

Epilepsy & Seizures:
All About Focal Seizures

EPILEPSY

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FOUNDATION

Artwork titled, "Dual Faces"

Artwork by Studio E participant Becky Howard (details on inside cover)

**About the Cover:**

Cover artwork was created by Becky Howard, a Studio E participant.

In her words...

“Studio E was a great experience. I was able to use different and new forms of art to express myself, and did this with people who could understand and relate to the emotions in the art. It was nice to be able to communicate and spend time with people with similar situations. ‘Dual Faces’ allowed me to express frustration and happiness at the same time and put it into a piece of artwork.”

Studio E is a multi-week art program open to people with epilepsy. Participants use art to creatively express themselves, build confidence, and make friends. Living with epilepsy can be challenging and art programs may be beneficial in working through how the condition impacts an individual’s life. Find out more about the program and where it’s available at www.epilepsy.com.

Disclaimer:

This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to treatment or activities based on this information without first consulting with their health care provider.



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All About Focal Seizures

When most people think of epilepsy, they think of seizures that cause loss of consciousness, falls, and shaking movements of the whole body. However, this is just one form of a seizure, called a tonic clonic seizure.

Focal seizures (previously called partial seizures) are not easily recognized and are easy to mistake for other conditions. This lack of understanding can lead to many problems for people with focal seizures and their families.

That's why we've written this pamphlet. We hope it will be the first step towards recognizing and living with focal seizures.

“ I've had seizures ever since I can remember. I thought everyone got them. I'd be playing and get this weird feeling in my head. Sometimes I couldn't speak. I would just sit and stare blankly into space. My seizures are so mild no one would know I was having one. ”



About Epilepsy

Epilepsy is a chronic disease that affects the brain. The main symptoms are recurrent, unprovoked seizures – this means that a seizure occurs more than once and is not provoked or caused by another medical problem.

Seizures are caused by sudden surges of electrical activity in the brain. These are caused by complex chemical changes in cells that affect how messages travel through the brain.

Can you tell me more about what happens in the brain during a seizure?

- Brain cells either excite (start) or inhibit (stop) other brain cells from sending messages. Usually there is a balance of cells that excite and those that can stop these messages.
- When a seizure happens, there may be too much or too little activity, causing an imbalance between exciting and stopping messages. These changes can lead to surges of electrical activity that cause a seizure. This is often called a storm in the brain.

How is epilepsy diagnosed?

Epilepsy is diagnosed when:

- A person has had two or more unprovoked or reflex seizures more than 24 hours apart. An unprovoked seizure means it is not caused by another health problem. A reflex seizure is one that may be triggered by a specific stimulus like flashing lights.
- A person has had at least one unprovoked seizure but is at 60% risk for more.
- A person has been diagnosed with an epilepsy syndrome. An epilepsy syndrome is another way of describing seizures – it includes other features such as age when it started, associated problems, and outlook.

What Causes Focal Seizures?

About 1 out of 3 people with focal seizures may have a genetic cause. Some people may have other problems that causes scarring or injury to the brain. This may make a person more likely to have seizures. Some cause of focal seizures include:

- Head trauma from a fall, an accident, or a severe blow to the head.
- Serious infections of the brain, like encephalitis or meningitis.
- Mass or tumor in the brain.
- Malformations or changes in the way the brain was formed at birth.
- Autism spectrum disorder.
- Other neurological problems such as Alzheimer's disease, multiple sclerosis or other conditions that affect the structure of the brain.
- Arteriosclerosis (hardening of the arteries) or any event that deprives the brain of blood or oxygen.

Seizure Types

There are many different types of seizures. People may have just one type or more than one.

- Seizures caused by epilepsy are often unpredictable. You may not know when they will happen.
- They are also stereotypic. This means that a specific type of seizure will look similar or the same each time it happens in a person.

“NEW” CLASSIFICATION OF SEIZURE TYPES BASIC VERSION ¹

FOCAL ONSET	GENERALIZED ONSET	UNKNOWN ONSET ²
Aware Impaired Awareness	Impaired Awareness	
MOTOR NON-MOTOR <i>Focal to bilateral tonic-clonic</i>	MOTOR <i>Tonic-clonic</i> <i>Other motor</i> NON-MOTOR <i>Absence</i>	MOTOR <i>Tonic-clonic</i> <i>Other motor</i> NON-MOTOR <i>Absence</i>

The International League Against Epilepsy^[1] has published new terms to describe seizures. Seizures are divided into 3 major groups, depending on where they start.

Focal Onset Seizures - These start in one or more areas of the brain, or in a network or group of cells on one side of the brain. The symptoms of a focal seizure affect

¹ Fisher, RS et al. (2017) Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology. *Epilepsia*, 58(4):522-530. doi# 10.1111/13670 <https://www.ncbi.nlm.nih.gov/pubmed/28276060>

² Due to inadequate information or inability to place in other categories

whatever activity or behavior those areas control. These seizures used to be called partial seizures.

- Focal seizures can also be described by how they affect a person's awareness, movement, and other symptoms.
- Behaviors that happen at the beginning of a seizure, like a funny feeling, taste, or dizziness, may be called an aura. It's actually the first sign of a focal seizure.
- The seizure activity may stay in one area, or spread to both sides of the brain. This is called a focal to bilateral seizure.

Generalized Onset Seizures - These affect large groups of cells on both sides of the brain or the whole brain at once. A person's awareness is affected in all types of generalized seizures. They can cause seizures that look like staring, convulsions, falls, muscle spasms, or jerking to name a few.

Unknown Onset Seizures - Many times we don't know where a seizure begins. This may happen if a seizure has not been seen by someone else or it has happened at night. Or maybe the person has not had testing to find out where the seizure starts. The Unknown Onset term would be used at these times until more information is known about the seizures.



I was talking to a neighbor when my seizure began as it always does, with a feeling of terror, then a feeling of déjà vu. I felt we'd had the conversation before and I knew what he was going to say. But suddenly I couldn't understand anything he was saying. It was like a foreign language. I tried to answer but nothing but gibberish came out. I finally went inside my house and the seizure ended after a few minutes.

Focal seizures can be described in a few different ways.

- The easiest way is if seizures affect a person's awareness of themselves and their surroundings.
- Or they can be described by whether movement or motor symptoms occur.
- More detailed ways of describing seizures may include other symptoms that happen during a seizure.

Focal or partial seizures used to be called simple partial or complex partial. The main difference between them is whether people remain fully aware or have a change in awareness during the event.

Focal Aware Seizures (simple partial)

Focal aware seizure is the new term used to describe seizures when a person is awake and aware of who they are and their surroundings. They may not be able to talk or respond during the seizure if language is affected.

This type used to be called a simple partial seizure.

Focal Impaired Awareness Seizures (complex partial)

Focal seizures that affect a person's awareness used to be called complex partial seizures. During this type of seizure, a person may look and act normally, but are not aware of their surroundings or what they are doing. They may have control of their movements, speech, or actions, but look confused or not remember what happens.

Some people describe feeling that they are in a dream or trance like state. A person may be able to speak but what they say may not make sense.

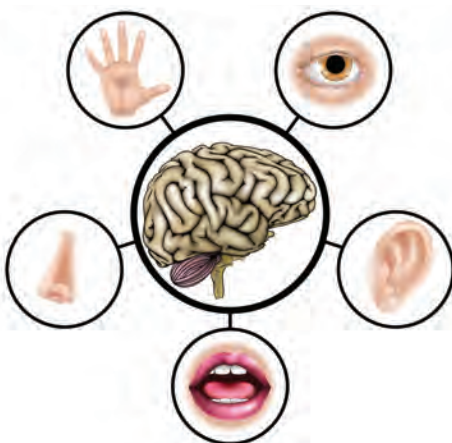
Although these seizures may start in different areas of the brain, they usually start in an area called the temporal or frontal lobe of the brain. Because of this, the condition is sometimes called “temporal lobe epilepsy” or “frontal lobe epilepsy.” “Psychomotor epilepsy” is an older term used to describe some types of focal seizures.

Seizures can be described by movements or other features

Any focal seizure can involve one or more different symptoms. The terms used below can be used to describe the seizures in as much detail as you want. Or you can just use the term Focal Motor or Focal Non-motor Seizure.

Motor symptoms may include:

- Jerking of an arm, leg, or both (clonic).
- Short muscle twitching of a group of muscles or body part (myoclonic).
- Sudden weakness or loss of muscle tone (atonic).
- Stiff or rigid muscles (tonic).
- Repeated automatic movements such as clapping, rubbing of hands, licking lips, chewing, or running (automatisms).



More about Motor Seizures

Uncontrolled movements can occur in just about any part of the body.

Eyes may move from side to side; there may be blinking, unusual movements of the tongue, twitching of the face.

Some focal seizures start out with shaking of a hand or foot which then spreads to involve an arm or a leg or even one whole side of the body. Some people, although fully aware of what's going on, find they can't speak or move on their own until the seizure is over.

A focal motor seizure may also have other things too. Yet if the main symptom is a change in movement, then the term focal motor can be used.

“ I was working in a television station, looking at a weather map, when I suddenly smelled a strange odor and there, in the middle of the map, was a vision of my brother driving a tractor on the farm. The vision suddenly faded, the odor got worse and I felt sick. I couldn't speak or respond at all until about eight minutes later. ”



Non-Motor symptoms happen in seizures that have little to no movement. These may include:

- **Autonomic** - changes in heart rate, palpitations, breathing faster or slower than usual, stomach aches, nausea, vomiting, skin color looks flushed or pale, or sweating.
- **Behavior arrest** - movement or language stops or is absent.

- **Cognitive symptoms** - these can include a variety of changes such as:
 - Problems with thinking, taking action, paying attention, remembering, understanding, talking or using numbers.
 - Unusual experiences such as déjà vu, jamais vu, objects looking larger or smaller than they really are.
 - Seeing, tasting or hearing things that are not happening (hallucinations) or things may look or be perceived differently than they are (illusions).
- **Emotional symptoms** - feeling of fear or something terrible is about to happen, worry or anxiety, agitation, irritability or anger, crying, laughing, or pleasure.
- **Sensory symptoms** - tingling, numbness, pain, hot or cold feelings, and changes in tastes, hearing, smells or vision.

More about Non-Motor Seizures

These focal seizures may have one type of symptom or they can include many different symptoms. For example, one seizure can include cognitive, emotional, or sensory symptoms.

On the other hand, a seizure may have just one symptom. New places and events may seem familiar as if they've happened before - a feeling called *déjà vu*. Sudden uncontrolled bursts of laughter or crying can be a seizure.

If they have one main symptom, you can describe the seizure using that type of symptom.

- A seizure with only numbness or tingling would be called a focal sensory seizure.
- A seizure with staring and unable to talk would be called a focal behavior arrest seizure.

In many ways, our usual, comfortable sense of familiar things and places may be disrupted by a focal or simple partial seizure. Well-known places may suddenly look unfamiliar.

Putting it all together - Focal Impaired Awareness Seizures

Regardless of other symptoms, just describing seizures in relation to a person's awareness gives a lot of information. Typically, during a focal seizure with change in awareness, a person has a blank stare and is not fully aware of their surroundings. Automatic movements, called automatisms, may be seen - such as chewing movements, lip smacking, picking at or fumbling with clothing, mumbling, or performing simple, purposeless movements over and over again.

“

When I have a seizure, I have been told I stare at my left hand. I just start rolling my left hand over and staring at it. And I play with my buttons. That's kind of weird when you've got a t-shirt on and you're picking at your buttons, but that's one of the things I do.

”



“

When I have a seizure there's an odor I smell and then I have blank periods where I will start out in one room and I'll end up in another room and I won't know why I was there. Or I'll blank out and keep on doing whatever I was doing but I won't know what's going on at that time.

”



Sometimes people wander during this type of seizure. For example, a person might leave a room, go downstairs, or walk into the street, completely unaware of what he or she was doing.

Occasionally, someone might try to dress or undress during a seizure, have flailing movements with their arms, or bicycling movements with their legs.

Changes in mood can lead to unusual movements too though a person may not recall the feeling afterward. For example, a sudden feeling of fear or terror can lead a person to run or cry out.



“When I have a seizure I only know what my husband has told me. My eyes widen. Then I sniff. Then I hug myself and always start to pick at my clothes or try to straighten them out. And then as I’m slowly coming out of the seizure, sometimes I get up and begin to walk. I’ll start talking to the people around me. I’ll say things like, “Please, please.” I’ll say, “I’m sorry, I’m sorry,” over and over again and just try to walk forever. But this is something I never know. I’ve just been told by people around me.”

People's actions and movements are typically unorganized, confused, and unfocused during a focal seizure. Yet, if a seizure begins while someone is in the middle of a repetitive action – like dealing cards, or stirring a cup of coffee – he or she may stare for a moment then continue what they were doing.

Dealing With Other People

Because someone having this type of focal seizure is unaware of what's going on around them, they may not be able to talk normally during the event. Usually they can't follow instructions or obey police commands. They may not even recognize danger from heat, water, fire, heights or other threatening situations. However, some people may be able to follow simple requests made in a calm, friendly voice.



When I have a seizure I stare and my speech is slurred. I also sit down. I've sat down in the middle of hallways at work, or sat down leaning against the wall. On one occasion I got up from the table and sat down in the middle of the floor in a restaurant.

Things To Remember

Although focal seizures affect different physical, emotional, or sensory functions of the brain, they have some things in common.



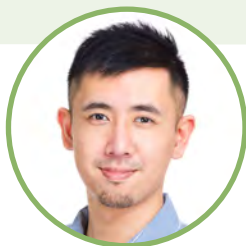
- **They last a few minutes.** Most last only a minute or two, although people may be confused and need more time afterwards to recover fully.
- **They end naturally.** Except in rare cases, the brain has its own way of bringing the seizure safely to an end after a minute or two.
- **You can't stop them.** Most people can't do anything during a seizure except wait for it to run its course and keep the person safe. In an emergency, medications can be used to bring a long, non-stop seizure to an end. If a person has a device to treat their seizures, it may help shorten or stop a seizure.

- **They are not dangerous to others.** In some cases, another person may be in danger if a person has a seizure while driving a car, using heavy equipment, or bathing an infant when alone during a seizure.
- **Stay with the person** until they are awake, able to respond and safe after a seizure.

“

One time I had a seizure in the street and a police officer grabbed hold of me and I became combative. He lost his hold and noticed that I calmed down right away. He thought this was unusual so he realized I had a medical disorder and wasn't drunk or on drugs.

”



Responding to Focal (Partial) Seizures

Most focal seizures don't require any special response except to recognize what's happening and be supportive until the seizure is over.

- Reassure others. Stay with the person until they are awake and aware. Explain that any change in behavior is temporary and that it will end in a few minutes.
- Remove hazards from the area.
- Guide gently away from anything that could be dangerous, like an open fire or a busy street.
- Don't restrain the person unless they are in immediate danger, especially if they are already agitated or confused.
- Be reassuring and helpful as awareness returns. Remember that people may get back their ability to hear and understand before they are able to speak again.

Possible after effects of a seizure include: feeling tired or sleepy, confused,

anxious or depressed, agitated or irritable, weak, or headaches.

- Most focal seizures only last a few minutes.
- People may feel confused after the seizure. Longer periods of confusion may mean that seizure activity is continuing and the person needs medical help.

“During a seizure I’m not aware of anything. Following the seizure I have a kind of anxious feeling. It’s a sense that I know I’m there and I know things are all right but I can’t quite put it together. It’s very helpful if people who are around are reassuring, tell me what happened, where I am. It makes me feel better.”

Treating Focal Seizures

Focal or partial seizures are first treated with medications. If medicines don’t work, other treatments like surgery, devices, or diets may be helpful.

Medication.

Several drugs are used to treat seizures. Most often, one drug is used at a time. Sometimes more than one drug is needed.



Medications for epilepsy are designed to prevent seizures. It does not cure the epilepsy.

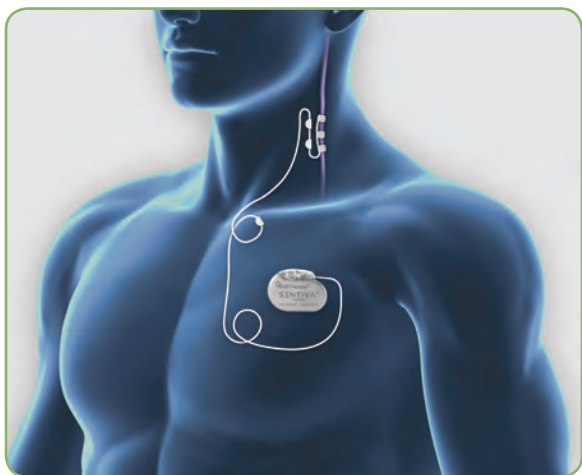
To work properly, medicine has to be taken every day, on time, and as prescribed. Stopping the medicine suddenly for any reason may cause more frequent or serious seizures.

Sometimes seizures continue even though the medication is being taken exactly as prescribed.

Focal seizures, unfortunately, are often more difficult to control with medication than other types of epilepsy. When two or three medicines fail to control seizures, a person should be referred to an epilepsy specialist or center for further evaluation and other treatment options.

Surgery. The most common form of surgery for focal seizures is called resective surgery. An area of the brain where the seizures begin can sometimes be removed. Focal seizures stop completely in about 6 out of 10 people after surgery. In other people, seizures may be less severe or happen less often. Sometimes, surgery doesn't help at all. Medicine may be needed to help control seizures after surgery. People who are seizure free after surgery may eventually stop medicines.

Vagus nerve stimulation. Another type of treatment, called VNS Therapy[®], works by stimulating a nerve going to the brain (called the vagus nerve). The stimulation helps to stop or lessen seizure activity in the brain.



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First, a procedure is done to place a small device under the skin on the upper left side of the chest. The generator is connected by electrodes under the skin to the vagus nerve in the left side of the neck.

The device is programmed to send regular, small pulses of energy to the nerve

One form of the VNS can also send stimulation to the brain when a person's heart rate increases above a certain point. This can help stop seizures when a person's heart rate speeds up during an event. While VNS may not control seizures completely, there's a good chance that about 1 out of 2 people with VNS will have fewer seizures over time.

Responsive neurostimulation.

The RNS[®] System by Neuropace is a device that can detect seizure activity directly from the brain and give bursts of stimulation to stop it. This system is used for people when medicines don't work and when surgery to remove a seizure focus is not possible. Placing the RNS requires surgery to put small wires or leads on the surface of the brain. A small battery powered device is then placed in the bone covering the brain. The device is programmed by the doctor to give brief pulses of stimulation to the brain and stop the seizure activity. The RNS



*Brain-responsive neurostimulation with the RNS System
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does not cure epilepsy, but may lessen the number of seizures in some people by 50 to 70%.

Dietary Therapy: Certain kinds of dietary therapies may help control seizures for some people. Diets used for epilepsy include the ketogenic, modified Atkins, or low glycemic index diet. A strict ketogenic diet may be hard for adults to stay on, but can be very helpful. The other diets are easier to use and can help control seizures in some adults when medicines don't.

New Therapies: New ways of treating seizures are being tested. People who continue to have seizures may be able to try one of these new treatments. For more information, visit epilepsy.com and learn about clinical trials and new therapies. (epilepsy.com/overview-clinical-trials)

Living With Focal Seizures

As we've seen, focal seizures take many forms and medical treatment does not always control them. People who live with frequent seizures may face many challenges. One involves personal safety.

Things like fire, heat, water, heights, certain machinery, and sharp objects are all potential hazards when people are unaware of what they're doing and don't feel pain.

There may be ways to reduce obvious risks. Talk with your health care team about your type of seizures. Discuss any safety risks and develop a plan to avoid hazards, lessen your risk for seizures, and stay safe.

"I had a bad automobile accident five years ago. I was in a coma for three weeks. A few months later the seizures started. I'd go to bed at night and wake up standing in the middle of the street, in my pajamas. I know my neighbors don't understand."

Although some risks can be limited, others are accepted by people with focal seizures as part of living a normal life.

Every day, people living with this type of epilepsy go to work, take care of their children, take part in sports, ride buses, cross busy streets, go on escalators, wait for trains, and – perhaps most difficult of all – risk having a seizure in front of a public that too often does not understand.

Dealing with the reactions of others may be the biggest challenge of all for people with focal seizures. That's because many people find it hard to believe or accept that the behaviors were due to seizure activity.

Lack of public understanding has led to people with focal seizures being unfairly arrested as drunk or disorderly, indecent exposure, or other unlawful activity.

These can also be misdiagnosed as signs of emotional problems or drug abuse, leading to inappropriate treatment and, in some cases, involuntary psychiatric hospitalization.

Can Someone Die From a Seizure?

Most people with epilepsy live a full and healthy life. However, you should be aware that people can die from epilepsy.

Some people with epilepsy may lose their lives from accidents, suicide, or the underlying cause of their condition, such as brain tumors or infections.

Sometimes long or repeated seizures can lead to a seizure emergency called status epilepticus. If this goes on too long, it can be life-threatening, so it's important to prevent breakthrough seizures and long seizures.

The most common cause of early death in epilepsy is SUDEP or sudden unexpected death in epilepsy. SUDEP refers to death in a person with epilepsy that happens with no warning and without a clear cause. SUDEP is uncommon but it can happen – each year, 1 of 4,500 children and 1 of 1,000 adults die from SUDEP.

We don't know all the reasons why, but the risk of SUDEP is higher in:

- people with tonic clonic seizures
- seizures at night
- people with developmental disabilities
- people with poorly controlled epilepsy

People understandably may feel scared hearing about SUDEP or early death, but knowing about it helps you learn ways to prevent it. Keeping track of seizures, knowing triggers, staying healthy and safe, and taking medicines consistently are important for everyone with epilepsy to know.



The Epilepsy Foundation and our local organizations are committed to making the public more aware of this type of epilepsy so that painful misunderstandings can be avoided. We invite you, as a reader of this pamphlet, to share it with others and to join us in our campaign to improve public awareness of focal seizures. Learn more at www.epilepsy.com

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About the Epilepsy Foundation

The Epilepsy Foundation, a national nonprofit with more than 50 local organizations throughout the U.S., has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is: to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. **For additional information, please visit www.epilepsy.com.**



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