

The Asperger Journey

We asked Lise Pyles, author of *Hitchhiking through Asperger Syndrome* to advise *Latitudes* readers who are seeking help for their child's Asperger-like symptoms.

When parents first suspect their child may have Asperger Syndrome (AS), they naturally turn to experts for medical and educational advice. They need to be aware that the diagnosis of AS has only been around a few years. Many doctors and school staff still have little or no experience with it and are not always helpful. Parents need to get comfortable doing their own research. They are already experts on their own child so once armed with knowledge of AS, they can begin leading the way in getting their child help. This might mean just knowing what to ask for, or it might mean working on issues themselves. Above all, I would advise them not to depend solely on outside interventions. School-based physical therapy, speech therapy, social skills classes and the like can be terrific, but often they are meted out in tiny doses and it is not enough. Parents need to roll up their sleeves and work the issues on a daily basis.

Some of the issues

Lack of social skills and communication difficulties are probably the largest areas to address. Our children may wish to have friends but not know how to make them, and they lack the intuition that

other kids have regarding facial expressions, appropriate conversation, body language, etc. The way we can teach them to cope with classroom and other social situations is through painstaking education—breaking things down piece by piece. They will gain the most coping skills when these things are overtly taught. Our kids do not just “pick up” how to behave, so they need specific instruction. Parents can give examples, model behavior, discuss when to use that behavior, and allow the child plenty of practice. The child with AS usually has acute senses, so a calm, predictable environment is important. Attention Deficit Disorder is generally a part of the picture, so help in organization and staying focused may be needed. Other Asperger traits—literalness, narrow range

of interest, sometimes motor clumsiness—are also subject to working on at home, especially the motor issues.

Many (but not all) children with AS have physical reactions to certain foods. If your child reacts physically to some foods, then identifying these will be extremely helpful. In our case, my son needed to eliminate dairy foods, and also oranges, vanillin, and artificial colors. We found, through using a food journal and observing him closely, that dairy caused him to be giddy, almost drunken-acting, echolalic, and zoned out, while the other foods I mentioned caused him to tantrum and act out and made him look generally unwell, with dark rings under his eyes, a pasty complexion, and red ears. Once we learned to watch for

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Hitchhiking through Asperger Syndrome

Pyles' book provides practical advice for families and practitioners. Topics include dealing with schools and the community, home-schooling, finding help, medications, and coming to terms with Asperger syndrome. Excellent.

Lise Pyles; 286 pages, pb \$18.95 US
Jessica Kingsley Publishers, London; www.jkp.com

A Description of Asperger Syndrome

The child with Asperger syndrome is socially awkward, has difficulty making or keeping friends, is generally egocentric and lacking, or seeming to lack, empathy or ability to see the other person's point of view. Communication may be literal. Thinking may be black and white and lack imagination (or show unusual imagination). Speech and language skills may seem somewhat odd compared with peers. That is, speech may be formal or pedantic (teacher-like) or may sound somewhat unusual. Nonverbal communication is lacking so that the child misses or misreads nonverbal signals (gestures, body language, facial expressions) and is ineffectual or limited in sending them. Personal interests (collections, hobbies, preoccupations) may be unusual in subject and/or narrow in range and/or pursued intensely. In addition, the child may gravitate to or take comfort in routines, rituals, and repetition and be upset by surprises. Intelligence, however, is average or better and initial language acquisition is within norms. There may be abnormal reactions to sensory stimuli (i.e., acute sensitivity to light, smells, tastes, tactile sensation, or sounds.) There is usually, but not always, physical clumsiness. **Lise Pyles**

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physical symptoms, it was easier to cope with the behaviors. After beginning my own study, I began giving my son a vitamin formula developed by Dr. Bernard Rimland, Super Nu-Thera, available through Kirkman Labs. I found this lifted his mood, made him more "in the moment," and lessened his headaches.

One important thing to remember is that only a certain subset of children with AS are going to respond to food issues or nutrients, and eliminating problem foods will not cure AS. My son still has acute senses, difficulty reading faces, still has quite narrow interests, and finds social settings a challenge. In other words, he still has Asperger syndrome, which is a lifelong condition. However, eliminating problem foods alleviated a lot of the behavioral issues. When his system wasn't upset and causing him to act out or zone out, then he was able to tune in to learning the coping skills that he needed. We've been able to make the most of his life education by tackling the lowly food issues.

My son is now 17. He watches what he eats on his own now, still takes vitamins, and is currently looking forward to college.

Resources

Autism Society of America
(800) 3-Autism; (301) 657 0881
www.autism-society.org

National Autistic Society
London; www.nas.org.uk
020 7833 2299

Advocacy issues:
advocacy@nas.org.uk

Autism Society of Ontario
(416) 246 9592
main@autismsociety.on.ca
www.autismsociety.on.ca

Treatment:
Autism Research Institute
www.autismresearchinstitute.com

Learning Disabilities Association of America
www.LDAmerica.org

Excerpt: Hitchhiking through Asperger Syndrome

Before we discovered the influence of diet, I had noticed that Chris, almost eight, had good days and bad days. I don't just mean that on some days he behaved better than others, although that was certainly true. I mean that physically *he* seemed to change from one day to the next. Some days he would be focused and we could have conversations in which he was obviously engaged. Other days he would be 'disengaged'. He would have more typically autistic traits. He would spend greater amounts of time off to himself, wagging his stick in front of his eyes, or bouncing off the walls without regard to whom he ran over in the process.

On those days, whether or not he was a behavior problem or was simply zoned out, there was a disturbing disconnectedness about him. He couldn't seem to hear us. He laughed at things that weren't funny. He felt no pain. He was more echolalic (repeating our words back to us), or answered questions with bizarre heaven-knows-what. He made less sense on those days and was giddy. Even his eyes looked different. They had a glassy appearance that seemed out-of-focus.

I remember one day when he was particularly bizarre and unmanageable. We'd finally had enough and Bill put him up in his room, sitting him in a chair facing the wall until he would calm down. I remember hearing Chris sitting up there in the gathering dusk, all alone in his room, laughing and laughing. As much as I had been trying to blame my husband and myself for his problems and assuming that we just hadn't figured out parenting, that night I had no such illusions. It was not parenting. This child was having serious troubles. I remember Bill and I had a very somber discussion that night, wondering out loud what the future held for us all and for our sweet boy. It was the night that all of our worries finally got said aloud to each other. This wasn't normal. Was it going to get worse? Was it ever going to get better? The discussion led to no answers, only disquieting questions.

Sometime after this I read *Is This Your Child?* by Dr. Doris Rapp, and learned how environmental factors can affect children. I was overwhelmed that "nearly anything" could cause a reaction. She wrote about a boy who had several food issues (so did Chris, as we later learned), but the part that put two and two together for me was reading that after drinking milk, the boy had become unmanageable and his eyes became glassy. Maybe Chris's problem was milk. I did nothing with this information for a while. We were soon to begin home schooling, and I decided to wait until I had

Chris home full time before fiddling with diet. . . Chris drank milk for breakfast, lunch and dinner. Yogurt and cheese slices were common snacks. We all ate a lot of ice cream. What if?

After we pulled Chris out of school and began home schooling, we were ready to experiment. I took Chris off of milk and all obvious dairy products. Within 24 hours, we had our first breakthrough, which I wasn't expecting. He didn't wet the bed. With the rare exception, bed-wetting had been a nightly occurrence up until this point, age eight. Even one dry night was cause for celebration. But suddenly, bed-wetting was a thing of the past, and sheets remained dry night after night. The wetting stopped completely, except for one lone accident a few weeks after that.

Other effects were less dramatic, but there. Chris still had behavioral meltdowns and still fussed or flew off the handle, so it was easy to think, "this milk thing isn't making any difference." But actually, it was making a difference. Chris might still have lots of issues, but he was gradually becoming more reachable. His eyes were in focus more and more, he was not talking as bizarrely, and he behaved more like a normal child would. He still had issues and he still had Asperger's Syndrome (the actual label coming years later), but if you sent him to his room, he would at least be upset about it, not sit in the dark and laugh. It was progress.

Excerpted with permission; adapted for space

Editor's note: This excerpt was selected because many parents report that their children with neuropsychiatric disorders react negatively to milk products. The detrimental process starts in the digestive tract and ends in the brain. Understandably, parents are often reluctant to remove milk from the diet. Milk products are not only used in favorite foods, but we've been taught that they are healthful. When people contact ACN and ask for something inexpensive and natural that they can do right away, we suggest they eliminate artificial flavors and colors, significantly reduce sugar intake, avoid scented products and toxic chemicals, reduce exposure to allergens—and cut out milk. Other broad nutritional recommendations may also be made. If preliminary progress is seen, families are usually inclined to take more comprehensive efforts to get to the root of the problem.