

**I Wish He May,
I Wish He Might...
Sleep Tonight**



Understanding Complex Partial Epilepsy and Autism

By Elizabeth Obrey

In most parenting circles mothers and fathers coyly reminisce about the early years of sneaking into a slumbering child's room to watch, with still breath, the rise and fall of their child's chest. Not so in our parenting circle, those of us who have children on the autism spectrum. The risk of waking our slumbering children is too high – unless you are willing to jeopardize a few scarce moments of your own and some well-deserved rest for your child. What parent hasn't been flummoxed by sleeping problems when autism is present in the child?

When they are babies we are told it is colic. When they are toddlers we are told it is night terrors and ear infections. After their diagnosis we are told many children with autism have sleeping problems. We learn behavior strategies, increase or decrease sensory stimulation, and we use melatonin to help them fall asleep. We lay by their bedside and the bravest of us attempt to wake them, just enough to reset their sleep cycle a half hour after they fall asleep. We push aside our own need for sleep, and after weeks, months, even years, become less effective parents because of it.

"Everyone knows children with autism struggle falling asleep, struggle staying asleep, or are just nocturnal." "Everyone" in our community may acknowledge this, but as the mother of a spectrum

child, one who knows intimately the sleep challenges of our children, I'm here to tell you there may be more to this picture than you realize, something not often mentioned, a condition that may be overshadowed by your child's diagnosis of autism.

At six weeks of age my son, Chase, began to twitch when he slept. He always woke suddenly with a scream. The two of us slept in a rocking chair and whenever he woke I rocked as hard and as fast as I could until sleep returned. When it did I was afraid to move, panicked by the thought that the screaming and thrashing would begin again. As months went by I traded the rocker for pacing. Our family's life revolved around Chase's sleep or lack of sleep schedule. To wake him was a sin. Doing so brought the terror of his nights into our day.

By age two Chase had begun an ABA program. While his tolerance and participation increased his first year the overwhelming observation at every six-week consultation was that Chase had minimal – if any – retention of skills learned. Autism was assumed to be the culprit.

Approximately three months before his third birthday and a variety of specialists later, Chase was diagnosed with Complex Partial Epilepsy. Misdiagnosis after misdiagnosis had resulted in our child being

completely unable to function by that point. We learned that a viscous cycle of sleep deprivation brought on continuous seizures, while the seizures made sleeping more than 25 minutes at a time a rare event.

We were bewildered, angry. How can a medical professional misdiagnose a seizure? How could I, his parent, not know my child had epilepsy for nearly three years? Such is the case with Complex Partial Epilepsy. Only part of the brain is affected. Chase can mumble, he can stim, he can stare off into space, he can eat, and he can hit you when you touch him – while having a seizure. Sleep videos of Chase show him batting away any hands that tried to sooth him.

Only by getting a second opinion from a neurologist recommended by a center for autism and neurological disorders was Chase's epilepsy finally recognized for what it was. Using the same videotape and neurological tests, this second neurologist explained what was happening to our son, how it impacted his autism, and what needed to be done.

Sensing my hesitation to jump on board a strict regimen of antiseizure medication in a child so young – how would I even get Chase to take it? – the doctor told me if left untreated the seizures

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More About Epilepsy and Complex Partial Epilepsy

Our brains have billions of nerve cells called neurons, which conduct nerve impulses by means of electricity. Seizures occur when too much electricity is in the brain and these neurons fire all at once. Seizures can be considered general (starting simultaneously from both hemispheres of the brain) or partial (starting from only one cerebral hemisphere). Partial seizures are further classified as simple (do not impair consciousness, but may affect functioning) or complex (impaired consciousness).

Seizures can be provoked or unprovoked. Provoked seizures can have a cause, such as a fever, head injury, or drug and alcohol use. Seizures become labeled epilepsy if an individual has two or more unprovoked seizures. The cause of an unprovoked seizure is usually not known.

Parents should suspect a complex partial seizure if they observe a child in a dreamlike state or with a blank stare and they are unable to draw the child out of this state through attention-getting means. This is not just lack of eye contact common in children with autism, but a trance-like state.

How partial seizures manifest is dependent upon the area of the brain affected. A partial seizure centered in the motor cortex may cause random muscle moments while one involved in the perception area of the brain may result in a specific sensory experience, such as seeing light, hearing music or smelling a particular scent.

During a seizure a child may come to you and seem to be interacting with you. He may be seen engaging in random, purposeless movements, such as

walking around, mumbling or pulling at his clothing. Less often individuals may repeat words or phrases, laugh, cry or scream. (These movements are called "automatisms.") Again: they are able to do this because only part of the brain is involved in the seizure. The child is not conscious of his behavior and will be unable to remember his actions. A child who wakes with unexplained sudden bouts of screaming and can't be comforted could be having seizures. These children can become sleep deprived, which in turn can increase seizure activity. Parents should also be aware that heavy periods of sleep sometimes occur after episodes.

While these symptoms and the inability to call the child to consciousness may be disturbing for a parent to witness, the child is not in pain. Most danger or pain from seizures is due to injury associated with unconscious behaviors.

Parents who suspect seizures in their child should seek out a neurologist who specializes in autism and/or epilepsy. The most common treatment for epilepsy is an anticonvulsant medication, and frequently requires trying series of different medications and doses to find what works for an individual child. Other treatments used in conjunction with medication include a ketogenic diet, vagus nerve stimulation, and vitamin B6 with DMG (dimethylglycine) or magnesium.

Misdiagnosis of seizures and/or epilepsy may lead to ineffective treatments. If progress isn't being made with a current physician, seek out a second opinion. ■

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could become grand mal seizures. Just as important, he reminded me of the intense early intervention program we provided for our son. He looked me straight in the eyes and said, “If you want his therapies to work you *have* to control his seizures.”

The first night Chase took his medicine he slept through the night. I woke up in the early morning hours, paralyzed in my bed, afraid to check on him. It had been nearly 1,000 days of neither he nor I sleeping through the night. Drawing on that deep well of courage mothers of children with autism know too well, with still breath I tip toed into my slumbering child's room. As I stood there, watching the rise and fall of his chest, there was no thrashing, no screaming, no rolling eyes, or stiff arms and legs. Only a child getting a good night's sleep.

Within days Chase became more attentive. He no longer spent time disconnected from us, staring off in a distant world we could not access. As sleep came his rested body and brain began

processing all of the exciting and important things he had learned that day. Therapy sessions were no longer just playtime. Retention came, skills were learned, and life began.

An estimated one-third of children with autism suffer from seizure disorders (Tuchman, 2006), and the condition can arise even in very young children. How would you feel and function if you could only sleep for 25 minutes at a time and woke in a state of confusion? Not all children with autism have seizures. But, all children need sleep, as do their parents.

Seizures break the sleep cycle, not only compromising the quality of sleep but also interfering with the part of the cycle that allows that day's information to be processed and stored. The confusion children feel upon waking after a seizure can create a state of panic, especially to children who are constantly coping with sensory stimulation. When seizures are occurring traditional methods of helping a child with sleep issues aren't always

effective. By controlling our son's seizures his life was no longer marked by turmoil. He found confidence in sleep and the ability to be comforted.

If my words have struck a nerve don't deny it. Looking back I still wonder how I let Chase's sleep problems get so bad. But, I was told what I wanted to hear: “He isn't having seizures.” Don't let your own fear keep you from facing this possibility.

Controlling the seizures transformed our family's life. Yes, Chase still has autism and needs anti-seizure medication twice a day. But, his screams are of joy now and his nights are peaceful. He is obsessed with the alphabet, cookies and pickles. And, life is sweet. ■

Elizabeth Obrey is the mother of five children; three have classic autism. Their family blog can be found at www.ObreyChronicles.blogspot.com.



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**As Appeared in the
March/April 2010 issue.**

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