



STAT:

Nurses on Duty Treating the Patient with Autism/Asperger's Syndrome

By Carolin Corum, RN

I had just returned from taking my 83-year-old fractured hip patient to surgery when the Team Leader approached me. "I have a direct admit for you. He is a five-year-old boy with a right distal radius fracture, and he is already on the floor in room twelve. Oh, by the way, I think he has autism."

While I am washing my hands and collecting my thoughts, I see the boy's father coming out of room twelve. He walks up to the Team Leader and asks, "When will my son see his nurse?" The Team Leader smiles and says, "She will be in shortly." The father starts to walk

away, then turns and asks, “Does the nurse know anything about autism?”

I feel a little bit of frustration rising up inside. I think, “Of course I know about autism. I went to school. Autism is a complex developmental disorder, with a defining characteristic of speech delay. What else does he want me to know?”

Patients with autism and their families want so much more than a textbook definition. They want true understanding and compassion, modeled in every duty performed. I know this because I am both a Registered Nurse (RN) and the mother of a child with autism.

Change is a constant within the field of nursing and taking the time to learn more about autism and people with it may seem like just one more thing to do in a vast sea of medical knowledge required for the job. However, autism stands out in its importance. It is on the rise – at alarming rates. More and more patients will be coming into hospitals and doctors’ offices for emergency and routine care. Now more than ever, nurses need to be knowledgeable and understanding.

Having been an RN “on the floor” in these situations and mommy to a dear son with ASD, I’ve put together some advice parents can share with nurses who encounter their children on a regular or emergency basis.

Nurse to Nurse Advice

1 Verbal Communication with a Patient with ASD

When talking with an adult with ASD, keep in mind they often will have a

slower response time in conversation. Wait for their response, rather than jumping in again with the question. This will only make things worse. Until you can properly assess their intelligence level it is best to assume intelligence. Keep statements short and focused, but never talk down to the adult. Speak slowly and provide factual information rather than emotional nuance.

2 General Communication with a Patient with ASD

Eye contact does not come naturally to people with ASD. If they are looking at your face it will more likely be your mouth, not your eyes. Be direct with your instructions, saying specifically what you want them to do. These individuals do not usually pick up on social cues. For example, they might not understand a nod of the head towards a table. Try to speak in concrete terms and avoid phrases like “The anesthesia will be a cocktail” or “This procedure is a walk in the park.” They interpret directions literally, unable to decipher social innuendo, so don’t think they are strange if they hop when you say to them, “Hop up on the table.” It’s what you asked them to do.

3 Tantrum Prevention

The medical world is full of strange smells and sounds, strange equipment and activities moving at a strange pace. Any hospital station or doctor’s office can suddenly turn into a frenzied place, highly unnerving and anxiety-producing for the spectrum person. Ward off a tantrum by having a set of headphones within easy reach to help calm the patient when excitement suddenly

appears. Or move a child with autism to a more quiet area of the hospital when calamity ensues. Close an office door to shut out visual and auditory stimulation.

4 Heed the Warning Signs of Impending Overload

People with autism often try to self regulate before a meltdown occurs. The child might start rocking, stimming (doing repetitive movements), speak in echolalia (repeating sounds, words or phrases) or even start chewing/biting (their clothing, their arm/hand, a close object, even you!). When these signs appear, give the child a break. Back off and dramatically reduce conversation for a few moments. If you keep pushing there is a good chance a meltdown will soon follow. For some children deep pressure will calm them at this time, but a light touch can cause further anxiety. Follow the parent’s lead, or ask before you touch. Parents may have odd suggestions, but parents know what has proven successful in the past. Trust what they tell you. They might suggest smooshing the child with a pillow, giving a very tight hug, squeezing the child’s head or singing a certain song.

5 Talk, Then Act

People with ASD often go through life not knowing what will happen next. Their ability to generalize one situation to the next, or realistically compare/contrast situations is compromised. They live in a constant state of anxiety of greater or lesser proportions. Alleviate their stress by explaining what you will do before you do it. For instance, “I need to get take these



Parent to Nurse Advice

Parents can quickly “fill in the gaps” when a situation involves a nurse unfamiliar with ASD. As a mom, here’s what I want my child’s nurse to know:

- 1. Every child with autism is an individual.** The autism spectrum is very broad and kids differ in how autism affects them. You may have met one child or a handful – please don’t stereotype their abilities/challenges. Listen carefully to the parents’ description of this child’s specific characteristics.
- 2. Say Less and Stress, Go Slow and Show.** These four S’s, from the book *More Than Words* by Fern Sussman, are a great model for communication. Keep your information very simple, short, do not talk too fast, stress the important words and when possible show objects or pictures to reinforce what you are saying.
- 3. A nonverbal or less verbal child can communicate without words.** Many children with autism use a simple sign language, and other children may point to pictures or hand you pictures to communicate. Be open to different forms of communication.
- 4. Autism does not mean unintelligent.** As a rule, we equate language with intelligence and social intuitiveness. This is a fallacy. Many children with autism are very advanced for their age in some areas, and talk like a “little professor.” Or they are nonverbal, yet highly intelligent in receptive communication. Don’t make assumptions based on stereotypical ideas about verbal ability and “disability.”
- 5. Their behavior is a form of communication.** When children with ASD start biting or hitting, covering their ears, screaming or throwing themselves on the floor in a tantrum, they are telling us something is amiss in their world that they can’t communicate through words. Parents often already know common triggers for the behavior, so please don’t judge, just listen and trust what we tell you. It could be fluorescent lights, a loud beeping sound coming from the next room (or down the hall), or that the child is in pain.
- 6. Not everything is autism.** Spectrum children have bad days just like the rest of us. They get cranky when they’re tired or hungry, just like the rest of us. Not liking the hospital food could have nothing to do with the child’s autism. Don’t generalize everything the child does under the label of autism.
- 7. Being the parent of a child with autism is not easy.** If you see parents struggling to control their child with autism, please extend some understanding. There are countless reasons a behavior outburst may be happening, and it’s generally not because of “bad parenting.” Be compassionate. Parents are just trying to do the best job they can.

samples to the lab and will return in 5 minutes.” A sudden unexpected pain can be very difficult to process. If a procedure does hurt, they will associate you with that pain. Walk in their room the next day and your patient may instantly burst into exaggerated behavior and anxiety – expecting you will again cause that pain. And, they have excellent memories. If you are a nurse in a physician’s office, you may experience the same reaction from a patient you treated a year ago. After a procedure give patients an opportunity to express themselves. In many cases they’ve tried very hard to comply for you. If the child is unable to speak, take an opportunity to draw the event or offer music that demonstrates how they are feeling.

6 Starting IV’s

Starting a peripheral IV has become a very common task for many nurses. It is generally unpleasant for patients, so nurses often take the approach, “We need to get this over quickly!” This is not necessarily the best tactic with the spectrum child/adult. First, these individuals may not easily feel pain and/or understand how to say, “Ow!” Second, letting them know what’s coming up helps alleviate anxiety. Explain the procedure briefly, what it will feel like, and how long it will take. “I am going to insert this needle into your vein, which may feel like a sudden prick that will hurt for a moment. The procedure will take less than 3 minutes to perform but you may feel some tenderness or coldness in that area afterwards.”

7 Off-floor Diagnostic Procedures

Sending a child with autism down for an X-ray or other diagnostic procedure can be very difficult, creating huge amounts of fear in the child/adult. Generally, diagnostic tests are not painful, but are uncomfortable, especially for a child with heavy sensory issues. Children with autism typically have a

hard time with surprises, so it is best to take as much of the mystery out of the procedure as possible. It may be very difficult to describe what the machine looks like or the kinds of sounds it will make ahead of time. One way to make the X-ray machine seem less scary would be to show the child a picture of the machine and have a recording of the sounds they will hear. Once the child arrives, try to explain the procedure, show him the equipment, etc. Or have mom or dad “test” the machine/procedure while the child watches, if this is at all feasible to do.

Putting on a Cast

Most people describe getting a cast as uncomfortable, but not painful. A child with tactile sensitivities, however, may find this touch excruciatingly painful. Ask parents about the child’s sensory challenges and suggestions for minimizing discomfort. Any child can

find it very difficult to sit still while you put on a cast. Some form of distraction is essential for this kind of procedure, and the well-prepared nurse will have a drawer of interesting items waiting. Do note, however, that these kids can like unusual items! The typical teddy bear or other stuffed animal may be cast aside in favor of their mother’s shoe, a piece of string, a favorite book or DVD box, or even flash cards. If you see a child on a regular basis, ask the child or parents what these favorite items are and have them close at hand. Another great option is having their favorite movie playing. Something familiar can be comforting and calming amidst all the new experiences of putting on the cast. And again, explain what you’ll be doing. Make sure the child sees all the materials used to make the cast and is aware of the textures and sensations they will feel.

Public perception and understanding of the myriad characteristics associated with autism spectrum disorders is yet in its infancy. Be willing to acknowledge “not knowing” and ask parents for help. Then listen to what they tell you, without judgment or preconceptions. There is still much misinformation and fear in the neurotypical medical community about autism, but there is also much hope. A healthy curiosity and willingness to step outside the typical way you function with patients will drive away your fears and those of your patient and create bridges of compassion and true understanding. 📌

Carolin Corum, RN, is a mother of two boys, one with ASD. Her second children’s book, *Buried Treasure* (April 2009 release), is about a family working together to overcome autism. Learn more at www.tatepublishing.com/bookstore.



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