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WEEKLY COLUMN

Troubled Relationships? Could It Be Asperger's? Women's Health

By Tracy Morris, updated 5/21/2008 at 11:06:02 PM

You and your friend have just experienced the same traumatic blow -- laid off from your job, told of another friend's death, or something equally like a swift blow to your heart. Your reactions vary because humans are unique that way. But are you also left wondering why you don't feel the impact and empathic connection to your friend that she seems to be feeling?

A growing number of people are starting to find relief in a controversial and relatively recent diagnosis: **Asperger's Syndrome**.

The relief they find from the label isn't because a cure exists; rather, they feel finally understood, their feelings and thoughts and behaviors finally put in a light that reveals explanation instead of criticism.



Like so many adults, Carley put the puzzle pieces together after his preschool aged son was diagnosed with AS.

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The symptoms of autism that Carley and his wife observed in their son were classic and disconcerting. At the age of two, he was significantly delayed in speech. Instead of playing with toys, he separated and sorted them, as he did with other household items. After speech and play therapy, someone mentioned AS.

Carley received the same diagnosis as his young son only a week later.

"In my particular case, and it varies certainly, what came naturally to others, I had to work harder for, especially with reading emotions of my own and other people. I was a 'tell it like it is' kind of guy, but I didn't really feel like I was that guy. People who weren't crazy about my differences thought of me as a 'rude so-and-so'. You struggle with all the perceptions of yourself."

He emphasizes that while plenty of his own experiences are in the book, it is not a memoir. Carley has written it primarily for adults who are wondering (and may have been for many years) about themselves. "More and more people are learning about AS and finding that it explains many of the social conundrums through which they've lived, often quite painfully."

Wondering If You Have AS?

As with any medical syndrome, AS is not as clearly defined as a disease or illness. There's no virus or infection to test for; a syndrome is a collection of symptoms. In the case of AS, it is a neurological condition that lies on what is referred to as the "autism spectrum," an imaginary line of severity, if you will. At one point, you would find people with life-debilitating levels of autism; individuals with pervasive developmental disorder (PDD) are also within the spectrum.

Michael John Carley is the best known advocate for people with Asperger's Syndrome, or AS. He runs GRASP, the Global and Regional Asperger Syndrome Partnership, the largest national non-profit run by and for people "on the autism spectrum," and he's known as a brilliant and vocal champion. His book, *Asperger's From the Inside Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome*, tells of both his own struggle for understanding and what he has learned from the

many others with AS he's encountered in his work.

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People with AS, to put it plainly, tend toward difficulty in their relationships, whether it's with loved ones, friends, or more casual relationships. However, as Carley explains, "These are individuals who, for the most part, are good at what they do. A lot of time, you're not seeing a person who has job performance issues, unless it's specific to social interactions."

He says it's common for people with AS to become good at 'faking it'. "There may be this thing inside you that says 'I really don't want to acknowledge that I feel like I process thought and experience differently than people I love.' That's very hard -- you love them, you don't want to feel different than them. So we tend to just avoid this thought, but it's still there..."

So it's not uncommon for the "neuro-atypical" as Carley and others refer to themselves to spend a lifetime wondering why they feel so odd.

"Women are falling through the cracks," in terms of accurate diagnosis, Carley says.

Diagnosis regardless of gender is tough. *Asperger's from the Inside Out* offers a comprehensive list of traits that individuals with AS may demonstrate, but Carley's disclaimer is that not a single trait in the list can be used to either diagnosis an individual or rule out AS.

For those of us straining to grasp and apply these behavioral clues, Carley points to "passionate interests, at least one sensory integration challenge, and difficulty engaging in reciprocal conversation" as potential key markers.

Autism in general has for many decades been thought of as a predominantly male condition. Carley and other advocates believe that much of that gender assignment may be based on less than complete understanding by professionals.

"If you take a couple of the more obvious bullet points -- say, like inability to maintain eye contact. In the society we live in, if a boy shakes your hand and doesn't make eye contact, something's wrong. If a girl doesn't look you in the eye, she's shy. Boys who aren't interested in team sports -- let's take a look at this kid. If a girl's not interested, she's just feminine."

As adults, people with AS may be perceived as very submissive. Submissive men often don't wind up with partners in our culture, so they get wondered about in regards to AS. Submissive women may find themselves in imbalanced, abusive relationships and thought of in terms of being depressed or un-empowered, but AS may not arise as a possibility to those around her.

Finding a good diagnostician is important. Be wary of Yellow Pages advertisements that tout "We really know AS" -- practitioners in need of a growth in their patient-load could be lurking behind perfectly good credentials but lacking in expertise.

Do your research. Contact a local autism society and even parents' groups. The GRASP website can also help you find professionals in your area.

The process will also involve whomever you live with and other family members who can comment on your behavior today and in your childhood.

Do You Really Want to Find Out?

One of the unique facets of the journey toward diagnosis for adults with AS is the amount of buried anger that might exist from a life of feeling misunderstood and, in many cases, poorly treated by others.

In fact, Carley says that while his own behavior was put in a positive context (for example, when he was screenwriting, he was thought of as "artistically eccentric"), the more common case is that people, especially as children, are demoralized by those around who don't accept them. The result can be serious levels of related anxiety, depression, and even post-traumatic stress disorder.

GRASP provides social support groups that can act as a safe harbor for muddling through the complex feelings that may arise from having the AS diagnosis applied to yourself. At present there are about 15 networks around the country.

"It's been fascinating to see the lines that our message cuts across," Carley muses. "We have people from literally every walk of life involved in our groups." GRASP's mission of educational outreach and advocacy is achieved with a by-law mandate that its Executive Director and all Advisory board members, plus half of the

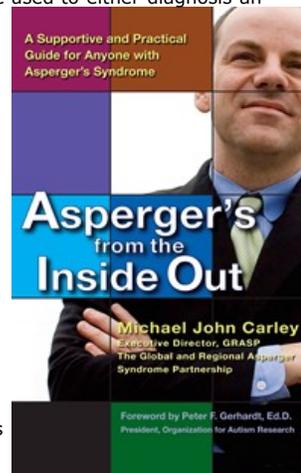
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Board of Directors, must have a diagnosis within the autism spectrum.

"I don't have the words to describe how liberating the diagnosis can be," says Carley. "Every relationship I have on this planet has been inordinately strengthened, not weakened, by my ability to face up to this diagnosis."

"There's a lot wrapped in someone's identity with this diagnosis," Carley elaborates. "but not because AS is the be-all and end-all of who you're going to be. As a matter of fact, it's nothing more than a context. It's like finally having the right toolbox with which you can re-evaluate those things that went awry in your past."

Besides explaining one's history, *Asperger's from the Inside Out* offers informed tools with which those with AS can finally base their future choices, including issues about disclosure of diagnosis: who to tell, when to tell, and what to tell them. GRASP is there to help change public perception about people anywhere on the autism spectrum.

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