

Many people have outdated or mistaken views of seizure disorders; they imagine an incurable disease, and patients convulsing on the floor. Family First looks at what life with epilepsy is really like, plus how medical advances are helping doctors successfully treat — and even cure — the disorder

The Changing Face of Epilepsy

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“Have a nice day at school,” Carole Cohen said to her son Robert, a strapping, six-foot-tall, healthy fourteen-year-old, as he walked out the door one morning.

A few hours later, she got a call from the school nurse. “Your son had a seizure and he’s on the way to the hospital.”

“You must have the wrong person,” Carole replied in a panic.

Driving to the hospital, she started imagining every worst-case scenario. *What could cause a healthy boy to have a sudden seizure? A brain tumor? A stroke? Cancer?*

“I was a mess by the time I got to the emergency room,” says Carole, who lives in Albertson, Long Island. “The CAT scan and MRI came back clean. That was good news. It was a huge relief that we weren’t dealing with a tumor. Rob played on the junior varsity football team. We wondered if perhaps he’d gotten knocked on the head. We had no answer. The doctors told us it was probably idiopathic — for 70 percent of seizure disorders, there is no known cause. You want to be one of those, because it means no brain injury, but still, this news was so shocking, it was really hard to swallow.”

In the middle of English class, Robert had what is known as a tonic-clonic (or grand mal) seizure. First he started having full convulsions, and then he lost consciousness. He was diagnosed with epilepsy and put on seizure medications right away.

“After the seizure, I wouldn’t let him be home alone, I even walked him to the bus stop. It made him crazy,” admits Carole.

She didn’t know what kind of life she could now expect for her son, but amazingly, once on seizure medications and after getting the doctor’s clearance, Robert was back to playing football on the varsity team. Today, the nineteen-year-old is doing very well as a college student in a demanding university. “Rob’s life won’t ever include climbing a mountain or swimming by himself, but otherwise, he is focused on living a normal life,” says Carole.

LIVING WITH EPILEPSY

Many years ago, the future of a person with epilepsy was uncertain. The disorder was not widely understood, and antiseizure medications were just in development. Even the term “epileptic,” formerly used to describe individuals afflicted with this disorder, is no longer used because the diagnosis doesn’t define a person. Today epilepsy is treatable, and an individual with the condition can likely live a life with few if any side effects once the seizures are under control.

Epilepsy

"I'd feel kind of out of it when I came around, but the seizures weren't painful or traumatic"

Like Robert, Joel Ackerman refused to let epilepsy limit his potential. He is a CPA, has a master's degree in taxation, and is a partner at a prominent accounting firm, where his career is flourishing. He firmly believes that having a seizure disorder has not interfered with achieving his life goals.

When most of us think of epilepsy, we imagine the dramatic seizures that Robert experienced. But in fact most seizures last less than a minute, and many types of seizures are unassociated with convulsions. Instead, such seizures may look like brief staring spells, or can be so subtle that they can go unnoticed.

This is the case with Joel, now in his forties, who was diagnosed with a seizure disorder in elementary school.

"I have the kind of epilepsy where I became what you might think of as a 'space cadet,'" explains Joel, who lives in Huntington, Long Island. "I didn't shake or drop to the ground. I'd just stare into space and be totally out of it. They started in kindergarten, and I remember many moments of people trying to wake me up. I'd feel kind of out of it when I came around, but the seizures weren't painful or traumatic to me — maybe just to the people around me."

Joel's parents took him through the rounds of medical testing, diagnosis, and then medication to control the seizures. Seventy percent of those with epilepsy are able to achieve full control over their

THE EMOTIONAL SIDE OF EPILEPSY

While the physical symptoms of epilepsy can usually be controlled, the fear and sadness that may accompany the physical symptoms also need to be dealt with. Here's how patients — and their families — cope.

"The seizure disorder was much harder on me than on Rob," Carole Cohen says about her son's epilepsy. She was always trying to prevent another seizure and admits that it was difficult to stop hovering around him. It didn't get easier when Rob went off to college: "I'd worry about him. Is he remembering to take his meds? Is he getting enough sleep?" (Stress and sleep deprivation can trigger a seizure.)

It's not uncommon for the "what if?" fear to plague family members more than epilepsy patients themselves. This may be partially due to the fact that, by the very nature of the condition, epilepsy patients are not aware of the seizure in the moment itself, nor can he or she witness it.

"I joined an epilepsy support group, which was a huge help," says Carole, who expresses tremendous *hakanas hatov* for the group. "I learned so much from the parents and social workers at the epilepsy center. They guided me to the right doctors, and they are friends for life."

Like Carole, Terri Gross also had to cope with the fear of "what if?" when she decided to marry Joel Ackerman, who has epilepsy. "I know that hypothetically Joel could have a seizure while he is driving," she says. "But frankly, I'm much more concerned about drunk drivers than I am about him! Once I was driving home from my job as a kindergarten teacher and a drunk driver drove the wrong way down the Long Island Expressway; if he hadn't swerved, we would have collided. That scenario is much more terrifying than some hypothetical possibility that Joel could have a seizure."

Terri actually can feel safe with Joel at the wheel; once a person has been seizure-free for an extended period of time, the chances of having a new unexpected seizure while driving are extremely slim.

Another way that Terri keeps anxiety at bay is by thinking of Israelis, who don't let the fear of terror attacks control their lives. "You know how the Israelis are adamant that they won't let the Palestinians win by sitting in their homes, afraid to go anywhere, because a crazy suicide bomber might blow up a bus?" asks Terri. "That's how I feel about Joel having epilepsy." Her positive attitude may stem from Joel's approach to epilepsy: He refuses to let the disorder traumatize him.

Unfortunately, not everyone copes emotionally with epilepsy so well. Depression can be experienced by 33 percent of individuals with a seizure disorder. But these sad feelings may not simply be a reaction to being diagnosed with a potentially debilitating condition. Doctors believe that the underlying conditions of the brain that gives rise to seizures can also cause biochemical changes that can lead to depression.

Once it's established that depression is a concern, doctors can meet with success in treating the concurrent depression with medication, therapy, and support groups. The individual with a seizure disorder and his or her family need to learn that the patient might experience ups and downs in mood as part of the disease. Thankfully, the depression usually passes, and is eminently treatable.

"I learned so much from the parents and social workers at the epilepsy center. They guided me to the right doctors and they are friends for life"

seizures. Joel is one of those. He has been on the antiseizure medication Dilantin for more than thirty years, with minimal side effects. Since then the only seizure he's had was in college, and it may have been triggered by a bad case of mono.

"What was really hard was that, by law, the state took away my license, so I couldn't drive for my whole senior year of college," says Joel. "But this turned out to be a good thing. I realized then that I had to do whatever it takes to prevent another seizure, because it would royally mess up my life if I lost my license again, especially now that I have a busy career and I'm the father of two children. Since then, I get my Dilantin levels checked two or three times a year, and I'm very careful to keep myself in check. I haven't had another seizure since then. My life is working well and my seizure disorder is totally under control."

FIGHTING SEIZURES WITH SURGERY

Even though Batsheva* was a first-time mother, she could tell that something was terribly wrong with her newborn daughter Penina.* As an infant, Penina was having dozens of seizures a day, but they were so mild, her doctor didn't believe there was anything wrong. He insisted that all babies make erratic movements and it was nothing to be concerned about. He didn't even recommend testing.

Batsheva wouldn't give up. She videotaped her daughter's seizures, which she

*Name has been changed.

later learned were “infantile spasms,” and didn’t rest until she found a highly recommended neurologist who helped diagnose her daughter. It turned out that the seizures were actually a side effect of a genetic disease that causes the growth of benign tumors throughout the body. Batsheva’s intuition could very well have saved her daughter’s life.

Penina was put on medication, but it wasn’t enough to control the seizures. Eventually doctors suggested another solution: brain surgery to remove a tumor that was causing an escalation of the seizures.

“Many patients and physicians have the false impression that brain surgery is a last drastic resort, when in fact, once you’ve tried two to three medications, the chances of complete freedom from seizures diminishes, and therefore a more intensive epilepsy evaluation is indicated,” says Dr. Alan Ettinger. His titles include epilepsy director at Neurological Surgery PC, professor of clinical neurology at the Albert Einstein College of Medicine, and director of the Epilepsy Wellness Center at Winthrop University Hospital and the Huntington Hospital Epilepsy Program.

Dr. Ettinger estimates that 20 to 30 percent of his patients are unable to entirely eliminate seizures through medication alone, and that surgery provides hope and very positive results for many of these patients.

Dr. Gad Klein, a neuropsychologist who specializes in epilepsy at the Neurological Surgery PC center, is especially excited about the major advances in surgical technique that now allow for certain patients with epilepsy to be entirely

cured — instead of controlled — through surgery.

As frightening as the words “brain surgery” sound, Dr. Klein explains why this option is viable (and perhaps better) for a certain number of his patients: “Medication makes a huge difference for many people who have seizures, but ongoing and uncontrolled seizure activity may have a significant negative impact on cognitive function, quality of life, and overall medical health.

“If, through video EEG monitoring, cognitive testing, and MRI, we are able to determine that the epilepsy is arising from

GETTING THE RIGHT HELP

If a kid has a partial seizure disorder, the staff at his or her school will likely be up to speed on how to respond to an attack. But they probably won’t know how to best help these individuals — each with their own specific needs — succeed academically. That’s when parents need to step in.

People with partial seizure disorders (the kind that never escalates to grand mal seizures) often have cognitive deficits in the areas of the brain where the epilepsy originated. That can lead to kids who are very strong in some cognitive functions, and relatively weak in other areas. “For example, a child might have focal epilepsy, and they test as having problems with classic linguistic skills, but they could be a whiz in math. Or perhaps a boy is struggling in Gemara, which requires a very different set of skills than learning English,” says Dr. Gad Klein.

Since these kids aren’t learning disabled — they’re just weak in certain areas — they often don’t receive the academic assistance they need in school. Even though “they are entitled to special accommodations and resource help, they aren’t getting it,” says Dr. Klein.

He warns parents of children who have a seizure disorder not to rely solely on the standard IQ tests and achievement tests given by school psychologists. “A child with epilepsy could be generally keeping up with the class, and he or she may score fairly well on these standardized tests, yet his processing speed, working memory, or attention can be impacted by the seizure disorder, and it may get overlooked.

“It’s very important that such a child be evaluated by someone who is capable of conducting a comprehensive neuro-psychological evaluation. This is usually someone who has completed an internship and hopefully a fellowship in clinical neuropsychology. Of course, training in epilepsy is ideal. But it’s not critical.” If you’re concerned about the cost of such a test, Dr. Klein reassures parents: “When a child has a diagnosis of epilepsy, the evaluation is often covered by medical insurance.”

a certain part of the brain that isn’t working optimally, the patient could be an excellent candidate for state-of-the-art brain surgery, where the portion of the patient’s brain that is causing the seizures is removed. In order to ensure that the patient will not suffer any lasting damage during surgery, we are able to map out the patient’s brain functions using functional MRI and cortical stimulation. When necessary, we have the patient remain awake while surgeons are removing the problematic source of the seizures, so we can monitor any problems as the surgery is occurring.”



Epilepsy is often kept in the shadows in the Orthodox community because there is so much worry about the possible impact on shidduchim

For patients who worry, “Isn’t removing a part of my brain going to make me even more compromised?” Dr. Ettinger points out: “Sometimes a certain area of the brain is so scarred from repeated seizures, it’s causing more havoc than providing good function.”

Because of Penina’s frequent seizures (despite medication), she was a good candidate for brain surgery. But that didn’t make Batsheva any less worried when her daughter, then nine years old, was admitted to the hospital. But the results were exactly what they hoped for: Penina’s seizures declined dramatically after the surgery.

Penina (now a confident teenager) and her mother are vigilant about doing whatever it takes to keep her disease and its ramifications under control. “My daughter is the bravest girl I know,” says Batsheva.

REDEFINING EPILEPSY

Thanks to medical advances, epilepsy is not as formidable as it used to be: EEGs, CAT scans, and MRIs can now determine the source of seizures in the brain, enabling doctors to come up with specialized treatment plans that may either successfully treat or, through surgery, cure the condition.

The uninformed public might lump epilepsy into a broad-brush general diagno-

sis, but professionals within the field recognize that there are, in fact, many causes for a seizure disorder, and likewise, very particular treatments depending on the type of seizure.

“Seizure activity can affect memory, language, visual-spatial skills, and executive functioning. However, the impact seizures have on brain development often depends on the type of seizures, how young the patient was when they began having seizures, and the kind of medications they are being treated with,” says Dr. Klein.

“Seizures that result in generalized convulsions, the grand mal type, can have more impact on cognitive development, whereas a lot of people have partial seizure disorders, where only a small part of brain is abnormally active. They might just space out, or be unable to talk for a moment, but it often doesn’t have as great an impact on normal brain development.” (If your child has a partial seizure disorder, see sidebar.)

SETTING THE RECORD STRAIGHT

Despite the fact that some epilepsy patients can lead very normal lives, there is still a strong stigma associated with seizure disorders. This may be due to false impressions, something that Dr. Ettinger is trying to fix.

“We are vigorously involved in combating stigma and promoting better knowledge about epilepsy in the country at large and among diverse cultural communities. For example, epilepsy is often kept in the shadows in the Orthodox community because there is so much worry about the possible impact on *shidduchim*. We, as a community, have been so influenced by the provocative image of the grand mal seizure and a lack of knowledge of how many effective treatments are now available to treat epilepsy, that we are not helping as many individuals with epilepsy as we could,” says Dr. Ettinger.

The first thing he wants to clarify is that epilepsy is *not* a form of mental illness. A seizure is a neurological event that happens when there is an excess of electricity in a part of the brain. Seizures are, in fact, very common and can happen to anyone. As many as one out of every ten individuals will have at least one seizure in their lifetime — for example, during a high fever in infancy or with a drastic drop in blood sugar levels in a person with diabetes. A tendency to have more than one seizure, on a recurrent and spontaneous basis, is what gets the designation “epilepsy.”

Dr. Ettinger often consults with parents in the *shidduch parshah* who mistakenly view people with epilepsy as possibly “damaged goods” or mentally deficient. Dr. Ettinger insists that this is mistaken: “For the vast majority of the patients I see, the seizures are readily controlled through medication, and individuals can go on to lead completely normal lives, driving, skiing, swimming, carrying and delivering healthy babies through normal labor — anything anyone else can do. Even among those who continue to have occasional seizures, most daily activities can still be pursued.

“Sadly, because of the stigma of epilepsy, I find that some parents are not getting their family members all the help that is available. They worry about what might happen if the term ‘epilepsy’ is on their medical record. They wouldn’t do this if it were a problem with their gall bladder, so why should it be any different for epilepsy?” asks Dr. Ettinger.

To uproot the stigma of seizure disorders once and for all, Dr. Ettinger hopes that people will start educating themselves about epilepsy: “It’s time we open up a dialogue so that we can get loved ones the help they need.” ■

