Discussion Guide

Talking to the People Who Need to Know

Sharing Your Seizure Action Plan

When a seizure happens, the person experiencing it may not be able to explain what they need. A Seizure Action Plan takes the guesswork out by clearly outlining what others should do. This guide helps you share your plan with the people who need to know, in a way that supports safety, clarity, and peace of mind.

seizureactionplans.org

Who This Guide is For

This guide is for **people living with epilepsy, as well as parents, caregivers,** and **care partners** who support them. It is designed to help you start thoughtful, practical conversations with the people who may need to know what to do in the event of a seizure, including family and close friends, roommates, teachers or school staff, supervisors and coworkers, romantic partners, and trusted community members. You are not expected to share everything with everyone. This guide helps you decide **what to share, when to share it, and how to approach these conversations** in a way that feels right for you and supports your safety.

Why These Conversations Matter

A Seizure Action Plan (SAP) is most effective when the people around you

- Know what seizures look like for you
- Understand what to do—and what not to do
- Can respond calmly and quickly in an emergency
- Know when to call for additional help

Having these conversations:

- Reduces fear and confusion during a seizure
- Improves safety in everyday environments
- Helps others support you with confidence
- Can reduce unnecessary emergency calls or injuries
- Builds trust and shared responsibility

Tips for Starting the Conversation

Before you talk with someone about your Seizure Action Plan:

Follow these steps to get started:

- **Choose the Right Moment:** Pick a calm, private time - not during a crisis
- **Keep it simple:** You don't need to explain everything at once
- **Use your SAP as a tool:** Let the plan do the explaining
- **Set boundaries:** Share only what you're comfortable with
- **Invite questions:** It's okay if people need clarification
- **Revisit the conversation:** Needs change over time - and that's ok

How Caregivers Can Use This Guide

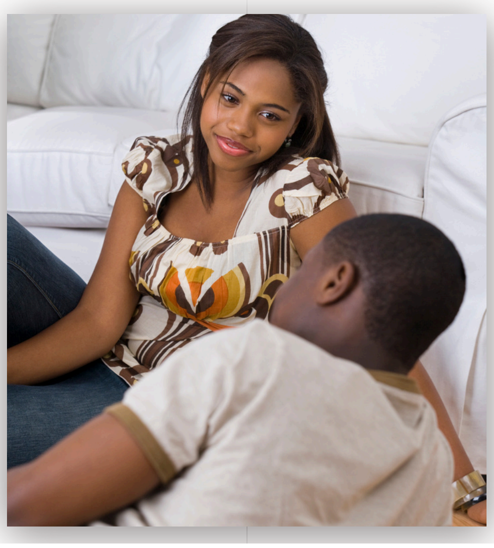
Caregivers can:

- Help initiate conversations with schools, employers, or care settings
- Role-play discussions ahead of time
- Advocate for safety while respecting independence
- Support the person with epilepsy in deciding what to disclose

Conversation Guides by Audience

Each section below includes:

- Conversation Focus (what matters most)
- Sample Role-Play Language
- Caregiver Notes (where applicable)



Family Members & Close Friends | Conversation Focus

- What typical seizures look like
- What to do and not do during a seizure
- When and how to call for help
- Where rescue meds are stored and how to use them
- What support looks like after a seizure

Sample Role Play Language

“I want to share my Seizure Action Plan with you so you know what to do if I have a seizure. Most of the time, I don’t need 911 - but there are specific signs when I do. This plan walks through that.”

“It would really help me feel safer knowing you’re familiar with this.”

“It’s important to me that the people I care about know how to support me if I ever have a seizure. In addition to being familiar with my seizure action plan, there are free seizure recognition and response trainings available to help you learn more.”

Caregiver Note

Reinforce that preparedness is about safety, not fear.
Encourage questions and practice scenarios if appropriate.

Roommates & Housemates

Conversation Focus

- What seizures may look like in shared spaces
- Nighttime or sleep-related seizure concerns
- Where rescue meds are stored and how to use them
- What to do in common areas
- When to call for help vs. when to wait
- What support looks like after a seizure
- How to access the Seizure Action Plan quickly

Sample Role Play Language

“Since we live together, I wanted to make sure you know what to do if I have a seizure. This is my Seizure Action Plan, which explains everything step by step.”

“You don’t need to memorize this. Just knowing where it is and when to use it is enough.”

Caregiver Note: If the person with epilepsy prefers, caregivers can help introduce the plan, be present for the conversation, or brainstorm ideas for the best place to store the SAP and ensure it’s easily accessible.

Teachers, Professors, or School Staff

Conversation Focus

- How seizures might affect attendance or participation
- Emergency procedures in the classroom
- Where the SAP is stored or filed
- Who should be notified if a seizure occurs
- Any formal accommodations in place

Sample Role Play Language

“I want to make you aware that I have epilepsy. I have a Seizure Action Plan that explains what to do if a seizure happens during class.”

“I’m not asking for special treatment; just understanding and preparedness.”

"I’m a student with epilepsy, and I want to make sure my professors and school staff are aware of my condition in case of a seizure or emergency. My plan provides all of the relevant information to keep me safe.”

Caregiver Note: If the person with epilepsy prefers, caregivers can help introduce the plan, be present for the conversation, or brainstorm ideas for the best place to store the SAP and ensure it’s easily accessible.

Supervisors & Coworkers

Conversation Focus

- What coworkers should do in an emergency
- Who should be notified if a seizure occurs
- Where the SAP is kept at work
- Any workplace accommodations (if applicable)

Sample Role Play Language

"I want to share my Seizure Action Plan, so the team knows what to do if a seizure happens at work. It's mainly about safety and clear steps."

"I'm happy to answer questions, but this document covers the essentials."

Caregiver Note: Caregivers can help with preparation, but the individual should lead when possible to maintain autonomy.

Acute Seizure Action Plan

Usual Seizure Pattern

Care

Standard Care Needed

Provide Rescue Treatment

Call for Emergency Help

Healthcare Provider Authorization

Seizure Action Plan Basics

1. **What is it?** Detailed seizure-related information about the individual.
2. **Who Uses It?** Every adult/individual who interacts with you daily.
3. **Where is it Kept?** With your family, your work or your school
4. **Why is it Necessary?** To recognize your seizures & determine when it's an emergency.
5. **Who Will Benefit?** Everyone can benefit!
6. **Where You Can Get it:** Seizure Action Plan Coalition

GET STARTED HERE

Romantic Partners

Conversation Focus

- What seizures look like in private settings
- Emotional and practical support needs
- Rescue medication use
- Safety during sleep or travel
- How epilepsy fits into the relationship

Sample Role Play Language

“Epilepsy is part of my life, and I want you to feel comfortable knowing what to do if I have a seizure. This plan explains it clearly.”

“I don’t expect you to be perfect, just informed.”

Caregiver Note: Encourage honest, paced conversations that evolve as trust grows.

Coaches, Faith Leaders, & Community Members

Conversation Focus

- Seizure safety during activities or events
- Emergency response expectations
- Who to contact for help
- Any triggers related to the environment
- Gym/Fitness-related concerns

Sample Role Play Language

“I participate regularly here, so I wanted to share my Seizure Action Plan in case something happens during an activity.”

“Having this on file helps everyone respond calmly.”

Final Reminders

- You are not required to disclose your epilepsy to everyone
- Sharing your Seizure Action Plan is about safety and support
- Conversations may feel awkward at first—but preparedness saves lives
- Revisiting these discussions over time is part of good self-care

Special thanks to Seizure Action Plan Coalition sponsor Neurelis for their support of the Coalition's 2026 initiatives. Their commitment helps elevate the importance of Seizure Action Plans and encourages conversations among people living with epilepsy and the care teams who support them. A plan becomes most powerful when it is shared, understood, and discussed.