

Using Seizure Diaries

GUIDANCE FOR SCHOOL PERSONNEL

What information should I track in a diary?

What to record depends on why you are tracking seizures and how much you know about them. Try to record as much information as you can each time you see a seizure or when someone tells you about one.

1. The day/date it happened.
2. The seizure type/name, if known.
3. How many happened at that time (1, 2 or a cluster or group of seizures).
4. Other information that's helpful:
 - How long it lasted: if you don't know the actual length, note if it was longer or shorter than usual.
 - What happened during the seizure: note the first symptom that happened or was seen and anything else that people noticed if it was different than usual.
 - What happened after the seizure (for example, tired, headache, irritable, confused, bitten tongue).
 - How long it took for the student to recover and feel back to your normal self.

How do I know what type of diary to use?

Recording seizures and other information can be done in many ways. The diary or calendar should be easy enough for school personnel to use on a regular basis. Make sure it can be shared with the family and epilepsy team.

Some people like to write in a journal, while others like forms that can be easily copied. If you have access to a computer, smart phone, or other device, seizure activity electronically.

Seizures can be tracked on a calendar - these make it easy to see when they occur and track patterns. Or use a log or record - these let you write more details about individual events. The goal is to find one that works for everyone!

Online Seizure Diaries

My Seizure Diary: Use the Epilepsy Foundation's My Seizure Diary. The diary owner (student or parent/guardian) can grant permission for a school nurse or caregiver to view or write in the diary.

- Track events over time or print out reports to share with doctors, nurses or other people.
- Keep seizure medicines up-to-date and track when rescue therapies are used.
- Keep a seizure action plan that can be easily updated.
- Attach notes or videos of seizures.
- Visit diary.epilepsy.com to get started and find links to companion apps.

Seizure Tracker: Another online seizure diary that lets you track seizures electronically, add videos of seizures and share your information with others. Visit seizuretracker.com to learn more and get started.



Paper Diaries

Using a Paper Event Diary: This type of diary allows people to record details of what occurs during a seizure. This is helpful for people with different types of seizures or when more information is needed. These forms can work well when many people record seizures for the same person. Visit www.epilepsy.com/seizure-forms for some print friendly calendars.

- Use 1 column for each event: write the date and time of an event.
- Check off all behaviors that apply for each event.
- Record location of symptoms: use an 'R' when right side of the body involved, 'L' when left side is involved, or 'B' when both sides of the body involved.
- If a person has a vagus nerve stimulator, record when the magnet is used.
- If a rescue is therapy or 'as needed' medicine is given, record what is given and when.

Using a Monthly Seizure Calendar: A monthly calendar is good to record how often seizures occur and detect patterns. They can be used to track seizures in relation to time of menstrual cycle (**for females**) or other triggers that may affect seizures.

- The calendars allow people to record different seizure types by letter. Writing the nicknames as well as the medical terms for the seizure type next to the letter helps.
- The number of seizure events can be recorded for each day, using the seizure name or letter.
- Find a monthly seizure calendar from the Epilepsy Foundation at epilepsy.com/seizure-forms.

Using Generic Logs or Lists: Simple logs or lists of when seizures happen can be made on paper, entered into a computer document, or listed on a smart phone. Electronic tracking using a generic calendar or app can be used too. Whatever is used, try to record as much information as you can.



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.

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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.