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After decades of being labeled 'weird,' a diagnosis offers relief

Pamela McLoughlin, Register Staff 08/07/2005

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MILFORD — Dorothy Sage Wolfe has always loved the story of "The Ugly Duckling" because she can relate to the ending, where the duckling discovers he's another kind of bird.

All her life, Sage Wolfe, 44, has felt different than other people. Then, much like the duckling who finally saw himself as a swan reflected in the pond, she realized in her 30s that she is different because she has Asperger's Syndrome, a form of autism.

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Asperger's was discovered in 1944 by Hans Asperger, but only became an official diagnosis in the medical community in 1994, leading not only many more children to be diagnosed, but also adults who knew for many years they were different but didn't know why.

"It was like being an alien on the planet," Sage Wolfe said. "I'm not a duck. I'm another kind of bird, but I got good at walking like a duck and talking like a duck."

Ami Klin, co-director of the Developmental Disabilities section of Yale Child Study Center and Harris associate professor of child psychology and psychiatry, said Asperger's is a neurodevelopmental condition, a variance of autism that results in socialization deficiencies.

Klin, one of the world's foremost experts on Asperger's, along with Dr. Fred Volkmar, also of the study center, said Asperger's impairs the ability to interact with others and develop relationships. He said it's hard to know how many people have Asperger's, but one out of every 1,000 individuals is autistic and within that group, one in every 250 have a variant autism, such as Asperger's.

People with Asperger's usually have at least average IQs, which sets them apart from most others with autism, Klin said.

Klin said he supports public talks to raise awareness of the condition, so that people know not to unfairly judge people with Asperger's.

According to experts, Asperger's is often characterized by obsessive routines and preoccupation with a particular, rote subject matter. Some typical traits include an inability to empathize, an inability to correctly interpret facial expressions and other nonverbal cues, poor eye contact and over sensitivity to tastes, smells, sights and sounds.

People with Asperger's, who often call themselves "aspies," also often make non-verbal sounds. For instance, Sage Wolfe howls when she's tired, in pain, sleepy or content.

"It's a different way of processing thought and experience," said Michael Carley, executive director of The Global and Regional Asperger Syndrome Partnership Inc., or GRASP, headquartered in New York City. "You just don't have the same instinctive wiring."

After discovering she has Asperger's, Sage Wolfe set out to educate the public and reach out to other aspies. In lieu of using the word "normal," for those without the syndrome, Aspies refer to them as NTs or neuro-typical.

"I like being an Aspie. I'm proud of the traits," Sage Wolfe said. "As I educate the NT world, we complement each other."

She is hoping to get her autobiographical manuscript, "Larger than Life: My Struggle to be 10-feet Tall," published. In recent months, she has given free talks on Asperger's to educate the public, parents and educators. A Bethlehem resident, Sage Wolfe has so far given talks in the Litchfield County area.

She will make her first appearance in this part of the state at the Parson's Government Complex at 7 p.m. Aug. 22. The appearance is at the invitation of Milford resident Al Pinto, 39, who, after a lifetime of struggling to fit in, learned just about a year ago that he has Asperger's. The two have become friends, forming a spiritual group that meets on Sundays at a Starbuck's in Watertown. Pinto wanted her to share her story in his hometown. Sage Wolfe, an ordained minister, leads the group, Stand Paladin Fellowship, that she says isn't about who's the holiest, but rather, the neediest.

Pinto said he learned why he was different about a year ago when his sister, a reading specialist in the Milford school system, was trained to recognize Asperger's. She found the diagnosis fit her brother. He was relieved to have answers and wound up at a support group in Wallingford, where he met Sage Wolfe.

"To know what it's called is a relief. It's given me a road map, a strategy, because you can't fight an enemy if you don't know what it is," Pinto said.

Pinto was never good at sports — awkwardness is another aspie trait — and so faced teasing and scrutiny by peers. He didn't fit in and struggled in school, and was told he had a learning disability.

Pinto went to college, majoring in computer science, a common profession for aspies, along with the artistic field. Pinto got a good job in the computer field and eventually became a supervisor, but ran into problems and stress in that position because of his difficulty relating to others.

Pinto went back to school and became an architectural designer and now works at an architectural firm in Hamden.

"My parents tried to teach me how to act. It was frustrating, they thought I was lazy, immature, self-centered," Pinto said.

Sage Wolfe's early training, like Pinto's, was in computer science, but she later went to school to study communications. She even attended a public speaking program to further her "NT" communication abilities. Now, she's using those abilities to spread the word.

Sage Wolfe married an aspie, who didn't know he was one at the time, she said, but he is reclusive and keeps a low profile. Aspies "speak the same language" she said, and interact with one another smoothly.

"My life's mission was not to be an aspie advocate," Sage-Wolfe said. "The need is screaming out there, so I jumped into it."

Carley oversees the support group in Wallingford that Sage Wolfe and Pinto attend. That group, referred to as the New England Conference, is one of seven in the country for aspies now run by GRASP.

Carley said that in 1994, once Asperger's made it into the official diagnosis book used by the medical community, it opened up an entire community of people who qualified for the diagnosis. Carley said accurate statistics are not available because no one knows how many people have Asperger's.

He said the public needs to be aware of what to look for because Asperger's could offer an explanation if they know someone who acts "different" and may wrongly be perceived as a danger.

It's also important to get the word out that autism is genetic and not caused, as was once believed, by cold mothers.

Anyone interested in learning more about Sage Wolfe's talk can e-mail her at dorothysagewolfe@yahoo.com or Pinto at scoots66@yahoo.com.

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