SEIZURES & EPILEPSY:

INFORMATION AND RESOURCES
LIVING WITH EPILEPSY

If you have been diagnosed with epilepsy or partial-onset seizures, it is important that you educate yourself about your diagnosis. The information in this brochure will help you to get started. You should discuss your treatment goals with your doctor to decide the best plan for your epilepsy care.
EPILEPSY IS MORE COMMON THAN YOU MAY THINK.

- Epilepsy is the 4th most common neurological disorder.
- Over 2 million people in the United States have been diagnosed with epilepsy.
- 1 in 26 people in the United States will be diagnosed with epilepsy at some point in their lives and about 60% of people diagnosed with epilepsy have partial-onset seizures.
WHAT IS EPILEPSY?

Epilepsy is a neurological disorder, and it is sometimes called a seizure disorder because seizures are the primary symptom. But a single seizure is not necessarily epilepsy. Epilepsy is defined by a tendency for recurrent seizures. Tests such as brain scans can determine if a person has epilepsy.

WHAT IS A SEIZURE?

A seizure is the result of a change in the normal electrical activity in the brain. Depending on the type of seizure—there are many—it can last for a few seconds or minutes, manifesting in various ways, with symptoms ranging from rapid blinking and staring at nothing in particular to loss of consciousness, falling, and muscle jerks.
WHICH DOCTORS TREAT EPILEPSY?

NEUROLOGIST:
A physician who specializes in diseases of the brain, spinal cord, and muscles, and is trained to investigate or diagnose and treat neurological disorders.

EPILEPTOLOGIST:
A neurologist who specializes in the treatment of epilepsy.

WHAT ARE THE DIFFERENT TYPES OF SEIZURES?

THERE ARE TWO MAJOR CATEGORIES OF SEIZURES.

PARTIAL-ONSET SEIZURES

Partial-onset seizures (also know as focal seizures) happen when one area of the brain is affected. According to the National Institute of Neurological Disorders and Stroke, about 60% of people with epilepsy experience partial-onset seizures, which include:

- Simple partial seizures, which do not impair consciousness and can cause twitching or the sense of an odor or taste that’s not actually there. An uneasy stomach sensation is also very common.

- Complex partial seizures, which impair consciousness so a person may appear dazed or confused, possibly unable to respond to others for a few minutes

- Secondarily generalized partial seizures, which occur when a partial seizure spreads to both sides of the brain, becoming a generalized seizure
Absence seizures (also known as petit mal seizures), which cause rapid blinking or staring into space.

Tonic-clonic seizures (also known as grand mal seizures), which can cause involuntary crying out, loss of consciousness, falling, or convulsive muscle jerks or spasms.
WHAT ARE THE CAUSES OF EPILEPSY?

The cause of epilepsy is unknown in the majority of people affected, according to the CDC (Centers for Disease Control and Prevention). This may be called cryptogenic or idiopathic epilepsy. For others, the cause of their epilepsy is clear: traumatic brain or head injury, brain tumors, birth defects, or stroke, for example.

THE DIFFERENT CAUSES OF EPILEPSY CAN HAPPEN AT ANY STAGE OF LIFE.

- A birth defect or brain injury during birth may lead to seizures.

- A mutation in genes may lead to specific childhood epilepsy syndromes.

- Head trauma or certain infectious diseases, such as viral encephalitis, can disrupt normal brain activity and lead to changes that make seizures more likely.

- Conditions that deprive the brain of oxygen, such as stroke and heart attack, are common causes of epilepsy in the elderly.
Partial seizures are the most common type of seizure experienced by people with epilepsy. Almost any movement, sensation or emotional symptom can occur as part of a partial seizure, including visual (seeing) or auditory (hearing) hallucinations.

As a result, there can be varying symptoms from person to person depending on what part of the brain is involved. Seizure symptoms often reflect the part of the brain where the seizure activity is occurring.

For example, one person may remain alert and aware, be able to respond to others and remember everything that occurred during the seizure. Others may lose awareness and become unresponsive.
WHEN THERE IS NO LOSS OF CONSCIOUSNESS, SYMPTOMS OF PARTIAL-SEIZURES TYPICALLY INCLUDE:

- Strange or unusual sensations
  - Pins and needles, electrical sensations
  - Strange smell or taste (e.g., chemical or metallic sensations, often unpleasant)
- Vision abnormalities (e.g., flashing lights, complex scene)
- Hearing things (e.g., buzzing, person’s voice)
- Sudden or restless movement (e.g., stiffening, twitching, jerking)
- Altered heart or breathing rate
- Sweating
- Dreamy or “out of body” feeling
- Altered sense of time
- Stomach or chest discomfort
- Sudden sense of fear

Sometimes these symptoms can be a warning or signal that a more involved seizure (also called secondarily generalized) is about to happen. In such cases, the person experiencing these symptoms may have time to adjust their position or where they are in order to avoid injury or embarrassment.
WHEN THERE IS LOSS OF CONSCIOUSNESS, COMPLEX PARTIAL SYMPTOMS MAY INCLUDE:

- Appearing dazed and confused
- Staring
- Random walking
- Mumbling
- Head turning
- Grunting or repeating words or phrases
- Lip smacking
- Chewing
- Swallowing
- Pulling or picking at clothing
- “Shuffling cards”

A person experiencing these kinds of symptoms will not likely be able to respond to questions or instructions. Afterwards the person may be confused for several minutes and may experience a few hours of fatigue. After the seizure, the person will be unable to recall what happened during the seizure. On the whole, partial seizures will last anywhere from about 30 seconds to 2 minutes.

While partial seizures can affect different physical, emotional, or sensory functions of the brain, and have different symptoms, they have some things in common:

- They don’t last long, although some people may need time (2 to 30 minutes) afterwards to recover fully
- In most cases they end naturally
- You can’t stop them while they are happening
HOW DO I RECOGNIZE MY SYMPTOMS?

Seizures are remarkably different from person to person, depending on the part of the brain where they begin and how they progress. People with epilepsy can experience a variety of seizure symptoms, although most people follow a consistent pattern of symptoms.

IT’S A GOOD IDEA TO KNOW WHAT YOUR OWN TYPICAL SEIZURE SYMPTOMS ARE FOR A COUPLE OF REASONS:

1. Knowing your personal symptoms can help you better communicate with your doctor and other healthcare team members.

2. Being aware of your typical symptoms can help you educate loved ones (friends and/or family) on what they could expect if you were to have a seizure in their company. It may also help you determine if there are changes in your symptoms.

Use the space below to keep track of your seizure symptoms. If you experience complex partial seizures, have someone close to you help create a list, as they may have noticed symptoms that you are not aware of.

MY SEIZURE SYMPTOMS ARE:

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WHAT ARE THE COMMON SEIZURE TRIGGERS?

COMMON SEIZURE TRIGGERS INCLUDE:

- Alcohol or drug use
- Certain foods, excess caffeine or other products that may aggravate seizures
- Dehydration
- Emotional stress (worry, anxiety, anger)
- Fevers or other illness
  - Unpredictable changes in metabolic factors, like vomiting, diarrhea and physical stress
- Flashing bright lights or other visual stimulation
- Hormonal changes
  (such as those that occur during a woman’s menstrual cycle)
- Missed medication or exposure to other medications
- Missing meals, low blood sugar
- Sleep deprivation (overtired or not sleeping well)

Educating yourself about seizures and being aware of your personal triggers and symptoms are key elements in seizure management.
TIPS FOR TAKING MEDICATION(S)

HOW CAN I REMEMBER TO TAKE MY EPILEPSY MEDICATION(S)?

The most common epilepsy treatment is antiseizure medication. Taking your medication(s) properly is very important in treating your epilepsy. It is important not to skip doses and to establish a schedule you can remember and follow. A few tips for sticking with your epilepsy medication schedule are:

USE A PILLBOX
Fill a pillbox with a week’s epilepsy medication. If at the end of the week you have leftover pills, consult with your physician on how to get back on track.

LEAVE YOURSELF NOTES
Write reminders in your daily calendar or put sticky notes on your medicine cabinet or refrigerator—anywhere you will see them.

PROGRAM ELECTRONIC ALERTS
For those of you who are technologically savvy, program your digital watch, cell phone, or e-mail program to alert you when it’s time to take your epilepsy medication.

EPILEPSY MEDICATION REMINDER TIPS

- PILLBOX
- NOTES
- ALERTS
RESOURCES

**EPILEPSY FOUNDATION®**
A non-profit organization dedicated to epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies.
www.epilepsy.com

**CANINE ASSISTANTS®**
A non-profit organization that trains and provides service dogs to enhance and improve the lives of people with physical disabilities, seizure conditions or other special needs.
1-800-771-7221
www.canineassistants.org

**MEDICALERT FOUNDATION®**
Inform people about what to do and/or whom to contact if you have a seizure. Purchase customized medical alert ID bracelets and necklaces from MedicAlert Foundation, a non-profit organization.
1-800-432-5378
www.medicalert.org

**THE AED PREGNANCY REGISTRY**
Is my anticonvulsant medication safe during pregnancy? The North American AED Pregnancy Registry is dedicated to answering this question. Anticonvulsants treat disorders like epilepsy, mood disorder, and chronic pain, but more information is needed about them to answer the question confidently. The purpose of this registry is to collect information about the safety of antiepileptic medicine during pregnancy.
1-888-233-2334
www.aedpregnancyregistry.org