

Sharing

A young woman with short, wavy brown hair and glasses is smiling broadly, showing her teeth. She is wearing a white, short-sleeved, V-neck top and a black skirt with white polka dots. The background is a plain, light-colored wall.

 Epilepsy Ontario

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Siblings and Epilepsy

A guide for
parents and
siblings whose
families have
been touched
by epilepsy

Epilepsy Ontario is a registered charitable nonprofit health organization dedicated to promoting independence and optimal quality of life for children and adults living with epilepsy and their families, through information, support services, advocacy, education and research.

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Note From the President, Mr. Lawton Osler:

I am left with emotion and just a little pride after I read the essay from the Dandelion Person.

Who is the Dandelion Person? In 2008, the OBCL Scholarship was presented with an essay about living with epilepsy that won a scholarship. This essay used the parable of a healthy person resembling a dandelion that did not need special attention and someone living with epilepsy resembling an orchid who required tender loving care 24-7.

The author of that essay, Sally, is the author of this relevant and clear treatise on how epilepsy can affect family relationships. I call Sally the Dandelion Person because she is as resilient as a dandelion!



(Continued on p.29)

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Siblings and Epilepsy

A Guide for Parents and Siblings whose families have been touched by Epilepsy

Sally Walker Hudecki

"At best, siblings are the most understanding and supportive of confidants, providing the stability of family with the commonality of a friend."

Epilepsy is a complicated disorder that reaches all aspects of one's life. The considerations necessary to successfully manage epilepsy affect many, whether knowingly or less so. Those living with epilepsy rely throughout their lives on parents, friends, and significant others to support them when they need it. As the circumstances of everyone's lives evolve, birthday to birthday and tick to tock, so do the circumstances of living with epilepsy. The constant fluctuations in how one feels about having seizures will affect how one relates to oneself and to everyone else.

Those diagnosed at a young age face many challenges: judgment at school, compromised self-image, safety concerns, and more. Teenagers with epilepsy (especially when newly diagnosed) often have trouble finding independence from their parents, and may isolate themselves from their peers. Sadly, it can still be hard for people of any age to find friends with whom

they can share their experiences of epilepsy. The complications of dating and romantic relationships can be multiplied by the effects of epilepsy, tangling issues of sexuality, guilt, stigma, and commitment.

For these reasons, those with siblings find themselves in a very fortunate position. At best, siblings are the most understanding and supportive of confidants, providing the stability of family with the commonality of a friend. At worst, they are antagonistic, competitive, jealous, guilt-ridden, and overly demanding of parental attention. Of course, every sibling relationship has both these best and worst black-bordered extremes, as do all relationships. The best anyone can hope for is a sibling relationship that balances healthily in the centre, especially when epilepsy is involved.



For Parents

Most Importantly

Parents of children with epilepsy must above all else remember that their children, with or without seizures, are normal. It is not enough to recall this fact, or even to remind your child of it. This concept must truly be an assumption of your family's day-to-day life. This is not a platitude. It is the truth. Your child with epilepsy is normal, as normal as their siblings with or without it, as normal as any child in their classroom. Emphasizing this

in word and deed is the most essential element; if your children grow up understanding this, they will treat themselves and each other with due respect. Of course, questions about the meaning of "normalcy" become more pronounced in adolescence, as your children become aware of many different world views and begin forming their own. Raising your children with openness towards differences will only help them, whether or not they have epilepsy.

Of course, there will be fear and uncertainty. Seizures are terrifying for everyone involved. However, you can learn to

balance the fear you and your family will naturally experience. There will be times when your child compares him/herself to his/her siblings, and if they don't all have epilepsy, this can be problematic. However, if they are all consistently reassured, directly and indirectly, that they are perfectly normal, then these comparisons will not drive distance into their sibling relationship. Your children need to be able to relate to each other and the world with the crucial understanding that epilepsy is neither who they are, nor something that is wrong with them, but simply something they experience.

Parental Attention

Parental attention is a dicey subject: too much, too little, the wrong kind, or at the wrong time can be detrimental for any child. It is an even more sensitive issue when epilepsy is involved. The most important elements are balance and fairness. Children are very instinctual observers of family dynamics and they know immediately when there are differences in treatment. The crucial balance of attention is easily threatened by any chronic illness, including epilepsy. The children suffering from it will naturally need more and different attention at some times (for example, doctor's appointments, school, the administration of medication).

The first step to make sure your children feel equally and fairly attended

to is honesty. Your full honesty, with all of your children, about epilepsy, what it means, how it happens, and how to help (dependent on their age and abilities), will make them feel included and trusted. This conversation is especially necessary if any of your children have witnessed a seizure, or if this is



a new diagnosis. Attempts at “protection” with sugarcoating, euphemisms, or not explaining it at all are unfair to your children and will eventually lead to resentment. Your children will feel underestimated, condescended to, or simply not important enough to be involved. They cannot learn to live with something they know nothing about. On the other hand, involving your children too much in the care-giving aspect will also lead to resentment and difficulty. This unfair burden of responsibility will lead to conflict between parents and children, and between siblings. Parents already shoulder significant stress when dealing with epilepsy, but it is not fair to anyone to distribute this stress onto your children. A balance in sibling

involvement and parental attention is not impossible.

Knowing your children's developmental stage will determine the amount of detail to share with them. Your openness to their questions, reactions, and emotions is invaluable. A good way to

does, and your children will sense the abnormality of it. It is important not to dwell, especially not on the fear or sadness you will sometimes feel. They need to feel that you are strong, and this will show them that epilepsy is a manageable thing. Epilepsy will be less scary for everyone if it is neither hidden nor highlighted.



The second step to maintaining a healthy and fair amount of attention is to remember that they are all normal, and treat them that way. Give them as many opportunities as possible to have fun and forget about their differences. Never let epilepsy rob you of your natural sense of humour and fun. Always emphasize your children's abilities and talents rather than their limitations. Do not unreasonably restrict your child's

introduce the idea of epilepsy to children is to emphasize the fact that everyone has something. If you say, "Daddy has glasses, Mommy has diabetes, and your brother has epilepsy," they will be less overwhelmed. Your children will be afraid and curious at some times. If they need to talk about it, it is important to talk about it. However, do not bring it up excessively. If your child has a seizure, or you are on the way to the doctor's office, you should explain plainly what is happening.

Try to talk about it at times when you are already together, like in the car on the way to school, or at dinner time. Gathering specifically for a talk about epilepsy is not something every family

activities, and try to give each of your children equal if not identical opportunities (if they must be modified for safety).

It will be heartbreaking to explain that there are some things your children should not do that other people can. "Special" treatment can be very hurtful and confusing to young children. They need to feel capable and self-reliant. However, overprotecting your child is as much of a disservice as not protecting them at all. An understanding sibling will help them feel better about having to take precautions, especially if they are comparing themselves to their peers. Your concerns about seizures will always be very important, but you must

be aware of when they are irrelevant. Telling your child that epilepsy does not affect who they are will have no impact unless you show them that it doesn't have to.

If you have one child with epilepsy and one without, do not hesitate to discipline them equally, for equally bad behaviour. Of course, it is important to understand the underlying causes of their behaviour and address it; for example, if one child is acting out because they are feeling under appreciated, then more than discipline is needed. This would be a good time for everyone to talk and understand each other's feelings.

Be open and listen closely to how your children interpret your actions. Also, remember that seizures can begin at any age. Even if one child develops seizures early on and the other(s) seem to be seizure-free, this does not necessarily mean they always will be. Keep an eye out for signs of epilepsy in all of your children. If you strive to spread your attention between your children in a balanced way, then when one of them inevitably needs more attention, the others are more likely to understand and have compassion.

Age Difference, Birth Order, and Sibling Roles

Your children's age difference and birth order will naturally affect how they interact. Sibling compassion and protectiveness will probably be intensified by epilepsy. Of course with the myriad of challenges any family already faces with epilepsy, avoiding any questions of sibling rivalry is vastly desirable. Remember

that all siblings clash, some more or less often than others, and some more or less severely than others. However, epilepsy can complicate those problems, and thus the issues should be defused as much as possible. As a parent, you can do a great deal to shape the kind of sibling relationship your children have.

First of all, use the same language to talk about epilepsy with all of your children, even if they do not have it. Do not say to one child that epilepsy does not change who he/she is, but say to the other that it is a terrible, dangerous disease that still has a stigma attached. This will only complicate their relationship with each other. Make sure that you answer your children's questions in a straightforward way, and educate them as much as they can understand. Acknowledge and accept their changing feelings about epilepsy as they grow.

As they become teenagers, it may be better to talk to them individually than to force communal discussions. Let them start their own conversations about epilepsy with each other when they feel the need.

Be conscious of the fact that although they deal with problems that are far too big for them, they are children and will understand their problems through the lens of their age. A child with epilepsy who has a younger sibling without it may go through periods of insecurity, resenting his/her limitations that the younger one does not have. A younger sibling with epilepsy who may have already experienced your limitations because of age, and with more limits due to seizures, he/she will likely feel overwhelmed.

It is normal and expected for siblings to sometimes feel either burdened or burdensome on each other. This is why you need to be active in your role as caregiver, and be thoughtful about the responsibilities each sibling has towards each other. However, even then, your children may still have feelings of guilt, fear, or helplessness. These will pass, and often as your children get older they may be more open to talking about epilepsy and creating their own relationship with each other.

At School

Having siblings at school will help your child, provided that their sibling is not saddled with the constant role of guardian while at school.

To avoid have your children bullied for differences, the best thing to do is not to hide their differences, but to acknowledge them in a way that is accepting and informative without singling them out. If they are bullied about this, speak to a teacher. However, reinforce to your children that they are okay the way they are. The more they believe this, the less hurt they will be by external cruelties.

It's likely that you will need to educate your child's teachers about precautions, as public understanding of epilepsy is still minimal. Embarrassment about seizures, to the point that your child's school is

unaware, is very dangerous. If you feel afraid or ashamed to talk to your children's teachers, remember that this is for their safety, and does not reflect on you or your family. If they react badly, or express stigma, do not be afraid to address it directly. As your children grow, their siblings can be an invaluable support to each other at school. Your chil-



dren will likely be very compassionate and protective of each other at school.

If you can, ask the teacher if their class could set aside some time for each person in the room to say one thing about them that makes them different. After each child comes up with something, the other children could ask questions about it. Because each child would have to do it, no one would be treated differently. Then when your child says that they have epilepsy, the atmosphere will already be one of curiosity and learning rather than fear or stigma. The teacher can help explain what epilepsy is, and the

class can move on.

Maintaining A Strong Sibling Relationship

Feeling that they have had your equal and fair parental attention for who they are as individuals is the greatest thing you can do for your children's sibling relationship. Everything else comes from that. Showing your children how to have a good sibling relationship while they are young means that the older they grow, the less they will need your assistance to connect with each other. They need to know from you that they do not have to compete with each other to be accepted. If not all of your children have epilepsy, then as they grow up, particularly in school age years, they should know that their siblings accept them just as you do. That is why it is best to discuss epilepsy as a family, not just with those who have it. That way, the burden is shared.

Allow all your children, whether or not they have epilepsy, to express their frustration, anger, and sadness about it. However, if they are experiencing insecurity about having seizures, you should not assume that every time your child seems to be upset, it is related to epilepsy. If you find that your child is isolating him or herself, having them play or hang out with their sibling(s) may help. Try not to "direct" their relationship as much as give them opportunities to create their own. Give your children toys and games that they can play with together, as well as their own individual toys and books. If you need help around the house, see if they can

do it as a team. If they have extra-curricular activities, let them have individual choices, but also involve them with their siblings, if that's what they want.

In essence, as they are growing up, the best you can do is to give your children many opportunities to have fun together, and when the not-so-fun times hit, approach them as a family. If you create this pattern when they are young, they will follow it in their relationships with each other for life. This may sound like advice that could apply to any family, and that is the point. Epilepsy does not make your family abnormal or wrong, it is just something that you all have to deal with. Do not make epilepsy the center of your children's relationship with each other. They deserve better.

Finally

You should read the parts of this book written directly for siblings. It might help you understand how your children feel and give you insight into their particular concerns. But there are some things that are worth being repeated for you.

No matter how often they happen, do not let seizures take over your life.

- Epilepsy is not your child, and it is not your family. It is something you experience. What is abnormal is the seizure activity, not your child.
- Seizures happen. They are terrifying and upsetting, but they can be prevented and controlled, sometimes fully.



- Your family will always have worries that others won't. But everybody has something to worry about.
- When it feels overwhelming, know at least that you are not alone. Know especially that there is nothing wrong with your family.
- You can help your children thrive, with or without epilepsy.
- You cannot take away their seizures, but you can take away their fear, sadness and shame.
- Your family does not have to be weighed down by epilepsy.
- Give your child the ability to be known for something other than having epilepsy, not only with you, but also with other family, with teachers, peers and doctors.
- Always emphasize their abilities, even if you have to explain their disorder.
- Always emphasize that your child's limitations are no more crippling than anyone else's.
- Show your children how capable they are and how little epilepsy affects their talents, intelligence, and personality.
- Give your children equal opportunities and let them be there for each other, as playmates, friends, supports, protectors, confidants—brothers and sisters.
- Your children are lucky to have their siblings, and with your conscious effort, their siblings will help them long after you cannot.

For Siblings

The Beginning: Start Here

The feelings that come with having siblings are incredibly complicated. Your relationship with your siblings will probably affect the rest of your life. The feelings that come with being close to epilepsy are also incredibly complicated, and will probably affect every part of your life at some time. Needless to say, having siblings and being involved with epilepsy can be a big, complicated mess. It is very normal to feel that growing up with epilepsy, or with a sibling who has epilepsy, is overwhelming, embarrassing, confusing, tiring and frustrating. It is normal to feel that you are a burden on your sibling, or that they are a burden on you. It is normal to wish that you could take epilepsy out of your family, to be angry that you have to deal with it, to wish you could take your sibling's problems for them, or to unload yours on them.

On the other hand, it is also normal to wish, in times of difficulty, that the source of difficulties would disappear, and to take out these frustrations on your siblings. It is normal to feel guilty for having all of these feelings. It is normal to feel guilty for being healthy. It is normal to feel none of these things, and regard epilepsy as no more complicated than having a tongue. It is okay to feel any of this; none of it makes you a bad person, or a bad brother or sister. Not only that, but you don't have to live with any of these feelings, no matter how normal and expected they are. They may be "normal", but they can feel awful and unfair.

That's because having to deal with epilepsy from a young age is awful and unfair. Seizures are frightening for anyone to experience or witness, and not everyone has to deal with them. However, none of your guilt or fear has to define you or your relationship with your siblings. You might always have those feelings hanging around, knocking down your door on the worst days, but you will be able to experi-

"You are more than capable of having any kind of life you want: extravagant, raucous, rock and roll, fascinating, jet-setting, peaceful, ambitious, or everything at once."

ence them and then let them go. You are more than capable of having any kind of life you want: extravagant, raucous, rock and roll, fascinating, jet-setting, peaceful, ambitious, or everything at once.

Epilepsy may be something that you must always keep in mind. However, it does not have to be the only thing you think about, nor do your feelings for yourself, your siblings, or your world have to be filtered through it. Epilepsy is something you and your family experience, not who you are.

I don't know who you are. I don't know whether you are the oldest, the youngest, or the middle child. I don't know if epilepsy is something that you have been around since you were born, or if it is new to your family. I don't know how severe the seizures are. I don't even know how old you are, what your name is, or your favourite colour, band or flavour of ice cream. I don't know how fond you are of your siblings, or if your parents give you all equal attention. I'm not sure if you've even read this far. Here is what I know: You were born, with a name, into a family. You have one or more siblings: a big brother or a big sister, a twin, or a little brother or sister. Maybe you have all of those.

I know that it is likely that your feelings about your sibling and epilepsy are complicated, wrapped up in a big ugly ball of compassion, love, fear, sympathy, guilt, embarrassment, confusion, responsibility, and need. Barely anyone will manage to untangle this angry ball without guidance. Hopefully reading this will help, and if you have trouble at all, then know that there is nothing wrong with asking for help. Everyone needs help with something, at some time. Not acknowledging how you feel is as bad as not acknowledging a red-hot meteorite headed on a straight sucker-punch course for your neighbourhood, and will not end much better.

Even if you have managed to sort through a lot of these feelings, there will always be a day when you need a reminder of how to be okay. These feelings will never disappear. Trying to make them vanish isn't going to work. Being told not to fear, not to feel bad, and to focus on the positive is only

helpful when you can choose what you focus on; much of the awfulness



of epilepsy comes from the fact that it is unexpected and uncontrollable. Seizures jut into your life no matter how positive you are. You can't change that. The only thing you can do is make the time between seizures—moments, days, weeks, months—as good as possible.

If Your Sibling Has Epilepsy, and You Do Not

You may think that because you do not have epilepsy, it is unfair to express your feelings about it. However, you are not your sibling; you don't need to experience what they do to have feelings about it. You need time, just for your-

self, to address your feelings so that you can have a healthy relationship with your sibling. You have every right to do this. Siblings are your closest relation, and what they experience is inevitably something you experience as well. Having your own life can sometimes feel impos-



sible if you also want to take care of your sibling, but they do not have to be mutually exclusive. You can be an independent individual who cares deeply for their sibling. The goal of untangling your feelings about epilepsy is to move past them and be able to have a good, supportive relationship with your brother or sister.

The first step is to understand and

acknowledge how you feel, even if you don't want to feel the way you do. You need to open yourself up to the truth. Most importantly, you need to actively think about your relationship. Think about your sibling, think about epilepsy, think about their experiences, and remember everything—even the upsetting things. Pay attention to your feelings and reactions. If you become overwhelmed by emotion, take time afterwards to trace your thoughts and feelings. If you don't know why you feel the way you do, try to walk backwards through each emotion: when exactly did this start? What were you doing or thinking at the time? Observing your thoughts is the best way to understand and acknowledge how you feel.

Talking about your feelings might also help, especially if you're not sure how you feel. Sometimes you don't realize how true something is until you hear it coming out of your mouth. This might be a good conversation to have with one or both of your parents, or a good friend. If you decide to talk directly to your sibling about it, choose your time carefully. If the subject comes up at a neutral time, (not like if they've had a seizure), then embrace it. Bringing up your feelings when they're already upset or recovering could be overwhelming and lead to conflict. Another excellent thing to do is to write in a journal, even if you don't think you have anything to say. Just start writing. I bet you that words will come out.

The next step depends on what feelings you have.

You may feel overlooked:

A lot of anger, sadness, confusion, and guilt can come essentially from the feeling that you are less important than your sibling. Often, this evaluation of yourself is through the eyes of your parents, or at least, from what you understand from their view. The feeling that your parents care less about you than your sibling can reverberate in countless ways. Even if your parents go out of their way to make you each feel equally appreciated, sometimes you can't help but feel the need to compete with your sibling. This is a very common, very frustrating, and completely valid way to feel. Know this: you can make it better.

Think of the interactions that you have with your parents every day. The attention that your parents give you depends on these interactions. You can separate the interactions you have with your parents into three types: positive, negative and neutral. Think of positive interactions as contact that makes you feel good, close to your parents, respected, understood, proud, and loved. Negative interactions, then, include scolding, nagging, condescension, guilt, disapproval, disrespect, and ignorance. These kinds of interactions can leave you feeling unappreciated, misunderstood, pressured, or underestimated. Then, there are neutral interactions. Usually, these account for the majority of interactions that you will have with anyone. Think of neutral interactions as emotionally irrelevant; things like idle conversation, driving, running errands, help with small things, having privacy.

Every relationship has a mix of these types of attention and interaction.

Parent-child relationships, especially, must include all of them to be healthy. No one gets along with their parents all the time. No one gets along with anyone all the time. And there's nothing wrong with that. You want to know that when you do something wrong, bad, or hurtful, your parents give you some kind of negative attention: discipline, disapproval, and punishment. You want to receive some kind of positive attention when you do something right or good: praise, pride, reward. You also want to receive a certain amount of attention that is emotionally neutral, day-to-day: conversation, privacy, courtesy. All of these expectations are reasonable. The problem arises when your parents' reactions to you do not match these expectations, and with a sibling involved, it becomes even more complicated.

Of course, your sibling sometimes needs more attention than you. Hopefully you know whether you feel overlooked because of a real disparity in parental attention, or because you feel jealous of your sibling. Both of those are valid problems that commonly arise. As you evaluate these feelings, try to give your parents the benefit of the doubt. If you feel unsure, and are trying to think of examples when your parents treated you differently, then they probably haven't. When your parents are trying, you know. Be honest with yourself about whether your parents give you and your sibling equivalent attention. ("Equivalent" is more realistic than "equal", because as you know, sometimes your sibling does require attention that you simply do not. That is not to say that you both don't deserve attention.)

Your parents may do all they can to keep you from feeling insecure, overlooked, or jealous, but you do anyway. You're not a bad person or a bad sibling if you feel this way. It's very hard to share those feelings, and it's very hard to shake them. This can result in a lot of guilt. There might be nothing you can do about these feelings. They will pass. Hang out with your sibling and parents. Pursue things that you enjoy, and share them with your family. Remember that your parents appreciate you for more than just being the "okay" kid.

On the other hand, you might feel insecure because your parents are not giving you the right amount of attention at the right time.

- Maybe your parents don't take your problems seriously, compared with your sibling's.
- Maybe your parents take your successes for granted.
- Maybe your parents have unrealistically high expectations for you.
- Maybe your parents punish you more strictly than your sibling.
- Maybe your parents don't know you very well, and don't try.

- Maybe your parents expect you to take full responsibility for your sibling.
- Maybe your parents' attention is otherwise conditional upon you doing or being something more than "alive."

If you're in this situation, there are two different paths you can take. The



first path is destructive. This is "first", because it includes strategies that you unconsciously use to address feelings that you may never have acknowledged. It is common not to realize you're on this path until you get off of it. The second path is constructive, and requires focus and readiness. You cannot fix a problem unless you are willing to make it better. If you are ready for it to be better, it can be.

You may be destructively seeking attention from your parents if you argue with them a lot, react defensively towards them, shut them out, stop talking to them, skip class a lot, drink or smoke a

lot, or fight with your sibling. You might feel very angry or sad without knowing exactly why. If this is what you're doing, you need to decide what kind of attention you're after, and whether your actions are going to achieve that for you. Those actions will get their attention—usually quickly. And that can be satisfying at first. But it really doesn't solve anything. It won't give you the type of attention that you want.

It's easy to become stuck in this spot, feeling like there's nothing you can change. But there is, and you have to do it. There's really nothing anyone else can say or do. If you're not ready to get out of it, then don't expect to get what you want. This path is destructive to you as well as your relationship with your parents. At some point you're going to have to say you're finished with all of the awfulness, and mean it. No one can do it for you.

The constructive path is not as hard as it looks. You need to communicate your feelings to your parents in a non-confrontational way. Nothing will change unless you say it out loud. Even if they don't respond the way you want them to, it will not be your responsibility. You will have done your best. The rest is out of your control.

Approaching your parents in this way is intimidating, but not impossible. Before you do, sort out exactly what your feelings are. It will help to write about it. Try writing a letter to your parents. Or just start writing about anything. Write about your feelings. Or write about times when you've felt overlooked by your parents. Once you feel you've expressed what you think is wrong, leave it for a day or two. You might come to some kind of clar-

ity—or forget about it entirely.

After a few days, read what you wrote. Is it still true? Is it mostly angry, sad, or something else? Did you come up with specific examples? Try to sort through your emotions and figure out exactly what it is that you are trying to say. Know what you feel, and what specific situations make you feel that way.

When you're prepared in this way, it's less likely that you will say something that you will regret. Choose a time to talk to one of your parents; it should be a time that you are already together, like driving somewhere, cleaning, or cooking. This way neither of you can leave the conversation easily, and you will have something to distract you.

Choose a time when you and your parents are calm. Don't bring up this issue when you are already fighting. Tell them you want to talk about something important. Explain your feelings realistically. Don't blame them, but point out examples of specific times when you felt overlooked. Acknowledge their side and keep an open mind. If you want to be treated fairly, treat them fairly.

Once you have explained what you feel you need to, let them respond and listen. Try not to make statements that include "always", "never", or exaggerations. While they might reflect the intensity of what you feel, they usually don't reflect the reality.

Be as direct and fair as you can. If you become emotional, either let it pass and continue the conversation when you are calm again, or ask that you resume the conversation another time. If your par-

“Hang out with your sibling and have fun: listen to music, go to a concert ... Connecting with your sibling by having fun will remind you that they are okay.”

ent becomes defensive, ask them if they want to talk about it another time. The more mature you act, the more respectfully they will treat you.

If you leave the conversation unresolved, come back to it in a day or so. Don't give up on it. Even if it seems like nothing's changed, you've made them aware. They might be turning it over in their minds. All you have to do is start the conversation.

You may feel a need to be perfect:

Many siblings of people with chronic illness deal with perfectionism, without realizing that these circumstances may be connected. Perfectionism in this sense will not necessarily be reflected in everything you do. Other people may never notice it. It is probably a standard, existing only in your mind, into which you try to slot every facet of yourself. If you can match this imaginary version of yourself, you will be perfect.

People may say that you can never fit that. But sometimes this standard feels like a good thing, because it forces you to do the best you can. Sometimes it seems like you really can be perfect. It usually seems like you can, in fact, until you sud-

denly can't. And the pressure of trying to, all the time, is unnecessary.

Being perfect does not help your sibling. It won't "fix" them. It won't make anything easier for your parents. It doesn't somehow compensate for your sibling. It doesn't make it less likely for you to develop seizures. If you could fit into this idea of perfection, nothing would change. It is something that exists only within you, and can only, therefore, affect you.

If you feel bad about something because it doesn't fit your idea of perfection, listen to your thoughts. Are you calling yourself names? Do you think that achieving a little less than "perfect" makes you stupid, lazy, ugly, defective, broken, or worthless?

If your brother or sister told you that they achieved a little less than they'd hoped for, would this make you think they were stupid? Or lazy? Or defective?

Why would you expect so much more from yourself than from your brother or sister? You may know that you can achieve great things, and think that the only way to do that is beating yourself up when you don't. But listen to the unpleasant sounds of not fitting into a standard that's too small, or too big, or just wrong. Say to yourself, "I made that up. I'm not fitting into something that I made up in the first place. Why does that make me bad?"

You may feel afraid for them:

Try not to become overwhelmed by these feelings. Feeling bad does not help your sibling, and it will not take away what they have. Hang out with your sibling

and have fun: listen to music, go to a concert, go shopping, watch television, look up funny videos together on YouTube, or just sit and talk about nothing. Connecting with your sibling by having fun will remind you that they are okay. They really are—what are not okay are their seizures. They are still your brother or sister; they are not their epilepsy.



diagnose you.

You may feel afraid for yourself:

You may feel afraid that because your sibling has epilepsy, you will begin having seizures too. There is some truth to this. Seizures can run in families, although it is rare. Seizures can also start at any time in your life. However, it is unlikely that you will develop epilepsy. You should ask your parents if they have ever observed you experiencing anything that seemed suspicious. They will be familiar at least with your sibling's type of epilepsy. If they are not sure, you can ask your doctor, or do your own research into different types of seizures. However, if you do your own research, be cautious about the type and source of information you're consuming. If your doctor is at all concerned, they will refer you to a neurologist who will be able to

However, it is very unlikely that you will have seizures just because your sibling does. They are not contagious, and rarely genetically linked. You can, and should, not scrutinize yourself, looking for signs of abnormality. Someday you may develop seizures, or you may not. Don't let the fear of what you may never have stop you from enjoying yourself now.

You may have to examine the possibility that your fear of developing seizures may stem from a desire to "take on" your sibling's seizures. You cannot take away their seizures, even if you develop them yourself. That is the bitter truth.

You may feel confused:

If you don't understand epilepsy or

your sibling's particular type, ask your parents or do your own research. If you're researching on the Internet, make sure that the web sites are reputable. A good place to start is the web site of your local epilepsy foundation or agency. They will have lots of information and links. Learn not only about their disorder, but also about how to help them in case of a seizure, reaction to their medication, or other emergency.

You may feel burdened:

Remember that your sibling is not your responsibility. You are not his/her parent. Epilepsy can be incredibly hard and very stressful to live with, especially if the seizures are frequent, severe, or both. Hanging out with him/her and having fun will remind you that he/she is still just your brother or sister. Remember that he/she did not ask to have epilepsy, and that by supporting them you are sharing this burden. However, you must remind yourself that the burden is the epilepsy, not your sibling. Epilepsy is a burden that you can help your sibling handle if they cannot always do it on their own. Make time for yourself too, to do whatever you like to do—sports, drawing silly pictures, watching movies, hanging out with friends. It's easier to feel burdened by your sibling's seizures if you are thinking about them all the time, so just take time to be you. You are not your sibling, and trying to take on their problems will not do them any good. Take care of your sibling as much as it is fair for both of you.

You may feel angry:

Anger often comes from a feeling of helplessness. When you feel that your sibling doesn't deserve to have seizures, you can

become overwhelmed with anger. However, you can use that feeling of unfairness to help people with epilepsy. Help your brother or sister, or volunteer for an epilepsy event, agency, or foundation. Remember that everyone has something, and that sometimes you have a choice; you can either stew in anger for a long time, or use it to drive your compassion and advocacy.

You may feel helpless:

Remember that your sibling is not your responsibility, and they do not expect you to help them. You can care for them without "fixing" them. This is certainly not your job, as much as you may wish you could. Your role in their life is to be a brother or sister, not a doctor, nor a therapist. Of course, you will want to help your sibling in every way. But the best way for you to help them is to be a caring and fun brother or sister, and to be the best in that particular role that you can be. As much as a doctor can help them in ways you can't, you can help them in ways a doctor can't. They will appreciate you for everything you do, even when you feel it's not enough.

You may feel guilty:

Guilt is one of the most common feelings for people whose siblings have epilepsy, especially while they are growing up. It can be extremely heavy and at the same time extremely quiet, so that you don't realize how much guilt you feel until it is too much. There are a few reasons for feeling guilty in this situation.

- You may feel guilty because you are healthier than your sibling.
- You may feel guilty for the times that

you did not get along with your sibling.

- You may feel guilty for feeling confused, burdened, angry, afraid, helpless, or sad.
- You may feel guilty for feeling guilty.

Guilt is not a friend to keep. All it does is wrap around your neck and whisper cruelty into your ear and weighty lies, like that you are a bad brother or sister. Don't listen to that. In fact, all of this guilt actually means that you are an exceptional brother or sister. It all comes from your love and compassion for your sibling. That, of course, doesn't mean that you have to feel guilty. But it also doesn't mean that you should be hard on yourself. There are enough things in the world to feel bad about; don't force it onto yourself. Guilt has never done anyone or anything any good. You don't have to feel guilty to be a good sibling. Let go of your guilt; don't hang on to it like some kind of rotting lifeboat.

Remember that as much as your sibling did not ask to have epilepsy, you did not ask not to have it. As much as they don't deserve to have epilepsy, you don't deserve to feel guilty. Feeling guilty will not help your sibling; it will not make their medication work, it will not take away their seizures, it will not allow you to take this burden from them, and it will not make them happier. Your brother or sister does not blame you for being healthier.

If you feel guilty for not always getting along with your sibling remember that all siblings clash sometimes. No one gets along with everyone all the time, not even their brother or sister, no matter what they have. It's not fair to expect

otherwise. In fact, those kinds of expectations make your sibling's epilepsy more central to your relationship than it needs to be.

If you feel guilty for your fear, sadness, guilt, helplessness, anger, or confusion, remember that there is nothing wrong with feeling anything. Usually this kind of guilt comes from the idea that you

“Likelier than not, your sibling will be a gift. Living with this condition, as harrowing as it is, can be a binding force between you.”

“should” feel something different. But you should only ever feel what you feel. Your feelings are your feelings; you have them for a reason. You are entitled to them. No one is happy all the time. No one is fearless. Not even people who have spectacular health, or who have seemingly fulfilling lives. Not even people who have accepted their fears and sadness feel okay all the time. Epilepsy is especially scary and heartbreaking because it drags a lot of uncertainty into your life. It is not something that you can see, predict, or control, and that makes it harder than if you could. You are allowed to feel whatever you do.

It is vitally important to remember this: whatever awfulness you feel—if it is too much—it is ten thousand percent okay to get under the covers, or into a closet, or into a corner, or into your mother's arms, and feel that awfulness rush through you.

It is okay to be overwhelmed, and to stop everything to be upset, if that is what you need to be. Do not lie to yourself about how you feel, and do not deny yourself the right to express those feelings. In our society, and especially at a younger age, expressing negative feelings is often discouraged. But if you truly feel upset, pretending you do not is only going to make it worse. Trying to act like you are okay is not going to fix anything.

Allowing yourself to show your emotions may not fix anything either, but at least it is true. There is nothing wrong with being afraid, sad, lonely, confused, and helpless. Remember to tell yourself the truth about how you feel. Tell your journal the truth about how you feel. Tell a friend, a nice person or your parents the truth about how you feel. You don't need to feel guilty about anything.

There are no steps after these. That is because these steps are not steps you take once and never again. They will be steps you retrace many times, until you know the way so well you can remind yourself of it. These feelings may never go away completely, but the steps you take to live with them will affect you much more permanently, as they comprise the journey you live as a brother or sister. Your sibling's epilepsy is not the centre of your relationship with your brother or sister, even if you have to take care of him/her sometimes. The centre of your relationship with them is the compassion and love you have for each other as siblings.

If You Have Epilepsy, But Your Sibling Does Not

There are many feelings to sort through if you have epilepsy, and even more if you have a sibling that does not. Having a sibling will likely affect the way you feel about having epilepsy, as will the attitude of the rest of your family. You might have grown up with well-controlled epilepsy and have very few feelings about it; on



the other hand, you may be newly diagnosed and struggling with the entire journey. If you have seizures, then you know that the one thing you can't talk yourself around is the precipice of uncertainty.

You can't get past it, across it, or around it. You have to live with it, somehow. Your own brain, the precious lump responsible for your ability to read these very words, can also betray you at any moment. You can't possibly know. Even on medication, you don't know if your seizures will always be controlled. Sometimes it seems

like your own brain is trying to kill you. You feel bereft of choice. However, one thing you can affect is how you feel about yourself and your epilepsy, and that will affect the people around you and how they feel about it.

Epilepsy is hard because it is yours alone. It is not contagious, and it is not something outside of yourself—it is your own brain. While your family and friends may help you deal with it, you are the only one in your

yet lots of people thrive. Everyone who has encountered epilepsy is exceptionally brave.

Your feelings about having epilepsy will likely run in circles for a long time. You will likely have three kinds of days: when you feel like epilepsy does not affect who you are, and you are strong, normal and okay anyway; days when you are vulnerable, upset, afraid, embarrassed, or tired of it; and days when you don't even think

about it. All of those feelings are equally valid, and you'll probably never feel just one of those ways forever. You might even jump through all three of these feelings in one day. Your feelings about having epilepsy are never going to be resolved, even if your feelings about yourself and your sibling are. The closest you can get is to accept that they will change, and to separate (as much as you can) your feelings about having epilepsy, and your feelings about yourself and your sibling. How you do this depends on what those feelings are, at any given time.



seizures. You are the only one who has to try the medications. You are the one who experiences side effects, and has to take extra precautions, who may never drive. Epilepsy is also usually chronic—meaning that it is not something you can have once, heal from, and feel better about. Even if that happens, it might come back. Some of us find that as soon as we start to feel safe and strong again, it's back. That's why people with epilepsy are some of the most courageous people in the world. Living with something like epilepsy is hard, and

You might feel confused:

If you are confused about what you have, ask your parent or doctor about it. You can also do your own research in a library or online, but make sure that your sources are reputable. A good place to start online is your local epilepsy foundation or agency.

You might also be confused about exactly how you feel about epilepsy. If this is the

case, try writing about it in a journal, or talk to your sibling or a close friend about it. If you have complicated or confusing feelings, remember that no feeling you have is “wrong” and that you are not alone.

You might feel insecure:

There is nothing wrong with feeling insecure. It is a very common feeling, although having epilepsy often intensifies it. A lot of insecurity comes with comparing yourself to others, including your very own sibling. You might tell yourself that “everyone else is normal” and you’re not. But that’s not true. You do experience things that are not normal. But that does not make you abnormal as a person. There are differences about your life that may make it harder and more complicated than other people, especially at a younger age. However, the strength that you have is admirable, even when you feel down and out. You are not your seizures; you are an exceptionally brave person who has different concerns than lots of other people. It is hard, I know, and surely you wish you did not have it. But there is nothing wrong with you—you are excellent and entirely okay; it is the seizures that are not.

You might be afraid:

Epilepsy is a very scary thing to be diagnosed with, and it remains frightening as long as you have it. Because it is often unpredictable, it seems easier and safer to isolate yourself. There may be some situations that you need to isolate yourself from. But in some cases, the fear can be almost as dangerous as the seizures, if you restrict yourself unreasonably. It can be terrifying to be constantly won-

dering when your brain will betray you next—will you be alone, at school, at work? However, think through what you can and cannot do, and talk to your doctor about risks involved in various activities. If you’re still afraid, keep people around when you can, just in case. However, you can prove yourself and your fear wrong by living as close to a “normal” life as possible. Everyone is afraid sometimes and that is okay. Allow yourself to be afraid. But don’t allow that fear to overtake you.

If you feel your sibling doesn’t understand the reasons you are afraid, talk to them about it. Don’t assume that you have to have all of this fear in your life and that they have none. Talk with them honestly and listen to what they have to say. Once they understand your concerns it may also help to hang out with them in ways that you feel safe—going to a movie, buying records, being active. If you share your fears, your sibling can help you feel a lot less fragile. Even if they can’t do that, they can help you feel okay about being vulnerable sometimes. Everyone is vulnerable or weak sometimes. You may be vulnerable more often, more severely, or for different reasons, but this in no way takes away from your value. Other people, especially your brother or sister, are there to share the weight of this burden. It may be yours, but you don’t have to shoulder it alone.

You might be sad:

Sadness is an understandable response, especially if you have been recently diagnosed. You might feel like you do not deserve this, and that it shouldn’t be you who has it. Those feelings are valid. This kind of sadness can linger for a long

time, and events that “should” make you happy (birthdays, graduations, holidays, and so on) may make you feel worse. It’s extremely saddening to compare yourself to those around you, and think of what could be if only you did not have epilepsy. You may wish strongly that it would just go away. Even being seizure-free can make you sad, knowing that it probably will not last forever. Realizing that you don’t know how long you will have epilepsy for can trigger a time of mourning. It is normal to “mourn” the loss of who you thought you would be if you did not have seizures. It is important to feel that sadness. Pushing it away or ignoring it will not make it go away. It may even prolong it. You need to feel it in order to move beyond it.

However, you need to reach a time when you realize that having seizures does not affect who you are. You are you, not epilepsy, not “an epileptic”. You are a person who experiences seizures. That does not change who you are, even if it complicates your life. You still may go through periods of sadness, but the sadness won’t hook you. The more times you tell yourself that epilepsy does not affect who you are, the more you will believe it.

It’s hard to talk about being sad, because there’s little that anyone else can change. They can’t take anything away. That

makes it more tempting to just live with sadness and never acknowledge it. But if talking makes no difference, you won’t lose anything by giving it a try. Talk to your brother or sister. Sometimes just telling the truth about how you feel can be a relief. Your brother or sister is a good person to talk to for several reasons. It will help them relate to you, especially if they have any trouble understanding epilepsy. It will also give them a way to help you; although they can’t change anything medically, they can help emotionally just by listening.



You might be embarrassed:

Anything that makes anyone different can be embarrassing. Seizures can be embarrassing, especially if they happen in public. It is normal to become embarrassed if you have had a seizure, likely because you were not in control. Anytime you lose control when people are around is frightening and potentially embarrassing. However, remind yourself that the worst that can happen is that people

won't understand. Maybe someone ignorant will make fun of you. What a cruel thing for a person to do. However, that person's ignorance does not reflect on you. You are still okay, no matter what stupid jokes anyone makes. You do not need to be embarrassed by a physical, medical issue that you cannot control. It is, in a way, like being embarrassed for having green eyes. Some people have them, some people don't. Of course it is embarrassing to lose control, and sometimes consciousness, in front of people. But how they react is their business. It does not affect you.

There is nothing wrong with you. If others react badly (teasing, laughing, and being afraid) it is because they do not understand what they have seen. If they did, they would not likely react that way. It might also be because they

You might be angry:

It would be surprising for you to never have felt angry about this at all. Anger is a normal response. Of course you feel angry. You do not deserve to have epilepsy. You are a good person. Yet, for seemingly no reason, you have epilepsy and many people, including your sibling, do not. Not only that, but all medications are flawed, and work to varying degrees with different people. The worst part is, there is little you, or anyone else, can do to fix it. The unfairness of the situation would make anyone angry. It really is unfair.

Your anger won't go away unless you express it. However, it can come out as hostility towards your friends or family, especially your sibling. If your sibling is close to your age (less than five years difference), then you might find that your anger becomes directed at them. You may drift apart. You may isolate yourself from people because they remind you of your limitations and reconcile you with your anger.

You need to remember that everyone has something. Most people have experienced and continue to experience circumstances that they have done nothing to deserve. It is not fair that you have seizures, and you have a right to feel angry about that. However, this anger should not interfere with your relationships with other people, especially your sibling. Your sibling, seizures or not, is an exceptionally valuable person. As much as you didn't ask to have seizures, they did not ask not to. As much as you feel angry that you have to deal with this unfair situation, they likely feel angry

"They will appreciate you for everything that you do, even when you feel it's not enough."

are frightened and do not know what to do, so they make themselves feel better by putting you down. Anything that is different can upset people. But the key word is different—not bad, not good, not wrong. From this thing that you may be very ashamed of, you have gained a huge amount of strength that most people do not have. You face things that frighten adults, things that most people would be overwhelmed by, and you live. What's so embarrassing about that?

for you. If you can talk with your sibling, and share your anger amongst yourselves, then you can begin to live around this unfairness—not with it, not through it, not without it.

You might feel insecure:

If you see yourself as someone who is “damaged”, “unwell”, or who is a lot of work to take care of, then guilt will be your natural response. It is easy to slip into guilty feelings, and reside inside them for a long time. If you feel guilty for even one event, then it can slowly colour your entire perspective of yourself. The more you think of yourself as being someone who demands a lot of work and sacrifice from your family and friends, the more you will feel that way, and the more believable it will seem.

You must remember that however your epilepsy affects your family and friends, their feelings about you will not change. They will not tire of you. They will not wish to be rid of you. They do what they do for you because they care about you, they love you, and they want you to be as happy and healthy as you possibly can be. There is no way that you are a burden to them. To them, you are much more than your seizures. They know it is not your fault. You have nothing to feel guilty about.

You might feel tired or frustrated:

It’s okay to be tired. It’s okay to be tired of every single thing you have to do. Taking pills is tiring. Taking new medications is tiring; reading about side effects and special precautions and risks and interactions is tiring. Many anticonvul-

sants themselves are physically tiring. Going to doctor’s appointments is tiring. Having seizures is tiring. Explaining your seizures is tiring. Making special arrangements is tiring. Being monitored is tiring. Going to school is tiring. Not being able to drive is tiring. Being afraid is tiring. Being alone is tiring. Much of loneliness comes from feeling different than everyone else. Feeling different for all the reasons above (and others) is very tiring. It seems that you have to be thinking about seizures all the time, while other people your age never have to worry about much. Even if you are doing well, no one wants to have to think about seizures all the time.

Sometimes the weight of it all will just be there, right there on your chest, squeezing out all of your resilient energy. Maybe one event will draw it all out of you. Maybe you will lose it gradually over days and days. Some people would like you to believe that you can never be weak, never say “I give up”, never ask for help, never give yourself time to feel wretched, and never want to stop. Don’t listen to those people. There is nothing wrong with being weak. No one is strong all the time. There is nothing wrong with saying “I give up,” as long as you give yourself a chance to keep trying. There is nothing wrong with asking for help. There is nothing wrong with feeling wretched. There is nothing wrong with stopping for a little while. What is wrong is pushing yourself when you feel tired and frustrated, and pushing those feelings away. It is wrong to lie to yourself about how you feel. When you feel tired, give yourself a chance to rest.

If you feel more tired than frustrated, talking about it may not help. You may feel tired because you have been keeping yourself from feeling sad. If that's true, then get under your covers and feel sad. Don't force yourself to do homework or pretend everything is normal. It won't help, once you are that drained. Give yourself time off. Do something quiet. Bake, read a childhood

conquer if you don't tell them. I know it seems that if they care about you, they should know what you go through. They should try it. They should imagine how it is.

Here's a cold truth: they can't. You have to help them. Instead of turning your frustration inwards, or outwards at the people who care about you, express it



book or sit and play guitar. Sometimes all you might need is an afternoon to yourself.

If you feel more frustrated than tired, talking is a good thing. Expressing that frustration is the only way to make it go away. You can't change the circumstances that cause the frustration. You can only change how you deal with it. If you feel like your parents, siblings, or friends don't understand how you feel, it's probably because they don't. However, they can't recognize the day-to-day challenges that you are forced to

with them. Show them how you feel. Tell them what you experience. If you feel that your parents won't understand, your sibling probably will. If you start with your brother or sister, you may find that it's easier to talk about it with everyone later—or that you no longer have to.

If you don't feel comfortable talking about it, then you need to find another way to vent that frustration. Write down all the worst things in a journal. Or just one word. As long as you're feeling it, and letting it out of you. Exercise

will help. Listening to or playing music will help. Drawing or painting will help. Do things that are not passive. Throw paint at a wall if you feel like it. Blast the angriest punk music you can find. Do things that allow you to stop thinking for a short time. You need to feel the frustration, and letting it out in a way that is constructive will show you that you are can be much more than a person with epilepsy. You already are.

If You and Your Brother or Sister Have Epilepsy

People who have little experience with epilepsy often underrate the span and variety of complications that epilepsy adds to one's life. No matter what kinds of cruel things your brain does (or does not) do to you, no one can say to anyone else that they understand exactly "how it is" to be them. When epilepsy is involved, it can be painful for siblings to feel that they fundamentally cannot share their interpretation of life with their brother or sister. Some may assume that in the event that both siblings have epilepsy, the level of complications would decrease. However, this is not necessarily true. There are, as in every set of circumstances stretching out to the horizon, a unique set of benefits and problems that come with having epilepsy, and a sibling who also has epilepsy. All of the feelings that people have about epilepsy, regardless of siblings, will be there. Your experience, like anything, will vary all the time. Sometimes the fact that you both have epilepsy will strain your relationship. Sometimes it will make it easier.

You will probably find it helpful to read the other sections of this book. Such is the nature of epilepsy that it makes us all feel alone. But alone, huddled in the corners of our lives, we all feel the same. Your parents might expect that with a sibling who has epilepsy, you will never feel isolated. But of course you will. You are not your sibling. And why should you be so glad to share this wretched, painful, frightening, awful thing with your sibling? Why would you feel better knowing that you both have something that could rob you of everything? How much would you give to take this away and never have heard of it in the first place?

You know the answers to these questions. However, much of your situation depends on answers that I don't know:

- What is the age gap between you and your sibling?
- When was your sibling diagnosed?
- When were you diagnosed?
- How controlled are your seizures?
- How controlled are your sibling's seizures?
- How open is the rest of your family to talking about epilepsy?
- What is the age gap between you and your sibling?

These factors all determine how and to what extent your relationship with your sibling will be affected by your seizures. The way that these factors interact will always change. While your age gap, and the ages that you were diagnosed will not change, the stability of your health and the openness of your family may. When your seizures are well controlled,

but your sibling is not okay, your feelings may mirror that of someone who does not have epilepsy at all, but has a sibling with it. Then, perhaps your situation may shift into the reverse.

Likelier than not, your sibling will be a gift. Living with this condition, as harrowing as it is, can be a binding force between you. As alone as you may feel, you must remember that you are probably not; at the very least, your brother or sister must have felt the way you do at some time in their lives. Remember

**“No matter how you feel or
what you do ... you’re brave
for being here.”**

not to shut yourself off from each other, but to keep talking, no matter the physical distance between you. Never assume that your sibling doesn’t understand how you feel, never assume that they can’t help you in some way, and never assume that you can’t help them. It will probably break your heart to see your sibling go through this, no matter how you get along day to day. When the crisis hits them, as they will, your heart will break. Be there for them, knowing that when the roles are reversed, their heart will break for you. This is what you can be for each other. You can’t save each other from seizures, but you can be there for each other. You can understand.

Conclusion

This essay is not about research or science. It is not about the mechanics of how your brain can take everything away from you. It is not about how violent electricity can steal your ability to talk, to walk, to think, to breathe. It is not about systems of waves, or the pharmaceuticals designed to police those systems. That cold scientific light, slowly dragging epilepsy out of shadowy skull after shadowy skull, is not enough. It can only explain so much. It cannot bring comfort, freedom from fear, catharsis, or the simple knowledge that you, as a person, are okay. It can strand you and your family out on an edge, waiting for a perfect treatment, a bio-chemical redemption, while your emotions inevitably come unfurled.

That is what this essay is about. It is about you and your family. It is also about my family and me. This is what we have to think about—fear, sadness, anger, isolation, advocacy, compassion. Use the words that help you and discard the ones that don’t. Try reading this all the way through, not only the sections that apply directly to you. Understand what you can of the lives that your mother, father, sister, or brother lead. Be sad, angry, guilty, upset, uncertain, confused, and anything you need to be. If something is true, saying it out loud doesn’t make it any truer. Don’t lie to yourself.

I won’t lie either; I won’t say you’re lucky for going through this, or that any of it has value. I won’t say that you will learn anything that you couldn’t have learned without this struggle. I’ve

lived through every single thing in this essay, and I hope that reading it helps you in some way. But with all the truth I can muster, I would rather not have written this at all. I'm incredibly grateful that these harrowing experiences can be turned bittersweet by helping others. Still, I would rather not be the one to do it. I'd rather you didn't have to read this. I'd rather no one ever had to have seizures, and I don't know why anyone does. But we do. And there's bravery in looking that in the face. No matter how you feel or what you do, no matter if you say, "I give up", or want to, or mean it, or lose your mind—no matter how many times—you're brave for being here.

The lessons in this essay are not lessons that are learned through words. They're not lessons learned through actions either. In fact, the nature of epilepsy means that the lessons in this essay cannot be learned. There will not be a time when you have finished this journey, when you can count every bullet point and tell yourself you're past each one.

You will have to live these lessons over and over again. When the seizures slow, it will feel like they might have gone forever. Your feelings will settle, and they may stay that way for weeks or years or only days. But you know that there will be a day when you are confronted with this again. You cannot learn any kind of lesson from seizures, because you cannot pin them down, you cannot explain them, you can't chase them away, or catch them or see inside of them. There is nothing you can do but breathe, keep breathing, and live.

(Continued from page 1)

I would like to share some experiences of the positive aspects of the family support circle.

Every early summer there is a celebration of the winners of the OBCL scholarships. The first year I was expecting the winners, of course, and mums and dads. I was surprised and delighted at the same time to see who arrived; brothers and sisters, grandmothers and grandfathers and peers of the award recipients. I have never seen a collection of prouder people.

One family had a long drive in rush hour and got lost and as a result were late. You could tell that it was a stressful trip but the moment they settled down at their table you could not wipe the smiles off their faces! What we see every year is the implementation of Sally's advice: actions not just words. The family members who attend this event are expressing their support in the best way.

When I look at this year's OBCL Scholarship winners, I will remember Sally's words:

"There's bravery in looking that in the face. No matter how you feel or what you do, no matter if you say, "I give up", or want to, or mean it, or lose your mind—no matter how many times—you're brave for being here."

Well written Sally Walker Hudecki!

- Lawton Osler
President, Epilepsy Ontario

Open to Ontario Students Living with Epilepsy

The



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