

Epilepsy and School

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Epilepsy and School: Frequently Asked Questions

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.

I haven't told the school yet about my child's seizures ... do I need to?

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.

I've told the school but they still don't know enough about my child's epilepsy

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 complex partial 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 this and can provide Epilepsy Awareness training for teachers and at times for students also.

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 seizure, descriptions of treatment, instructions for seizure management, first aid, administration of emergency medication if required and whether or not the child needs medical attention. It contains contact details for parents, the GP, emergency services and other relevant numbers also. There is a template for a plan in the Epilepsy Ireland Teacher's Pack. 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, and agree it with the school, sign and date it. The care plan needs to be updated as seizures and treatment change over time.

Things have changed over the summer with the seizures, should I tell the school?

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 the subject levels chosen or restrictions around

sports or practical subjects. Any changes to seizures or to treatment should be written into the care plan as an update.

Things have changed with my child's treatment, 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 don't assume any 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 about any new teachers who are not familiar with my child's epilepsy?

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 a Teacher's Pack from Epilepsy Ireland to be given to the new staff.

Seizures could happen during school hours, what can I expect the school to do?

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.

If my child only has sleep seizures should I still tell the school?

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.

My child's seizures are controlled; does the school still need to know?

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.

My child attends boarding school. What can I ask the 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 that bed alarms, seizure detection devices, and ventilated pillows can help reduce risks.

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. Medication needs to be taken as prescribed and in the absence of parents the staff or school nurse need to ensure the child is taking the medication as required. Medication reminders can be programmed into a child's mobile phone if they are allowed to use one in school.

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.

Are staff willing to give buccal midazolam if needed?

Sometimes this can be an issue in schools as there is often a policy of not giving routine medication. However, emergencies are different. In the case of epilepsy, especially prolonged seizures, not intervening isn't an option. While all staff can't be forced to give emergency medication there needs to be a designated staff member, such as an SNA (Special Needs Assistant), who can give it. There also needs to be at least one other staff member trained as a back-up and willing to give it in case the designated staff member is not available.

What about buccal midazolam storage and expiry dates?

The school needs to store buccal midazolam safely but in a place where key staff can access it easily. There are two forms of buccal midazolam: Epistatus which is a bottle of liquid, and Buccolam which comes in pre-filled syringes. When storing the bottle the lid needs to be screwed on securely because the liquid could evaporate if it is loose. Parents need to keep a note of expiry dates of medication and replace it when it has gone out of date.

Is epilepsy considered a special need?

Epilepsy may be considered a care need and this means a child can sometimes be granted access to an SNA. The National Council for Special Education (NCSE) is responsible for providing resources and SNAs through their network of Special Educational Needs Organisers (SENOs) throughout the country. See the NCSE website for further details.

Do school staff have information on epilepsy and a Teacher's Pack as standard?

Epilepsy Ireland sent a teacher's pack to every school in the country when it was published 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 in case of seizures?

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 or a tracksuit can be kept in the locker as a back-up.

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.

These in turn can affect learning. It's good to deal with this early before a child falls behind.

Can my child do PE, swimming or sports?

Every child's epilepsy is different but it's important that children with epilepsy are not too 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 attached to contact sports like rugby and hurling.



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.

Can my child take practical subjects?

Most children with epilepsy can 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 technical subjects like woodwork and metalwork 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?

It can be for many students with epilepsy. It's good to think about ways to lower stress such as relaxation and mindfulness, particularly in the run up to exams. These are skills for life too. Schools may bring in trainers to work with groups of children or there may be classes in your area. Your local Epilepsy Ireland office may have details.



What if my child is bullied in school?

Unfortunately bullying is common in schools. It can harm confidence and cause stress for a student with epilepsy and lead to more seizures. Ask for the school's bullying policy and discuss concerns with the teacher or principal.

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

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 at least some teachers in the school know.

Should the other students be told and what should they 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 have found it helpful to give their own presentations about their epilepsy to their class.

My child is worried about how others will react if they have a seizure

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.

My child gets a warning and goes to the toilets to be alone to have their seizure

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.

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 they miss a lot of school due to seizures and hospitalisations?

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?

Is there transport available for my special needs child?

If your child has special needs arising from another disability and cannot access the regular school bus service there may be an option of special needs transport. See the Parents section of www.education.ie for information on school transport.



What if they have a seizure on the school bus?

The driver needs to be aware of the child's epilepsy and how to deal with a seizure.

Tips for managing tonic clonic seizures on buses

- Time the seizure.
- Passengers in surrounding seats should be moved to allow space to be cleared around the child.
- Raise the arms of seats to allow the child to lie lengthways, preferably on their side, across seats.
- Remove any objects that could cause injury.
- Protect the head area with blankets, pillows or rolled up coats.
- Do not place anything in the mouth.
- Do not restrain the child during the seizure.
- After the seizure they should remain lying on their side in the recovery position until recovered.

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.

My child is a wheelchair user. What can I tell the school about managing seizures?

There may be different symptoms, depending on the kind of seizure experienced.

Convulsive seizures: loss of consciousness, unresponsiveness, stiffening of body, limb jerking and laboured breathing are common signs.

Non-convulsive seizures vary a lot. A child may be confused, have tremor on one side, have affected speech or consciousness to an extent, or there may be vague symptoms like auras (déjà vu).

For wheelchair users, the wheelchair brake should be put on if the child is having a seizure.



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

- Remain calm and time the seizure.
- Apply the brake and make sure the chair is secure.
- 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.
- Allow the child to remain seated in the chair during the seizure this is safer than moving them which could lead to injury.
- Move objects that could cause injury to the child.
- The seatbelt or harness should prevent falling from the chair. If there is no belt you may need to support (not restrain) the child to stop them falling out of the chair.
- Cushion or support the head area.
- At the end of the seizure the child can be moved from the chair and placed on their side in the recovery position.

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.

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.

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, LCD screens and plasma don't flicker. Anti-glare is built into screens but 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: <http://trace.wisc.edu/peat/help/>

Can the school offer extra educational support?

If the child has been diagnosed with another disability or learning disability they may be eligible for resource teaching hours. Many children with epilepsy don't quite satisfy the current criteria and aren't eligible for resource time. The NCSE has responsibility for providing these resource supports and SNAs for care needs in schools (www.ncse.ie) through the local SENOs. If a child doesn't have access to resource teaching hours but is performing in the lowest range in class they may be referred to Learning Support for a time. This is decided in the school.

Is there any help for my child doing state exams?

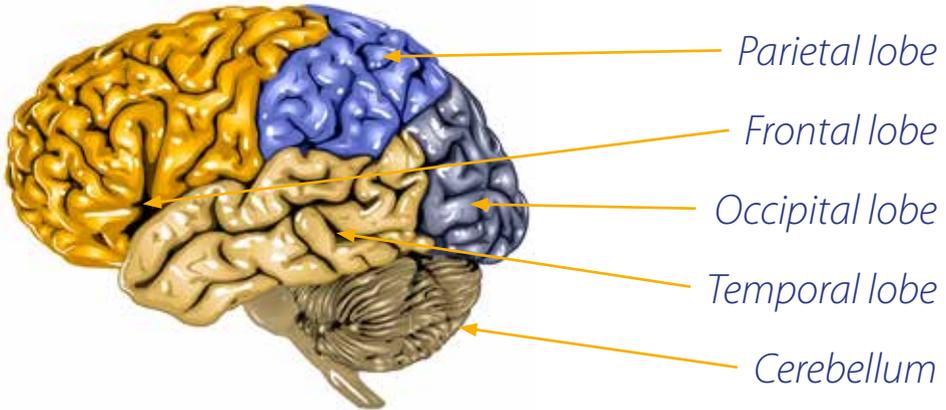
Yes. They can apply for RACE or Reasonable Accommodations in Certificate Examinations from the State Examinations Commission (www.sec.ie). In this way they can have a separate room and supervisor during the exam, which can take away some concern about having seizures publicly. They may have a rest break 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. In cases of nocturnal or early morning seizures medical evidence may be taken into account if the student misses the morning exam or part of it.

What is the DARE programme?

The DARE programme can help students with disabilities who are nearing the Leaving Cert. 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.



Location of focal seizure and related possible effects:



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. The follow are 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

Frontal Lobe Focus

Possible specific difficulty

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

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



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