

School

Fact Children with epilepsy often report that they feel “out of control.”

Parents of children with a seizure disorder often ask themselves, “How will my child perform in school? What should I expect academically? How will my child fit in with the other kids? Will antiepileptic medication affect my child's learning?” It is important to remember that most children with epilepsy do well in school and do not have learning problems. But as Freeman, Vining and Pillas caution, “There is reason to be aware that school problems could occur, since they do occur more frequently in children who have epilepsy.”

Freeman, Vining and Pillas. *Seizures and Epilepsy in Childhood: A Guide for Parents*.
Baltimore, Johns Hopkins University Press. 1990:239.

A number of factors may affect your child's learning potential and development. If your child is experiencing learning difficulties in school, you must consider more than the actual seizures and look at other potential contributing factors. The frequency of seizures may affect your child's learning experience, as may your child's attitude toward school, intellectual ability, self-image, the side effects of medication, the teacher's attitude towards epilepsy, and the attitude of fellow classmates.

Attitudes of Teachers & Parents

Teachers' and parents' attitudes affect every child's learning experience — positively or negatively. These attitudes can be particularly important for your child who has seizures. Parents can help by becoming a good resource for their child's teachers and by keeping the teachers updated about any changes. Helping the teacher to see your child's seizures as a short term, temporary interruption should ease any anxiety the teacher may have. Sharing first aid and safety information with the teacher will enable the teacher to develop the skills and confidence to manage seizures at school. A teacher who understands your child's seizure disorder and feels able to manage during a seizure will feel more confident than a teacher who does not have this information.

Forms for an Information Sheet and Letter to my Teacher are provided within this kit.

Develop realistic expectations for your child which permit striving in all the usual important activities, such as Girl Guides, Cubs and Scouts, 4H clubs, music, camp, sports, nursery school, drama. The practical and social skills gained from involvement in these activities are just as important for your child who has a seizure disorder as they are for a child who does not.

On the other hand, not motivating or encouraging your child to complete homework assignments or to become involved in extra curricular activities, for fear of having a seizure, can restrict both the child's learning and social experiences. This may encourage your child to use epilepsy as an excuse to avoid challenges and responsibility. It is best to encourage your child to engage in the kinds of activities s/he would have done had s/he not had a seizure disorder.

At times, some parents and teachers may have lower academic and behavioural expectations for children with seizures. This may be due to misunderstandings of the affects of epilepsy on the child or to a fear that pressure to do well may increase the child's stress level, resulting in an increase in seizure activity. In these instances, it may help to consult with the child's doctors, local epilepsy organization or parent support group.

Children need routine and structure in the school setting just as they do in their home environment. This may be especially true for the child with epilepsy, whose life — as a result of seizures — may feel unpredictable and out of control. When a seizure pulls your child off track, established routines can help your child get back on track. It is important for parents to share with teachers some helpful information regarding their child's routine.

The Importance of Teachers

1 to 2% of children have epilepsy. Despite the prevalence of epilepsy, many teachers report that they have never had a student with epilepsy in their class. This is probably not the case. Rather, the child's seizures may have been well controlled with medication, the child's seizures may not have occurred during school hours or the child's seizures may not have been noticed by the teacher.

Teachers and other caregivers need information to help them recognize when a child having a seizure, to teach them how to respond positively to the child having the seizure, to teach them the first aid that should be administered to a child having a seizure, and to help them teach other students about epilepsy.

Attitudes must also change so that children with epilepsy and their families will feel comfortable enough to tell the child's teachers and other school officials about the child's epilepsy. Aside from being an important safety issue, it is also an important message to send to the child: that it is okay to have epilepsy.

The school setting is perhaps second only to the family in being an influential social institution for children and youth. School interactions affect the self, play a role in academic achievement and have an enduring impact on later years. Young people with serious health conditions are significantly at risk for psychosocial adjustment problems when compared with their "healthy" peers. Doctors can help bring the child's seizures under control, but it is the child's teachers who can help bring the child's life under control. Teachers are in a position to influence the attitudes of future generations. How teachers relate to the child with epilepsy can impact on how the child with epilepsy and his/her classmates feel about epilepsy for the rest of their lives.

Teachers can be very effective in averting any permanent, negative reactions on the part of the other students by displaying calm and open attitudes and behaviour. Teachers must ensure that the child with epilepsy feels accepted. Other children may react by feeling fearful, upset, or confused after witnessing a seizure or learning that a classmate has a seizure disorder. These negative feelings may cause the child with epilepsy to be teased or ostracized, and can end up doing more harm than the epilepsy itself. Teachers can help prepare the class regarding what to expect and how to deal with a seizure. This will help the class become less unsettled and more supportive of the child with epilepsy when s/he experiences a seizure at school.

Epilepsy and Learning

Learning is a life-long process. The learning skills that children develop during childhood will stay with them for the rest of their lives. It is important that learning should be a positive and enjoyable experience.

Children with epilepsy fit within the normal range of intelligence. However, even if a child has average or above average intelligence, s/he may not perform at that level. A child's performance may be adversely affected by many things.

- ∩ Lowered expectations of the child by parents or teachers.
- ∩ Poor attitude towards the child by parents, teachers or peers because s/he has epilepsy.
- ∩ Absence seizures which may disrupt learning by causing a child to miss important parts of the lesson. (The child may end up having gaps in knowledge.)
- ∩ Side-effects from medications. (Hyperactivity can cause problems with the child's concentration and attention. Drowsiness will affect alertness and related activities.)
- ∩ Side effects of the seizures themselves, which may include memory problems.
- ∩ Poor school attendance due to school absences following seizures and/or medical appointments.
- ∩ Psychosocial effects of seizures, including poor self-image, poor attitude toward school, social problems.
- ∩ Difficulties at home.

Myth All children with epilepsy have learning problems.

If the child with epilepsy is having learning problems in school, it may or may not be related to the epilepsy. Most children with epilepsy do very well and do not have learning or social problems in school. However, teachers and parents should be aware of the possibility of a learning or social problem as children with epilepsy do have an increased chance of experiencing school related problems. Learning problems are also more common in children with epilepsy. If these difficulties are identified early, steps can be taken to correct them and reduce their effects.

Psychosocial Implications of Epilepsy

Expectations of the Child with Epilepsy

Lowered expectations of the child with epilepsy can be very detrimental. It may send a message to the child that s/he is not able to succeed which may eventually cause the child to accept these lessened expectations. Parents and teachers must set realistic and attainable goals for children. Children with epilepsy demonstrate the same variation in academic performance as children without epilepsy. Thus, the expectations for children with epilepsy should be the same as those for the rest of the class.

Effects of Being Diagnosed with Epilepsy

Early onset of epilepsy in children is associated with increased problems. When children are diagnosed with epilepsy, there is a period of adjustment involving new medications, doctors appointments, various types of testing, etc. During this time, the child's behaviour and personality may change as the child struggles with the newly diagnosed condition.

Children often feel embarrassed after experiencing a seizure in public. They may feel isolated because they are "different", which may lead to feelings of low self-esteem and low self-worth. Children who are having difficulty adjusting to their seizures may exhibit hyperactivity, anxiety or aggression, which may further distance them from their peers.

Effects of Seizures and Medications

Teachers may perceive the child with epilepsy as unmotivated, not comprehending the cognitive effects that medications or seizures may have on a child. Anti-seizure medication may impair concentration, lead to poor processing ability, lower alertness, cause drowsiness, and cause hyperactivity. Children who take several medications may have an increased risk of behavioural and cognitive side effects. Therefore, doctors usually prefer to treat children with only one medication (monotherapy) to decrease the side effects associated with the use of multiple medications.

The disruption of seizure activity itself may also affect a child's learning process by causing that child to miss important pieces of the lesson.

The type of seizure a child has may also affect learning. Different parts of the brain are responsible for different functions, such as speech development, visual processing, and spatial arrangements. Seizures may

affect some brain functions, depending upon the area of the brain in which the seizures originate.

Even when children appear to be seizure-free, they may still be experiencing seizure activity in their brain, called interictal discharges. These interictal discharges may cause inability to focus, difficulty taking in new information, and/or behavioural disturbances.

Effects of Overprotection

Many parents and teachers are overprotective of children with epilepsy. This may be very damaging since all children — including those with epilepsy — need to have a vast number of experiences for healthy psychosocial development. Teachers have an important role in preventing other children from having lasting negative reactions toward the child who experiences seizures. Teachers should not expect any less from a child with epilepsy. However, allowances must be made for classes missed for medical appointments and for recovery following a seizure, if necessary. The effects of medication must also be considered. One way to reduce the child's anxiety is for the teachers to reassure both the parents and the child that s/he will take proper care of the child during the seizure.

Disclosure

Informing the Teacher about Epilepsy

It is very important for parents to inform their child's teachers and principal, and other school officials about their child's epilepsy. This will help to ensure that teachers and fellow students will be prepared to deal with a seizure, should one occur. The teacher's attitude about epilepsy influences not only the child's self-perception but also the attitude of his/her peers.

Parents should encourage teachers to discuss any of their concerns regarding the child's disorder. It is especially important for parents to speak to the child's physical education teacher and express any limitations they feel their child may have. Safety is always the priority but all children must have some involvement in physical education for normal development.

It is very important for teachers to recognize seizures and know the proper first aid treatment for any child who experiences a seizure. The manner in which seizures are handled should be consistent at home and school. Teachers should contact parents for information as well, and keep parents informed about their child's condition.

When teachers and the school are prepared to deal with seizures, classroom disruption will be minimal and less attention will be brought onto the child with epilepsy.

Informing the Class About Epilepsy

If there is a student with epilepsy in the class, the teacher should introduce the students to epilepsy and discuss it. It may not be necessary to refer to the actual child in your class who has epilepsy; this decision should be made in consultation with the parents and the child. If the child denies having seizures or gets upset, the teacher should respond with understanding of the child's feelings. If it seems difficult to continue a discussion with the child, the subject should be left for a while. The teacher can bring it up later or wait until the child raises the subject.

Teachers play a central role in the acceptance and self-development of the child who has seizures. When teaching your class about epilepsy, keep the following points in mind.

- ▷ Emphasize that epilepsy is not a disease.
- ▷ Explain that epilepsy is not contagious.
- ▷ Avoid using the word "epileptic"; instead use the term "child with epilepsy".
- ▷ Avoid using "Grand mal" and "Petit mal" to describe seizures, as these terms are out-dated and inaccurate. Instead, use "tonic clonic" and "absence".
- ▷ Avoid using the word "fit" to describe a seizure.
- ▷ Keep in mind that the emotional and educational needs of a child with epilepsy are essentially the same as for other children.

Teachers should have a basic understanding of epilepsy, how to manage epilepsy, its effects on the child's emotional, social and physical development, and its effects on learning. If teachers can understand the stresses which are placed on the child with epilepsy and his/her family, they may be able to better understand how epilepsy affects the student's learning, social skills, emotional development, etc. Parents are the best source of information regarding their child's epilepsy and how their child copes with it.

Teachers should encourage the parents of the child with epilepsy to provide as much information as they can. This will help the teacher have greater insight into dealing with the child with epilepsy. Unfortunately, some parents feel that teachers will be insensitive when dealing with their child's condition or that, discovering that their child has a condition such as epilepsy, other students will tease their child. This can be very detrimental.

It is important for teachers to know if a student has epilepsy. Teachers should reassure parents regarding any concerns they raise and discuss how confidential information will be safeguarded. Parents and teachers should come to an agreement regarding what and how much information will be relayed to other teachers and their child's classmates. The parents may need time to open up. This is understandable as parents are very protective of their children and their children's rights.

When teachers have a student with epilepsy in their classroom, they should contact the child's parents

before doing a class presentation on epilepsy. Parents should be informed about what the teacher intends to cover and parents should be encouraged to discuss any concerns that they might have. Teachers should also consider including the child with epilepsy in the planning or presentation if the student and his/her parents agree. If the child does not want to reveal epilepsy, those wishes must be respected. The teacher may want to introduce the topic of epilepsy to the class initially without referring to the child with epilepsy, as a general discussion of chronic health problems.

Primary Classes

Teachers should make their discussions about epilepsy very basic. They should start by discussing how people are all alike or different and get the class to create lists of these similarities and differences. Then, they can introduce epilepsy and explain how it is one of the ways that people are different. Teachers should explain what a seizure is, what it looks like and how to help someone having a seizure. Using a simple picture of the head and brain may be helpful. It is also important for teachers to discuss the emotional effects of having epilepsy and the importance of not making fun of people who are different.

Junior/Intermediate Classes

Teachers may start a discussion by asking their class what they already know about epilepsy. Then, the class should be provided with a clear definition of what epilepsy is, using pictures of the head and brain. In the discussion, teachers should be sure to include the different types of seizures, what the different types of seizures look like, and how to provide first aid to someone having a seizure. Finally, the emotional effects of having epilepsy (the importance of peoples' feelings, self esteem issues) should be addressed.

How to explain epilepsy to students depends on their age and level of understanding. Teachers should consider the following suggestions about educating their students about epilepsy. These points can be simplified or expanded on as necessary.

- ♣ Seizures are the result of the brain sending mixed up messages to the body.
- ♣ Seizures last only a few seconds or minutes and, when they are over, the brain and body work properly again.
- ♣ Except for the short time while the child is having a seizure, children with epilepsy are just like everyone else.
- ♣ Epilepsy is not a disease and it is not contagious like chicken pox or a cold.
- ♣ Children with epilepsy take medication to prevent seizures but sometimes seizures happen anyway.
- ♣ Seizures usually stop by themselves, but everyone needs to know first aid so that they can help protect their friend who is having a seizure so that s/he doesn't get hurt.
- ♣ We all have unique and different features, and we should accept them all.

Tips for Teachers

- ∅ Maximize the amount of instruction time that the student with epilepsy receives by keeping the child in the classroom if possible. (The child may be able to just listen for awhile or participate in easier tasks.)
- ∅ Try to make the child's experience as "normal" as possible.
- ∅ The range of intelligence is the same for children with or without epilepsy.
- ∅ Children don't require special education simply because they have epilepsy. Some children with epilepsy may require special education just as some children without epilepsy may require special education.
- ∅ Some neurological disorders that cause epilepsy may also cause learning difficulties.
- ∅ Often when a child with epilepsy is not experiencing a seizure, there is still some seizure activity going on in segments of the brain which can alter the child's thought processes or alter the child's mood. These fluctuations in brain function can't always be controlled with treatment.
- ∅ Side effects of the child's antiepileptic medications may affect brain functions leading to lack of concentration, mood changes, drowsiness or hyperactivity.
- ∅ The type of seizure a child has can affect the child's memory or the way patterns, shapes, numbers or letters are perceived.
- ∅ The number of seizures that a child has can influence the learning process by causing him/her to miss parts of the lesson.

The Undiagnosed Child with Epilepsy

There are some special considerations for teachers who think that they may have a child with undiagnosed epilepsy in their class. The following suggestions may help teachers raise their concerns to parents.

- ∅ Record observations of the child's behaviour, noting what the behaviour looks like, which parts of the body are involved, the time of day at which the behaviour occurs, the duration of the symptoms, and in what activities the child was engaged before and after the behaviour.
- ∅ Verify your observations with the school nurse, other teachers who teach that child, a school counsellor or the principal.
- ∅ Do not make a diagnosis when reporting your observations to parents. Instead, be explicit, discuss any of the parents' concerns, recommend that the child see a physician, and offer to report your observations to the physician if necessary.
- ∅ Be sure to comply with your school's policy on reporting your observations to parents.

Taking Medications at School

Some children are required to take medication during school hours. If this is the case, the parents may have to fill out forms giving the school permission to administer the medication to the child. The parents may also be required to provide a letter from their physician. The medication should be stored in a locked area (in the school office) and provided to the child by a secretary, teacher or principal (according to school policy).

Peers

While at school, learning does not simply involve instruction from the teacher. Children learn a great deal by interacting with one other. Children learn many important social skills including how to form friendships, how to communicate, how to problem solve, how to listen and how to share. Negative experiences encountered in school can have long lasting implications on future social relationships and situations. When the child with epilepsy is teased by classmates, s/he may feel isolated from others. A major problem that children with epilepsy encounter is a lack of acceptance by their peers. "Fitting in" is extremely important for children at school. The teacher can play an instrumental role in educating the other students about epilepsy and influencing the way in which other students interact with the child who has epilepsy.

Tips for Parents

It will help if the teacher knows all of the things that your child can do. If there are special instructions or precautions which must be followed, then share all this information with your child's teacher. Having an informed teacher who is comfortable with seizures should give your child freedom to take part in the various activities offered by the school.

Learning also occurs when your child is playing with other children, developing friendships and sharing. If other children tease your child about epilepsy, it may tend to separate your child from his or her peers. Again, both teachers and parents can be instrumental in supporting the child. A teacher, who is knowledgeable about epilepsy and the impact seizures can have on a child's life, can share this information with the class and influence the way in which other children in the class responds to your child with epilepsy. Your child must also be equipped with information and self confidence to deal with other people's responses.

Inform both the school and your child's teacher specifically that most seizures are not a medical emergency.

Help your child to understand epilepsy. It is important to openly talk with your child about seizures.

Give your child the words to explain his/her seizures to classmates and teachers.

Your child may have a seizure in school. Suggest to the teacher that a nap for your child would be preferable to sending him/her home. This would help everyone to avoid the inaccurate concept of illness.

Contact your local epilepsy organization if you run into difficulty. It can help advocate, mediate and solve problems with your school and help explain seizures to school staff.

Working in Partnership with your Local School

It is important for parents to work in partnership with the local school to ensure the best possible education for their child. This is particularly true when seizures are not well controlled. Both the parents and the school need to contribute to the partnership.

The Parents' Contribution

General Information about Epilepsy

Many teachers and administrators have never seen a seizure and may be uncomfortable dealing with a child who has them. Parents should ensure that the school gets accurate information about epilepsy, first aid, seizure types, and the possible effects of anticonvulsant medication. If you wish, your local epilepsy organization can contact the school for you and provide this information. If seizures are not well controlled, it may be a good idea to educate the other children in the class. Many epilepsy organizations can provide Kids on the Block, a puppet show designed to educate grade-schoolers about epilepsy and other health-related issues.

Specific Information about your Child

Parents will want to provide the school with specific information about their child. This should include: the type of seizures, a description of the seizures, warning signs (if any), procedures to follow during seizures, medications taken by the child, side effects of medications and/or seizures, the name of your doctor, and triggers for your child's seizures (strobe lights). The school will need your permission to share pertinent information with the appropriate personnel.

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The School's Contribution

Networking

The school can facilitate extra educational support when needed. The school can also put parents in touch with the local epilepsy organization.

Informal Process

Informal meetings may be requested by any staff member or parent who has concerns about a child. Meetings are a good way to share information about seizures, etc. Relevant people may meet to set up a plan-of-action tailored to your child's needs.

Formal Process

Many provinces in Canada offer some form of an Identification, Placement, Review Committee (IPRC) to determine how the school can best meet the child's special needs. It includes the parent as a member. Either the school or the parent may request an IPRC. Parents may have to agree in writing to have their child reviewed. They usually have the final authority to accept or refuse decisions about a child's exceptionality.

Additional Possibilities

To further facilitate the process of working together, the school may want:

- ∂ to arrange teacher/parent meetings with the child or with other involved persons before the child is enrolled;
- ∂ to provide special lessons related to epilepsy for the other students;
- ∂ to show a video tape of seizures; and
- ∂ to ask the local epilepsy organization to provide workshops for the staff.

Learning is a process that occurs both inside and outside the school walls. It is important that parents and schools work together in the child's best interest.

Physical Activity

Physical exercise is necessary for all children. All physical activities pose some risk, whether or not a child has epilepsy. However for children with epilepsy, physical activity may involve some additional risks. The risks of any activity should be weighed against the benefits to the child. Whenever possible, students who experience seizures are encouraged to participate in a full range of physical activities. Children with seizures which are not well controlled should participate cautiously in activities in which having a seizure would put them or someone else in danger. When deciding on child's limitations, the child's seizure type, severity, frequency and doctor's advice must be considered.

Prospect of Employment for Students with Epilepsy

The prospect of employment becomes a growing concern for children with epilepsy as they mature. Teachers can help students become aware of their abilities at an early age. All students should be encouraged to select occupations which satisfy their interest and capabilities. It is important to consider that epilepsy is a chronic condition for some people and there may be certain realistic restrictions which must be respected. It may be very upsetting for a student to learn that some professions are closed to him/her, but you should be honest with the child so that s/he doesn't begin planning for a job for which there is no hope for employment. All students should be proud of the things that they can do and should be encouraged to concentrate on them.