

Epilepsy and School
A Guide For Parents
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Epilepsy and School: A Guide for Parents

Whether your child is starting school for the first time, or returning to school, you will need to consider what the school should know about their epilepsy. Most children with epilepsy will have positive experiences of school, but problems can arise, so it's good to have thought about how to deal with them. Parents often have concerns about what to tell the school, and when. A big worry can be how the school will handle seizures. This is understandable. This booklet deals with common concerns parents raise and gives suggestions for dealing with the school.

Do I need to tell the school about my child's seizures?

Yes. You will need to tell them as it's best for your child that the school staff know how to deal with seizures. Otherwise, the seizures might be misunderstood or the wrong first aid could be given. Not everyone in the school may need to know, but key staff need to be informed on how to support your child.

What information will the school need?

They will need information about the particular type of epilepsy the child has. Epilepsy varies from child to child, so staff need to know what to expect and what to watch out for. The support a child with absence seizures needs is different from what a child with tonic clonic seizures needs, and both will be different again from children with focal impaired seizures. The school may have experience of children with other kinds of epilepsy, or, they may have no experience at all to rely on. The best way to get a feel for their understanding is to meet with the staff and discuss it. Epilepsy Ireland staff can help with this and can provide Epilepsy Awareness training for teachers and for students also. Our Education Information Pack for pre-school, school and college staff is available from all of our offices.

What is an epilepsy care plan and do we need one?

An epilepsy care plan is a document that sets out what's to be done in school if your child has a seizure, who is to do it, and when they are to do it. It contains:

- Descriptions of the seizures
- Descriptions of treatment
- Instructions for seizure management
- First aid
- Administration of emergency medication
- Description of when medical attention is needed
- Contact details for parents
- Contact details for GP
- Contact details for emergency services
- Other relevant contact details.



There is a template for a plan in the Epilepsy Ireland Education Information Pack (see www.epilepsy.ie). The school should keep a copy on file and parents should keep a copy too. It's a good idea to draw up a care plan at the beginning, as soon as the child has been diagnosed, agree it with the school, sign and date it. The care plan needs to be updated as seizures and treatment change over time.

What if my child's seizures changed over the summer?

If your child's pattern of seizures has changed in any way over the summer months then let the school know how this affects them. If the child is having more seizures the school can look at ways of supporting them. The school can take account of their seizures if there are any academic problems, or if days are missed due to seizures, hospitalisations or appointments. If seizure control has improved it could mean looking again at decisions about restrictions around sports or practical subjects. Any changes to seizures or to treatment should be written into the care plan as an update.

The treatment has changed, should I tell the school?

Epilepsy medications can sometimes have side effects on thinking, memory, behaviour and mood. The school staff need to know about possible side effects so that they understand that not all problems are due to poor behaviour or lack of attention. In this way they can take these effects into account, and even adjust the workload if necessary.

What if my child has new teachers this year?

If your child has new teachers don't assume the information will just be passed on to them. Ask the principal or another teacher to explain what the new teacher needs to know. Take in an Education Pack from Epilepsy Ireland to be given to the new staff, and the school can arrange training with the Local Community Resource Officer.

How should seizures in school be handled?

The staff should follow the epilepsy care plan that you agreed with them and that is kept in the school. If they need more training they can request a talk from Epilepsy Ireland.

My child has sleep seizures, does the school need to know?

Yes. Sometimes sleep seizures can affect the child's alertness or energy levels during the day. It's best the school know so they can take it into account. Also if overnight trips are planned they would need to know. A boarding school will certainly need to know.

Does the school need to know about controlled epilepsy?

Yes. In the event of seizures returning they need to know what to look out for and what to do. Also, it means the staff can be more aware of any other learning and behaviour issues that could be connected to the epilepsy, or the treatment.

What if my child is prescribed the ketogenic diet?

School staff will need to know that this diet does not prevent a child taking part in school activities but that the child can only eat foods set in by their parents, (and eat all of it), and that no other foods can be given.

What can I ask my child's boarding school to do?

Firstly, the school needs to know about all the aspects of the child's epilepsy and treatment that can have a bearing on school life. The school is also the child's home from home, and the staff need to take what safety measures they can to support the child and reduce their injury risk. This could mean ground level accommodation, if available. In cases of sleep seizures the school need to know that top bunks are not safe and also whether a seizure detection device or ventilated pillow is to be used. In boarding schools, staff or the school nurse need to ensure the child is taking their daily epilepsy medication as prescribed. Medication reminders can be programmed into the child's mobile phone, if they are allowed to use one in school.

What about Buccal Midazolam storage and expiry?

Buccal midazolam needs to be stored safely, but in a place where it can be easily reached if needed. Parents need to keep note of expiry dates of buccal midazolam and replace it when it has expired.

Are school staff trained in the use of Buccal Midazolam?

Unless they have had a child in the school previously who needed it, it is unlikely the staff will have this training. The school can link in with the local public health nurse for a demonstration and they can request the full 'Epilepsy Awareness and Buccal Midazolam' training from Epilepsy Ireland which we can offer throughout the country.

Can staff give Emergency Medication in schools?

Prolonged seizures can become medical emergencies and so emergency medication, such as Buccal Midazolam, is often prescribed for such situations. A school policy on medication will deal with the storage and administration of prescribed medication in a particular school. While school staff cannot be directed to administer medication, schools will often have staff who are willing to so, and to become trained. It is important that there is a minimum number of trained staff to cover in the event of staff absence.

Is epilepsy considered a special need?

Epilepsy may be considered a care need and this means a child can sometimes be granted access to a Special Needs Assistant or SNA. The National Council for Special Education (NCSE) is responsible for providing resources and SNA's, through their network of Special Educational Needs Organisers (SENO's) throughout the country. See www.ncse.ie for further details.

How can schools get more information on epilepsy?

Epilepsy Ireland can distribute Education Information Packs to schools and extra packs are available from all our local offices. A resource pack called Managing Chronic Conditions in Schools has a section about epilepsy in it and can be downloaded from www.epilepsy.ie and www.into.ie

Is there anything else I need to give to the school?

If buccal midazolam is prescribed you need to give it to the school to keep safely. If the child is likely to wet or soil themselves in seizures a spare set of clothing can be kept in the locker as a back-up.

Can the school offer extra educational support?

If your child is having difficulties with learning, speak to the school about whether they can offer resource teaching hours, or learning support. If homework and study are concerns discuss these with the class teacher. For information about epilepsy and learning, see page 16, and for accommodations for state exams, see page 18.

Can my child use computers and whiteboards safely?

Generally this isn't an issue, even if a child is photosensitive. Photosensitive epilepsy is tested for on an EEG and so you can check if it applies to your child. Only 3-5% of people with epilepsy have this type. Modern equipment, such as LCD and plasma screens don't typically flicker. Anti-reflective screens can help reduce glare and brightness can be adjusted too. Whiteboards or computers aren't typically a problem in themselves unless a flashing image is being shown. Some websites use PEAT analysis to screen their content and schools can check

to see if sites are seizure safe, see trace.wisc.edu/peat and sites can also be checked using the Harding FPA, see www.hardingfpa.com

Can my child take practical subjects?

Most children with epilepsy take practical subjects like science and home economics. It's important that teachers know about the risk of seizures and how to support the child who is having one. If there are concerns on safety grounds the school can apply for SNA access to support the child to continue the class. For technical subjects like woodwork and metalwork, the neurology team can give an opinion on whether or not these subjects are safe for the child at this time, and the same advice about seeking SNA access will apply. This is better than having a child drop a subject that could be important for them later on.

What about school trips and outdoor activities?

Every reasonable effort should be made to ensure a child with epilepsy can take part safely in school life, including trips and activities. If you are in any doubt about which activities are safe, the neurology team can give you the best advice based on your child's epilepsy and needs.

Is stress a trigger before exams?

Exams can be stressful for many students and for those with epilepsy there can be concerns about stress triggering seizures. Schools may bring in trainers to work with groups of children or there may be relaxation classes in your area. Your local Epilepsy Ireland office may have details of stress management and relaxation classes that may help.

What if my child stays in the toilets when they get a warning?

It is not safe to do this. It's risky for the child to isolate themselves in this way as no-one knows they are having a seizure, if they have hurt themselves, or if they need medical attention. It's better for a child to tell someone that a seizure is about to happen, and then stay in the company of people who can help manage the seizure properly.

Can my child do PE, swimming or sports?

Every child's epilepsy is different, but it's important that children with epilepsy are not unnecessarily restricted from taking part in sports. Most children with epilepsy can do PE without a problem. The PE teacher needs to know about their seizures and what is safe for them to do. If a child is having frequent seizures then their use of high bars and climbing equipment might be restricted, but floor activities might be quite safe. Most children with epilepsy can swim once they are in a pool under supervision, where there is a lifeguard, or an assistant on hand who can handle seizures in water. Many track and field sports that are played in schools are considered quite safe for children with epilepsy, once the usual safety measures are followed. However, there can be risks, such as blows to the head with contact sports like rugby. In such cases it's best to be guided by the neurology team as to what is a safe activity for your child at this point. If seizures improve, restrictions can be reviewed.



What if my child doesn't want the teachers to know?

There are key staff who need to know. Mainly, they are the principal, vice-principal, class teacher, class tutor or year head and your child's subject teachers. Whether other teachers are informed is something to consider as the need arises, particularly if they are likely to be in charge of extra curricular activities, after school clubs or trips. It is important that key teachers in the school know.

Should the other students be told?

The entire school may not need to be told, but some students feel more comfortable letting a few close friends know. While friends of students with epilepsy have often handled seizures well, it is not their responsibility to do so and the key decisions need to be made by staff. Epilepsy Ireland can give talks covering epilepsy awareness in general. Some students with epilepsy find it helpful to give their own input about their epilepsy to their class, if they feel comfortable and wish to do this.

What should we tell their friends?

This depends on their age and level of maturity. Young children are likely to be with adults and might just need a simple explanation, and to be told to tell an adult. Epilepsy Ireland has books which are suitable for all ages. For children aged 8 to 12, books explain epilepsy in more detail. Teens need to know what to do if a friend has a seizure, so keeping a text message of first aid instructions, or an epilepsy app on their phone, is a useful idea.

What if my child is worried how others will react?

This is a common concern and an understandable one too. The fear of having a seizure is sometimes a huge issue for a student. If a seizure happens in school then it is likely that other students will come to know about it. It is best to discuss this with your child to prepare them, and support them if they are anxious about it. Having a school talk for students can raise awareness without mentioning that a particular child has epilepsy. This has often helped children feel more secure that others will support them if they have a seizure.



What if my child doesn't want to go to school?

It's important to ask them why they don't want to go to school. It could be a bullying issue for instance. If your child is out of school for a long time there is a service called Tusla which can help with school refusal or absenteeism. See www.tusla.ie for details.

What if my child is bullied in school?

Bullying can be a problem in schools generally and it affects children whether or not they happen to have epilepsy. Ask for the school's bullying policy and discuss concerns with the teacher or principal.

What if they miss a lot of school?

Schools must report if a child has missed 20 days of school. Where there are legitimate reasons, such as medical needs, it's important to discuss the reasons with the principal. An Educational Welfare Officer can support a family where a child has missed a lot of school. See www.tusla.ie for information.

Can we get a teacher to teach them at home?

If the child can't attend school for medical reasons it may be possible for them to get home tuition for up to 10 hours per week, or 20 hours if they have a special educational need and are awaiting a school place.

See www.education.ie for more details.

Can my child walk or cycle to school on their own?

This really depends on a number of factors, including the level of seizure control, whether the child has daytime seizures, how independent the child is, and the traffic in the area. You will have to judge whether this is a safe option, but if you have any doubts, consider other arrangements if possible. Can they use the school bus service or can you take them yourself? If not, can they walk to school with a group of children under adult supervision, as with the walking bus? Can they get a lift with a parent you trust?

What if my child can't attend school without transport?

If a child cannot attend school on medical grounds, unless conveyed by transport, an application for school transport on medical grounds can be made to the Department of Education, who must be fully satisfied that the child cannot attend school otherwise. For more information about eligibility see:

<https://www.education.ie/en/Parents/Services/School-Transport/School-Transport-Schemes/School-Transport-Children-with-Special-Educational-Needs.html>

Is there transport available for my special needs child?

The Department of Education provides school transport for children with special educational needs under the School Transport Scheme. The SENO can apply to

the Department to employ an escort to accompany a child with care and safety needs. School transport may not be available in all areas, and where it cannot be provided, parents may be eligible for a special transport grant to assist with costs of private transport. There are eligibility criteria attached to the School Transport Scheme in regard to special educational needs, and the school and class attended. For more information about the School Transport Scheme see: <https://www.education.ie/en/Parents/Services/School-Transport/School-Transport-Schemes/School-Transport-Children-with-Special-Educational-Needs.html>



What if they have a seizure on the school bus?

The driver or escort, if applicable, needs to be aware of the child's epilepsy and how to deal with a seizure.

Tips for managing tonic clonic seizures on buses

In the event of a tonic clonic seizure the child's individual care plan should be followed. The care plan should state whether the child should remain seated or be placed across seats on their side during the seizure, and how their seizure should be managed. The guidance below is general. The bus driver will need to know in case an emergency stop is needed.

- Remain calm and note the time.
- Passengers in surrounding seats should be moved if possible to leave space around the child.
- Armrests should be raised.
- Protect the head with pillows, blankets or rolled up coats.
- Place nothing in the mouth.
- Let the seizure run its course.
- Do not restrain.
- Monitor the length of time the seizure lasts. Some children may need emergency medication to stop the seizure.
- When a seizure lasts more than 5 minutes, or longer than is normal for the child, or more seizures follow in a cluster without recovery in between this is a medical emergency.
- If the child is injured or has another medical condition they may require medical assessment.

NB If the child has vomited during or after the seizure they should not be lifted up or moved onto their back but should remain on their side in the recovery position until recovered.

Seizures longer than 5 minutes could be a medical emergency. If the child is injured or has another medical condition they may need medical attention.

Tips for managing non-convulsive seizures on buses

- Gently protect the child from obvious dangers (like wandering in a busy road).
- Keep other people away.
- Talk to the child quietly.
- Remember they may be dazed when they come around.
- Very rarely, they may become agitated. Do not obstruct them. Wait and observe closely, intervening only if necessary.
- **DO NOT** try to stop the seizure – you will not succeed.
- **DO NOT** send for an ambulance unless the seizure lasts a long time. (More than 5 minutes when that is unusual for the child, or if the child's usual pattern is unknown.)
- Stay with the child until you are sure they are fully recovered.
- After a non-convulsive seizure it is not unusual for a major seizure to follow.

Tips for managing a tonic clonic (convulsive) seizure in a wheelchair user:

In the event of a seizure it is important to follow the child's individualised care plan devised by their medical team. The care plan should state whether the child should remain seated during the seizure and how the seizure should be managed. The guidance below is general.

- Remain calm and note the time of the seizure
- Apply the brake and ensure the chair is secure. For an electric powered chair consider how to safely stop it from moving
- Set the chair to partial recline (unless the care plan states otherwise)
- Don't restrain the child or attempt to stop the seizure
- DO NOT put anything into the child's mouth
- Wipe away any saliva that may collect around the mouth
- Let the child stay in the chair during the seizure – (unless their care plan states otherwise)
- Move objects that could cause injury to the child
- The seat belt should prevent falling from chair
- If there is no belt you may need to support (not restrain) the child to prevent them from falling out of the chair
- Lean the person gently to one side to allow saliva to drain (unless their care plan states otherwise)
- Cushion the head area using a rolled up coat or a cushion
- When the seizure stops – the care plan should explain what to do and whether to put the child in the recovery position and when to call an ambulance
- Check the airway is clear
- Don't give food or drink, don't restrain, and don't tilt the chair back on it's wheels

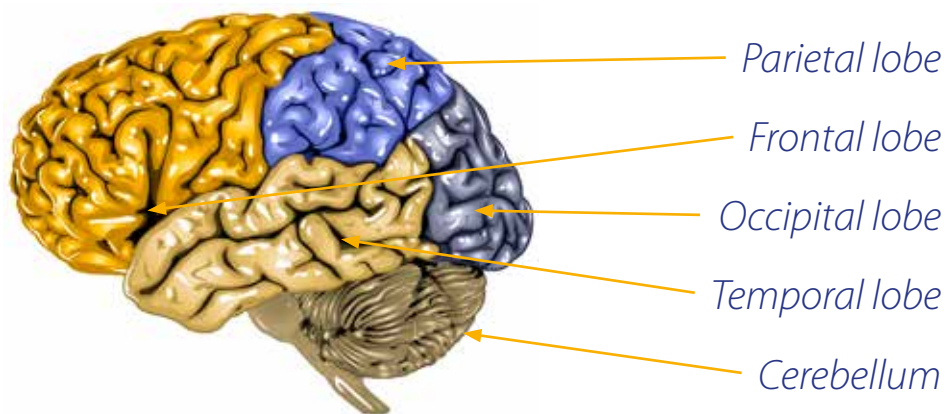
There is no need for an ambulance unless the seizure is over 5 minutes, there's an injury, it is the first seizure, or another condition is a concern.



Can epilepsy affect my child's learning?

This can be a difficult thing to be sure of, but if you think it could be the case, then ask the teachers about it. It may be possible to get referred for a psychological assessment, or sometimes this can be done through the hospital. Most children with epilepsy have the same range of abilities as other children. However, having epilepsy and being on medication can lead to difficulties with concentration, memory and information processing for some children. These in turn can affect learning. It's good to deal with this early before a child falls behind. If your child is having difficulties with learning, speak to the school about what supports they can offer.

Seizure focus and possible effects on learning



Where no focus is identified, as in generalised epilepsy, a range of possible effects can be seen, such as auditory, verbal, visual, motor and memory difficulties. Children who develop more than one focus, or who have generalised epilepsy, can have a combination of difficulties. On the next page there is a list of possible effects that may be seen from a seizure with a focus in a specific part of the brain.

Right Temporal Lobe Focus

Possible specific difficulty

- Visual-spatial perception
- Recognising symbols
- Memory
- Understanding speech
- Reading
- Handwriting
- Practical tasks
- Co-ordination
- Sequencing
- Perception of time
- Non verbal processing
- Left/right confusion

Left Temporal Lobe Focus

Possible specific difficulty

- Language comprehension
- Language expression
- Verbal reasoning skills
- Auditory skills
- Phonetics
- Spelling
- Memory
- Speech sounds/words/order
- Analytical skills
- Calculations
- Attention to detail

Occipital Lobe Focus

Possible specific difficulty

- Written word recognition
- Visual processing
- Perception
- Reading and writing
- Visual disturbances
- Recognising colours
- Object movement/position

Parietal Lobe Focus

Possible specific difficulty

- Confused directionality
- Naming objects
- Visual attention and focus
- Hand-eye co-ordination
- Spatial awareness
- Body awareness
- Academic skills
- Perception of touch

Frontal Lobe Focus

Possible specific difficulty

- Attention
- Planning
- Organisation
- Executive functioning
- Judgement
- Problem solving
- Sequential thought
- Expressive language
- Making decisions

Is there any help for my child doing state exams?

Yes. They can apply for RACE, or Reasonable Accommodations in Certificate Examinations, from the State Examinations Commission (www.sec.ie). In this way, they can have a separate room and supervisor during the exam, which can take away some concern about having seizures publicly. They may have a rest break which is added onto the end of the exam. If a seizure happens during the exam the student can complete the exam later in the same day provided they remain under supervision.

What is the DARE Scheme?

The DARE programme can help students with disabilities to access college places on a reduced point basis. It is part of the CAO process. Epilepsy is an eligible condition as it is a neurological condition. See www.accesscollege.ie for more information.

Can students with epilepsy access support in college?

When a student with epilepsy applies to college through the DARE Scheme they are required to register with the Disability Office for support. If they have not come to college through the DARE Scheme, they may still register with the Disability Office in order to be able to access supports the college can offer.

What is Training For Success?

Training for Success is Epilepsy Ireland's one year full time access programme based in the Institute of Technology, Sligo. The programme is a QQI level 5 in General Studies within the National Framework of Qualifications. No Leaving Certificate is required and student intake is from all over Ireland. All eligible students receive a training and accommodation allowance from Mayo, Sligo and Leitrim Education and Training Board. The course is the only one of its kind in Europe specifically for students with epilepsy to identify goals, build confidence and decide on a career of their choice. For more information see www.epilepsy.ie or contact the course manager on 071 9155303.



Epilepsy Ireland Resources

FREE TO DOWNLOAD

from our website www.epilepsy.ie



Information Resources



We provide up-to-date information about epilepsy for you, with a range of booklets and resources available from our offices or from our website www.epilepsy.ie. We have information packs for professionals also – education staff, health professionals and employers.



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