

## Epilepsy and the Family - Parents' Experience

When you learn that your child has epilepsy, it can be stressful and overwhelming, and it is often a significant life change. Witnessing your child having seizures can make you feel helpless and afraid, especially when you don't understand what is happening. Fortunately, most seizures are not medical emergencies, and it is likely that your child will be able to live a happy and healthy life with their epilepsy as just one aspect of their identity. Information about epilepsy and seizures can be very helpful during this time so that you can learn what to expect and how to manage and respond to seizures. We have a variety of programs to teach you and the people in your life about epilepsy and seizures. Educating your support system can help them to know how to be there for you in the ways that you need.

In addition to needing information and support from your family and friends, it is important to know that you may grieve a variety of secondary losses along your journey. These losses are valid and should be acknowledged as such. You may begin to mourn the life that you had before the diagnosis and the different future that you will have together. Your hopes and dreams for your child's future may change as you wonder if they will have learning difficulties, be able to drive, or find meaningful employment. You may lose the sense of security that you had before and find yourself forever on the lookout for seizures and their triggers. Family activities and vacations may look differently as you consider the things that are unsafe for your child or as they are interrupted by seizures and the necessary recovery. You are not alone in these thoughts, as approximately 1 in 100 people live with epilepsy, and although everyone's experience is different, there are many similarities. Allow yourself grace as you come to terms with all these changes. Emotional support is available to you, from epilepsy educators and other parents of children with epilepsy.

Alongside your grief, you are likely to have a lot of complicated feelings. You may feel anger, frustration, sadness, denial, or shock. You may feel guilty, wondering if your child's epilepsy has been caused by something that you did or didn't do. You may want to find someone to blame. You will likely experience increased stress and worry for your child and have concerns about how others will treat them. Talking about these feelings with people you trust may be helpful in the process of letting go of what was and learning to accept what is.

In this new reality, you may wonder how you can offer your child both independence and safety, without overprotecting them. You may struggle with trying to balance your child's needs against those of their siblings, or the needs of you and your partner. Finances may become a challenge as you are called away from work to care for your child more often than is financially feasible and you will likely become your child's best advocate as you traverse the medical system, the school system, and the wider world. We can walk that path with you and help you find your way through. We can also connect you with peers who are further along the path and can provide reassurance and support.

Although there will be difficult moments along the way, it is likely that you will find inner strength and adaptability that you didn't know you had. You'll be so proud of your child and their resilience and their bravery. You'll become a myth buster and an informal epilepsy educator. You'll administer medication with newly acquired expertise. You'll become a researcher in the evenings and an interviewer during your child's appointments. You'll learn to be creative and flexible and a great cheerleader. But most of all, you'll continue to love your child with all your heart and know that they can still find success and happiness.

You are now a parent of an epilepsy warrior. Welcome to our community.