



A letter to parents of children newly diagnosed with Tourette's Syndrome

Preface

In 1989, my son was officially diagnosed with Tourette and Attention Deficit Hyperactivity Disorder. Eventually he would also be diagnosed with Obsessive-Compulsive Disorder. A few years later, when I realized my daughter also had Tourette's Syndrome, I felt overwhelmed. How could both my children be "struck down" this way? Remembering the confusion and fear I felt back then, and having spent over 15 years on our journey now, I wish I'd known then what I know now. If you are a parent of a newly diagnosed child, you may also be experiencing a lot of intense emotions. This is my message to you.....

Dear Parent,

If you've only recently learned that your child has Tourette's Syndrome, this can be a confusing and stressful time for you. If you have been running from doctor to doctor for a while, you may feel relieved to finally have someone confirm that yes, there is something "wrong" and you weren't crazy to be so concerned. But at the same time that you might be feeling a bit of relief, you may be feeling a lot of other emotions as well -- grief, fear, and guilt are all reactions that parents may experience in the process of coming to accept their child's diagnosis. Educating yourself and coming to accept the diagnosis and situation takes time for most people. Give yourself a chance to get used to things.

If you're anything like I was/am, you will want to find and read everything you can. It can be overwhelming at the beginning, though, and you may want to read a bit and then give yourself time to absorb before going on to another section on this site. Similarly, as you read or visit online support groups or mail lists, remember that you are more likely to encounter parents or adults who have had the more severe cases. The folks who are doing just fine often don't feel a need to participate and are too busy just living their lives.

Many parents who hear the words "Tourette's Syndrome" have an immediate dread that their child will land up with "coprolalia" (the uncontrolled swearing or socially unacceptable utterances). This image of Tourette's Syndrome as the "cursing disease" is misleading as only a minority of patients with TS actually develop coprolalia. In this case, the public's image is largely due to media fascination with the more extreme or unusual cases. For many children, the symptoms of Tourette's are often mild and do not even require treatment.

As a parent of a newly diagnosed child, one of your other immediate questions is likely to be, "Is there any way to tell if my child will have a severe case or a mild case?" The answer to that is "no." Just as there is no way you can know whether your child will among those who will have a complete or significant remission. And no amount of worrying about it will prevent your child from going through the ups and down of tic symptoms, because that kind of "roller coaster" variability is the hallmark of Tourette's Syndrome.

Worrying can increase your child's stress and make their symptoms worse, though. So let's think about how to support you so that you can support your child by helping your child accept that there will be times when they may experience some discomfort or difficulty from the tics and symptoms of their disorder. If you go "up and down" on an emotional roller coaster every time your child goes through a to-be-expected period of symptom worsening, you will land up exhausting yourself and not providing your child with the kind of support and parenting that s/he may need.

Unfortunately, there are no hard and firm answers out there for many of the most important questions parents have. Expect to encounter controversy as you read on these topics. And recognize that there are many well-meaning people out there who will give you firm advice based on their own personal experience. Their experience may not be yours, however. In the long run, much of what you learn about how to help your child will be trial and error -- informed by the experiences of those who have gone before you, but ultimately your trial and error. And isn't that true of all parenting?

If there are four thoughts I could impart to you as you begin your journey in understanding your child, it would be these:

Remember that your child is not a disorder, but just a child. Never lose sight of your child in the symptoms or any rough periods.

Not everything wrong or bad will be from "TS." Sometimes bad behavior is just plain old bad behavior. Learn what age-appropriate behavior is so that you don't fall into the trap of pathologizing everything or attributing it to a "disorder" when it is really the kind of behavior we expect from kids at that age.

Catch your child doing something good, and smile and share a hug. There are always difficult patches in childhood. Children who have TS will experience ups and downs just like any other child. If you place your child under a microscope watching anxiously for signs of TS, you will miss out on many opportunities to just enjoy your child. If you teach your child that everything they do that is unacceptable is from "their TS," you do them a disservice. Children need firm consistent loving structure and discipline to help them learn the boundaries and expectations. "Discipline" doesn't mean punitive consequences: it means "teaching." You are their most important role model.

Take care of yourself. Don't burn yourself out. Read in small doses if you start to feel anxious or overwhelmed. Make it a point to get away or out for some socialization and relaxation with friends.

TS is a syndrome. It is not a fatal disease. Your child sees him/herself through your eyes. If s/he sees you looking with fear or anxiety, that will affect her/him. If you get depressed, they will feel anxious and depressed. If they see you smiling and coping and finding humor and enjoyment in life, they will be more likely to find it, too. If you expect their childhood to be miserable, it probably will be. If you model and teach them realistic coping strategies and help them discover a sense of humor, they will thank you later on.

Postscript of December 2004:

I wish you well as you begin your journey. My journey began over 15 years ago, and I still learn every day. My children have been my best teachers, as between them, they have probably managed to have almost every symptom and neuropsychiatric condition imaginable. Neither of my children had severe cases of Tourette's Syndrome, but at the time, their symptoms seemed severe to me. It took me years to gain a wider perspective and find where to set the bar for expectations and limits.

Today, my son is working full time and goes to school nights to pursue his professional interests. My daughter will be a junior in college and hopes to become a psychologist and work with children and teens with Bipolar Disorder.

They have both been through rough years and have learned to accept and support each other and others. Our family is stronger than most families as a result of the incredible challenges we have faced together. As a family, we have fought for our children's rights. As a family, we have stood up for each other. As a family, we have told each other the truth and not let each other use a "disability defense" for misbehavior that could have been controlled or avoided.

As you read my web pages, you will find materials that are based on my experiences as a mother, as a psychologist, and as an advocate for children and teenagers with disabilities. I have been wearing all those hats for a while now. And with all of my hats on, I say to you:

Your child needs your understanding, acceptance, and support. You have the opportunity to make a world of difference in your child's life. Take that opportunity and make the most of it. And while you may want to change the world to make it a safer place for your child, while you're out trying to change the world, remember that we need to help our children fit into the world as it is.

Leslie

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