



REAL LIFE STORIES: GRANDPARENTS OF CHILDREN WITH TS

It is often said that grandparents get to spoil their grandchildren, unlike parents who must provide discipline as well as love. But grandparenting can be so much more. Grandparents can be mentors, role models, confidants, friends and provide unique links to family traditions and history. They can help celebrate big and small milestones while helping children see the "big picture" from the perspective of experience.

Children with TS, who may have a hard time at school, feel the sting of competition with their siblings or wonder why they've been singled out for a mysterious neurological disorder, benefit from that extra dose of unconditional love that only grandparents can provide. One-on-one time with a grandparent—on a special excursion or just over ice cream—can give children with TS the opportunity to talk candidly about their feelings, or just enjoy time when no one is concerned about the tics that strangers may find distracting.

Barbara, Jesse and Jordan

Barbara Shefsky has two grandsons with TS—Jesse and Jordan. She describes her daughter Kathy, the boys' mother, as being "very astute" in diagnosing her sons' TS. Kathy has also been dogged in her pursuit of the scholastic accommodations that both boys need to stay in their local public schools. Barbara and her husband sought out the late Dr. Donald Cohen who was very helpful in guiding the family's education about TS. The boys are now fifteen and twelve. With their parents in solid control of the medical and educational aspects of the boys' lives, Barbara gets to play the role of fun grandma.

"I see them as often as I can. I live in the City (New York) and the boys live in New Rochelle. We're good friends. When they were younger I would treat them to Broadway shows—like the Lion King. Now the biggest treat is going out to dinner. They like a Japanese restaurant where

you cook your own dinner at the table. They are both very affectionate kids and close to their cousin who is sixteen. She has a learning disability and they are patient and understanding with her—and she is with them."

Barbara recently received a wonderful compliment from Jesse who asked her to take him on a clothes shopping expedition for his birthday. "He didn't just want the money. He wanted to go together." But Barbara is "cooler" than the average grandmother. She often listens to rap music with the boys when they're in the car. "I like some of it. I don't like the tough lyrics, but the kids know the words."

She believes that the genetic link to TS is the family of her deceased first husband. In her immediate family it has always been a topic open for discussion, but members of the extended clan have responded with varied degrees of candor. She recalled an incident involving the young son of a cousin.

"A year or two ago, one of my cousins, had been away in England for a year with her five or six year-old-son. The boy came back with all kinds of tics. My side of the family all thought it was TS. I invited my cousin and her husband to dinner and told her. It looks like your grandson has TS, maybe I'm supersensitive, but it looks that way. Her husband denied it completely, but she said maybe. The same cousin had a son who had a tic as a young boy, a tic that he outgrew."

"There seems to be a thread running through my late husband's side of the family. It was interesting that nobody discussed it with us (my daughter and I) knowing about our involvement with TSA. But I'm pretty loose about it, because of how I felt when I lost my husband to cancer. In the beginning I was in denial. It's a little embarrassing, that feeling of contagiousness. I tried to keep it low key, but as he got sicker and sicker I realized that I needed help, support and knowledge. That's what happened with TS. I needed

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