Recommendations for Care of Adults with Epilepsy

Seeking the best treatment from the right doctor at the right time!
This booklet is to help adults and their caregivers know when it is appropriate to seek treatment for seizures. For additional resources about epilepsy and tools to help manage your condition, please visit www.epilepsyfoundation.org.
What Type of Doctors Treat Adults with Epilepsy?

There are several types of doctors who treat epilepsy. For some adults, epilepsy can be treated and successfully managed by a primary care physician. This is often the case for those whose seizures are well controlled on one medication or who live in rural areas and must travel for hours to see an epilepsy specialist.

Most epilepsy patients are treated by a neurologist. A neurologist specializes in diseases of the brain, spinal cord and nervous system. A neurologist learns about treating epilepsy in adults and is involved in their care during their residency.

An epileptologist is a neurologist who completes a one or two year subspecialty fellowship in clinical neurophysiology and/or epilepsy in addition to the training in epilepsy that all neurologists receive. An epileptologist typically has a medical/clinical practice which predominantly cares for patients with epilepsy.

Epilepsy centers have epileptologists, psychologists, pharmacists, nurse-clinicians, nurse educators and other specially trained professionals to work with patients and their families to provide the services needed for optimal epilepsy care.
New Onset Seizures

- About 25-30% of seizures in adults are caused by a sudden illness such as a stroke, head injury, alcohol or drug withdrawal, blood chemistry imbalance or overdose of medication. Having one seizure does not necessarily indicate epilepsy. However, some patients need antiepileptic medication to prevent additional seizures during their recovery.

- Epilepsy is diagnosed when a person has one or more seizures and a significant risk of additional seizures in the future. This is usually after two unprovoked seizures, but sometimes it can be diagnosed after a single seizure.

- An adult experiencing a first seizure should be treated immediately in an ER. A physical examination and an assessment of cardiac, neurological and
mental status are important. An eyewitness account of the seizure helps the
doctor determine if a person experienced an epileptic seizure.

• A CT (computed tomography) scan to identify any brain abnormalities
and blood tests will help determine if a significant illness may have caused
the seizure.

• A neurologist should see the patient as soon as possible for early diagno-
sis and treatment.

• Diagnosis and treatment of epilepsy depend on one’s medical history, a
neurological examination and tests for brain abnormalities.

• An EEG (electroencephalogram) is a test that records the electrical activ-
ity created by the brain. One should be performed after the first unprovoked
seizure to look for abnormal spikes or sharp wave discharges. This may help
determine if more seizures are likely to occur. An unprovoked seizure is a sei-
zure that occurs in the absence of a medical or external cause such as head
trauma or other circumstances.

• MRI (magnetic resonance imaging) is the preferred method of evaluating
adults with new onset seizures, especially if there are signs that the seizures
start in a particular area of the brain.

• If seizures recur despite treatment with antiepileptic medication, an
epileptologist should be seen as soon as possible.

• If the diagnosis cannot be made, get a referral to an epilepsy center.
Patients Taking Epilepsy Medications

• Approximately 70% of people with epilepsy will be seizure-free with the use of antiepileptic drugs, although many have side effects or other epilepsy-related problems (driving restrictions, depression, etc.).

• When seizures are controlled with medication, there should be very little impact on a patient’s quality of life. The goal of your treatment should be **no seizures** and **no side effects**.

• Tell the doctor if your medication is causing problems. Some common side effects are fatigue, sleepiness, dizziness, mood changes, weight changes, and memory or concentration difficulties. An adjustment in the dose of your medication or a new medication altogether may be necessary.

• Once epilepsy is under control with medication, the likelihood of remaining seizure-free after stopping the medication is dependent upon what caused the seizures. Stopping medication is usually not an option for people whose epilepsy is due to a brain abnormality, a result of a head injury, or a family history of seizures. For this reason, it is very important to try to determine what caused the epilepsy.

• Epilepsy should not be ignored by patients whose seizures are controlled. Medication must be taken exactly as prescribed and missed doses avoided. Follow-up with the treating physician should be at least once per year.

• Routine health maintenance is important even when seizures are well controlled. Avoid situations that can trigger seizures such as sleep deprivation, excessive stress, alcohol abuse, and missed doses of medication.

• There are some long-term problems associated with some epilepsy medications, but they can be avoided. One problem is weakened bones (osteoporosis). Ask the doctor if vitamin D and calcium supplements should be taken; and whether or not your bone density should be checked.

• Certain epilepsy medications can reduce the effectiveness of birth control pills, so discuss this with the physician. Higher dose birth control pills may be necessary. Please read the Special Patient Groups section of this brochure for information about women and epilepsy.
• If your pills change in shape, color, or appearance, ask your pharmacist why and tell your doctor about it immediately. Whether generic medication can be substituted for brand name (or a generic medication can be substituted for another generic medication), depends on the medication and your medical situation so any changes to your medication are best handled with the doctor.
Adults with Uncontrolled Seizures (Refractory Epilepsy)

Medications
• About one-third of epilepsy patients do not respond to the first two medications tried. For patients who continue to have seizures, the first step usually requires adjusting their medication. For the best results, it is very important to 1) keep track of seizures, 2) monitor side effects, and 3) share the information with the treating physician. It should not be necessary to suffer intolerable side effects from antiepileptic medication.
• There are currently more than 20 medications available on the market to treat the various forms of epilepsy. If there is no response to an adequate dose of one medication then another should be tried. To learn more about the various medications for epilepsy, dosages and potential side effects, go to www.nomoreseizures.org.

Epilepsy Surgery
• Epilepsy surgery should be considered for those who continue to have seizures. An evaluation for surgery is recommended after two appropriate antiepileptic medications have failed to control the seizures. If the seizures start in one place in the brain it may be possible to remove this area and cure the epilepsy. Sometimes, even those with generalized epilepsy benefit from one type of epilepsy surgery. Surgical evaluations are best done in specialized epilepsy centers. A list of epilepsy surgery centers can be found at www.naec.org.
• The most common type of epilepsy surgery involves removal of a portion of the temporal lobe, which is where seizures begin in many patients. The majority of these become completely seizure-free following the procedure. Many people are also able to stop the antiepileptic medications.
• Removal of epileptic tissue from other lobes in the brain (frontal, parietal, or occipital) is less common and typically does not have as high a success rate. Other types of surgery are performed under special circumstances.

Other Options
• Vagus nerve stimulation (VNS) may help control seizures. VNS stimulates the vagus nerve in the neck through wires that are fed from a generator implanted in the chest. VNS is about as effective as switching to a new drug but does not typically cause side effects like fatigue or drowsiness.
• Seizure diaries are often helpful and can help identify seizure triggers. Patients and their doctor should determine if seizures are less frequent at each visit.
Making the Most of Your Office Visit

Preparing for an appointment at an epilepsy specialty clinic can help achieve the best outcome. Seeing a new doctor can be stressful and people often forget important information. Keeping a seizure diary and writing down information about unusual behaviors, mood swings or unusual events are important for understanding the course of a patient’s epilepsy.

Some of the things you can do:

• Keep a seizure diary. When did the first seizure occur? When were you diagnosed with epilepsy? What is the longest seizure-free period you have had?
• List the antiepileptic medicines, the doses you have been on, and the reasons the drugs were stopped.
• Bring your current medicines with you (in the bottle with pharmacy label).
• Be able to describe your seizures. Try to list the seizures by type, if you have more than one type. Did you have an aura or warning? What behavior did you have during a seizure? Did you have convulsions? How did you behave after a seizure? Did the seizure cause you to miss work or result in an injury? It is best to go with someone who has seen your seizures and is able to describe them to the doctor.
• What are you expecting to gain from this visit? Communicate your expectations at the beginning of your visit.
• Bring with you any test reports or scans you have had done.

Before you leave the office ask the doctor:

• to write down instructions for changes in medications or tests that need to be scheduled
• about other resources such as a local Epilepsy Foundation or an epilepsy center
• what type of seizures you are having
• to describe possible side effects of the medications being prescribed
• about an emergency treatment plan for those times when seizures are prolonged or repetitive.

Special Patient Groups

Women with Epilepsy

• Most women with epilepsy can have successful pregnancies, but some seizure medications can cause birth defects. A seizure is dangerous to a mother and her unborn child. Therefore, women of childbearing potential (whether or not they intend to become pregnant) should have a discussion with their doctor and consider using the lowest dose possible to control seizures.
• Because many pregnancies are not planned, all women of childbearing potential should take folate daily to reduce the risk of birth defects.
• Seizure medications can interfere with vitamin K, which can place an infant at risk for serious bleeding shortly after birth. Pregnant women should discuss the potential need for a vitamin K injection to be administered to a newborn at birth.
• A woman’s blood levels must be monitored during pregnancy because metabolic changes may lower the amount
of antiepileptic medication in the blood and cause a seizure.

- Certain seizure medications can interfere with oral contraceptives causing them to be less effective.
- Women who take seizure medication are at increased risk for osteoporosis and should have their bone density checked.
- For some women, seizures are related to their menstrual cycle and most likely occur mid-cycle. It is thought that this is due to changes in hormone (estrogen/progesterone) levels.

**Elderly Patients with Epilepsy**

- The elderly are more likely than younger people to have recurrent seizures after experiencing their first seizure. For this reason, they are more likely to be prescribed antiepileptic medication after their first seizure. Since most elderly people are taking other medications, they are more likely than others to develop drug interactions after being started on an antiepileptic drug.
- The elderly are also more likely than others to have side effects like memory loss and confusion. Lower doses of medications are often recommended. High drug concentration in the blood can lead to falls, fractures, fatigue or other side effects.

**Disabled Patients with Epilepsy**

- Seizures due to brain abnormalities that also produce physical and cognitive disabilities are among the most difficult to treat. Seizure control can require multiple medications and side effects are harder to recognize.
Epilepsy Foundations throughout the country have additional materials and offer a variety of programs to help people understand this common disorder. For further information about epilepsy and the name of the Epilepsy Foundation near you, log on to www.epilepsyfoundation.org or call 800 332-1000.

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