

My ABCs of Living with Asperger's Syndrome

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TRAIN WITH KI AIKIDO I have been training with the principles of Ki Aikido since 1993. It is the most important element of my life that has enabled me to both understand what Asperger's Syndrome is all about and how to cope with daily life. Ki aikido is different from other martial arts philosophies in its focus on resolving conflict with compassion. Ki energy flows within you and extends to others in social interactions. When you see someone you know from across a room, the feeling of warmth towards that person is your Ki energy connecting the two of you before you're close enough to embrace or talk. On a physical level, Ki Aikido has significantly improved my coordination, not only in the way the left and right sides of my body cooperate, but also between my arms and legs. The feedback I normally receive is limited to one body area at a time so I'm not aware of what the rest of my body is doing as I move. Now that I can connect with Ki energy, I'm more aware of my body as a whole entity so I can lead the attacker with more confidence. On an emotional level, I can face that person without wearing a defensive shell of ice that served me well when I didn't know that Asperger's Syndrome was creating my sense of not fitting in. It's difficult to relax and lead effectively when you don't know who you are. On a spiritual level, I've discovered that Asperger's Syndrome creates a sense of dis-connection with humanity that's responsible for the feeling of being from another planet. Through my training, I've been able to reclaim that connection for brief precious moments.

READ BODY LANGUAGE IN MOVIES The magic of Hollywood clarifies some of the complexity of social interactions with its use of music, plots and backdrops that allow the viewer to be part of the scene. In the years before video, I used to drive my siblings crazy trying to keep characters and plot twists straight in my head while getting lost in some detail of the set, or the rhythm of the background music. Modern movies seem to do a better job of leading the viewer through the story. I experience a much larger range of emotions when I can watch the body language of the actors while listening to them. In real life, I can only listen or look but not both. When there is no talking, I can read body language more clearly using visual matching to the examples I've seen in the movies.

CONNECT WITH KINDNESS NOT FEAR Kindness with no strings attached is the definition of compassion. I've found some people I can look in the eye because, when I do, their eyes are welcoming like arms open wide that reflect an open heart, not full of distractions like crossed arms that deter trust. I function in a state of flight-or-fright all the time with an autonomic nervous system on overdrive. It feels natural to be afraid of people and not trust them. So I came up with a social experiment, 3 years ago, that I'm continuing today as an employee of Busch Gardens in Williamsburg, Virginia. As a cashier, I'm able to practice kindness through good customer service, from greeting with a smile to clarifying questions about menu items. Eye contact is easier because it's brief, or a function of clarifying information I already know. I'm still at a loss for how to maintain eye contact in casual social encounters while actively listening.

LEARN BALLROOM DANCING As a college student, I discovered the benefits of ballroom dancing classes that helped me experience dance patterns. Although I can play musical instruments and sing, I didn't know how to feel the rhythms of dance music. Parks and recreation programs are a great source for adult lessons in addition to dance studios. Once the basic pattern of a dance style becomes a routine, elements like turns can be added as confidence increases. When freestyle dancing is expected on a small dance floor, I've learned to hold my husband's hands to isolate my feet so they can move to the beat without the stress of tuning into multiple body parts at the same time.

RECOGNIZE EMOTIONAL VS. TACTILE DEFENSIVENESS Emotional defensiveness is more prevalent in autism, but often mistaken for tactile defensiveness, since they both create a need to defend one's personal space. The easiest way to tell them apart is to compare your reaction to touch when you can see the person approaching and when you cannot. If your sensitivity is strong only when you can watch as you are touched, then you have emotional defensiveness that is heightened by visual anticipation and is reduced by exposure to textures and heavy work activities, which enhance a low feedback system from your skin and muscles when pushing, pulling lifting and carrying objects around.

FEEL IN PICTURES When I experience complex emotions, I visualize them as a metaphor that helps my heart to know how to feel, by painting a picture so I can experience the richness of the moment with familiar visual elements. For example, when I talked about training with Ki Aikido, I mentioned that I used to wear a defensive shell of ice. The experience of feeling that ice melt away is straight out of Santa Claus is Coming to Town when the winter warlock was transformed by a toy.

CLARIFY GAME RULES Whether you're playing a board game, card game or Twister, make sure to clarify what version you are playing. It is extremely frustrating to discover different playing styles in the middle of the game that aren't described on the box and can quickly lead into meltdowns. Trying to learn the rules of social games is like building a puzzle that contains only red pieces so you're stuck with a long process of trial and error to find some sort of pattern to follow. Try to ask questions of trusted people to find win-win solutions.

USE HUMOR TO GET UNSTUCK My husband came up with the best way to diffuse my panic attacks that he describes as “extrapolation to disaster”. He comes up with more far-fetched examples of what might happen and I can’t help but laugh about what now sounds like a minor inconvenience.

INVEST IN A MANUAL CAR I originally bought my current car to give my left leg more exercise in city driving to compensate for damage from a blood clot. But I discovered that changing gears manually gives me a better sense of control on the road and I’m far less prone to road rage. Because there’s more involved to drive than just stepping on the correct pedal, I don’t feel like the car is the one doing the driving especially during rush hour gridlock.

JOIN SPECIAL INTEREST GROUPS I’m a strong advocate for letting your special interests lead you to a group as a vehicle for fitting in. I met my husband through the shared experiences of an adventure club that offers unique opportunities to try new things from international cuisine in restaurants to sky diving.

KEEP SMILING I’m not a big fan of lemons but I love lemonade. One of my biggest strengths is to adapt to situations through problem solving. However, I don’t seek out problems to solve. So I can turn a coffee table into a footrest without noticing the ottoman a few feet away. A positive attitude is possible when you see possibilities. I love to find meaning in serendipity to connect random events into purposeful patterns. This past school year, I was presented with an unexpected adventure. Our OT department usually consists of 2 therapists, one to cover the elementary school and one to cover the middle and high schools. When the other therapist left over the summer, it was assumed that the position would be filled before the school year began. Instead, I was responsible for the entire caseload. It was a daunting task, to say the least, and it required grouping students to fit everyone in the schedule. Asperger’s syndrome makes it difficult to lead more than one person at a time even if they don’t have behavior issues. I could keep smiling because I had the opportunity to work with elementary students who have usually not developed fixed maladaptive patterns and they are more eager to try new things. I also learned to rely more on the teachers to help with paperwork and data collection. Asking for help is not easy when you have an independent spirit. When you order from a restaurant, you may not recognize what comes on your plate, but taking a taste anyway can reveal a new culinary favorite. I also don’t dwell on timelines to achieve life goals so I open each day like a present and smile.

LISTEN TO VOCAL TONES When eye contact is not an option, I listen to more than words. It’s also helpful when my literal thinking gets in the way of getting jokes. If the person telling the joke uses an exaggerated voice, I can resist the urge to believe that what they are saying is fact not fiction and I can laugh along with them.

STRIVE TO MAKE A DIFFERENCE This is a motto I use to cope with the day-to-day stress of autism. There is a story that goes with this motto I’ve experienced as the lead character. One summer day, I was walking along a beach in coastal Washington State. I came across at least a hundred starfish that had washed up on the beach. I proceeded to throw as many as I could, one-at-a-time, past the surf back into the sea until I was out of strength. In the story, an observer says that it’s a waste of time to fight such a losing battle but the reply is always the same, “I made a difference to this one,” as another starfish gets lobbed into the ocean. Find your starfish and set it free.

LET NO BE YOUR GUIDE Limit testing serves as a security blanket. When someone gives you “no” for an answer, it shows that they care about you. They’re establishing boundaries that promote growth like tending a garden by clarifying expectations for acceptable behavior and giving you the freedom to explore what you’re capable of without fear. Self-confidence is strengthened when you test limits knowing that someone is helping you blossom.

REDUCE SENSORY OVERLOAD When sensory experiences are processed in a typical way, it’s like being an electric skillet. If you put a scoop of crushed ice into it and wait awhile the ice will melt and eventually evaporate. You can keep doing this all day as long as it’s turned on. With sensory overload, the skillet isn’t plugged in so the ice just piles up and even falls out of the skillet. I have various sensory sensitivities that can interfere with my ability to think straight. Fluorescent lighting, carpets with busy patterns, cell phone chatter and stuffy rooms all put me on edge. When I’m not able to escape their chilling influence, I wear safari hats to minimize glare, use physical barriers to reduce eye contact with visual patterns, and keep a personal fan handy to compensate for my canary lungs that need fresh air. I also avoid cell phone addicts and smokers like the Plague.

BUILD PUZZLES Jigsaw puzzles are a low-tech source of leisure that can captivate my attention for hours. Puzzles help you learn that problems can be broken down into patterns when you find a way to see the picture on the box. Details are easier to focus on, but when you find the connections between them, you can build the big picture.

QUESTION EVERYTHING “Why?” is a wonderful word because it stimulates curiosity and builds knowledge. It’s easy to feel stuck and spin your wheels trying to find answers. But when you can feel free to ask for help, you can hopefully move in the right direction. There is also a drive in Asperger’s Syndrome to want to know all the details and we assume that others share that perpetual pursuit of knowledge. My husband came up with a strategy that lets me know he doesn’t want to go into details. He simply says “yes” when I ask a question and I know to stop my inquiring mind. Getting attached to details is like panning for gold in Alaska. You spend so much effort looking for tiny treasures that you miss the amazing beauty that surrounds you so it’s good to look up occasionally and take in the landscape.

APPRECIATE REDUNDANCY As you may have noticed in my ABCs, there are no repeated verbs in my list. Redundancy has been a pet peeve of mine for a very long time, both in written work and spoken conversation. But it's also based on a mind-blind assumption that others can understand my perspective. Redundancy replaces novelty with routine and stimulates emotional stability by evening out mood swings with predictability.

TRUST SAFETY LINES AND NETS Although I have many sensory sensitivities, I'm also sensory seeking as long as some sort of safety system is present to keep me physically connected. In our adventure club, safety systems have enabled me to receive the "No Fear" award for completing activities such as bungee jumping, tandem skydiving, hang gliding, riding extreme roller coasters, and fire walking. But trust in people has been far more difficult to come by. Social dyslexia is what I call the way I go brain dead when I try to make friends because I feel clueless all the time. I'm used to depending on myself rather than a friend network. As I mentioned at the beginning of the alphabet, I've become more familiar with compassion that leads to trust in others enough to ask for help to be included.

MONITOR TANGENTIAL TALKING My mind organizes ideas by association rather than logical sequencing unless I'm studying for a test. In that case, I memorize my notebook pages as they are written. I am indebted to whichever teacher in high school introduced me to outlining. By taking notes in outline form, the columns of letters and numbers created wavy patterns instead of paragraphs that were easier to recall like the notched edge of a key. My talking style, on the other hand, is a collection of ideas that are loosely connected by shared words or meanings. It's especially pronounced if I'm talking about a special interest. There is such a profound joy in sharing the knowledge that it's difficult to pause and check to see if the person I'm talking to understands or even cares about the topic. Working in a school setting gives me access to many neurotypical people who confirm that good listening skills are more important than talking skills to interact effectively. It's difficult to listen for the meaning of the other person's message that may not be conveyed in the actual words used. I'm very new at listening with my heart and not my head, but it needs the exercise.

EXPLORE UNDERWATER REALMS I've been scuba diving since 1988. The sensation of being suspended in water with neutral buoyancy is both exhilarating, as the surrounding water boosts my weak feedback system that's supposed to provide a sense of body position in space, and relaxing, as I glide through the water like a fish (once you get used to the Darth Vader sounds you make as you breathe through the regulator). It's a similar sensation of being suspended as tandem skydiving where you feel suspended in the air during freefall instead of falling. My sensitivity to diesel fumes and cigarette smoke can combine with rocking seas to make boat dives risky for nausea. But I have learned a method to cope with the waves alone using the analogy of driving a car. When you're the driver, you don't get car sick because you're aware of the road conditions and anticipate where to look and how to steer the car smoothly. On a boat, you can also become a driver by standing up and letting your body balance as the waves rock the boat instead of sitting and looking past the waves trying to pretend that they are as calm as the horizon. If you need a tamer experience of marine life, I recommend a swim with the manatees here in Florida. They are very gentle and curious creatures that will come to you when they need their back or belly scratched.

CELEBRATE VICTORY AND DEFEAT Losing is no fun, but winning all the time would lose its specialness if it was guaranteed. Be willing to challenge yourself to make mistakes, even though it goes against a cardinal rule of Asperger's Syndrome. It's not about being perfect or being right all the time that we strive for, but to avoid mistakes so we don't have to change what we know to be true. Defeat offers the opportunity to be humble and to appreciate the luck and/or skills of others we can learn from.

PAUSE TO WONDER EVERY CHANCE YOU GET One of my favorite features of Asperger's Syndrome is the access to a state of childlike wonder in response to moments of natural beauty, discoveries of new ideas, and mesmerizing music. I can't imagine any drug being more powerful.

CHANNEL EXPERTISE INTO A CAREER As an occupational therapist I put my skills as a problem solver to good use every day with each student I see. When you find a career that naturally incorporates what you do best, it's easier to fit in with the working world. It may not pay well but if it's something you enjoy then it's worth doing.

ACT YOUNG I don't let age dictate my behavior. I find something to enjoy about life every day. In a way, I have a version of Peter Pan syndrome in that I shy away from leadership roles and I love the Ben & Jerry's motto that says, "If it's not fun, why do it?"

ZIP YOUR LIP When I speak my mind, it doesn't like to be tempered because truth is more important than tact. However, that attitude also pushes people away. Talking in an autistic way is like being on stage with a spotlight shining on you. The voices of the audience evoke fear because they are heard randomly from any direction and the darkness makes them disembodied. You tend to talk at the audience so you're not able to listen for their point of view. Support groups can help you feel more relaxed as a member of an ensemble so the spotlight isn't so blinding and your awareness of the audience changes so you can hear their encouragement to do well and you end up talking with them.