



Beating Bad Seizures, Part 3 of 3

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in *Exceptional Parent* magazine, Volume 35, Issue 8,
pages 40-46, August 2005 (reprinted with permission.) www.eparent.com

This is the final article in a set of three designed to help you take control over seizures. In the first article we learned what epilepsy is, the importance of a correct diagnosis, and the key role the parent plays in getting the diagnosis right. In the second article we learned about treatment strategies. There are four treatment approaches that can be used to control seizures: lifestyle changes, medication, surgery, and brain stimulation. A fifth approach, genetic therapy, is only in the early experimental stage at this time. In this last article about the medical aspects of epilepsy, we will put all of this information together to get the best seizure control possible for your child.

After this article, our work together will continue. I am not going to stop with the medical challenges of epilepsy. You already know that epilepsy is more than just a medical diagnosis. Epilepsy affects the entire family. Epilepsy can play emotional havoc not just with the child, but with the parents, too. Epilepsy can affect the child's development, social skills, and school performance. In four future articles I will go on to discuss the psychological, family, social, school challenges of epilepsy along with some practical ways to overcome these problems. Information on practical coping skills is one of the hardest things for parents to find. These future articles will include some of the key skills that are taught in the Seizures & Epilepsy Education (S.E.E.) program. But for now, we are going to tackle seizures. Our goal – no seizures and no side effects.

STOPPING BAD SEIZURES

A recent study found that 47 percent of patients became seizure free on the first antiepileptic medication tried. Another 11 percent became seizure free after changing to another appropriate medication. Only 4 percent became seizure free after trying a third medication after the first two failed. The take home message of this study is that the doctor can tell relatively early which patients are likely to have difficult to control seizures. Nearly 40 percent of patients in the study were in that category.

When a patient has failed to gain seizure control after two or three trials of well-chosen and well-managed medications and possibly one appropriate combination of medications, that person's seizures are called "**refractory**." The term "refractory" refers to seizures that are resistant to control – in this case resistant to control with antiepileptic medication. There is some disagreement over how many medications should be tried before seizures are called refractory. Some epilepsy specialists think failure on two medications is enough. In any case, after a certain point it appears trying additional medications not very likely to result in success. So what can be done to control difficult to control seizures? A lot!

You have already read about the many diagnostic and treatment possibilities open to you and your child. In Side Panel 5, **Beating Bad Seizures Check List**, I provide a brief list of things to consider in your effort to get the best seizure control possible. There are more things you can do beyond this list, but it is a good start. The items on this list are discussed in more detail either in this article or in the June and July articles. Be sure to go back over all three articles when you are reviewing the Check List.

The very first place to start is to ask, “Are we successfully maintaining blood levels of the medication in our child’s therapeutic range each and every day?” Research finds the most common cause for unnecessary seizures is failure to maintain proper blood levels. Levels must be maintained throughout every day, of every week, of every month, of every year. Yet so many things can interfere with this effort even if you are paying close attention. (See the Figure 2 in the July article, **How Medications Behave in Your Child’s Bloodstream**.) Check constantly for everything that could cause the blood levels to go out of range, including forgetting doses, taking other medications, over the counter medications, herbal supplements, and certain foods. Work closely with your doctor and pharmacist and ask lots of questions.

Taking blood levels is a critical step to understanding what is going on with your child’s medications and seizures. If the child suddenly has an increase in seizures, is it due to a drop in blood levels or is it due to something else affecting the child? It is hard to tell unless you have a blood level drawn and compare those results against what you have learned is your child’s therapeutic range. If the blood level is where it should be, then you know that something else is responsible for the seizures. You can start looking at lifestyle issues (sleep deprivation, fatigue, hypoglycemia, etc.), other medications or supplements that may have lowered your child’s seizure threshold, another illness that may have lowered seizure threshold, or activities that might encourage seizures (for example, watching TV all day instead of getting adequate exercise and maintaining physical health.) Paying attention to all these possibilities will help you identify the potential culprit. From there it is easy to make the necessary changes.

If the blood level is lower than it should be, what was the cause? Missed doses, addition of another medication or supplement, a growth spurt, etc.? Again, once you have figured out the cause, the solution is easy.

You should also remember that epilepsy is a natural condition. Like the wind, it can blow hard some days and be calm on others. Seizures frequency can also vary on its on, for reasons we do not yet understand. Some children go from periods of relative calm to periods of increased seizures. Too often I see parents running to the doctor asking for a treatment change the moment there has been a temporary increase in seizures. It is my opinion that the feeling you must do something every time seizures become worse is a leading cause of overmedication and unnecessary switching from one medication to another. I know it can be hard, but have a little patience. If this is just a slight increase in seizures, find out if the winds will calm again. You don’t want to abandon a medication that works pretty well most of the time for another that may or may not be helpful. You also don’t want to subject your child to continual increases in dosage that lead to toxic levels of medication. However, use your judgment. If there is a serious increase in seizures or if seizures are suddenly prolonged, then seek help right away.



What if you are 1) consistently maintaining adequate blood levels of medication and 2) you are following correct lifestyle hygiene, yet your child is still having seizures? Then the question becomes is your child receiving the right medication for his or her type(s) of seizure? Different medications work best for different kinds of seizures. Medication needs to be well chosen for your child's particular epilepsy. But keep in mind there is both science and art to selecting medications. Sometimes an unexpected medication works for a particular child. A certain amount of trial and error may be required.

The place to begin in selecting a medication is to be sure the diagnosis is correct. You have already learned how difficult diagnosis can be. An accurate diagnosis is necessary for selecting an appropriate treatment. If there is any question about your child's diagnosis, it needs to be answered. Intensive monitoring may be in order. It is the most reliable way to establish an accurate diagnosis. Sometimes videotaping your child's seizures will prove to be enough. My experience with thousands of people who attended Seizure & Epilepsy Education (S.E.E.) programs is that after going through training in seizure types and seizure observation, about 40% discover they have an entirely different kind of epilepsy than they thought they had. Would a 40% error rate make a difference in treatment success? After S.E.E. programs I get letters and emails from parents and patients who say they have much improved seizures or they are seizure free after getting their diagnosis right and getting on the right medication.

Does your child have an epilepsy syndrome? Certain syndromes have difficult to control seizures. These include Infantile Spasms (West syndrome), Lennox-Gastaut, Sturge-Weber, Rasmussen's syndrome, Severe Myoclonic Epilepsy of Infancy, and other rare but serious epilepsy syndromes. (See the side panel from the June article, **Epilepsy Syndromes**.) Medications are still primarily selected based upon the type(s) of seizures the child is having. However, doctors have also developed experience over time regarding which medications are most likely to work best for these syndromes. It used to be thought that severe syndromes meant a lifetime of seizures, but recent research suggests that as many as a third of patients will have become seizure free at some point in their future.

Does your child have a difficult to control seizure type? Any seizure type can be difficult to control, but most often this is the exception rather than the rule. However a few types of seizures are very often difficult to control. These include less common types of seizures such as myoclonic, atonic, and tonic seizures. Complex partial seizures are the most difficult to control of the common types of seizures. If your child falls into any of these categories, you will probably want to make use of more than one therapeutic approach: lifestyle, medication, surgery, or brain stimulation. (See the side panel in the June article, **Common Seizure Types**.)

If your child has Complex Partial seizures or Partial Seizures Secondarily Generalized, does he or she have mesial temporal sclerosis? A high resolution MRI scan is usually required to find this problem. This kind of scan usually needs to be done by a group of experts (neurologists, radiologists) familiar with the problem of mesial temporal sclerosis and what it looks like on medical imaging. Special software and procedures may be required to detect this problem. Epilepsy specialty centers are usually the best place to go for this imaging. If mesial temporal sclerosis is found as the cause of the epilepsy, you can predict that medications are not likely to work and surgery is the treatment of choice.

Is your child a surgical candidate? Partial seizures have a place in the brain where they start. Most partial seizures start in the temporal lobe. This is why temporal lobectomies are the most common surgical procedure for treating refractory seizures. This type of surgery has been done for decades and epilepsy centers have a lot of experience with it. Sometimes the seizure focus is located elsewhere in the brain. It may be possible to remove the focus through a procedure called a "cortical resection." If the seizure focus is in a part of the brain that cannot be removed, it may be possible to isolate it with another surgical procedure called "multiple subpial transaction" to stop the seizures. Some of the more difficult syndromes such as Infantile Spasms, Lennox-Gastaut, Tuberous Sclerosis, Sturge-Weber syndrome, Rasmussen's

syndrome, and atonic seizures have benefited from surgery. For some “catastrophic” (very severe) epilepsies of childhood, surgery may be the best solution.

If medications have not worked and your child is not a surgical candidate, there are two additional approaches worth trying. One of these is the ketogenic diet described in the last article. While the diet is difficult, some children have dramatic results.

If the ketogenic diet is either not successful or not an option, the Vagus Nerve Stimulator (VNS) might be the answer. While it seldom succeeds in making a child seizure free, it has provided significant reductions in seizure frequency for many. Patients on the VNS generally continue to take antiepileptic medication. However, the stimulator may allow reduction of medications to just one at a more moderate dose. In a child who was previously taking more than one medication, the resulting improvement in quality of life could be as significant as the improved seizure control.

See A Specialist!

This is probably my most important suggestion: If you are not having treatment success despite good effort, **see a specialist**. Epilepsy specialists are called “**epileptologists**.” Like any other branch of medicine, there are doctors who have special training and interest in treating difficult cases of epilepsy. Epilepsy is not one disorder, but many kinds of disorders. Thousands of different kinds of seizures have been reported, scores of different syndromes probably exist – and many are very obscure. The availability of medications has doubled, brain scan technology has mushroomed, genetic contributions are being discovered, surgical techniques are evolving, and brain stimulation is a new reality. This is too much for a family physician or general practice pediatrician to keep up with.

If yours is a difficult case, you need a specialist who can bring the depth and breadth of cutting edge practice to your child. You may have to travel. Treatment may be more expensive *in the short run*. However, the specialist can often figure out the problem, design a successful treatment, and then refer the whole thing back to your local physician to carry out. I may seem like I am beginning to shout at this point, but I cannot emphasize enough how important getting specialty care can be. I have seen family after family go from terrible seizures to manageable seizures and even complete seizure control as a result of going to an epilepsy specialist or to an epilepsy specialty center (usually called a “**comprehensive epilepsy program**.”) Some kids do not respond, no matter what is tried. But many more do respond. And for the future of your child, it is better to reach for success now rather than later. (See the Side Panel 6, **Finding Specialized Epilepsy Care**.)

This is my other most important suggestion for beating bad seizures: **Learn everything you can!** I would guess that as a result of reading this series you already have some new ideas of things you could do to help your child. I was able to cover only the basics. I did not have time to discuss add-on therapies like psychological techniques for seizure control and methods to abort seizures. There is much more information available. The more you learn, the more you will be in a position to help your child and to succeed in conquering seizures. As I said at the beginning, knowledge is power – and seizure control. (See Side Panel 7, **Educational Resources**.)

Finally, **keep on trying**. It used to be thought if a person’s seizures were refractory, his or her seizures would never come under control. Recent research has found that a significant percentage of refractory patients eventually achieve seizure control. It may take some years, but it can happen. The key to success is to never give up on seizure control for your child. Determination and perseverance are the two most powerful therapeutic tools known to man!

CONCLUSION

I hope this series of three articles has provided you with some practical ideas for improving your child's seizure control. I expect you found you were not at the end of your rope, but just at the end of your knowledge. There is much more you can learn to help your child. Visit the growing number of websites that provide credible information. There are good books that give honest information. Attend programs like Seizures & Epilepsy Education (S.E.E.) that provides in-depth information about taking control of seizures and taking your life back. Check with your local Epilepsy Foundation. They also run educational programs throughout the year. Never give up. The goal is no seizures and no side effects. I have had the pleasure of seeing hundreds reach that goal armed with nothing more than good information and determination. Become one of those success stories for your child and for yourself. You can make a difference.

I'll see you in October, when we will talk about overcoming the psychological challenges of epilepsy – for your child *and* for yourself. If these articles have helped you, let Exceptional Parent know. They were kind enough to make this space available for me to share my experience with you.

Side Panel 6: Beating Bad Seizures Check List

Things to check on if your child is still having seizures

- ❑ Knowledge is power – and seizure control. Have you learned everything you can about your child's epilepsy and its treatment?
- ❑ Are you maintaining proper blood levels every day? Failure to do so is the leading cause of unnecessary seizures.
- ❑ Is the medication(s) at the correct dosage level for your child (either too low or too high can make seizures more likely)?
- ❑ Side effects can be as important as seizures. Are you keeping the doctor informed of any problems? See "diary" below.
- ❑ Are blood levels of antiepilepsy medications being measured to learn the concentration that works best for your child and to see if a change in seizure frequency (worse or better) is due to a change in that concentration?
- ❑ Are your child's seizures correctly diagnosed? (Different medications tend to work best for different kinds of seizures, and not all seizure-like events are due to epilepsy.)
- ❑ Is your child on the correct medication for his or her type(s) of seizure or epilepsy syndrome?
- ❑ Is your child avoiding seizure triggers (missed doses, sleep deprivation, fever, etc.)?
- ❑ Is your child living a healthy lifestyle (proper rest, exercise, nutrition, etc.)?
- ❑ Is your child taking other medications that may interact with seizure medicine or lower seizure threshold?
- ❑ Is your child taking nutritional supplements or herbals that may interact with seizure medication or lower seizure threshold?
- ❑ Is your child taking recreational drugs that may interact with seizure medication or lower seizure threshold?
- ❑ Are you keeping a written diary of seizures, all medications and supplements, side effects, seizure triggers, lifestyle changes, etc.? It's hard for you and the doctor to know if you are winning or losing – *or what is making a difference in seizure frequency* – if you don't keep score!
- ❑ If your child has partial onset seizures, has he or she been given an appropriate high resolution MRI to see if a treatable cause can be identified?
- ❑ Does your child have mesial temporal sclerosis?
- ❑ Is your child a candidate for surgery for epilepsy?
- ❑ Has your child been evaluated for the ketogenic diet or the Vagus Nerve Stimulator?
- ❑ Have you taken your child to an epilepsy specialist (epileptologist) or an epilepsy specialty center?

Side Panel 6: Finding Specialized Epilepsy Care

UNITED STATES

www.naecepilepsy.org	National Association of Epilepsy Centers website. The website lists over 60 epilepsy specialty treatment centers throughout the U.S. Most are associated with university medical centers. Many have outstanding research and treatment programs.
www.aesnet.org	American Epilepsy Society (AES) website. AES is the national professional society for epilepsy, including physicians and other healthcare professionals. They recently opened their membership list to the public. Click on “Search AES’ Online Membership Directory.” You can find physicians in your area who are interested in epilepsy.
www.epilepsyfoundation.org	This is the website of the Epilepsy Foundation, the national advocacy group for people with epilepsy and their families. In addition to containing information about epilepsy, it allows visitors to search the American Epilepsy Society Membership Directory. It is a little easier to use than the AES website.
www.epilepsy.com	This website provides a <u>lot</u> of information about epilepsy. They list “Clinical Trials,” where you will find links to experimental medications, experimental devices like brain stimulators, and more. The links cover more than just epilepsy.
www.andrewsreiter.com	This is one of the oldest and most established centers providing adjunctive (add-on) alternative treatments for epilepsy. They primarily treat Complex Partial Seizures through helping people identify warnings of seizures (aura), identifying seizure triggers, use relaxation techniques, abort seizures, and improve breathing, diet, and other factors.

CANADA

www.epilepsy.ca	This is the website of Epilepsy Canada. They have a listing of selected “Treatment Centers” organized by province. This site also has information about epilepsy.
www.epilepsymatters.com	This is the website of the Canadian Epilepsy Alliance. It links to local Epilepsy Associations that provide information on epilepsy, including where to find care.

Side Panel 7: Educational Resources

Epilepsy Websites

www.epilepsy.com	Huge collection of information about epilepsy. Goal is to be the “one stop” source for information about epilepsy. You can spend hours here. Done by epilepsy experts.
www.epilepsyfoundation.org	Website of Epilepsy Foundation, the national group for people with epilepsy in the U.S. Has information, services, links, book store, and more.
www.edmontonepilepsy.org	Has excellent set of information booklets to download free – get them!
www.epilepsyontario.org	Has a large amount of information about epilepsy, extensive information about seizure types, extensive information about medications.
www.epilepsy.cc.ca	This website has a lot of information. Good section on child and school issues. New streaming video section.
www.epilepsy.org.uk	Website of the British Epilepsy Association. Very good information on epilepsy syndromes in children, good explanation of the International Classification of Seizures, and practical methods for coping with epilepsy in everyday life.
www.epilepsy.org.au	Website of the Epilepsy Association of Australia. They have a great section for kids with epilepsy. Good information aimed at teaching kids about their epilepsy.
www.brainsrule.com	Fun place for kids to go to play educational games that teaches about the brain. Sections appropriate from kindergarten to high school. (P.S. You’ll have fun too.) University of Nebraska.
www.epilepsytoronto.org	Epilepsy Toronto website has information on most antiepileptic medications including Sabril (vigabatrin).

Individualized Education Plans (IEP)

www.wrightslaw.com	Provides information about IEP laws
www.Ldonline.org	Excellent source of IEP examples
www.pacer.org	Extensive links for special education. Help for self-advocacy
www.disabilityresources.org	<u>Huge</u> collection of links (with commentary) for disability resources.

Seizure Assistance Dogs

www.4pawsforability.org	Information about seizure assistance dogs and a place to start looking in the U.S.
www.epilepsyontario.org	Has listing of epilepsy service dog trainers and providers in Canada

Books

Orrin Devinsky, M.D.	Epilepsy Patient & Family Guide, 2 nd ed., F.A. Davis, Philadelphia, 2002. Paperback that provides extensive information in an honest and understandable manner. Special section on children, detailed AED information, daily life. Highly recommended.
Adrienne Richard & Joel Reiter, M.D.	Epilepsy: A New Approach. Walker & Co., New York, 1995. Paperback that provides information on behavioral and holistic strategies for controlling seizures, including nutrition, relaxation, seizure triggers, aborting seizures, and others.
John Freeman, M.D., Jennifer Freeman, Millicent Kelly	The Ketogenic Diet: A Treatment for Epilepsy, 3 rd ed., Demos, New York, 2000. Paperback that provides extensive information about the ketogenic diet.

Training for Parents

www.theseeprograms.com	Website for Seizures & Epilepsy Education (S.E.E.), a two-day seminar for parents of children with epilepsy and people with epilepsy and their families. The program teaches about the medical aspects of epilepsy to get the best seizure control possible, and teaches coping skills for the emotional, family, social, work, and school challenges of epilepsy in order to get your life back.
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