

Self-Advocacy

Boosting Your Ability to Make Decisions

Kari Jones, MS, CHES
Executive Director
Epilepsy Advocacy Network

**epilepsy
advocacy
network**

Member Organization of Epilepsy Alliance America

April 29, 2026

Welcome and Intros

Advocating in the Community

Understanding Self-Advocacy

Building Advocacy Skills

Discussion Time/
Open Table

Advocating in Healthcare

Resources

What is Self-Advocacy?



Self-advocacy means speaking up for yourself to make sure your needs are understood and respected. You can use it in healthcare, in the community, and with family members.



When you hear the word 'advocacy' what feelings come up for you?

Barriers to Self-Advocacy

Common barriers:

- Fear of not being taken seriously.
- Feeling rushed during medical visits.
- Stigma and misunderstanding from others.
- Fear of discrimination in school, work, or the community.





Navigating the Healthcare System



- Write down questions and bring them to appointments.
- Track incidents, medications, and side effects.
- Ask for clear explanations in plain language.
- Bring a trusted support person.
- It's okay to get a second opinion.

“I need more time to understand this option before making a decision.”

Prepare for Your Visit

- Make a list of any concerns since your last visit, thinking about:
 - Symptoms you have experienced
 - Medication side effects
 - Mood changes
 - Any ways you have felt unsafe
- Put accommodations in place:
 - Do you need any communication assistance?
 - Do you need any special considerations for noise, lights, etc.?

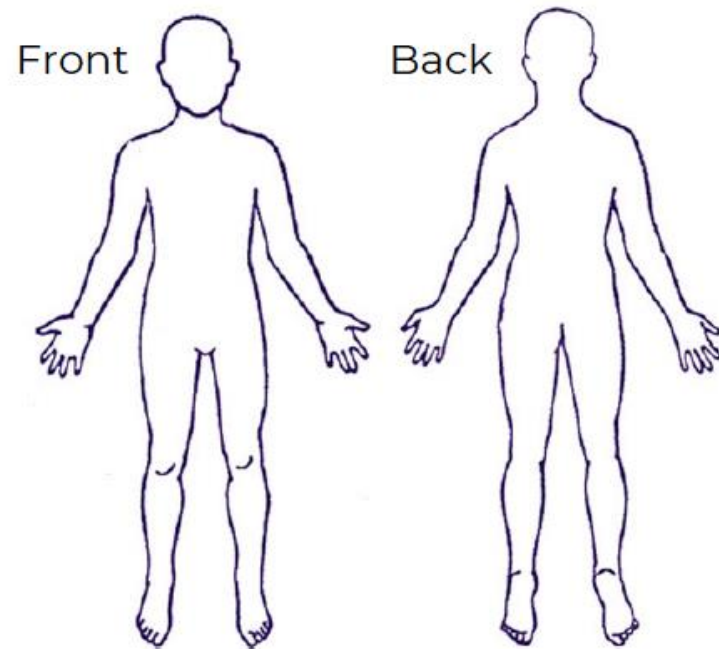
Self-Advocacy at Medical Appointments

Why I'm going:

- Healthy check-up _____
- Sick: _____
- Injured: _____
- Other: _____

My symptoms:

Where my symptoms are:



When my symptoms started:

How you can help me feel comfortable:

- Tell me what you're going to do.
- Talk slowly.
- Write information down.
- Use hand gestures.
- Use pictures.
- Avoid medical jargon.
- Talk to me first, not my support person.
- Bright lights bother me.
- Loud noises bother me.
- Other: _____
- Other: _____

My questions & concerns:

Wong-Baker FACES® Pain Rating Scale



©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org. Used with permission. Originally published in Whaley & Wong's Nursing Care of Infants and Children. ©Elsevier Inc. Wording modified for adult use.

Example Resource

What Your Support Person Can Do

- Review your questions beforehand and help you prioritize them
- Remind you if you forget to ask a question that was important to you
- If you get overwhelmed at any point, they can continue with the questions you prepared
- Take notes for you while you are in conversation with the doctor
- Be an extra set of ears and summarize the key points of the appointment at the end

IT'S OKAY TO ASK FOR ANOTHER PERSPECTIVE



- * A second opinion helps you confirm your diagnosis, explore treatment options, and feel confident in your care.
- * It is your right as a patient; seeking another perspective is common and accepted.
- * Prepare your records: bring test results, medications, seizure logs, and questions!

***What questions would you want answered
in a second opinion?***

Communicating Your Needs Confidently

Together, We Speak. Together, We Are Heard. Together, We Thrive.

**BE HONEST & EXPRESS
YOUR GOAL**



**EMPHASIZE
COLLABORATION**



**NORMALIZE IT. IT IS NOT A REFLECTION
OF YOUR PROVIDERS COMPETENCE.**

“I’d like a second opinion to better understand my treatment options.”

I’d like a second opinion to explore all available options and feel confident in my treatment plan.

“I value your expertise and want another perspective before making a decision.”

“I hope to get another perspective while still keeping you involved in my care.”

“I really value your expertise and the care you’ve given me. To make sure I fully understand all my options and feel confident in my treatment plan, I’d like to get a second opinion. Could you help me with my records or a referral? I hope to keep you involved in my care as I explore this.”



Advocacy in the Community



What is one situation in your daily life where more awareness would make things easier for you?



"I live with _____, and here's what helps keep me safe..."

Community Advocacy

SCHOOL

IEP/504/Seizure Action Plans

WORKPLACE

Accommodations, Seizure Action Plans, staff trainings

MYTHS

Correct myths that exist about your condition

FUNDRASING/ AWARENESS

Join local awareness events/ volunteer to help

SUPPORT GROUPS

Attend in-person or virtual support groups

SHARE YOUR STORY!

The best way to advocate is to educate those who may not understand! Share your experiences!

Advocate at Work

- Accommodations for you
- Trainings for your colleagues



By Disability By Limitation By Work-Related Function By Topic By Accommodation

By Limitation - Find information on accommodations organized by limitation.

Q Filter Limitations

Begin typing search phrase to filter results

Category: - None -

Attentiveness/Concentration	Executive Functioning Deficits	No Speech	Speech Disfluencies
Auditory Discrimination	Eye Strain / Asthenopia	Noise Sensitivity	Speech Impairment
Auditory Processing	Feeling/Sensing	Non-compliant Behavior	Squatting
Auditory Sequencing	Fine Motor	Non-Stuttering Speech Disfluency	Standing

Advocate at School

- **Accommodations for you**
- **Trainings for staff and classmates**

IEP

Falls under the Individuals with Disabilities Education Act (IDEA)



For students aged 3-21. May or may not carry over into accommodations for college or postsecondary programs



Provides individualized special education and related services to meet a student's unique needs



Has a narrower definition of a disability



Provides postsecondary transition services



504 Plan

Falls under Section 504 of the Rehabilitation Act of 1973

For students aged 3-22. May or may not carry over into accommodations for college or postsecondary programs

Provides a blueprint for how the school will provide support and remove barriers for a student with a disability

Has a broader definition of a disability

Provides postsecondary transition services

Example Resource


A **Seizure Action Plan (SAP)** is a written guide that explains an individual's specific seizure types, how to respond safely during a seizure, when to seek emergency help, and any medications or precautions needed. It includes emergency contacts and important safety information.

Importance:

- **Safety:** Ensures others know exactly what to do during a seizure.
- **Advocacy:** Gives you a clear way to communicate your needs in school, work, or public settings.
- **Preparedness:** Reduces fear, uncertainty, and stigma.
- **Empowerment:** Puts YOUR voice at the center of your care and daily life.

Acute Seizure Action Plan

Name: _____	Birth date: _____	Today's date: _____
Care partner phone numbers: _____	Provider name/facility: _____	Provider phone numbers: _____





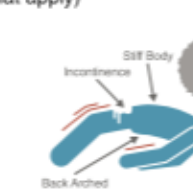
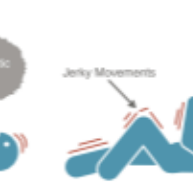

Usual Seizure Pattern

Triggers: _____

Pattern of seizures: _____

Allergies: _____

What the seizures normally look like (Check all that apply)

 <input type="checkbox"/> Atonic seizure (also called drop)	 <input type="checkbox"/> Absence seizure (also called petit mal)	 <input type="checkbox"/> Tonic seizure	 <input type="checkbox"/> Clonic seizure	 <input type="checkbox"/> Focal impaired awareness seizure (also called complex partial)
---	---	---	--	--






Describe: _____

NOTES: _____

Care

Standard Care Needed

If this happens, _____ provide standard care

 Time the seizure NOTES: _____	 Keep person safe NOTES: _____	 Don't restrict NOTES: _____	 Stay with person NOTES: _____	 Keep a record NOTES: _____
--	--	--	--	---

Provide Rescue Treatment




If this happens, _____ provide standard care (above) **and** rescue treatment

<input type="checkbox"/> Rectum	<input type="checkbox"/> Nose	<input type="checkbox"/> Mouth
---------------------------------	-------------------------------	--------------------------------

Specific instructions: _____

Other: _____

Call for Emergency Help

If any of these happen,	Get help now
 <input type="checkbox"/> Seizure longer than _____ minutes	 <input type="checkbox"/> Unusual seizure
 <input type="checkbox"/> Injury/Blue lips	<input type="checkbox"/> Other: _____

Call Healthcare Provider if: _____

Call for Emergency Help if: _____

NOTES: _____

Healthcare Provider Authorization

Signature: _____ Provider Printed Name: _____ Date: _____ For use from: _____ to: _____

©2021 NEURELIS, INC. ALL RIGHTS RESERVED.

Self-Advocacy in Legislation

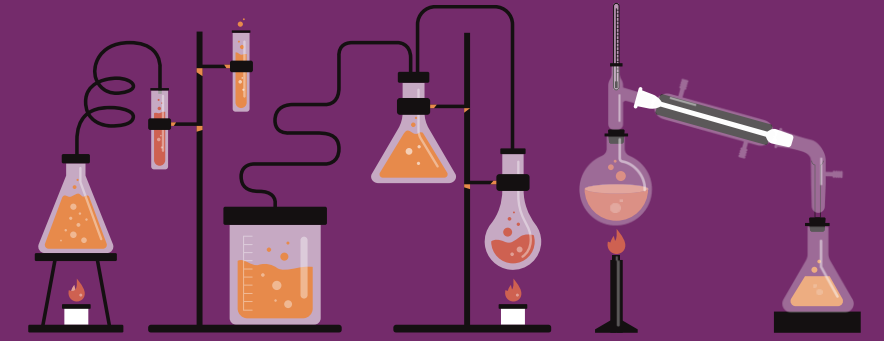
- Vote for candidates who listen to and support you and members of your community
- Get on advocacy mailing lists for your community
- Pay attention to new bills that may impact you (legiscan.com)
- Write a letter or talk to your representative about how they can support you and your community

From Patient to Self-Advocate: Practical Skills

➤ "I'm the expert in my experience; you're the expert in medicine. Let's work together."



Skills Toolbox



Rights

Learn about disability protections, patient rights, and reasonable accommodations if needed



“I”

Use “I” statement (“I need...”, “I feel...”)



Document

Keep log/journal for records of symptoms, interactions, calls



Allies

Identify supportive people who you can lean on



Ask

Ask for clarification, Seek 2nd opinion if needed



Practice

Advocating take practice and repetition. Listen to build understanding and trust. Don’t give up if the first answer is “no”.

“Advocacy is not just for me – it’s for every person living with epilepsy.”

“I want to contribute fully, and that means making sure my health needs are respected.”

“Please slow down. I want to fully understand before we move on.”

**Empower
Educate
Advocate**

YOU MATTER

Advocating for yourself isn't always easy – it takes courage, practice, and persistence. But every time you speak up, you protect your safety, your rights, and your future.

Questions/ Comments/ Connect

info@epilepsyadvocacynetwork.org

815-846-0881

Kari Jones



OPEN
Discussion

ADVOCATING
FOR
YOURSELF

