

*A Letter to Parents of Children Newly Diagnosed with Tourette syndrome*  
- Leslie E. Packer, PhD

*Preface*

In 1989, my son was officially diagnosed with Tourette syndrome 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 and obsessive-compulsive symptoms, 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 30 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 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, you will want to find and read everything you can because you don't want to leave any stone unturned in seeking help for your child. 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 read more. Similarly, as you read or visit online support groups or web sites, 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. And always keep in mind that just because a web site looks like it should be providing accurate information, it may not. Figuring out who provides accurate information is important, as is figuring out who keeps current with research and treatment options. If you do not know where to start, start with the national support organizations and ask them for their professional referral list for your area. Then connect with your local or nearest support chapter and ask the parents there what doctors or professionals they use for their family.

Many parents who hear the words "Tourette syndrome" have an immediate dread that their child will land up with "coprolalia" (the uncontrolled swearing or socially unacceptable utterances). This image of Tourette syndrome as the "cursing disease" is misleading as only a minority of patients with TS ever experience coprolalia. In this case, the public's image -- and your fear -- is largely due to media fascination with the more extreme or unusual cases. As you will learn, most cases of Tourette's generally involve much milder symptoms.

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 "not really, although there is some evidence that severity of any obsessive-compulsive symptoms somewhat predicts later tic severity." But no prediction is a guarantee of anything. Most children do not have a very severe case of Tourette's, even though it may appear severe to their worried parents. And most kids will have few or no tics as adults. And what you need to remember is that 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 syndrome.

Worrying can increase your child's stress and make their symptoms worse, though. If your child sees you hovering over them and looking worried, and you are pretty much putting every tic

under a microscope, they will become more self-conscious and more worried, which will likely make their tics even worse. 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. Research on TS has tended to focus on the scientific or medication aspects, and very little attention has been paid to the kinds of issues parents often raise -- issues of how to respond to a child's symptoms or how to help the child in school if they're struggling. 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. When 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 of society. "Discipline" doesn't mean punitive consequences, though. 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.

### You're Not Alone

Remember that you are not alone. Support is out there -- lots of it. Contact your local TS organization or chapter of Tourette Association of America. Join the organization and attend parent support groups if you feel that you need an understanding ear or shoulder. If you're struggling with your child's school, ask your local TAA chapter about advocacy assistance. Some areas have a lot of resources, other areas don't. Find out what's available in your area so that you don't burn yourself out rediscovering the wheel. And do check the organization's web site (and my site) for free handouts you can use to educate yourself or your child's teachers.

TS is a syndrome. It is not a fatal disease. Your child sees him/herself through your eyes. 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.

I wish you well as you begin your journey. My journey began 30 years ago, and my children were my main teachers, because between them, they managed to have almost every symptom and comorbid disorder imaginable. Today they are both married with children. In the end, it wasn't the TS that was the source of either one's biggest challenges growing up.

If you read my articles or books, you will find materials that are based on my experiences as a mother, as a psychologist, and as an advocate for people with TS. I have been wearing all those hats for 30 years now. And with all those hats on, I say to you:

Your child needs your understanding, acceptance, and support. You have an opportunity to make a world of difference in your child's life. Take that opportunity and make the most of it.

Leslie

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