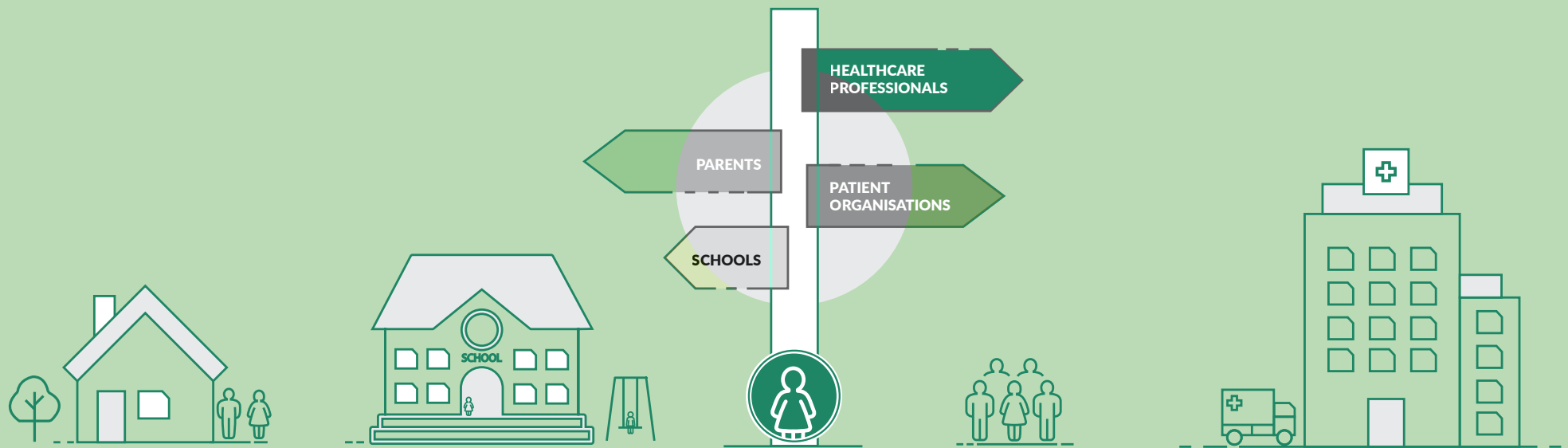


Improving the management of prolonged convulsive seizures for children in schools

An advocacy toolkit



This toolkit was developed and drafted by a multi-stakeholder group of epilepsy patient and parent representatives, educational and clinical experts, who volunteered to form a working group to help create greater political awareness and engagement on the need to improve the management of prolonged convulsive seizures in children outside of hospital.

This toolkit was initiated and funded by Shire, who commissioned The Health Policy Partnership to help develop it. Members of the expert group had full editorial control over the content.

The toolkit is based on a policy paper authored by the group, which may be found [here](#).

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This project was initiated and funded by Shire

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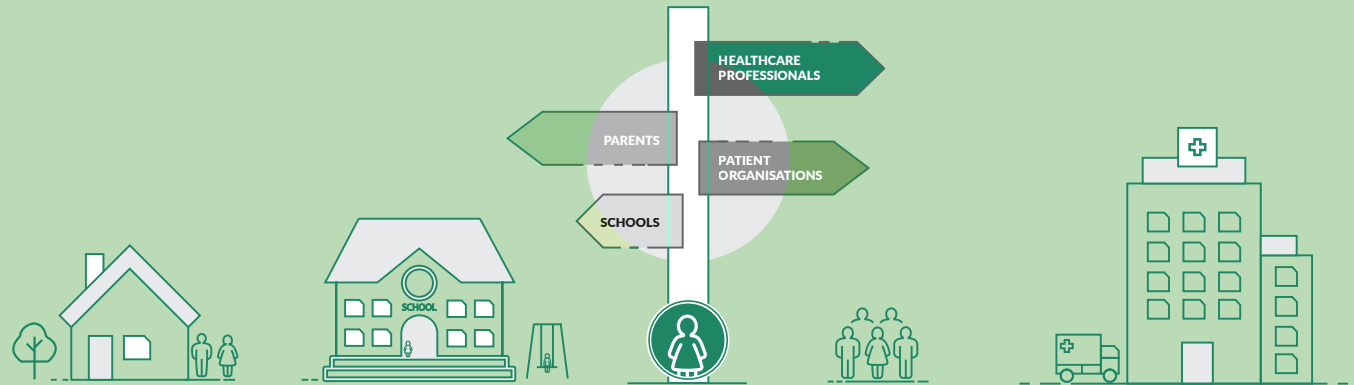
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About this toolkit



Why this toolkit?

Children with epilepsy who experience prolonged convulsive seizures are a particularly vulnerable group.

These children suffer social exclusion and impact on their quality of life,¹⁻³ and without emergency medication they risk serious long-term health consequences.⁴

The needs of this group of children have, until now, been poorly addressed. Appropriate policies, processes and guidance are often not in place,⁵ leaving parents to find solutions on a case-by-case basis.

Who is this toolkit for?

This toolkit is written principally for parents of children who have prolonged convulsive seizures – to help them ensure the needs of their children are met during the school day.





However, it can be used by anyone who wants to help ensure the needs of children with prolonged convulsive seizures are met at school.

The school environment presents an opportunity to 'get this right'.



What's in the toolkit?

This toolkit includes:

-  **Introduction**
Key facts and information on prolonged convulsive seizures
-  **'We need...' statements**
Key actions that need to be put in place
-  **'I am a...' sections**
Specific actions and tools for use by parents, schools, patient organisations and healthcare professionals
-  **Tools**
Useful resources and examples of good practice that could be replicated, including:



Case studies

Examples you can draw from



Factsheets

Accessible summaries of key information



Checklists

Printable lists to help guide discussions



Introduction



Children with prolonged seizures are a vulnerable group of children with epilepsy

- Epilepsy is one of the most common neurological conditions in children,⁶ yet it remains poorly understood. As a result, many children are at risk of stigma and discrimination.¹⁻³
- One group of children with epilepsy may be particularly vulnerable to discrimination – those who experience prolonged convulsive seizures.⁴
- In contrast with most other seizures, prolonged convulsive seizures are unlikely to stop spontaneously, and require emergency medication to be stopped.^{5,7}

The administration of emergency medication is a simple task to perform

- Emergency medication must be administered by a trained caregiver, as children are usually unconscious during prolonged convulsive seizures.⁵
- This is a simple procedure that does not require any medical knowledge or expertise, but does require specific training to ensure it is done safely.

A lack of guidance leaves every family to fight for their own solutions

- Schools are often not aware of what to do if a child has a prolonged seizure. Many lack adequate policies and guidance, and resort to calling an ambulance every time a child has a prolonged seizure.⁵
- Parents often don't know where to turn to find the right information, and are left to find solutions on a case-by-case basis.

Every child who experiences prolonged convulsive seizures should be able to receive timely and appropriate emergency medication while at school.

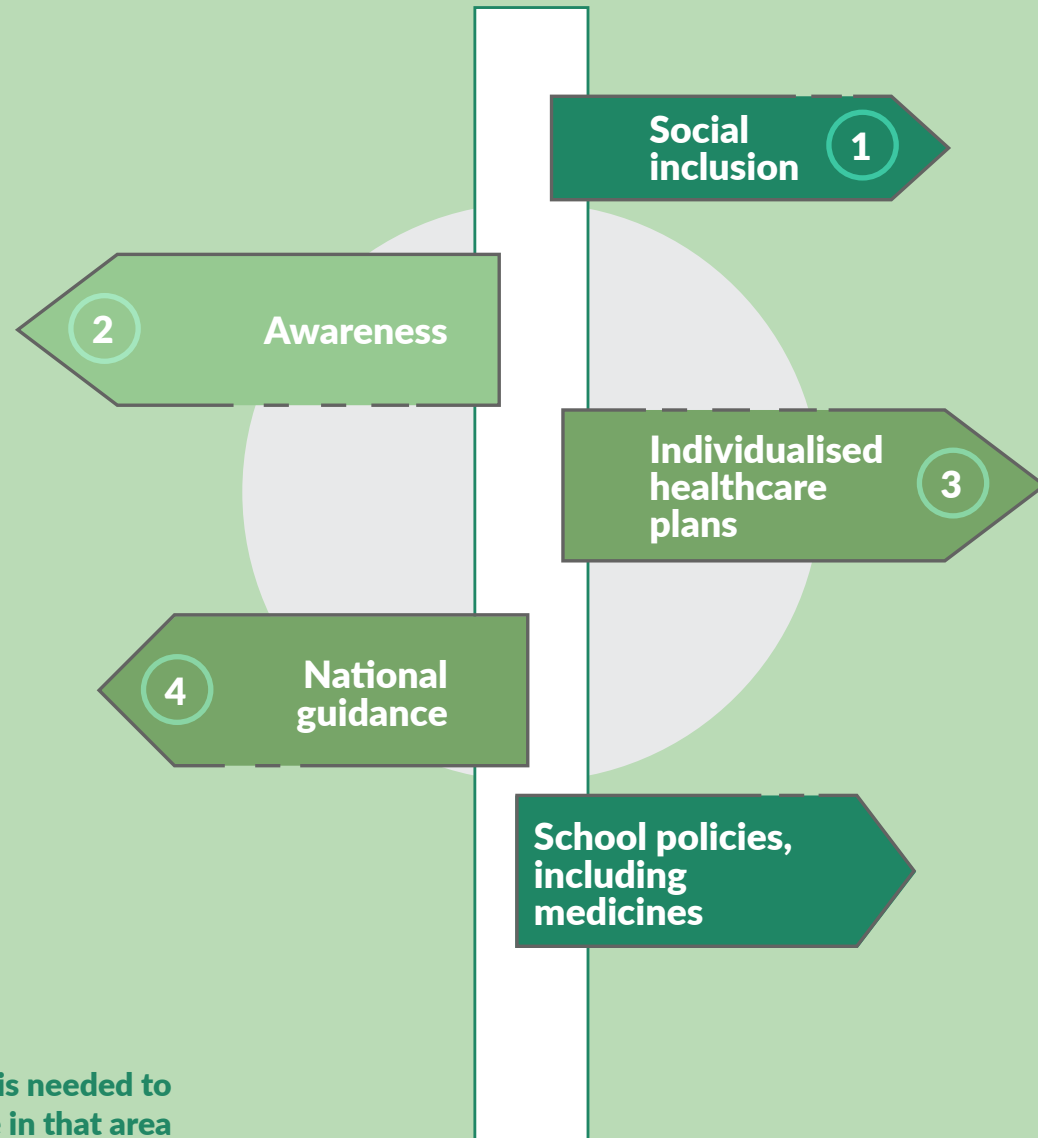
This toolkit aims to help make this happen, by providing information and resources to ensure policies and guidance exist and are applied in practice.

You are here: What do we need?

What do we need?

Every child with a history of prolonged convulsive seizures should be able to receive emergency medication at school.

The school environment presents an opportunity to 'get this right'.



Click on a sign to see what is needed to drive change in that area

You are here: [What do we need?](#) > Social inclusion

Social inclusion

We need children with epilepsy to be included in EU and national-level anti-discrimination and social inclusion policies

1



Why is it important?

Children with epilepsy can be at risk of discrimination and exclusion from school and other activities due to inadequate understanding of their condition.⁸

All children with epilepsy deserve to have the opportunity to grow up, learn and socialise normally with their peers.

Social and educational inclusion policies are a first step to ensure this happens.

What do we need?

We need social and educational inclusion and anti-discrimination policies. These can come from:

- **National ministries of health and education.** They should promote and protect the right to an inclusive education free from discrimination for all children with epilepsy, through appropriate policies and legislation.
- **The European Parliament and European Commission.** They should explicitly include children with epilepsy in EU-level legislation on inclusive education, social integration and anti-discrimination, to provide an example that can be replicated at the national level.

What can I do?

- **Write to your national Member of Parliament to ensure that all children with epilepsy, including those who have prolonged convulsive seizures, are given due recognition in equality laws – and that their right to an inclusive education is protected.**



See useful [Factsheets](#) that may help



Click [here](#) for an example letter



You are here: [What do we need?](#) > [Social inclusion](#) > Factsheet

Factsheet

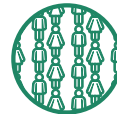
Epilepsy in children: facts and figures



Epilepsy is a condition characterised by repeated seizures that are caused by abnormal excessive electrical discharges in a part of the brain.^{9 10}



Epilepsy can start at any age, and can be caused by a number of underlying conditions.^{9 10}



Epilepsy is one of the most common neurological disorders in children, affecting approximately 1 in every 200 (0.5%) children.⁶



There are many different types of seizures, each with their own impact, symptoms and severity.⁹ A range of management options exist, although many people are able to manage their condition effectively with antiepileptic drugs.^{9 10}

Key links:

<https://epilepsy.org/about-epilepsy/>

<http://www.who.int/mediacentre/factsheets/fs999/en/>



You are here: [What do we need?](#) > Awareness

Why is it important?

What happens at school has a significant and long-term impact on children's overall wellbeing and how accepted they feel by their peers.

People tend to fear epilepsy as they don't know what to do if a child has a seizure. Awareness training for teachers and the whole school may help dissipate fears and create an accepting environment for all children with epilepsy (see [Factsheet](#)).

What do we need?

We need epilepsy awareness training for all staff, as well as students. This training should include:

- Simple and accessible information on epilepsy
- Explanations of the different types of seizures, and what to do in the case of prolonged convulsive seizures
- Information about individualised healthcare plans, which clearly describe what each child's individual needs are in terms of medical attention and care.

What can I do?

- **Ask your child's school whether they provide epilepsy awareness training, or offer to give a school talk on epilepsy and ask your child's treating physician to attend.**



We need teachers to better understand epilepsy and seizure management, including how to manage prolonged convulsive seizures

2



See [Case studies](#) to provide examples



See useful [Factsheets](#) that may help



You are here: [What do we need?](#) > [Awareness](#) > Case study

Case study

A video for schools to raise epilepsy awareness



[Click here](#) to see the
video



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 was launched on International Epilepsy Day 2016 and is accompanied by a toolkit to help inform schools about epilepsy and seizure management.



You are here: [What do we need?](#) > [Awareness](#) > Case study

Case study

Government leadership in epilepsy awareness in France



The Fondation Française pour la Recherche sur l'Épilepsie (France) has worked with the French ministry for national education to develop a resource to help improve understanding of epilepsy in schools.

The document highlights the need for teachers and educators to understand the nature of epilepsy and seizures, and make necessary arrangements to address the needs of children

who may have seizures in class. This includes the administration of emergency medication. The resource also speaks about the need to promote the inclusion of children with epilepsy in all appropriate school activities and to raise awareness of epilepsy throughout the entire school.

This resource is available on the national website for teachers.



Link:

http://cache.media.eduscol.education.fr/file/Action_sanitaire_et_sociale/87/7/Accueillir_et_accompagner_un_eleve_atteint_epilepsie_737877.pdf

You are here: [What do we need?](#) > [Awareness](#) > Factsheet

Factsheet

Why raise awareness of epilepsy in schools?



Evidence suggests that there is often poor awareness and understanding of epilepsy in schools, putting children at risk of discrimination and social exclusion.¹⁻⁸

This can have wide-reaching and long-term effects for the child – impacting their self-esteem, social integration and overall quality of life.¹⁻³

What does the evidence say?

Germany:

- A 2013–2014 survey of teachers found that just 54% of respondents reported a prior familiarity with epilepsy in children.⁸

Italy:

- 87% of teachers received information on epilepsy from the child's parents – but only 50% knew what to do if a child had a seizure.¹¹

UK:

Over three-quarters of schools in England have at least one child with epilepsy in their school.¹² Of these:

- Less than 40% have a written epilepsy policy
- 26% had not had epilepsy training for staff in the last three years.

France:

In a survey of the French population in 2016:¹³

- 32% were uncomfortable with the idea that their child might be taught by a teacher who has epilepsy
- 11% were uncomfortable with the idea that their child might be friends with a child who has epilepsy.



You are here: [What do we need?](#) > [Awareness](#) > Factsheet

Factsheet

What are prolonged convulsive seizures?



Approximately 30% of children with epilepsy experience seizures despite being on antiepileptic medication.¹⁴ Of these, a number will be prolonged convulsive seizures.¹⁵

Prolonged convulsive seizures do not stop on their own, so it is essential that there are adequate resources readily available to manage this condition.



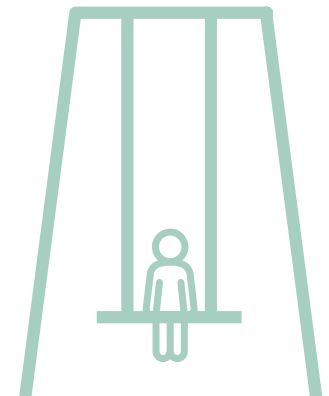
Children face real risks if their seizures are not stopped within a very short timeframe – a matter of minutes. If there are delays, the child risks status epilepticus, a life-threatening condition which may lead to:

- poor response to treatment¹⁶
- respiratory disturbance/failure¹⁷
- brain damage.^{16 17}

Most children are unconscious during this type of seizure, so they must rely on someone else to administer medication, where prescribed.^{4 5}

At home, this is usually carried out by their parents. At school, teachers or other staff members must take on this vital role to ensure the child's safety and health.

Administering emergency medication, where prescribed, is simple and does not require any specific medical expertise – but it does require specific training to ensure it is done safely.



You are here: [What do we need?](#) > Individualised healthcare plans

Individualised healthcare plans

We need each child with a history of prolonged convulsive seizures to have an individualised healthcare plan

3



Why is it important?

The individual healthcare plan contains essential information and guidance on how to meet the medical needs of children with epilepsy at home, at school, and in other non-medical settings.

The treating physician should write clear instructions in the plan on when and how to give medication, what training is needed for caregivers, and what to do if the seizure doesn't stop.

If schools have this information at hand, they can plan appropriately to meet the needs of each child.

What do we need?

Each child with a history of prolonged convulsive seizures should have an individualised healthcare plan.

- The plan should be written by the treating physician, in close consultation with the parents, child, school and any relevant local services (see [Case study](#) and [Checklist](#))
- The school should have designated staff in place who have clear accountability for knowing the contents of children's individualised healthcare plans and ensuring all resources are in place to meet their needs at school.

What can I do?

- Find out whether your child has an up-to-date individualised healthcare plan.
- Organise a meeting with your child's doctor and school to ensure everyone is clear about your child's needs and how to address them.



See [Case studies](#) to provide examples



See useful [Checklists](#) for guidance



You are here: [What do we need?](#) > [Individualised healthcare plans](#) > Checklist

Checklist

What to look for in an individualised healthcare plan^{4 5 7 18}



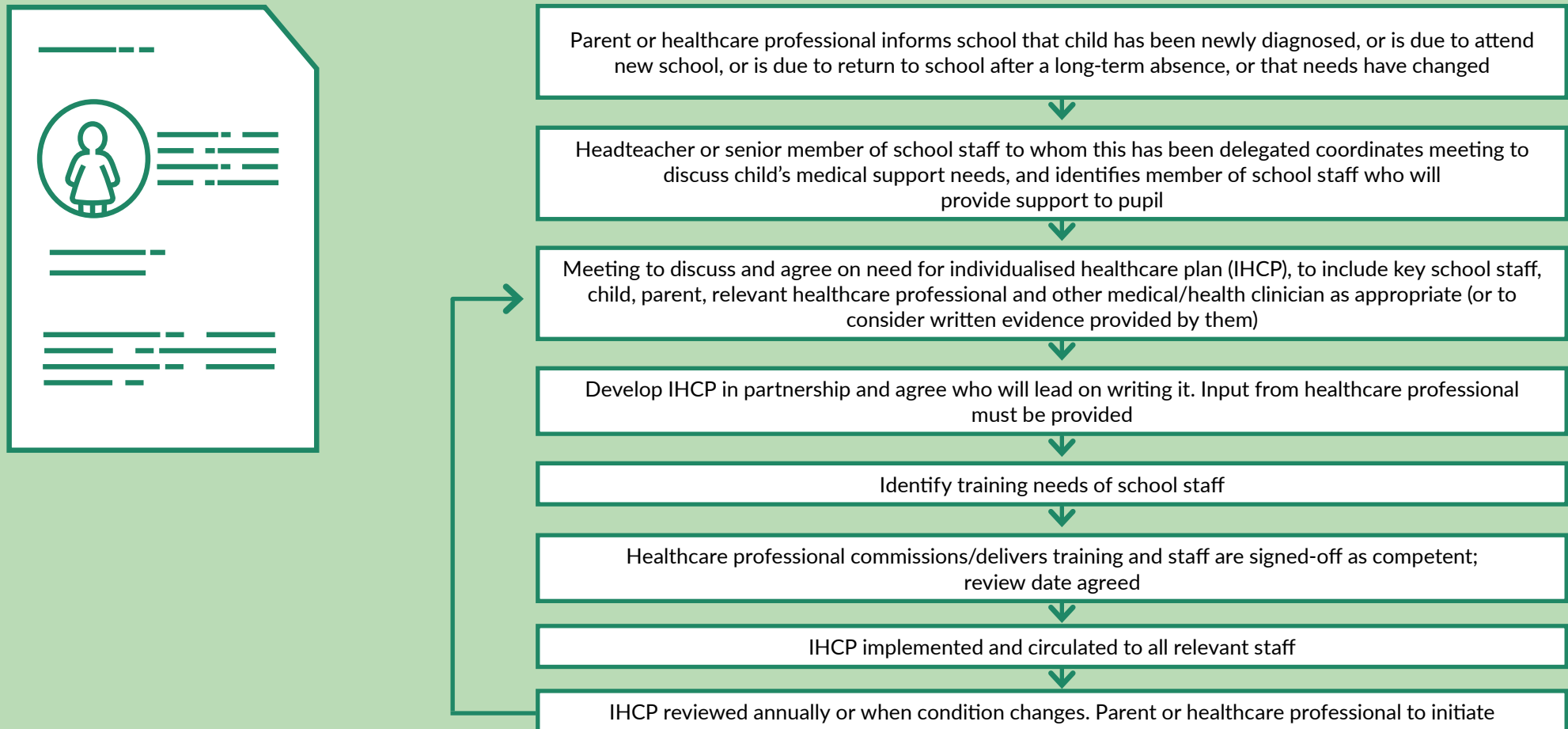
You may wish to print this checklist and take it with you when discussing the plan with your physician and school, so you can tick each item as it is addressed.

- ☐ Does it have the interests of the child at heart, respecting their dignity and independence?
- ☐ Has it been developed in close partnership with parents, the treating physician, school administration, school nurse or doctor (if available) and other relevant health or educational professionals?
- ☐ Does it provide detailed classification of the child's type of seizures and their presentation?
- ☐ Does it give written instructions on the child's prescribed medicines, including correct dosage and administration and storage?
- ☐ Does it make clear what constitutes an emergency and what to do if the treatment is not effective?
- ☐ Does it explicitly list processes and individuals to administer emergency medicines, alongside whom to contact in the case of a prolonged seizure occurring?
- ☐ Has it been shared with all school staff looking after your child?
- ☐ Does it make clear what activities the child can take part in to avoid unnecessary exclusion (e.g. from school trips)?
- ☐ Is it updated annually or when any changes to medicines or treatments occur?

You are here: [What do we need?](#) > [Individualised healthcare plans](#) > Case study

Case study

Process for setting up an individualised healthcare plan



This example is from the Department for Education, England¹⁸

You are here: [What do we need?](#) > National guidance

Why is it important?

In a study of six European countries, most lacked clear guidance and policies addressing the needs of pupils with prolonged convulsive seizures.⁵ Even where guidance exists for the management of medical conditions in schools in general, the specific needs of children with epilepsy are not always mentioned or well-defined.

Implementation of guidance is often inconsistent between schools.⁵

As a result, parents are left to find solutions on a case-by-case basis to protect the safety of their child during the school day.⁵

What do we need?

National-level guidance on emergency medicines, which:

- clearly states that all schools must have a written policy on how they address the needs of children requiring medical assistance at school, including emergency medication for children who have prolonged convulsive seizures
- is monitored regularly by educational inspectorates.

What can I do?

- If national guidance doesn't exist, work with your local epilepsy patient organisation to write to your local Member of Parliament and/or the ministry of education and demand that appropriate guidance be drafted.



See [Case studies](#) to provide examples



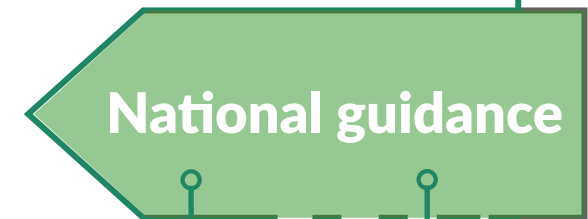
See useful [Factsheets](#) that may help



See printable [Checklists](#) for guidance



Click [here](#) for an example letter



We need national guidance to ensure all children with a history of prolonged convulsive seizures can receive their emergency medicine at school

4

You are here: [What do we need?](#) > [National guidance](#) > Case study

Case study

Why is national guidance important?



It can clarify who is permitted to administer emergency medication to children.

- In some countries, it is still unclear whether non-medical personnel are allowed, even with specific training, to administer emergency medication for prolonged convulsive seizures.^{5 19}

It can help address potential fears of liability.

- Some staff members may refuse to administer emergency medication for fear of liability in case anything goes wrong¹⁹ – and many teachers feel poorly prepared for an emergency resulting from epilepsy.⁸

It can specify who, within each locality, is responsible for providing training to school staff.

- Responsibility for training schools should not be left to parents.

It ensures regular monitoring of implementation.

- This will ensure guidance is being applied in practice and corrective measures can be put in place as needed.



You are here: [What do we need?](#) > [National guidance](#) > Checklist

Checklist

What should be included in school policies relating to seizures?¹⁸



You may wish to print this checklist and take it with you when discussing the policy with your school, so you can tick each item as it is addressed.

- ☐ Clear information about what prolonged convulsive seizures are and when emergency medication may be most appropriate
- ☐ Medicines storage and disposal information
- ☐ Details of who is responsible for ensuring sufficient staff are suitably 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.

You are here: [What do we need?](#) > [National guidance](#) > Case study

Case study

How patient organisations work with schools in 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.

FIE conveys the message to schools 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.

FIE also provides support to families when meeting with schools in helping to ensure their children's needs can be met.

Link:

<https://www.fiepilessie.it/>



You are here: [What do we need?](#) > [National guidance](#) > Factsheet

Factsheet

Why schools must be equipped to manage prolonged convulsive seizures



If left untreated, prolonged convulsive seizures may cause:

- poor response to treatment¹⁶
- respiratory disturbance or failure¹⁷
- brain damage.^{16 17}

If children who need emergency medication cannot receive it 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 may cause:

- 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.⁵

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 – in terms of lost productivity and caregiver time.



You are here: [What do we need?](#) > [National guidance](#) > Example letter

Tool: Example letter

Example letter to your Member of Parliament



This example letter may provide you with a useful start if you would like to write to your local politician or representative about your child's needs.

You may wish to also provide them with some of the information materials within the Toolkit, such as the Factsheets.

[Click here](#) to download a template of this letter



Dear [Name],

As your constituent, I am writing to ask for your support for children with epilepsy who experience prolonged convulsive seizures. These children, including my child, [child's name], often face difficulties being fully integrated into normal school activities – for no reason other than that clear processes are not in place to allow them to receive potentially life-saving medication if they experience a seizure during the school day. Without access to this medication, they are at risk of severe clinical consequences, and are effectively denied their right to a full, normal education.

Epilepsy is a medical condition that causes recurring seizures, of which there are many types. My child experiences prolonged convulsive seizures. Unlike many other seizures, these seizures are unlikely to stop spontaneously and my child needs to be given emergency medication to stop the seizures once they start.

As my child spends a lot of [his/her/their] time at school, schools should ensure that this medicine is provided safely and effectively every time my child has a prolonged seizure. This is consistent with [refer to your country's equality legislation or guidance on management of children with medical conditions at school, if it exists].

If my child does not receive medication in time, [he/she/they] risks serious long-term health consequences, including potential brain damage. This is in addition to other impacts that [his/her/their] seizures have, such as significant social exclusion and even discrimination – impacts which may affect [his/her/their] self-esteem for the rest of [his/her/their] life.

However, all this can be avoided if my child receives emergency medication quickly. This is a simple task that, with very basic training, any adult can undertake. You don't need to be a doctor or healthcare professional to provide this emergency medicine.

Unfortunately, many teachers do not receive this simple training to provide emergency medication. As a result, the school has

two choices if a seizure occurs: call me, as the parent, or call an ambulance. Both options can delay access to emergency medication, putting my child at great risk.

For example, last time my child had a prolonged convulsive seizure, [if you wish to share a story or experience, you may do so here].

It is not just my family who faces this situation. It is estimated that [number] children have epilepsy in [country] – and many of these will have prolonged convulsive seizures. [This information should be available from your local epilepsy organisation.]

I am writing to ask you for support for [my child/name] and many others like [him/her/them]. These children deserve the opportunity to grow up, learn and socialise as equals with their peers. They need your help to ensure their right to an inclusive education is protected, and that national guidance for the administration of emergency medicine in schools is developed and implemented.

I would like to refer you to a very helpful policy paper that an international group of experts – representing parents of children with epilepsy, patient organisations, clinical experts and educational experts – have written: http://www.healthpolicypartnership.com/wp-content/uploads/CE_policy_paper.pdf. This provides clear recommendations on what policymakers like you can do to help protect the rights of these children.

I would appreciate a meeting to discuss further what you could do to help my child, and how you can support us. [Consider asking for something concrete such as: ...and how you can support upcoming legislation/the school district/my patient organisation.]

I look forward to hearing your response and speaking with you soon regarding this important matter.

Yours sincerely,

[Your name and contact details]

You are here: [What do we need?](#) > School policies, including medicines

School policies, including medicines

We need individual schools to have medicines policies that include emergency medicines for prolonged convulsive seizures and adequate training for their use

5



Why is it important?

Many schools do not have provisions for emergency medicines for prolonged convulsive seizures in their general medicines policy, which may delay the use of medicines in emergency situations.⁵

Anyone administering emergency medication needs to have specific training to do so. This training is simple and does not require medical expertise. It is often unclear who is responsible for training school staff. This is often left to parents, placing an unnecessary burden on them.

What do we need?

Every school should have written policies on how to meet the needs of children who require emergency medication during school hours.

These should include:

- adequate provisions for liability insurance, which are communicated to all staff and reflect up-to-date legislative requirements.
- appropriate training for staff who volunteer to administer emergency medicine for prolonged convulsive seizures (see [Case study](#)).

What can I do?

- **Meet with the school administration to ensure existing policies meet the requirements set out in your child's individual healthcare plan.**
- **Link the school with your local epilepsy patient organisation to find out what training is available for school staff.**



See [Case studies](#) to provide examples



See useful [Factsheets](#) that may help



See printable [Checklists](#) for guidance



You are here: [What do we need?](#) > [School policies, including medicines](#) > Checklist

Checklist

Key questions to consider in your school's medicines policy



You may wish to print this checklist and take it with you when discussing the medicines policy with your school, so you can tick each item as it is addressed.

- ☐ Does it contain information about management options for children with prolonged convulsive seizures, including specific information on appropriate use of emergency medication, where prescribed?
- ☐ Does it make clear the training and support needs for all staff who volunteer to assist, especially in cases where there may be a need to administer emergency medication?
- ☐ Is there a regular calendar for updating?
- ☐ Are provisions included for medicines storage, safety and disposal?
- ☐ Are there provisions and clear accountability for checking medicines have not expired?
- ☐ Is someone responsible for checking the policy against pupils' individualised healthcare plans, to make sure no gaps exist?

You are here: [What do we need?](#) > [School policies, including medicines](#) > Case study

Case study

Guidelines for training standards by Epilepsy Ireland



Since 2009, Epilepsy Ireland 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.* By the end of 2016 this training had been provided to 5,224 people.

The programme is delivered in accordance with Joint Epilepsy Council UK and Ireland guidelines on training standards for the administration of emergency medication. It aims for participants to:

- develop a greater understanding of epilepsy
- be instructed in the administration of buccally administered emergency medication
- undertake two written assessments
- view a 45-minute DVD on seizures.

Upon passing the assignments, a certificate of attendance is provided and delegates are competent to administer the specific buccally administered medicines* covered in an emergency.

*Note: There are several forms of emergency medication available to manage prolonged convulsive seizures;²⁰ however, these training guidelines specifically focus on buccally administered medicines.



You are here: [What do we need?](#) > [School policies, including medicines](#) > Case study

Case study

Developing a medical conditions at school policy in the UK¹⁸



In 2015, the Health Conditions in Schools Alliance lobbied the UK government to issue new guidance on the management of medical conditions at school. The resultant policy document provides statutory guidance for governing bodies 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

1

Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions

2

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

3

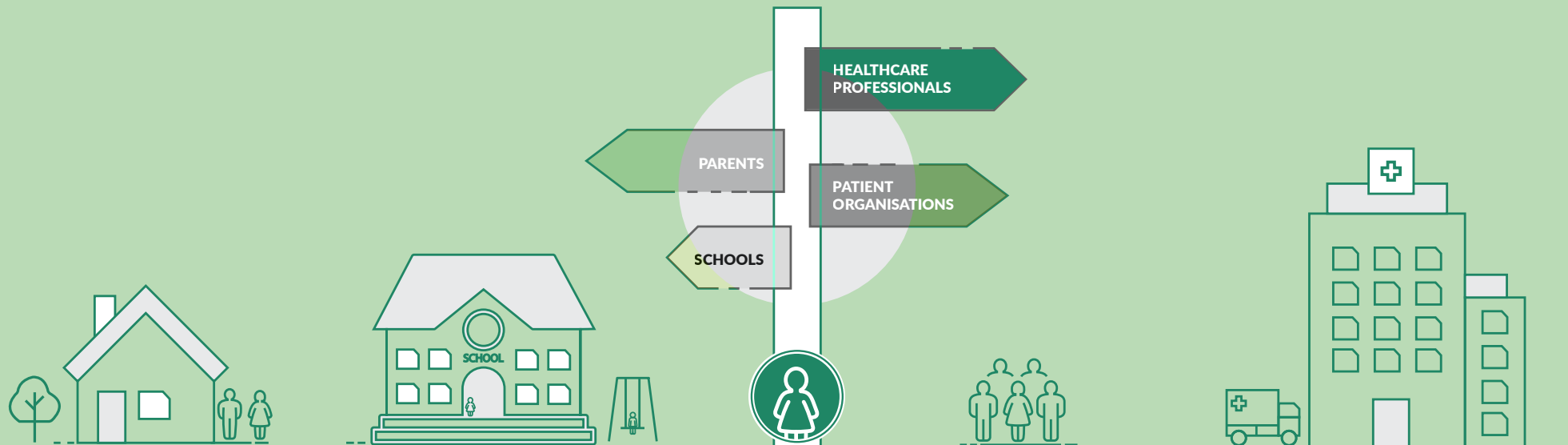


You are here: What can I do?

What can I do?

Although this toolkit has been designed mostly with parents in mind, all of us can help ensure the needs of children who have prolonged convulsive seizures are met at school.

This section gives specific actions that you may take to help make this happen.



Click on the appropriate icon if you are a parent, a school, a patient organisation or a healthcare professional to find out what you can do.

You are here: [What can I do?](#) > I am a parent

I am a parent

As a parent of a child with epilepsy, you may find that managing your child's condition is often left to you – but the school has a responsibility to look after your child. You can be proactive in ensuring the school's policies and training are adequate and up to date.



What can you do?

1. Find out whether your school has awareness training on epilepsy and seizure management – including prolonged convulsive seizures.
2. Ensure your school has an up-to-date medicines policy, covering the provision of emergency medicine and information on prolonged convulsive seizures.
3. Offer to speak to your child's teachers to explain the condition and help them better understand your child's needs.
4. Ensure that your child has an individualised healthcare plan, and that this has been jointly discussed with the school administration and relevant healthcare professionals.

Tools you could use:

Case studies	Factsheets	Checklists
A video for schools to raise epilepsy awareness	Epilepsy in children: facts and figures	What to look for in an individualised healthcare plan
	Why raise awareness of epilepsy in schools?	What should be included in school policies relating to seizures?
Process for setting up an individualised healthcare plan	What are prolonged convulsive seizures?	Key questions to consider in your school's medicines policy
	Why schools must be equipped to manage prolonged convulsive seizures	

You are here: [What can I do?](#) > I am a school

I am a school

As a school, you can develop a supportive environment for all children with epilepsy and prolonged convulsive seizures, and for staff volunteering to provide emergency medicines.



What can you do?

1. Check whether you have epilepsy awareness training that includes prolonged convulsive seizures.
2. Check that your written medicines policy includes guidance about emergency medication, training and an updates calendar.
3. Nominate designated staff members to oversee individualised healthcare plans at your school.
4. Ensure staff who volunteer to provide emergency medication are adequately supported and protected by liability insurance, and provide clear policies on ongoing training.

Tools you could use:

Case studies	Factsheets	Checklists
A video for schools to raise epilepsy awareness	Why raise awareness of epilepsy in schools?	What should be included in school policies relating to seizures?
Process for setting up an individualised healthcare plan		
Guidelines for training standards by Epilepsy Ireland	Why schools must be equipped to manage prolonged convulsive seizures	Key questions to consider in your school's medicines policy
Developing a medical conditions at school policy in the UK		

You are here: [What can I do?](#) > I am a patient organisation

I am a patient organisation

There is power in numbers, and as a patient organisation you are key to driving change. Giving a voice to children with prolonged convulsive seizures is crucial, as there has been little advocacy support for this group of children in the past. You may also play a role in drawing support from politicians, schools and healthcare professionals.



What can you do?

1. Include information on prolonged convulsive seizures on your website.
2. Write to or meet Members of Parliament, asking them for national guidance and legislation on medicines policies and emergency medicines at schools. Use facts, figures and children's experience to support your points.
3. Work with schools, councils and healthcare professionals to provide appropriate awareness materials and training curricula on epilepsy and prolonged convulsive seizures.
4. Explain any existing national legislation or guidance to parents seeking information or support, and offer to accompany them in discussions with schools.

Tools you could use:

Case studies	Factsheets
A video for schools to raise epilepsy awareness	Epilepsy in children: facts and figures
Government leadership in epilepsy awareness in France	
Why is national guidance important?	
How patient organisations work with schools in Italy	Why raise awareness of epilepsy in schools?
Guidelines for training standards by Epilepsy Ireland	

You are here: [What can I do?](#) > I am a healthcare professional

I am a healthcare professional

As a healthcare professional, you are well placed to advocate for supporting medical needs of children at school. By helping your patients' schools understand their individualised healthcare plan, you can help them create a supportive environment that looks after the medical needs of your patients at school.



What can you do?

1. Ensure the individualised healthcare plan for your patient includes clear instructions on how prolonged convulsive seizures are managed, and any training needs.
2. Ensure the individualised healthcare plan is kept up to date, and advise parents to let the school know whenever a change has been made.
3. Offer training on epilepsy in schools, aimed at teachers and pupils, to help them better understand epilepsy and prolonged convulsive seizures.
4. Work with your national epilepsy organisation or patient groups if they need support in developing template individualised healthcare plans or educational materials.

Tools you could use:

Case studies	Factsheets	Checklists
Process for setting up an individualised healthcare plan	Why raise awareness of epilepsy in schools?	What to look for in an individualised healthcare plan

You are here: Tools

Tools

The following tools can help provide more information and support you to drive change. Click on each [link](#) to find out more.

Case studies

- [A video for schools to raise epilepsy awareness](#)
- [Government leadership in epilepsy awareness in France](#)
- [Process for setting up an individualised healthcare plan](#)
- [Why is national guidance important?](#)
- [How patient organisations work with schools in Italy](#)
- [Guidelines for training standards by Epilepsy Ireland](#)
- [Developing a medical conditions at school policy in the UK](#)

Factsheets

- [Epilepsy in children: facts and figures](#)
- [Why raise awareness of epilepsy in schools?](#)
- [What are prolonged convulsive seizures?](#)
- [Why schools must be equipped to manage prolonged convulsive seizures](#)

Checklists

- [What to look for in an individualised healthcare plan](#)
- [What should be included in school policies relating to seizures?](#)
- [Key questions to consider in your school's medicines policy](#)

Example letter

- [Example letter to your Member of Parliament](#)

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