The ABCs of Asperger's Syndrome: An A-to-Z Guide to Understanding the Symptoms of Asperger's

One woman and her grandson use the alphabet to explain personal perspectives on this mild form of autism.

By Josephine Mele, *Parent Magazine*, https://www.parents.com/health/autism/symptoms/understanding-aspergers-syndrome/

Asperger's (ASP) is a type of mild autism; kids with Asperger's might have unusual behaviors, even though they don't have language or intellect problems. To help parents better understand the symptoms and behaviors of Asperger's syndrome, I wrote this alphabet with help from my 10-year-old grandson, Nick, who was diagnosed with Asperger's when he was 6. He is clever, warm, honest, helpful, bright, and thinks outside of the box. Nick refers to Asperger's as his "problem" and often wishes he didn't have it. Nick would love it if everyone had information about Asperger's. "If they just gave me a chance, they would see that I am really very interesting and I know a lot of interesting stuff."

According to findings from Centers for Disease Control, published in 2012, Asperger's and other autism spectrum disorders (ASD) affect an average of 1 in 88 children in the U.S. Most scientists agree that genes are one of the risk factors that can make a person more likely to develop an ASD and that poor parenting does not cause ASD behavior. Many historical figures have shown symptoms of Asperger's, including Wolfgang Amadeus Mozart, Albert Einstein, Marie Curie, and Thomas Jefferson.

Kids with ASP are often socially and physically awkward; they may have attention problems, difficulty making friends, and an all-absorbing interest in specific topics. A child with one or two of these symptoms, though, may not have Asperger's. To be diagnosed, a child must have a combination of symptoms and significant trouble with social situations that affect family, friends, self-esteem, or schoolwork. Ask your child's pediatrician and school psychologist for help in testing your child. Many kids with ASP need medication to help with concentration, aggression, or depression some time in their life. But over time, with the right help, kids often improve and can begin to learn how to read social cues.

Here, we offer different points of view about Asperger's -- mine from an academic perspective, Nick's from a personal one. Our hope is that this alphabet will help other families be more aware and educated about Asperger's so they can help children learn to interact more successfully despite any differences.

A Is for Aloof

Kids who have Asperger's are often onlookers, not participants. They seem aloof but, in reality, their lack of social skills is holding them back. Because "play" is an abstract word, autistic children are better at games with step-by-step rules that involve taking turns rather than free-for-all games without structure.

Nick: Sometimes kids think I don't want to play, but I do. I just don't know how to ask to be included, so I'm waiting for an invitation. Other times I'm not sure what other kids are doing, so I'm watching to see what the rules are.

B Is for Behavior

Most people think those on the <u>autism spectrum</u> have a behavior problem, but this isn't true; they have a medical problem. When their brains get overstimulated or they get frustrated, they often act out, sometimes with aggression.

Nick: My brain gives me too many messages at once. It's like having 10 people telling me to do different things at the same time. When I get confused, I might knock things off the table, shout "Stop talking," or walk away. I need a few minutes to get my thoughts organized. My teacher lets me take a "chill" break in the hall for a minute when I need one.

C Is for Conversation

Conversation may feel awkward and lack the usual give-and-take because "small talk" is something a child with Asperger's doesn't understand. For that child, the reason for talking is to share information by asking or answering questions. An adult may ask, "How was Disneyland?" and get a one-word answer, such as "Fine," or ask, "What did you like the best?" and get an answer of "Everything." You can keep prompting but get no more responses.

Nick: It's hard to start or continue a conversation because I'm not sure what I should say when I don't have a question. I often just answer "yes" or "no" to a question. But ask me about trains, planes, computers, electricity, or tornadoes and I will talk until you walk away. Please try to start a conversation with me anyway.

D Is for Different

Around age 7, a child with Asperger's usually becomes aware that he is "different" from the other kids in the class. He might struggle with filtering out the teacher's voice from all the other things vying for his attention. Visual learning tools that work for other kids (such as colorful, attention-grabbing bulletin boards or interactive blackboards) can be the very things that causes confusion and distress because of sensory overload.

Nick: My teacher treats me differently than the other kids now that she knows about my problem. She knows that my being in the middle of the row is confusing and makes me nervous, so she lets me sit at the end of the row. She knows I feel crushed standing in line if someone is in front and behind me, so she lets me be first or last.

E Is for Eye Contact

For children with Asperger's, eye contact is usually avoided, even when they are infants. Kids with ASP might look past you, up, or down, but not right at you. This makes it impossible for them to read faces and know when a person has lost interest or is unhappy with their behavior, or is trying to give them certain cues.

Nick: Just because I'm not looking at your face doesn't mean I'm not paying attention or listening. Looking in someone's eyes seems really weird and uncomfortable to me. Sometimes when I look in a person's eyes I have trouble concentrating on what she is saying.

F Is for Favorite Subjects

Kids with Asperger's have specific favorite subjects that can include robots, the weather, the news, reading, playing with water, and the Discovery Channel. They usually want to (and try to) talk about every detail of each subject, whether you're interested or not. Interests include building things out of Legos, paper, sand, and wood or just about anything they can find.

Nick: I like building things. It took me six weeks to build a paper city because I kept getting new ideas. I only stopped when my cat ran through the city and demolished it. I like to watch programs on science and machines; they give me ideas for my own inventions. I am good at math, spelling, and science, but not so good at penmanship, art, or PE.

G Is for Groups

Groups are a problem because kids with Asperger's have an unusually strong sense of hearing, and being in a large group can be unsettling because of the noise level. They will usually act immature, make rude noises, act out, or ask to leave. These reactions can make family gatherings, movies, recess, and school assemblies problematic. When you sense tension building, ask the child if he needs a break and help him find a quiet place.

Nick: The noise in a group, like the lunchroom, playground, and the classroom, can get too loud for my brain. I might cover my ears and put my head down to make it quieter so I can think. One time I left an assembly where African drums were being played because they were so loud they made my whole body shake.

H Is for Hyperactive

Hyperactivity is a common symptom for kids with Asperger's. They might run around the playground by themselves for no apparent reason; go without sleeping through the night; talk incessantly on a subject that interests them; shout repetitive words; tap hands, feet, pencils, etc., constantly; and blurt out words or sounds at inappropriate times.

Nick: Sometimes I make noises like a cat or dog; spin my pencil, or kick the furniture while I'm thinking. I have no idea I'm doing this until someone tells me to stop. Sometimes I blurt things out; my brain just needed to say things right then and it didn't ask for my permission.

I Is for Impulsive

Impulsive behavior can be embarrassing for parents in social settings. Kids have an inability to see things from another person's perspective. By age 9, other children can usually control their impulse to blurt out, interrupt, make rude noises, or hide under tables. As children with Asperger's grow up, these social faux pas will become a bigger problem. Parents should role-play with them about socially acceptable behaviors. Inform everyone -- relatives, friends, neighbors, and teachers -- of your child's condition and what his behavior might look like so they can be prepared and supportive.

Nick: When I was in third grade, I asked my grandma, who is a teacher, to visit my school and talk to my classmates about Asperger's. After the talk, kids treated me nicer and were more understanding because they found out I was not just being a brat or a baby.

J Is for Jokes

Some kids with Asperger's have brains wired for facts and they absorb information literally; they often have difficulty with understanding humor or playing pretend. They love information, especially on topics they like, but they can't tell when you're being serious and when you're being humorous.

Nick: I don't get jokes or understand when you're kidding. I have difficulty noticing the expressions on your face or the different tones of your voice. I usually respond by saying, "Really"? I become confused because I think you mean every word you say. Please tell me when you're just being silly.

K Is for Kindergarten

Kindergarten is especially difficult for a child with ASP. Everything is new and unfamiliar -- teachers, classmates, noise, rules, daily routines -- and there is no quiet place to go. This all adds up to a lot of confusion. To ease a child's transition, make an appointment to meet with the teacher and to see the room before the first

day. Bring along information on Asperger's and ask if there's a daily routine. Better yet, plan a playdate with one or two classmates before school starts so the child will know someone in the room.

Nick: I couldn't wait to go to kindergarten. When I got there, I was surrounded by lots of kids I didn't know and by lots of noise. I felt like I couldn't breathe. My teacher thought I had a behavior problem and yelled at me every day until my grandma and my mom talked to the school principal. The principal must have talked to my teacher because she was nicer to me after that, and I started to like school again.

L Is for Listening

Listening (as in hearing, not minding) is something that kids with Asperger's are skilled at even when it seems as if they aren't paying attention. They can repeat every word they hear on the topics that interest them, but if you're talking about something that doesn't interest them, they may not be listening.

Nick: If I like something, I'll try to tell you every detail I know, even if you're talking about something different. Just say, "It's my turn to talk now," and I'll try to listen to what you are saying until I think of something I think you should know.

M Is for Motor Skills

Difficulty with muscle control is common in children on the autism spectrum. Their gait might look a little different; they might misjudge the location of a moving ball; and they may have difficulty with motor skills such as climbing, skipping, balance, and running, because they are not sure where their body is in space.

Nick: Mom said she worried that I had a problem when I was 2 years old and couldn't walk or talk as well as my cousin who was the same age. She took me to a special preschool gym that helped me with balance, running, and climbing. I have an after-school aide who helps me throw and dribble a basketball, stretch my muscles, and improve my balance.

N Is for Naive

Kids diagnosed on the autism spectrum are often the target of practical jokers and bullies. They are honest and have good intentions, and they believe that others are the same. A fast talker can confuse a visual learner who doesn't hear or process every word spoken and doesn't always understand the nuances. Often, kids with ASP refer to school bullies as friends because the bullies pay attention to them. Also, they may take things at face value and believe things without question or skepticism.

Nick: I saw a program on TV about the apocalypse. When I told my grandma, she said that people have been predicting the end of the world since she was a little girl. I said, "But this time it is true. I saw it on the Discovery Channel, so it has to be true." She told me it was the Mayan calendar and because we weren't Mayan I could stop worrying, so I did.

O Is for Order

Order is important and everything must be in the same place all the time. It's unclear if this is because it helps kids with Asperger's maintain a sense of control or because it makes things easier to find. If things aren't where they belong, a meltdown is sure to happen.

Nick: I like my shirts and pants hung by similar colors so I can find the ones I want to wear. My desk is neat so I can find things quickly. I sort my toys into bins by color and size. I don't even like different foods touching

each other on my plate. It seems wrong to me to have things crowding each other. I like everything in its own space.

P Is for Patience

Kids on the autism spectrum have no patience when they want something, but they seem to have more patience with babies, animals, people with special needs, and older adults than other kids do. They are more communicative with these groups than they are with their peers. They don't see them as different and they give help freely. They are open-hearted, well-intentioned, and kind with those they trust.

Nick: My grandpa needs help getting things so I do it for him. He messes up the remote a lot and asks me to help him find Netflix. I don't mind because I'm good at that. When Grandma gives me a cookie, I always ask for one for Grandpa too. We talk a lot about buildings; he was a contractor and knows a lot of interesting stuff about design and construction.

Q Is for Questions

Many kids don't have a social filter and ask questions at the most inappropriate times but kids with Asperger's don't respond to a hint or even a direct comment to stop. They just keep going until they resolve the issue for themselves. When I took my 6-year-old grandson to the store, he asked the clerk if she had a baby in her stomach. She answered, "No." I glared and shook my head no. He pressed on, "Then why is your stomach so fat?" I told him that he wasn't being polite. As we were leaving, he said, again, in a very loud voice, "But her stomach is kind of fat!"

Nick: I ask a lot of questions because I want to know things. My brain is curious about a lot of stuff. I don't understand what it means to be polite or rude. If you have a question, shouldn't you ask it? How will you learn stuff? My mom came up with the word "zip" when she thinks I should stop talking. It doesn't always work.

R Is for Routine

Setting times for meals, getting dressed, leaving the house, doing homework, and going to bed are vital elements of a daily schedule. Routines are absolutely necessary and serious meltdowns can be triggered by major or minor changes in the schedule and by changing rules (even if they're to the child's advantage). Set a plan and have everyone in the family stick to it.

Nick: I'm happiest when I know what's going to happen next. On Sunday I get to write on a white board what's going to happen for the week. I don't like surprises or being told something will happen in 10 minutes. I like to know the rules and follow them. My teacher has a lot of rules in our classroom and I like it that way. Sometimes kids make fun of me or call me names when I tell them they are breaking a school rule.

S Is for Sitting

Unless a child with Asperger's is totally involved in what is going on, sitting still is difficult. Muscles may cramp or twitch, which makes sitting still a physical problem. If a child doesn't find what you're saying interesting, she might walk away.

Nick: Sitting for a long time is hard for me, and my body needs to move around. When I was in kindergarten, my legs hurt if we sat on the floor for sharing circle. My teacher got me a special wiggle pillow (it's filled with air that lets me shift my weight without standing up) that made it easier for me to sit longer. Now that I'm older I don't need it anymore. I went to see a play and the special effects were so interesting I could sit through the whole show without having to get up.

T Is for Tantrum

You haven't really seen a tantrum until you've seen one thrown by a child with Asperger's. This is not a hold-your-breath-until-you-get-what-you-want-tantrum, but an out-of-control-ranting-possessed-arms-flailing tantrum. You may never know the reason for the tantrum and sometimes the child doesn't either. Keeping a journal of what happened before the tantrum might help you find the trigger.

Nick: When I'm very tired, I can get out of control because my brain can't do or hear one more thing. I have thrown and broken things I like, tipped over a table, ripped up homework, yelled at people, and started crying. I usually wear myself out, and fall asleep, but I'm fine when I wake up.

U Is for Understanding

Kids on the spectrum need more understanding than most because they learn differently and don't understand some things. The typical brain progresses in a general to specific direction, but the autistic brain is just the opposite. Our brains take in information and cross-reference it, but kids with ASP have to be taught to cross-reference, think in categories, apply concepts, and identify cause and effect. Parents should get involved with a support group, read books on the subject, and talk to specialists at school. Share information with family and friends so they can better understand the child and offer the needed support. Remind them that Asperger's is a medical problem, not a behavioral problem; the brains of kids with Asperger's are wired differently.

Nick: My brain is like an untrained dog. You have to keep telling it the same thing over and over until it gets it. If you want to understand me, read a book or look online for information. You can also read my favorite book, *All Cats Have Asperger's Syndrome*. I hope you'll be more understanding and help me by being my friend and by not letting others make fun of me.

V Is for Voice

When a child with Asperger's reads aloud, his voice can sound flat and boring, without much intonation or emotion. His voice may be singsong, robot-like, or high-pitched. Each word is a stand-alone bit of information, not part of a story.

Nick: My voice gets very quiet, loud, or squeaky when I'm nervous. Sometimes it sounds like I inhaled helium from a balloon. When I'm talking in front of the class, I can sound like I am singing. I can't control it at first, but after a few words, when I feel safe, I can sometimes be in charge of my voice.

W Is for Weight

A weighted vest, heavy blanket, sleeping bag, or strong bear hug can calm down an overactive brain. Full-length body contact is soothing and calming. The movie *Temple Grandin* is about a woman with autism who achieves a Ph.D. in animal science and becomes a professor and an inventor. While in college, Grandin invented a squeezing machine to calm herself down when she was stressed out.

Nick: Sometimes I need to pile pillows and blankets on top of myself to stay calm. A friend has a vest with weights in it that he uses when he feels out of control. Sometimes squeezing my mom real tight helps me to feel comfortable and safe.

X Is for X-ray

Doctors are conducting research on patients, using X-rays and scans of the brain in action, to figure out the causes of Asperger's. They have already noticed more activity in many different parts of the brain of an ASP

patient who is performing the same tasks as a non-ASP patient. Scientists seem to agree that autism spectrum disorders are genetic problems and are trying to isolate the affected genes.

Nick: If you had X-ray vision you would see that my brain works differently than yours. Many parts are working at the same time and sending me lots of messages while yours are sending only a few messages to one part of the brain. I saw this demonstrated on the Discovery Channel.

Y Is for Young

Diagnosing a child with Asperger's can be difficult because there is no medical test, like a blood test. All children should be screened for developmental delays during regular well-baby visits, specifically at 18 and 24 months. Youngsters with a sibling or another family member with Asperger's are usually at a higher risk, and boys are at a higher risk than girls. The younger a child is diagnosed, the sooner he can get the necessary help to be successful.

Nick: Mom said she had never heard of Asperger's until the doctor told her I might have it when I was very young. She knew something was wrong but didn't know the problem. She read a lot about Asperger's, and then some of the things I didn't do as a baby -- like look her in the eye, follow her finger when she wiggled it, try to hold myself up -- made more sense to her.

Z Is for Zone

When a child with Asperger's is deeply involved in a project or on the computer, it is difficult to get her out of the zone to focus on you. Often, when a child is in the zone, she can say things out loud when no one else is around. Setting a time limit, taking required meal and bathroom breaks, and giving a 10-minute warning can help avoid problems.

Nick: I usually set a timer so I know when to stop building Legos or playing computer games. I get so involved in what I'm doing that I don't realize how long I've been doing it. Once I played Legos for six hours and told mom I wasn't done when she said it was time to stop. When mom showed me the clock, I was surprised. Sometimes I concentrate so hard on what I'm doing that I don't even know someone is talking to me. You might have to tap my shoulder. I'm not ignoring you -- I don't even hear you.

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