



S.E.E. Program Manual

How (and Why) to Tell Others about Your Epilepsy

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Probably one of the most challenging dilemmas facing people with epilepsy and parents of children with epilepsy is if, who, when, and how to tell others about the epilepsy. There is fear of stigma and rejection. Yet there remains the need to reveal seizures before they reveal themselves without your control. Telling others is the way to take control of the disclosure and insure the best chance of acceptance and even support by others. This is the first of a set of four articles that will provide you the understanding and practical skills for revealing epilepsy and seizures to others. I begin with “why.” Before the “if”, “when”, and “how” make any sense you need to know “why.” The “why” explains just how important the “how” is to you or your child.

Epilepsy and seizures are conditions that have been well known to man throughout history. Before science and modern medicine, epilepsy had to be explained by what people understood back in that day. In ancient times afflictions of all kinds were often thought to be the work of evil spirits or demons. This particularly made sense for epilepsy. When a seizure occurred the person was unconscious and appeared to have left his or her body. So it must be that some sort of demon took control of the body to cause the thrashing and foaming at the mouth. The person would only “return” once the event was over and the demon gave back control of the body. For thousands of years this was the explanation for seizures.

Ironically around 500 B.C., Hypocrites in ancient Greece wrote that epilepsy was a physical disorder based in the brain. His thinking was much too ahead of his time. The ancient world did not have the kind of medical tools needed to show seizures were indeed a physical disorder. Instead the common ancient beliefs in spirits, gods, and demons were used to explain illnesses and assign a cause to traumatic events such as seizures.

Out of this heritage grew the idea that seizures were caused by demons or evil spirits. This reasonable explanation for ancient times survived through the Middle Ages and as late as the 1800s. This explanation appears in many religious and medical writings that date back to that time. With such a long history, this “understanding” of epilepsy has persisted in a subtle form even into the modern day.

The ancients believed for a person to be possessed by an evil spirit, the person must have done something wrong or evil. Thus the person must somehow be bad. It is the ancient idea of guilt by association. If you have something evil in you, you must have done something bad. This is the origin of stigma in epilepsy.

This line of thought remains unbroken in many cultures, including our own. The idea has been changed by current medical understandings, but it still persists. Today most people do not believe seizures are caused by evil spirits or demons (though some still do believe this.) Instead these ideas have been changed to fit our culture’s current understandings of physical illnesses. Like Hypocrites we understand that epilepsy is a

physical disorder arising from the brain. But through this lens of modern understanding, the old beliefs and “guilt by association” still persists.

Persons with epilepsy are often thought to be not as intelligent as other people or they are mentally handicapped. People with epilepsy are often seen as more emotionally fragile and less able to cope than those without epilepsy. And worse, there is still a sense of shame associated with having seizures – the clearest remnant of “guilt by association” after three millennia of “demons.”

Certainly if you were to ask someone about these thoughts and feelings, they would deny their opinion has anything to do with evil spirits. Instead these ideas have become subtly imbedded in the teachings of our culture, which is rooted in past history. These cultural ideas are so widespread even parents of children with epilepsy often hold these notions about their child in the back of their minds, even if they would deny any such feelings if asked directly. The test for this is easy. Just think about how enthusiastic you would be to tell friends, relatives, and coworkers about your child’s seizures compared to how easily you might tell them about your child’s recent bout with strep throat. (For a complete discussion of the impact of epilepsy on parenting, see EP’s three-part article series on “How to Raise a Child with Epilepsy.”)

The same test can be applied to the community in general. How much more willing are people to hear how a child got a broken arm versus how enthusiastic are they to listen to a blow-by-blow description of the child’s last seizure. In digging these responses up, there is a natural tendency for parents and others to feel guilty about having these (normally) hidden feelings and ideas that stigmatize. In truth, it is not the parents’ fault. They have nothing to feel guilty about. These are just the feelings our culture has taught us all to have. And our culture has done this without our awareness or permission. These feelings are just one small part of a huge iceberg of feelings and ideas that our culture has taught us about many different things, not just epilepsy. These feelings and ideas that fall below the surface of our conscious, everyday thought, yet nonetheless influence our day-to-day feelings, judgments, and actions.

The Self Psychology of Telling Others

Curiously, whether or not to tell others has a stronger affect on ourselves than the person we are talking to. How can this be?

What does not telling about epilepsy do to the person who hiding this secret from others? If there were nothing wrong with having epilepsy, why would a person keep it a secret? Certainly if the person had just won an award for her business performance or received an “A” in a school course, she would not hesitate to tell others about it. She would feel pride in sharing such information. *The act of sharing would make her feel good about herself.* Chances are good this behavior would be repeated among many people, each time raising her level of self-esteem and self-acceptance.

Lets think about the person who decides not to tell others about epilepsy. By not telling others, this person is keeping a secret about himself – and a rather large secret at that. The other person, of course, is unaffected by this. Other person doesn’t know of the secret so they don’t have a feeling or idea about the first person’s epilepsy at all. The person not telling knows he has something about himself he refuses to share. Why the refusal? Because he is ashamed of it and is afraid of personal rejection. *By keeping epilepsy a secret, the person is telling himself that there is something about himself that he is ashamed of.* By keeping the secret, he is telling himself that others would reject him if he disclosed it. He is telling himself he is not really socially acceptable if others know of his medical condition.

Each time he refuses to tell someone about epilepsy, he is telling himself in a loud, clear voice, “There is something about me to be ashamed of.” Each time he refuses to tell someone about his epilepsy he is telling

himself in a loud, clear voice, "I am not acceptable as a person the way I am." Each time he refuses to tell someone about his epilepsy, his self-esteem drops. All of this has no effect upon the other person because the other person has no idea what is going on. All the emotional consequences fall upon the person with epilepsy. Shame builds and self-esteem suffers.

Not telling can become a vicious circle. Each time the secret is kept the person feels worse about herself and less attractive to others. But the problem does not stop there. *When you feel bad about yourself and you feel unattractive to others, the natural reaction is to begin avoiding people.* This is made even worse if you fear a public seizure might blow your secret. As a result, the person who is afraid to tell others isolates herself from others. Each avoidance reminds her again that she is ashamed of herself and unacceptable to others. As the feelings grow, so does the isolation. For many people with epilepsy these feelings and behavior can grow to the point where the only relationships they have are with their immediate family. The rest of the world becomes lost to them. This is a miserable way to live and depression is a common consequence.

What happens when a person does tell others about her epilepsy? First of all, it gives her the chance to find out that there are many others who won't reject her out of hand when they find out. In fact, some research has found the most common reaction by others to telling about epilepsy is curiosity, not stigma. "Really?" "Does it hurt when you have a seizure?" "Do you have many of them?" "What do they look like?" "Should I do anything if you have a seizure when I am around?" It gives her an opportunity to teach the other person about epilepsy (and it is good to know some facts for this process, which I will share later.)

What effect does revealing epilepsy have on the person with epilepsy? *By sharing the fact that he has epilepsy, the person is actually telling himself that it is OK to have epilepsy, that it is not a personal failure but simply a common medical problem* (approximately one in every 30 people will have epilepsy in their lifetime.) It is saying that there is nothing about me to be ashamed of. It is telling himself that there is nothing in me that is socially "bad" and epilepsy is just a medical disorder. Rather than tearing down self-esteem, telling others builds self-esteem. Each time epilepsy is shared it reaffirms to the person I am fine with others just the way I am.

Are you going to encounter people who will reject you for your epilepsy? Of course! There are always people who will reject others for any number of things. Some people don't like other skin colors. Some people don't like people who are too skinny or too heavy. Some people don't like certain hairstyles or clothing styles. Some people don't like others they think are too old or too young. The list is endless, and epilepsy is certainly not at the top of it. You can't expect everyone to like you. Just because they don't doesn't mean there is something wrong with you having seizures. It is just the way life is. But if you buy into the idea that each rejection says you are unacceptable because you have epilepsy, you are handing the fate of your self-esteem over to someone who is obviously ignorant, or more likely, unknowingly culturally programmed to think epilepsy is bad. Is handing over your self-esteem to someone who is unknowingly ignorant about epilepsy a good thing for you to do?

The only self-esteem worth having is the self-esteem that comes from inside you. There are always going to be people who reject you, even if you don't have epilepsy. If you believe their rejection is a true comment on your worth as a human being, I can predict right now you are going to be hurt repeatedly and suffer a miserable life. The irony is that the person may be rejecting you more for the way you look or dress than your epilepsy.

Think about it. Most people have their own clothing style they like. They expect that some others will like their style and some won't. Yet they won't change their style and they feel none the worse for those who "don't get it." In my case, I have a very unusual moustache. Some people love it and some people

absolutely hate it. It makes no matter to me because *I* like it and have kept it for 30 years. The same is true for epilepsy. Some will get it, some won't. Either way it doesn't really matter. If you like yourself and believe in your own mind that you are a worthwhile human being and believe there are people you are important to (and there are), you are going to do just fine.

Telling others shows trust in them. All true friendships are based upon trust. If you had a good friend and you did not tell them you had epilepsy, and then one day you had a seizure, what do you think that good friend would think? "If I am such a good friend, why didn't she tell me?" "She obviously doesn't trust me to be her friend, so why should I trust her to be my friend?" Keeping secrets just lost you a friend as well as your self-esteem.

Teaching others to Stigmatize You

It turns out that there is another sinister problem that occurs when a person hides her epilepsy. Research has found that trying to keep epilepsy a secret seldom actually works. While the person with epilepsy thinks she has successfully hidden her condition from others, the research found that most people around her know she has epilepsy anyway. We'll call the person with epilepsy, Rachel.

Lets look at the "secret" from the standpoint of the others. They know Rachel has epilepsy. Rachel obviously does not want to talk about it. What conclusions are others supposed to draw from this situation? First, if epilepsy were no big deal, Rachel would talk about it. So obviously, epilepsy must be a big deal. If Rachel doesn't want to talk about this big deal, it must be embarrassing. Second, that means people with epilepsy must be embarrassed about their condition. So there must be something wrong with having epilepsy. Epilepsy must be bad, and people with epilepsy must be ashamed of their condition. Third, by her silence, Rachel has just succeeded in teaching others around her that it is a socially undesirable to have epilepsy. Rachel has just taught stigma to others without saying a word.

*Three more articles will follow this one. In the June edition of **Exceptional Parent** you will learn the "Basics of How to Reveal Epilepsy." In the July edition you will learn "How to Tell Friends and Dates about Epilepsy." In the October edition you will learn practical skills for "Revealing Epilepsy to Neighbors, Schools and in the Workplace." If you missed the three article series, "How to Raise a Child with Epilepsy" you can obtain copies from the EP website at www.eparent.com.*



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The Basics of How to Reveal Epilepsy

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*In the April, 2009 edition of **Exceptional Parent** we learned WHY it is so important to tell others about you or your child's epilepsy for your own emotional well-being. This month we will discuss the basics of how to reveal epilepsy to others, including some additional advantages you will receive in doing so.*

First of all, let's not be stupid and just blurt it out. The cultural iceberg is out there. People are pre-programmed to react negatively without even knowing their thoughts and judgments have been already determined by our culture. *It is important to give others time and space to warm up to the idea and begin thinking for themselves.* That means you will have to show some patience with others. Because of the cultural iceberg, you should not react to a few initial negative comments by rejecting the other person yourself. Often the other person doesn't even realize what they say or do might be hurtful or might be based upon terrible ignorance.

On the other hand, you will often be surprised by the other person's response. Epilepsy is so common that the person you are talking with may have it herself or have epilepsy in her family. There is more understanding in the community than you may expect. If you keep epilepsy a secret, you will never give yourself a chance to find that understanding.

An Executive Director of an Epilepsy Foundation once told me a true story. There was a gentleman in his 50s who had epilepsy for many years. He was terrified at the prospect of telling anyone outside of his family. The Director eventually managed to get this gentleman to join a self-help group composed of eight women about his age. Now the women had no difficulty telling anyone about their epilepsy. They decided their goal was to get this man to tell at least one other person about his epilepsy. They worked on him for months. Finally the gentleman mustered enough courage to tell his neighbor of 18 years. He went home after one of the self-help meetings and found his neighbor mowing in the back yard. He walked over to the hedge and motioned to his neighbor to come over to talk. With some hesitation the gentleman told his neighbor that he had epilepsy. His neighbor's response: "Gee, that's a relief, so do I."

The point of this story was by not telling, the gentleman had deprived himself of 18 years of understanding and support from a good friend.

This story also brings up another important point. *It is good to give the relationship some time to build up before you discuss your epilepsy* (though don't wait 18 years!) There will need to be some basis of trust to engage in a discussion of epilepsy. The other person will have many questions and probably some concerns. To talk about those issues effectively, you need to have a relationship and communication tools

already in place to handle a sensitive discussion. This applies to relatives, friends, coworkers, and to dating situations.

The most important tools are friendship and trust. *When you talk about your epilepsy, you are actually building further trust.* Not talking about it breaks down trust. You need to have enough of a relationship for the other person to stay talking with you, even if their culturally pre-programmed reaction is to withdraw. If you try too early there won't be that bond between you and those outdated cultural misunderstandings might win out.

When you talk about your epilepsy or your child's epilepsy, *never blame the other person for their misconceptions or ignorance.* No one chooses to be ignorant, and we all like to take pride in our own intelligence. If you somehow suggest that the other person is ignorant you will be insulting them and their intelligence. There is no quicker way to get them to stop listening and learning from what you have to say. All they are truly showing is their cultural training and the fact that they have not yet had the opportunity to begin thinking about epilepsy for themselves. Give them respect and room to start thinking for themselves.

Should a person say something like, "Aren't people with epilepsy mentally slower than others?" don't jump on them for what you might think is a put down. Remember, it is the culture doing the thinking at this moment, not the person. Instead, you might say something like, "You know, there are a lot of people who have that misconception, but people with epilepsy are just like everyone else. Some are slow, most are average, and some are very bright; just like the rest of us." You might go on to explain that seizures have little effect upon intelligence. It is the underlying brain disturbance, independent of the seizures that may affect intelligence. However, in 70% of people with epilepsy, the brain disturbance is so small or so subtle that it cannot be found by medical tests. That is why so many people with epilepsy have normal intelligence just like everyone else.

Explaining Seizures and Dealing with Fear

A lot of people think that talking about epilepsy is a matter of educating other people. Certainly, information campaigns are necessary for public education. But when it comes to one-on-one communication, information takes a back seat to an issue that is far more important: **fear**. Fear of seizures is one of those emotions pre-programmed into our subconscious by cultural training. People are not familiar with seizures commonly react to seeing a seizure with fear. The idea of losing complete control of one's body and mind is frightening to nearly everyone. This is our culture at work again. Our culture puts a very high price on being in control of oneself at all times. Seizures appear to break this cultural rule of big time. It is even common for people with epilepsy to have exaggerated fears about seizures, too.

In revealing your epilepsy, your most important challenge and goal is to relieve the sense of fear in the person you are talking to. When you talk about epilepsy and seizures, don't use the word "fear." The way you reduce people's fear about epilepsy in general is to tell them while a seizure may seem dramatic, it is very, very seldom harmful. People with heart conditions, asthma, or diabetes are at greater risk, yet most people don't think twice about those disorders in their friends. In fact, seizures are rare in most people with epilepsy. When they do happen, they last only seconds or minutes and after a short rest, the person recovers just fine. That's the way it was for Thomas Edison.

Here is the real trick to defeating any fear of your (or your child's) seizures: *Describe what you do during your seizure in detail.* Most people's reaction of fear comes with the sudden onset of unexpected changes in your behavior during a seizure. These behaviors are often dramatically not typical of you. You may have the type of seizure where you have convulsions (tonic-clonic) or the type where you may wander around or make strange movements while being unresponsive to others around you (complex partial.) (For an

explanation of different types of seizures, see the three article series “How to Beat Bad Seizures.”) Either condition can be frightening to your friend if it comes on suddenly, if they don’t expect it, and – especially – if they don’t have a clue as to what is going on.

However, if your friend, Jenny, has a complete understanding of how you behave during a seizure, the sense of fear will not last long. Instead recognition and prediction of your behavior will come into play. A typical response to a seizure might be “What the...!” (surprise) “Oh, Charlie is having a seizure!” (recognition) “He said his right hand will come up and his head will turn to the right!” “There it is!!” “Then he said he would get stiff all over and could fall.” (prediction) “I had better help him lay down.” (action.) Then he said he would start to shake in a way that looks like convulsions. I should not let anyone put anything in his mouth and I should turn him on his side (action.) Note *the reaction moved quickly from surprise (fear), to recognition, to prediction, and then to appropriate actions.* Charlie’s friend knew what to expect and what to do about it. Fear (surprise) faded quickly from the scene when the friend knew exactly what to expect and what to do.

And how do you think Charlie’s friend Jenny felt after the seizure was over? Terrible? Or, did Jenny just have the opportunity to feel good about herself for being able to help Charlie? You see, *telling others about your epilepsy gives others an opportunity to feel good about themselves.* There is little in life more self-satisfying than to be able to help someone else. I can guarantee you that Charlie’s seizure made Jenny’s day. By trusting his friend, as I say in the S.E.E. program, Charlie gave Jenny the opportunity to be a “hero for the day.” Charlie got help when he needed it and Jenny got a chance to feel great about herself.

As I have repeated above, when talking to someone about your epilepsy or your child’s epilepsy, your first and primary goal is to reduce the sense of fear about seizures that the listener might have. Unfortunately, fear of the seizure itself is not the only fear connected to epilepsy. Other fears include the person might die from seizures, that the person may suffer brain damage from the seizures, that people with epilepsy will be mentally retarded or otherwise mentally handicapped, and the people with epilepsy will be emotionally disturbed in some way or may be socially incapacitated. These are all culturally taught misconceptions that you will have to address in your discussions – though not all at once. (Please see “How to Raise a Child with Epilepsy” for further information on this.)

Unfortunately there can be some truth to these culturally held beliefs. Epilepsy is a sign of an underlying brain disturbance. For some individuals, the brain disturbance is great enough to actually impair intelligence or behavior. It is important to realize it is the underlying brain disturbance, and not the seizures, that is likely responsible for changes in intelligence or behavior *if these changes are present.* There is good evidence that persons with epilepsy are more likely to suffer depression, anxiety, or other mood disorders than those without epilepsy, though only a minority has these problems. These are most often “reversible” problems with the right kind of patient education, such as the S.E.E. program and/or with therapeutic help. There is growing evidence that some persons with epilepsy have problems understanding social situations, especially if seizures come from the temporal lobe of the brain. The result is that there is real life evidence to support old cultural biases for *some* people with epilepsy.

However, none of these conditions apply to everyone with epilepsy. There are persons with epilepsy with above average intelligence. There are persons with epilepsy who have exceptional behavior. There are persons with epilepsy who are well adjusted emotionally and who are socially successful. *Epilepsy is not one thing, it is many things.* Epilepsy does not affect the people who have it in one predictable way, but can affect each person in a different way. It depends upon what particular ability or talent in a person you are measuring. For example, some people with epilepsy can be outstandingly bright, but still have problems understanding interpersonal situations. Some can be the life of the party, yet have problems remembering

what happened at the party. Most people with epilepsy have none of these effects at all. It is all up to individual cases.

As a person with epilepsy (or child with epilepsy) it is important to understand the specifics of your individual case. Like anyone who doesn't have epilepsy, there will be some things you are good at, some things where you are average, and some things where you are not exactly the sharpest tool in the shed. If you want to achieve at your maximum level, you need to know that those things are. And you need to be honest with other people about them. In many ways, this is a no brainer (small pun.) Others will find out soon enough for themselves. It is always better for you to help them anticipate your assets and liabilities than to try to cover them up. Remember, hiding is lying and people will think less of you for it. If you have trouble remembering things, tell others so they know in advance.

Making Your Environment Safe

There is another reason for telling others you have epilepsy: *Less fear for you!* The fact is, we know that fear of harm from seizures is one of the biggest problems for people with epilepsy or parents of children with epilepsy. If people were only afraid of seizures when they had them, little of their lives would be affected by epilepsy because little time is actually spent having seizures. But for persons with epilepsy, family members, and parents of children with epilepsy, fear and worry are constant companions, during seizures and especially in between seizures.

One of the profound ideas that the S.E.E. program teaches is that “*Epilepsy is less a physical disorder than it is a DISORDER OF ANTICIPATION.* Seizures last minutes or less, but worry about the next seizure can last a lifetime.” It is this worry about the next seizure that makes life with epilepsy miserable for so many, especially parents of children with epilepsy.

First, people affected by epilepsy should know that seizures very rarely cause harm. Second, one of the most important things people can do to lessen this fear is to insure that everyone around them knows exactly what to do when the person has a seizure. This requires telling everyone around you that you or your child has epilepsy. Already we have learned that this has positive consequences for building self-acceptance and self-esteem. Now you will learn it has a third benefit – making your environment safe for you – or your child's environment safe for him or her.

As in all situations when you tell others about your epilepsy, goal number one is to reduce the fear your partner might experience when you have your first seizure in their presence. *An important step in reducing fear is telling others what they should do for you when you have a seizure.* This takes *prediction* of seizure behaviors and then appropriate first aid *action*. This empowers your friend to take control of the situation, an ability that further reduces fear and a sense of helplessness during seizures. This completes your friend's coping process from surprise to recognition, prediction, and then to action.

When your friends, relatives, and co-workers know what to do if you have a seizure, you can go out into the world not worrying about anything bad happening if you should have a seizure. When teachers, classmates, friends, and relatives know what to do when your child has a seizure, you do not have to worry about the safety of your child. In both cases there will be people there to help. *And people will want to help.* There is nothing more satisfying to human beings than to be able to help someone in need. The person gets to be “a hero for the day.” There is no stigma in that – only joy and a boost in self-esteem for the person who helps. It is a win-win for everyone involved. The helper will feel kinder to the person having the seizure because of what that person did for the helper's self-esteem that day. And the person having the seizure will have further cemented a friendship he or she can count upon.

Bottom line, if everyone around you knows you have epilepsy and if everyone around you knows what to do if you have a seizure – you have just created a safe environment.

*Now that we have discussed why to tell others about your or your child's epilepsy and explained the basics of how to do it, we will move on to some practical examples. In the July **Exceptional Parent** we will discuss "How to Tell Friends and Dates about Epilepsy." This article focuses upon the nuts and bolts of revealing epilepsy and gives suggestions for some "ice breakers" to get the conversation going. The final article "Revealing Epilepsy to Neighbors, Schools and in the Workplace" will appear in the October issue of **Exceptional Parent**. If you missed the first article, "How (and Why) to Tell Others about Epilepsy" or the two three article series, "How to Raise a Child with Epilepsy" or "Beating Bad Seizures," you can obtain copies from the EP website at www.eparent.com.*



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How to Tell Friends and Dates About Epilepsy

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This is the third in a series of four articles about how to tell others about your or your child's epilepsy. If you missed either of the first two articles of the series "How (and Why) to Tell Others about Your Epilepsy" or "The Basics of How to Reveal Epilepsy" you can obtain copies from the EP website.

Telling a Friend

I said in the last article, don't blurt epilepsy out right away! Because of the Seizures & Epilepsy Education (S.E.E.) program, I meet thousands of people with epilepsy. There are always a few that wear their epilepsy on their sleeve. They come up to people and say, "I'm Paul and I have epilepsy." To me and many others, this is a big turn-off (and I am interested in epilepsy!) Think about it. *You aren't looking to have others make friends with your epilepsy – you want them to make friends with you.* People need to get to know you first before they are ready to listen about your epilepsy.

Give your friendship a chance to develop independent of your epilepsy. Others are interested in a person who is comfortable to be with, who understands and listens to them, who is funny, and who generally shares similar interests and opinions. Pay special attention to "who understands and listens to them." If you are wallowing in your epilepsy, you are forcing attention on yourself and not giving attention to the other person's thoughts and feelings. The relationship becomes one-sided and the other person will become disinterested in you. Not because of your epilepsy, but because of the way you are using them in the friendship. So focus upon being a true friend and listen.

Friendships take some time to develop. It is important to give that development a chance to begin. The time to talk about epilepsy is when you have succeeded in establishing an early friendship and when you are able to talk with each other about things deeper than the weather, fashions, or sports. When you and your friend start to talk about personal family issues is a good clue your relationship is probably ready to deal with your epilepsy.

One mistake people make is they try to tell the other person everything about their epilepsy all at once. That is usually much more than most people can take right off the bat. A little bit at a time is a good idea. Let the other person's questions about your epilepsy guide you as to how far to go. If the other is interested in getting more information at the time, they will ask you questions to get at that information and to keep the conversation going. No questions are a good cue to switch to other subjects for now. When the other person is ready to hear more, they will ask about it again.

Another mistake often made is people often try to tell their friend their whole life history with epilepsy. Again, too much (often boring) information. Don't forget your goals: you are revealing your epilepsy to establish trust and reduce fear. A description of your seizure and a few answers to your friend's questions about epilepsy is all that is needed at this stage. Even information on first aid can wait for another conversation.

I suggest you use the term "seizure disorder" when you are first telling someone else you have epilepsy. The term "seizure disorder" does not carry as much cultural baggage as "epilepsy." It gives the other person a little more room to get emotionally comfortable with the information. But remember, "seizure disorder" is only a tool to give the other person some room to get used to the idea. What you really have is "epilepsy" and that word needs to come out in time. If the person asks, "Isn't that like epilepsy?" your answer should immediately be "yes."

Keep your voice "matter of fact" when discussing epilepsy. Your tone of voice will carry more information about how the other person should react to your telling them you have epilepsy as what you say will carry. And don't be apologetic for the condition. Remember, epilepsy is just a physical disorder like diabetes, asthma, or high blood pressure. There is no need to apologize for any one of them.

Here is the important part when it comes to keeping the friendship going. After spending a few minutes talking about epilepsy, immediately get back to talking about something of interest to your friend. Remember, friendships are not built or maintained upon epilepsy, but upon shared interests and sympathetic listening. Let your friend do the talking for a while.

Don't worry if your friend has an initial bad reaction to your disclosure. Remember, such reactions are cultural thinking, not your friend's thinking. Your friend may need a few days to let things sink in. She may need those few days to realize that you are still the same person she liked before she found out about your epilepsy. Give your friend the time needed to let her start thinking for herself. If this happens, a good clue that your friend is ready to talk further about your epilepsy is when your friend asks you some question about it. So be patient.

Getting the Conversation Started

For most people, getting the conversation started is the hardest part. Here are a few suggestions you might use to "break the ice." These will help give you some ideas – you should not be afraid to come up with your own way of starting. Please let me know what you have said or your own ideas at DrMittan@theSEEprogram.com. I will share your good ideas when I update this article.

"Since we are friends, there is something I would like you to know about me..."

"I have a medical condition that may come up. If it does, I would really appreciate your help..."

"I have an interesting medical condition I would like to tell you about..."

Always thank the person for their help in advance after your conversation about first aid. Something like, "If I have a seizure, I know I won't be able to thank you at that moment, so I would like to thank you now, in advance, for helping me out. It really means a lot to me that you will be there when I need you."

Dating Situation

In dating, trust is even more important than in friendship. There is a special kind of closeness in romance that is greater than in friendship. To make romance possible, trust between partners is paramount. This requires a delicate balancing act between letting the relationship develop and the choosing the right time to talk about epilepsy.

When you do tell your partner, don't be apologetic for your epilepsy. Don't say something like, "There is something I need to tell you about myself and it is OK if you don't want to continue going out with me when you hear." That is already telling your partner that what you are about to discuss is a bad thing. Epilepsy is not a bad thing; it is just a medical condition you cope with. If you have chosen your partner well, he or she will cope with your epilepsy and with finding out about it. *At this very moment, you need to trust your partner more than your partner needs to trust you.* And you need to trust yourself. Remember, sometime in life your partner will have a medical condition to cope with – it is a normal part of the human condition. So don't worry, you will get your chance to return the favor. I guarantee it.

Don't portray epilepsy as some kind of curse you have to live through. This is another way to teaching that epilepsy is a stigma. You may not be happy you have epilepsy, but that does not entitle you to share your misery with the rest of the world. A romantic relationship is about sharing happiness and love; it is not about getting stuck in self-pity. If you find yourself going in that direction, you may not be ready for a romantic relationship yet. How would you expect your partner to accept your epilepsy if you don't accept it yourself? If need be, go to a counselor or therapist and get this problem resolved. You want to be able to focus more on the "we" in your relationship than the "I."

So when to tell? That depends a little on the circumstances. The best situation is that you have not hidden your epilepsy from those that know you and your new partner is already aware of your condition. This situation is wonderful because you know up front that your partner is willing to accept your condition as a part of that special package that is "you." You will still need to have the discussion, but you can wait for a few dates before going into the details. Your partner may also ask about your epilepsy, and that is the cue that your partner is ready to listen.

As in all situations where you tell others about your epilepsy, goal number one is to reduce the fear your partner might experience when you have your first seizure in their presence. Again it is important to tell your partner exactly what happens during your seizures. This moves your partner from fear of the unexpected to prediction of the seizure behaviors. Going on to discuss what your partner should do for you when you have a seizure then takes prediction to appropriate first aid action. This empowers your partner to take control of the situation, an ability that further reduces fear and a sense of helplessness during seizures. This completes your partner's coping process from surprise to prediction to action.

If your seizures are not well controlled, you will want to tell your partner earlier. Otherwise you will be spending much of your date worrying about whether you will have a seizure rather than putting your full attention on your partner. In this case I suggest you tell your partner after the first two or three dates, as soon as it appears your partner is interested in you for more than just a couple of dates.

Your partner is likely to have some of the old cultural misconceptions of epilepsy as well. Those subconscious ideas people with epilepsy are not as bright as others or they are more emotionally fragile. Getting at these feelings are more difficult because they are unconscious. It does not hurt to say in your first discussion to say "People with epilepsy are like most other people in their everyday lives." That won't entirely take care of those hidden cultural teachings that are lurking beneath your partner's conscious mind, but it is a start.

The time to deal with those cultural misunderstandings is when they show up in your partner's behavior. Your partner might say he doesn't want to ask you to do too much because he is concerned the stress of those demands might cause a seizure. You can tell him that he should hold you to the same expectations he would have for anyone else in the same situation. Assure him that there is nothing in epilepsy that prevents you from being a full and equal partner.

Another situation may be that your *partner is embarrassed when you have a seizure with her in public*. This is a classic example of cultural learning. It is important that you be sympathetic regarding this reaction. Your partner will not only experience the embarrassment, but also guilt over being embarrassed in the first place. You will need to reassure her that this embarrassment is a normal reaction given our culture's values. You can note that it shouldn't be that way because all that happened was a common physical disorder that lasted for only minutes. Neither the seizure nor what she felt at that moment changes who you are or the love you have for your partner. Let your partner know that this normal reaction is OK and that with time and experience it will gradually lessen and go away. Let her know it is something you are willing to help with and wait for.

Another misconception commonly held both by persons with epilepsy and their partners is that seizures are more likely during intimacy. Again, this is simply not true. Emotional, mental, and/or physical focus all work to make seizures less likely, not more likely.

If your partner can't handle your disclosure of epilepsy, then that person is not someone you can build a successful relationship with. When dating, one of my clients called disclosing his epilepsy to his date "the epilepsy test." He considered it a crucial test the other person had to pass to earn his time and emotional investment. He is now happily married and has two daughters in college.

Trust is the foundation of a romantic relationship. Honesty about epilepsy and frank discussions about the ways epilepsy affects the relationship are essential. For the most part, epilepsy should not have much impact upon the relationship. Who you are as a person and what the two of you together can become are what are important. So your discussions should focus upon those topics, not epilepsy.

Getting the Conversation Started

While getting the conversation started for a friend may seem difficult, getting it started for a romantic partner may seem overwhelming. Here are a few suggestions you might use to "break the ice." These will help give you some ideas – you should not be afraid to come up with your own way of starting. Please let me know of what your own ideas at DrMittan@theSEEprogram.com. I will share your good ideas when I update this article.

Here are some examples of opening lines:

I care for you and I think it is important to be open. Now we are getting closer together, I would like you to know I have a medical condition...

I have come to trust you and I would like to share something about myself...

All of us will have physical challenges sometime in our lives. Who knows what the future will hold – diabetes, heart disease, even Alzheimer's. I already have a challenge, a seizure disorder...

*The final article "Revealing Epilepsy to Neighbors, Schools and in the Workplace" will appear in the October issue of **Exceptional Parent**. If you missed either of the first two articles of the series "How (and*

Why) to Tell Others about Your Epilepsy” or “The Basics of How to Reveal Epilepsy” you can obtain copies from the EP website www.eparent.com.



S.E.E. Program Manual

Revealing Epilepsy to Neighbors, Schools, and in the Workplace

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This is the fourth in a series of four articles about how to tell others about your or your child's epilepsy. If you missed either of the first two articles of the series "How (and Why) to Tell Others about Your Epilepsy," "The Basics of How to Reveal Epilepsy," or "How to Tell Friends and Dates about Epilepsy," you can obtain copies from the EP website.

Telling Another Parent

If your child has epilepsy, you will be confronted with the need to tell the parents of your child's friends about your child's epilepsy. This can be exceedingly difficult for a parent the first few times. We all like to think of our child as perfect, and admitting that our child has epilepsy feels like we are admitting our child is flawed. The stigma that goes with "epilepsy" from the cultural baggage lurking deep in our unconscious feelings makes this matter worse. Especially as another piece of cultural baggage makes the whole thing worse: That the health and welfare of our children is a direct reflection of how good a parent we are. In other words, if there is something wrong with my child, there is something wrong with my parenting. Then heap on the concern that the other parent might react with social rejection of your child or common cultural misconceptions such as your child must not be as bright as others and you can see parents face a daunting task in revealing epilepsy.

What I have discussed is just the tip of the cultural iceberg which makes revealing epilepsy such an ordeal for parents. For a complete discussion of this situation and what you can do to understand it and get your attitude right, my three part article series "How to Raise a Child with Epilepsy" is a must read. We will assume you have read these for the rest of this section.

The other parent needs to know that if their child and your child play together, your child might have a seizure. *Telling another parent about your child's epilepsy has the same primary goal as telling a friend – managing fear.* The strategy for telling is virtually the same as well: A little overview of epilepsy itself (how common it is; that harm is very rare), a description of what your child's seizure looks like and how long it may last (for recognition and prediction), and instructions about proper first aid for your child's seizure (for action.) In the case of a child, first aid instructions should include how to get in touch with you or your spouse at the moment a seizure might occur. Cell phones are a big help with this.

Again, *don't be offended if the first reaction you get from the playmate's parent is a withdrawal or rejection.* Remember, that is unconscious cultural thinking coming to the fore and it takes some time for the parent to think about the situation for herself or himself. If a negative reaction occurs, you may have to give

them some time for things to sink in far enough that the playmate's parents become ready to deal with the situation. Fortunately if your child and his or her playmate are good friends, the kids will eventually force the issue. Why? Because they will continue to play together despite the parents' apprehensions. This will eventually provide the playmate's parents with enough of a nudge to get them talking again.

Getting the Conversation Started

As I mentioned at the start of this section, getting the conversation started might seem overwhelming. Here are a few suggestions you might use to "break the ice." These will help give you some ideas – you should not be afraid to come up with your own way of starting. Please let me know what you have said or your own ideas at DrMittan@theSEEprogram.com. I will share your good ideas when I update this article.

Here are some examples of opening lines:

Does Mary have any medical conditions I should know about?... Johnny has one you should know about – a seizure disorder...

My child really enjoys playing with Mary! Since they are spending time playing together, there is something you should know about Johnny...

Johnny has a common medical condition you should know about...

Telling a Child

Telling a playmate's parent also means you will have to tell the playmate as well. After all, when they are playing together, your child's playmate is the one who is most likely to be nearby if your child has a seizure. It is best if you can arrange to tell your child's playmate with the playmate's parent(s) present at the time. As with every other circumstance, *your primary goal is to manage fear* as it happens in kids, too.

How you go about telling the playmate depends upon the child's age. For children in Middle School and above, a discussion of epilepsy, the seizure, and first aid can be conducted in words. You can describe the situation to the child in a manner similar to the way you did it with his or her parent. You may need to simplify your words a bit, depending upon the child's educational level. It is important to emphasize to the child that even though the seizures might look dramatic, they are not going to hurt your child and that the seizure should be over in a few minutes.

For younger children it is important to use demonstration – descriptions in words are just not enough. Young children's language and thought abilities are too limited to fully grasp a description entirely in words. Instead, they need a demonstration to understand seizures and to practice appropriate first aid and notification of adults. Having a person demonstrate the seizure also does much to reduce the child's fear of the event. Here is how it is done:

"Mary, Johnny has a medical condition called epilepsy. When someone has epilepsy they sometimes have seizures. There are a lot of kids who have epilepsy. When Johnny has a seizure, it looks like this." At this point an adult, but preferably Johnny himself imitates the seizure. "See Mary, it doesn't last too long and after a little while, Johnny feels OK again." "Now let's have Johnny have another seizure and I'll show you what you can do to help." Johnny repeats the seizure and Mary is physically coached through proper first aid for the type of seizure Johnny has. This can be repeated again, with Mary taking over the first aid without coaching to see if she understands the procedure. Additional repetitions can be made until Mary has mastered first aid without coaching. Mary, of course, should be praised throughout this process – as should Johnny for doing such a good job at imitating his seizures.

At first blush, many parents might think this demonstration is not a good idea. However, this is actually a clever method of teaching about epilepsy and seizures. It has a lot of built-in benefits for everyone involved. First, Mary has the experience of witnessing and then managing Johnny's seizures at least three times. If a seizure happens for real, Mary will already be fully equipped to handle the situation, and will be well past the "surprise" stage because the seizure behavior is already familiar to her. She will be pleased with herself that she can handle an important situation, thus adding to her self-esteem. Having her practice first aid assures both sets of parents that Mary is up to the task and knows what to do to help Johnny. This reduces concerns both parents may have and increases their level of comfort when the two children are playing together.

Less obvious, but just as important, the three or more repetitions will also get the playmate's *parents* used to seeing Johnny's seizures, placing them well past the "surprise" stage, too. In addition, Mary's parents should feel confident about providing first aid themselves seeing that even little Mary is capable of managing the situation.

Finally, Johnny receives an important "unconscious" message through this exercise. When Johnny is encouraged to imitate his seizures, this sends a message to him that seizures are not a frightening thing and that the people around Johnny – parents and kids alike – are capable of helping him out should a seizure occur. *This is a very powerful means of helping reduce Johnny's fears about seizures.* Similar to the situation of others witnessing a seizure, what Johnny does not know about his seizures is more frightening than the reality of knowing about the seizure behavior itself in detail.

Getting the Conversation Started

In addition to the suggestion above, here are a few openings you might use to "break the ice." These will help give you some ideas – you should not be afraid to come up with your own way of starting. Please let me know your own ideas at DrMittan@theSEEprogram.com. I will share your good ideas when I update this article.

Here are some examples of opening lines:

Mary, do you know there is something really important you can do to help Johnny some day?
Mary, do you ever imagine being a nurse or a doctor? How would you like to do something like one of those grown-ups?

Telling the School

This is one of the few circumstances where it is important to let people know about epilepsy right away, especially if your child's seizures are not under good control.

"Since you are going to be working closely with Johnny over the next year, there is something you should know. He has a seizure condition and it is possible that he may have a seizure in the classroom or on the playground. Let me fill you in on the details." As in all the previous situations, *the biggest goal you have is not information – it is to reduce the teacher's level of fear.* People unfamiliar with seizures commonly react with fear and are prey to cultural misconceptions. The idea of losing complete control of one's body and mind is frightening to think about. This is culture at work again. Our culture puts a very high price on being in control of oneself at all times. Seizures appear to the uninitiated to break this rule big time.

One of the keys to reducing the teacher's fear is to describe what happens in your child's seizure in great detail. Most of the normal reaction of fear comes with the sudden and unexpected change in behavior to something that is not typical of the child. However, if the teacher has a thorough understanding of how the child behaves during a seizure, the sense of surprise will not last long and instead observation, prediction, and appropriate action to deal with of the child's seizure will come into play. This will help bring calm to the teacher. And when the teacher is calm, the rest of the classroom will respond with greater calm as well.

Because of their own cultural baggage, teachers might assume that your child is not as bright as other students or not as able to handle the full workload of the classroom and homework. If your child does not have any special limitations, be sure to tell the teacher you expect your child to fulfill all the work expected of any student in the classroom, including class work and homework. If your child does have special limitations, these should be shared with the teacher, along with ways that previous teachers worked around them.

Follow your meeting with the teacher with a written note that repeats all of the relevant details. If the teacher has not dealt with a child with epilepsy before, it is likely he or she will be able to understand only a part of what you have to say. The note will help insure that all of the critical details will be remembered. Be sure to thank the teacher for his or her assistance at the beginning and end of the note.

After the first seizure, arrange a conference so you can "debrief" the teacher and go over any of the teacher's concerns or questions. This is a "golden moment" for learning. If you show an interest in sharing information, the teacher will in all likelihood show a genuine desire to learn from you. Also, be sure to immediately schedule a conference with the teacher if there is some kind of major event that occurs. An example is a child that usually has complex partial seizures unexpectedly has a secondarily generalized (grand mal) seizure (see the article series "How to Beat Bad Seizures" if you are not familiar with these terms.) Another example might be when Jenny unexpectedly has many seizures in a day when he usually would only have one. The teacher will be most appreciative of your information and support. That will translate into better care and teacher attention for Jenny in the classroom.

Getting the Conversation Started

While getting the conversation started for a friend may seem difficult, getting it started for a romantic partner may seem overwhelming. Here are a few suggestions you might use to "break the ice." These will help give you some ideas – you should not be afraid to come up with your own way of starting. Please let me know what you have said or your own ideas at DrMittan@theSEEprogram.com. I will share your good ideas when I update this article.

Here are some additional examples of opening lines:

Johnny has a medical condition you should know about...

Mary might need help with a medical condition she has...

Paul has a medical condition and you will become an important part of the treatment team...

Revealing Epilepsy at Work

As far as I am concerned, the disclosure of epilepsy in the workplace starts with the hiring process. It is my advice that you always disclose your epilepsy to prospective employers. Keeping it a secret until after your employment will raise in the mind of your employer "what else did she not tell me" before she was hired. "If she kept this secret from me, what other secrets does she have – and how serious might they be to her job

performance and this company.” This immediately sets off a climate of distrust that will affect your employment for years to come. Not a good way to get started on a job. The issue of interviewing for employment is beyond the scope of this article, but will appear in an upcoming article.

In many respects, the work situation is similar to the friendship situation. *It is a good idea to allow workplace relationships to get started before you reveal that you have epilepsy to your coworkers.* It is important to keep in mind that your coworkers are likely to already know you have epilepsy (especially if you take the good advice above.) The workplace rumor mill will be in full swing as it always is. This means waiting too long to tell your workmates may teach stigma in the way I discussed in the first article about the effect of keeping epilepsy a secret from others (see “How (and Why) to Tell Others about Epilepsy.” Still, wearing epilepsy on your sleeve and just blurting it out on the first day on the job is not a good idea either.

A little judgment is going to be required to balance these two conditions – waiting for the coworker relations to develop versus waiting too long and thus encouraging stigma to develop. Again, the matter is waiting long enough that the necessary tools for talking about a sensitive subject like epilepsy are in place. You will need the beginnings of a relationship and the necessary speaking tools. Your co-workers should feel comfortable listening to you and feel sufficiently comfortable to ask you questions about your epilepsy. At the bottom of all of this is trust.

If you are fortunate, some of your coworkers in the rumor mill will start asking you about your epilepsy. Generally they will wait until they feel comfortable enough to bring up the subject with you. That means they are comfortable enough to hear about seizures and they also feel comfortable enough to ask you about them. It is a sign that your relationship has progressed to the point that the basic communication tools needed to deal with a sensitive topic are present.

The ideal circumstance to bring up your epilepsy is with a group of coworkers. It does not have to be everyone, but a group of three to five is ideal if possible. One or two is OK if circumstances make it necessary. The group approach has several advantages to it. First, groups together enforce appropriate social behavior. That means the group is more likely to treat you with socially required respect and consideration. A group has a second advantage of generating more questions about epilepsy than a one-on-one situation might bring. This gives you a better opportunity to describe your epilepsy and seizures in more detail. Third, the group means you have more people remembering what you had to say, so more of the information you share will “stick.”

Here is a big key: *Once the discussion is over, get back to talking about other everyday things as soon as possible.* Epilepsy is only a part of your life, and only a very occasional one at that (considering how infrequently seizures occur.) However, in the lives of your co-workers, football, fashion, family, leisure activities, or complaints about how the company is run are everyday concerns. Bring yourself, your attention, and your conversation back to these everyday matters as soon as possible – and keep them there. Once the issue of epilepsy is brought out in the open, if any of your co-workers want to know something more, they will ask you. Leave it up to them!

The only exception to this important “Leave it up to them,” rule is if there is some significant change in your medical condition that requires your coworkers to be aware of that change. An example might be a change in medication that may result in a temporary increase in seizures and a greater likelihood of having a seizure on the job. Of course, all that would be required is a brief explanation of what is going on and a request that your co-workers keep a careful eye out for you. And for heaven’s sake, don’t forget to thank them for their extra help, whether it turns out it is needed or not.

The workplace always seems to harbor an individual that will harass you for your epilepsy. The workplace is a small version of the larger society and you know there will be some people in society that are so bigoted that they will never accept someone different from themselves. These people are usually miserable, with very low self-esteem. The only way they can feel better about themselves is to find ways to put others down. If you encounter a workmate who puts you down for having epilepsy, it is likely one of these people.

Unlike a potential friend, you can't just write these people off and cut off contact because you are still compelled to work with them. There is a strategy for handling these people. Most people think that when someone says something hurtful to you, you should shoot back with a zinger of your own. Most of us are not that quick at comebacks. That is actually OK. *If you engage in a word war with this person, you are playing his game and you have already lost.* Instead, ignore the comment and engage him in pleasant chat on another topic. He may get the hint at that point. However, if he is a persistent put-down artist, he will come back at you again at another time. If he does, you can use this to your advantage.

Those people who persist are trying to get a rise out of you. Instead, ignore the comment and pleasantly talk about some other everyday topic. Be friendly towards this person, even though he may not deserve it. If you don't respond, he will try harder and his insults will become more outrageous. Respond exactly as before. He will continue to escalate until he finally steps over the line – and one of your other coworkers who overhears will tell him to “lay off!” When that happens, that person will no longer be a problem and your coworkers will have become your defenders. All it takes for this to work is patience.

Getting the Conversation Started

Telling your coworkers about epilepsy is absolutely essential for establishing trust between yourself and them. Here are a few suggestions you might use to “break the ice.” These will help give you some ideas – you should not be afraid to come up with your own way of starting. Please let me know your own ideas at DrMittan@theSEEprogram.com. I will share your good ideas when I update this article.

Here are some examples of opening lines:

Since we will be working closely together, I would like you to know I have a medical condition you might help with...

There is something I would like you to know about me. There is a possibility that I might have a seizure while on the job. Hopefully it won't happen, but if it does I could use your help...

I have a common medical condition I would like you to know about...

Conclusion

You can make your world safer for yourself or your child by telling other people about seizures and epilepsy. Such honesty helps make the world a more accepting place. It is also a great way to find out who has the character to deserve your friendship. As good as all of that is, the very best thing is telling others makes you a better person. Each time you tell someone else, you affirm your worth as a person. You make it clear that epilepsy is something you have, not something you are. All it takes to succeed at this are the practical communication skills we have discussed in this article. Don't worry if things don't go exactly right the first time. Like anything else, learning how to tell others about epilepsy is a skill. It requires the knowledge shared in this article and then a lot of practice. And practicing will make life better for everyone!

If you missed either of the first three articles of the series “How (and Why) to Tell Others about Your Epilepsy,” “The Basics of How to Reveal Epilepsy” or “How to Tell Friends and Dates about Epilepsy”

you can obtain copies from the EP website. If you missed the two three article series, “How to Raise a Child with Epilepsy” or “Beating Bad Seizures,” you can obtain copies from the EP website at www.eparent.com.