

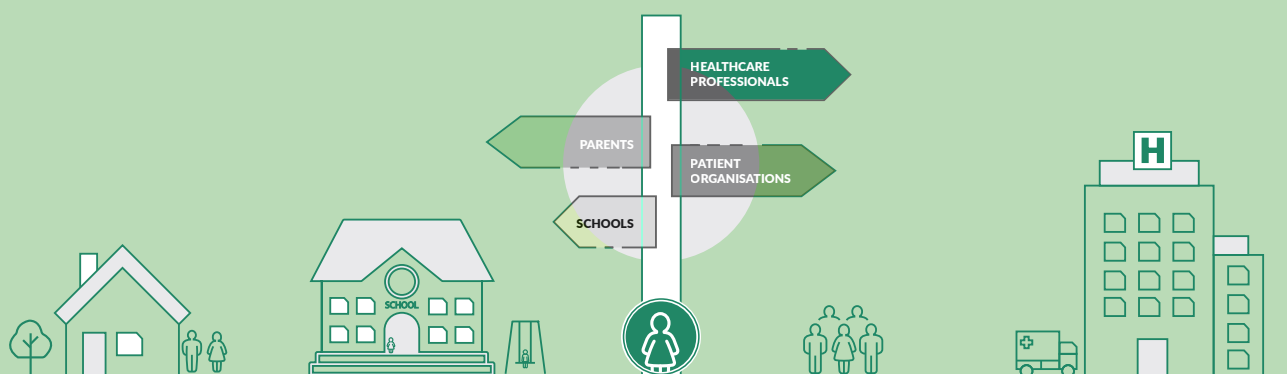
Ensuring appropriate management of prolonged convulsive seizures in children with epilepsy outside of hospital

A policy paper to ensure a safe and inclusive education for at-risk children

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Executive summary

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Stigma and discrimination: a risk for children with epilepsy

Epilepsy is the one of the most common neurological conditions in children, yet it remains poorly understood.

As a result, many children are at risk of stigma and discrimination.

Most children with epilepsy are able to attend mainstream school, even in the presence of associated disabilities. The school environment acts as a testing ground for how well these children can integrate with their peers, and whether they are subject to discrimination because of their condition.

The management of prolonged convulsive seizures

A small group of children with epilepsy who may be particularly vulnerable to discrimination are those who experience prolonged convulsive seizures. Unlike most other seizures, prolonged convulsive seizures do not stop spontaneously; they require emergency medication because the longer a seizure lasts, the less likely it will stop on its own without medication.

Most children are unconscious during prolonged convulsive seizures, therefore they require a trained caregiver to administer their medication immediately. Administration of emergency medication is a simple procedure that does not require any medical training.

Schools: an opportunity to get this right

Children spend a large part of their time at school. As a closed environment, schools offer a key opportunity to create a positive setting for children with epilepsy. This requires appropriate awareness-raising of epilepsy and seizure management, among all staff and pupils.

To meet the needs of children with prolonged convulsive seizures, awareness must be accompanied by specific school policies to ensure children can receive their emergency medication in a timely and appropriate manner and as indicated in their individualised healthcare plans. This involves identifying members of staff who volunteer to provide emergency medication to children; offering them appropriate training; having up-to-date medicines policies; and ensuring accountability

mechanisms are in place to address any fears of liability on behalf of staff in case of adverse events.

If such measures are not in place, parents are left to find solutions on a case-by-case basis to protect the safety of their child during the school day. Children risk exclusion from school activities and general discrimination from their peers, not to mention significant anxiety and impact on their overall quality of life.

A lack of policy and guidance

Until now, the needs of children with prolonged convulsive seizures have received little attention in either health or educational policies at the European or national levels. Most countries lack clear guidance, policies, information and resources to ensure that all

schools meet the needs of pupils in their care who have prolonged convulsive seizures. Even in areas where such guidance does exist, it is inconsistently implemented.

Recommendations

Policymakers have a critical role to play to redress this situation, and ensure the rights of this vulnerable group of children are met – and the school environment presents a clear opportunity to do so.

Against this background, we advise that **the following steps should be put in place at a European, national, regional and local level**, taking into consideration the specificity of local contexts and existing policy frameworks:

- 1 European institutions, particularly the European Commission, should ensure that the needs of children with epilepsy are **included in policies on inclusive education, social integration and anti-discrimination**.
- 2 National government policies must **promote and protect the right to freedom from discrimination and an inclusive education** for all children with epilepsy across all types of educational settings.
- 3 Ministries of education should **make basic epilepsy awareness and seizure management training mandatory** for all teachers and relevant school staff.
- 4 Ministries of health and education should work together to develop **joint national guidance** on the administration of emergency medication in schools, and include children with epilepsy in these proposals.
- 5 Epilepsy specialists, working together with the child's family, the school and other relevant stakeholders, should provide each child at risk of prolonged convulsive seizures with an **individualised healthcare plan**. This plan should guide all actions taken to ensure appropriate management of a child's epilepsy at home, at school and in other non-hospital settings.
- 6 Schools should create **clear accountability** for the implementation of these individual health plans across all aspects of school life.
- 7 Schools should include specific information on the administration of emergency medication in their **medicines policies**, and update these policies on a regular basis.
- 8 Local councils (or their equivalent) should be mandated and appropriately funded to provide **dedicated training resources for teachers and other school staff** on the management of prolonged convulsive seizures. The specifications of what training is needed for each child will be defined within his or her individualised healthcare plan.
- 9 Schools should take out **liability insurance to protect teachers** from any wrongdoing in administering emergency medication, in accordance with national regulations.
- 10 National educational inspectorates should **monitor and evaluate** the implementation of guidance on the management of prolonged convulsive seizures across all schools.

Main report

Context

Epilepsy in schools – the need for greater awareness

Epilepsy is one of the most common neurological disorders in children, affecting approximately 1 in every 200 (0.5%) children.¹ Yet most people would not know what to do if faced with a child having a seizure – and many children suffer **stigma and discrimination as a result.**²

The majority of children with epilepsy attend mainstream schools, even if they present with additional disabilities. For these children, being in a school that fosters awareness and understanding of epilepsy and seizures will be key to their social integration. How well-accepted they are by their peers will also have a significant long-term impact on their self-esteem, social integration and overall quality of life.²⁻⁴

Unfortunately, evidence suggests that there is generally poor awareness of epilepsy in mainstream schools, putting children at risk of discrimination and social exclusion (see *Box 1*).^{5,6}

Box 1. Awareness of epilepsy is inadequate in schools

- According to a 2015 survey, 54% of German teachers reported a prior familiarity with epilepsy in children.⁵
- 87% of Italian teachers received information on epilepsy from the child's parents – but only 50% knew what to do if a child had a seizure.⁷
- Over three-quarters of schools in England have at least one child with epilepsy.⁸ Of these:
 - Less than 40% have a written epilepsy policy
 - 26% had not had epilepsy training for staff in the last three years.
- In a survey of the French population in 2016:
 - 32% of respondents reported they were bothered or uncomfortable to have their child educated by a teacher who has epilepsy
 - 11% were uncomfortable with the idea that their child might be friends with a child who has epilepsy.⁹

Addressing the needs of children who present with prolonged convulsive seizures

Protecting the right to an education free from discrimination is critical for a vulnerable group of children with epilepsy who experience prolonged convulsive seizures.

Most children with epilepsy will never have a seizure at school. However, approximately 30% of children experience seizures despite being on antiepileptic medication.¹⁰ Of these, a number will experience prolonged convulsive seizures.¹¹

Prolonged convulsive seizures are seizures that do not stop on their own. They must be treated with emergency medication, otherwise status epilepticus may develop – a life-threatening condition which may lead to neuronal damage and other clinical consequences.^{12 13}

Most children are unconscious during a prolonged convulsive seizure. They therefore rely on a trained caregiver to administer their medication.¹⁴ At home, this is typically a parent or family member. Outside of the home, if a parent is not available, someone else must take on this role – and receive specific training to do so.

The school environment – an opportunity to ‘get this right’

Prolonged convulsive seizures may occur anywhere – however, schools offer a closed environment where a teacher or other staff member may act as a designated caregiver to ensure children receive their emergency medication in a timely and appropriate manner.

Until now, there has been a lack of political attention to the needs of children with prolonged convulsive seizures in schools – or in other non-hospital settings.

A review article on a number of studies has shown that there is generally a lack of clear guidance on the administration of emergency medication to children with prolonged convulsive seizures in schools and other non-hospital (community) settings.¹⁴ Existing policies and legal frameworks are vague or non-existent. Even where national guidance exists, it is inconsistently applied. Information available to schools and families is also very limited. As a result, families are left to struggle alone to find solutions on a case-by-case basis.

This policy paper aims to ensure that policies, processes and resources are in place so that every child who has a prolonged convulsive seizure at school receives their emergency medication in a timely and appropriate manner.

Although this paper is focused on the school environment, recommendations apply equally to other community settings such as leisure centres or sports facilities.

The management of prolonged convulsive seizures at school

Prevention of clinical and psychological harm for children

As mentioned previously, prolonged convulsive seizures do not stop on their own and require emergency medication to stop the development of status epilepticus, a life-threatening condition.

Therefore, if processes are not in place to ensure children receive their emergency medication as quickly as possible at school, children may have increased risk of brain injury, reduced response to treatment or respiratory disturbance/failure – often requiring prolonged hospitalisation. This may severely affect children’s ability to lead a normal school life and cause significant anxiety to them, their parents and the entire school body (see *Box 2*).

Box 2. Why management of prolonged convulsive seizures is needed at school

- **If left untreated, prolonged convulsive seizures may cause:**
 - poor response to treatment¹⁵
 - respiratory disturbance/failure¹⁶
 - brain damage.^{15 16}
- **If children cannot receive emergency medication at school, they are at increased risk of:**
 - **Poor social integration** with their peers
 - **Lack of independence** due to their constant reliance on parents to be ‘on call’ in case they have a prolonged seizure
 - **Discrimination** and possible exclusion from school (and other) activities.
- **If parents cannot be guaranteed that the medical needs of their children are addressed at school, this causes:**
 - **Anxiety and fear** for the safety of their child during the school day
 - **Potential loss to productivity** as they have to be ‘on call’ in case a prolonged seizure occurs.¹⁴
- **Calling an ambulance every time a child has a prolonged seizure at school results in avoidable costs:**
 - **For healthcare systems** – waiting for an ambulance to arrive may delay the administration of medication to the child, increasing the risk of status epilepticus and leading to prolonged and costly hospital stays
 - **For families** – parents may have to limit their productivity if they have to be ‘on call’ in case a prolonged seizure occurs.¹⁴

The importance of training

Schools cannot oblige their staff to take responsibility for administering emergency medication. This is a voluntary role in all EU countries. Schools should, however, support staff who accept responsibility for administering emergency medication to children, by providing clear guidance and information in the form of written school policies. They should also provide staff with appropriate training, and update their training as necessary.

An important message to convey to all staff volunteering to administer emergency medication is that training is straightforward and does not require any medical knowledge or expertise. What's more, specific guidance appropriate to each child in terms of dosage and processes to follow will be contained within the child's individualised healthcare plan, which should be developed by their treating physician in collaboration with other relevant caregivers.

Addressing the fear of liability

Even in the presence of clear guidance, a number of barriers may need to be addressed to ensure every child receives their emergency medication in a timely manner. Teachers' fear of liability is often the most important hurdle to overcome (see *Box 3*).

Some staff members may refuse to administer emergency medication for fear of liability in case anything goes wrong. Evidence suggests that teachers, for example, often feel poorly prepared for an emergency resulting from epilepsy.⁵ In a German survey, teachers cited lack of knowledge about administration (34%), lack of guidance and clear authorisation (28%) and fear of liability (7%) as the main reasons for their reluctance to administer emergency medication.⁵

Box 3. Key barriers to the appropriate management of prolonged convulsive seizures in schools

Lack of specific guidance on the management of prolonged convulsive seizures: Some countries have recently developed guidance on the management of health conditions at school. However, specific information and guidance on how to manage prolonged convulsive seizures is rarely included (PERFECT 1).¹⁴

Lack of clinical guidelines: There are no European guidelines on the management of prolonged convulsive seizures outside of hospital. And epilepsy specialists are not always aware of the challenges their patients face in securing administration of their medication at school (PERFECT 2).¹⁷

Unclear accountability for training: Training of school staff is often left to the responsibility of parents – or provided on a voluntary basis by patient organisations. Schools are often unclear on their training requirements, and teachers fear liability as a result. In some countries, guidance does not clearly specify whether non-medical personnel are allowed, even with specific training, to deal with emergency medical situations in schools.^{14 18}

The way forward

Finding solutions is not just the responsibility of schools. It requires close collaboration between educational and health authorities, epilepsy specialists, patient organisations and families.

Ensuring that every child with a history of prolonged convulsive seizures receives appropriate and timely emergency medication at school is complex – and requires close collaboration between a number of stakeholders. Ministries of health and education must provide leadership to ensure the needs of this vulnerable group of children are met. They should develop joint guidance and put in place adequate resources and clear accountability mechanisms to secure implementation at the national, regional and local level.

Key recommendations

We advise that the following steps are put in place to ensure that every child with a history of prolonged convulsive seizures may receive appropriate and timely emergency medication at school, and in other non-hospital settings.

- 1 Include children with epilepsy in all EU-level anti-discrimination and social inclusion policies**

European institutions, particularly the European Commission, should ensure that the needs of children with epilepsy are included in policies on inclusive education, social integration and anti-discrimination – following on the principles outlined in the WHO Resolution Report on epilepsy (2015)³ and the European Written Declaration on epilepsy (2011; 2016).^{2,4}
- 2 Ensure the right to an education free from discrimination for all children with epilepsy**

National ministries of health and education should promote and protect the right to freedom from discrimination and an inclusive education for all children with epilepsy through appropriate policies and legislation.
- 3 Make training on epilepsy and seizure management mandatory for all teachers**

All teachers, educators and staff, from preschool to secondary school, should be given basic epilepsy awareness and seizure management training as part of their mandatory health and safety training (see *Case studies 1 and 2*).
- 4 Develop national guidance on the administration of emergency medication in schools**

Ministries of health and education should work together to issue joint guidance on how to ensure children with epilepsy who require emergency medication may receive it at school. This may be standalone guidance on epilepsy or take a broader approach and cover the management of all health conditions at school (see *Case study 3*).
- 5 Provide each child at risk of prolonged convulsive seizures with an individualised healthcare plan**

All children with a history of prolonged convulsive seizures should have an individual healthcare plan (see *Case studies 4 and 5*). This should be developed by their treating physician with input from parents, the school administration, school nurse or doctor (if available) and other relevant health or educational professionals. The individual healthcare plan should guide all efforts to meet the medical needs of children with epilepsy at home, at school, and in other non-hospital settings e.g. appropriate dosing of medication, what to do in case of an adverse event etc.

6**Create written school policies on the administration of emergency medication**

Schools should have clear, written policies on how they will meet the needs of children who require emergency medication during school hours (see *Case study 6*). They should designate a specific person, or persons, to oversee the implementation of individual healthcare plans across all aspects of school life, and ensure staff who volunteer to administer emergency medication receive appropriate training to do so (see *Case study 7*). Policies should be updated on a regular basis.

7**Include specific information on the administration of emergency medication in medicines policies in schools**

Any school that has a pupil with a history of prolonged convulsive seizures should include specific provisions for the administration of emergency medication in its general medicines policy. These policies must be updated regularly to make sure they reflect children's current individual healthcare plans.

8**Require local authorities to provide dedicated training resources for school staff on the management of prolonged convulsive seizures**

Local councils or their equivalent should be held responsible for providing appropriate training to all school staff on the management of prolonged convulsive seizures, and given appropriate resources to do so. This should not be left to the responsibility of parents (see *Case study 8*). Specific training needs relevant to each child should be made explicit in their individualised healthcare plans.

9**Make liability insurance mandatory for schools to protect teachers**

All schools that have pupils with a history of prolonged convulsive seizures should be obliged to take out appropriate liability insurance and accept full liability for teachers administering emergency medication to children at school.

10**Monitor and evaluate the implementation of guidance**

The national educational inspectorate (or equivalent body) should include clear criteria on whether schools have appropriate provisions in place to meet the needs of children at risk of prolonged convulsive seizures.

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Case study 1

Raising awareness of epilepsy within the school environment – a video for schools

To help raise awareness of epilepsy in schools and familiarise school children and teachers with what happens during seizures, the International Bureau for Epilepsy and International League Against Epilepsy have created a series of educational videos featuring Campi, a seahorse who has epilepsy.

This series of videos has been launched on International Epilepsy Day and is accompanied by a toolkit to help inform schools about epilepsy and seizure management.

Link: <https://www.youtube.com/watch?v=ILvf4vJ9a5I&list=PLDtaVe7oIIxzoYkS4R3eBQJFGEIZ8oFS&index=1>



Case study 2

Government leadership to improve awareness and integration of children with epilepsy in France

The Fondation Française Contre l'Epilepsie (France) has worked with the French ministry for national education as well as the national committee on epilepsy to develop a helpful resource to help improve understanding of epilepsy in schools.²⁰ This resource is available on the main website for teachers nationally and resulted from the work of a multidisciplinary committee over several months.

The resource consists of a two-page information sheet and starts with the citation from William Lennox, a pioneer of epilepsy research, stating: 'Epilepsy is the only condition whose stigma, prejudices and social consequences are often worse than the condition itself.' The document highlights the need for teachers and educators to understand the nature of epilepsy and seizures, and make necessary arrangements to address particular needs of children who may have seizures in class. This includes the administration of emergency medication if needed. The resource also speaks about the need to prevent the exclusion of children with epilepsy from all school activities and to raise awareness of epilepsy among the entire school body. These steps are needed to allow children with epilepsy to enjoy a normal childhood and exercise their full rights to an inclusive education, social life and citizenship.

Link: http://cache.media.eduscol.education.fr/file/Action_sanitaire_et_sociale/00/4/Accueillir_et_accompagner_un_eleve_atteint_d_epilepsie_version_consultable_739004.pdf

Case study 3

Developing a ‘medical conditions at school’ policy – the example of the UK

In 2015, the Health Conditions in Schools Alliance – a group of over 30 patient organisations representing long-term medical conditions that require some form of medical assistance in school (including epilepsy) – lobbied the UK government to issue new guidance on the management of medical conditions at school. The resulting guidance, *Supporting pupils at school with medical conditions*,²⁰ provides statutory guidance for the governing bodies and owners of schools in England on how to address the needs of children with medical conditions.

The three main points of the guidance are:

- ‘Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education
- Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported.’

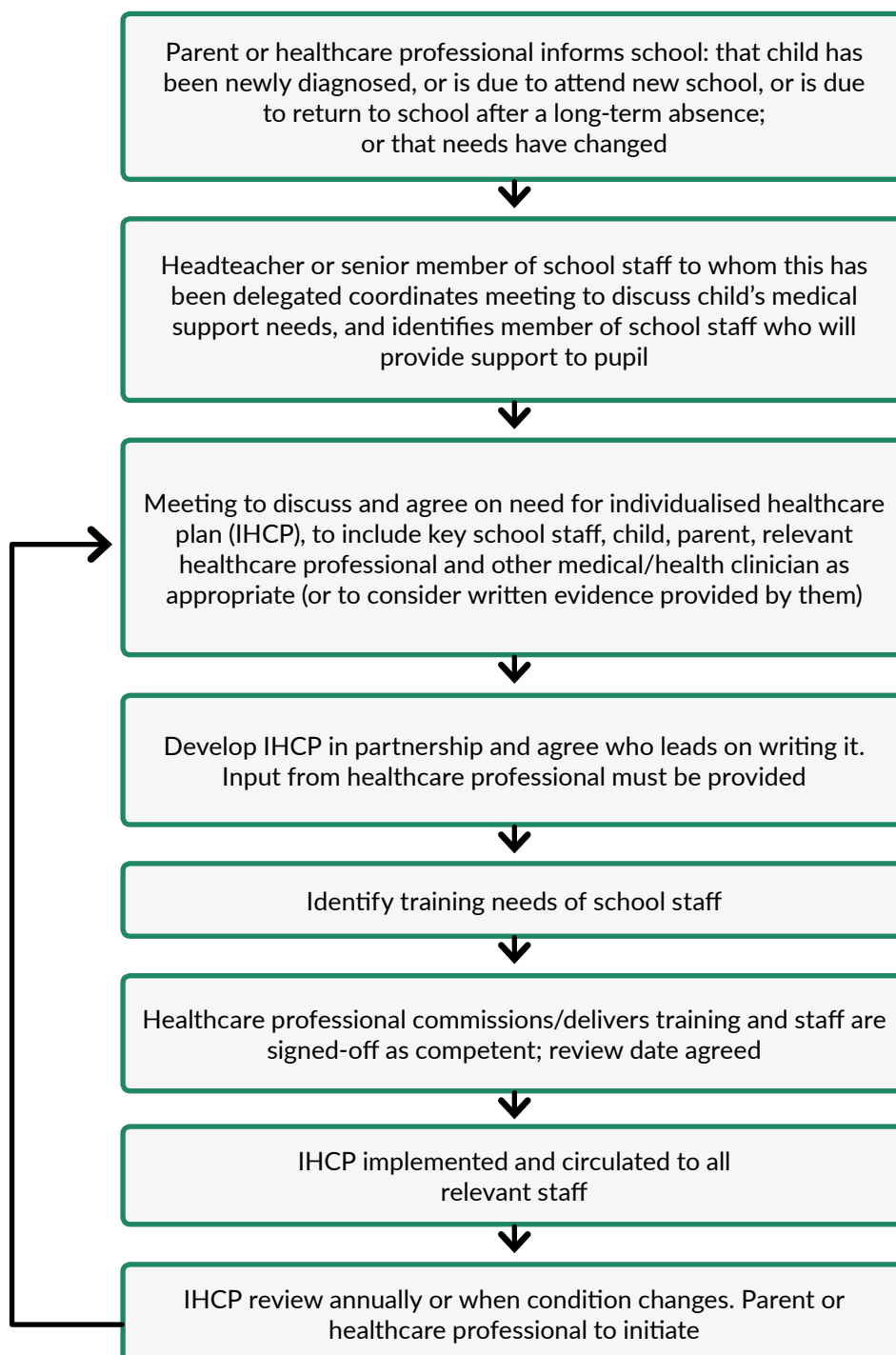
Case study 4

Individualised healthcare plans – what should they do?^{14 20-22}

- Have the interests of the child at heart, respecting their dignity and independence in terms of the most appropriate treatment choice
- Cover all aspects of a child's life with epilepsy at school and in other settings
- Provide detailed classification of the type of seizures involved and describe their manifestation
- Provide full details and written instructions on the medicine prescribed, correct dosage and administration, as well as information for storage and renewal
- List explicitly who is allowed to administer emergency medication to the child and has received appropriate training to do so
- Provide full contact details of who should be contacted in case of a prolonged seizure occurring (e.g. parents)
- Make clear what constitutes an emergency and what to do if the treatment is not effective
- Make clear when a child can be considered safe to remain in school after a seizure, or when an ambulance must be called
- Make clear what the child can and cannot do, and avoid unnecessary exclusion (e.g. from school trips).
- Be evaluated on a regular basis to ensure they are up-to-date.

Case study 5

Process for setting up an individualised care plan – example from the Department for Education, England²⁰



Case study 6

School policies to create accountability for the management of prolonged convulsive seizures in children²⁰

What should school policies include?

- Details of who is responsible for ensuring sufficient staff are suitable trained
- A commitment that all relevant staff will be made aware of the child's condition
- Cover arrangements in case of staff absences or staff turnover, to ensure someone is always available
- Briefing for supply teachers
- Risk assessments for school visits, holidays and other school activities outside of the normal timetable
- Monitoring of individual healthcare plans.

Case study 7

Guidelines for training standards by the Joint Epilepsy Council of the UK and Ireland

Emergency medication

It has been recognised that the administration of emergency medication for the control of prolonged or continuous seizures is an effective treatment which can be lifesaving. Given promptly, this relatively simple procedure can prevent major disruption to daily life resulting from hospital emergency treatment.

The use of emergency medication is recommended in the UK's National Institute for Health and Care Excellence (NICE) clinical practice guideline on the diagnosis and management of epilepsy in children and adults, published in 2004.

There are several possible routes of administration of emergency medication. Buccal administration is considered to be a less invasive procedure than rectal administration of the medicine. The issues of privacy and dignity are less compromised and in situations where it is not acceptable or convenient to administer medicine rectally, buccal administration is an effective alternative.

Epilepsy Ireland

Epilepsy is a condition characterised by a tendency to have recurring spontaneous seizures. Epilepsy can affect anyone at any time. It is estimated that up to 37,000 people in Ireland (over the age of five) have some form of epilepsy.

Epilepsy Ireland was established in 1966 and has since provided support nationwide to people with epilepsy, their families and friends. Epilepsy Ireland also aims to improve public understanding of epilepsy and eliminate prejudice and misunderstanding about it; to encourage and assist research into the causes and treatment of epilepsy; and to promote awareness of the condition.

Since 2009, Epilepsy Ireland – in response to feedback from health professionals who identified this as an unmet need – has been providing training to health professionals, allied health professionals, school teachers and special needs assistants in epilepsy awareness and the administration of buccally administered emergency medication.

The programme is the only one of its kind in Ireland and is delivered in accordance with the Joint Epilepsy Council guidelines on training standards for the administration of emergency medication. The aim of the training programme is for participants to develop a greater knowledge of epilepsy in general, understand the role of the emergency rescue medications and receive instruction in the correct buccal administration of specific emergency medications.

At the end of 2016, Epilepsy Ireland had delivered a total of 508 training days, providing this important training to 5,224 people.

Course information and objectives

This course has been developed in conjunction with the Joint Epilepsy Council of the UK and Ireland (JEC) guidelines. Its objectives are:

- Participants develop a greater understanding of epilepsy.
- Participants are instructed in the administration of buccally administered emergency medication.
- Participants undertake two written assessments.
- Participants view a 45-minute DVD on seizures.
- Successful participants will receive a certificate of attendance.

The course contains general information about epilepsy awareness, as well as specific guidance on the administration of buccal emergency medication.

Participants take a written assessment at the end of each module. On successfully passing these assessments (pass = 75%), participants will receive a certificate of attendance (valid for two years). Delegates are then deemed competent to administer the specific buccally administered medicines covered in an emergency situation. It is the responsibility of the organisation to ensure that the necessary support procedures are in place for the safe administration of these medicines in accordance with JEC guidelines.

For more information, contact: Paul Sharkey, Training Manager, Epilepsy Ireland at psharkey@epilepsy.ie.

Case study 8

Overcoming fears of liability – the case of Italy

In Italy, the Federazione Italiana Epilessie (FIE), a large patient organisation dedicated to epilepsy, works with families of children with epilepsy to establish good relationships with schools and ensure that the needs of their children are met.

Their overall message to schools in the case of children who require emergency medication is that:

- **The administration of rescue medication is not a complex medical intervention:** parents do it at home, therefore it is completely reasonable to expect non-clinically trained personnel to administer rescue medication. This is important because in some countries (e.g. France), only medical personnel can take responsibility for dealing with emergencies. **From a medical perspective, there are minimal risks** associated with providing emergency medication in terms of adverse events.
- **Parents should accept full responsibility in case of any adverse events** when signing the individualised healthcare plan.

Two recent cases, provided courtesy of the FIE, illustrate the need for this guidance:

Case 1

- The family of a 15-year old boy attending secondary school came to the FIE. He has a form of epilepsy that responds well to medication and no other associated disabilities or health issues. The family asked, in case of prolonged seizures, to administer rectally based emergency medication.
- At first, the school contended that the medication would need to be brought to school and refused to allow the child to attend school until the medicine was received at school. Then, it gave the medicine back to the family, refusing to administer it. The school asked the family to sign a written declaration whereby they accepted all responsibility in case anything happened to the child as a result of an epileptic seizure. The parents issued a complaint to the local magistrate.
- The FIE suggested an informal meeting with the school to give staff a training session on epilepsy and seizure management, but the school refused.
- If the child were to have a prolonged seizure at school, the school would simply call an ambulance.

Case 2

- A six-year-old girl with pharmaco-resistant epilepsy was enrolled in the first year of primary school. Her parents asked the school to administer buccal emergency medication in case of a prolonged seizure – as she had these several times per month. The school refused and the child could not attend this school. The neuropsychiatrist who looks after the child, when informed of this by the parents, came to the FIE. The organisation contacted the school and offered an informal meeting with the teaching staff to explain, together with the doctor, the nature of the child's condition, the risks to the child if her prolonged seizures were not treated immediately, and the simplicity of the intervention needed i.e. administration of emergency medication. The FIE also emphasised that no technical skills were needed to administer emergency medication, and that these seizures are easily recognisable given their duration.
- The outcome of this meeting was positive, as the school then accepted responsibility for administering emergency medication to the child in question, and the child was able to attend school normally thereafter.
- The school put together an individualised action plan which was developed jointly with its staff, the child's family and the medical team.
- This action plan is now being used for other children who have conditions that require medical attention at school, in addition to epilepsy.

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