Epilepsy Foundation

Traumatic Brain Injury and Epilepsy

Important Information for Service Members, Veterans and Families

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THE EPILEPSY FOUNDATION

What is the Epilepsy Foundation?
The Epilepsy Foundation is the national agency dedicated to the well-being of the more than 3 million people with epilepsy in the United States and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, people with epilepsy throughout the United States are served by more than 50 Epilepsy Foundation affiliates.

Who Runs the Foundation?
The Foundation is governed by a board of directors made up of business leaders, health care professionals and client representatives, with the advice and counsel of a professional advisory board of more than 60 members who are among the world’s leading epilepsy physicians and health experts.

How is the Foundation Funded?
The Epilepsy Foundation is funded through individual donations from the general public, and receives support from the federal government, foundations and private industry. The organization participates in the Combined Federal Campaign and is a member of the National Health Council and the International Bureau for Epilepsy.

What Kind of Programs and Services Does It Offer?
Some of the Foundation’s national programs include:

- Veterans Outreach Program
- Jeanne A. Carpenter Epilepsy Legal Defense Fund
- Epilepsy Gene Discovery Project
- Helping Other People with Epilepsy (H.O.P.E.) Mentoring Program
- Career Support Center
- Public Policy Institute
- Hispanic Outreach Program
- Senior Initiative
- Research Grants Program

The Foundation Provides These Services in Local Communities:

- Information and referral
- School alerts
- Counseling
- Community education
- Patient and family advocacy
- Support groups


Learn about Epilepsy
This guide has useful information on the relationship of traumatic brain injury (TBI) and post-traumatic epilepsy (PTE) for veterans and their families. Read on to learn more about:

- Traumatic Brain Injury (TBI)
- Post-Traumatic Epilepsy (PTE)
- Seizures
- Diagnosis and treatment
- Seizure first aid
- Living with epilepsy

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TBI IN THE MILITARY
Personnel with wartime injuries have a higher incidence of missile wounds and blast injuries, both of which may cause severe impairments.

- Between 50 and 80 percent of all TBIs are due to blast injuries sustained during combat.
- Penetrative wounds have historically been more likely to lead to PTE.
- The likelihood of PTE increases with severity of injury.

PTE in the Military
PTE is a seizure disorder that is caused by a TBI. It is most likely to occur after an open or penetrating wound to the head, but sometimes it can follow a closed head injury. PTE is also often associated with:

- Skull fractures
- Subdural hematomas (accumulation of blood between the brain and the skull, caused by a ruptured blood vessel)
• Intracranial hematomas/hemorrhages
• Brain contusion (bruise)

In the general population the risk of PTE increases with the severity of the TBI:
• **Mild TBI:** 1.3 times as likely to develop PTE
• **Moderate TBI:** 2.9 times as likely to develop PTE
• **Severe TBI:** 17.2 times as likely to develop PTE

**Incidence of PTE in the Military**
• 1.64 million Soldiers have served in Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF)
• 320,000 of these Soldiers (19.5 percent) will experience TBI
• Between 15-34 percent of TBI patients have PTE, and active-duty military rates can be as high as 53 percent
• Therefore, between 48,000-169,600 Soldiers serving in OIF/OEF are expected to develop PTE.

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**WHAT IS EPILEPSY?**
Epilepsy is a medical condition that produces seizures that affect a variety of mental and physical functions. When a person has two or more seizures, they are considered to have epilepsy.

**What is a Seizure?**
A seizure happens when a brief, strong rush of electrical activity affects part or all of the brain. Seizures can last from a few seconds to a few minutes. They can have many symptoms, from convulsions (jerky muscle contractions) and loss of consciousness to some that are not always recognized as seizures, like blank staring or lip-smacking.

**What is Post-Traumatic Epilepsy?**
PTE is a seizure disorder that is caused by a TBI. It is most likely to occur after an open or penetrating wound to the head, but sometimes it can follow a closed head injury.

*The incidence of PTE is highest in the military as soldiers are at a higher risk for TBI than the general population.*

**Epilepsy vs. Seizures**
Seizures are characterized by a sudden change in movement, behavior, sensation or consciousness produced by an abnormal electrical discharge in the brain. Epilepsy is a condition of spontaneously recurring seizures. Having a single seizure does not necessarily mean a person has epilepsy. High fever, severe head injury, lack of oxygen – a number of factors can cause a single seizure.
Epilepsy, on the other hand, tends to be a lifelong condition that affects how electrical energy and connections behave in the brain.

**Types of Seizures**
There are many different types of seizures. People may experience just one type or more than one. The kind of seizure a person has depends on which part and how much of the brain is affected by the electrical disturbance that produces seizures.
Nonepileptic Seizures
Nonepileptic seizures briefly change a person’s behavior and often look like epileptic seizures. The person having nonepileptic seizures may feel like they are having an epileptic seizure.

Partial Seizures
Partial seizures produce electrical disturbances that originate in one region of the brain. Partial seizures are subdivided into simple partial seizures, complex partial seizures, and partial seizures with secondary generalization.

- **Simple partial seizure:** People who have simple partial seizures do not lose consciousness during the seizure. Sometimes they can talk quite normally to other people during the seizure and they can usually remember exactly what happened to them while it was going on.

- **Complex partial seizure:** During a complex partial seizure, a person typically cannot interact normally with other people, has limited or no control of his or her movements, speech or actions, doesn’t know what he or she is doing, and cannot remember afterward what happened during the seizure.

- **Partial seizures with secondary generalization:** These particular seizures present symptoms that are initially associated with a preservation of consciousness that then evolves into a loss of consciousness and convulsions.

Partial seizures are the most common type of seizure experienced by people with epilepsy. Almost any movement, sensory or emotional symptom can occur as part of a partial seizure, including visual or auditory hallucinations.

Status Epilepticus
Status Epilepticus is a term describing a state of continuous seizure activity. Most seizures last less than four to five minutes but any seizure that goes on for five minutes or longer is operationally considered as status epilepticus.

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DIAGNOSING EPILEPSY

**Special Consideration for the Military:** Military personnel may underreport mild TBI to avoid removal from combat situations or active duty and therefore may automatically be underdiagnosed. Also, limited time and resources available at forward medical commands can prohibit thorough TBI evaluation, which results in Service members returning to duty with symptoms of undiagnosed TBI. Diagnosing epilepsy is a multi-step process, usually involving the following evaluations:

- **Confirming** through patient history, neurological exams and supporting blood and other clinical tests – that the patient has epileptic seizures and not some other type of episode, such as fainting, transient ischemic attacks, hypoglycemia or nonepileptic seizures.

- **Identifying** the type of seizure involved.

- **Performing** a clinical evaluation in search of the cause of the epilepsy.

- **Selecting** the most appropriate therapy based on all previous findings.

Doctor’s Investigation
If you’ve had a seizure, your doctor will investigate to answer these questions:

- Was the seizure caused by a short-term problem (like fever or infection) that can be corrected?
- Was it caused by a continuing problem in the way your brain’s electrical system works?
- Is there anything about the structure of your brain that could cause seizures?
- Was the seizure an isolated event, or does it mean that you have epilepsy?

Diagnostic Methods and Tools
The doctor’s main tool in diagnosing epilepsy is a careful medical history with as much information as possible about what the seizures look like and what happened just before they began. The doctor will also perform a thorough physical examination, especially of the nervous system.

Other Diagnostic Tools:

- An electroencephalograph (EEG) is a machine that records brain waves picked up by tiny wires taped to the head. Electrical signals from brain cells are recorded as wavy lines by the machine. Brain waves during or between seizures may show special patterns that can help the doctor decide whether or not someone has epilepsy, or is at risk for epileptic seizures. A normal baseline EEG does not rule out the possibility of an underlying epileptic disorder.
- Imaging methods such as computerized tomography (CT) or magnetic resonance imaging (MRI) scans may be used to search for any growths, scars, or other physical conditions in the brain that may be causing the seizures.
- There are numerous other tests that can be performed to analyze the area of the brain causing seizures, but most of these are only done when a patient is being evaluated for possible epilepsy surgery.

Which tests and how many are ordered vary, depending on how much each test reveals.

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TREATMENT
Treating epilepsy involves many different people. The team may include your primary care doctor, nurse, psychologist or social worker, and specialists such as a neurologist. You may want to bring along a family member or friend to help describe your seizures or to take notes during visits to your doctor.

Once the doctor has made a diagnosis of seizures or epilepsy, the next step is to select the best form of treatment. If epilepsy – that is, a continuing tendency to have seizures – is diagnosed, the doctor will usually prescribe regular use of seizure-preventing drugs.

If drugs are not successful, other methods are considered, including surgery, a special diet or vagus nerve stimulation (VNS). The goal of all epilepsy treatment is to prevent further seizures, avoid side effects, and make it possible for people to lead active lives.

Types of Treatment
Medication
Medications do not cure epilepsy but, for many, the medication will prevent seizures as long as they are taken regularly. Most epilepsy medicines are taken by mouth. The doctor’s and patient’s choice of which drug to consider depends on what kind of seizure a person is having. Other factors include patient’s age, other medications, other medical problems, allergies and potential
side effects of the medication. Some people experience side effects, while others may not. It may take some time to find exactly the right dose of the right drug.

It is reported that antiepileptic drugs provide complete control for more than half of all patients with epilepsy, and significantly reduce the number of seizures in another 20-30 percent. The remaining 20 percent do not respond to current medications and must look at other treatment options.

**Surgery**

When antiepileptic drugs fail to control or substantially reduce seizures, brain surgery may be considered. Surgical removal of seizure-producing areas of the brain has been an accepted form of treatment for more than 50 years.

Some seizure medications may have to be continued, usually for a year or two. Then, if no further seizures occur, the medicine may be slowly withdrawn. At this point, chances of living free of seizures and free of medication are good. However, many people will have to continue with medication and some do not benefit significantly from surgery.

**Vagus Nerve Stimulation (VNS)**

VNS is a type of treatment in which short bursts of electrical energy are directed into the brain via the vagus nerve, a large nerve in the neck which connects to the brainstem. The energy comes from a battery, about the size of a silver dollar, which is surgically implanted under the skin, usually on the left side of the chest.

Although complete seizure control is rarely achieved, the majority of people who use VNS therapy experience fewer seizures. In some, its effectiveness increases with time, and patients report an improved quality of life. It will almost always be necessary to continue antiepileptic medication, although the patient could be on less medication than before.

**FIRST AID**

**Convulsive Seizures**

When providing seizure first aid for generalized tonic-clonic (grand mal) seizures or partial seizures with secondary generalization, these are the key things to remember:

- Keep calm and reassure other people who may be nearby.
- Don’t hold the person down or try to stop his/her movements.
- Time the seizure.
- Clear the area around the person of anything hard or sharp.
- Loosen ties or anything around the person’s neck that may make breathing difficult.
- Put something flat and soft, like a folded jacket, under the person’s head.
- Turn him/her gently onto one side. This will help keep his or her airway clear.
- Do not try to force his or her mouth open with any hard implement or with fingers. A person having a seizure CANNOT swallow his or her tongue. Efforts to hold the tongue down can injure teeth or the jaw.
- Don’t attempt artificial respiration except in the unlikely event that a person does not start breathing again after the seizure has stopped.
- Stay with the person until the seizure ends naturally.
- Be friendly and reassuring as consciousness returns.
- Offer to call a taxi, friend or relative to help the person get home if he or she seems confused or unable to get home by himself.
An uncomplicated generalized tonic-clonic (grand mal) seizure in someone who has epilepsy is not a medical emergency, even though it looks like one. It stops naturally after a few minutes without ill effects. The average person is able to continue about his/her business after a rest period, and may need only limited assistance or no assistance at all in getting home. In other circumstances, an ambulance might need to be called.

When to Seek Emergency Treatment
If repeated seizures occur, or if a single seizure lasts longer than five minutes, the person should be taken to a medical facility immediately. Prolonged or repeated seizures are known as status epilepticus (nonstop seizures) and require emergency medical treatment.

Nonconvulsive Seizures
You don’t have to do anything if a person has brief periods of staring or shaking, unless they are nonstop. If someone has the kind of seizure that produces a dazed state and automatic behavior (behavior performed without conscious knowledge or under conscious control), the best thing to do is:
- Watch the person carefully and explain to others what is happening.
- Speak quietly and calmly in a friendly way.
- Gently guide the person away from any danger, such as a steep flight of steps, a busy highway or a hot stove. However, don’t grab the person, or try to move them forcefully unless some immediate danger threatens.
- Stay with the person until they are fully conscious again and you can offer to help them get home.

Head Injury During a Seizure
If the person hits his or her head while falling, his or her post-seizure condition should be carefully monitored. Although sleepiness and confusion are normal postictal (post-seizure) problems, it should always be possible to wake the person without difficulty after a few minutes have passed. A person who fails to return to consciousness after a seizure needs further medical assessment. If a head injury is a possibility, the person should be closely observed for:
- Difficulty in maintaining consciousness
- Vomiting
- Vision problems
- Excessive sleepiness two or more hours after the seizure
Immediate medical attention is required if any of the above signs are observed, or if the patient has:
- A persistent headache after a rest period
- Unconsciousness with failure to respond
- Unequal pupil size or excessively dilated pupils
- Uncharacteristically weak limbs
- Concern that they have suffered a cervical spine (neck) injury

When to Call an Ambulance
An ambulance should be called if:
- The seizure happened in water.
• The person is not wearing any medical ID, and there is no way of knowing whether or not
  the seizure is caused by epilepsy.
• The person is pregnant, injured or diabetic.
• The seizure continues for more than five minutes.
• A second seizure starts shortly after the first has ended.
• Consciousness does not start to return after the shaking/convulsing has stopped.

If the ambulance arrives after the person’s consciousness has returned, the person should be
asked whether the seizure was associated with epilepsy and whether emergency care is needed.

Safety Tips
These safety tips should reduce the chance of injury during a seizure:
• In the bathtub/shower, consider using a seat with a safety strap.
• When showering, set the water temperature low so you won’t be scalded if you lose
  consciousness while the water is running.
• Carpet the floors with heavy pile and thick under-padding.
• Pad sharp corners of tables and other furniture.
• Use plastic dishes and cups with lids to prevent cuts or burns from spills.
• When you use the stove, use the back burners.
• Wear rubber gloves when handling knives or washing dishes and glassware in the sink.
• Stand back from the road when waiting for a bus and stand back from the platform edge
  when taking the subway or train.
• Wear a life vest when you are on or close to water.

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EMPLOYMENT
Today, people with epilepsy are working at thousands of different kinds of jobs. While most of
these people have excellent seizure control, not all of them do. Having occasional (or even fairly
frequent) seizures may make your job hunt more difficult, but not impossible.

People with epilepsy can face significant challenges in the workplace, and there are many efforts
to increase employment of people with epilepsy and their success rates in the workplace. The
Americans with Disabilities Act (ADA) and the Americans with Disabilities Act Amendments
Act (ADAAA) were enacted to prohibit disability-based discrimination, including discrimination
by employers or potential employers. These laws have particular impact on people with epilepsy
who face issues like safety-sensitive jobs and reasonable accommodation.

Military Service
Although there are many laws now that protect individuals with disabilities, the armed services
are not required to follow them. The military is exempt from the mandates of non-discrimination
imposed by the civil rights laws of the federal government. Department of Defense (DoD)
requires readiness for worldwide service at any time, with few limitations. Assignments may be
made to areas where medical facilities are nonexistent or inadequately equipped to treat specific
disorders. Although there are provisions for retaining members who develop a medical condition
that prohibits them from being assigned to such areas, the size of this population must be kept as
small as possible to prevent an inability to deploy personnel in the event of a military emergency.

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COMPENSATION AND BENEFITS FOR SERVICE MEMBERS AND VETERANS

Health Care Benefits: TRICARE

TRICARE is the health care program serving active-duty Service members, National Guard and Reserve members, retirees, their families, survivors and certain former spouses worldwide. To be eligible for TRICARE benefits, you must be registered in the Defense Enrollment Eligibility Reporting System (DEERS). The benefits you are entitled to and how you access them will depend upon your status as an active-duty, National Guard, Reserve, or retired Service member. If you are separated, but not retired, you may still be entitled to some TRICARE benefits. It is important that you speak with your regional managed care contractor or MTF TRICARE Service Center or benefit counselor for more information. Visit the TRICARE website “Plan Wizard” at www.tricare.mil/mybenefit for more information.

You may call the DEERS Support Office at 1-800-538-9552 (TTY/TTD: 1-866-363-2883) if you have questions about your eligibility status in their system. However this office cannot determine your eligibility; your unit personnel office enters that information into DEERS.

The Disability Evaluation System (DES) Process

When you suffer a wound, illness, or injury, the doctors and staff of an appropriate medical facility will treat you. For many members, this is the end of the process if they are cured of the disease or fully recover from their wound or injury. For a small number of members, a wound, illness, or injury can result in a permanent condition that may make them unfit for continued duty in their current job. If you suffer a permanent or long-lasting effect from a wound, illness, or injury, the doctor will refer you to the DES.

Generally, the steps are:
1. Evaluate Service member’s fitness for duty.
2. Authorize a return to duty for those members who are found fit.
3. Approve disability separations or retirements, to include making a benefits determination, for those Service members who are found unfit.

Pay and Allowances

Depending on the outcome of the DES, you may receive compensation from the government. Pay and allowances may include:

- Severance pay
- Temporary Disability Retirement List (TDRL) pay
- Permanent Disability Retired List (PDRL) pay
- Combat Related Special Compensation (CRSC)
- Concurrent Retirement and Disability Payments (CRDP)
- Access to special/partial/casual pays
- Basic Allowance for Subsistence (BAS)
- Pay and Allowance Continuation (PAC)
- Travel for your family
- Family Separation Allowance (FSA)
- Hardship Duty Pay Location (HDP-L)
- Hostile Fire Pay/Imminent Danger Pay (HFP/IDP)
- Combat Zone Tax Exclusion (CZTE)
- Savings Deposit Program (SDP)
Veterans Administration (VA) Benefits
VA offers a host of programs that you may be eligible for, depending on your situation. A few of the programs you might be eligible for include:

- VA Health Care
- Disability Compensation
- Pension
- Increased Compensation Based on Unemployability
- Servicemembers’ Group Life Insurance (SGLI) Traumatic Injury Protection Payment (TSGLI)
- SGLI Disability Extension
- Veterans’ Group Life Insurance (VGLI)
- Service-Disabled Veterans Insurance (S-DVI) and Supplemental S-DVI
- Veterans’ Mortgage Life Insurance (VMLI)
- VA Education Benefits
- Survivors’ and Dependents’ Educational Assistance
- Vocation and Education Counseling
- Vehicle Purchase and Adaptation
- Housing Adaptation
- Clothing Allowance

VA Vet Centers
Vet Centers offer readjustment counseling – a wide range of services provided to combat veterans in the effort to help them make smooth transitions from military to civilian life. Call these centers toll free during normal business hours at 1-800-905-4675 (Eastern) and 1-866-496-8838 (Pacific). You can locate a Vet Center near you by going to their website at http://www.vetcenter.va.gov/.

Veterans Benefits and TRICARE: The VA and TRICARE have some similar benefits, but there are some significant differences as well. It is important for you to understand your benefits under both programs to ensure you choose the health program that best meets your needs. It is highly recommended that, after checking with the VA to determine your benefit eligibility, you also check with TRICARE. You can go to TRICARE.mil and create your own profile to tailor information about your specific benefit needs.

A complete Wounded, Ill and Injured Compensation and Benefits Handbook is available for download at:

Social Security Benefits
Military Service members can receive expedited processing of disability claims from Social Security. Benefits available through Social Security are different than those from VA and require a separate application. Social Security pays disability benefits through two programs:

- The Social Security disability insurance program, which pays benefits to Service members and certain family members if you are insured, meaning that you worked long enough and paid Social Security taxes.
- The Supplemental Security Income (SSI) program, which pays benefits based on financial need.
**How does military pay affect eligibility for disability benefits?** You cannot engage in substantial work activity for pay or profit – also known as substantial gainful activity – and receive disability benefits at the same time. Active-duty status and receipt of military pay does not, in itself, necessarily prevent payment of disability benefits. Receipt of military payments should never stop you from applying for disability benefits from Social Security. If you are receiving treatment at a military medical facility and working in a designated therapy program or on limited duty, your work activity will be evaluated to determine your eligibility for benefits. The actual work activity is the controlling factor and not the amount of pay you receive or your military duty status.

For more information:
- Visit [www.socialsecurity.gov/woundedwarriors](http://www.socialsecurity.gov/woundedwarriors).
- Go to your nearest Social Security office.
- Call 1-800-772-1213 (TTY 1-800-325-0778).

**HELPFUL RESOURCES**

**The Epilepsy Foundation**
The Epilepsy Foundation’s website provides detailed information on epilepsy, living with epilepsy, epilepsy research and epilepsy advocacy. Valuable information on specific medications is available as well as a tool to find a medical professional who specializes in epilepsy treatment. Sign up to receive their eNewsletter or join one of the eCommunities interest groups at: [www.epilepsyfoundation.org/ecommunities](http://www.epilepsyfoundation.org/ecommunities).

**Defense Centers of Excellence for Psychological Health and Traumatic Brain Disorder (DCoE)**
DCoE assesses, validates, oversees and facilitates prevention, resilience, identification, treatment, outreach, rehabilitation, and reintegration programs for psychological health (PH) and traumatic brain injury (TBI) to ensure the Department of Defense meets the needs of the nation’s military communities, warriors and families: [http://www.dcoe.health.mil/](http://www.dcoe.health.mil/).

**Defense and Veterans Brain Injury Center (DVBIC)**
DVBIC is specifically committed to prevent, treat, and provide education on TBI for US military members currently on active duty, National Guard and reservists recently injured in the line of duty, their dependents and retired military personnel: [http://www.dvbic.org/](http://www.dvbic.org/).

**National Resource Directory (NRD)**
Developed by DoD, the Department of Labor and VA, this website provides information and access to the full range of medical and non-medical services and resources you need to achieve personal and professional goals. You can find the directory at: [http://www.nationalresourcedirectory.org/](http://www.nationalresourcedirectory.org/).
National Association of Epilepsy Centers (NAEC): http://www.naec epilepsy.org/.
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