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BEING A MOM

Making it Work



Taking Care of Them
*How women with epilepsy
are looking after their health,
and raising informed kids.*



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INTRODUCTION

If you're reading this, you may be a mom who has epilepsy.

Or perhaps you're one of more than one million American women with epilepsy who are of child bearing age. Perhaps you're wondering whether you should have a child. You're wondering how you would cope with pregnancy and all the demands of motherhood. Maybe you're wondering how your epilepsy would affect your child's life.

There are no easy answers to these questions. But moms and moms-to-be can take comfort in the knowledge that thousands and thousands of women with epilepsy are looking after their own health, raising their children—and making it work.

This publication is about how epilepsy affects women. It's also about how epilepsy affects childbearing and raising a family. It's about ways to deal with some of the issues that come up along the way. It's about how having a plan can help you manage the unexpected.

We've divided the information into two booklets: *Being a Woman* and *Being a Mom*.

You may have to do both to make it work.

We hope you find this material helpful. It's based on what the experts tell us about epilepsy and what moms with epilepsy tell us about their lives, their kids, their challenges and their victories.

The Epilepsy Foundation thanks all those moms who've shared their experiences and the caring professional people who've offered advice.

As we all know, no matter how hard we try, there are no perfect mothers. There are no perfect families.

Every woman's situation is a little different and may require different approaches from the ones offered here.

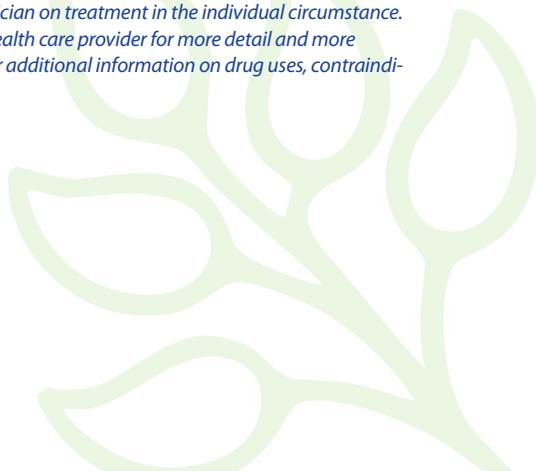
Raising children is an exciting, often scary, mix of joy, worry, and the unexpected. Epilepsy adds one more element to the mix. But it doesn't change the basics. Like mothers everywhere, women with epilepsy are doing everything they can for their children. Most of all, they want to help them grow into confident, compassionate, independent young people. And they will.

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This information is intended to provide accurate, general information as of the date of publication. Indications for all drugs and treatment alternatives described herein have been recommended in the medical literature and reflect the practices of experts in epilepsy. This information is not intended to be medical advice or to substitute for the judgment of the physician on treatment in the individual circumstance. Please consult your health care provider for more detail and more recent information for additional information on drug uses, contraindications, and dosages.



Taking Care of Them

As a mom who has epilepsy, you are just as much a vital caregiver for your family as any other women. You may need some extra help—so do lots of other women. You may be limited in how much you can do each day, or how much you can participate in your children's activities or the activities they would like to be part of.

But that doesn't change the central role you have in their lives. And it doesn't change the fact that they will look back and remember with pride how hard you tried, how much you did, and how important you were and are in their lives.

Taking care of them means loving them and keeping them safe.

Taking care of them means having a plan to deal with the unexpected.

Taking care of them means helping your younger children cope with mom's having a seizure without being scared.

Taking care of them means helping your older children understand what epilepsy is and how you are dealing with it.

Taking care of them means doing the best you can to keep epilepsy from being a barrier to their full involvement in school and in the neighborhood.



YOU AND YOUR BABY

“My victory is having a daughter, keeping a job, having seizures, and still being able to function.”

Congratulations! You've come through pregnancy successfully. Now you're responsible for a new little person who is completely dependent on you. Your best sources of help are your partner, your other family members, your friends, and your community of support. But for a lot of the time, it's you and your new baby. Fortunately, research and the experience of many other women can give you some pointers on what to expect.

Breast feeding

Doctors recommend it. Many women want to do it. And fortunately, breast feeding appears to be a safe option for moms with epilepsy and the baby, even as mom continues to take epilepsy medication.

Some epilepsy medications are present in breast milk. The fact is, if you've been taking these meds during your pregnancy, your baby has been getting some of them throughout. His system is used to them. In most cases, the level in breast milk is low.

However, there are some cautions. Babies of women who take phenobarbital or primidone (Mysoline) may be irritable or extra sleepy because of epilepsy meds in breast milk. If you take both of these medications, experts advise you not to breast feed.

If you take diazepam (Valium), lorazepam (Ativan) or clonazepam (Klonopin) to prevent seizures, check with your doctor. High levels of these drugs may make baby too sleepy to eat, and you don't want that. Ethosuximide (Zarontin) is another drug that may show up at high levels in breast milk. Check with your pediatrician. It may be that a combination of breast milk and a high quality formula is best for your child.

Baby care

Washing. Feeding. Changing. Cuddling. Loving. Baby care is a constant round of interactions between mom and baby. Some of them would be affected if you were suddenly to have a seizure that caused you to black out. If that's not a risk for you, skip this section. But if it is, here are some suggestions from the experts, and from expert moms, on what you can do to reduce risks and keep baby safe.

Try to get enough sleep during the day, knowing that you may have to be up during the night to feed the baby. Lack of sleep may make seizures more likely to happen.

- If you can, get help during the day so you can take a couple of hours for yourself to rest. Family, friends and neighbors may be willing and able to help.
- Keep the baby next to your bed at night and feed her in bed with you—sitting up, so you don't run the risk of falling asleep during the feeding.
- If loss of sleep makes you more likely to have seizures, have your husband, partner or other family member give the baby a bottle for the night feeding. If you are breast feeding, pump enough breast milk so that it can be frozen and then given in a bottle during the night.
- If you are alone and bottle feeding, don't carry the baby with you into the kitchen to warm the milk or formula. Leave baby in the crib while you prepare the bottle and bring it back into the bedroom or baby's room with you.

If you still have a lot of seizures, and you're caring for the baby by yourself, consider some of the following suggestions:

- When feeding the baby at any time of day, sit on the floor with your back against a firm piece of furniture or a wall. That way, if you should have a seizure, the baby will not fall.
- Dress, change and sponge bathe the baby on the floor, using a changing pad to sop up the water.
- Don't give the baby a tub bath unless there's another adult with you.
- Keep an older baby snug in a stroller, sturdy infant seat or high chair with straps while you're feeding him.
- Use a light stroller to move the baby from room to room, so you don't have to carry him everywhere.
- When you're home alone, keep an older baby in a playpen or good sized play yard so he can't crawl into danger if you have a seizure. Keep "baby gates" locked.
- When it's time to take the baby out in a stroller, get one with an automatic stop if you release your grip on the handle. Or use a bungee cord to link your wrist with the handle so that if you had a seizure, the stroller would not roll away.

- "Baby proof" your home to keep an active toddler safe. Secure furniture so it can't tip over if the baby tries to climb up on it. Put power cords out of reach. Put plugs in all electrical outlets. Secure all kitchen cabinets containing glass or toxic cleaning materials. Put gates at the top and bottom of flights of stairs.
- Make sure toddlers and your older children wear life jackets when playing near water.
- Keep all epilepsy and other medicines in a secure place, well away from exploring toddlers and older children.

Consider getting help or arranging day care for the baby if you're having a lot of seizures and have to be alone during the day. A well run day care center or home care by a trusted friend or neighbor may be a good solution until your seizures are under better control.



FRIENDS AND FAMILY: A COMMUNITY OF SUPPORT

"I've done a lot of research myself. Now I realize how other people feel is important. I've sought out support groups and support groups for children."



Your friends and family. They're the people who know you best, who have your interests at heart and who want to help. At the same time, you want to be as independent as you can be and not have to rely completely on their goodwill. It's all a matter of balance—and a lot of that depends on other people's understanding of what epilepsy is and what you're going through.

As a mom, you will always be dealing with a whole host of people who interact with your children and with you. Speaking out with confidence to teachers, Scout leaders, coaches, other parents, neighbors, and everyone in your circle who needs to know is your own private educational campaign for better understanding of what it is to have epilepsy.

Telling people you have a heart condition is usually met with nothing but concern and offers of help at any time. How can you make a disclosure of epilepsy produce the same reaction? Most women say the best plan is to speak out, be straightforward, and above all, be casual and confident in what you are saying—even if you're not feeling that casual and confident inside.

When you talk about having epilepsy, you may be surprised by how many people will confide in you about their own relatives with the same condition, or the childhood friends who had seizures.

Most people recommend describing epilepsy in simple terms. Say how it affects you. Be upfront about any risks that you are aware of. Invite questions. Being open and matter of fact gives people permission to ask you things that might be troubling them. Chances are, you will find that most people are quite interested in what epilepsy is and even more so in how you experience it.

Creating a support network

Your support network is important. Especially if you do not drive. Especially if you are a single mom. Think about the people in your family who would be willing to help and think about friends in the neighborhood. Think about things you might need help with and try to link a particular person with that special need.

Maybe you need child care while you go to your doctor for a routine check up. Maybe you need someone who will come over every once in a while to give you a break—or allow you to make a special meal or complete a special project. Maybe there's someone at your church, synagogue, or mosque who'd help you out in an emergency. Or perhaps you can identify commercial child care and home help services in your community that would provide assistance on a regular or emergency basis.

Think, too, about the services you can offer to your support community. Think about the contributions you can make to neighborhood projects or events; the shopping you could pick up for a helpful neighbor on your weekly trip to the store with family members; the contributions you could make to your house of worship, your willingness to pay for gas when your neighbor drives you or your child to a special activity.

You may never need to call on all these good people, but building a network, person by person, is like building a safety net. You may never need it, but you'll be glad it's there.

As already noted, your local Epilepsy Foundation is another important source of support. Most local groups offer women with epilepsy opportunities to get together, network, and form bonds. Again, online networks through the Foundation's e-communities section offer women a chance to interact, share experiences, and talk about many areas of mutual interest.



YOU AND YOUR OLDER CHILD

“I’ve taught my daughter some key phrases: ‘Momma’s having a seizure. Poppa has low blood sugar seizures.’ They tell me she shows compassion and maturity at day care.”



If you have seizures from time to time, it’s important for your older children to understand what those episodes are. Children may be frightened if it seems that mom is suddenly ill and unable to talk to them. It’s important for them to know what’s happening and what they should do.

A lot of families handle this by explaining seizures in kid-friendly terms and practicing, through role playing, what the child should do. It’s easiest to explain if you sit down with your child after a typical seizure has happened. For example, if you’ve had a generalized convulsion, you may want to say something like this:

“Mommy has something called epilepsy. Every so often it makes mommy black out and fall down asleep. It may sound as if it’s hurting me, but I don’t feel anything, really. Mommy will wake up after a while and be okay. But we want you to tell another grown up when this happens. If it happens to Mommy when you’re around, go and get _____ (a neighbor or other person in the house).”

Or, you may want your older child to make a phone call—to a spouse, a parent, even 911. If so, practice.

Do some play acting where mom pretends to have a seizure and the child practices dialing the number (on a non-functioning phone!). Put the number in a special place so the child can see it easily. Go over what the child is going to say. For example: to a relative or friend: “Mommy has had a seizure. Would you come over please.” To 911: “My mommy has had a seizure. She’s asleep on the floor. I live at: (address).

If you have partial seizures, where you briefly lose touch with what’s going on around you, explain it

in terms of “Mommy has something called epilepsy that makes her daydream for just a little while. She may not be able to talk to you for a few minutes, but then she’ll be fine again.”

As children get older and learn about how the brain and body work, you can explain that some people have brain cells that don’t work properly all the time and that can make a seizure happen. The Epilepsy Foundation has written materials on how to talk about epilepsy with children.

Some children worry that epilepsy is catching or that they will have seizures in the future. They need reassurance that it is not catching and it is unlikely that they will develop seizures later on.

If a child has seen a seizure and been scared, take time to find out what the child is feeling. He or she may be afraid you will die during the seizure. You can explain that’s not likely to happen. The child may clam up and not want to talk about it at all. When that happens, you have to gently bring up what happened and ask questions about what he thought was happening and encourage him to talk about it with you.

You can also help your child open up and talk about what’s happened by telling stories about how it feels for you to have a seizure and how much it means to have the child there when you wake up.

You can give even a young child something helpful to do, like getting a blanket for mommy or stroking mommy’s hair during a seizure while talking to her and waiting for her to wake up. Giving children a task helps take away some of the uncertainty and fear of the unexpected.

Simple steps for older kids

Older children will also be able to help when mom has a seizure. They will want to help and will develop self confidence because they know what to do: to place something soft under their mother’s head, turn her on one side and keep her safe until consciousness returns. You will be able to tell them when to call for help if the seizure goes on longer than usual. You’ll find they’ll develop a sense of responsibility that will serve them well in the future.

Many moms find that an unexpected benefit of being a mother with epilepsy is that their children grow up to be more accepting and understanding of other people’s disabilities. An accepting heart and a generous spirit are true gifts and something to be celebrated.

Explaining use of meds

Everything in our culture says to children: “Don’t take drugs.” But mommy has to take drugs to prevent seizures. So some explanation may be in order. First, try to call the meds “medication” or “medicines” when you talk about them. Explain to children that mom takes medicine to keep her well. Older children should understand that mom takes meds to keep from having seizures.

Maintaining a sense of the normal

As a mom with epilepsy, an important part of keeping family life normal and predictable is keeping yourself well.

That means getting enough rest and helping your family deal calmly with the unexpected. We’ve already talked about helping children understand

what seizures are and setting up plans to deal with them. That's the first step. The second is developing plans to support your children's daily activities. And that can be a real challenge.

We live in a world where the key to all kinds of activities, for adults or children, is access to a car. If seizures prevent you from driving, planning—and a good support system—may help. Check with the school, or the team if your child is involved in sports, to see what opportunities there are for car-pooling.

Possibly your husband or partner or other family member can drive team members on weekends if other parents can drive during the week. Perhaps another parent can step in if you offer to babysit or provide some other service in return—like paying for gas, or baking the cookies when it's the other parents' turn, or hosting committee or other school meetings in your house.

Arranging for your children's activities to continue even if you can't be actively involved is a major contribution to their daily lives and social standing.

But sometimes, your children may not be able to do all the things that they would like to do. And that's all right. Yes, you want them to have the best. You want them to have all the advantages that other children have. You try hard to make that happen. But sometimes it just doesn't work out.

The best explanation to your children is that you are sorry, that next time you hope the outcome will be different, but that at this point there is nothing you can do about it.

And don't worry too much that your children will be resentful and angry with you over the long term.

Yes, they'll be disappointed and upset at the time. Children get upset with their parents over all kinds of things, especially restrictions on what they want to do. But when all is said and done, they'll love you for what you are and what you try to do for them—and in the long run, they'll understand.

Surviving difficult times

Some women, especially single moms raising children on their own, worry that other people will think having epilepsy disqualifies them from caring for a young child. They worry that a neighbor's complaint might lead child protective services to remove the children from the house.

Similarly, women who are going through a divorce may worry that having epilepsy will disqualify them from gaining custody of the children. These are real concerns.

The best way to confront them is through a supportive network of people who can speak to your parenting skills, a physician who can speak to your abilities to function despite seizures, and a good lawyer who is familiar with cases involving parents with disabilities.

The Epilepsy Foundation's website has an active section on legal issues, including child custody. If this is an issue for you, check it out.

Managing other people

People react to illness and disability in a variety of ways. Some are immediately supportive and helpful. Others want to help but aren't sure how. And some have a kind of instinctive reaction that makes them draw back and stay as far away as possible.

Children are no different. Some worry about mom's health and even blame themselves if a seizure happens. As already described, they need reassurance and as much information as you can give them, suitable for their age. They should always know that nothing they did made you have a seizure.

A tougher problem may be the parents of your children's friends. You hope that they would be understanding and supportive, but that doesn't always happen. All kinds of fears can be fed by ignorance. Again, when that happens, the only thing you can do is to be straightforward and open to their questions. Emphasize that epilepsy is not catching, is not somehow associated with the supernatural (yes, that comes up sometimes!) and is not in any way a danger to others. Believe it or not, some of those irrational fears are still around. The best treatment is openness and a willingness to talk about how epilepsy affects you.

Sometimes a child will feel embarrassed because a parent has epilepsy. Sometimes the other children will mirror what they've heard at home and tease or isolate your child.

It's a good idea to set aside time to talk about what's going on at school, and what your child is experiencing. Help him or her to open up about any thing at school related to mom's epilepsy that may be bothering him.

If your child is going through a rough patch of teasing because of mom's situation, go right to the child's teacher and, if necessary, to the principal. Sometimes, offering to give a presentation about epilepsy at the school will help. Many local Epilepsy Foundations conduct school presentations about epilepsy. While

these programs are usually designed to improve children's attitudes towards other children with epilepsy, a parent's experience could also be presented as part of the program.

A FINAL WORD

Being a parent is a challenging, wonderful, scary experience, full of uncertainty and a whole lot of trial and error—for everyone. Epilepsy may be the part of your life as a parent that adds the most in uncertainty and peril. Overcoming and coping with epilepsy's challenges is not easy, by any means. Still, the evidence is clear: planning, good care, goodwill on the part of others, and above all, love, can limit epilepsy's unwanted effects on you and your children—and may even produce some unexpected benefits along the way. For example:

"There has been a stigma attached to epilepsy for so long. I figure that if I can go and tell others yep, I have epilepsy, I have seizures. I still can do things. Then they will view the word 'epilepsy' and people with epilepsy differently."

"My son said to me: 'I can't believe how strong you are.' My having seizures has taught compassion to my kids."

"Sometimes my daughter imitates me. She wears a bracelet for her mom who has seizures."

"I took part in the Epilepsy Foundation's National Walk for Epilepsy. I wanted to do something."