

Epilepsy and School

School is a child's workplace; it is a place where your child spends a lot of time, learns many things, and challenges him or herself to grow. The adults at your child's school have accepted the serious responsibility of helping your child become the most informed, responsible person that he or she can be. School can also be a place that is frustrating to children who have difficulties in learning or getting along.

Some strategies are the same for most parents and children: Form a partnership with the teachers and administrators and help out when asked. Most schools have opportunities for parents to help, including going on field trips with the class; providing treats for holiday parties; sharing a special skill or talent; and attending Parent-Teacher Organization meetings. Watch for these opportunities and help out as much as you can. Schools have a difficult job. It is easier to ask for help with your child's issue if the people at school know you as a parent who helps the school.

Most schools pass out student handbooks at the beginning of the school year. Keep the student handbook available so that you can look up how important issues are handled in school policies. For example, most schools have policies on bullying; the student handbook will outline how the school prefers to deal with that. If you think your child is being bullied, you should contact the person listed in the student handbook to address bullying.

Here are some resources on bullying that you might find helpful

aacap.org/cs/Bullying.ResourceCenter
stopbullying.gov/index.html

nasponline.org/resources/bullying/index.aspx
cdc.gov/violencePrevention/pub/understanding_bullying.html

Everybody benefits when they have information; keeping your child's school informed about your child's epilepsy is key. Set up a meeting with your child's teacher, the school nurse, the school counselor and all of the key people (bus driver, school aide, etc.) who will be interacting with your child. Create a folder with all the important information about your child's epilepsy, the seizure action plan, the medications and the doctors who are prescribing them. Include a picture of your child and your family to make it more personal. This can help the school understand your child better.

efof.org/index.php/children-and-family-and-resources/resources-a-documents

Children with special needs should get acquainted with all of the people at school who can be helpful, including the school nurse (if there is one), guidance counselor, school psychologist and principal. Learning the role of each of these people is important so that you can ask the right person for the kind of help you need. It is important for the school to know about your child's epilepsy. They should know what happens during a seizure and what to do when a seizure happens during school time.

The school should know what antiepileptic medications (AEDs) your child is taking, and when they are increased or decreased so they are more aware of side effects when a change in medication occurs. A *seizure action plan* (SAP) is an important document that *every child with epilepsy should have at*

the school, with detailed information about the student's epilepsy. This document provides clear guidelines on how to respond when a student is having a seizure. The student's parents (or guardian), pediatrician and epileptologist/neurologist will help develop the seizure action plan. Every individual who interacts with a student with epilepsy will benefit from this information. It will also help the student to know that all the key adults in his or her life know what to do when he or she is having a seizure away from home. The seizure action plan also helps the school to know when to call 911 in case of seizures.

epilepsyfoundation.org/livingwithepilepsy/educators/socialissues/schoolnurseprogram/upload/seizure-action-plan-pdf.pdf

Education empowers

Children with epilepsy, and with mental health issues, are often misunderstood by other children. If a child has a seizure at school, it can look scary to others, and children often make fun of what scares them. You might ask the school nurse if you and your child could lead a discussion about epilepsy. Many schools have classes on mental health issues; students sign up to learn about a particular issue or condition and present a report to the class. Sharing knowledge can take the mystery out of epilepsy and mental health issues.

People fear what they don't know. It can be helpful for other children to know about epilepsy, the signs of a seizure and what they can do to help. Empowering people with information about epilepsy will help them know what to do when a seizure is happening. This way, they will be able to act appropriately if your child is having a seizure at school. Fear can lead to misunderstanding and rumors. Youth with epilepsy might struggle because other children are afraid of them after having witnessed a seizure. Different organizations provide school education to help school personnel, peers and teachers to learn about epilepsy. These educational sessions can be very helpful in decreasing the fear and misunderstanding about epilepsy in the school.

Coaching your child on how to approach the people at school can be helpful. You can set up a role play by saying, "Now, let's pretend you're not feeling well at school. I will be (fill in name). Let's practice asking me for help." Sometimes, children are afraid to ask to leave class or are told that they shouldn't ask. You can practice this situation, too. "Let's practice asking (teacher's name) to leave class." The more you practice at home, the more confident your child will be in school.

If your child needs special accommodations, you can have an *Individualized Education Program* (IEP) written. (This process is described in detail in Section III of the epilepsy booklet.) Your child will participate in observations and testing in order to determine what needs to be in the IEP. At the end of this process, you will be asked to attend a meeting with the team that works with your child. A lot of information will be presented in a short time; the team will ask you to sign the program they have created for your child. Take some time to read the information and react to it. You can also ask to have an educational advocate attend the meeting with you and suggest what you can do as a next step. A *Seizure Action Plan* (SAP) for your child can be put into the IEP; the IEP can cover all aspects of your child's school day.

School-based Interventions

Many children with epilepsy may need supportive services at school. Here is some information on how to go about getting needed services for your child. As a parent, you have the right to request a new IEP meeting if you feel your child's educational needs are not being met. If you have concerns, talk to your child's teacher and principal. They can help you decide if the IEP team should meet to discuss your child, your concerns and/or your child's progress.

How to get an IEP for your child

If you have concerns about your child's performance at school for either medical or behavioral issues, you can ask for a multi-factorial evaluation (MFE) to see how your child is doing. Your doctor also can send a letter asking

the school to evaluate the services provided for your child, and his or her needs. If a child is found eligible for special education, the IEP team has to develop a program that includes:

- Current test scores on the MFE
- How the child's epilepsy is affecting his or her progress
- A set of annual learning goals that can be measured
- All the services (specialized instructions, special aids, special therapists, services and program modifications) that have to be provided for the child to make sure he or she is benefiting from the educational intervention
- A description of the reason why the child is not to be educated in the regular education school system

Some of the services that may be required to help a child with epilepsy to benefit from special education:

- Speech and language therapy
- Physical therapy
- Occupational therapy
- Transportation services
- Parent counseling and training
- School nurse services
- Behavioral intervention specialist
- Applied behavior analysis
- Reading intervention specialist

Supplementary aid and services:

- Dedicated aide
- Use of communication assistance devices, word processors
- Special seating in class
- Furniture that is tailored to the child's physical needs
- Use of calculator
- Use of tape recorder
- Eyeglasses
- Use of hearing aid or device

Special accommodations for testing:

- Small group setting
- Extra time when taking tests
- Repeated directions

- Oral or written directions
- Small periodic breaks

Other important interventions that can be requested:

- Behavior intervention plan (BIP)
For those students with behavioral and emotional disturbances that are affecting their learning
- Extended School Year (ESY) services
For those students who, during summer vacation, may lose the skills they just learned
- Transportation Plan
For those students who need transportation services
- Transition Services Plan
For any student from 14 to 18 years old (if appropriate)

As a parent, you are a key part of the IEP team. Other members of the team include:

- One regular education teacher
- One special education teacher
- A representative from the school district who knows the district's available resources
- Someone who can interpret results and instructional implications of the MFE results
- In some cases, the child
- If parents request, a parent advocate or others who have important knowledge about the child

Before the conference

- Evaluate all the information that you have about your child. Gather all the important evidence to make your point (notes from different providers, therapists, outside evaluations. You can ask your doctor to write a letter for this meeting.)
- Think about any important questions that you have. Make sure you understand the program; this will be easier if you write your questions before the meeting.
- Think about the big picture of your child's strengths and needs. Are all your child's needs addressed in the IEP? Do you have any specific concerns about the current educational program? Is there any evidence that something in the current plan is not working? As a parent, you have the right to request copies of all school

records that are related to your child.

- Make sure you have a copy of all the assessments before the meeting, and be sure you understand what they mean. If you don't, request a meeting with the school or your mental health provider to discuss any assessment information.
- If you need any extra support you can always bring someone with you to the IEP meeting (spouse, friend, relative, educational or parent advocate). If English is not your first language, you can request a translator or bring someone that you trust with you to translate.

The IEP meeting is very important; it is your best opportunity to share your view about the current educational program and how it is helping your child. Nobody else in the room will know your child better than you; sharing information about how your child is at home, after school and in other social situations will help the school create the best plan for your child.

If there are parts of the program that you don't agree with, let the team know. Changes can be made if you are able to explain your ideas and the reason. Although school staff will want you to sign the IEP at the end of the meeting, you do not have to. You can ask to take a copy home to review, or ask someone who cannot be present at the meeting what they think.

If you feel the teachers and other school staff are doing a good job, let them know. Recognize the effort and reflect on the impact that you are seeing in your child.

It may be helpful to ask your child's physician and others who know your child well if there are accommodations that they would recommend. School personnel may recommend things that they have experience using. If your child needs a different accommodation, it may be helpful to have others suggest it to you.

Some children with epilepsy might have problems with learning at whatever school they are attending. Many studies have shown that no matter how intelligent kids are, epilepsy increases the risk of poor performance in school. It may be for medical reasons (the severity of epilepsy), or behavioral disorders since those tend to be underdiagnosed and undertreated in this population.

Some of the behavioral problems that have been associated with epilepsy have also been related to poor performance in school. These include:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Major depressive disorder (MDD)
- Anxiety disorders
- Autistic spectrum disorders (ASDs)

These problems can severely affect the way the child deals with things – how much the child is interested in learning, how engaged in his or her homework, and how well he or she interacts socially with peers and school personnel.

If a child is taking many medications at the same time to control epilepsy, he or she may have side effects that can affect school performance. Problems with controlling seizures may help determine which school your child attends, and may keep him or her out of a mainstream education.

Sometimes despite all your efforts and the school's efforts, you might feel that your child is being discriminated against because of the epilepsy. There are some Epilepsy Foundation resources to help parents of children with epilepsy who have questions or concerns about these issues: See epilepsylegal.org or call 1.800.332.1000.

Make use of advocacy resources. It is important to have a good knowledge about epilepsy, your child's medications, and their side effects, but you don't have to do all this by yourself. There are good resources in the Epilepsy Foundation's compilation of materials for parents and teachers at epilepsyclassroom.com

Resources for Schools

1. Epilepsy Foundation of America National school alert program
efwp.org/programs/ProgramsPSA.xml
 - a. For educators
epilepsyfoundation.org/livingwithepilepsy/educators
 - b. Forms for school nurses and parents
epilepsyfoundation.org/livingwithepilepsy/educators/socialissues/schoolnurseprogram/

2. Kids on the block

kotb.com/

3. National epilepsy awareness month

epilepsyfoundation.org/getinvolved/neam/index.cfm?gclid=CLG1pa_nibYCFYxaMgod4g0AIA

4. Folder about your child

This resource was created by Epilepsy Foundation Florida, on all the important information that you should know about your child with epilepsy:

efof.org/index.php/children-and-family-and-resources/resources-a-documents