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Understanding Tourette

Stereotype not apt in underdiagnosed disease

BY JULIE KIRKWOOD
STAFF WRITER

Newburyport resident Jack Hanke loves to talk about his favorite after-school activity of gathering classmates to play Dungeons and Dragons.

"I'm a dungeon master and it has infinite possibilities and adventures," Jack says. There are dice rolls. He can make the players crawl through the desert and take "constitution damage" or find their way to a tower and fight a villain.

An untrained ear could miss the verbal tic that slips into his speech. In response to a question about writing for a Web site, Jack gets a little tripped up.

"I normally just, I normally just write it," he blurts out, and in a low voice repeats to himself, "I normally just write it."

Then he forces the rest of the thought, "Mostly I just write adventures on paper."

Jack, 12, has Tourette syndrome, a physical disorder of the brain that causes involuntary repetitive movements and noises, known as "tics."

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Jack's verbal tic is an example of "palliilia," which involves repeating one's own words or sounds.

Tourette syndrome occurs in as many as 1 in 100 children. It is four to five times more common in boys than girls and it tends to occur along with more serious conditions, such as attention deficit hyperactivity disorder or learning disabilities.

Dawn Erickson of the Tourette Syndrome Association said it's common for doctors to identify and treat the other conditions but miss the underlying Tourette diagnosis.

"It's a misdiagnosed and underdiagnosed disorder," said Erickson, the mother of two boys who have Tourette. "Families have a lot of trouble."

The interesting thing about Tourette syndrome is there is no medical reason it has to be
treated, said Edward J. Hart, a pediatric neurologist at North Shore Children's Hospital in Salem, Mass., and Massachusetts General Hospital in Boston.

Drugs are available for people who find the tics intolerable or embarrassing, he said, but they don't work perfectly and they have side effects. The ideal situation is for the patient to accept the tics for what they are and not to take medications, he said.

Since there's no need to treat Tourette, there is the question of whether it matters if a doctor misses the diagnosis.

The value, Hart said, is understanding that the tics are not intentional.

Jack's younger brother, Ben, for example, developed a habit around age 6 of clearing his throat in a way that sounded like belching.

"It was quite loud," said their mother, Laurel Hanke. "At the time I didn't know it was a tic so I was admonishing him to stop doing that because it was rude."

Though Ben, 9, has not been formally diagnosed with Tourette syndrome, it tends to run in families, and Hanke has noticed facial tics in addition to that episode of repetitive sound. If it truly is a case of Tourette, Ben had no choice but to make the noise. No matter what his mother said, he couldn't have stopped.

A tic is like a sneeze, in the sense that it can be held back briefly or occasionally stifled but it ultimately forces its way out, Hart said.

"There are times in the office I will explain this to families and parents will break out in tears," Hart said. "They've been saying,"

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"When we can't understand Jack, at times when it's particularly bad, it's very stressful because he only wants to repeat things a certain number of times and then he's frustrated," his mother said.

Some children outgrow Tourette as they get older, but many have the tics for life. Jack's mother has looked into it and found that most adults with Tourette do fine once they tell their co-workers about their condition.

Jack dreams of working for Wizards of the Coast, a company that makes Dungeons and Dragons and other role-playing games, fantasy video games and books like the one he is currently reading, "The Crystal Shard."

In the short term, he's just hoping to make it through seventh grade without too much difficulty and is working with a speech therapist.

"Really, I just want to speak better," he said.

To the extent the verbal difficulties are tics, there may not be much he can do. That's why his mother is also preparing her sons to cope with whatever tics they may have for the rest of their lives.

"Hopefully their personalities will shine through," she said. "People will appreciate them for who they are and start becoming oblivious to the tics."