Epilepsy in Children
Also by Orrin Devinsky, MD


*Alternative Therapies for Epilepsy* (with Steven C. Schachter and Steven V. Pacia)
To all of the parents and our patients
who have taught us so much about epilepsy
and even more about caring
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The three of us came to health care from very different backgrounds and perspectives—nursing, medicine, and nutrition. Our paths crossed over the care of children with seizures. We have been fortunate to share their lives and learn from them, as well as from their parents and caregivers. This book is inspired by all of our patients and their families. Their questions, experiences, and hope for their child’s future are reflected in these pages.

Great questions unfortunately outpace good answers. From diagnosis and treatment options to where the limits of our current knowledge extend, this book will hopefully help parents navigate what at times can be an overwhelming period in their child’s life. There has been exponential growth in scientific data, lay Internet sites and community chat rooms, YouTube seizure videos, and disease organizations for which epilepsy is a common thread. The amount of information and connections can be endless and confusing. Our goal is to help parents by providing a home base in the pages of this book to better understand seizures and epilepsy.

We hope to simplify the information while keeping the depth and extent of coverage sufficient to make it comprehensible, approachable, and informative. There is a wide range of the epilepsies in childhood. Seizure types in infants can differ greatly from those in toddlers. Parents should understand their child’s epilepsy, but understanding it in the context of the spectrum of epilepsy and associated disorders can better place their child’s disorder in perspective.

There is no single face of pediatric epilepsy. Many children with epilepsy enjoy extremely successful academic, social, and athletic lives. Others face challenges—ranging from mild attention and learning disorders to severe limitations in communication, psychiatric disorders, and physical limitations. This diversity presented our greatest challenge. There is a desire to paint the world through rose-colored glasses so as to help overshadow, at least in part, the stigma that has long cast a dark shadow on these children. Parents have the greatest power to disarm stigma through understanding and comfort. They must first come to accept epilepsy—what it means and doesn’t mean. It is important to see through
the epilepsy and other disabilities and see their children for who they are. The truth is more simple and enduring. We strove to follow our own advice.

Parents have assumed a new role in health care. They have transitioned from passive passengers on a journey led by the health care team into active participants. Indeed, parents have fueled much of the innovation in epilepsy research, access to information, advocacy, and how health care is delivered. Parents not only challenge us to do more, they help us provide more sensitive care, think of more ambitious research questions, collaborate in novel ways, and to join forces as partners. We hope this book empowers more parents to challenge and encourage all health care providers to work together in the fight against epilepsy.
Acknowledgments

All ventures are collaborations, and this one extends far beyond the three authors. We hope to have accurately and accessibly conveyed a snapshot of our medical knowledge and quality-of-life issues for children with epilepsy. While these pages largely reflect our perspective, we knew that our view was too constrained and occasionally flawed. We leaned on our colleagues and our patients’ parents to keep us honest. They reminded us when our views were contradicted by facts and when our answers failed to capture the nuances or diversity of reality. We cannot thank them enough: Peter Camfield, Karina Fischer, Jacqueline French, Mike Jasulavic, Warren Lammert, Eric Marsh, Kate Pico, Angela Stone, and Maggie Varadhan.

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All forms of seizures are caused by an excessive release of electrical activity in the brain. But what these seizures look like, and how they affect the life of the child in whom they appear, can vary greatly. Epilepsy is a disorder with a tendency toward two or more seizures.
Epilepsy is any condition in which a person has seizures that persist over time. There are many types (syndromes) of epilepsy and many types of seizures. These types of epilepsy vary in their symptoms and causes, though often the cause is unknown. One thing all epilepsies have in common is that they affect the brain and feature seizures as a main symptom. In fact, the word epilepsy comes from the Greek word *epilambanem*, meaning “to seize.”

What exactly is a seizure? A seizure is a brief, excessive discharge of electrical activity in the brain that changes how a person feels, senses, thinks, or behaves. When your brain is functioning normally, the stimulation (excitation) of its cells and the dampening (inhibition) of that stimulation are in balance. Epileptic seizures happen when an abnormality in the brain’s coordination and control of this nerve-cell activity disrupts the balance. Some seizures are quite minor and might go completely unnoticed by a patient or parent. Others are unmistakable. Some seizures don’t require any treatment, and some respond easily and completely to treatment and will have little impact on a child’s quality of life. Other seizures require extensive treatment and/or may not respond well to treatment. We go into specific types of seizures in Chapter 2 and specific types of epilepsy syndromes in Chapter 3. (For more about the brain’s anatomy and how it functions, turn to Appendix A.)

**TERMS AND TOOLS**

As you begin learning about your child’s particular type of seizures and syndrome, you’ll encounter diagnostic and treatment tools mentioned later in this book. One of the most common diagnostic tools, and most frequently referenced in these pages, is an *electroencephalogram*, commonly known as an EEG. An EEG reading is taken by a machine that measures the electrical activity in a person’s brain using flat disks temporarily attached to the person’s scalp. It is a painless test, but does not always provide diagnostic information. (For more about the EEG, see Chapter 5.) For example, some people with epilepsy have normal EEG results, the same as a person without epilepsy. Others show the
characteristic *spike-and-wave* pattern that can definitively diagnose certain epilepsy syndromes. This illustrates one of the most important truths about epilepsy: every case is different, as every child is different, and a test or treatment that works for many patients may not show results in your particular child. This is why diagnosis and treatment for the disorder can involve quite a bit of trial and error. That’s not a failing on your medical team’s part, but merely a fact when dealing with epilepsy. Diagnosis is often complicated. Sometimes it turns out that your child’s seizures are actually not epilepsy. Some patients are revealed not only to have epilepsy, but to have more than one type of seizure or syndrome. And finally, these things can change over time. A child with one type of seizure when diagnosed can develop a second type of seizure or syndrome, or may find that the seizures disappear altogether. All of these are reasons that open, comfortable communication between parents and their child’s health care team is vital, as is an understanding that there won’t always be quick or easy answers.

We’ll also talk a lot about *antiepileptic drugs* (AEDs), since they’re the first line of treatment for many children. AEDs are drugs that have been specifically approved for the treatment of epilepsy and have proven successful for certain syndromes and seizures. The idea of their child going on drugs can seem scary at first for some parents, but the proliferation of AEDs is good news. These medications have helped to control seizures and have brought a better quality of life to many children. The same can be said about surgery and the dietary therapies and medical devices now being used to treat epilepsy. When we talk about *dietary therapies*, we’re referring to the ketogenic and related diets that require careful monitoring of your child’s meals but have shown great success in lessening seizures. Any treatment that your doctor recommends will be one that’s almost certainly deemed safe and likely to help your child. Whatever the course your child’s epilepsy takes, your child’s well-being should remain the central concern with each decision you and the medical team make. This means that your decisions will be based not simply on whether the treatment works to stop the seizures, but also on its side effects and how the treatment will affect your child’s quality of life. Managing epilepsy is a matter of finding this appropriate balance between treatment, side effects, and quality of life. Sometimes finding that balance is easy, but sometimes it means making compromises.

**LOOKING AHEAD**

It can help to think of epilepsy simply as a seizure disorder, which to many people sounds less frightening than the word *epilepsy* itself. Try to remember that the disorder is only one facet of your child’s life, even though at times it can feel all-encompassing. And as seizures can be outgrown, so can epilepsy: 70 percent of children with epilepsy outgrow the disorder.

Even before outgrowing their seizures, most children with epilepsy live normal or near-normal lives. Approximately 50 million people worldwide have epilepsy, and the majority are able to work or go to school and have full academic,
athletic, and social lives. Still, some children do have more severe cases of epilepsy, more complicated syndromes, more demanding treatment plans, or cases that don’t respond to treatment. Many of these epilepsies are accompanied by intellectual disabilities, autism, depression, anxiety, and physical disabilities. We have written this book to help *all* children with epilepsy, whether their disorder is merely a bump in the road or whether it paves a more difficult path. Our understanding of brain function remains very limited, but is growing exponentially, and many new therapies are being developed. In the meantime, understanding your child’s own seizures and syndrome is the first step in confirming a diagnosis and working toward effective treatment.