

Using Seizure Action Plans: The Foundation of Epilepsy Education

A Resource for Healthcare Professionals



What is a seizure action plan (SAP)?

- An individualized tool to inform patients, families, school personnel, and other caregivers about a person's seizures and how to respond when one occurs
 - Focuses on seizure recognition, first aid, and preventing/managing emergencies
 - Includes basic epilepsy education—critical information that people with epilepsy and families need to manage seizures
- A living document that is updated throughout a person's life; people with epilepsy and their families/other caregivers should have the most current version on hand at all times
- Can be as simple or complex as needed; for example, SAPs for people with complex epilepsies or comorbid conditions may be lengthier and incorporate information on managing other health conditions vs those without comorbid conditions

Who creates an SAP?

- Anyone can create an SAP at any time, but best practice is to start one as soon as possible and to include input from patient, family, and healthcare team
- Everyone should agree on and understand the information included in the plan
- Example situations:
 - Patient/family member starts SAP on their own and brings it to next healthcare professional (HCP) visit to complete together
 - School nurse/residential care facility nurse starts SAP at beginning of school year and shares with treating HCP and patient/family to complete together
 - Treating HCP writes SAP before patient's visit but reviews and edits with patient/family before completing



Key Takeaway

There is no “magic” time or way to develop an SAP. As long as it is started as soon as possible and includes input from the entire team, it does not matter who initiates it.

It is important for the entire team to be in agreement and understand the SAP, as they represent the people who will be using it! An SAP will be used only if it is relevant, understood, and easy to implement.

How is an SAP shared, and when should it be updated?

- Sharing
 - SAPs should be shared with anyone who may be in a position to experience and help the person during a seizure (eg, employers, classroom teachers, housemates)
 - Children with epilepsy: Usually required to share with school nurse and/or school personnel; camp counselors or medical staff also should receive a copy
 - Adults with epilepsy in full- or part-time care facilities: Develop and share with appropriate staff
 - If a patient changes HCPs, they can share the SAP with their new team and update as needed
 - Patient should be involved in decisions about sharing the SAP whenever possible, as SAPs contain personal information, and disclosing a seizure diagnosis can be a sensitive topic
 - Sharing an SAP can help a person with epilepsy have conversations about the epilepsy, get help if needed, and feel less anxious or stigmatized; the person with epilepsy may find it helpful to talk with a counselor or HCP about how to disclose seizure information and educate others
- Updating
 - HCPs should revisit the SAP with patients at least annually or if treatment or seizure activity changes
 - Set a scheduled time in your practice to review SAPs, such as at the beginning of each year, during National Epilepsy Month (November), or whenever is convenient for your practice



Key Takeaway

Sharing an SAP can be a positive, advocating step for patients. Encourage them to share it with those who are likely to be with them during a seizure.



Sample Phrasing

“I have epilepsy and may have a seizure while we are together. If I do, there are instructions in my seizure action plan. I keep it in my [purse/top left drawer/bathroom cabinet].”

Considerations When Developing an SAP



Choosing a Template

Numerous templates can be used to start an SAP. They share common elements, but their focus or intended audience may differ. Whichever form you choose, make sure it can provide the necessary information in a way that is user friendly for all.

- **Consider a person's literacy**, primary language spoken and read, and knowledge of their seizures and treatment
- **Consider the clarity of the form**: Are the words or pictures clear and simple? Is it crowded, or is there enough spacing so that people can easily differentiate the sections? Can it be printed out or stored electronically to share with others?
- Selected resources:
 - epilepsy.com/sites/default/files/atoms/files/GENERAL%20Seizure%20Action%20Plan%202020-April7_FILLABLE.pdf
 - epilepsyallianceamerica.org/wp-content/uploads/2021/11/Acute-Seizure-Action-Plan-Distributed-by-EAA-English-Fillable.pdf
 - epilepsy.com/sites/default/files/atoms/files/Seizure-Description-Form-English-Spanish_0.pdf
 - seizureactionplans.org/sap-examples

Formatting Tips



- Forms with room to write in information are easiest to edit and individualize (**Figure 1**)
 - Forms with check boxes are easy to use, but they are not conducive to individualizing plans
 - If using a form with check boxes, be sure there is room to add individualized notes on what to do after a seizure, whom to call, and when to seek further help
- Rescue medication section needs to allow enough room to individualize instructions, as plans will vary for different people
- Be careful with use of pictures to depict seizure types; if including pictures, they must be very clear and easy to understand
 - Although they may be helpful for people who cannot read, pictures may not accurately depict what happens in a patient's seizures and may be interpreted differently across cultures (**Figure 2**)

Figure 1. Sample of SAP template with room to write in individualized information.

Seizure Information

Seizure Type	How Long It Lasts	How Often	What Happens

Credit: epilepsy.com. ©2020 Epilepsy Foundation of America, Inc.

Figure 2. Considering interpretation of pictures in SAPs.



Time the seizure

VS

Time the seizure

Credit: epilepsyallianceamerica.org

Although both pictures are intended to convey the same message, the image on the left may be misinterpreted by a user. Someone may believe that a seizure needs to be timed only if the person ends up convulsing on the ground or that all seizures involve convulsions and falls. The image on the right is less likely to be misinterpreted, as it focuses on the timing instruction and omits an image of any type of seizure.

What to Include in an SAP



Demographics

- **Patient:** Make sure the person's name and date of birth are on the SAP! If the person goes to an emergency room, basic demographics are needed
- **HCP:** List the name and contact information of the HCP who should be contacted if needed
- **Caregivers:** Include name(s) of parent/guardian or main caregiver, including contact information, especially for minors or adults who may not be able to speak for themselves
 - If the form is specific to a setting (eg, school, residential facility, or day program), it may need to include the facility's main contact



Key Takeaway

Contact information for the patient and all people involved in their care should be clearly provided at the top of the SAP.

Seizure Information

This provides an opportunity to talk with patients/families about which type of seizures they have and decide what the best descriptive words are for them.

- **Consider primary language and literacy level of patient/family; avoid words that they do not understand or use**
- Ideally, include both the clinical term and the term most understandable to patients/families/nonmedical professionals
- Description of the main seizure features, usual length, and how often they happen
 - Helps to identify seizures and track any changes or atypical events
- Common triggers
 - Patient/family can write these in on their own
 - Helps identify patterns and develop strategies to avoid triggers



Key Takeaway

Everyone needs to understand and be on the same page about accurate seizure terminology (eg, which kind of seizure it is, how to describe it).



Terminology Examples

- **Clinical:** atonic seizure; **layperson:** drop seizure
- **Clinical:** tonic-clonic seizure; **layperson:** big seizure
- **Clinical:** focal aware seizure; **layperson:** little seizure or aura seizure

Be careful with use of "staring seizure"—patients/families often mistake focal impaired awareness seizures for absence seizures and call both "staring seizures"

Maintenance Seizure Medications

Not all SAP templates include a space for maintenance medications, but it is a helpful section to have, especially if a person ends up in an emergency room, is somewhere alone, or is without anyone who knows their medical history. Including a list of medicines used by the patient can help prevent emergency personnel from giving a person a new medicine.

- List medication names, doses, and dosing schedules.

Rescue Therapies/Medications (see Table for more information)

If a rescue medicine is prescribed, enter complete information!

- Medication name, dose (in both mg and number of tablets, liquid, or sprayers), and route of administration (ie, intranasal, rectal, buccal, oral)
- Instructions on how to administer
- When to use it (**important!!**)
 - Be as specific as you can to avoid user errors; using written instructions vs check boxes is ideal here
 - For example, “If XX (eg, ≥ 2 seizures, seizure lasting X minutes) happens, then XX (eg, give 1 dose of X)”
 - Include instructions on if and when an additional dose should be given
- If you have recommended more than 1 rescue medicine or 2 different ways to use a single rescue medicine, include them all in the SAP
 - For example, Step 1: Use Drug A at XX mg if ≥ 3 focal seizures in 24 hours; Step 2: Use Drug B at XX mg for tonic-clonic seizure ≥ 5 minutes and call HCP
- Information on adverse events or problems to look for
 - For example, when to watch and wait, when to call the HCP, when to call 911
 - Respiratory depression is not a common adverse event, but the SAP should include information on watching for changes in breathing and color
- Most common reason to call for help is when seizures do not stop or more occur after the second dose is given

Emergency Care



Many people do not need to go to an emergency room after a seizure. To avoid unnecessary emergency room visits, it is important to provide specific information on what is considered an emergency.

- Seizure features or situations that would require emergency room care (eg, seizures last too long or continue after rescue medicine, person is injured, breathing difficulties) vs those that can be managed without emergency room care
- This information may be written out in full or listed as check boxes (**Figure 3**)

Signatures



The HCP who completes or updates the SAP and the patient/family should sign it to make sure everyone is clear about what is in it

Figure 3. Check boxes for emergency instructions.



When to call 911

- ☐ Seizure with loss of consciousness longer than 5 minutes, not responding to rescue medication if available
- ☐ Repeated seizures longer than 10 minutes, no recovery between them, not responding to rescue medication if available
- ☐ Difficulty breathing after seizure
- ☐ Serious injury occurs or suspected, seizure in water

When to call your HCP first

- ☐ Change in seizure type, number, or pattern
- ☐ Person does not return to usual behavior (ie, confused for a long period)
- ☐ First-time seizure that stops on its own
- ☐ Other medical problems or pregnancy



Credit: epilepsy.com. ©2020 Epilepsy Foundation of America, Inc.

Table. FDA-Approved Seizure Rescue Medications

	Diazepam Rectal Gel	Diazepam Nasal Spray	Midazolam Nasal Spray
Approved for	Patients aged ≥2 years	Patients aged ≥6 years	Patients aged ≥12 years
Indication	Acute treatment of seizure clusters, acute repetitive seizures, or periods of increased seizures* Give during seizure cluster or episode; can be given by nonmedical personnel (trained in its use)		
Dosage forms/strengths	Prefilled applicator comes in 2.5-, 10-, and 20-mg doses Prescribed dosage is set (or “dialed in”) for applicator by pharmacist prior to patient pickup. “Dialed in” dose options: 2.5, 5, 7.5, 10, 12.5, 15, and 20 mg	Prefilled nasal sprayer: 5, 7.5, and 10 mg - For 5- and 10-mg doses: 1 sprayer of either dose - For 15-mg dose: Two 7.5-mg sprayers - For 20-mg dose: Two 10-mg sprayers	Prefilled nasal sprayer: 5 mg
Dosing	Based on age and weight		1 spray (5 mg)
How to administer	- Remove seal pin from applicator and apply lubricant - Turn person on side - Insert applicator into rectum and count to 3 while pushing in plunger, before removing syringe, and while holding buttocks closed after removing syringe (to minimize leakage and maximize absorption)	- Hold nasal sprayer between first 2 fingers with thumb on plunger DO NOT prime the plunger until ready to use - Place tip of sprayer into 1 nostril until fingers touch bottom of nose - Press plunger in firmly (no inhalation necessary; the medicine spray passively disperses into nose) - Remove sprayer from nostril <i>If second sprayer is required, administer in opposite nostril</i>	
Additional doses	Do not use more than 2 doses for 1 seizure episode/cluster		
	- If second dose needed, can give 4-12 hours after first dose - Frequency of use: 1 seizure episode/cluster every 5 days or ≤5 times per month	- If second dose needed, can give ≥4 hours after first dose - Frequency of use: 1 seizure episode every 5 days or ≤5 times per month	- If second dose needed, can give ≥10 minutes after first dose - Frequency of use: 1 seizure episode every 3 days or ≤5 times per month
Pharmacokinetics	- Bioavailability: 90% - Peak (T_{max}): 1.5 hours - Half-life: 46 hours (parent) 71 hours (metabolite)	- Bioavailability: 97% - Peak (T_{max}): 1.5 hours - Half-life: 49 hours	- Bioavailability: 44% - Peak (T_{max}): 17 minutes - Half-life: 2-6 hours (parent) 2-7 hours (metabolite)
Considerations	When receiving medication from pharmacy, make sure dosage is “dialed in” and green READY bar is visible on applicator 	- Do not push in plunger before ready to give dose - When 2 sprayers are used, give one in each nostril	Consider test dose if patient is at risk for respiratory depression

Table references: Diazepam nasal spray PI. Diazepam rectal gel PI. Midazolam nasal spray PI.

***Refer to prescribing information for each rescue medicine. Clinical terms may differ from terms used by patients/families.**

Resources:

- Diazepam rectal gel [prescribing information](#) and [instruction sheet](#)
- Diazepam nasal spray [prescribing information](#) and [instruction sheet](#)
- Midazolam nasal spray [prescribing information](#) and [instruction sheet](#)