

Tourette Syndrome: Disorder is no curse

Nixa resident uses personal experience to explain life with disorder; how it is not just 'the cursing disease.'

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Michael DeFilippo has heard all the misconceptions of Tourette Syndrome—especially the disorder's perception of being "the cursing disease." From the exaggerations in TV shows and movies to the concerns and questions of friends, he has intimate experiences about what the syndrome is not.

And is.

"For two years, all I heard from my friends and family is that I don't have Tourette, because I don't curse," DeFilippo said.

"I got tired of hearing it."

That motivated the technical writer to put together "Getting Personal: Stories of Life with Tourette Syndrome." The 190-page book features the stories of 21 people affected by the disorder, including his own experience.

Tourette Syndrome is a neurobiological disorder characterized by repeated, involuntary vocalizations and movements. These "tics" can be as simple as sniffing or blinking; complicated as repeating words, uttering sounds or cursing.

The disorder can be difficult to detect in children, however. Because diagnosing the disorder depends on noticing repetitive motions and sounds, the symptoms can be masked by other childhood disorders, or just from the everyday actions of being a kid.

DeFilippo first started to tic when he was seven years old, growing up in the Bronx in New York City. The friends he had never mentioned his tics.

"I was kind of a nervous kid," DeFilippo said.

"When I started to tic, my family just wondered what my new habit was."

He went through most of his life, never suspecting he had the syndrome. It wasn't until the mid-'90s when he was approached in a Nashville, Tenn., coin-operated laundry. A man asked him if he had Tourette Syndrome.

DeFilippo said "no" at the time, but then started to wonder. His initial research led him to think he was right.

But a couple of years later, a conversation with his spouse brought the subject back. He researched Web sites about the syndrome and found a phrase which changed his perception of the disease: "Uncontrollable urge."

"The first research I read talked about Tourette by using involuntary, repetitive movements and sounds," DeFilippo said.

"I imagined muscle spasms; something you couldn't control. But, when I went back to my research, I came across the phrase, 'uncontrollable urge.' And that was it—I have the urge to tic."

DeFilippo said he can control his tics; one of his tics is an urge to turn his head to his shoulder.

"I've sat in job interviews and not ticced," he said.

"When I got back to the car, I was a man in motion, of course."

He was finally diagnosed with the disorder when he was 40. One of the more difficult things for DeFilippo to deal with was the perception of his friends and family.

He said representations of the disorder in movies and TV has not helped to adequately describe what it is.

"Movie companies will research World War II and other historical events thoroughly," he said.

"All it would take is for them to research, and they would find out that (uttering or shouting obscenities) exists in less than 10 percent of the population with Tourette."

He was convinced to write a book about the disorder by people on a writer's Web site. But he didn't want to add to the already -vast diagnostic library, so he approached it from a different angle.

"I decided the best way to define the syndrome is to let others tell it like it is," he said.

"It was better to show Tourette Syndrome in the form of its effect on people, instead of getting clinical."

DeFilippo put out the call for stories and received a large response. He narrowed the pool down to 21 stories and included them in the book.

Additionally, he published the book himself through Second Chance Publishing, and covered the cost of his first print run.

Though the contents of the book were important, the cover was a blessing. Gretchen Schuler, an art director with Reader's Digest Books, heard that DeFilippo would be donating portions of book profits to the story contributors, the Tourette Syndrome Association of Tennessee and the Betsy-Tacy Society's Sept. 11 Children's Book Fund.

She designed a professional cover for his book free of charge.

DeFilippo has no immediate plans for a follow-up book, but he said he will continue to educate people about the syndrome.

One of the things he has found is the syndrome goes hand in hand with other conditions, such as attention deficit disorder or obsessive-compulsive disorder. Also, more of the cases are being diagnosed as mild.

However, he also notes the challenges of finding the disorder. He said two of the groups who need to know the most are probably those who know the least: Teachers and doctors.

"Some neurologists miss it, and they are not taking the time to look at it deeply," he said.

"And teachers spent eight hours a day with children. If a child is acting out, they may be called 'willfully disruptive,' but they may not be able to control it."

He has become accustomed to life with the syndrome, and sees "the cursing disease" as something which has blessed more than cursed.

"All else being equal, I wouldn't mind not having it, but it's probably one of the reasons I'm as creative as I am," he said.

"It's contributed to who I am, and it's been around so long, I don't know what I would do if I didn't tic."

"Getting Personal" is available through Amazon Books at www.amazon.com, and will be available through major bookstores in the future.

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