

# Carpe Diem – Seize the Day Blog

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What are cluster seizures? Are you ready to respond to cluster seizures? According to Mark Gurarie, cluster seizures are groupings of seizure attacks within a short span of time. However, there is some debate about the exact definition of this condition. There is one definition that states if you have cluster seizures if you have more than two to three seizures within a 24-hour period.

Cluster seizures arise in more difficult cases of epilepsy, a disorder that affects the electric signaling of the brain and central nervous system (CNS). Also known as acute repetitive seizures (ARS) or crescendo seizures, cluster seizures will most likely occur in those who have refractory or intractable epilepsy, a type of epilepsy for which drug therapies have not been effective.

Between 20% and 30% of people with epilepsy experience cluster seizures which can lead to hospitalizations and significantly impacting both quality of life and overall function. By nature, cluster seizures can be difficult to treat. However, there are several medications that can be utilized to stop the cluster seizures. ***Most commonly, drugs in the benzodiazepine family are prescribed as rescue medications and are used generally after the 5-minute mark of a seizure after the onset of the cluster seizure attacks.***

As previously stated, cluster seizures represent the repeated onset of seizure within a limited period of time. A majority of such cases are associated with focal seizures: those in which the electric disturbances affect only specific parts of the brain. Symptoms of these include:

- Uncontrolled muscle spasms or tightness, often one side of the face or body.
- Involuntary muscle movements.
- Muscular weakness and paralysis after the seizure.
- Residual effects based on the affected part of the brain.

Clusters attacks can also arise as generalized seizures, which implies disorders in both sides of the brain. These types of seizures cause:

- Loss of consciousness.
- Falls.
- Massive, uncontrolled muscle contractions

Cluster seizures are often considered a medical emergency, in part because of the lingering effects of the condition. Untreated, they can lead to:

- **Status epilepticus**: Sometimes life-threatening, this essentially is a prolonged seizure-state (30 or more minutes), in which the person does not fully regain consciousness between attacks. It can be “convulsive,” meaning seizure symptoms are visible, or

“nonconvulsive,” characterized by confusion, irritability, loss of consciousness, and sometimes coma.

- **Sudden unexplained death in epilepsy (SUDEP)**: In rare cases, people with epilepsy die for no discernible cause, and the rate of SUDEP is significantly higher in those who experience seizure clusters. The risk of this condition is mitigated with regular medication.<sup>3</sup>

The causes of cluster seizures, in most cases, mirror those of epilepsy in general. That said, a variety of conditions can lead to epilepsy, and the exact origins of the condition are often unclear. Epilepsy can arise due to conditions that affect the brain and blood flow, including:

- Brain tumors
- Head trauma
- Stroke
- Inflammation in the brain (encephalitis)

Notably, seizure clusters arise most often in certain cases, including:

- Intractable seizure (seizure resistant to treatment)
- High frequency of seizures after the onset of epilepsy.
- Younger age of onset of seizures<sup>1</sup>

Finally, cluster seizures can be triggered by:

- Disruption of sleep cycles.
- Fever or other illnesses.
- Missed medications or changes in dosage.
- Alcohol use.

As noted, while there is some debate about it, seizure clusters are typically defined as the Given the severity and intensity of seizure clusters, management may involve everything from taking prevention medications to epilepsy surgery. Since causes vary, multiple treatment approaches may be attempted. The goal, however, is always the same: to prevent hospitalization and reduce the severity and danger posed by attacks.

A common strategy for managing cluster seizures is with the use of the family of benzodiazepine drugs. These are prescribed to be used as "rescue medications" to reduce severity after onset.

“Rescue Medications” be organized based on their routes of administration:

- **Rectal drugs:** Diastat (rectal diazepam) is a drug approved by the Food and Drug Administration (FDA) specifically for seizure clusters. A form of diazepam that is injected as a foam into the anus, it acts quickly and is reserved for emergency situations.
- **Taken by mouth:** Several benzodiazepine drugs are prescribed, usually as a more preventative means of managing attacks. These include Valium (oral diazepam), Klonopin (clonazepam), and Ativan (lorazepam). Since they are swallowed, onset is slower, so they have less utility during a cluster.
- **Placed on the inner cheek:** Administered using a “buccal” method, in which a strip is placed on the inside of the cheek, midazolam can be applied for rapid effect. Application

may leave a bitter taste in the mouth and increase the risk of aspiration, in which medicine gets into the airways and lungs.

- **Inhaled with the nose:** Intranasal diazepam (Valtoco) and midazolam (Versed) come in devices that squirt medication into the nose. This form of administration leads to very rapid onset, so intranasal approaches are appropriate after the onset of a cluster.

When epilepsy is severe and resistant to treatment—leading to seizure clusters—doctors may consider surgery. The idea of these approaches is to remove the abnormal or damaged portion of the brain that is at the root of the cluster attacks. Here is a quick breakdown of the most common approaches:

- **Focal resective surgery:** If the epilepsy is focal—located in a specific region—surgery removing the damaged portions may help. Neurosurgeons aim to take out the smallest possible portion to preserve neurological function. This may also involve removing any tumor that has formed.
- **Hemispherectomy:** Epilepsy can be caused by severe impairment on one side (hemisphere) of the brain due to a range of severe neurological conditions, including perinatal stroke and Rasmussen’s encephalitis (a type of inflammation). This surgery removes damaged portions of the brain and disconnects the two halves to stop clusters.
- **Corpus Callosotomy:** Some kinds of epilepsy can be treated by essentially splitting apart the two halves of the brain. This involves cutting the corpus callosum, a dense bundle of nerves that connect the hemispheres.<sup>5</sup>
- **Thermal ablation:** Using a special device, a doctor directs a laser to the specific part of the brain that are causing the seizures. This creates heat, essentially burning and killing problematic neurons in what is a less-invasive procedure.<sup>3</sup>

Epilepsy can also be treated by using electrical stimulation of the brain using specialized, implanted devices. The vagus nerve stimulation device, first approved in 1997, implanted in the lower neck, emits electricity in short spans, which prevents seizures from forming. This approach has been found to reduce attacks by 20 to 40%.

A newer type of electrical stimulation approach, responsive stimulation, relies on implanted sensors to detect when seizure attacks are forming. When problems are detected, such devices, like the NeuroPace, provide a small electric signal in response.<sup>3</sup> This can serve to disrupt the progression of the condition.

### When to Call the Doctor

While most attacks do not require care, it is important to know when to call for help. According to the Centers for Disease Control (CDC), call 911 if:

- The person has difficulty breathing afterward.
- There is injury.
- There is a bluish discoloration of the skin.
- The seizure lasts longer than five minutes.
- There is a second attack shortly after an initial one.
- The seizure is happening to a person in water.

## Seizure Plan

Even if you are very careful and vigilant, attacks can be unpredictable, so it pays to be prepared and careful. It is important, both as someone experiencing the condition and a partner or loved one, to have a seizure plan in place. This means:

- Having first-aid accessible.
- Good access to anti-epileptic rescue drugs.
- Ensuring you or the person with epilepsy have a safe place to recover.
- Being ready to call 911.

## Coping

Given how disruptive and severe seizure clusters can be—and that managing these attacks is not a straightforward process—people may face a significant emotional and psychological fallout. In fact, studies have shown both those with this condition and caregivers experience a lower quality of life and higher rates of depression and anxiety.<sup>6</sup>

So, what can you do if you or your loved one experience these emotional and psychological effects?

- **Consider therapy:** Working with a professional can help you address the stigma and burden associated with your condition.
- **Seek support:** Support groups and online communities can also help those struggling; it is always helpful to share experiences. Patient advocacy organizations, such as the Epilepsy Foundation can also be excellent resources for help and information.
- **Communicate:** Talk to your family, friends, and co-workers about your condition if you feel comfortable doing so. Know that they will want to help.

Other aspects of daily living may also require care, including:

- **Driving:** If you have epilepsy, many states and the District of Columbia will not give you a driver's license unless you can prove that you can be seizure-free for long periods of time. Some states allow you to drive if symptoms of onset are milder and you do not lose consciousness.
- **Recreation:** Care needs to be taken with certain activities, as a seizure cluster at the wrong time can be disastrous. Be careful about taking part in sports, climbing, swimming, and others. While physical activity does not increase the risk of onset, you should still be careful about hydration and overexertion.
- **At school:** Ensure that teachers are aware of any students with epilepsy and can act effectively if anything happens. Children who have seizure clusters may require additional accommodations from the school may be necessary. If you are a parent, make sure to advocate for your child.
- **Working:** While, by law, you cannot be discriminated against in the workplace for having epilepsy, care needs to be taken. In particular, anti-epileptic drugs may cause side effects that interfere with work, and your coworkers may need to be aware of potential attacks.
- **Pregnancy:** A person with epilepsy may safely bear children. However, there is a small but not insignificant chance of passing it along. Dosages of any drugs may need to be altered during this period, so be sure to let your obstetrician know about your epilepsy treatment.<sup>3</sup>

Living with seizure clusters can be very challenging. While there is no simple, straightforward “cure” for seizure clusters, treatments are better and more effective than they have ever been. And as doctors continue to learn more about epilepsy and brain function, these treatments will only improve. There are plenty of reasons to have hope.

Hard as it may sometimes, seizure clusters are manageable. Remember: you are not alone in this. With a solid medical team, as well as the support of loved ones, family, and friends, you can certainly get a handle on this disorder.

***Editor’s Note: The Carpe Diem – Seize the Day Blog will be distributed and posted weekly.***  
Always remember – **CARPE DIEM – SEIZE THE DAY!**

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