

REVIEW

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# Recommendations for the community-based management of prolonged convulsive seizures in children in Europe

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## Abstract

Typically, convulsive epileptic seizures self-terminate within 2–3 min. A duration exceeding 5 min defines convulsive status epilepticus (CSE), a condition that could have detrimental neurological, cognitive and psychiatric consequences. As seizure duration extends towards 5 min, the risk of progression to CSE increases. A prolonged convulsive seizure (PCS) represents a medical emergency with a need for urgent treatment since the chances of spontaneous cessation are low. Generally, a PCS exceeding 5 min should be promptly treated with a rescue medication. However, for those who have already experienced a PCS, or who are at particular risk of a PCS, time to rescue medication administration should be individualized. Buccal midazolam and rectal diazepam are the current first line rescue medications available to treat PCS in Europe in the community setting. Given its ease of administration and social acceptability, buccal midazolam is currently considered by caregivers and neurologists the preferred rescue medication option in the community for children older than 6 months. This document contains the first expert panel recommendations for the management of PCS in children in the community in Europe, including an algorithm for the management of pediatric patients after the first PCS, and provides guidance for a seizure action plan (SAP).

**Keywords** Prolonged convulsive seizures, Pediatric, Community, Caregivers, Rescue medication, Buccal midazolam, Rectal Diazepam, Seizure Action Plan, Global outcome

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## Background

Although more than 30 antiseizure medications (ASM) are currently available across Europe [1, 2], it is estimated at least one third of children and adolescents with epilepsy are drug-resistant and continue to experience seizures [3] including prolonged convulsive seizures (PCS). PCS is also referred to as “prolonged acute convulsive seizures” for regulatory purposes or even as “prolonged motor seizures”. However, PCS is the most commonly used term in clinical practice and will be used throughout this document.

The International League Against Epilepsy (ILAE) Task Force proposed a conceptual definition of status epilepticus with two operational dimensions: length of seizures and time point from which there is ‘continuous seizure activity’ ( $t_1$ ) and time of ongoing seizure activity after which there can be long-term consequences ( $t_2$ ). This definition includes abnormally prolonged convulsive seizures lasting longer than 5 min ( $t_1$ ) and with a risk of long-term consequences if the seizure activity continues for more than 30 min ( $t_2$ ) (Fig. 1) [4, 5]. Currently, there is no universally accepted definition of PCS. However, we agreed that PCS is defined as a motor seizure that lasts at least 5 min.

PCS can occur at any time or place in the community [6]. However, there are currently no European recommendations on the management of PCS in the community. This may result in distress for patients and caregivers, as well as increased healthcare costs due to the use of emergency ambulance services and emergency hospital visits [7]. For this purpose, a panel of European experts in the management of PCS in children was gathered to devise a possible way forward. An important component of the management of PCS in the community

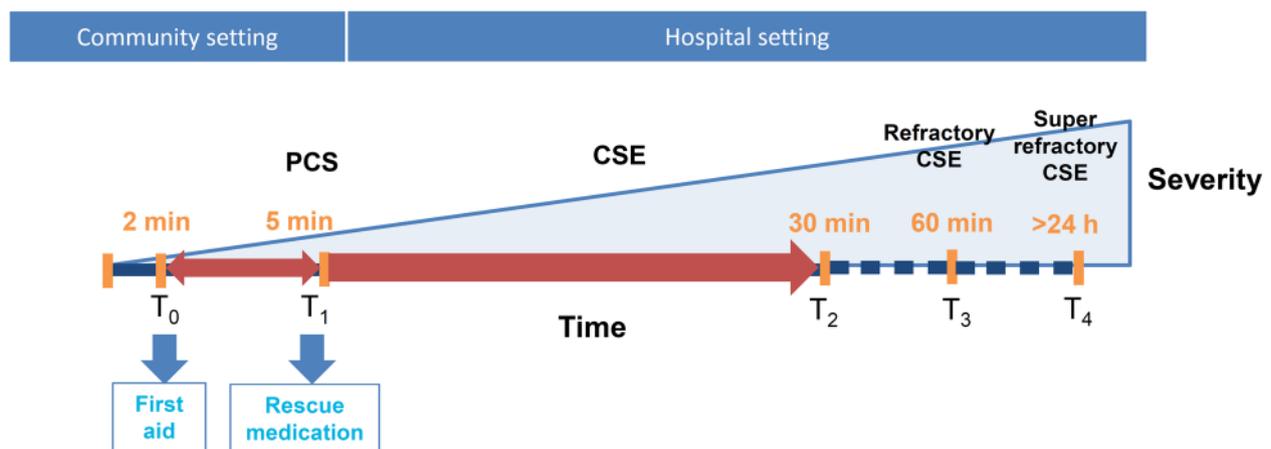
is the development of a seizure action plan (SAP), which is a personalized emergency plan with clear written instructions provided by the doctor or nurse on how to manage seizures [8].

Current rescue medications available to treat PCS in children in the community in Europe include buccal midazolam (midazolam oromucosal solution) and rectal diazepam. Such rescue medication will likely be administered by caregivers, such as family members or school staff.

The aim of this project was to provide European expert recommendations for the management of PCS in children in the community setting.

## Methods

In October 2023, two bibliographical searches were conducted: a systematic non-exhaustive literature review on PCS rescue medication in the community for the pediatric population in Europe, and a search for most recent international guidelines and recommendations on epilepsy and PCS treatment in children and adolescents. Main search terms were “prolonged convulsive seizures”, “prolonged acute convulsive seizures”, “prolonged seizures”, “rectal diazepam”, “buccal midazolam”, “oromucosal midazolam” and “community”. In November 2023, an outline was written to guide a European multidisciplinary expert panel meeting. The experts, child neurologists specialized in epilepsy care, reviewed the outline and provided their comments. In January 2024, this expert panel met to discuss and agree the recommendations on rescue treatment in PACS in pediatric patients in Europe. This paper presents the results of the meeting.



**Fig. 1** Representation of the evolution of convulsive seizures showing the increasing grade of severity over time. Based on Trinka et al. 2015 [4] and Minardi et al. 2019 [5]. This chart is for generalized tonic–clonic seizures. For focal seizures with impaired consciousness,  $t_1 = 10$  min and  $t_2 = 1$  h.  $T_0$ : time to start with first aid and preparing the administration of rescue medication according to neurologist recommendations and the seizure action plan.  $T_1$ : deadline to start rescue medication for prolonged convulsive seizures.  $T_2$ : period after which seizures could result in neural cell death, modifications in neural networks, and functional deficiency.  $T_3$ : refractory CSE.  $T_4$ : super refractory CSE. CSE: convulsive status epilepticus

## Prolonged convulsive seizures

### Prolonged convulsive seizures and convulsive status epilepticus

The definition of PCS is debatable but, as stated above, the expert panel defined PCS as a motor seizure lasting at least 5 min (Fig. 1) [4, 5]. However, some factors may change the duration of what is considered, at an individual level, a prolonged seizure, such as the patient age, the underlying etiology or precipitating factors, or the epilepsy syndrome (e.g., Dravet syndrome) [9, 10]. Furthermore, even though PCS and CSE are different conditions [4], sometimes these terms are used interchangeably, causing confusion.

CSE is the most common medical neurological emergency in children [11]. Its incidence varies depending on the defined duration for CSE [4, 12]. Current ILAE definition considers a duration longer than 5 min [4] but in the past, most clinical and epidemiological studies used the old definition of CSE, seizure activity lasting longer than 30 min [12]. Applying that old definition, the annual incidence in Europe ranged between 17 and 23 cases per 100,000 children [11], with the highest incidence in children younger than 3 years [11]. In a recent Scottish study using the new CSE definition (a duration of at least 5 min), the annual incidence of CSE in children (aged 0 to 14 years) was 81 per 100,000; and for seizures longer than 30 min, the incidence was 18 per 100,000 per year [13]. There are no epidemiological data on PCS because there is no agreed definition. PERFECT-3 is one of the few studies providing specific data on PCS. It included 256 patients with at least one PCS per year, and 44.9% of patients had 3 or less PCS per year. The mean number of PCS episodes per year was  $23.6 \pm 59.8$  and the median was 4 (range 1–400) [14]. The expert panel considered these incidences underestimated because not all patients with prolonged seizures will call an ambulance and/or present to the emergency department. This is especially true if the caregiver already has rescue medication and is experienced in managing prolonged seizures.

It is important to identify whether the patient has a history of previous prolonged or acute repetitive seizures (ARS), since these are the most important risk factor for CSE [15]. Currently, there is no standard definition of ARS [16], although several definitions have been proposed [17]. The most widely accepted practical definition of ARS is “the occurrence of an increased frequency of a person’s usual pattern of seizures during a defined time period” [16]. However, rescue treatment of ARS represents an unmet need in Europe because, unlike in the United States, no rescue medication is approved for this specific indication by the European Medicines Agency (EMA). Nevertheless, both PCS and ARS could progress to CSE (Fig. 1) [4, 5], and therefore should be treated

early with rescue medication according to the recommendations of the responsible physician [4, 5].

### Impact of prolonged convulsive seizures in children

A PCS lasting at least 5 min is unlikely to cease without intervention and should be managed as a medical emergency to prevent progression to CSE and potential short- and long-term neurological and systemic consequences [2]. CSE may require hospitalization and possibly intensive care unit admission [18]. CSE-related mortality in children is low, with a short-term mortality of 3–5% [12, 19] with no significant effect on long-term mortality [12]. However, neurological morbidity may be up to 22%, including focal neurologic deficits, cognitive impairment and behavioral problems, in addition to ongoing seizures [20]. Short-term consequences of refractory CSE, defined as a CSE resistant to ASM and requiring anesthetic drugs [18], can be severe, including cardiorespiratory compromise, electrolyte abnormalities, respiratory or renal failure, rhabdomyolysis and raised intracranial pressure [21]. Long-term outcomes of CSE largely depend on the underlying etiology, although there appears some increase in the risk of neurological impairment if the convulsive activity lasts for more than 30 min [22]. These neurologic sequelae may occur in less than 15% of patients [23], although cognitive impairment has been reported in up to 34% [24].

The longer the duration of a convulsive seizure, the more likely seizure control will be difficult with potential risk of increased morbidity [20], especially in refractory CSE [22]. There is clear evidence that rescue therapy of PCS in the community setting reduces seizure duration [14] and the progression to CSE [25]. Early PCS treatment has an 80% response rate, declining rapidly with treatment delay [26].

### Profiles of children at risk of prolonged convulsive seizures

Even though the first PCS will likely be managed in an emergency department, it is important to identify patients who are at risk of PCS recurrence. This risk is related to factors or certain epilepsy syndromes that predispose the individual to prolonged seizures, such as Dravet syndrome or PCDH19 clustering epilepsy, as well as a previous history of CSE [27]. Twenty-five per cent of patients with a first unprovoked seizure are at risk of PCS and CSE [28]. In infants and children, the most common cause or trigger factor for CSE is fever, accounting for about a third of all pediatric CSE events [20]. Risk and trigger factors and epilepsy etiologies associated with the risk of PCS are summarized in Table 1 [12, 27, 29–31].

In this article we are focusing on the pediatric population, but we also wish to highlight the importance of the continuity of care through the transition period from adolescence to adulthood.

**Table 1** Main risk factors, trigger factors and epilepsy etiologies associated with prolonged convulsive seizures. Based on [12, 27, 29–31] and expert opinion

Risk factors and trigger factors	Epilepsy syndrome/ etiologies
<ul style="list-style-type: none"> <li>• Febrile illness</li> <li>• Withdrawal or change of ASM</li> <li>• History of previous seizure emergencies (PCS, CSE, ARS)</li> <li>• Poor or non-compliance to ASM (teenagers)</li> <li>• Drug-resistant epilepsy</li> <li>• Young age (infancy)</li> <li>• History of febrile seizures</li> <li>• Perinatal injury</li> <li>• Hypoxic injury</li> <li>• Infections</li> <li>• Intellectual disability</li> <li>• Fatigue</li> <li>• Sleep deprivation</li> <li>• Prior neurosurgery procedure</li> <li>• Early age at epilepsy onset</li> <li>• High seizure frequency in the first 12 months after the onset of epilepsy</li> <li>• Changes or addition of other medication that modify the absorption of ASM</li> <li>• Stress (adolescence)</li> <li>• Alcohol ingestion (adolescence)</li> </ul>	<ul style="list-style-type: none"> <li>• Developmental and epileptic encephalopathies</li> <li>• Dravet syndrome</li> <li>• PCDH19 mutation</li> <li>• Monogenic early onset epilepsies</li> <li>• Structural epilepsies</li> <li>• Sturge-Weber syndrome</li> <li>• Focal cortical dysplasia</li> </ul>

The most frequent factors associated with risk of prolonged convulsive seizures are highlighted in bold. Infancy: from 1 month to 2 years. Childhood: longer than 2 to 12 years. Adolescence: longer than 12 to < 18 years

ASM Anti-Seizure Medication, PCS Prolonged Convulsive Seizures, CSE Convulsive Status Epilepticus, ARS Acute Repetitive Seizures, CNS Central Nervous System

### Rescue therapy in the community setting in Europe

Benzodiazepines are the most commonly used first-line rescue medication for the treatment of PCS [32, 33]. Current rescue medications approved by the EMA and commercialized in most European Union (EU) countries are rectal diazepam solution [34], approved in 1978, and oromucosal midazolam solution (buccal midazolam) [35], approved in 2011, although options available depend on the country. Buccal midazolam is available in 26 European countries and some international markets too (e.g., Japan, Australia, UAE), but access can vary. In certain countries, availability is more limited due to several factors, like regulatory timelines or price and reimbursement policies. In summary, buccal midazolam is considered standard of care in many countries, while in others its adoption is still progressing [36].

In April 2022, the EMA granted marketing authorization for the use of intranasal midazolam as PCS rescue management in some countries [37]. However, in January 2025 the product was still not available; therefore, the experts cannot provide any recommendations for this product.

Any decision relating to the administration of rescue medication needs to be individualized. Several factors must be considered in choosing the right therapy: the

**Table 2** Comparative of the characteristics of the ideal rescue medication for PCS treatment in pediatric patients between buccal midazolam and rectal diazepam

Characteristic	Buccal midazolam	Rectal diazepam
• Broad spectrum of efficacy [39, 41]	+++	+++
• Rapid onset of action [39, 40, 42, 43]	+++ <sup>a</sup>	++
• Easy administration [39, 44, 45]	+++ <sup>b</sup>	+
• Socially acceptable and privacy protection [44, 45]	+++	–
• Easy portability [35, 41, 44, 45]	+++	+++
• Minimal adverse effects and rapid return to normal life [35, 41]	+++	+

PCS Prolonged Convulsive Seizures

<sup>a</sup>Less than 10 min [40]

<sup>b</sup>Four steps for buccal midazolam vs. seven steps for rectal diazepam

drug and route of administration properties; the patient's environment; cost-effectiveness, preferences and skills of patients/parents/caregivers, and drug availability in the country [38].

The ideal drug for rescue medication should possess some key characteristics, listed in Table 2 [39–45]. Buccal midazolam has advantages over rectal diazepam in patients older than 6 months and consequently should be considered a first-choice rescue medication in the community setting. Several differences between buccal midazolam and rectal diazepam formulations exist, including pharmacokinetics, posology, and convenience (Table 2 [39–45] and Table 3 [34, 35, 46]). The elimination half-life of buccal midazolam is shorter than that for rectal diazepam (3.5 h vs. 1–2 days); thus rectal diazepam may accumulate after multiple doses resulting in more prolonged sedative effects [34, 35]. The short elimination half-life of buccal midazolam and its active metabolite implies a short duration of action [40]. The rapid onset of action of buccal midazolam, less than 10 min, is due to rapid absorption across the buccal membrane [40]. Onset of action of rectal diazepam is similar, but drug absorption is erratic [47] and therefore onset of action can be delayed. As absorption of rectal diazepam is potentially unpredictable in patients with constipation or diarrhea [48], administration of buccal midazolam is preferable to rectal diazepam in these patients. Buccal midazolam also potentially advantages those patients with tumors or bleeding in the rectal area and those who have recently undergone intestinal surgery [49].

Buccal midazolam has been compared to rectal diazepam in randomized controlled trials [42, 43] and observational studies [50, 51], as well as in a meta-analysis [47]. Data from comparative studies indicate the average time required to administer treatment is shorter with buccal midazolam compared to diazepam, both intravenous (less than 1 min vs. 2 min;  $p < 0.001$ ) [52] and rectal (2 min vs. 3 min;  $p < 0.001$ ) [53]. However, according to

**Table 3** Rescue medication approved in Europe for pediatric patients (aged less than 18 years). Based on Buccolam® Summary of Product Characteristics [35], Desitin® Summary of Product Characteristics [34] and Olkkola, 2008 [46] +

Rescue medication	Midazolam oromucosal solution	Rectal diazepam																		
Indication	Treatment of prolonged, acute, convulsive seizures in children and adolescents (3 months to less than 18 years)	Treatment of epileptic and febrile seizures in patients > 1 year of age (> 10 kg). <sup>b</sup> Use in children < 10 kg (< 1 year) is not recommended																		
Administration route	Buccal	Rectal																		
Administration																				
Elimination half-life	3.5 h	1–2 days																		
Posology	<table border="1"> <thead> <tr> <th>Age</th> <th>Dose</th> </tr> </thead> <tbody> <tr> <td>From &gt; 6 months to &lt; 1 y<sup>a</sup></td> <td>2.5 mg</td> </tr> <tr> <td>From &gt; 1 y to &lt; 5 y</td> <td>5 mg</td> </tr> <tr> <td>From 5 y to &lt; 10 y</td> <td>7.5 mg</td> </tr> <tr> <td>From 10 to 17 y</td> <td>10 mg</td> </tr> </tbody> </table>	Age	Dose	From > 6 months to < 1 y <sup>a</sup>	2.5 mg	From > 1 y to < 5 y	5 mg	From 5 y to < 10 y	7.5 mg	From 10 to 17 y	10 mg	<table border="1"> <thead> <tr> <th>Weight and age</th> <th>Dose</th> </tr> </thead> <tbody> <tr> <td>10–15 kg (1–3 y)</td> <td>1 tube of 5 mg</td> </tr> <tr> <td>Above 15 kg (&gt; 3 y)</td> <td>1 tube of 10 mg</td> </tr> <tr> <td>Adults</td> <td>2 tubes of 10 mg</td> </tr> </tbody> </table>	Weight and age	Dose	10–15 kg (1–3 y)	1 tube of 5 mg	Above 15 kg (> 3 y)	1 tube of 10 mg	Adults	2 tubes of 10 mg
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10–15 kg (1–3 y)	1 tube of 5 mg																			
Above 15 kg (> 3 y)	1 tube of 10 mg																			
Adults	2 tubes of 10 mg																			
Presentations	Pre-filled syringes: • 2.5 mg/0.5 ml, yellow label • 5 mg/1 ml, blue label • 7.5 mg/1.5 ml, purple label • 10 mg/2 ml, orange label	Monodose tubes: • 5 mg/2.5 ml • 10 mg/2.5 ml																		

+ The information included may differ in different countries

<sup>a</sup>Patients from 3 to 6 months of age (dose of 2.5 mg) should be treated at the hospital

<sup>b</sup>Include 3 other indications: (1) to relieve muscle spasm caused by tetanus; (2) as a sedative in minor surgical and dental procedures; (3) initial use in anxiety and agitation, when the disorder is severe, disabling or subjecting the individual to extreme distress

y, years

the expert panel, this difference is not significant enough to have a major clinical impact. Furthermore, the onset of action of buccal midazolam is faster than rectal diazepam, median time of 4 min vs. 5 min ( $p < 0.001$ ) [53]. Similarly, treatment response time is more rapid with buccal midazolam compared to intravenous and rectal diazepam [43, 53, 54], with cessation of seizures within 5 min in 100% of patients receiving buccal midazolam and 82% of those treated with rectal diazepam ( $p < 0.001$ ) [53]. It is obvious that the drug administered intravenously has a much faster action, but the mean time for initiation of treatment is significantly less with buccal midazolam or rectal diazepam [52, 53]. Finally, for seizures recurring within the next 24 h, there was more seizure-free time when using buccal midazolam (median time 5.1 h vs. 1.8 h with rectal diazepam;  $p = 0.001$ ) [54]. However, although buccal midazolam appeared superior to diazepam in some studies, others found no statistically significant differences, potentially due to limited sample size [42]. The expert panel considered the efficacy of both medications comparable.

Furthermore, in clinical practice, buccal midazolam is associated with fewer adverse events, with less sedation compared to rectal diazepam [55]. Buccal midazolam is easier to administer than rectal diazepam during tonic–clonic seizures [49, 56], particularly in wheelchair users and those with preserved consciousness [49], and it is also more socially acceptable [55], thus more suitable for community administration. Many family members, teachers and other non-family caregivers prefer to avoid rectal administration [42].

Rectal diazepam can be more economical than buccal midazolam. However, in cost-effectiveness studies conducted in different EU countries [53, 55–58], buccal midazolam was cost-saving in the treatment of PCS in the community reducing ambulance need, hospitalizations and intensive care admissions. In all the modelled countries it demonstrated incremental health benefits, measured as quality-adjusted life-year (QALY) [53, 55–58]. For these reasons, buccal midazolam is considered by the experts the preferred treatment for prolonged seizures in the community for children from age 6 months [57].

Buccal midazolam is approved for the treatment of PCS in many European countries [58–67]. It is considered first-line treatment in PCS by the National Institute for Health and Care Excellence (NICE) guidelines in the UK [58]. Buccal midazolam is authorized for the treatment of PCS in children from 3 months of age and also for adult use. The expert panel considered the thresholds for rescue medication use in PCS management should be consistent for all pediatric ages, throughout the transition and into adulthood.

**Table 4** What to do and what not to do as first aid for epileptic seizures [70–72]

YES	NO
<ul style="list-style-type: none"> <li>• Clear area around the patient to avoid injury from objects</li> <li>• Only move the patient to another place if they are in danger</li> <li>• Roll patient onto one side if possible</li> <li>• Put something soft under the head of the patient</li> <li>• Maintain clear airways</li> <li>• Monitor time of seizure: note start and finish time</li> <li>• Keep onlookers away from the patient</li> <li>• Stand by the patient's side the whole time of seizure</li> <li>• Stimulate patient at the end of a seizure</li> </ul>	<ul style="list-style-type: none"> <li>• Leave the patient alone, unless necessary to call for help</li> <li>• Forcibly hold the person down</li> <li>• Restrain jerking movements</li> <li>• Put anything in patient's mouth</li> <li>• Give food or drink before full recovery</li> <li>• Cardiorespiratory resuscitation maneuvers</li> </ul>

**Table 5** When to call an ambulance for prolonged convulsive seizures [70, 72, 73]

Call an ambulance in case of:

- First-time prolonged convulsive seizure
- Prolonged convulsive seizure lasting longer than the usual pattern
- Prolonged convulsive seizure continuing 5 min after administration of the rescue medication
- The person does not regain full consciousness or has recurrent seizures without regaining consciousness
- The person is injured during the prolonged convulsive seizure
- The person has difficulty breathing or vomiting after the prolonged convulsive seizure
- If the full dose of the rescue medication is not delivered (e.g. vomiting after oromucosal administration or defecation after rectal administration), or if the caregiver cannot administer rescue medication

When there is no need to call an ambulance:

- Immediately when a prolonged convulsive seizure begins in a person with known epilepsy and frequent seizures
- You have a care plan provided by a neurologist and you have been trained how to administer rescue medication and the above triggering to call an ambulance does not apply

## Recommendations for the management of prolonged convulsive seizures in the community setting

### Management of prolonged convulsive seizures in the community setting

Recommendations for PCS management usually focus on the hospital treatment of CSE rather than in the community setting. This is discussed in the NICE guidelines for epilepsies in children, young people and adults (2022) [58] and in a 2023 review of the new Advanced Paediatric Life Support (APLS) guideline on the management of the convulsing child [6]. According to a review, national clinical guidelines about the management of PCS in six European countries do not provide specific guidance on issues related to training or individualized protocols for children [68]. Moreover, a European working group composed of pediatric neurologists and epileptologists, epilepsy patients and their parents, highlighted

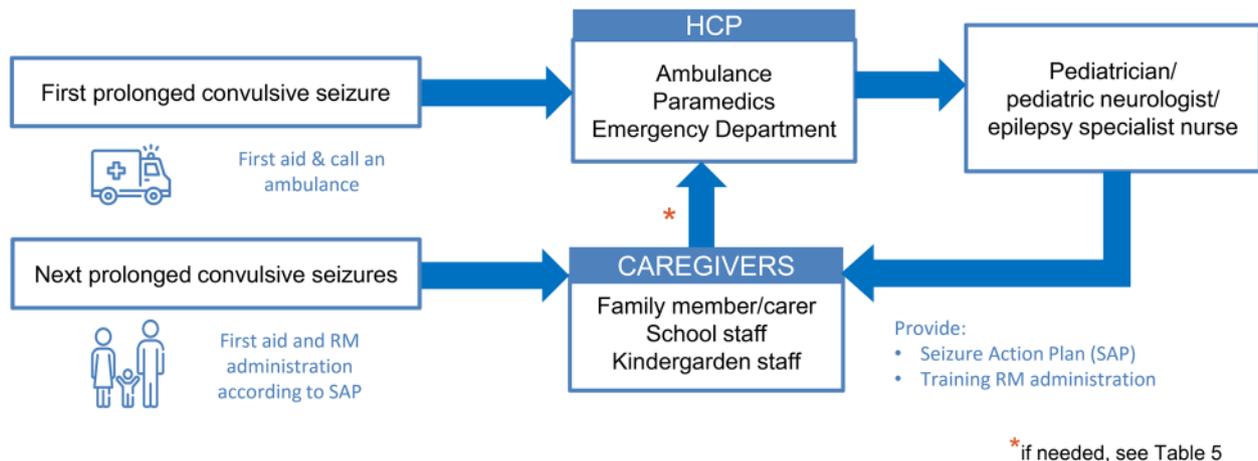
the relevance of early PCS management at school [69]. Nevertheless, the policy paper was not focused on rescue therapy use [69]. Although many US-based publications address rescue medication and seizure action plans (SAPs), they may not apply to the EU because products and their indications differ. Consequently, the following PCS management recommendations are intended primarily for application to children in the community in European countries.

Caregivers, such as parents, other family members and school staff, should be trained to recognize and manage PCS in the community setting. They should be trained in immediate, emergency management of seizures, including what to do and what not to do (Table 4) [70–72], and when to call an ambulance for PCS (Table 5) [70, 72, 73]. Furthermore, they should be trained in administering rescue medication according to the recommendations on the individual patient's SAP. Children at high risk of PCS, such as those with Dravet syndrome, should have an individualized SAP and a prescription for rescue medication (see later) [74]. In cases of highly drug-resistant epilepsy with possibly multiple prolonged seizures a day, the SAP should preferably include information on when to call emergency services, as this may differ from the standard protocol.

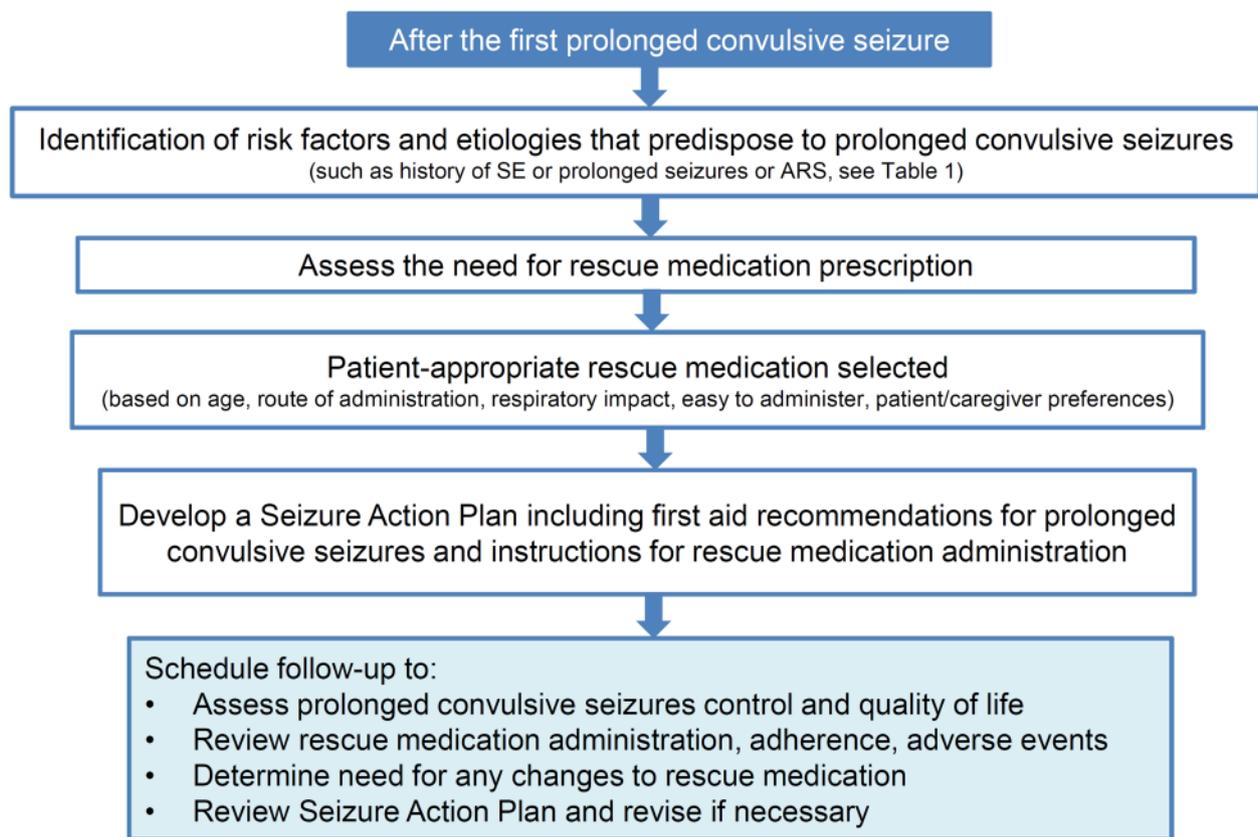
### Rescue medication use

In cases where a first PCS has already occurred, treatment of PCS in the community should be initiated where the seizure occurs (e.g. home, school, park, or other public place) by trained caregivers or school staff members [14]. Generally, rescue medication should be prescribed at least to children with a history of a convulsive seizure lasting longer than 5 min and longer than the usual pattern. However, there are some individual exceptions such as for children with Dravet syndrome, where time to rescue administration should be individualized considering the risk factors, usual seizure duration and the frequency of the convulsive seizures for any given patient.

Caregivers should measure seizure duration and follow the ABC (Airway, Breathing, Circulation) protocol as well as first-aid recommendations [75]. Most non-prolonged seizures last around 2 min. However, if the convulsive seizure lasts for longer than 2 min, caregivers should start first aid; if the convulsive seizure persists, they should prepare to administer rescue medication and if the convulsive seizure lasts at least 5 min, they should administer rescue medication (Fig. 2) [4, 5], always according to the individual patient SAP. If the seizure does not stop after 5 min from the first dose or as instructed in the SAP, caregivers should call an ambulance and may administer a second dose of rescue medication following the recommendations contained in the SAP [75].



**Fig. 2** Management of first and next prolonged convulsive seizures in the community setting. Based on Trinkka, 2015 [4] and Minardi, 2019 [5]. *RM* Rescue Medication, *SAP* Seizure Action Plan, *HCP* Healthcare Professionals



Local regulation or guidelines should be taken into account when applicable. In some countries rescue medication is prescribed to almost all patients.

**Fig. 3** Algorithm for management after the first prolonged convulsive seizure. Based on Ramsay et al. 2023 [75] and expert opinion

Once in the ambulance or in the hospital, the experts suggest administering intravenous treatment where access is available. If not, they recommend a second dose of buccal midazolam if not previously administered by the caregivers. In-hospital treatment of CSE is described

elsewhere [6, 57, 75] and is not within the scope of this paper.

The proposed treatment algorithm for children with PCS is presented in Fig. 3 [76]. After the first PCS, the identification of factors and etiologies predisposing to

**Table 6** Examples of seizure action plan

Source	URL
International League Against Epilepsy (ILAE)	<a href="https://www.ilae.org/files/dmfile/seizure-action-plan-sample.jpg">https://www.ilae.org/files/dmfile/seizure-action-plan-sample.jpg</a>
Epilepsy Foundation	<a href="https://www.epilepsy.com/sites/default/files/2023-08/SeizureActionPlan2023ACCE.pdf">https://www.epilepsy.com/sites/default/files/2023-08/SeizureActionPlan2023ACCE.pdf</a>
Child Neurology Foundation	<a href="https://www.childneurologyfoundation.org/wp-content/uploads/2018/04/CNF_Seizure_Action_Plan_v4_fillable.pdf">https://www.childneurologyfoundation.org/wp-content/uploads/2018/04/CNF_Seizure_Action_Plan_v4_fillable.pdf</a>
Seizure Action Plan Coalition	<a href="https://seizureactionplans.org/sap-examples/">https://seizureactionplans.org/sap-examples/</a>
Defeating Epilepsy Foundation	<a href="https://www.defeatingepilepsy.org/seizureactionplan/">https://www.defeatingepilepsy.org/seizureactionplan/</a>
French Ministry of National Education and Youth	<a href="https://eduscol.education.fr/document/7763/download">https://eduscol.education.fr/document/7763/download</a>
Penovich et al., 2021 [8]	<a href="https://www.sciencedirect.com/science/article/pii/S1525505021005254">https://www.sciencedirect.com/science/article/pii/S1525505021005254</a>

**Table 7** Content which should be included in a Seizure Action Plan for children with prolonged convulsive seizures

- Name and birth date of patient
- Emergency contacts
- Epilepsy/seizure type(s)
- Antiseizure medication
- First aid recommendations (Table 4)
- When an ambulance should be called (Table 5)
- What to do when waiting for an ambulance to arrive
- When to administer rescue medication and how, route and dose of rescue medication
- When or if a second dose of rescue medication should be administered
- If the patient goes to hospital, hospital recommendations and procedure (usual anti-seizure medication or what kind of medication should be avoided due to the history of patient)

PCS is important. Subsequently, assess whether a rescue medication prescription is required and if so, prescribe an appropriate rescue medication (based on age, ease of administration, patient/caregiver preferences). The expert panel members are aware that in clinical practice the 5-min limit is often not followed. This is understandable if dealing with patients who habitually present with PCS or are at risk of CSE. In these cases, earlier administration of rescue medication after 2 or 3 min, or even at seizure onset, may be warranted if a patient is known to always go on to a PCS. According to the expert panel, time to rescue medication needs to be individualized after considering the usual duration and frequency of the patient's convulsive seizures. As a consequence, an individualized SAP should be developed with the required information, and a series of measures related to PCS control, rescue medication and review should be scheduled. SAP will be updated at follow-up visits if needed.

#### Importance of a seizure action plan (SAP)

A SAP includes patient-specific details about management of seizures, including advice on administration of

rescue medication. All patients diagnosed with epilepsy should have an individualized SAP, specifically those predisposed to experiencing PCS (Table 1) [12, 27, 29–31]. Having a SAP does not always mean a prescription for rescue medication in all countries. A SAP also educates patients and caregivers (family and other caregivers, such as school staff) and provides a management strategy [8]. It should be individualized, although published or available models can be used as a template (Table 6). A SAP for patients with PCS should include key information relating to seizure management in the community (Table 7), but in selected cases also in hospital. The value of a SAP lies not only in tailoring the timing of rescue medication but also in adapting the route of administration to the comfort and feasibility for each caregiver. In this context, caregivers of young children may often prefer rectal diazepam because it is perceived as easier to administer [75], whereas in school and other out-of-home settings the rectal route is generally less acceptable. In addition to a SAP, in patients with rare or severe epilepsies, such as Dravet syndrome, a written letter with additional information should be included.

In most cases and countries, rescue medication is prescribed, and an individualized action plan is defined only after a first PCS. In all patients with risk factors for PCS (Table 1) [12, 27, 29–31], rescue medication and a SAP should be established even before a first PCS (for example, in patients with Dravet syndrome).

For the transition period to adulthood, when transferring patients from pediatric to adult care, it is important to ensure that an updated SAP is available to share with individuals who will administer the rescue medication in the community setting.

#### Management of PCS in kindergarten and schools

Awareness of epilepsy and, consequently, of PCS, has been reported as poor or inadequate in European schools [69]. In addition, epilepsy rescue medication is not usually mentioned in the guidelines for using medicines at school [68]. As a high percentage of pediatric patients spend considerable time in educational settings [77], it is important that kindergarten and school staff be trained in first aid and in managing PCS [69]. School nurses have the required skills and experience, but they are not present in all schools in all EU countries or may cover more than one school so may not be physically present on site. Therefore, teachers or other staff members of centers with children diagnosed with epilepsy should be trained by the school doctor/nurse, or the local health service [68], or via face-to-face training by patient organizations [78]. Training increases confidence in administering rescue medication and dealing with PCS and other seizures [79]. Interventions can include short videos (available in different European languages) [80–83], materials or

e-training programs by the pediatrician/pediatric neurologists or nurses. In brief, school staff should know: what to do in case of seizures and when to intervene. Ideally, in EU countries, caregivers should provide the school with all the relevant information received from the pediatrician or pediatric neurologist, as well as a request to administer rescue medication to the child when needed [68]. However, the administration of rescue medication to children and adolescents is a voluntary task for school staff in the EU [69] and there are differences on that subject in legal frameworks between European countries [68]. In addition, these legal frameworks are not well-defined and therefore their application can be complicated [68].

The most important issue for the management of PCS is that a SAP should be implemented in all educational settings. The healthcare professionals and parents/caregivers should jointly develop a SAP with the support of the school policy on medicine administration, local protocols between health system and educational services, or both [68]. Subsequently, the resulting document should be shared with school staff. Furthermore, a SAP must be written in such a way that it can be understood and implemented by the staff in all educational settings.

## Conclusions

This document constitutes the first expert panel recommendations for the management of PCS in children in the community setting in Europe, developed by pediatric neurologists specialized in managing epilepsy. The experts emphasize the importance of recognizing that a PCS lasting more than 5 min presents a medical emergency with a need for urgent rescue medication since the likelihood of spontaneous seizure cessation are low. Their key recommendation is thus that a PCS should not exceed 5 or more minutes without administration of rescue medication. It is important to adhere to this time maximum to increase chances of successful seizure termination and to avoid further seizure progression. However, time to administration of rescue medication should be individualized and thus potentially shorter for any given patient, this mainly applies to those with a history of PCS (e.g., patients with Dravet syndrome or drug-resistant epilepsy with a tendency to have recurrent PCS), depending on their risk factors, usual seizure duration and seizure frequency.

It is important to individualize a SAP for PCS management according to each patient's profile and it should be reviewed periodically. All patients at risk for PCS should therefore have an individual SAP including first aid recommendations and instructions on timing of rescue medication administration. It is essential that caregivers, usually family and kindergarten/school staff, are trained to recognize and treat PCS with rescue medication in the

community setting, following the recommendations in the SAP.

In general, the expert panel agreed that the preferred rescue therapy to manage PCS in the community setting is buccal midazolam beyond the toddler age, due to its characteristics compared to rectal diazepam. Buccal midazolam is available in most European countries as pre-filled syringes at different dose levels that are easy to administer by caregivers, is well tolerated and effective, as well as socially acceptable, and preserves the privacy of children and adolescent patients.

The current document includes practical considerations for PCS management in the community setting that we hope can be implemented in all European countries, including content for developing a SAP, first aid and when to call an ambulance, and a treatment algorithm for children with PCS.

## Abbreviations

ARS	Acute Repetitive Seizures
ASM	Anti-Seizure Medication
CSE	Convulsive Status Epilepticus
EMA	European Medicines Agency
EU	European Union
ILAE	International League Against Epilepsy
NICE	National Institute for Health and Care Excellence
PCS	Prolonged Convulsive Seizure
SAP	Seizure Action Plan
UK	United Kingdom

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## Authors' contributions

FV, AA, SA, AMK, BL, MMB, SP, PS and HC reviewed available literature and participated in the meetings to decide the outline of the paper and the caregiver survey, as well as to reach an agreement on different concepts and recommendations. Furthermore, all authors read and approved the final manuscript.

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No datasets were generated or analysed during the current study.

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Not applicable.

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