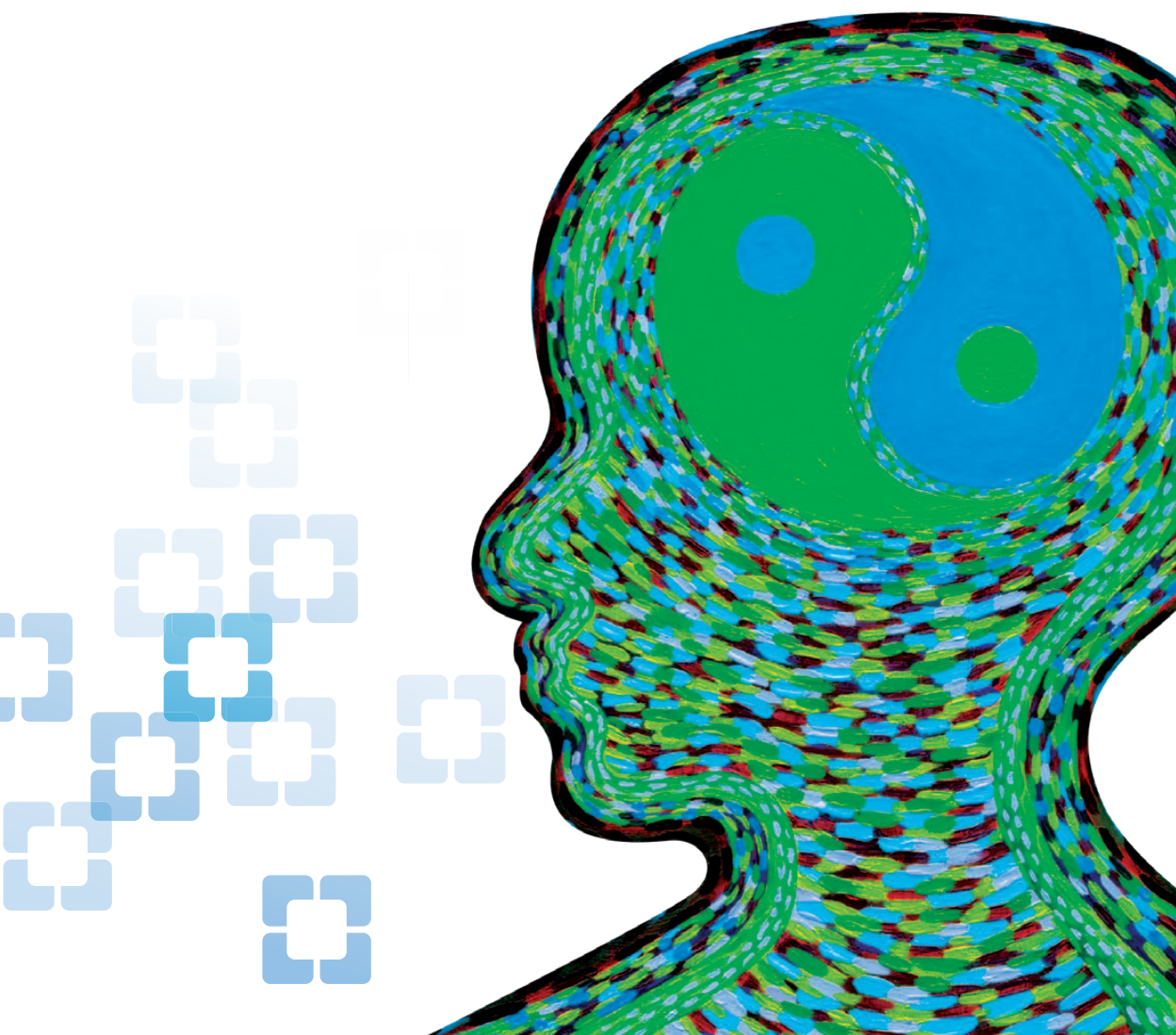




A RESOURCE FOR PARENTS

What you should know about mental health in youth with epilepsy



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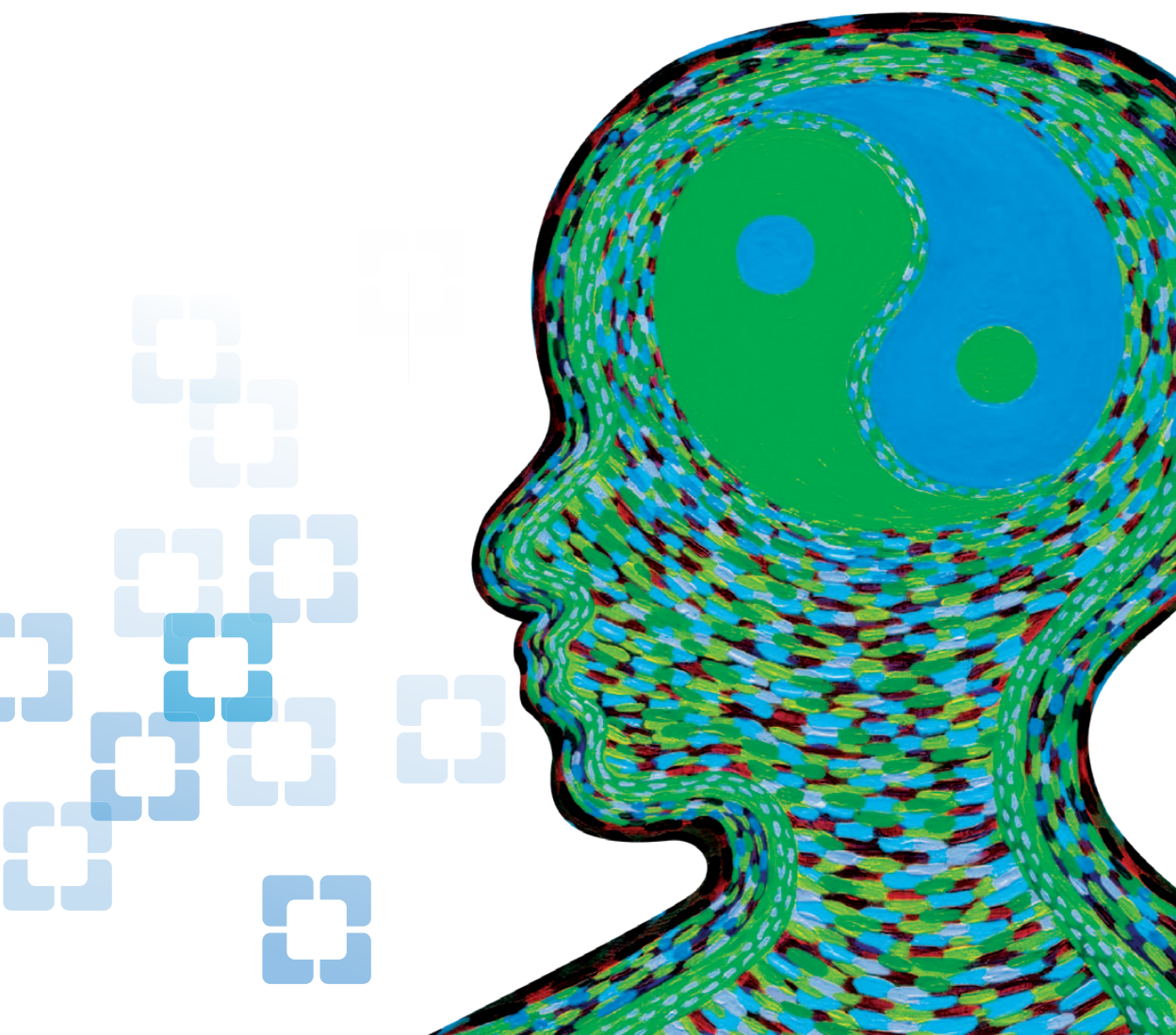
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The information contained in this mental health tool kit is not intended to be a substitute for professional medical advice. A physician or mental health practitioner should be consulted about any specific mental health care and treatment decisions.

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“I learned that the best way to face this situation is KNOWLEDGE and by only understanding what is happening with my child (physically and mentally) we would be able to include her epilepsy as part of our family daily life”

— a father

Introduction

Dear Parent,

It is hard to cope with all the difficult challenges that epilepsy can bring. The purpose of this tool kit is to help you understand some of the mental health issues that youth with epilepsy can face at some point in their lives. The nature of epilepsy and the fact that it is a disease that affects the brain can certainly have an impact on your child's behavior, thoughts, emotions and social skills. The fact that epilepsy is unpredictable and ongoing might have an impact on your child and your family functioning. It might also influence how your child gets along with other children and adults.

This tool kit was written to help you understand some of the issues that your child might be facing, and treatments that can be effective in helping him or her cope with epilepsy and mental health issues. We know that as a parent you probably have a lot of questions. This tool kit doesn't have all the answers, but it can be an important resource guide to help you find important information and to point you in the right direction.

Some of the different sections of the toolkit came from interviews with parents and what other professionals have told us about the needs of youth with epilepsy. We know mental health information may not be readily available for parents and providers, and sometimes it can take a long time before the child is referred for appropriate treatment. Learning about the issues your child can face will help you recognize them sooner so that you can seek help sooner. Some of the information presented may be upsetting if it is something that you are not currently experiencing. We have attempted to address this by dividing the toolkit into sections, with the third section dealing with specific mental health issues in epilepsy.

We hope this tool kit is helpful to you.

Tatiana Falcone, MD

Jane Timmons-Mitchell, PhD

Section I

Children

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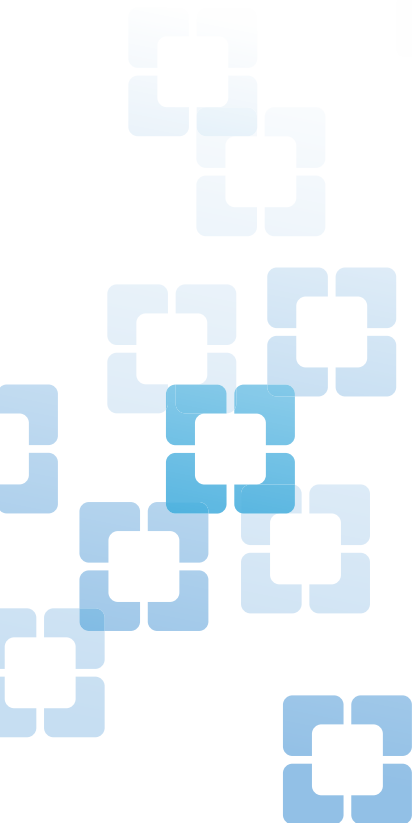
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Section I

Children

All children have a lot in common. They start out small and grow, and as they grow, they learn and develop. They grow up in families, and how they get along with the important people in their lives has a lot to do with who they become. They go out into the world, beginning with school, and they learn to get along with others.

Of course, children with epilepsy show important differences in some of these aspects, but perhaps not all, and not all of the time. We conclude this first section on childhood by discussing coping and resilience (being able to bounce back or cope with difficult events), which are important for everyone; they are especially important for children with epilepsy and their families.





Child Development

Daily life, for both the child and the family, is affected by having a child with epilepsy. Providing medical care as needed for the child is only the beginning. Since the medical condition is chronic (lasts a long time), and since it can require more care at any time, it may be difficult to set up routines for the child and for the family. But it is very important to establish daily, weekly, and monthly routines, as well as family traditions, since these add to the enjoyment of family life and make the adjustment easier for the child with epilepsy.

It may be difficult to balance the needs of a child with epilepsy with the needs of other children in the family. We know that the brothers and sisters of children with chronic illness can adapt. Therefore, parents should not feel guilty about the time that they must spend addressing the needs of the child with epilepsy at the expense of the other children. This is important since we know that when a parent feels guilty, it can affect everyone in the family.

Establishing a “new normal” may help everyone to cope. Also, scheduling special time with the other children in the family is important too, so they also feel care and love.

Tasks to be accomplished at different developmental stages

Infancy: In infancy, parents care for children's needs. A major task for the infant is to develop strong attachments with parents and family members, and to begin establishing a foundation for social, emotional and intellectual development. Since many children with epilepsy are diagnosed very early in life, learning how to manage daily life for infants should include play time and enjoyable activities that teach these skills. If a child attends an early intervention program, the list of programs will include needed activities.

Parents can also add activities to challenge a child at whatever level helps the child build on what he or she can already do. Sometimes parents choose to delay or refuse early intervention services, thinking "my child will catch up on their own." This can be a mistake that is often driven by stigma (feeling like identifying your child's epilepsy will cause negative labeling). There is an important window from birth to age 8 where children are more likely to make the gains in their language and other important areas of their development. The longer the help is delayed, the more difficult it may be for the child to develop up to his or her potential.

Preschool: In the toddler and preschool years, children are actively exploring the environment. This may be challenging if a child is injured because of a seizure. However, it is important to provide ways for the child to explore while ensuring his or her safety.

Children at these ages are also developing friendships with other children. It is important to help your child make friends and maintain friendships. Since *social skills* can be affected in children with epilepsy, you may need to supervise play opportunities that are geared to your child's interest and skills. While controlling the seizures is very important, you should also make sure that your child takes part in regular family activities. Also, different groups in the community might have weekly playtime, which is a great way to meet and connect with other parents.

Elementary School: By about the age of 10, every child should have identified something that he or she is good at and enjoys doing. This may be more important for children with epilepsy. The types of possible activities may be limited, but having a special skill or strength is a great way to build self-esteem. In elementary school, children are learning and exploring through computers and video games, as well as reading.

If a child has an *intellectual deficit*, or special needs, the school work may be tailored to his or her abilities. Doing as much as possible should be the goal. The child must feel that he or she is able to do his or her school work, so he or she can feel effective and successful at one of the basic tasks of being a kid: school. Remember, you are the best support your

child has; no one knows your child better than you. If you feel that the school work is too hard or not appropriate, schedule a meeting with the teacher to discuss your concerns.

Middle School: Adolescents are known for making fun of children who are different, which may make it more difficult for a child who has epilepsy to make friends. Try to find welcoming groups for your child to take part in. Faith-based communities often provide socialization and service projects for youth. Boy Scouts and Girl Scouts offer rich opportunities; in some communities, troops have been formed to address the needs of youth with health issues and other differences. Boys and Girls Club of America (bgca.org) is an organization for children ages 6 to 18 years. It offers recreational activities and opportunities to participate in team activities in your community. Your city could have a local branch or chapter for this organization.

Promoting social interaction in this stage is key. Helping your adolescent to make long-lasting friendships and encouraging social interaction is very important.

High School: A main goal in adolescence is for the youth to begin to chart his or her own path in the world. For youth with epilepsy, the goals may need to be seen through the prism of what is possible. For instance, some children who are doing well on medication and who have learned how to manage their illness may be able to drive, to move out on their own, to work and/or to go to college. Adolescents with ongoing seizures should not drive. Driving and epilepsy regulations changes from state to state. To find the recommendations for your state, please visit epilepsyfoundation.org/resources/drivingandtravel.cfm

This is also an important time to start thinking about transition of care; for example, helping your child to learn how to use medical services and take their medication, and making sure he or she talks directly to the doctor and gets answers to all of his or her questions and concerns. You should also address key issues, such as contraception. Female patients should discuss with their epilepsy doctor the importance of planning for their reproductive life. Patients should also discuss the issues of drugs and alcohol, driving and the different laws in each state.

These are very important questions that should be addressed during the epilepsy appointments, as well as the switch from pediatrics to adult providers (epilepsy doctor, pediatrician to internal medicine or family doctor). It will be helpful to discuss these issues with your pediatric team to assure the change from pediatric care to adult care goes smoothly.



Family

Children are born into families; the family nurtures the child from the beginning of life and helps the child learn how to develop roots and wings. Families are somewhat alike in structure (parents and children), but can be very different in how they deal with major parenting tasks. From about the age of 2, when a child becomes very mobile and learns the word “No,” a major task of parenting is how to balance discipline with encouragement. Major styles of parenting have been categorized as: **authoritarian**, **authoritative** and **permissive**.

The **authoritarian** parent is very strict and forbids many activities without including the child’s point of view. The **permissive** parent does not set many rules and often tries to be the child’s friend. Both of these parenting styles can lead to difficulty later. The **authoritative** parent sets limits but discusses them with the child, and balances strong praise with punishments or consequences that are tied to how the child is expected to behave.



Parenting a child with a chronic health condition can make it difficult to find the middle ground between holding the line and allowing the child to do what he or she can do. It takes some adjusting by everyone in the family. It is also important to set expectations, though these will be based on what the child will be able to achieve. Chronic health conditions can also create stress between parents, and between parents and extended family. Seeking support is vital for parents of children and youth with epilepsy.

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 the key people (bus driver, school aide) 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

Social Skills

Getting along with other people is an important part of life. Examples of social skills include cooperation, assertion, responsibility, self-control and empathy (compassion). Children and youth with epilepsy may find it hard to get along with others, partly because epilepsy may limit some activities (like physical activities, in which children learn rules and establish friendships). Other children may make fun of them. Parents may keep them from taking part in some activities for fear that they may have a seizure.

Unfortunately, these patterns may end up teaching children to avoid activities or people.

The good news is that most children with epilepsy have nearly the same social skills as their brothers and sisters who do not have epilepsy. Problems with social skills may be the result of a learning disability and other family difficulties which may or may not be related to epilepsy.

Coping and Resilience

Resilience, **being able to bounce back or cope with difficult events**, is helpful when thinking about coping with the stress of having a child with a chronic illness such as epilepsy. The stress can increase if the child also has a behavioral or mental health issue. Resilience is the idea that we develop strength in response to stress, and we can use that strength to help us get through trying situations. It can be summed up in the old adage, “Whatever doesn’t kill you makes you stronger.” It is our strengths plus the coping mechanisms we develop that help us.

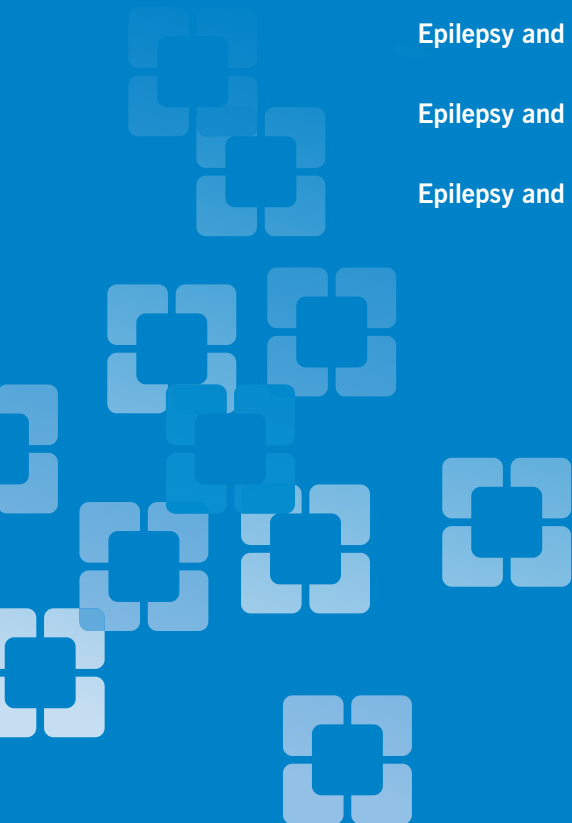
Some common coping mechanisms that can help parents of children with epilepsy:

- Having a good social support network, including good family support
- Having a ready source for informational questions
- Using a problem-solving approach to issues that arise

Section II

Epilepsy and Mental Health

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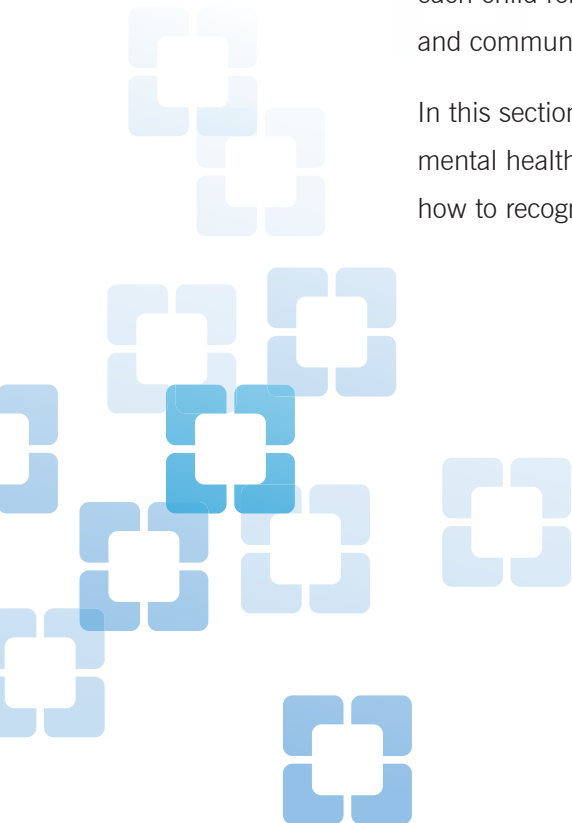
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Section II

Epilepsy and Mental Health

Many children with epilepsy can also have mental health issues. Some of the most frequent mental health issues are depression, anxiety and ADHD. How much these issues impact each child relates to how the family, school and community support the child.

In this section we describe the most common mental health issues for youth with epilepsy and how to recognize them.





Epilepsy and Depression

Depression is a medical condition that affects about 10 percent of the general population. Girls are more likely to be depressed than boys, and teenagers are more likely to be depressed than younger children. Depression is common in patients with epilepsy; up to half of children with epilepsy develop depression at some point in their lives.

The longer the symptoms of depression last, the more difficult they are to treat. Some studies have reported a definite relationship between depression and epilepsy. It is important to recognize the symptoms and degree of severity early on, since children and youth with epilepsy are at risk for *attempted suicide*.

How does depression look in youth with epilepsy?

It is sometimes hard for parents to recognize the symptoms of depression. Depression in children and adolescents can look very different from how it looks in adults with mood disorders. Children with depression normally don't appear sad. They might appear irritable; they might be uninterested in regular activities. Sometimes parents will notice

a decrease in school grades or important changes in behavior such as refusing to do regular chores or routines.

Some of the important symptoms observed in children with depression:

- Problems falling asleep or staying asleep;
- Sleeping too much
- Changes in appetite
- Greater sensitivity to rejection
- Poor self-esteem
- Hopeless thoughts
- Thoughts of suicide

Note: If you truly believe your child is at risk, consider taking him or her to the Emergency Room.

What is the impact of depression in the life of my child?

Patients with epilepsy and depression usually have a poor quality of life, even when seizures are under control. Sometimes parents decide to wait to get treatment for depression until the seizures are under control, but the longer the depression lasts, the tougher it is to treat. Symptoms of depression usually don't improve unless they are addressed.

In addition, the issue of how children who have epilepsy feel about themselves, and how they get along with others, is still not completely understood. Some studies suggest that children with epilepsy might have lower self-esteem because of their disorder. Other studies show that children with epilepsy have poorer self-concepts than children with other chronic medical conditions and frequently struggle in school and other social settings. These experiences might lead to poor self-esteem and symptoms of depression.

Suicidality in Epilepsy. Studies have consistently shown that patients with epilepsy are at higher risk for committing suicide. Patients with epilepsy have two to four times greater mortality (death) rates compared to the general population. In patients with epilepsy, thoughts of suicide occur more often in patients who are depressed. Among patients who have epilepsy, those with temporal lobe epilepsy are at higher risk for suicide compared with other types of epilepsy.

Other important risk factors for suicide in patients with epilepsy:

- Symptoms of depression
- Irritability
- Temporal lobectomy (surgery to remove part of the temporal lobe of the brain)
- Having epilepsy early in life
- A tendency to be impulsive and outbursts of violent behavior

Some of the risk factors associated with suicide:

- Mood disorders (major depressive disorder and bipolar disorder)
- Psychotic disorders
- Personality disorders
- Substance abuse (for example, drugs and/or alcohol)
- Earlier suicide attempts
- History of suicide attempts or completed suicides in the family
- Critical life events

Other epilepsy specific risk factors are the stigma, (negative labeling) associated with epilepsy, and changes of mood very close to the time of the seizures. According to studies, an epilepsy patient who commits suicide is more likely to be someone who:

- Has early onset epilepsy
- Is an adolescent
- Has seizures often
- Takes two or more antiepileptic medications (AEDs) at the same time, and
- Has a history of major depressive disorder

The severity of depression is probably the most important risk factor.

If a child talks about feeling suicidal, it is very important to listen and to connect with your physician as well as with a mental health professional. It can also be important to supervise your child's activities closely and to be sure that your child does not have access to a ready means of harming him or herself. For example, if you have firearms, be sure that they are taken apart and stored properly, with ammunition stored separately from the gun itself. Likewise, it is important to store medicines and other implements, like sharp knives, in a lockbox which can be kept in the trunk of your car. If any of the

behaviors that concern you lasts for more than a few days, you should contact your physician (your primary care physician, epilepsy doctor or family doctor).

Epilepsy and Anxiety

Anxiety is a condition that affects about 18 percent of the population. Although everyone experiences stress, and sometimes fear, anxiety disorders last at least six months and can get worse if they are not treated. Types of anxiety that may require treatment include panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder (PTSD), phobias (including social phobia) and generalized anxiety disorder.

Up to 40 percent of children with epilepsy develop anxiety disorders.

Anxiety disorders are very common in youth with epilepsy; the very nature of epilepsy can cause children to develop anxiety symptoms. Children with epilepsy often struggle with communicating their feelings effectively, which may affect how they cope and increase their anxiety. Sometimes kids who struggle expressing how they are feeling report more symptoms such as headaches, stomach aches, back pain, nausea or vomiting.

In children, anxiety might look different than it does in adults; they might seem more argumentative, irritable or aggressive at times, perhaps having angry outbursts or destroying property. Sometimes parents feel that the child is misbehaving and ignore important warning signs. For example, your child may have trouble doing the usual things, like going to sleep, getting out of bed or going to school because of worry about what will happen. Your child may avoid activities that he or she likes and has engaged in recently. Your child may also show fears, either specific or general, including spiders, heights or social situations. Some children may need to check something over and over, like whether they left a light on.

Epilepsy can affect the way children think. This can decrease their attention and understanding, and school work may suffer. When this happens, children might unconsciously try to avoid school tasks, pretend to feel sick, and refuse to go to school. It is true that sometimes, because of the severity of the epilepsy, a child will have to miss school; sometimes kids get behind and it is hard for them to catch up. Getting the appropriate resources and asking the school for help early on can decrease the likelihood that the child will skip school.

Epileptic seizures can be really traumatic at times for children. When the seizures occur during the school day, or in public places, children and youth with epilepsy might feel embarrassed about other classmates seeing them while they are having a seizure. Educating your child's school might help reduce negative labeling about epilepsy and might help your child feel more comfortable in the event that he or she has a seizure during the school day.

Epilepsy and ADHD

What is ADHD?

Attention Deficit Hyperactivity Disorder (ADHD) is a disorder in which a person struggles with paying attention and staying on task. ADHD usually starts before age 8. To make the diagnosis the symptoms have to be present in two different settings (for example, home and school), and the symptoms should be affecting the everyday life of the patient. Some patients just have symptoms of inattention, some just have symptoms of hyperactivity, some patients have impulsivity, and some patients might have all of the symptoms, or a combination of any of them. It is not necessary to have symptoms of hyperactivity to make the diagnosis of ADHD.

ADHD is probably the most frequent school-related issue found in youth with epilepsy. The high incidence of ADHD in this group might be related to the area of the brain where the epilepsy is coming from: Some areas of the brain have been recognized as especially important for information processing and attention. Difficulties related to ADHD can have negative impact on a child's development at home and at school. They can also keep kids from making and keeping friends.

How is ADHD diagnosed?

The American Academy of Child and Adolescent Psychiatry (AACAP) has developed some guidelines for the diagnosis, evaluation and treatment of children with ADHD. Ask your doctor about referring your child to a child psychiatrist or child psychologist if you are worried that your child might have ADHD. Doctors sometimes use scales to help in the diagnosis; sometimes they ask for information from school teachers or other important people who know your child well in settings where your child might be struggling with symptoms of ADHD.



What are the differences between children with epilepsy and ADHD and children with just ADHD?

We do not know much about how seizures affect ADHD. Some of the attention symptoms can be caused by the side effects of the medication, the effect of poor control of the seizures or problems with the child's thinking skills.

What comes first: ADHD or Epilepsy?

The relationship between epilepsy and ADHD is a two-way street. Many studies have reported that the symptoms of ADHD sometimes start before the first seizures, and despite good seizure control, patients still struggle with ADHD. Also, many parents decide to wait until the seizures are well-controlled before addressing the ADHD. Studies have reported that ADHD symptoms can negatively affect the quality of life of youth with epilepsy even more than the seizures. Talk to your neurologist about the right time to address the ADHD symptoms and what treatments your child needs.

What other factors are important to consider when thinking about ADHD?

The symptoms of inattention occur equally in boys and girls. Boys may have more symptoms of hyperactivity early on (before age 8); this may be why girls, who have inattention symptoms, are sometimes not diagnosed until they are teenagers.

Another important consideration is the presence of intellectual disabilities. Some studies have reported that youth with epilepsy that comes from the frontal lobe might have more attention problems compared to epilepsy coming from other parts of the brain.

How frequent is ADHD in youth with epilepsy?

In the general population, the estimate of ADHD is around 3 to 7%; in youth with epilepsy it ranges from 12% to 57%.

Do antiepileptic drugs (AEDs) have any impact on the ADHD?

Yes. Some of the AEDs, such as topiramate, phenobarbital, benzodiazepines, tiagabine, and zonisamide, might have a negative effect on attention. It can be really useful to diagnose ADHD, when there are reports of inattention (or concern by the parents), before the AED is prescribed.

It is always important to tell the specialist your concerns about your child's attention problems: if you feel your child is worse on the medication, you need to let someone know. As an important part of the health care team for your child, you are in a great position to help make the best decisions for your child, which might include trying a new AED or decreasing the dose if necessary. **Do not stop or slowly reduce the medication on your own! This can cause problems, such as a breakthrough seizure, for your child.**

Is it true that kids with ADHD tend to have other behavioral issues?

In youth with epilepsy, the impact of ADHD on school work and on other behavioral disorders is often seen. Other behavioral disorders can include: intermittent explosive disorder (IED) and oppositional defiant disorder (ODD).

What if we decide to wait on treatment (either medication or therapy)?

As long as you know and recognize the risks of not addressing the symptoms, this is your decision. When youth feel they are not doing well in school, their self-esteem suffers,

which increases the risk of depression. This becomes a cycle in which lack of success contributes to a disconnection from school, which leads to additional lack of success, and so on. Sometimes the teacher sees this and expects less from a child with epilepsy.

Is there a relationship between ADHD, social skills and epilepsy?

Children who started having seizures before age 8 tend to have more problems with social skills than children who start having seizures after age 8. Some are diagnosed with autism spectrum disorder or any other diagnosis in the social spectrum. These patients have more attention, impulsivity and aggression issues than other children with epilepsy with no autism spectrum disorder.

When do we need neuropsychological testing?

Every youth with epilepsy should have neuropsychological testing to measure how they are doing in school. These scores can help us find problems with learning that can be addressed in the IEP (Individualized Education Plan, discussed under School).

Do kids with ADHD and epilepsy have more trouble sleeping than other kids?

Yes, children with ADHD have a higher rate of sleep problems. Patients with Electrical Status Epilepticus (ESES) during sleep have more problems with attention and hyperactivity. Patients with nocturnal frontal lobe epilepsy can also have more problems with inattention and sleep.

Important questions:

1. What was recognized first, the epilepsy or the ADHD?
2. Did the ADHD become worse after a new AED was started?
3. Are the school demands higher?
4. Are there other behavioral problems?
5. Is the child sleeping well at night? The quality of sleep can have an impact on the behavioral issues.
6. Are there things your child was able to do and learn that he or she is not able to do and learn anymore?

Epilepsy and Family

For all of the activities that are discussed in this and the next section, the parents have to take part and lead. As such, it is important to do what you need to do to take care of yourself. That may mean finding support groups or hotlines, lining up professionals to address particular needs, and meeting parents who have had experience with children and youth with epilepsy. Try to stay positive and hopeful; if you feel that you are slipping, see a case manager or other appropriate person who may be able to listen to your concerns and direct you to services as needed. Help is available!

In the next section, you will find descriptions of medication and psychotherapeutic techniques (talking therapy) to address your child's needs. When considering the talking therapies, if your child is young, these may include you as an active participant. These ways of working with children, youth and families have been shown to be helpful.

Epilepsy and School

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 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 can they 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 might be 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 Plan* (IEP) written. (This process is described in detail in Section III.) 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 plan 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.

Epilepsy and Social Skills

Children with epilepsy sometimes struggle with social skills, especially children who start having seizures early in life (before age 8). The earlier the epilepsy starts, the greater the chance that it will affect the child’s social skills. This, in turn, can affect the way children act with peers and adults, making it harder for them to do activities that might be routine for other kids (for example, calling someone on the phone or recognizing other people’s emotional needs). The more severe, generalized type of epilepsy can have more impact on the quality of life. Sometimes parents recognize these problems early on, and sometimes they are recognized by the school or peers.

Some patients with epilepsy might also be diagnosed with different social skills disorders such as autism spectrum disorder (ASD) or pervasive developmental disorder. Also, up to one third of the patients diagnosed with autism have had seizures. Children with ASD might be more sensitive to lights and sounds. Exposure to certain lights and sounds (including videogames) can increase the number of seizures. Talk to your epilepsy doctor if you are worried about your child getting worse after viewing certain television shows or video games.

The sooner the epilepsy is controlled, the greater the chance that social skills will improve. In patients with severe focal epilepsy who have epilepsy surgery, social skills greatly improve when the patients become free of seizures. The first eight years of life are key for social development; it is important to take advantage of the available resources early.

Section III

Treatment/Intervention for Children with Epilepsy and Mental Health Issues

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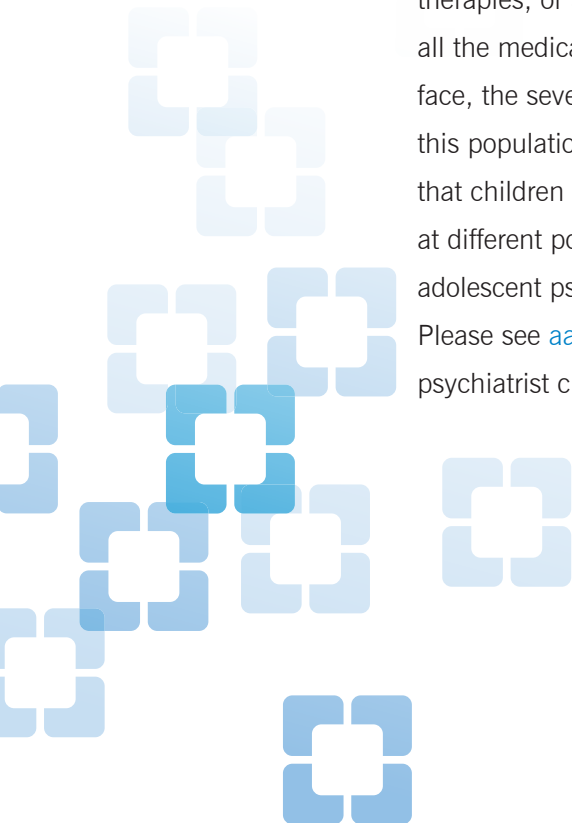
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Section III

Treatment/Intervention for Children with Epilepsy and Mental Health Issues

There are effective treatments for mental health conditions, including medications, psychological therapies, or a combination of both. Considering all the medical issues that patients with epilepsy face, the severity of mental health issues in this population, and the different medications that children with epilepsy might be taking at different points, it is best that a child and adolescent psychiatrist manage the medication. Please see aacap.org/ for how to locate a child psychiatrist close to you.





Psychopharmacologic (Medication) Treatment

Depression

For medications, the treatment of choice is a type of antidepressant called Selective Serotonin Reuptake Inhibitors (SSRIs). For therapy choices, cognitive behavioral therapy (CBT) is discussed below under psychotherapy.

Does the treatment for depression makes the seizures worse?

According to several studies, there is no difference in the number of seizures before and after treatment with SSRIs. Antidepressants must be closely monitored by a child psychiatrist to detect any side effects or possible interactions early.

Do antiepileptic medications cause thoughts of suicide?

In January 2008, the U.S. Food and Drug Administration (FDA) issued a black box warning about the increased risk for thoughts of suicide in the clinical trials of 11 antiepileptic drugs (AEDs). Another important risk factor is whether any of the child's first-degree relatives (parents, brother or sister) have any mental illness; this can predict whether the child will develop psychiatric symptoms.

AEDs are the only treatment available for epilepsy; therefore, it is important to continue your child's medication to prevent seizures. You can always talk to your physician if you feel your child is having symptoms of depression after starting a new medication. Together, you and the doctor can make the best decision to help your child. Stopping any medication, especially antiepileptic medication, is very risky and can have a long-lasting negative effect on seizure control.

Do antidepressants cause thoughts of suicide?

In 2004, the FDA put a black box warning on pediatric antidepressants because studies showed a small increase in suicidal thoughts and behaviors in patients who were taking these drugs (although there were no actual completed suicides reported in any of these studies).

The evidence strongly supports the treatment of children and adolescents with depression, despite the risks. Pediatric depression is a severe and real illness. Effective treatments for depression are available. Although antidepressant treatment carries risks, untreated depression has potentially worse risks, and treatment is effective, especially when started early. *Depression* is a serious illness when it occurs in childhood. In addition to the human suffering that occurs, the symptoms of depression interfere with everyday living, school work, interactions with friends and family relationships, and causes delays in development. Untreated depression can have serious consequences; longer episodes last from six to nine months. It can increase the risk for other issues such as substance abuse, eating disorders, teenage pregnancy and suicidal thoughts and behavior.

It is very important to have SSRIs prescribed by a child psychiatrist and closely monitored for children with epilepsy. Creating a partnership with your doctor will help detect possible problems in early stages. Stopping the medication suddenly, rather than slowly, can produce bad side effects for the patient.

To learn more about antidepressants in the treatment of depression see the following link.

parentsmedguide.org/pmg_depression.html

Anxiety

The treatment of anxiety disorders is very similar to the treatment for depression. For medications, the treatment of choice is SSRIs (please see the section on depression). For therapy choices, cognitive behavioral therapy can be very effective (on page 34).

ADHD

ADHD can be treated with medication and therapy. The most effective medications to treat ADHD are stimulants. Studies in children without epilepsy have demonstrated that after treatment with a combination of medication and psychotherapy, patients' ADHD symptoms improved. Among children with epilepsy that is well-controlled, the stimulant methylphenidate (MPH) reduces the symptoms of ADHD.

Behavior therapy should always be the first treatment, especially if children are younger than 8 years old.

While stimulants are generally the first medication used for ADHD, there are other medications that can be discussed with your doctor, such as guanfacine, clonidine and atomoxetine. However, these medications may not be as effective as stimulants.

Are there any differences in the medication side effects with different epileptic syndromes?

Patients with lower IQ and ADHD have more brain abnormalities and different epileptic syndromes that may increase the risk for side effects of medications. In children with epilepsy, genetic and central nervous system abnormalities are often responsible for learning disorders and lower IQ. Severity can worsen with the impact of ADHD.

The medications for the ADHD treatment should be managed by a child psychiatrist.

A summary of medications for the treatment of mental health comorbidities in youth with epilepsy

Different kinds of medications are used for different conditions:

- 1. Antidepressant medications:** Antidepressant medications are the treatment of choice for patients with depression, anxiety disorders, obsessive-compulsive disorder (OCD) and panic disorder, among others. There are different types of antidepressants. The most frequently used for the treatment of these conditions in children are Selective Serotonin Reuptake Inhibitors (SSRIs), which are effective for the treatment of mood disorders and anxiety disorders in children. In children and youth with epilepsy, antidepressants can help improve the symptoms of depression without having a negative impact on the seizures.

Common brand names: (Prozac®, Zoloft®, Celexa®, Lexapro®, Paxil®)

Common generic names: (fluoxetine, sertraline, citalopran, escitalopram, paroxetine)

- 2. Stimulant medications:** There are two families of stimulants: methylphenidate (MPH) and dextroamphetamine. These medications have been shown to be safe and effective for youth with ADHD without epilepsy. Quality of life of youth with ADHD improves with stimulant medication treatment. These medications are better than behavior treatment and routine community care.

An important question remains: Are stimulants safe to use in the treatment of children and youth with epilepsy? Parents should move carefully when making this decision, especially in patients whose epilepsy is poorly controlled, and in patients with recent (in the last three months) history of generalized tonic clonic seizures or those with history of status epilepticus.

Stimulants for youth with epilepsy should be closely watched by a child psychiatrist. If the number of seizures increases in the three months after the medication is started, other treatments should be considered for ADHD in these children. Children with lower IQ and those in the autism spectrum are more sensitive to the effects of the stimulants, and may have increased irritability, aggression and additional side effects. Special consideration might, therefore, need to be taken when considering stimulants with these children. Children who have heart defects or heart disease might need to have an EKG. If there are abnormalities a cardiologist should be consulted.

Common brand names: (Ritalin®, Focalin®, Concerta®, Daytrana®, Adderall®, Adderall XR®, Vyvanse®)

Common generic names: (methylphenidate, dexamethylphenidate, methylphenidate ER, methylphenidate transdermal system, dextroamphetamine)

For more information on the medication treatment for ADHD, see the following link:
parentsmedguide.org/pmg_adhd.html

3. **Atypical antipsychotic medications** are frequently used in the treatment of bipolar disorder, psychosis, aggression and violence, in combination with SSRIs to increase the effect of antidepressants. Atypical medications can be highly effective in controlling agitation in children and youth with epilepsy who are also in the autism spectrum. Children who take these medications must be watched closely since most of these drugs (with the exception of aripiprazole and ziprasidone) can affect blood glucose and appetite. While taking these medications, your child will have blood tests twice a year; in addition, he or she will be weighed every month in case his or her appetite increases. Other important side effect with these medications are an increase in seizures, especially in those patients with poorly controlled generalized epilepsy tonic-clonic seizures.

Common brand names: (Risperdal®, Abilify®, Geodon®, Zyprexa®, Seroquel®, Clozaril®)

Common generic names: (risperidone, aripiprazole, ziprasidone, olanzapine, quetiapine, clozapine)

Important questions to ask before starting any psychotropic medication:

1. Was my child examined by a child psychiatrist who recommended the psychotropic medication?
2. Were other treatment choices (psychotherapy) explored before a new medication was started?
3. Did the symptoms we are observing begin soon after my child started taking a new antiepileptic medication?
4. Is there any history of any mental health condition in the family? Is there any history of suicide attempts in the family?
5. Is the psychiatric problem affecting the patient in more than one setting? If not, what can we do to improve the stressful situation?



6. If there is anyone in the family with a similar condition? If so, are they taking any medication that has been effective?
7. Are the symptoms related to how severe the epilepsy is? Do the symptoms get better a couple of days after the last seizure?
8. What are the risk, benefits and alternatives of taking this medication?
9. Does the child have any conditions or other reasons not to take this medication?
10. For how long the medication should be continued? What happens if we miss a dose of the medication?
11. Is it okay to stop the medication on the weekends?
12. What are the major side effects and the most common side effects?
13. Is there any interaction between this medication and any of the other medications my child is taking?
14. Who is going to follow this new medication and how frequently should we see the doctor? If I have any questions, whom should I call?

Psychotherapeutic Treatment

Children and youth with epilepsy often feel badly about themselves, are depressed or have other issues that can be addressed using psychotherapy, in addition to medication. Your child's doctor may recommend that you look into psychotherapy, since some kinds of talk therapy can be useful.

There are a few things to look for in psychotherapy for your child:

1. Developing a positive attitude toward epilepsy has been shown to be helpful. Both you and your child can take steps to do this. A therapist skilled in cognitive behavioral therapy (CBT) can help you develop a step-by-step guide to support a positive attitude toward epilepsy. For example, developing a reward system, so that your child receives praise or other desired rewards for taking medicine on time, is one way of supporting a positive attitude toward epilepsy.
2. Learning skills to support self-esteem can be helpful. A cognitive-behavior therapist can help you and your child with problem-solving skills, in which a step-by-step approach is applied to challenges and social skills training, which teaches and practices the best ways to interact with others in social situations.
3. Practicing new ways to think about challenging situations can help. Cognitive-behavior therapists work with your child to decrease the kind of thoughts that are self-defeating (seeing things as all black and white, thinking the worst about everything) and learn new problem-solving skills.
4. Learning how to relax and manage stress can help with most areas of living with epilepsy. A cognitive-behavior therapist can teach your child deep breathing and muscle relaxation, which are effective ways to keep focus.

Homework, charting and journaling are often used to practice and keep track of skills your child is learning.

Sometimes cognitive behavioral therapy is just for your child; sometimes you and your child may meet together, and sometimes the therapist will want to talk with you separately. In some settings, group therapy for children and youth may be provided. Since cognitive behavioral therapy is usually focused on goals and is often very structured, it usually lasts only a short time, such as three to five months.

Other kinds of therapy may be recommended for you and your child. Psychoeducational (informational) support groups help increase knowledge about how to manage epilepsy. For younger children, play therapy that incorporates cognitive behavioral therapy may

be helpful. For children with behavioral issues who also have a developmental disability, behavior therapy may be appropriate. In behavior therapy, caregivers are trained to ignore bad behaviors and reward good behaviors. Children can change behavior by responding to the rewards offered. Behavior therapy has been shown to be effective in working with a wide range of health-related conditions. Other therapies may be recommended by your child's physician.

Depression

Behavioral health treatments for depression include: cognitive behavioral therapy, parent management training, psychoeducational or support groups, behavior therapy, and play therapy.

Some of the things that you and your child may do if you go to a behavior health specialist:

- Learn about feelings, and how to recognize which feeling is which
- Change thoughts that are not based in reality and may get in the way
- Make a plan to increase social and physical activity
- Make a plan to communicate with everyone who works with your child
- Talk with the entire family so that everyone communicates with your child in the same way

Cognitive Behavioral Therapy (CBT): Cognitive behavioral therapy is appropriate for children who are approaching the teen years and who are able to think about themselves and their relationships with others and with their illness. CBT helps the child interrupt and change the negative thoughts that sometimes pile on when things are not going well.

CBT can be very effective; it takes the expertise of a behavioral health specialist who can coach the child to learn and practice strategies that help to improve mood. It also takes the family and the patient to practice these techniques.

Parent management training (PMT) is often helpful for children up to about ages 10 to 12, depending on their maturity. A behavioral health specialist works with parents to teach them parent management skills, including:

- Helping parents define certain behaviors that the child needs to change
- Setting up a “behavior contract,” based on rules, consequences and rewards
- Teaching children how to show more of the “good” behavior



Since depressed young children often break rules, teaching them to follow rules can improve their mood.

Anxiety

CBT. Cognitive behavioral therapy is appropriate for children who are approaching the teen years and who are able to think about themselves and their relationships with others and with their illness. Many specific aspects of cognitive behavioral therapy address anxiety; they all help the child interrupt and change the negative thoughts that sometimes pile on when things are not going well. CBT can be very effective; it takes the expertise of a behavioral health specialist who can coach the child to learn and practice strategies that help to manage anxiety.

Key things you and your child may address if you go to a behavioral health specialist:

- Learning about feelings and how to recognize which feeling is which
- How to change thoughts that are not based in reality that may get in the way
- Making a plan to increase social and physical activity

- Teaching relaxation skills; for instance, how to rate anxiety, using a rating of 0-10, with 0 being no anxiety and 10 being extremely anxious
- Identifying things that cause fear or worry, and developing a plan to deal with them in small steps
- Developing a plan to manage fears
- Making a plan to communicate with everyone who works with your child
- Talking with the entire family so that the everyone communicates with your child in the same way

ADHD

Psychotherapy to treat ADHD is best when used in combination with medications. Another type of therapy is the Children's Summer Treatment Program (STP), a wide-ranging intervention for children with ADHD and similar behaviors. The program focuses on the child's relationships with other children, school work, and parenting skills – three important areas where success can help children improve.

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 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 can also 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 plan 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 therapist, 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 Services (ESY)
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, therapist, 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 plan; 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 plan 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 staffs 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 risks of poor performance in school. It may be for medical reasons (the severity of epilepsy), or behavioral disorders (ADHD, MDD), since those tend to be underdiagnosed and undertreated in this population.

Some of the behavioral problems that have been associated with epilepsy (ADHD, MDD, anxiety disorders, autistic spectrum disorders) have also been related to poor performance in school. 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, 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 School

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 was resource 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

Social Skills

Special social groups for kids with epilepsy and support groups for parents, as well as summer camps, can be found through resources such as the Epilepsy Foundation. Some will focus on helping children socialize and take advantage of community opportunities. Resources through the local board of developmental disabilities (MRDD) might be available if the child is diagnosed with a cognitive impairment.

What can you do to help your child who needs help with social skills?

A good way to address this is to send your child to a social skills group run by a mental health professional, usually a social worker or a psychologist. In social skills groups, children and youth meet regularly with others to learn and practice how to get along more effectively. The mental health professional may present situations in which the child is required to stand up for him or herself and ask for ideas about how to address the situation. Then, when a strategy has been worked out, the members of the group may take turns practicing how to carry out the strategy. Group members give feedback about how the child presented him or herself, and suggestions about what could be done differently to improve the communication.

Social skills development through rehearsal and feedback has been shown to help children do better with others. Living a healthy lifestyle and taking part in social activities, sports, and community events are key in the development of every child. Incorporating the child with epilepsy into the family activities is very important.

For resources, see :

autismspeaks.org/family-services/epilepsy

videogameseizures.wordpress.com/2012/06/07/canaries-autism-and-sensory-overload/

silentlyseizing.com/

autismspeaks.org/family-services/tool-kits

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Section IV

Medical Home and Resources

A key part in the care of youth with epilepsy is care coordination. In this section we include important information on how to build your medical home for the needs of your family. Also included are some resources to aid you in your journey.





Medical Home

What is a Medical Home?

A family-centered medical home is an approach to care that is based on the needs of the patient and the family. According to the Institute of Medicine, a *Medical Home* is “respectful and responsive to individual patient preferences, needs and values.”

What are the important components of a medical home?

Accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective.

What can the Medical Home provide?

Preventive and primary care: The patient gets all the appropriate screening according to age and needs, short-term care in the case of medical illness, and long-term management of the disease.

Coordination with subspecialty care: This is key for youth with epilepsy, since patients with families may visit many different specialists. Communication between the primary care doctor and each one of the subspecialties is important. Coordination can help improve the patient's care, making sure that all of the providers knows the critical issues the patient is facing, the medications he or she is taking, who is providing what care and when the next appointment with each provider is needed. Coordination helps the family know whom to contact for specific issues.

Visit medicalhomeinfo.org/ to build your Medical Home tool kit.

Coordinating Behavioral Health Care with the Medical Home

The physician who is in charge of your child's care for epilepsy should be the primary contact. If you have a Medical Home, there may be another person (a pediatrician, family practice doctor, a care manager, or a nurse practitioner) who is also a contact. These professionals can put you in touch with behavioral health specialists, often psychologists or social workers, who can help you design a treatment plan to address mental health issues. If you have a Medical Home, the behavioral health specialists may work as part of the team or be located in the same facility.

If there is not a Medical Home, your physician or other contact person can refer you to a knowledgeable practitioner. The behavioral health specialist may work in an office building close to you, or may work in a medical facility. Some behavioral health specialists may be able to come to your home.

Your contact person should take into account how far you will have to travel to see the behavioral health specialist, since these appointments usually occur on a frequent (often weekly) basis for a period of time.

The behavioral health specialist will:

- Need a complete history of your child's epilepsy
- Want you to describe the child's behavior that concerns you. Before your appointment, think about the things that concern you. Also think about things that are special strengths of your child, since the description of your child should include strengths as well as needs. Write these down and take to the appointment.

Try to be as specific as possible about how you would like things to look when change has occurred. This will help the specialist work with you to set goals.

Together with the specialist, you will set goals and design a treatment plan. The treatment plan will ask you to keep track of how things are working. If you are not used to recording and charting your child's behavior, you may want to ask the specialist for tools to help you do this.

You will meet with the specialist to review how things are going. If needed, you may agree to try different things in order to achieve your goals.

Patient and Family Advocacy: The key role of the family is being the champion for your child, since nobody knows your child better. It is important for the family to promote the patient's needs with the physician. In the case of children and youth with epilepsy, many of the medications have side effects that can seriously affect quality of life. The family should note all of the side effects and communicate them effectively to the physician, so the family, the patient and the physician can make the best decision for the patient. There are many family- and patient-centered groups focused on advocating for the different needs of patients with epilepsy:

medicalhomeinfo.org/tools.care_notebook.html

Family-centered self-assessment tool

familyvoices.org/

Family Voices

nami.org/

NAMI

epilepsyandmychild.com/epilepsyfoundation.org/ecommunities

Coordination and Community Resources

It is the role of the physician to connect the family with different resources they may need. **When a child is newly diagnosed with epilepsy, it can be very overwhelming; having support from different community organizations and parents who have a child who was diagnosed with epilepsy and is now under control can make an important difference in the life of a child and the family.**

epilepsyfoundation.org/

Epilepsy Foundation

See extreme parenting video project by Elizabeth Aquino:

youtube.com/watch?v=iZ78gHne0LM

Parents are really the managers of the care for the child or youth with epilepsy. It is the parents' job to recruit the best professionals to manage the child's epilepsy and any of the other conditions associated with it. Before every medical or specialty visit, it is important to think about your goals for the visit:

1. Write all the questions that you want to ask your doctor and let the doctor know that you want these questions answered. Don't wait until the last five minutes of the appointment to ask your questions.
2. Gather all the information necessary to make informed decisions: how the patient is doing at school, if there any improvements observed by other key people in the child's life (teacher, providers, therapist).
3. If you are not happy with your child's treatment, let your doctor know. If you are concerned about side effects, discuss them. Your doctor will appreciate that you are discussing your concerns.
4. If the medication has to be taken at school, have you filled out a seizure action plan for the school? Does the school nurse know that your child has epilepsy? It is very important that all the key providers are informed and ready to help your child.

Having a seizure action plan is very important – every child with epilepsy should have one. You can download this template and fill it out with your doctor in the next visit.

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

Resources for a parent of a newly diagnosed child:

epilepsyfoundation.org/livingwithepilepsy/parentsandcaregivers/index.cfm

Parent tool kit with useful school forms and seizure observation form:

epilepsyfoundation.org/projectaccess/findaresource/forfamilies/toolkits-Care-Books.cfm

Manual for parent of a child with epilepsy:

epilepsyfoundation.org/livingwithepilepsy/parentsandcaregivers/parents

CDC – Epilepsy Tool kit for parents of teens:

cdc.gov/epilepsy/toolkit/index.htm

It is important to track how frequent the seizures are; here are some resources for seizure diaries:

webease.org/Overview.aspx

seizuretracker.com/

epilepsy.com/seizurediary

Some resources to learn more about medications:

drugs.com

dailymed.nlm.nih.gov/dailymed

professionals.epilepsy.com/page.medications.com

To learn more about generic medication vs. brand name:

nomoreseizures.org

Some websites offer some medication assistance:

[epilepsyfoundation.org/aboutepilepsy/treatment/upload/
Patient_Assistance_Programs-February-2013.pdf](http://epilepsyfoundation.org/aboutepilepsy/treatment/upload/Patient_Assistance_Programs-February-2013.pdf)

needymeds.org

Standard of care for epilepsy:

naec-epilepsy.org/spec_care/guidelines.htm

Seizure assistance dogs:

assisteddogsinternational.org

k94life.org Canine partners for life

ChelseaHutchinsonFoundation.org

(for fundraising to get a dog)



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