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Introduction to use of an acute seizure action plan for seizure clusters and guidance for implementation

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Abstract

It is important for patients with epilepsy and their caregivers, including care partners, to understand the patient's seizure clusters and what to do when they occur. In many instances, seizure clusters are unique to each patient. The knowledge gained from understanding a patient's seizure cluster or seizure pattern provides a foundation for taking prompt action to prevent worsening to prolonged seizures, status epilepticus, and potentially death. Seizure action plans (SAPs), which are similar to the disease-related treatment action plans for other conditions, can be developed by a health care provider (HCP) in conjunction with the patient with epilepsy and/or caregivers, and SAPs are specifically customized for the individual patient and his or her seizure management. However, the current literature lacks unified guidance on how to design SAPs that will help prepare patients and caregivers for rapidly determining and initiating appropriate treatment of acute seizure emergencies in the community and at home. Here, we examine the current usage and value of SAPs for pediatric and adult patients with epilepsy, and we introduce the concept of the acute SAP (ASAP) for use specifically during seizure emergencies, such as seizure clusters. This type of standardized, simplified, and customized plan can rapidly and concisely provide patients and caregivers with a practical protocol to treat a seizure cluster consistently, appropriately, and in a timely manner. Details on potential content and formats of ASAPs are provided. Following this is a discussion of barriers to ASAP use that may affect HCPs or patients and caregivers, including lack of standardization, relevance, and personalization and pitfalls associated with technology. This leads into a discussion of guidance for developing, implementing, and updating ASAPs that suggests ways to address the barriers and ensure that the ASAP is best suited to the patient's needs.

KEYWORDS
acute repetitive seizure, epilepsy, rescue therapy, seizure emergency

1 | INTRODUCTION

For chronic conditions that may require acute treatment, such as asthma and diabetes, treatment action plans developed by health care providers (HCPs) have been shown to successfully provide appropriate instruction on treatment management.[1–4] Seizure action plans (SAPs), broadly based documents that include epilepsy education and treatment information for patients and their caregivers, serve a similar function, although such plans have not been consistently adopted.[5] Although plans for other chronic conditions may be provided to patients and caregivers at discharge following emergency care in a hospital,[6] this may not be the case for patients with epilepsy, making it likely that an action plan will need to be proactively developed in the outpatient office setting.

SAPs are useful to all patients with epilepsy to help alleviate fears and to provide a clear and consistent management strategy.[7] The plan can provide education in community settings (e.g., school, work).[8,9] SAPs can provide practical, easy-to-use self-management/caregiver information such as concise steps to take during seizures and clear timing for interventions.[10] The SAP format can be a printed or electronic document or may have options for either format.

Studies evaluating the use of SAPs based on outcomes measures have shown conflicting results for patients with this complex and unpredictable condition. In one study, 60 pediatric patients in a general epilepsy population who received an SAP were followed up for 18 months and evaluated for health care utilization (e.g., emergency department visits, hospitalizations, clinic telephone calls, and clinic visits) in comparison to 60 historical controls from before the implementation of the SAP.[11] No statistically significant difference in health care utilization was found between the groups; in the SAP group no reduction in health care utilization was found, and there was an increase in clinic visits. However, the authors of the paper suggest that they may not have identified the appropriate outcome measures to reflect SAP efficacy.[11] Others have suggested that the use of educational and quality-of-life measurements could be more appropriate.[12] More details regarding the impact of seizure clusters on patient and caregiver quality of life are discussed by Kapur et al. in *Consequences: Bench to Home* in this supplement.[13] One study looked at health care utilization outcomes and scores on the Modified Impact on Families (MIF) questionnaire at 3 and 12 months in 54 patients with epilepsy who received an SAP and 48 patients who had standard care alone.[14] Differences in health care utilization were not seen between the groups; however, among patients with

> **Key Points**
> - Epilepsy is unpredictable; SAPs can be used to educate patients and caregivers and provide a management strategy
> - Although action plans have been shown to be successful for other conditions, <50% of pediatric and adult epilepsy patients have an SAP
> - Compared with the broad SAP for daily use, ASAPs are designed to guide acute care during a seizure emergency
> - ASAPs should provide patient-specific details about seizures and when and how to use rescue medications, in a brief, modifiable format
> - Customization, standardization, education, and other keys to development should be used to address potential barriers to ASAPs

≤12 seizures per year, seizure comfort scores on the MIF questionnaire at 12 months were significantly higher in the SAP group compared with the standard care group. Also, patients without an SAP had a significantly higher proportion of missed clinic appointments (75% vs. 55%, $p = .04$), suggesting better compliance and improved care in this area for the patients with SAPs.[14] Both studies that did not find improvement in health care utilization with SAPs were limited by small populations and lack of power[11,14]; thus, this end point needs to be further addressed in larger populations. Additionally, one cannot underscore enough the importance of caregiver comfort with epilepsy and seizure care.

2 | VALUE OF AN SAP FOR ALL PATIENTS

Owing to the unpredictable nature of seizures, patients with epilepsy and their caregivers need education and support to be prepared as they go about their daily lives.[5,14,15] Epilepsy can have a broad impact on patients and their families, causing concerns about life such as the potential for losing independence, worsening condition, and public loss of seizure control.[5] SAPs can be designed to help with the management of epilepsy, by providing information on seizures, what action to take, and how to use rescue medication.[10] Being prepared can quell anxiety about what to do when seizures occur, increasing the likelihood of taking appropriate action and improving quality of life through understanding of self-management.[15,16]

3 | USAGE OF SAPs BY PEDIATRIC AND ADULT PATIENTS

Pediatric patients are more likely to have SAPs than adults, although the proportion in both age groups has been shown to be lower than 50% (~45% and ~30%, respectively).[5,16] SAPs may be more common among pediatric patients because this type of plan may be required to be on file at schools.[17,18]

As the pediatric patient grows older and transitions into the adult health care system, review of the SAP should be included in the transition process.[19] Along this aging spectrum, HCPs will need to consider the appropriateness, effectiveness, and dosages of the prescribed anti-seizure medications and potential interactions with new medications, such as contraception.[20] At all life stages, an SAP should be tailored to the individual patient.[21]

4 | INTRODUCTION TO THE ACUTE SAP

4.1 | Purpose of an acute SAP

Penovich et al. introduced the concept of the acute SAP (ASAP)[7] that is further developed in this paper. ASAPs are designed to be used at the time of an acute seizure emergency, such as at the onset of a seizure cluster or prolonged seizure, and focus on prompt identification of initial and recurrent seizures and applicable treatment (e.g., first aid, rescue therapy, or calling emergency services).[7,10] Rapid treatment of seizure emergencies is necessary; delay can lead to increased risk of prolonged seizures, status epilepticus, reduced quality of life, complications, and death.[22–24] Timely acute treatment may help minimize the need for invasive interventions such as intubation, emergency room visits, and hospitalizations.[22] Because seizure emergencies can occur spontaneously and unpredictably in the community setting, which could be urban or distant rural, and the arrival of emergency medical services may require a lengthy wait time, the focus of acute treatment is rescue therapy and safety.[10,25]

Having access to an ASAP can address patient and caregiver concerns about not being prepared for a seizure cluster and help reduce associated anxiety.[7] It also can serve to trigger reminders about use of rescue medications in these acute settings. Some of the life activities in which patients and caregivers may experience negative impact from seizure clusters include the ability to work, travel, participate in hobbies and social activities, and perform other activities of daily life. Use of an appropriately developed ASAP may help clarify questions about these activities by reinforcing what is meant by appropriate care at the time of seizure emergencies, such as the use of rescue medications that have been associated with fewer injuries and emergency room visits.[7,26] It can serve as a guide for others to follow for when rescue treatment is needed.

4.2 | Content of an ASAP

ASAPs can help bolster the knowledge of patients with epilepsy and their caregivers by providing organized, individualized information about rescue medications, when and how to administer the correct medication, and what to do if the seizures persist.[16] It is critical for the ASAP to include specific details regarding the patient's prescribed rescue therapy that are straightforward and easy to understand and follow during the stressful experience of an acute seizure cluster. These details also should be easy for the physician to modify when there are changes in the prescribed therapy. More details about rescue therapies are discussed by Gidal and Detyniecki in *Rescue Therapies for Seizure Clusters: Pharmacology and Target of Treatments* in this supplement.[27]

The ASAP can be customized to include patient-specific details such as type of seizure, type of home setting, emergency contact information, details for recognizing whether a seizure is atypical, information on how and when to administer first aid, step-by-step instructions for administration of prescribed treatment, and information on how to recognize the patient's seizure milestones (e.g., when to start medication and when to transition to requesting emergency assistance).

4.3 | Format

To be of immediate use during a seizure emergency, the format of the ASAP should be easily accessible and the content kept brief, straightforward, and easy to use. For example, HCPs, patients, and caregivers may find that concise text associated with check boxes on a printed ASAP or with drop-down menus on an electronic ASAP can be easily and quickly used.[7] This type of format allows for seizure information to be on hand as a quick reference when and where it is needed, including outside the home in the community, which can aid in reducing the confusion that may develop if patients and caregivers are upset or anxious about seizure episodes.[7,28] When interim caregivers such as babysitters are used, rescue therapy and the ASAP provided together may give the patient and caregiver a sense of security and confidence that the patient will get appropriate care in an emergency.[14,22] The format should also allow for modification when needed based on a review of its usefulness to the patient and

caregiver and for changes in treatment.[7] The ASAP can be part of a full SAP or a separate document. A sample ASAP is included in Figure 1.

5 | POTENTIAL BARRIERS FOR DEVELOPMENT AND IMPLEMENTATION OF AN ASAP

Development of a self-management plan tailored to an individual patient with epilepsy should involve collaboration between the HCP, the patient, and the caregiver.[29,30] However, there may be challenges that impede appropriate development of the management plan and stand as barriers to its implementation and adoption. One systematic review looking at self-management interventions for patients with epilepsy in 13 studies found that 11 studies noted the presence of barriers to the process that were related to such issues as intervention relevance, personalization, and technology considerations.[29] To address previously identified barriers, we propose potential associated solutions as well as which groups could be involved in developing and implementing those solutions (Table 1).

5.1 | Potential HCP barriers

The structure of patient visits and the settings in which they occur may provide challenges to the HCP developing an ASAP. Such a plan may not be front-of-mind for some HCPs who are focused on other topics during clinic visits. There also may be no clear procedure for who initiates a plan or how to initiate it, and for many patients, especially adults, plans are not being initiated; therefore, HCPs should take responsibility for the plan.[30] In a survey of 100 families with children with epilepsy, rescue medication was prescribed for 87%, but only 61% received training and fewer than half (45%) had an action plan.[16] Among respondents to a Harris poll, there was a disparity between clinicians and their adult patients, with 52% of clinicians reporting that a majority of their patients had a seizure emergency plan, but only 30% of patients reported having a plan. This finding serves as an opportunity for improvement.[5]

In some practice settings, the lack of an available form or designated electronic medical record (EMR) location for action plans can be a barrier. Lack of a standardized, streamlined, concise form can make development of an action plan time-consuming for the HCP.[34] Not having a unified location or structure in the EMR for action plans also can be a challenge to providers and to supplying the document electronically to patients who could lose a printed form.[34] Also, a lack of standardization of the form

as well as interoperability across EMR systems may pose difficulties.

In general, limited time is a challenge for HCPs. A study including survey interviews of 101 professionals with ≥16 years of experience in the epilepsy field found that they gave the answer of "time limitations" as the greatest difficulty faced when caring for patients with epilepsy.[35] Among the responses related to this topic were references to limited consultation time and pressure to quickly move the patients through the office or clinic, resulting in less time for using education and management skills.[35]

Second on the list of greatest difficulties reported in that study was inability to focus, which was described as a perception that the system had a narrow view of the clinician's role that was limited to treating seizures and did not allow the clinician to have a more global view of the patient.[35] When limited by time and focus, HCPs may encounter challenges with ASAP development because of lack of appropriate training for properly implementing such a plan.[35] HCPs may lack education in such key areas as how to incorporate plan use and revision into the patient's overall care, how to discuss the plan with the patient and caregiver, and how to encourage and perpetuate continued use of the plan.

5.2 | Potential patient and caregiver barriers

Challenges also may arise if the content of the action plan does not account for the patient's and/or caregiver's perceptions of how epilepsy should be managed.[29] For example, patients and caregivers may not understand and accept the need to treat seizures acutely.[30] Also, barriers may be encountered when there is disagreement about what content is necessary in the ASAP; whether the content included is too general to be of use or is not tailored to the patient; and when the patient's cognitive issues, preferences for format, and access to health care are not addressed.[29] In a survey of 291 adults with epilepsy and their caregivers, 87% of respondents said that they were directly involved in writing their plan; however, fewer respondents (66%) said that the plan included their views on how support will be provided.[36] Other barriers may include logistical issues, such as lack of clarity for follow-up schedule with the HCP and unclear instructions for caregivers on their role in the management of epilepsy.[29]

Technology also may present challenges for patients and caregivers who have an action plan provided electronically. They may not be aware of the types of devices available and how to use them to access the action plan, resulting in confusion and isolation.[31] Also, there may not be written or printed action plan materials for the patient and caregiver to use when electronic devices are

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)   Describe: _____

☐ Atonic seizure (also called drop)   ☐ Absence seizure (also called petit mal)   ☐ Tonic seizure   ☐ Clonic seizure   ☐ Focal impaired awareness seizure (also called complex partial)

NOTES:

Care

Standard Care Needed

If this happens, _____ **provide standard care**

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

Provide Rescue Treatment

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

☐ Rectum   ☐ Nose   ☐ Mouth   ☐ Other: _____

Specific instructions: _____

Call for Emergency Help

If any of these happen,   **Get help now**

☐ Seizure longer than ____ minutes   ☐ Unusual seizure   ☐ Injury/Blue lips   ☐ Other: _____

Call Healthcare Provider if: _____

Call for Emergency Help if: _____

NOTES: NOTES:

Healthcare Provider Authorization

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

FIGURE 1   A possible acute seizure action plan format.[7] Reprinted with permission.

TABLE 1 Categories of potential barriers for ASAPs,[29,31–33] proposed potential associated solutions, and groups for developing and implementing the solutions

Description	Examples	Proposed solutions	Groups for developing and implementing solutions
For HCPs • Appropriateness of development, delivery, and implementation of plan	• Lack of preparation/education regarding the plan • Developed plan is not standardized or too complex • Lack of time during visits	• Utilize standard form template with individualizable fields • Have available IT support in implementing standard form in EHR • Use nursing or pharmacy personnel to provide education	• HCPs • Nursing and support staff • Pharmacy/PharmD • IT • Clinic management for scheduling, timing of appointment
Relevance to patient and/or caregiver • Appropriateness for enhancing patient and caregiver management skills • Individualization to patient's physical, social, and environmental characteristics	• Patients and caregivers may view their needs differently than HCPs • Views of the content needed differ from HCP • Content is too general and not tailored to the patient • Patient cognitive or memory limitations • Patient disinterest in participating in the plan • Not considering the influence of the patient's demographics and socioeconomic status on use of plan	• Use SAP and ASAP as shared decision-making tools between patient and provider • Use color coding and images for ease of understanding • Ensure adequate readability of form	• HCP • Patient/caregiver • Nursing/education staff • Care management team
Technology • Availability, use, familiarity, and ownership of devices	• Patient's lack of knowledge about technology • Individual preferences about using technology • Lack of help for users • Lack of access or lack of written materials	• Have SAP and ASAP available as printable documents and also available via patient portal • Develop cell phone app for patient/caregiver access • Provide education to accompany SAP and ASAP	• IT • Patient/caregiver • Care management team
School/workplace • Use of the plan to manage seizures in the school/workplace setting	• School/workplace personnel's lack of training and misconceptions about epilepsy • Belief or protocol that emergency services should always be called • Lack of confidence in managing seizures • Nurse may not always be on site	• Partner with school/workplace to provide access to SAP and ASAP given by health care provider • Have SAP and ASAP available in electronic form for all to view and easily modify	• Patient/caregiver • School/work personnel • Local advocacy groups • School/workplace initiatives like Seizure Smart Schools

Abbreviations: ASAP, acute SAP; EHR, electronic health record; HCP, health care provider; IT, information technology; SAP, seizure action plan.

not accessible.[29] Regarding content, patients and caregivers may be concerned about the quality and accuracy of the information on the electronic platform and about the privacy provided by this format of information delivery.[29] Logistic and assistance barriers also may be encountered with technology, such as lack of access to the necessary device or application or not having support if technical difficulties occur.[29] Also, a lack of

communication with HCPs about the use of technology may be a barrier to use.[31]

For pediatric patients in school and their caregivers, there may be barriers to the use of action plans that are specific to management of seizures in the school setting. Schoolteachers and other staff may lack seizure-related training, and teachers or other school personnel may have misconceptions about epilepsy.[32] Some jurisdictions may mandate that any seizure requires a call to emergency services.[33] Also, some school nurses may not feel confident about administering rescue medication for seizures, especially if the treatment is associated with privacy issues.[32]

6 | GUIDANCE FOR DEVELOPING, IMPLEMENTING, AND UPDATING AN ASAP

6.1 | Keys to development

One of the keys to addressing many of the barriers encountered in the usage of an ASAP may be to ensure that the plan is appropriately and accurately customized to the individual patient.[29] This ensures that the plan is relevant to the specific patient, and that it continues to be relevant when modifications are needed.[29] Other considerations for the development of an ASAP include having a format that is clear, concise, and user-friendly; having step-by-step instructions; and being practical for use in the community setting where seizure emergencies often occur (Figure 2).[10,21]

Having a standardized ASAP such as the one in Figure 1 easily available to HCPs for customization to the individual patient may provide for less variability among practices and patients. A standardized plan also may reduce the time needed for an HCP to initiate and develop the plan and educate the patient and caregiver about its

use. A study examining provider utilization from a baseline of no standardized plan to 3 months after the use of a standardized plan found that >50% of providers used the standardized plan.[34] That study also found that a standardized plan that is easy to locate, fill out, read, share, and update can be easily adopted by providers,[34] cutting down on their time used in the development and modification stages. Shortcuts within the plan, such as check boxes and drop-down menus, also may help save time when developing and modifying the plan.

6.2 | Feasible strategies to enhance ASAP implementation

For HCPs, patients, and caregivers, education on ASAP content, format, and use contribute to successful implementation. For HCPs, discussion of the ASAP can be added to staff meetings, and the form can be tested for a short period of time to evaluate utilization and need for revision.[34] For patients and caregivers, office visits to develop the ASAP can be used as a platform for education about specific facets of the patient's epilepsy, such as seizure type, rescue medications, terminology, and when to call for emergency assistance.[7] Also, nursing staff could provide ASAP education at discharge from a clinic visit, which allows for face-to-face interaction and clarification of any content, such as administration instructions or terms, that are not fully understood.[37] The plan should be distributed to all caregivers who will be attending visits with patients. In addition, educating persons in the community who are in contact with the patient, such as classmates and coworkers, can be beneficial, as long as privacy regulations are upheld. If there is a clinical pharmacist in the clinic, they may participate in development of the ASAP and assist with providing clarification and reinforcing use.[14,37]

Standardization, education, and availability of the ASAP also may clear obstacles to technology issues. In the EMR, the plan should have a standard location for timely access by HCPs, patients, and caregivers.[34] Enhanced electronic health information-sharing legislation such as the 21st Century Cures Act can provide patients and their HCPs with improved access to medical records.[38] As with the content of the ASAP, the use of technology also should be tailored to patient and caregiver individual characteristics, including ownership and familiarity with devices such as computers and mobile phones.[29]

For ASAP implementation in schools, preparation in the form of education and training of personnel may contribute to confidence in assisting students experiencing seizures.[32] Along with school nurses, education should be extended to teachers, administrators, and coaches.[33]

Keys to Development
- Customized
- Clear
- User-friendly
- Step-by-step instructions
- Practical to use

Keys to Implementation

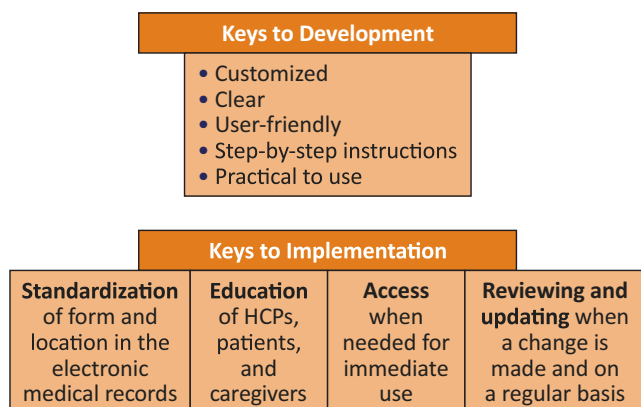| **Standardization** of form and location in the electronic medical records | **Education** of HCPs, patients, and caregivers | **Access** when needed for immediate use | **Reviewing and updating** when a change is made and on a regular basis |

FIGURE 2 Key suggestions for successful development and implementation of an acute seizure action plan. HCP, health care provider.

School nurses may be called on to educate the student population.[33] The Epilepsy Foundation provides guidance for schools in its Seizure Safe Schools initiative, which recommends the following: training in first-aid response for school employees, mandating an SAP in the student's file that is available to personnel responsible for the student, ensuring that US Food and Drug Administration-approved prescribed medication is available to the student, and educating the student community about epilepsy.[39]

6.3 | Reviewing and updating the ASAP

The ASAP should be reviewed on a regular basis by the HCP and the patient and caregiver to ensure that it is understood and up to date with the management plan.[7] In addition, rescue medication dose changes/updates may be needed in the pediatric and adult populations, which should occur concurrently with ASAP review. According to the Epilepsy Foundation, the action plan should be reviewed with the patient at least once per year or at any time when treatment changes occur.[28] A best practice alert reminder that requires user acknowledgment can be set up in EMR systems that include clinical decision support tools to aid providers.[40,41] A notification could appear as a pop-up window on the HCP's computer screen that the ASAP needs to be reviewed.[40] The patient and caregiver also can review the plan and suggest updates, possibly on a memorable date such as a birthday, back-to-school time, or at the start of a new year, as appropriate for pediatric and adult patients.

7 | CONCLUSIONS

Expanded use of a brief, user-friendly ASAP as part of individualized care plans is needed across all age groups. Standardization, customization, and education are useful for successful implementation. This proposal emphasizes the need for multiple stakeholders in the development and implementation of the ASAP, and addresses the barriers that could prevent successful adoption in practice. Importantly, outcomes studies on the application and impact of broadly based SAPs and ASAPs for seizure emergencies, and additional studies on health care utilization that are appropriate and adequately powered are needed.

AUTHOR CONTRIBUTIONS

Writing–original draft preparation: Both authors developed the initial content outline for the manuscript. Writing–review and editing: Both authors provided critical review and revision. Both authors approved the final version of the manuscript for submission to *Epilepsia*.

CONFLICT OF INTEREST

A.D.P. receives research support from the National Institutes of Health and Pediatric Epilepsy Research Foundation; receives institutional research support from Stoke; receives compensation for being a member of the Greenwich Biosciences Education Content Workgroup; is an advisor for Neurelis; and receives compensation for webinar development from Medscape and Neurology Live. D.A.B. is a speaker for Neurelis, SK Life Science, Supernus, and Neuropace, and is an advisor for Neurelis, SK Life Science, and Supernus. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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