



A community of support
for people living with
seizure clusters



No two people will experience seizures or seizure clusters in the same way

That's why seizure clusters can be difficult to define by the people who experience them, their caregivers, and even healthcare providers. Recognizing seizure clusters is extremely important because, without treatment, they can lead to serious, long-term problems.

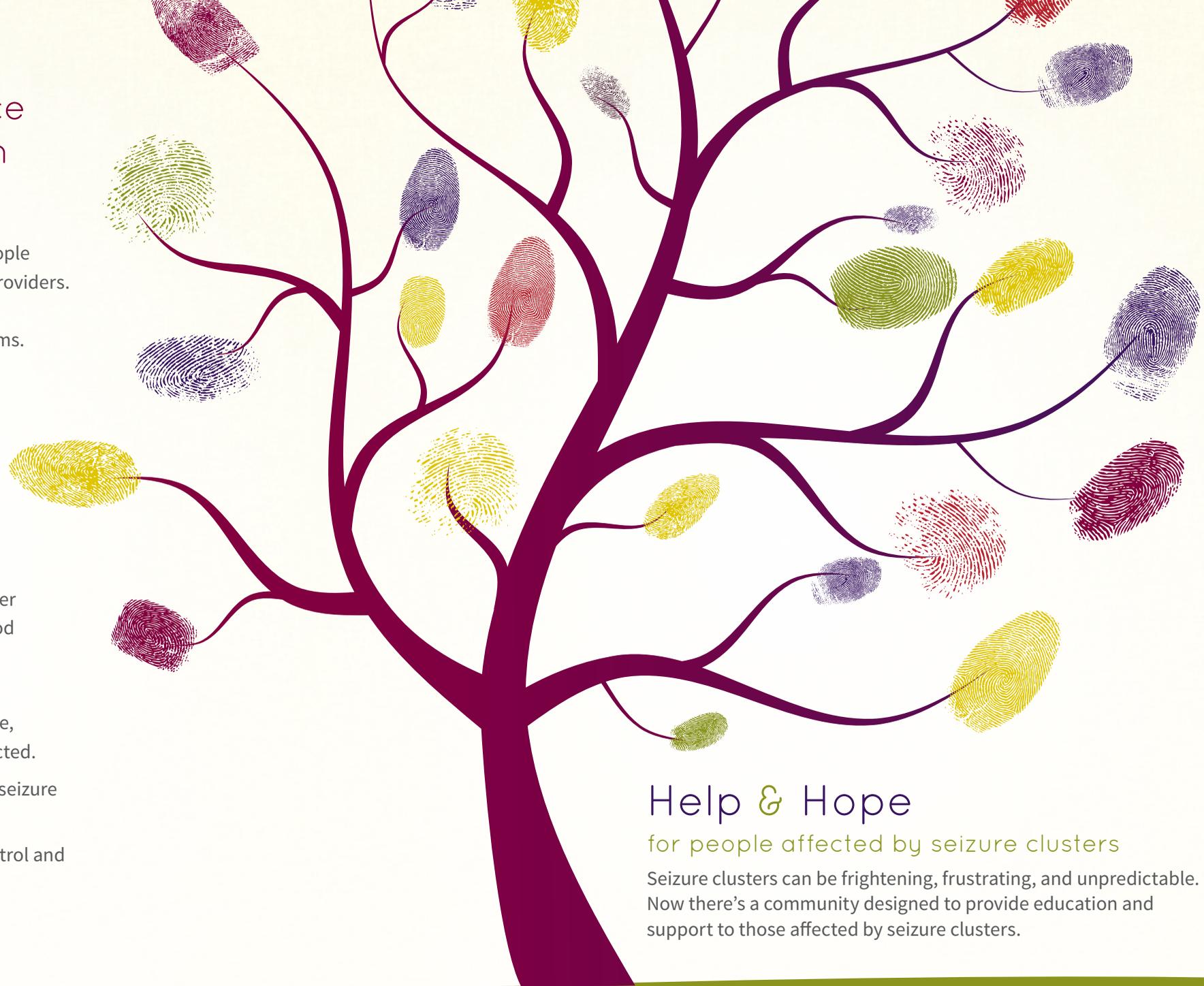
What are seizure clusters?

Seizure clusters are described as seizures that happen one after the other over a short period of time. There is a recovery period between each seizure and a pattern that is different from the usual seizure pattern.

Anyone who has epilepsy can have seizure clusters—at any age, at any time—even when taking antiepileptic medicine as directed.

This brochure has been designed to help readers understand seizure clusters and how they can find help.

For many people, being prepared helps them feel more in control and hopeful about the future.



Help & Hope

for people affected by seizure clusters

Seizure clusters can be frightening, frustrating, and unpredictable. Now there's a community designed to provide education and support to those affected by seizure clusters.



What words do people use to describe seizure clusters?

Seizure clusters are also called flurries, serial seizures, acute repetitive seizures, and bouts of increased seizure activity, among others. They all refer to seizures that happen one after the other over a short period of time.

FLURRIES
SERIAL
SEIZURES
ACUTE
REPETITIVE
SEIZURES
BOUNTS C
INCREASES
SEIZURE
ACTIVITY



“Most patients and their families have their own individual understanding of epilepsy through their own experience. Sometimes when you’re talking to them and say, ‘It sounds like you’re having clusters of seizures.’ They say, ‘Oh, is that different?’ ”



Derek Chong, MD

Consultant, New York, NY

Assistant Professor of Clinical Neurology

Director of Clinical Trials, Epilepsy and Sleep Program

Columbia University Medical Center

“Every time a patient has a seizure, the threshold for the next seizure is lower. When the brain ‘fires’ and keeps on firing, it’s a lot easier for the next seizure to fire off. So you have to stop the firing to prevent status epilepticus.”



Wendy Mitchell, MD
*Professor of Clinical Neurology
Children’s Hospital of Los Angeles*

Who has seizure clusters?

Anyone who has epilepsy can have seizure clusters—at any age, at any time—even when taking antiepileptic medicine as directed. However, there are some people who may be at higher risk for seizure clusters. They are people who:

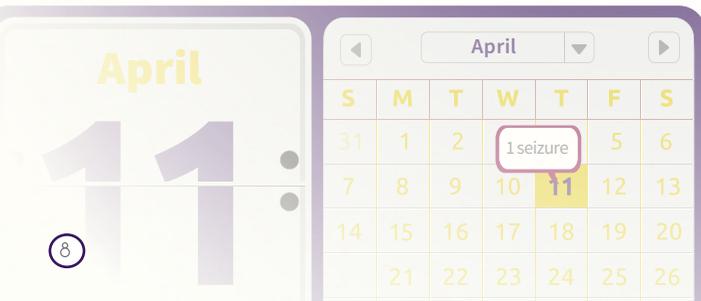
- **Have seizures that are not well controlled by medicine**
- **Have had head trauma resulting in loss of consciousness**
- **Have extratemporal epilepsy.** In this type of epilepsy, the seizures start outside of the temporal lobes of the brain
- **Have a type of epilepsy that is caused by a past problem, such as a brain injury, infection, or tumor**



152,000
people

in the United States were
estimated to be affected
by seizure clusters





How will I know if I've been having seizure clusters?

Keeping track of seizures is an important part of your epilepsy care. This record of seizure activity also can help you and your healthcare professional know if you have experienced seizure clusters. Your healthcare professional will typically look for seizures that have been described as seizures that happen one after the other over a short period of time. There is a recovery period between each seizure and a pattern that is different from the usual seizure pattern.



“Whenever we meet with a family, we try to get an understanding of the person’s seizures, including seizure frequency and what the seizures looked like.”



Lawrence Brown, MD
Associate Professor of Neurology,
Children’s Hospital of Philadelphia

There are many ways to track your seizure clusters—from seizure tracking forms and booklets to computer calendar programs and websites.

Learn more by visiting the Epilepsy Foundation at www.epilepsy.com

How can I get help for seizure clusters?

Many general physicians, internists, and neurologists treat epilepsy. Also, there are doctors called epileptologists who have special training in seizures, antiepileptic medicines, and surgery. Epileptologists may be found at hospitals, group or private practices, academic teaching hospitals, or specialized epilepsy centers. You may be able to get a referral from your primary care doctor to see an epileptologist.

What kind of information about my seizures should I share with my healthcare professional?

You and your healthcare professional can work together to determine whether or not you are experiencing seizure clusters. Information you'll want to share with your doctor includes:

- Date and time of the seizure(s)
- Start and end time of each seizure
- Start and end time of the entire episode
- Triggers that may have caused the seizure(s)
- Auras, sensations, or warning signs
- Number of seizures that occurred
- Whether or not there was a period of recovery between each seizure
- If rescue medicine was used and the results

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If rescue medicine was used and the results

Number of seizures that occurred

“I went through 4 days of clusters last week... I hate the seizures. I hate the warnings—if and when I have them. I hate the uncontrollable crying afterward...”



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Living with Epilepsy

How are seizure clusters managed?

Seizure clusters should be treated right away with what is called a “rescue medicine.” A rescue medicine is given to stop a seizure and to prevent another one from happening.

Rescue medicine can be given in a hospital setting by injecting it intravenously (into a vein). But there are medicines that can be given at home or carried with you to take when needed in an emergency.

It’s important that you and your doctor create a plan for using rescue medicine. That way, you and the people in your life will know exactly when and how to use the medicine.

Right now, the only rescue medicine approved by the FDA (US Food and Drug Administration) for use outside a hospital setting is given as a rectal gel. Currently, there are ongoing studies for rescue medicines that may be given by nasal spray or by injection.

Are seizure clusters an emergency?

Seizure clusters should be taken very seriously. Seizure clusters that are not treated and controlled may become more severe and lead to other health problems such as status epilepticus or brain injury. Status epilepticus is also a medical emergency that can be life-threatening if not treated.



How do seizure clusters affect a person's life?

Seizure clusters can have an impact on a person's health and well-being.

In fact, some people say that living with seizure clusters can influence all parts of life, including a person's ability to drive, attend school, or maintain a job. They are also said to cause **anxiety**, **worry**, **isolation**, **shame**, and feelings of being **drained**, **out of control**, and **overwhelmed**. Since seizures in a cluster start and stop many times over a short period of time, some people say they can be hard to manage.

Seizure clusters can also affect caregivers and family members who are fearful that their loved ones may be injured during a seizure or may suffer permanent brain damage.

“The impact of epilepsy is not only on the individual, it's on the entire family. We try to provide education so people can react appropriately—to do the right thing, do it safely, and hopefully have a better life.”



Jack Pellock, MD

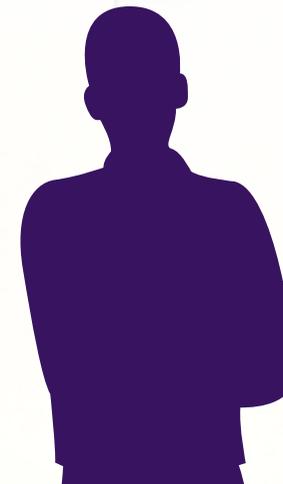
*Professor & Chair, Division of Child Neurology,
Virginia Commonwealth University*

Can a seizure care plan help?

Some people who live with seizure clusters say that having a care plan helps them feel more prepared and in control. A seizure care plan lets family, friends, coworkers, and others in the person's life know what to do when seizure clusters occur.

A seizure care plan is the plan put in place for "what to do" and "who to call" when seizure clusters happen. This helps the people in a person's life be prepared to help if seizure clusters occur. Some of the information that can be shared includes:

- ✓ Name of the person with the seizure disorder
- ✓ Notification that this person is being treated for a seizure disorder
- ✓ How to recognize a seizure emergency and how to respond
- ✓ Names and numbers of contacts such as caregiver(s) and treating physician(s) should a seizure emergency happen
- ✓ Basic seizure first aid instructions
- ✓ Instructions on how to capture seizure details such as time, date, number of seizures, length of seizure episode, description of the seizure(s), and how the person responded



"A care plan helped me feel more confident to leave the house, live life, and not just wait around for the next seizure to occur."



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Living with Epilepsy

I'm a caregiver. Where can I go for help?

The demands on caregivers of people with epilepsy or epilepsy with seizure clusters may seem overwhelming. Caregivers must remember to also take good care of themselves and not neglect their own needs.

Connecting with other caregivers is a great way to gain emotional support. There are many communities you can join. You'll find online groups, organizations that offer toll-free numbers, and even live events where you can meet with others who are facing similar challenges.

No matter how you go about finding support, it's important that you reach out to others so that you get the help and hope you need.

Where can I find support?

Here are some online resources that may be helpful to you or someone you care for.

angelwingsfoundation.net

Angel Wings Foundation's vision is to create a new housing model that will service adults with epilepsy.

epaeg.org

Epilepsy Advocacy and Employment Group (EPAEG) provides employment assistance and support to those affected by epilepsy and seizure disorders.

epilepsy.com

This is an excellent place to get reliable information about epilepsy, seizures, and treatments as well as legal affairs and community services.

mayoclinic.org

The Mayo Clinic is a world leader in developing innovative ways to diagnose and treat epilepsy in children and adults.

naec-epilepsy.org

This is the website of the National Association of Epilepsy Centers. It can help you find a comprehensive epilepsy center near you.

sturge-weber.org

The Sturge-Weber Foundation provides education, resources, tools, research updates, and community news for people who experience seizures related to Sturge-Weber syndrome.



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www.SeizureClustersConnect.com/YouTube

The Seizure Clusters Connect™ YouTube Channel features experts on the subject of seizure clusters: how to recognize them, the importance of keeping a seizure diary, the impact on families, and much more.

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And we share the goal of making life moments matter for the people who rely on us for the therapies we develop.

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