Putting Autistic Patients at Ease
An editorial supplement to 'Understanding Autism,' June 2004 JEMS

Editor's note: The following tips are meant to be read in conjunction with "Understanding Autism: How to appropriately & safely approach, assess & manage autistic patients," by Loralee Olejnik, in June 2004 JEMS.

To recap: According to the Autism Society of America, autism—a neurological disorder that typically appears during the first three years of life—specifically affects brain function in the areas responsible for the development of communication and social interaction skills (www.autism-society.org). Centers for Disease Control and Prevention (CDC) statistics place the prevalence of the disorder at two to six per 1,000 people. Although individuals with autism may otherwise appear perfectly normal, the disorder makes it difficult for them to function and communicate in socially appropriate ways. The inability to be understood may cause frustration and confusion for both the patients and those interacting with them, and often makes the autistic person appear to be acting bizarre or abnormally.

"There are elements surrounding ambulance calls that bother many autistics," says one high-functioning autistic who also happens to be a working paramedic. "It has taken me years to 'get used to' things, especially noise, on these scenes. Some days are better than others. I still have problems with AC vents blowing air on me, especially into my face. We've all got our quirks, I guess." So what's the best way to recognize, approach and assess an autistic patient? Olejnik offered several tips in the June article. The following tips on how to put autistic patients at ease come from the paramedic mentioned above.

Autistics at Risk

Suicide attempts by autistic patients are common, especially among high-functioning autistics. Because they have difficulty with non-verbal communication and also take things literally, autistics tend to miss social cues. Autistics are wired differently from the general population. They often lack the ability and experience to deal with school and/or office politics. These traits make autistics easy targets, and many are harassed and ostracized for reasons they cannot comprehend.

Most autistics are emotional wrecks by the time they reach middle school, and are at high risk for depression and suicide. Many receive "generalized" treatment and counseling that is confusing or demeaning to them, only making things worse. As a consequence, some autistics don't trust potential caregivers. Some have a general fear of "the system" from past experiences, so they don't seek assistance. These individuals aren't likely to be forthcoming with EMS personnel who are trying to help. They need a different EMS treatment plan.

When autistic patients flee their caregivers, they are often attempting to escape the sensory overload of this sudden "invasion" into their space. Most autistics attempt escape solely to get away from the strange people, voices and equipment invading their familiar realm. Autistics have difficulty adapting to rapid change. Patience and time are vital to successfully treating and transporting these patients.

Easing autistic patients

Explain all assessments and treatments. Many autistics crave information and will want to know more about what's happening. Explain those "hows" and "whys" as best you can, and be prepared to discuss specifics. If they understand why a procedure is being done, they're more likely to allow it. It must make sense to them.

Autistics are comforted by familiarity. Allow patients (especially children) to bring a security toy or blanket with them. Some autistic patients might become agitated when a strange object touches their skin. Scratchy blankets or disposable sheets can be uncomfortable, while softer, cloth sheets and flannel blankets (similar to those often used in hospitals) generally are better tolerated. The best option is to allow these patients to bring their own blanket along in the ambulance.

Always tell autistics where (and why) you need to touch them during an exam or treatment, especially when you are about to touch them with medical equipment. Metal, plastic or other objects of different temperatures can feel like pinpricks to autistics. Adhesive tape or ECG patches also can be difficult for autistic patients with tactile sensitivity.

Some autistics can be calmed by moderate pressure (wrapping a blanket around themselves, several blankets piled atop the patient, hugging familiar people), but they can be agitated by "light" touches (the pressure of only a light sheet, the sensation of air blowing on them, taps on the shoulder, etc.). For these reasons, you're likely to have more problems wrapping a BP cuff around a patient's arm than by inflating it. Oxygen masks and nasal cannulas also might not be well-tolerated because of the doubly uncomfortable sensation of blowing air and having something on/over their faces.

Autistic trauma patients require constant patience and reassurance. Develop an early and calm rapport with trauma patients, especially if they must be immobilized. Many autistics have had negative experiences with restraints and are likely to make things worse by fighting them. Again, explain every assessment and treatment before it happens, as well as everything they're likely to see, hear and feel during the extrication and/or splinting procedure.

Innovation is the key to successfully transporting an autistic trauma patient. Make sure equipment fits snugly; this will be easier to tolerate than something that rubs or fits loosely. However, many autistics have problems with cervical collars (regardless of the fit) because they can't tolerate something against the base of their chins/necks. Others can't stand the feeling of head straps across their foreheads.
Watch your language—literally. Autistics tend to take everything literally. Double meanings, slang and joking that everyone else takes for granted can be confusing to an autistic. Saying things like, "You're silly," might be taken as an insult by an autistic (who didn't intend to be silly).

If autistic patients suddenly become agitated or "zone out," consider sensory overload as a cause. Many autistics have heightened sensory abilities that are difficult to ignore. Increased sensitivities to auditory, tactile and visual stimuli are common and only get worse in a crisis situation. They might seem to be zoning out, but they actually are drawing on coping mechanisms to deal with everything around them.

You're more likely to see "stimming" (flapping, screaming, playing with hands, rocking, etc.) when patients are overwhelmed by sensory stimuli. They're doing what they need to do to cope. Some high-functioning autistics cope instead by withdrawing (plugging their ears, closing their eyes, etc.).

Autistics might appear mesmerized by on-scene lights and noise. Many have ultra-sensitive hearing and can detect sounds not always apparent to others. Emergency lights emit high-pitched, "whistle" sounds (akin to fingernails on a blackboard). Portable generators, helicopters, sirens and other loud noises also can cause autistics to "withdraw" within themselves to escape it. Even "quiet" ceiling fans can overwhelm autistics because of the fan-induced breeze and the "flashing lights" generated when the blades rotate.

Remember that ambulances are loud. For autistics, the collective cacophony inside a running ambulance can be overwhelming and is sometimes worse than the chaos on scene. Ambulance interiors echo with noise that is made worse when too many providers are crowding inside and talking all at once.

The AC/heating unit's noise is compounded when that air is blown on people. Turn the vents upward, away from the patients. If they still can't tolerate the noise, consider turning off the AC/heating unit. Many autistics are more tolerant of temperature changes than they are of noise.

Interior lighting also might be an issue, for two sensory reasons. Many autistics can see and hear the 60-cycle frequency of fluorescent lights and can become agitated if one of those lights is wearing out (the cycle is out of sync from other lights). Although some can ignore flickering lights, most autistics can't.

Autistic people focus on everything, and seemingly on nothing. Prepare to have your stretcher's click-straps inspected. They also may focus on the coiled cords to the medical equipment, the upholstery stitching on the bench seat, the patterns of linoleum on the floor. While staring out the rear windows, an autistic might not notice scenery passing by, but might instead be troubled at the uneven distribution of road dirt across the outside windows.

Autistics appreciate order. If something's not "right" (tangled ECG monitor cords, sloppy IV tape jobs, wadded sheets/blankets, general disorganization, etc.), they're gonna know it and might tell you about it so you can fix it (because it's "not supposed to be that way").

The best intervention is preparation. If you know of autistic individuals in your service area, offer them (and parents/caregivers) the opportunity to tour your ambulance when they have time to ask questions, touch equipment and "get used to" the way things are. Discuss your procedures and the reasons why they're done. Be prepared for lots of questions. This gives EMS personnel the opportunity to get to know autistic patients, and vice versa, before a crisis situation. That familiarity can literally be a lifesaver, especially if the patient is prone to running away from caregivers.

The link below is to an online sidebar story featuring tips and advice from a paramedic who has autism. "Putting Autistic Patients at Ease" is an editorial supplement to 'Understanding Autism,' June 2004 JEMS article. The full report should be online within a week.

http://www.jems.com/jems/exclus04/e0604b.html