

Importance of Recording Seizures

Why is recording seizures important?

Getting and keeping seizure control is the number one goal for most people. Keeping track of seizures is the best way to know how many seizures a student has, what type, and how they affect the student. This information helps the epilepsy team know what treatment may be best.

For 2 out of 3 people, medicines may control seizures. When medicines don't work, some people may be helped by surgery, a special diet, or a device along with a seizure medicine.

What is seizure recording?

Recording or keeping track of seizures means finding a way to record when someone has a seizure and what happens.

Sometimes people may be aware of what happens during a seizure or someone else sees it. If so, writing down what they see helps a lot.

Sometimes, the student doesn't know what happens during a seizure or can't remember. Recording as much as you can about what you or others see can really help - even if it's just the day or time it happened.

The most important part of seizure recording is to find a system that works for you and is easy to use.

How do I know what type of seizures a student has?

Often, people do not know the kinds of seizures they have.

- Seizures may have changed over time and the name used is no longer correct (e.g. grand mal is now called tonic-clonic)
- Sometimes people are told the wrong names for seizures or have been told names that are no longer used.
- Testing such as EEG monitoring may have helped clarify a student's seizure type.
- Some people are not told a name for their seizures, or they use words like "big seizures" or "little seizures." While these terms may be easy to use for the person recording seizures, it can be confusing for others.

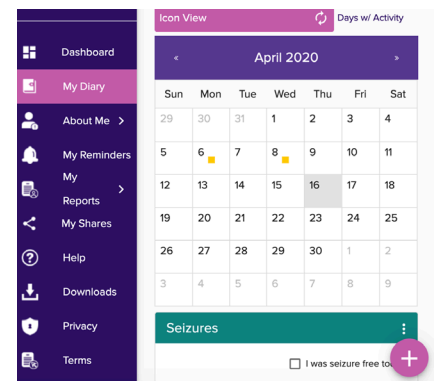
The only way to know a student's seizure type is to talk with the family and the student's health care providers. Ideally, review the history, test findings, and descriptions of what happens during a seizure.

Make sure that the school team is using the same words to describe seizures that the epilepsy team is using. Also, if the student or family uses a 'nickname' for their seizures (i.e. big or little one, staring spell), match the medical term with the word used by the family.

Getting and keeping seizure control requires teamwork from everyone!

This information is for you if:

- You care for students with seizures/epilepsy.
- You don't know how to record or track seizures or how it would help.
- You teach other school personnel about helping students with seizures in school settings.



How does seizure recording help?

Recording seizures helps in many ways. While an EEG or other test may tell the doctor what is going on in the brain, it doesn't tell them what is going on in daily life.

Knowing what happens during a seizure and how often they happen are two of the most important seizure details. Keeping track of seizures can help:

- **Know if the events are seizures:** A first-person report of what is going on will help the provider tell if the events are seizures and what kind.
- **Know how to respond to a seizure:** Knowing the seizure type helps everyone know what to do during a seizure and when to get emergency help.
- **Choose treatments:** Not all seizure medicines work for all types of seizures. Some are better for focal seizures than for generalized seizures or in people with a specific type of epilepsy syndrome.
- **Know if a treatment works:** Recording seizures can help know if a treatment is working.
- **Identify and manage side effects:** Recording side effects of medicines can show how side effects get better over time or go away when a dose is changed.
- **Identify triggers:** Writing down when and what happens around the time of a seizure can help you recognize possible triggers.

Tools to record seizures

- **My Seizure Diary:** diary.epilepsy.com
- **Seizure Tracker:** seizuretracker.com
- **Texting 4 Control:** texting4control.com
- **Paper Seizure Tracking Forms:** epilepsy.com/seizure-forms

Talk to the family about what they use to track seizures and what to track. Find what works for your school and share information with the family and epilepsy care team.

Some common seizure triggers:

- Missed seizure medicine
- Changes in medicine
- Poor sleep or lack of sleep
- Stress
- Alcohol or drug use
- Hormonal changes
- Illness, infections, fevers
- Some other medicines (prescribed, over-the-counter, or herbal products)

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 their health care provider.

This publication is made possible with funding from the Centers for Disease Control and Prevention (CDC) under cooperative grant agreement number 1NU58DP006256-04-00. Its contents are solely the responsibility of the Epilepsy Foundation and do not necessarily represent the views of the CDC.

About the Foundation: The Epilepsy Foundation, and its network of 50 organizations throughout the United States, leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. To learn more, please visit epilepsy.com.