



S.E.E. Program Parents' Manual

How to Raise a Kid with Epilepsy Part 3: Coping with Guilt

Robert J. Mittan, Ph.D.
Seizures & Epilepsy Education (S.E.E.)
www.theseeprogram.com

in *Exceptional Parent* magazine, Volume 35, Issue 12,
Dec. 2005 (reprinted with permission.) www.eparent.com

Approximately 5% of children with epilepsy have seizures so frequent or prolonged that the epilepsy is clearly to blame for the child's social disability. In the first article of this series, "Coping with Fear," an alien from outer space observed children with epilepsy. It noticed the vast majority of children went days and even weeks without seizures. Yet research finds most children with epilepsy suffer social impairment out of proportion to the physical and medical challenges they face. How can this be? It appears that the disability of epilepsy is not so much a physical disability as it is a "*learned disability*."

In the first article we discovered that for most families, epilepsy is not so much a physical disorder as it is a *disorder of anticipation*. The unrelenting worry the child might be harmed by seizures lead to parent coping behaviors that (unintentionally) taught the child fear and prevented him from gaining a sense of self-worth, competence, independence, and social skills. The result of common childrearing practices was to *teach* disability while doing little to contribute to safety. The article showed how parenting decisions are often determined by strong forces outside of conscious awareness. However, once we were aware of the how the *disorder of anticipation* unconsciously influences childrearing practices, it became easy to make conscious decisions to help our child develop the skills she needs to succeed in life.

The power our culture has over parents through its unspoken beliefs about epilepsy was examined in the second article of the series, "Coping with Stigma." We discovered cultural stigmas used stealth to take root in our minds and hearts without our consent or knowledge. Like fear, these stigmas corrupted childrearing practices in hidden but powerful ways. These practices unintentionally taught stigma and disability – not just to our child with epilepsy, but also to our other children, to ourselves, and sometimes to those around us. Surprisingly, it turned out to be the family, not society, that taught stigma and the "*learned disability*" of epilepsy. However, when the cultural stigmas hidden in us were exposed, we learned how easy it was to stop teaching stigma and disability.

In this final article on "Coping with Guilt," we are going to discover how our culture attacks the emotional well being of parents of children with epilepsy. Guilt, like fear and stigma, unconsciously influences childrearing decisions for the worse. However with guilt most of the damage done is to the parents. Parental guilt occurs with any child with an illness or disability, so much in this article applies to anyone with a disabled child. The source of guilt comes from what I call the "*disorder of hyper-responsibility*." As you might guess from the previous articles, the disorder of hyper-responsibility has its roots in the beliefs our society teaches us without our awareness or consent.

Where Guilt Comes From

Cultural worship of physical perfection: Our culture is obsessed with physical perfection. You see it every day on television, in newspaper and magazine ads, and in the booming cosmetic and weight loss industries. This obsession spawns anorexia, steroid abuse, and \$100 blue jeans. If you look carefully, there is not a similar obsession for perfection in our intellectual and emotional abilities. In fact, we enjoy the mental and emotional shortcomings of our favorite, beautiful or handsome actors and entertainers through gossip and the tabloids. Physical perfection is everything. Our bodies must be perfect. And so must our children. This intense cultural value of physical perfection is the first of two cultural values leading to parental guilt.

Parents Are 100% Responsible: Our culture harbors a profound belief of what a parent is. It is belief we are all very familiar with, even if we have never put it into words. Our culture believes the parent is completely, totally, absolutely, and thoroughly responsible for everything about their child. This responsibility begins with creating the child, it includes every aspect of the child's physical makeup, and it includes every event that occurs in that child's life throughout childhood – and beyond!

Like other cultural values, we would be hard pressed to be able to say exactly when, where, or how we learned it. Also, like many cultural values, we are seldom aware of how deeply rooted it is in our minds and hearts. We are even less aware of how much it influences our feelings and behavior.

Parents' total responsibility for their children is a useful cultural value. It bonds parent to the child throughout the child's twenty-year development. It is society's way to insure its children are adequately cared for. For the most part, we like this value, even though we are only dimly aware of its full implications. Think of how often you or another parent has taken a great deal of pride *and credit* for a child's accomplishments – good grades, athletic prowess, community service, etc. And because others share this cultural value, they give *us* credit for our child's accomplishment, even though our child did the work. Society sees us as ultimately “responsible” for our child's good work.

Like many things our culture plants deep into our minds, this one is a two-edged sword. We get credit if the child does well. But we also get the blame if our child does poorly. How often have you heard poor discipline at school is a “parent problem” on the news or in pop psychology?

The unspoken, yet absolute belief that we parents are completely responsible for everything about our children is deeply rooted in our minds and hearts. This means at the very core, society holds us responsible for our child's epilepsy – and, consciously or not, we hold ourselves responsible, too.

If you don't believe me, let me ask how many nights have you laid awake thinking about what you did wrong during your pregnancy that caused your child's epilepsy? How often have you wondered if past drinking, drug use, or illness lead to your child's seizures? How many times have you gone over and over in your mind the things you should have done to prevent an accident, illness, or birth defect that lead to seizures?” The belief in our personal responsibility for our child's epilepsy is deeply rooted in us by our cultural training. Emotionally, this belief about our responsibility is absolute.

There is more. Our culture not only teaches us we are responsible for everything our child *is*, it teaches we are also responsible for everything that *happens* to our child. That means we aren't just responsible for our child's epilepsy; we are also responsible for *every single seizure*.

Don't believe me? How much time have you spent going over the events before a seizure, searching for something you *should* have done to stop it? And you are not the only one expecting *you* to stop seizures.

How many relatives, neighbors, or friends have asked you “Can’t you do something (more) to control your child’s seizures?” The people around you, especially those close by, seem to treat each seizure as a personal failure on your part. After all, “*You are the parent, you are responsible!*”

Before you are tempted to protest such unfair treatment by your relatives and friends, look inside yourself. You will find you have already held yourself completely to blame. Both your self-blame and their (hurtful) question are products of the same deep-rooted cultural belief. Their question came from the same cultural belief in “absolute parent responsibility” that lead to your own self-condemnation. This simple remark from a relative, friend, or acquaintance stabs right to the core of your adequacy as a parent, yet none of them would have any idea of how deeply they were wounding you.

Understanding this still does not quell the sting. Because our culture says you are entirely responsible, and because this belief is as deeply rooted in others as it is in you, their comments about your child’s seizures throws in your face the fact that you are “failing” as a parent. It stings so badly because you already feel you are failing as a parent. Like every loving parent, you have been blaming yourself from the first day. And since that first day, every single seizure causes your stomach to twist and your sense of adequacy to decline.

Our cultural training and the people around us who unconsciously *enforce it* have created what I call the “*disorder of hyper-responsibility*.” The disorder of hyper-responsibility occurs when your feelings, behavior, and self-perception are controlled by the cultural belief you are absolutely and completely responsible for everything about your child. In the *disorder of hyper-responsibility*, you are responsible for the child’s epilepsy. In the *disorder of hyper-responsibility*, you are responsible for each and every seizure.

When this teaching is put into words, it sounds utterly ridiculous – *and it is*. You are no more responsible for the electrical and chemical behavior of specific cells in your child’s brain from moment to moment than your pet cat is. Unfortunately, our culture does not see it that way. The belief the parent is entirely responsible is real and active in us, and in everyone we know.

This process is not conscious. Usually only the resulting distress is evident to your conscious mind, and not even that if you are fighting hard to keep your feelings under control. Without your consent or awareness, the *disorder of hyper-responsibility* has taken control of the way you see yourself and the way others see you. The epilepsy is your fault. Every seizure is your fault.

Guilt

Two other cultural beliefs come into play with the *disorder of hyper-responsibility*. The first is that you must be *punished* for your parental failure to bear and maintain a physically healthy child. The second is that you must make *restitution* for the damage you have caused your child. Like other cultural beliefs, these are simple, black-and-white rules that have no regard for personal circumstances. When operating in their usual manner, which is beneath conscious awareness, they can be brutal to the emotional well being of each parent.

Epilepsy puts the parents in emotional jeopardy from the outset. Father and mother have both “failed” to have a physically perfect child; something our culture demands. Guilt is how culture has taught us to punish ourselves for this failure. Guilt begins with the first seizure. Since having an “epileptic” child is a huge grievance in our cultural beliefs, guilt must be imposed in great quantity. Self-esteem must pay. You are not allowed to feel like you are an outstanding parent when you have an “epileptic” kid. Husband and wife, originally excited about having a child, are suddenly confronted with their failure to be good biological stock. Each parent’s self-esteem is damaged – as is their image of themselves as a couple.

In the *disorder of hyper-responsibility*, every seizure represents another failure of the parents to control their child's seizures. Every seizure is (and must be) punished by more guilt. Self-esteem continues to suffer with each seizure. Cultural learning says you are not allowed to feel good about yourself when you continue to "fail" your child repeatedly. As seizures recur, guilt builds and self-esteem erodes further. The emotional trauma to parents can be overwhelming. Some parents fail under the stress and leave the family.

Some readers might wonder how parents make it through this mess. Almost all parents of children with epilepsy know the answer. There is something that fear, stigma, guilt, and culture cannot overcome – it is the sheer love parents have for their child. I have seen single parents and couples endure this and more out of love. Many have limped through. Only a few get through with flying colors, though you should remember few parents of "normal" kids get through with flying colors either.

Restitution

Our culture teaches us we must to make up for any harm we have caused to another person. As loving parents, we feel heartbroken for our child. Feelings of guilt quietly fill us as we watch what he has to go through to endure each seizure, each stigma, and the side effects of treatment. The *disorder of hyper-responsibility* has left us feeling deep inside this is our fault. We feel a strong need to make restitution to our child for what our *disorder of hyper-responsibility* claims we have done to her. Parents feel compelled by their guilt to somehow make it up to the child. But can anyone really "make up" for a lifetime of epilepsy?

Yet, feeling like we are failing our child is agonizing. Most parents would do anything they could to avoid letting their child down. The result is a strong urge to "make up" for the epilepsy by pampering and indulging the child. The child gets more attention than his brothers and sisters. More praise is given for his accomplishments. The rules are "bent" for him more than others. Discipline is less. Fewer chores and demands for performance are placed upon the child. She may get a television in her bedroom, or video games, or extra clothes or jewelry to help her "feel better." These attempts to "make up" for the seizures are also unconsciously meant to help the parent to feel less guilty. Parents acting on the delusion they can "make up" for the epilepsy and for each seizure is how our cultural beliefs and the *disorder of hyper-responsibility* corrupts parents' childrearing decisions in a way that ends up teaching the child disability, not competence.

So what is the developmental result of this extra attention? In the parents' determination to "make up" for epilepsy, the child is unintentionally taught that she is due attention and gifts beyond what others get. The child with epilepsy is taught that his or her role in the family is that of prince or princess.

What happens when a child grows up believing they are entitled to extra consideration? What happens when they grow up and leave the family to make their way in the world? At the most, society will treat him as it treats everyone else – no special favors. As a person with a disability, society may even treat him with less kindness and rewards than others. A childhood of indulgence leaves him totally unprepared for this new reality, and trouble rapidly follows.

The family teaches the child his social role and the role of others. Overindulgence teaches him his social role is to take and that others' roles are to give to him. When society does not meet the expectations he was taught in the family, he will be angry and blame others for not treating him "fairly." Other people will neither understand nor respond to his expectations for special treatment. They will find his resulting anger unreasonable and they will have little to do with him. Overindulgence teaches the child a disabling way of interacting with others. The disability of epilepsy is a *learned disability*.

Redemption

There is a path to redemption in the *disorder of hyper-responsibility*: **cure the epilepsy**. How often have you dreamed of that? Probably with every seizure, every visit to the doctor's office, every side effect from treatment, and many nights when you are trying to fall asleep. Charitable foundations for epilepsy (and every other medical disorder) intentionally or accidentally tap into this deep-rooted emotional obsession for a "cure" to encourage generous donations. Look at the next charitable solicitation you receive. I'll bet the farm that you won't see them say "give to make things a bit better for people with epilepsy now;" they will say "give so that we may find a cure." Only sometimes do they say "in the future;" most seem to leave that part out.

We desperately want our child to be "normal" and not to have to suffer the problems of epilepsy. We want our child to be well. We want our child to be happy and to succeed. We want a cure for it all.

The desire to cure the epilepsy also means much for us. We are tired of the struggle and want it to end. We want the burden of constant, exhausting worry (*disorder of anticipation*) to stop. We want to stop that feeling that somehow we were not good enough parents. We want the guilt (*disorder of hyper-responsibility*) to end. Curing our child's epilepsy ends our own distress as well. Not only would a cure would end worry and guilt, a cure would make us feel great as parents. We could show others we had the extraordinary talent as a parent to overcome epilepsy and heal our child into a physically perfect youngster. How often have you dreamed of being that superparent?

The fantasy of what a cure would mean to our child and to us makes the need to achieve it intense. Hours and hours are spent thinking about a cure and how it might be achieved. High expectations are placed on the doctor to succeed in treatment. We are dissatisfied with slow results. We may rush the child back to the doctor for every small increase in seizures. We become impatient and even angry when calls to the doctor are not returned right away. The intensity of our own need for a cure gets acted out in our relations with the doctor. We expect his or her powers to be as great as our expectations. Friction occurs when the two don't meet. This is how the *disorder of hyper-responsibility* leaks into medical care to cause problems.

Guilt and the Marriage

The *disorder of hyper-responsibility* can make parents feel like failures. The "failure" of having a child with epilepsy and the ongoing "failure" to control seizures wears away at the parents' self-esteem with each seizure. After the initial blow to self-esteem by the diagnosis, further losses may be slow and imperceptible, but the damage can stubbornly worsen. This is a hazardous development for the marital relationship.

When self-esteem wears down, it becomes difficult to feel that we are worthwhile enough to be loved. We begin doubting the sincerity of our spouse's love for us. How could he possibly love someone who mothered an "epileptic" child? How could she love someone who can't afford to send the child to the best doctors? As our self-esteem suffers, we become defensive, trying to preserve every shred of self-worth we can. One sign of this is the "blame game."

The blame game starts early with the attempt to explain how the child got epilepsy. Blame begins inside ourselves. The classic example is the mother who goes over her entire pregnancy trying to figure out what she did wrong to cause the epilepsy. Both parents might go over their past medical conditions, drug use, prescriptions, and family history.

The blame game erupts to the surface when spouses begin accusing the other of being the cause. Things such as "It must have been your side of the family," or "You used too many drugs in school" or "You

shouldn't have had anything to drink while you were pregnant," are attempts to assign responsibility to the other spouse. We try to preserve our own self-esteem by laying the blame at someone else's doorstep. It assigns the *disorder of hyper-responsibility* to the other spouse and saves you some guilt in the process.

The blame game is extended to cover responsibility for everyday seizures. The husband asks, "Didn't you make sure that Alice took her medications yesterday?" or "Why didn't you ask the doctor to...when you were at the appointment this afternoon?" The wife responds, "Why don't you ever go to the doctor with us?" "Why don't you hold him during seizures for a change?" Interaction becomes dominated by a desire to assign and avoid blame rather than by cooperation and mutual support. Once the blame game is started, it is very difficult to stop. The marriage suffers. Remember, you and your spouse are no more responsible for the electrical and chemical activity of certain cells in your child's brain from moment to moment than is your pet parakeet.

The disorder of hyper-responsibility often creates another marital problem. The amount of guilt a parent feels and the need to make it up to the child can become intense. In response, one parent, usually the mother, devotes herself to the afflicted child. Throughout the day her energy, thought, and emotion is dedicated to caring for the child. This devotion, added to worry for the child's safety (*disorder of anticipation*), sometimes drives the mother to sleep with the child instead of her husband.

This single-minded devotion results in the neglect of the spouse and other family members. The husband can feel shut out and resentful. Siblings also feel short changed and often resort to acting out in order to get the mother's attention. In the meantime, the mother feels emotionally exhausted with the constant vigil and caring for the child with epilepsy. She doesn't understand why her husband is not supporting her and replenishing her emotionally. She doesn't understand why her other children seem bent upon making her life harder when she already has enough problems.

All of these difficulties stem from the *disorder of hyper-responsibility*. It comes from the underlying belief that the parent is responsible and the parent has to make it up to the child. You are not responsible. "Making it up" to the child is only a fantasy. No matter how much you indulge the child, he will still have epilepsy. And the more you indulge the child, the more disabled she becomes. And the rest of the family is sacrificed. The battle is really in your own head. To raise a well adjusted child **you** have to give up the *disorder of hyper-responsibility*, (and the *disorder of anticipation*, and your *cultural stigmas*.)

It is essential for you as parent to restore the normal emotional balance in your family. Each member, including you, should get the amount of attention, affection, *and expectations* he or she is due. Life is uncertain. Your "normal" child or spouse could be the one run over by a truck tomorrow. Enjoy life and companionship with each and every family member for today. If it is a seizure free day, so much the better. Don't spend any part of your day worrying about the next seizure. The time you have right now is the only time you get to live in. Bask in it. The past is over and the future always runs way ahead of you.

Guilt and Parenting Decisions

Guilt has a powerful effect on childrearing decisions. Parents already feel enough guilt for their child's epilepsy. Parents develop a strong feeling for the huge extra burden epilepsy places on their child's life and emotions. Not surprising, the size of the burden the parent feels the child must carry is very similar to the amount of guilt the parent feels. It's easy to give in to the feeling that it is not fair to *ask more* of the child – he already has enough to deal with. There is a strong urge to cut the child some slack. You feel sorry for him and for the extra effort he has to make to accomplish things other children take for granted.

Children pick up on these feelings quickly. Your desire to make restitution. Your reluctance to make demands on behavior or place high expectations on performance. Your willingness to cut the child extra slack. The child figures out that he can exploit these indulgences to get her way.

Johnny needs to take out the garbage, something he really doesn't like to do. When you ask him, he might tell you he doesn't feel well and thinks he might have a seizure. The normal reaction is to let him off the hook. This will only encourage the "*epilepsy excuse*" to be used again – and in other situations. A better response is to tell him, "Take out the garbage, then have a seizure or have your seizure, then take out the garbage. The choice is up to you."

It is very important that early in life the child (*and you*) learn epilepsy cannot be used as a crutch. The minute the child discovers she can use epilepsy to get out of work, avoid expectations, or dodge unpleasant situations or school assignments, the child is at risk of being disabled for life. If the "*epilepsy excuse*" works, the child will use it again and again. The more unpleasant or threatening the task, the more epilepsy will be used to avoid it. ***Repeated over time, epilepsy changes from an excuse to a barrier. The disability of epilepsy is learned.***

Do you think society is going to cut your child slack for a lifetime just because the poor thing has epilepsy? Is an employer going to let your son do only a part of his job year after year just because he has seizures now and then? Is that college going to think epilepsy is an adequate excuse to admit your daughter even though she never developed the ability to get through all of her homework?

The world doesn't give breaks to three-legged dogs – I know because we have one. The dog has to learn the skills it needs to fit into the world *on the world's terms*. Have you ever watched a three-legged dog? He certainly has a handicap, but does he seem to be bothered by it? The dog accepts three legs as a part of life – in fact doesn't think of it. It is just a natural part of him. He isn't jealous of four legged dogs. He doesn't whine on the floor and lick his stump for hours and hours day after day. Instead, he finds a way to play catch. He chases squirrels like he is going to catch them every time. He shows not the slightest decrease in love and affection. He is happy with himself and with his family.

If you want to see how to get past the barrier that guilt poses to the development of your child, think of the three-legged dog. Just like the dog, you and your child need to accept epilepsy as a normal part of her life. You wouldn't keep reminding the dog that he has only three legs, so don't spend a moment worrying about the next seizure (the *disorder of anticipation*.) Focus on what your child loves to do; chasing after a ball on a sports field or chasing after the latest concept in physics. Expect your child to perform the basics to life like any other child. Like a three-legged dog, she may have to work harder at it than others, so it is best to get the earliest possible start. She won't be jealous of children without epilepsy unless you teach her to be.

Patience is a critical skill in overcoming guilt. You may feel sorry for the three-legged dog's failing attempts to jump onto the couch, but would he ever learn if you lift her every time? Given enough time, the dog will succeed. He will get better and better at it until he can do it every time. And in the process he will have learned a valuable life lesson that "determination" can result in success. Your child will struggle and fail. You will want so bad to excuse him or give him a boost. But how will he learn to meet life's demands on life's terms if you do it for him?

Don't let the feeling of guilt over watching the struggle lead you into disabling your child by doing any part of it for her. I know this sounds hard on the surface – leaving her to struggle, and possibly fail time after time. But if you give her that boost, *whose feelings are you really taking care of?* – your child's or your own? While it seems loving to help, it is actually a selfish act that makes your guilt feel better. It costs your child the opportunity to learn to persevere, to learn to cope with failure, and eventually, to learn to triumph

on his own. It costs your child the opportunity to succeed in meeting life on its own terms with his own strengths and challenges.

None of this means you cannot teach your child. Teaching is enabling. Doing it for her is disabling. By all means share as much wisdom and strategy as you can, but then stand back and let the child put the pieces together for herself.

Guilt and Healthcare

For much of the history of epilepsy, little of real value could be done to prevent seizures. Only very recently has modern medicine opened the door to practical treatments that can reduce and even stop seizures altogether. The last dozen years has seen the introduction of nine new antiepileptic medications, advancements in brain scans that seem like science fiction, and a huge increase in our understanding of the medical management of epilepsy. If it was your child's fate to have epilepsy, out of all of history this is the best possible time.

In these articles on "Raising a Child with Epilepsy" we have found that even good things can be two-edged swords. This is true about the modern medical treatment of epilepsy. While the many diagnostic and treatment options available for your child dramatically raises the chance for seizure control, parents find themselves in the midst of a confusing set of medical choices – and a complex and overburdened healthcare delivery system that provides little support or information to help with those critical decisions.

Parents are responsible for their child's health care. That responsibility exists in our cultural values and it exists in the law. Parents find themselves having to make healthcare decisions that will affect their child's future, and possibly their child's very survival. If the parent chooses well and the treatment is a success, there is much to celebrate. The child is whole again and the parents can take credit for outstanding talent in childcare. They have triumphed over the terrible condition of epilepsy.

But credit for the outcome cuts both ways. If treatment is a failure, it means the parent has chosen the wrong treatment, the wrong doctor, or somehow did not manage the child's care adequately. The *disorder of hyper-responsibility* causes parents to see treatment failure as their own personal failure to adequately care for their child. The guilt for this comes by the barrel.

The tremendous guilt parents face in making healthcare decisions isn't even on the radar in most medical practices. Yet, the parent is set up for guilt with the current practice of medicine. The high tech, the doctor's strange language, the rushed review of treatment choices, and the lack of time for questions put parents at a huge disadvantage. In the U.S., healthcare cost and time pressures make it almost impossible for the parents to learn enough from the doctor to become comfortable in their roles as healthcare team members and decision makers. In managed care countries, both time and healthcare choices can be limited. As a result, parents may feel frustrated and powerless to help their child. It is not surprising parents feel overwhelmed and fearful about making decisions. It feels like they are being forced to take shots in the dark. Loving parents are terrified of making a mistake. The *disorder of hyper-responsibility* can raise parent fears over healthcare decisions to the point of desperation.

Guilt doesn't stop with the decision-making process. Once the therapy is set, I have found parents continually second-guess their decisions – especially if there are problems. Parents not only feel guilt over treatment failure, but also feel *tremendous guilt for the side effects* their child experiences from treatment. I have known many parents with seizure free kids who have been wracked with guilt over the fact that the medication has left their child less able to function. Should they have less medication and more seizures or the opposite? The *disorder of hyper-responsibility* says the outcome of any such decision is their fault.

What if seizures are not controlled – do they abandon a medication that helped some for a new medication that might not work and may have its own side effects? Parents can agonize for months over these decisions. The *disorder of hyper-responsibility* can make it impossible for parents to ask for a change. If the change results in a worse outcome, the parent’s guilt could be unbearable. I have seen many parents frozen by this fear, unable to make any changes in treatment.

Hopefully the “Beating Bad Seizures” series made clear the goal in epilepsy treatment is “no seizures *and* no side effects.” It is the doctor’s responsibility to find a treatment that does best to meet both treatment goals for your child. Your responsibility is not to punish yourself and not to let your fear prevent action. Your critical role is to let the doctor know when there is a problem, to describe the problem thoroughly, and to record the exact time and circumstances of each occurrence of seizures or side effects in your child’s seizure or medical diary.

The disorder of hyper-responsibility also causes parents to write off one of the most important and successful treatments for epilepsy: surgery. The idea of brain surgery is frightening enough, but parents are terrified that their decision for surgery could leave their child disabled for a lifetime. Imagine the guilt! But the risk of surgery is small; it is the *disorder of anticipation* that makes the surgery seem life threatening. But what really stops parents from acting is the guilt they would feel if any of these terrible anticipations came true. As a result, children are regularly left to suffer seizure after seizure, usually until the children are “old enough to participate” in the decision about surgery. The irony is by the time the child can help with the decision, the damage to development is already done. Then parents don’t understand why the adolescent or adult child remains disabled despite becoming seizure free from the surgery (Reason – by waiting the child has had plenty of time to *learn the disability of epilepsy*.)

The disorder of hyper-responsibility complicates medical care in a much more common way. Parents, feeling responsible and guilty for each seizure, often become very demanding upon the doctor for immediate success. Every occasion where there is a small increase in seizures brings the parents running back to the doctor with the demand that treatment be changed and the seizures be controlled. The intensity of parents’ demands on doctors is, in my opinion, one of the greatest reasons children with epilepsy are so often overmedicated. Parents insist, and back it up with multiple calls to the office and complaints to nursing staff and anyone else who will listen. In an effort to accommodate the parents, the doctor increases the dose, or worse, adds an additional medication to try to control the seizures. The irony is the child is being medicated to treat the parents’ *disorder of hyper-responsibility* and their *disorder of anticipation*. I think physicians have a responsibility to resist this, even when parents up their demand by threatening to “get a second opinion.”

Parents need to know that the natural course of epilepsy is one of waxing and waning of seizure frequency in children whose seizures are not completely controlled. It is normal for there to be periods when seizures increase temporarily. It is also normal for quiet periods to occur. It will take parental cooperation and a good bit of experienced judgment by the doctor to determine if a treatment change is really in the child’s best interest. If your child is a difficult case, take the advice of the “Beating Bad Seizures” articles and get your child seen by an epileptologist. The extra experience can make a big difference.

The real tragedy in medical care is the *disorder of hyper-responsibility* and the *disorder of anticipation* convert the parent doctor team from a cooperative effort into an adversarial one. In the process, the child often pays dearly, both in seizure control and quality of life from side effects.

A huge source of guilt in healthcare is money. In the U.S. medical system you can get the best care in the world for your child – if you have enough money. Many, if not most parents in this country have trouble

paying for healthcare. Many are in healthcare plans that dictate who they can see. The latest medications are extremely expensive. Parents can suffer tremendous guilt for not being able to afford the care they want for their child. To these parents, I suggest they ask their healthcare provider or a social worker about programs that help cover treatment and medication costs. Look on the Internet and in the library for such programs, too. Many drug companies have programs that offer their medications at reduced cost or for free. Learn about epilepsy and its treatment. You will discover there is a surprising amount that can be done with limited resources. The answer to your child's seizures could be that easy. In any case, don't allow your financial circumstances to feed the *disorder of hyper-responsibility* and guilt. You are an outstanding parent if you do all you can with the resources you have.

What can you do to overcome the *disorder of hyper-responsibility* for healthcare for your child? Become educated. Just 20 years ago your job was much easier. The physician was seen as a sort of god and whatever he or she said was what you would do. This god-like stature relieved the parent of much medical responsibility.

Today patients and families have been given responsibility to question and choose among diagnostic and treatment approaches. As a society we wanted this change, and it is very appropriate. This change occurs at a time when the complexity of medicine and the treatment alternatives have become staggering. You cannot read a brochure or two from your epilepsy association and consider yourself prepared anymore. To meet the challenge of your responsibility in your child's medical care, you need to be educated. You need to understand what epilepsy is, what the different seizures are, how epilepsy is diagnosed, how it is treated with medications, what the different medications are along with their side effects, what are the alternative treatments such as surgery, ketogenic diet, and the Vagus Nerve Stimulator. You need to know when they should be used, and you need to know what the prognosis is for your child (how the epilepsy will affect your child's future and abilities.) This is just the short version of the list.

Because you must know about the medical aspects of epilepsy to be a successful parent, I started out this series of articles on epilepsy with the three on "Beating Bad Seizures." Those articles gave you some of the key pieces of medical information you needed to manage your child's healthcare. That medical knowledge was also necessary for you to understand how to successfully raise a child with epilepsy – the subject of these last three articles on "Raising a Kid with Epilepsy." Since space was limited, I could only provide you with the basics, but in epilepsy, the basics are powerful. If you have read all of these articles you should feel a new sense of control over epilepsy and a new ability to steer the course of your child's life – and your own.

If you liked what you got out of these articles, there is more you can do. For medical information, I have already recommended Dr. Orrin Devinsky's book, *Epilepsy: Patient and Family Guide*, 2nd Edition. I would also recommend you consider taking a "crash course" in the medical, family, and emotional aspects of epilepsy and how to cope through the Seizures & Epilepsy Education (S.E.E.) program. The advantage of both of these resources is that they put the entire picture of epilepsy together for you, though the S.E.E. program deals in greater depth with the emotional, family, and social parts. As you know, epilepsy is complex. You need to know the many ways one thing can affect another. If you go to the Internet to find information, you will find the information is piecemeal. This makes it very difficult to get a handle on epilepsy. Supersites like epilepsy.com are good for research on *specific* issues. Other suggested sites were listed in the "Beating Bad Seizures" articles in *Exceptional Parent* magazine.

Guilt and these Articles

There is one last source of guilt that does not come from culture. It is the guilt you might feel after reading these articles. I have laid bare the process of how children with epilepsy are *taught to be disabled*. I have tried to lay it out so clearly that it nearly jumps in your face. The damaging consequences of common ways of coping with a child with epilepsy were exposed to a bright light. These ways of coping are so universal that I know many apply to you. The temptation is great for parents to feel badly about things they have done to their children in the past. Don't do it to yourself. It is only another example of the *disorder of hyper-responsibility*.

Learning how to raise a child with epilepsy is a behavioral skill, just like learning how to play the piano is a behavioral skill. You aren't going to just sit down one day in front of a piano and play Beethoven (who had epilepsy.) To play Beethoven well, you need someone to teach you how to play that piano – and you have to practice. Now, let me ask you; do you think learning to successfully raise a child with epilepsy is any easier a behavioral skill than learning how to play the piano? If you think that somehow you are a failure as a parent, then *tell me who you had as a teacher about raising a child with epilepsy*. How long did you get to practice before you had to do the real thing in front of others? If you felt bad about some of what you read, you are not to blame. My guess is you never had a teacher.

There is no manual and there is no teacher for successfully raising a child with a disability, let alone one with all the cultural baggage of epilepsy. As sophisticated as we think we are as a civilization, we're still figuring out the fundamentals of how the human mind and personality develop. We know even less about how children successfully develop under the challenge of medical illness and social stress. Every parent out there who has raised a child with epilepsy is a hero in my eyes. You have braved the almost absolute darkness in this area of our "expert" knowledge. You have persevered alone, with unwavering love and courage, and you have succeeded beyond all reasonable expectations. I only hope that these articles provide a small candle of light to help you on your courageous way.

Guilt from the *disorder of hyper-responsibility*, worry from the *disorder of anticipation*, and *cultural stigmas* silently conspire to control your childrearing decisions. Left hidden in the deep recesses of your mind and heart they taught your child the disability of epilepsy. That is no longer you. You have found their hiding places and you are tearing them out by their roots. You have insight beyond most parents.

You know the *disability of epilepsy is a learned disability*. Now you can choose not to teach disability to your child. Now you can see how childrearing decisions affect your child's future. Now you have the understanding to grow a more confident and capable child who has the tools to fulfill the true potential that lies within. Do it, and you will have the satisfaction of being an Exceptional Parent.

Conclusion

You have learned throughout this article that guilt hurts your own self-esteem and serves to disable your child. Give it up (I know it won't be easy) along with any notion of trying to "make it up" to your child. Instead start celebrating the time you have together. Your child will see an immediate improvement in his quality of life and you will feel happy to be a parent again.

Those of you who have seen the S.E.E. program witnessed the unbridled enthusiasm I have in presenting the latest advancements in epilepsy care. However, after 25 years of talking to thousands of parents, I am heartbroken to see epilepsy care in this country still focus so exclusively on the medical treatment of the child. For most children the physical part is the least disabling part of the disorder. It is the emotional impact of epilepsy, the cultural stigmas, and parents' guilt that infect the next generation within the family.

The result teaches disability to the child and devastates parents' self-esteem. Epilepsy is not something a child has. *Epilepsy is something the entire family has.* One person may have the seizure, but the entire family suffers from fear, stigma, guilt, and the *learned disability* of epilepsy. You now have the knowledge to take back control of your life and your child's development. The future for you and your child is much brighter.

This series of three articles on "Raising a Child with Epilepsy" in the October through December 2005 Exceptional Parent magazines were designed as a practical handbook for succeeding in one of the most challenging projects anyone will ever face – raising a kid (epilepsy or not!) To get the most from this series, read these articles again and again over the years. Each time you will take back more control over your destiny and that of your child. Re-reading will refresh your awareness of how cultural beliefs attempt to control your parenting decisions. Re-reading will help keep you focused on real ways you can help your child realize his or her full potential. Exceptional Parent magazine has made this pioneering series of articles possible. If these articles help you, be sure to let Exceptional Parent know.