



S.E.E. Program Parents' Manual

How to Raise a Kid with Epilepsy Part 1: Coping with Fear

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in *Exceptional Parent* magazine, Volume 35, Issue 10,
pages 60-69, Oct. 2005 (reprinted with permission.) www.eparent.com

Epilepsy has one of the worst social outcomes for child development of the common disabilities. It shouldn't be that way, though. For most children, epilepsy is not nearly the physical challenge that many other chronic health disorders are. The problem in raising a child with epilepsy is much more emotional and social. Any parent can handle those matters. In many cases they can be handled with surprising ease – if you know what you are trying to deal with.

In this series of three articles, I am going share the information and skills you need to raise a happy and competent child who happens to have epilepsy. In addition, I am going to give you back more peace of mind than you probably have known in some time. The key to raising a successful child with epilepsy is inside you – and that is saying more than you think. When you know how to get yourself right while managing the unique challenges of epilepsy, everything else seems to flow. You will easily understand what you need to do for your child, your family, and yourself. You will able to figure out situations for yourself, but I have included a lot of specific suggestions to help out.

The main struggle will be in getting your own thoughts and feelings right. The fact that they need adjusting is not your fault – our culture bears most of the blame. The change is easier than you think, but the problems we'll conquer sound tough to begin with. The articles will cover the three fundamental challenges of epilepsy for parents: fear, stigma, and guilt. This Parents' Manual assumes you are already taking control over the medical aspects of epilepsy by reading my earlier series of three articles, "*Beating Bad Seizures.*" Together, the three medical articles and these three parenting articles will give you an easy to follow blueprint for success. You'll discover raising a child with epilepsy is not like wrestling a bear; it's more like raising a house cat.

Just what is the problem?

Epilepsy is a very unusual disorder. If an alien were to arrive on this planet and watch a child with epilepsy, it would notice that 99 percent of the time the child wasn't having seizures. The alien would surely wonder what all the fuss was about. It would notice seizures occupied only a very small amount of time in a child's life in nearly all cases. The alien would have thought to itself, if an Earthling had to have a physical disorder and was allowed to pick one, intelligent Earthlings would surely pick a physical disorder that would rarely affect them; a disorder that would disappear for days or even weeks at a time. They would pick epilepsy.

Epilepsy is like that. If you look at epilepsy through the eyes of an alien, you will notice most of the day your child is unaffected by seizures. He can run and jump and play without seizures stopping every action. She can read, draw, and play and instrument without epilepsy barring the activity.

So why is epilepsy so devastating? For most parents it is not the physical challenges of epilepsy that are the problem – it is the emotional challenges. *Seizures last minutes or less, but worry about the next seizure can last a lifetime.* For most parents and older children, it is the daily, unrelenting worry about the next seizure and its imagined consequences that makes epilepsy so difficult. Epilepsy is not so much a physical disorder as it is a *disorder of anticipation.*

With epilepsy, there are exceptions to every rule. There are a few children with truly severe epilepsy or prolonged seizures every day. Our alien would find the seizures themselves to be the problem for those children. For those children the strategies for seizure control discussed in my first three articles need to be the focus. However, the majority of children go days, weeks, or even months between seizures. For them and their families, the daily consequence of epilepsy is the *disorder of anticipation.*

As a parent, you already know it. The emotional impact of unrelenting worry about your child being harmed physically or socially by seizures cannot be underestimated. Worry is exhausting. It draws away the emotional energy required for the other parts of your life. It disturbs your sleep. It complicates family relationships. It chases away feelings of happiness and satisfaction with life.

Parents who live under such circumstances live lives of quiet desperation, but they also live lives of heroic proportions. Despite relentless worry, those of you who struggle through it all to make a life for yourself, your child, and your family are showing strength, love, and determination. You are overcoming obstacles more stubborn and insidious than most people face. While I suspect you have rarely felt like a hero, there is no question that you are.

Taking back control

Since you have the character required to beat the emotional challenges of epilepsy, I will share some practical coping tools to make your effort easier. In the first three articles about “Beating Bad Seizures” you found that knowledge was the key to taking control of seizures and treatment. You will not be surprised to hear that knowledge is key to taking back control of your life and your child’s life.

Epilepsy and seizures take over your emotions and change your behavior in hidden and sneaky ways. These changes affect how you feel about yourself, they affect your family relationships, and they affect your child’s development. Taking back control is a matter of understanding the sneaky things epilepsy does to your feelings and to your family. Taking back control requires practical steps that put you in charge rather than the worry and bad anticipations epilepsy is so outrageously good at creating.

Let’s say we’re taking an afternoon hike in the woods. On the way we come across a cave. Being curious, we enter to explore. As we go deeper, it gets very dark. Finally, it is so dark we start crawling on our hands and knees to find the way. As we reach out, one hand feels fur and claws. What is in that cave with us? Almost everyone would say it was a bear.

But could it also be a house cat? Certainly it could, but in the suffocating dark, the thought of a house cat occurs to very few people. When the human mind is left in the dark about something, its natural tendency is to assume the worst – not the best. That is exactly what happens with epilepsy. Epilepsy is a ferocious bear. When you are left in the dark, with little information about how seizures will affect your child’s life, your mind naturally jumps to the worst conclusions.

Doubt me? How many of you, upon finding out your child has epilepsy, immediately thought of all of the good things that epilepsy would do for your child? Or did you start worrying immediately about possible harm from seizures and lifetime limitations?

Fear of Death

Let's get the biggest worry about epilepsy into the open. I have talked with several thousand parents at S.E.E. programs. One of the questions I ask is, "What did you think was going to happen to your child the first time you saw her have a seizure?" With only one exception in 22 years, every parent thought his or her child was going to die. ***Fear starts with the first seizure.*** And fear doesn't yield its grip as long as you remain in the dark. Worry begins with the first seizure, and the ***disorder of anticipation*** takes root.

How do you overcome the fear? Become informed. It is common for parents to cry tears of relief at S.E.E. programs. Why? Because when the light of understanding is turned on, that bear looks much more like a house cat.

People can die of seizures. They also die from driving, from taking over the counter medications (one group reports 7,600 deaths per year in the U.S. due to aspirin, acetaminophen, ibuprofen, and the like), and an increasing number of us die from super-sizing our fast food. Most people with epilepsy will eventually die of circulatory problems – like the rest of us – not from their seizures. If you want to worry about what is most likely to harm your child, you are going to need to fuss over weight and exercise. We take an aspirin or get into a car without concern. Yet with epilepsy, each seizure brings the prospect of death to mind. Why? Epilepsy is a ***disorder of anticipation.***

Seizures do pose risk. The risk can be reduced with some commonsense approaches. Research suggests the risk of death from seizures can be reduced and nearly eliminated by getting good seizure control. My first three articles gave you ways to achieve that goal.

There are two kinds of epilepsy-related death you should know about. One is status epilepticus: the condition of being in a continuous, non-stop seizure or in a continuing series of seizures. This risk is relatively small, accounting for maybe one percent of epilepsy deaths. The most common way people under treatment for epilepsy go into status is by not taking their medications properly and especially by suddenly discontinuing their medications. The risk of status can be greatly reduced for most children just by maintaining proper blood levels at all times. There are a very small number of children who have a tendency to go into status no matter what. They need more extraordinary medical measures, and use of an add-on medication like Diastat®.

The more common way people with epilepsy die is a condition known as Sudden Unexpected Death in Epilepsy, or SUDEP. SUDEP accounts for maybe ten percent of death in epilepsy. The person is suddenly found dead. Only sometimes are seizures witnessed at the time, though seizures are suspected to be part of the cause. Like with status, research suggests good seizure control dramatically reduces the risk of SUDEP. Again, prevention involves maintaining proper blood levels of antiepileptic medications at all times and constantly striving for freedom from seizures. *Status, SUDEP, and their prevention are discussed in the "Beating Bad Seizures" articles, June through August in this magazine.*

About six percent of epilepsy related death is due to accident. Almost all of those accidents are due to two things – driving and drowning. If your child's seizures are not well controlled, he shouldn't drive. If your child's seizures are not well controlled, she shouldn't swim or take baths (shower instead.) Those two simple measures will afford considerable protection. While you are at it, you should also be concerned

about your child without epilepsy looking both ways when he crosses the street. Accidents are one of the most common causes of death among *all* children. Everyone faces risk in life. Don't get carried away about epilepsy. And don't forget to pay attention to the risks for accidents your other children face – they could be even greater!

Children with epilepsy are likely at greater risk of harm from the things you know and seldom think about – the same things that put your other children at risk. If you are doing the right things medically and you have good seizure control, you can pretty much cross the anticipation of death off of your list of worries.

Fear of Brain Damage

Parents' fear that seizures will cause brain damage is even more common. The way epilepsy is often explained to parents doesn't help with this. How many of you have heard, "seizures are like a short circuit in the brain," and "seizures are like a brain storm." Images of a short circuit with a loud bang and a shower of sparks or of lightning ripping through a tree trunk only serve to worsen parents' fears. As I explained in my June "*Beating Bad Seizures*" article, epilepsy is like the "wave" at a football stadium. People are not hurt in that cheer. Seizures are like the "wave."

Much research has gone into trying to understand epilepsy's affects upon intelligence. There is evidence epilepsy can change the way the brain is "wired" in certain spots in some people. There is evidence that some people lose some brain cells in a small part of the temporal lobe. Epilepsy researchers are still arguing whether seizures cause this loss – or if this loss causes the seizures. More important, it is not at all clear these changes have a significant impact upon intelligence. Some new research suggests that 20 – 30 years of uncontrolled seizures may result in a measurable decrease in cognitive (thinking and memory) abilities. These changes escaped reliable detection by researchers for many years. But just because we can measure a change does not mean the change makes a difference in a person's quality of life.

To complicate matters further, if epilepsy causes significant brain damage, why do seizures go away so often? Approximately 80% of people will stop having seizures at some point in their life. If seizures cause irreversible damage to the brain, why does epilepsy go away so often? Shouldn't it just be getting worse and worse? The natural course of epilepsy suggests that in most cases the brain "heals" itself somehow. We do know from other research that the brain has remarkable recuperative abilities.

Actually, the more common problem in epilepsy is seizures can affect brain function temporarily. After a seizure many children are confused for a short time while the brain "resets" itself. A musician with epilepsy, David Biro, has performs a funny song about this called "Reboot." Your child may have trouble speaking initially, though this problem usually goes away in minutes. Your child may have more prolonged difficulty with memory and learning after a seizure. This may last from minutes to hours.

This problem, called "*post-ictal confusion*" (post = after, ictal = seizure, confusion = memory disturbance) can temporarily affect the child's ability to learn in school or to carry out instructions at home. Normal function, including learning and "obedience," eventually returns. However, if you were not familiar with this common event, it would be easy to become alarmed that your child might be suffering brain damage from a "short circuit" or suffering from behavioral disorders. Not all kinds of seizures cause post-ictal confusion. It is most common in complex partial seizures, tonic-clonic seizures, and secondarily generalized seizures (please see "*Beating Bad Seizures*.")

Some children do have increasing problems with thinking or memory, or show developmental delay or other neurological problems. In almost all cases, when deterioration in mental abilities occurs, it is the *underlying brain disturbance* that is the culprit, not the epilepsy. Epilepsy is only a *symptom* of the

underlying brain disturbance. There is one important exception to this: status epilepticus. While there is little evidence that typical seizures cause injury to the brain, prolonged seizures can cause problems in some cases. When the child has a prolonged seizure (over five minutes for a convulsive seizure or over 30 minutes for a non-convulsive seizure), medical attention is required. Coping with prolonged seizures was discussed in the August article on “*Beating Bad Seizures.*”

Overmedication can cause what looks like mental deterioration. In my years of talking with parents, I think overmedication is a greater problem than is generally recognized. If you suspect your child is having problems with thinking, learning, emotions, behavior, or muscle coordination due to too much medication, you might be right. This problem is most likely when children are on more than one antiepileptic medication, but can also happen with too high a dose of a single medication. Trust your feelings and have the child checked out by the doctor. An adjustment in dosage or medication generally fixes this problem quickly.

Nearly three-fourths of children have epilepsy for no clearly identifiable reason. The doctor can't find any damage to the brain. There is no increasing deterioration in brain function. Seizures in and of themselves have little effect upon mental abilities except for the seizure and post-ictal recovery. As a result, you can reasonably expect that seizures will not have long-term mental consequences for your child. You can cross that worry off of your list and instead get back to the same concerns you should have about exercise, diet, risk behaviors (like drug use and sexual activity), and general safety that you should have for your other children – and even yourself.

Teaching Fear:

There is nothing in a 19-month-old child that is inherently frightened of seizures. The child may feel sick or uncomfortable if they have a partial onset seizure and can feel it coming on or if they remain aware during part of the episode. But to them, it is just like any other “being sick.” So how do even young children become so afraid of seizures and epilepsy? *We teach them.* The lessons begin with the very first seizure.

As a parent, you are well aware children who are still too young to talk have “emotional radar.” They know what you are feeling – often before you know! Children quickly pick up on your fear of seizures. From your fear they learn to fear.

Here is an example. Mary is 19 months old and can say a few words. She has her first seizure. If you remember from above, parents' reaction to a first seizure is fear their child might die. Since seizures last only a short time, Mary soon begins coming out of her seizure – and looks up to see what on Mom and/or Dad's face? Whether you are aware of it or not, that look of terror on your face conveys tons of emotion to Mary. Do you think Mary hasn't figured out something very wrong has happened? To make matters worse, strangers in funny clothes come and start poking and prodding her. The EMTs load her into a rattley bed and take her away from Mom and Dad in a white truck with an ear-splitting siren. Do you think Mary hasn't figured there is something very wrong? Soon Mary finds herself in a very bright and smelly place full of other strange people dressed in white. They stick her with needles and wires are glued to her hair. Do you think Mary hasn't figured out that there is something very wrong? For the next week or so there are trips to see other strangers who do odd things to her. Throughout this all, she overhears the hushed and emotionally charged talk between Mom and Dad. Do you have any doubt this 19-month-old knows there is something very wrong with her?

Then comes the day when the parents get the diagnosis. Mary is probably with a relative so the parents can talk freely with the doctor. The doctor gives the diagnosis of epilepsy and prescribes antiepileptic medication. The parents come home and tell Mary, “The doctor wants you to take these pills to stop that

thing that happened the other day from happening again.” The parents end with a forced smile and, “Don’t worry, everything will be OK.”

Now think about this carefully. You are a 19 month old. You have seen the look on your parents’ faces. You have been to the hospital and endured shots. Your parents have just told you had to take yucky stuff to stop something from happening. Then they cut off the discussion. You know there is something very wrong with you.

What could be so wrong that your parents looked terrified and didn’t want to talk about it? To a 19-month-old, the only thing that can be that bad is she is going to die. The parents’ well-intentioned desire not to frighten the toddler with the fact she has epilepsy has instead succeeded in frightening the child with death. And can the toddler talk with her parents about her fears? No! Plus, the parents’ behavior has already made clear they don’t want to talk about it.

What I have described is what almost every parent I have talked to has done with a young child. If this story fits your situation, you are a normal parent. Don’t feel bad about it. You may be given the diagnosis, but I doubt you were taught how to explain epilepsy to a young child at your appointment. Instead, this well meaning parental attempt to spare a child *thought* too young to understand has actually had the opposite effect. Rather than sparing the child from fear, we have taught it in spades.

What could we have done? In the case of a young child, words are not going to be a lot of use. Instead, the parent might say to Mary, “You know that thing that happened that scared us? It was a “seizure.” Mommy and Daddy had never seen one before, but the doctor says lots of kids have them. You had one. Yours looked like this...” And Mom or Dad gets on the floor and shows what the seizure looked like. “That’s what it was. It didn’t last long. What do you think about it?” (The last opens the topic for discussion.)

I have known many parents reluctantly go through this exercise, only to hear the child say, “Mommy, do it again!” Kids enjoy a parent behaving oddly. Does that sound like fear to you? Certainly not. Just as with adults, we have taken this event and bathed it in light. The child discovers that rather than being in a cave with a ferocious bear, seizures are more like a house cat rubbing its back on the floor.

Older children can do well with a description in words (but demonstrations are still great – don’t miss your opportunity to entertain your child.) In any case, as a parent you want to take the mystery out of the event. You want your child to see and understand the seizure for what it actually was. Rather than foster fear, this reduces it. It also serves notice to the child that there is an open channel of communication. Keeping that channel open is one of the most powerful tools you have for managing the emotional aspects of epilepsy in your child – *and in yourself*.

Worrying, or how to ruin a child without even trying

Fear is further taught to children by how parents typically manage the child with epilepsy. “Don’t climb that tree. You might have a seizure and fall.” “You can’t go out and play with your friends because I can’t watch you right now.”

Johnny is 9 years old and has epilepsy. His seizures are pretty well controlled, but he has one occasionally – a common situation. It is about 4:30 p.m. and Johnny asks his father if it would be OK to go out to play ball with the other kids at the schoolyard. Dad just got home from work and is tired. He’s trying to read the newspaper and catch the sports news on TV before dinner. In a typical fatherly manner, he says, “Go ask your mother!” Johnny goes to the kitchen. Mom is in the midst of making dinner for the family. Johnny

asks, “Mom, can I go play ball with the other kids at the schoolyard? I promise I’ll be back in time for dinner.”

What do you suppose the answer will be? In almost all cases the answer will be “No.” Why? Because Mom can’t go along with him to make sure Johnny will be safe. Dad gave the same answer, but left the dirty work to Mom. Research has shown parents think children with epilepsy need to be under constant supervision for safety and protection. After talking with thousands of parents, I agree with those findings.

Parents are not just reluctant, they are often *terrified* to let their child with epilepsy go off on her own. Why? Because the child might get hurt. What if the child had a seizure and the parent wasn’t there to help? What if the seizure was in the street? What if the other children did not know what to do? What if it was a particularly bad seizure? What if Johnny fell and got a big gash on his head from hitting the batting cage? What if someone carried him off while he was unconscious? What if Johnny had trouble breathing? What if he bit his tongue? What if... What if... What if...

What is happening here? It is the *disorder of anticipation*. In reality the chance that Johnny would have a seizure in the next 45 minutes is very small. The chance this unlikely seizure would lead to some sort of injury is even more remote. Add to this the fact physical activity raises the seizure threshold and makes a seizure even less likely. You can see most of the concern is in Mom and Dad’s *imagination*, not in the actual risk of a seizure.

Those of you with children old enough to want to be out on their own can think back to many similar events in your household. We keep our child near us to keep her safe. It is just one little thing we are saying “No” to, but over time these little events begin to number into the hundreds.

Let’s take a look of the consequences of this commonplace event. While Johnny is kept “safe,” he is also deprived of an opportunity to interact with his peers. His absence isolates him from the other children in the neighborhood. Soon he is no longer just one of the guys because he can never come along or he can’t come without his mother being with him. Other kids start seeing him as a “Momma’s boy” or a “scaredy cat” and now Johnny can add stigma to social inadequacy.

The refusal to let him out on his own has other consequences. The parents’ decision gives Johnny the *unspoken message* that it is not safe to be out in the world on his own. Worst of all, it teaches Johnny fear. “It is dangerous to be out in the world on your own.” “You have to constantly fear the possibility of a seizure...it could happen any time and you could get hurt.” “Someone needs to watch out for you all of the time to keep you safe.” It teaches him that being independent is dangerous and not allowed.

What makes these messages most troublesome is these lessons are not put in words. *What we do speaks louder to children than what we say*. If you asked Johnny, he would probably deny his parents ever taught him it is dangerous to be alone or that he needs to be afraid his seizures could hurt him at any moment. These lessons were taught beneath the level of words and conscious expression. Once taught, these lessons linger for a lifetime. Since these fears and beliefs are not spoken, they are very difficult to expose and are very difficult to change. Your expressions of fear, through your behavior and the everyday decisions you make, teach your child for a lifetime.

Worry is among the most destructive parent activities in raising a child with a disability. Worry acts in two ways. In the example of Johnny, who wanted to do nothing more than play baseball for 45 minutes, we saw worry lead to a decision that taught fear, disability, and stigma without a word being spoken. However, worry does not just teach silent lessons. Worry speaks out loud as well. We tell the person we are worried about them.

Fifteen year old Alice wants to go on a study date to the library with her girlfriends. “Alice, please be home no later than 5 p.m. or I’ll be worried something happened to you,” said Mom. This seemingly simple statement says several things. First, it says, “I love you Mary.” It also says, “I think there is a real risk of something bad happening to you,” “You must follow my every direction to be safe.” And it says, “Don’t do anything that will make me worry about you.”

Nothing in the examples of Johnny or Alice teaches skills for independence. Neither of these interactions helped the child gain confidence that he or she can get along well in the world on their own. Nothing in these common events taught Johnny or Alice that the outside world is a safe and inviting place. Both of these “little” events taught fear.

Epilepsy is a “*Learned Disability*”

After 25 years of talking with patients and families I have come to the conclusion that in most cases the disability of epilepsy is a “learned disability.” What do I mean? Of all of the common health disorders that afflict children, research finds epilepsy to be among the most destructive to a child’s development and life outcomes. Many of these disabilities, such as muscular dystrophy, are present every day and hinder physical or social activity from moment to moment. Yet epilepsy often takes a greater emotional toll on the person despite seizures being absent for days, weeks, or even months at a time. Why? I believe most of the “disability” in epilepsy is taught to the child through the processes I have just described. Fear was taught at the very start to toddler Mary. Fear and social isolation were taught to Johnny and stigma was taught to Johnny’s friends. Fear and lack of confidence were taught to Alice.

It is the *disorder of anticipation* that is so destructive in epilepsy. Worry is the most obvious example of the bad anticipations that lurk in parents’ minds. Worry is far more powerful and sneaky than most people realize. Without our awareness or consent, worry can take control of our childrearing practices. Worry causes us to make decisions and carry out restrictive behaviors that seem protective, but in reality are destructive. Our worry robs our children of self-confidence, independence, competency, and emotional well-being. Our worry teaches fear and stigmatizes our children.

Taking back control

So how can we parents change this situation? First we need to be aware of how powerful the disorder of anticipation is and its terrible legacy of worry. **We need to understand the incredible influence worry can have on our childrearing decisions** – especially upon the little, day-to-day decisions that slowly and imperceptibly accumulate into a powerful course of training that will affect the entire life our child.

Second, worry has a very nasty secret that it keeps hidden even from the parent. Worry has the power to make us ignore the needs of our child in order to cope with our own emotional crises. When we said “No” to Johnny being outside without our supervision, whose head were we taking care of? Johnny’s head – or our own? Many of the decisions made out of worry are made to control our own bad anticipations and threatening feelings. In Johnny’s example, Mom and Dad were taking care of their own heads. By keeping Johnny in the house, they did not have to worry something terrible might happen. What would have been best for Johnny’s head? Enjoyable recreation and time well spent with his friends.

I have been helping families long enough to know these revelations can be tough for parents to take. Often a flood of “wrong” decisions sweep into awareness and tears come as parents see the impact of past childrearing decisions. If you are one of these parents, good for you! You are now at a whole new level of understanding how to raise a child with epilepsy.

Before any self-blame begins, however, I would like to point out two very important things. First, I am able to talk about these behaviors because virtually every parent I have talked with has done the things we just discussed. These childrearing decisions were not only normal, they were universal! That means you are every bit as good as other parents who are courageously facing life with epilepsy.

Second, raising a child with epilepsy is a skill. Like any skill, it must be learned and practiced to become effective. If you are feeling some regret over certain childrearing decisions you have made, I would like to ask at what time before you had your child with epilepsy did you attend an in-depth training program on how to raise a child with seizures? You wouldn't blame yourself for being unable to fly the space shuttle without training. Don't blame yourself now if you discover you were not trained to raise a child with epilepsy.

Making things right

O.K., so how do we proceed from here? **First, your worries and bad anticipations have to be your own.** They need to be separated from your childrearing decisions. You can't use your child's life to make your worries less.

One way to make this adjustment easier is to **lose your worries**. That is what the Seizures & Epilepsy Education (S.E.E.) program does – it shines a light that changes the bear into a house cat. If you can't attend S.E.E., there are other things you can do. Read the three articles on “*Beating Bad Seizures*” in the June through August, 2005 issues of *Exceptional Parent*. The August issue also has suggested reading, including *Epilepsy: Patient and Family Guide* by Dr. Orrin Devinsky. It is outstanding and can give you the medical information that you need. Get connected with your local Epilepsy Foundation. They have educational materials and programs that can help you out. You might want to join a Self-Help Group for Parents of Children with Epilepsy for a while if one is available. Ask your community epilepsy organization. In some places “Phone Buddies” are arranged between pairs of parents, especially if you live in remote or urban areas. The Epilepsy Foundation (www.epilepsyfoundation.org) also has chat rooms online you can use.

Think about your child's development when you need to make a childrearing decision. Before saying “yes” or “no” to your child's request or activity, ask yourself, “Is this decision going to encourage my son's self-confidence, sense of independence, sense of self-competence, and/or social relations?” Also think, “Is what I am about to say going to teach my daughter fear or will it give her greater confidence that she can handle epilepsy throughout her life?” Measure every decision against your *long-term goals* for your child's development. You want your decisions to foster competence, independence, initiative, exploration, and an ability to feel safe in the world whether she is with others or alone.

The hardest thing parenting a child with epilepsy is not figuring what the right thing is to do – you will have little trouble with that now. The hardest thing will be ***catching yourself making a decision*** in the first place. This will take some practice. Some decisions will slip past you – decisions that on hindsight you would have done differently. Don't worry about those. Just learn from the circumstances the signs that one of those decisions is about to be made again. You will have plenty of chances to get it right.

Twenty-five years of working with parents of children with epilepsy has taught me the greatest single problem causing disability in epilepsy is fear. ***Epilepsy is a disorder of anticipation.*** Seizures last minutes or less, but worry about the next seizure can last a lifetime. You now know where fear comes from. You know what fear does to you. You know the powerful and sneaky ways fear tries to take control of your

childrearing decisions. You know the harm acting from fear does to your child. *Your knowledge now puts you in control.*

Just knowing this stuff is the biggest part of the battle, so you have already won. There are two other challenges you face in raising a child with epilepsy. I will cover the issue of stigma and the issue of guilt over the next two months. I will reveal what they are, where they come from, how they influence childrearing, and most important, what you can do about it. But before I go, I would like to share a true story with you that will help you beat the *disorder of anticipation*.

I knew a very attractive woman in her early twenties that had epilepsy. There was nothing in her behavior or social skills to give even the slightest hint of being disabled by her condition. One day I had the chance to ask her mother how this came about. Her mother told me her daughter was a tomboy from day one. At age 5 the daughter insisted on climbing a tall tree in her back yard. The mother was terrified her daughter would have a complex partial seizure, fall out of the tree, and get seriously injured. To stop the climbing, the mother punished her daughter. She grounded her daughter to the house for increasing periods of time, but to no avail. As soon as the daughter hit the back yard, she was up the tree again. In desperation, the mother took her daughter to their neurologist, looking for support. She explained the situation to the neurologist fully expecting him to issue a stern warning to the youngster. After listening carefully, the neurologist looked at the both of them and said, "I would rather see a little girl at the base of that tree with a broken arm, then that same little girl at the base of that tree with a broken heart." The Mom said from that moment on their lives changed. The girl was allowed to climb the tree (and do all the other kid things.) For her entire childhood, the daughter never had a seizure while in that tree. The bad anticipation never came true.

P.S. My eldest daughter, who does not have epilepsy, fell out of a tree and broke her arm. She is still allowed to climb trees. Talking to boys is still a different matter.