy Book Store at www.wellnessbooks.com/epilepsy/, the International League against Epilepsy (ILAE) at www.ilae.org, and Epilepsy Alliance America at www.epilepsyallianceamerica.org or 800-642-0500. Epilepsy Florida offers free educational programs for students, faculty, and administrators. Your school nurse may also be available to provide education. Information is also available at www.epilepsyalliancefl.org or 877-553-7453.

71 DOES THE SCHOOL HAVE TO CALL AN AMBULANCE EACH TIME MY CHILD HAS A SEIZURE IN THE CLASSROOM?

No, providing the teacher and the school staff with general information about epilepsy and your child's epilepsy in particular will help them to know what to do when a seizure occurs. Such information may avoid unnecessary trips to the Emergency Room. An ambulance must always be called in the event of a prolonged seizure lasting five minutes or more, back to back seizures without recovering consciousness between seizures, if the seizure occurs in water, even shallow water, or if an injury has occurred.

72 CAN MY CHILD RECEIVE SPECIAL CONSIDERATION AT SCHOOL DUE TO HIS SEIZURES?

Yes, depending on the type and/or frequency of the seizures your child may be eligible for a number of special services, accommodations and modifications, nursing services, one to one care taker, or financial assistance. Check with your child's school to access these services if needed.

73 CAN SEIZURES GO AWAY WITH THE ONSET OF PUBERTY AND ADOLESCENCE?

No one can accurately predict when seizures will go away. However, some children will stop having seizures during adolescence and puberty. Some types of epilepsies are often outgrown such as Benign Rolandic Epilepsy, some types of Absence Seizures, and others.

74 CAN MY CHILD GO OFF TO COLLEGE AND LIVE A NORMAL LIFE?

Yes, most teens and young adults with epilepsy will be able to live normal lives. For some this may mean going off to college. These students may face additional challenges. This may be the first time they are away from home and responsible for their own medication, health care, and diet. A realistic, optimistic, and flexible attitude on the part of parents is most encouraging for the student. Guidance and vocational counselors are also required to discuss career and develop a specific plan of action tailored to meet the specific student's vocational and personal needs.

75 CAN FAMILY PROBLEMS AFFECT THE FREQUENCY OF SEIZURES IN MY CHILD?

Yes, family problems can cause stress in any child and in a child with epilepsy, stress can lower the seizure threshold. Building a supportive family environment for the child and developing good family relationships will help avoid increased seizure frequency.

76 MY DAUGHTER DOES NOT LIKE TO EAT BREAKFAST IN THE MORNING, CAN THIS ALTER THE EFFECTIVENESS OF HER ANTI-EPILEPTIC MEDICATIONS?

Yes, proper nutrition is important for persons with epilepsy taking AEDs. Some AEDs are prescribed to be taken with meals, including breakfast, in order to delay absorption and prevent side effects.

77 MY RELATIVES WILL BE VISITING SOON. SHOULD I TELL THEM MY CHILD HAS EPILEPSY?

Not necessarily. If your child's seizures are under good control, you may want to tell only your immediate family and closest friends or those involved in your child's care. However, if you want to tell your relatives, being straightforward about epilepsy will educate and assist in reducing negative stereotypes, fear, and some of the other myths and stigmas about the disease.

78 MY REBELLIOUS TEENAGER IS NOW REFUSING TO TAKE HIS MEDICATION. IS THIS COMMON?

Yes, it is. The teen years can be difficult for both parents and teens with epilepsy. Sometimes as a way of showing their independence or because of social pressure from peers, teens may stop taking their AEDs. The embarrassment of revealing they have a medical condition or having friends around who are not taking medication or starting to use alcohol or drugs are other reasons a teenager may stop his/her AEDs. As a result, seizure control may suffer and, in turn, loss of control or exacerbation of seizure activity will create poor self-esteem and isolation. A way of preventing this is by having open communication between parents and teens.

79 MY CHILD RECENTLY WITNESSED HIS MOTHER HAVING A SEIZURE AND IS NOW SCARED. WHAT CAN WE DO TO PUT HIM AT EASE?

The child's age will dictate how and what you will tell him about his mother's condition. Be honest and explain as unemotionally as possible what happens during a seizure and how the child will be able to help. You may also wish to contact Epilepsy Alliance Florida for family education and other educational resources.

80 HOW DO I TELL MY CHILD I HAVE EPILEPSY?

Many parents do not disclose their epilepsy to their children, fearing their children will react negatively. It's best to tell children about your epilepsy before they witness a seizure. Explain to them what epilepsy is, what happens during a seizure, how they can help, and why you take medication. You may also wish to contact Epilepsy Alliance Florida for family education and other educational resources.

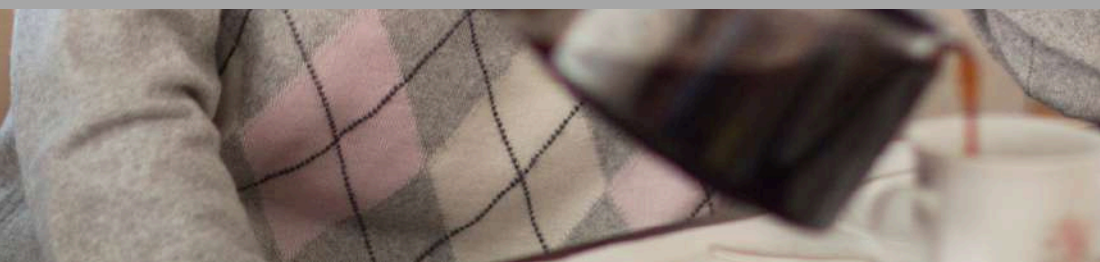
81 WHAT IS BENIGN ROLANDIC EPILEPSY?

Benign Rolandic Epilepsy, the most frequent of the benign partial epilepsies of childhood, represents about 15 % of all epilepsies in children and occurs more often in boys. The seizures typically occur at night and do not result in any neurological or intellectual deficits. Because the seizures may be mild, infrequent, and usually occur at night, many children do not need to be treated with medication. This syndrome is categorized as benign given the tendency of the seizures to remit over time and often stop altogether during adolescence.

82 WHAT ARE CATASTROPHIC EPILEPSIES?

Catastrophic epilepsies are age-related epileptic syndromes characterized by a variety of behavioral seizure manifestations, malignant EEG patterns, and devastating outcomes including intellectual disabilities and frequently, shorter life expectations (due to SUDEP or other causes). Most syndromes are resistant to anticonvulsant therapy, occur early in life, and include the following: 1) Dravet Syndrome (severe myoclonic epilepsy of infancy), 2) Lennox Gastaut syndrome, 3) Early Infantile Epileptic Encephalopathy, 4) Early Myoclonic Encephalopathy, and 5) West Syndrome (infantile spasms). Given the severity of the catastrophic epilepsies, a multidisciplinary approach is required to develop innovative, effective, and non-toxic modalities of treatment to try to stop or at least ameliorate the severity and frequency of the multiple types of seizures. Respite care for parents, relatives, and care takers of these children is recommended.

ADULTS AND SENIORS



83 CAN STROKE CAUSE EPILEPSY?

Yes. Stroke is the most frequent cause of seizures in seniors. Because arteries may become clogged or narrowed as people age, the brain may be deprived of blood and oxygen. The result may be a stroke. Bleeding in the brain may also result in seizures.

84 DOES EPILEPSY WORSEN WITH AGE?

It is known that as we age, our bodies begin a natural and normal physiological degenerative process that can make epilepsy more likely to occur. Other health problems associated with epilepsy including stroke, brain tumors, head injury from falls, heart disease, high blood pressure, depression, Alzheimer disease/dementia, and increased sensitivity to medications may also contribute to the difficulty of treating epilepsy and the resultant worsening of the disease in the elderly population.

85 DOES THE AGING PROCESS AFFECT THE WAY THE MEDICATION WORKS?

Yes, aging along with other health issues can affect the way medication is absorbed, metabolized, and eliminated. This is why it is important for seniors to have neurological check-ups and blood monitoring of body functions frequently and periodically. Sometimes lower doses of medication may be required when moderate to severe impairment of essential body functions such as liver or kidney functions are identified.

86 ARE SENIORS MORE SENSITIVE TO THE NEURO- PSYSCHIATRIC SIDE EFFECTS OF A DRUG OR COMBINATION OF DRUGS CO-ADMINISTERED WITH ANTICONVULSANT DRUGS?

Yes, especially when they are taking a combination of medications that may lead to altered mood, changes in behavior, depression, anxiety, perception, feelings, cognition, intellectual functions, memory, and ideation (suicidal/homicidal). Some medications may negatively interact or change the effect of other drugs enhancing the potential for these side effects.

87 I AM HAVING SIDE EFFECTS DUE TO MY MEDICATION, CAN I JUST STOP TAKING IT?

No, you must never stop taking your AED abruptly without first consulting your physician. Doing so may augment the risk for increased seizure frequency or precipitate status epilepticus or SUDEP.

88 I'M 72 YEARS OLD AND I AM TAKING MEDICATION FOR A NUMBER OF HEALTH PROBLEMS IN ADDITION TO MY EPILEPSY MEDICATION. IS THIS A PROBLEM?

Taking a number of medications daily may be hard to track. They may have negative side effects or reduce the effectiveness of other prescribed drugs. If you are receiving medical treatment for several co-existing illnesses and you are seeing various specialists, be sure each knows all the drugs you are taking and the reason why you are taken them.

89 ARE ADULT LIVING FACILITIES OR NURSING HOMES AND THEIR STAFF CAPABLE OF CARING FOR SOMEONE WITH EPILEPSY?

Assisted Living Facilities (ALFs) are required by Florida Statute to provide various in-service trainings to their staff. ALF and nursing home staff and particularly staff in "direct contact" (means direct care staff) receive comprehensive, specialized training in working with individuals with mental health diagnoses and disabling conditions such as epilepsy, Alzheimer's disease, and others. ALFs and nursing homes are licensed and approved to care for persons with epilepsy and other health conditions under the supervision of the Florida Department of Elders Affairs.

90 MY FATHER, WHO HAS EPILEPSY, HAS BEEN INJURED AT HOME NUMEROUS TIMES DURING SEIZURE ACTIVITY. IS THERE ANYTHING THAT CAN BE DONE TO PREVENT THESE INJURIES?

Having someone available to take care of your elderly father at home is one solution. Other alternatives include having family members and neighbors periodically stop by to check on him, carpeting floors, using padded furniture, clearing trip hazards, and using electronic tracking or motion detecting devices and other similar technology designed for constant video-monitoring. You may also contact trained professionals who can provide help in these areas, including occupational and rehabilitation specialists.

91 IS THE TREATMENT OF EPILEPSY DIFFERENT NOW THAN 40 YEARS AGO?

Yes. There have been many technological advances in the field of epilepsy care during the past 40 years including new medications, surgical options and techniques (Gamma-Knife, robotic surgery and MRI guided ablation surgery), implantable electronic devices (Vagus Nerve Stimulation, NeuroPace and deep brain stimulation), electrodiagnosis (magnetoencephalography), neuroimaging (functional MRI –fMRI and other procedures), newer neuro-psychological testing and others leading to a better understanding of how the brain works, leading to the development of more accurate diagnostic procedures and more specific and efficient modalities of treatment for epilepsy.

PSYCHOLOGICAL AND EMPLOYMENT ISSUES

92 SINCE MY HUSBAND WAS DIAGNOSED WITH EPILEPSY, HE HAS GONE THROUGH PERIODS OF DEPRESSION AND ANGER. IS THIS NORMAL?

Yes, it is. Many epilepsy patients go through periods of denial, anger, and depression after receiving the diagnosis of epilepsy. Most, through time and counseling, will learn to cope better with feelings and lead productive lives once again. However, scholars have consistently reported a higher incidence of depression and suicide among patients with epilepsy than the general population or others groups with chronic conditions such as diabetes or cardiovascular diseases. Patients with epilepsy usually respond well to medication and are successfully treated with low doses of antidepressants.

93 WHAT CAN I DO TO GET THE BEST OUT OF MY VISITS TO THE DOCTOR?

Come prepared to your clinic visit. Be honest with your physician about how you feel physically, mentally, and socially and report any seizure(s) you may have had since your last visit. Keep an accurate seizure calendar and bring a list of all the medications (and dosages) you are taking. Prepare questions prior to the consultation. Learn as much as you can about epilepsy and its treatment. Good open communication between physician and patient is a must in the treatment of epilepsy. Bringing a caregiver, relative, or friend to the medical visits can enhance the accuracy of what you report to and learn from your doctor and enable compliance with all his/her recommendations.

94 WHY SHOULD I NEED A NEUROPSYCHOLOGICAL EVALUATION?

The neuropsychological evaluation is a performance-based method to assess cognitive functioning in order to evaluate for brain damage, brain disease, and severe mental illness. Cognitive impairment, short and long-term memory deficits, mood, behavior, personality, and other affected higher cortical functions in persons with epilepsy require neuropsychological assessment. Neuropsychological tests also measure how the quality of life in these persons has been affected. However, if these brain functions are well preserved in the individual with epilepsy, this testing is not required.

95 WHERE CAN I FIND SUPPORT GROUPS TO HELP OUR FAMILY TO COPE WITH EPILEPSY?

Epilepsy Alliance Florida offers support groups. Other possibilities include contacting your local United Way, your physician, or virtual groups in the internet. You can also create your own group.

96 CAN A PERSON WITH EPILEPSY BE EMPLOYED?

Yes, people with epilepsy can do most jobs depending on the quality of the seizure control. The unemployment rate for people with epilepsy is significantly higher than that of the general population and many people with epilepsy who work are underemployed. One study shows that persons with epilepsy have better safety and productivity records than other workers. However, the employee with epilepsy should avoid hazards or keep risks at a minimum (operating heavy machinery, working with heights, driving, etc.) to prevent personal injuries or harm to others.

97 DO I HAVE TO TELL MY EMPLOYER THAT I HAVE EPILEPSY?

Not necessarily, although it may be a good idea. It may be best to tell your employer if your seizures are not fully controlled. Providing information to your employer, staff, and co-workers will enable them to help you if a seizure occurs and also will help them to better understand your medical condition. You do not have to tell employers during the interview process unless the issue is addressed, e.g., through driving restrictions. The Americans with Disabilities Act (ADA) was passed in 1990 to protect employees who have disabilities. You do not have to disclose you have epilepsy either if you have remained seizure free for at least 2 years unless you are taking a drug that will be reported in the mandatory drug screening test. Finally, you do not have to disclose your condition to the employer at all if you have been seizure free for years and still seizure free after at least one year without any anticonvulsant treatment.

98 DO PEOPLE WITH EPILEPSY WHO ARE EMPLOYED MISS MORE DAYS OFF FROM WORK THAN THEIR COWORKERS?

Studies show that most employees with epilepsy have good attendance records and that workplace accidents are no more frequent in employees with epilepsy than other employees. In fact, it has also been reported that employees with epilepsy make efforts to be more productive than their non-epileptic co-workers in an attempt to get extra credits and retain the job.

99 CAN I OBTAIN HEALTH INSURANCE IF I HAVE EPILEPSY?

Yes, you can. The Health Care Reform Plan officially named Patient Protection and Affordable Care Act (PPACA) or Affordable Care Act (ACA) for short prohibits discrimination and denial or termination of health insurance coverage to individuals with pre-existing conditions. If you work with a company that offers an employee health group plan, you can obtain insurance. If your employer does not offer insurance coverage, you can contact the Marketplace directly or Epilepsy Alliance Florida (EAFLA) which is a state licensed and federally certified provider of in-person Navigation assistance for Floridians utilizing the Marketplace. For assistance and/or additional information, contact EAFLA at 877-553-7453 or www.epilepsyalliancefl.org.

100 WHAT CAN I DO IF I FEEL I HAVE BEEN DISCRIMINATED AGAINST IN A WORKPLACE?

Always try to resolve this matter first with your employer. If this does not meet your satisfaction, you may call Epilepsy Alliance Florida for advice and the local or national Equal Employment Opportunity Commission (EEOC) offices for assistance. To fill out a complaint at the Miami District Office in person, the office is located at Miami Tower, 100 SE 2nd Street, Suite 1500, Miami, FL 33131. You can also obtain assistance by calling 1-808-669-4000

101 CAN I FILE A DISABILITY CLAIM IF I HAVE EPILEPSY?

Yes, you can but some regulations apply. According to Social Security Administration (SSA), applicants with seizures may be eligible for benefits if the seizures remain uncontrolled in spite of strict compliance with medical treatment for at least the past three months from the date of application. Frequency and severity of the seizures, duration of the post-ictal state (time required to regain full control of bodily functions and mind after the end of a seizure), as well as the severity of medication side effects are evaluated by the adjudicator prior to granting benefits. Applicants for disability based on the diagnosis of epilepsy whose seizures are well controlled or occurring only sporadically (less than one generalized tonic-clonic seizure per month or less than 2–3 focal onset seizures with impairment of consciousness per week) are not eligible for disability benefits.

Absence seizure: A generalized non-convulsive seizure starting abruptly, lasting a few seconds, and ending abruptly without warning or postictal period. The person stops what he/she was doing at the beginning of the seizure and resumes the activity immediately after the end of the seizure, there is no recollection of the episode. This type of seizure is related to a genetic cause.

Ablation: A surgical technique that removes damaged tissues using a laser beam or other heat sources.
Acquired epilepsy: Disease developed due to a specific preceding underlying condition such as brain infection (meningitis), stroke, tumor, or an injury after head trauma. This kind of epilepsy is also called symptomatic-related epilepsy.

Ambulatory EEG: A portable type of EEG recording of the electrical activity of the brain continuously over a period of several hours, usually 24, 48, or 72 hours. Electrodes are attached to the scalp and connected to a recorder that the person wears on a belt around the waist. This type of EEG can be performed with or without video recording.

Modified Atkins Diet: A special high-fat diet used for difficult-to-treat seizures but less restrictive than the Ketogenic Diet (see below). It allows unlimited amounts of protein foods and fats. Food does not need to be weighed and recipes do not need to be precise. This diet can be used in children, teenagers, and adults.

Alzheimer's disease (AD): This is the most common form of dementia. AD is a neurologic disease characterized by a loss of mental ability severe enough to interfere with normal activities of daily living, lasting at least six months, and not present from birth. AD usually occurs in the elderly, evidenced by a decline in cognitive functions such as remembering reasoning and planning.
Antipsychotic drugs: A class of medicines used to treat mental illness and emotional conditions.

Brain tumor: A mass inside the brain originated by abnormal growth of brain cells, neurons, or supportive cells.

Congenital malformation (CM): A physical defect present in a newborn that can involve any part of the body including, but not limited to, the brain, heart, lungs, kidneys, intestinal tract, bones, extremities, and face. CM can be genetic or acquired by exposure of the fetus to a malformed agent such as alcohol, drugs, and radiation (X-Rays), particularly during the first trimester of the pregnancy.

Cryptogenic epilepsy: Epilepsy is presumed to have an underlying anatomic cause that remains unidentified.

Dravet syndrome (DS): Also known as Severe Myoclonic Epilepsy of Infancy is a rare and catastrophic form of epilepsy resistant to medical treatment that begins in infancy. The onset of seizures usually begins in the second year of life. Several types of seizures may co-exist in the same child and development remains on track initially but progressive decline typically begins in the second year of life affecting every aspect of daily living. Individuals with Dravet syndrome face a higher incidence of SUDEP.

Dietary supplement: A product intended for ingestion that contains a “dietary ingredient” meant to add further nutritional value to the regular diet. A dietary ingredient may be one or more than one of the following substances: a vitamin, a mineral, an herb, or another botanical.

Epilepsy: A chronic neurological disease characterized by the tendency to have repeated, unprovoked seizures. Its name derives from the Greek word Epibalaneim which means “to seize” or “violent shaking”.

Focal seizure: An older term for partial seizures. A seizure originated on a small focus in the brain.

Food and Drug Administration (FDA): U.S. federal agency responsible for the enforcement of federal regulations on the manufacture and distribution of food, drugs, medical devices, and cosmetics. The regulations are intended to prevent the sale of impure or dangerous substances.

Gamma Knife Surgery: A surgical procedure not actually performed with a knife at all. It is a stereotactic, radioactive, non-invasive (skull is not opened) surgical procedure performed with a device that treats malignant and benign brain tumors, vascular malformations (also known as arteriovenous malformations - AVMs), and other causes of epilepsy.

Generalized seizure: A seizure involving the whole brain and impairment or loss of consciousness results since its onset.

Idiopathic epilepsy: Epilepsy where the cause of the disease is not known but is suspected to be of genetic origin.

Juvenile Myoclonic Epilepsy (JME): Also known as Janz syndrome is a fairly common form of idiopathic generalized epilepsy, representing 5-10 % of all epilepsy cases. The disease typically manifests between the ages of 12 and 18 with brief episodes of involuntary muscle jerks occurring early in the morning. Most patients also have generalized tonic-clonic seizures and absence seizures. The disease is an inherited form of epilepsy.

Ketogenic Diet: Created in 1921, the Ketogenic diet is a medical therapy for children with difficult-to-control epilepsy. This high-fat, moderate protein, very low carbohydrate diet induces a ketotic state (acidosis) that theoretically leads to seizure reduction.

Lennox-Gastaut syndrome (LGS): This is a severe form of catastrophic epilepsy. Seizures usually begin before 4 years of age and very often, more than one type of seizure co-exists in the same child. These types of seizures include tonic (stiffening of the body, upward deviation of the eyes, altered respiratory pattern), atonic (sudden brief loss of muscle tone and consciousness, causing abrupt falls), atypical absence (staring spells), and myoclonic (sudden muscle jerks). Generalized tonic-clonic and complex partial seizures can also be seen. Children with LGS also experience variable degrees of intellectual disability, developmental delays, and behavioral disturbances. LGS can be caused by brain malformations, perinatal asphyxia, severe head injury, central nervous system infections, and inherited, degenerative, or metabolic causes. In 30-40 percent of cases, no cause is found.

Lyell's syndrome: A severe and often fatal cutaneous reaction primarily to drugs but also due to other causes such as infections or cancer, characterized by bulla formation, sub-epidermal separation, and widespread loss of skin leaving raw denuded areas. This disease is considered a more severe form of Stevens-Johnson syndrome.

Magnetoencephalography (MEG): This is a functional neuroimaging technique for mapping brain activity by recording magnetic fields produced by electrical currents occurring normally in the brain. This is a modern diagnostic method to detect abnormal electrical activity in patients with epilepsy and evaluate brain functions for surgical planning in patients with brain tumors or intractable epilepsy.

Neurons: Building blocks of the brain made of a cell body, the axon, and dendrite projections which allow them to communicate with each other.

Partial epilepsy: Epilepsy originating from a part of the cerebral cortex.

Petit Mal: Old medical term for Absence seizures.

Positron Emission Tomography (PET): It is a nuclear, 3-dimensional brain scan that gives information about the function and structure of the brain.

Reflex seizures: These may occur in reflex epilepsy (also known as environmental epilepsy) and they are the result of sensory stimulation caused by the environment such as photosensitivity, noises, odor, and others. The type of stimulus precipitating the seizures defines the type of reflex epilepsy: e.g., photosensitive epilepsy, reading epilepsy, hot water epilepsy, music-induced epilepsy, math epilepsy, and many others.

Responsive Neurostimulation: The Response Neurostimulation System (RNS) is a responsive direct brain stimulation used to treat difficult-to-control seizures in individuals with medically refractory epilepsy. The RNS utilizes a neurostimulator (NeuroPace) implanted in the skull with one or two leads implanted in the brain at the focal points generating the seizures. The neurostimulator monitors the brain's electrical activity and when the device identifies pre-programmed seizure activity, it attempts to suppress the seizure by sending small electrical stimulation pulses through the leads to that portion of the brain. The device is powered by a long-life battery. The neurologist has a programming device while the patient has a remote monitor to provide information from the stimulator to the neurologist.

Robotic surgery: This is a method to perform surgery using very small surgical tools attached to a robotic arm. The surgeon controls the robotic arm with a computer.

Stevens-Johnson syndrome: A severe and sometimes fatal inflammatory eruption of the skin, mucous membrane, and viscera, usually affecting children and young adults. It is characterized by the acute onset of fever bullae on the skin and ulcers on the mucous membranes of the lips, eyes, mouth, nasal passage, and genitalia as well as viscera internally. It may be due to an allergic reaction to drugs, infections, or radiation therapy.

Teratogenic effect: The consequences of consuming harmful substances such as alcohol or drugs or exposure to environmental hazards such as X-Rays on a developing fetus causing abnormal growth deficiency (also called congenital malformation) and/or intellectual disability.

West syndrome: Also known as infantile spasm is a form of catastrophic epilepsy and is characterized by infantile spasms usually beginning in the first year of life, typically between 4 – 8 months of age. The seizures consist of a sudden bending forward of the body with stiffening and hyperextension of the arms and legs. Spasms tend to occur after awakening or after feeding and often in clusters of up to 100 spasms at a time. Infants may have dozens of clusters per day. West Syndrome usually stops by age 5 but may be replaced by other seizure types and /or evolves into Lennox-Gastaut syndrome.

NOTES

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