

# Considerations for EMS Response to Autistic Patients

*Picture being trapped in your vehicle. You're not sure what happened. You were on the way to school. Your mom was driving. Now you can't move, your arm feels funny and your mom is beside you moaning softly. Strangers are stopping. They are pounding on the windows. Why are they pounding? You are going to be late for school. Late isn't good. You get a tardy. You begin to hear sirens, loud sirens. And now there are lights. Don't look at them—flashing lights give you seizures, your mom says. Your hands begin to flap. You start rocking. People are yelling. They've opened the door now and are asking you lots of questions. Your mom told you not to talk to strangers. They grab your head and won't let you move it. You need to rock, but you can't move because they are holding you still. You are definitely going to be late now. Your hands flap wildly...*

Being involved in a medical emergency is stressful for anyone, but when the patient is autistic, the associated stress is considerably higher because of the inherent nature of the EMS response. While the flashing lights and sirens of an approaching police car, ambulance or fire truck may bring a sense of comfort to some, for those that are autistic, these sounds meant to help may only add to their discomfort.

## **What is Autism**

The word autism has been in use for about 100 years and was first used to describe a group of symptoms associated with schizophrenics. It originates from the Greek word auto, meaning “self,” and describes a condition where persons are removed from social interaction, hence an isolated self.<sup>1</sup>

Autism is considered a spectrum disorder. Affected individuals may range from non-verbal individuals with severe learning disabilities to those with above average IQs.<sup>2</sup> Wolfgang Amadeus Mozart, Andy Warhol and Tim Burton all have been considered to possess traits that are associated with those on the autistic spectrum.<sup>3</sup>

Autism now affects 1 in 68 children, occurs in all racial, ethnic, and socioeconomic groups and is almost 5 times more prevalent in boys than girls. It is important to note that the majority of persons on the autistic spectrum do not have a co-existing intellectual disability.<sup>4</sup>

## **Signs and Symptoms of Autism**

Individuals with autism have difficulties in three main areas, including social interaction, social communication and social imagination. They may appear indifferent to others and have difficulty understanding others' points of view. They often are very literal thinkers and are have difficulty with change.

One of the earliest signs of autism is a delay in speech development. Those with autism may not be able to communicate at all or may have difficulty interpreting body language, respecting personal space or may have trouble holding a conversation.

Autistic individuals often have very restricted interests and prefer repetitive motions such as flapping, spinning or twisting. These repetitive behaviors often become more pronounced when the individual is under stress or heightened anxiety. There may also be a hyper- or hypo-sensitivity to sound, light, touch,

pain or other external stimuli. This puts the autistic individual at a greater risk of injury as sensations such as hot and cold may be interpreted differently.

### **Considerations for EMS Providers**

Caring for the autistic individual brings many challenges for the EMS provider, especially when time may be a factor. Taking into consideration the three main areas of difficulty and adjusting the plan of care accordingly will provide better outcomes for the patient and the provider.

#### ***Before the Emergency***

EMS providers may wish to seek to identify those persons in their communities with a diagnosis of autism. As part of a community outreach education program, EMS providers can help families register with their community 911 service and provide stickers or other identifiers to be placed on the door or window of the home. The Autism Society offers a personal identification record that allows autistic individuals or their caregivers to outline information which may be pertinent in the case of an emergency.<sup>5</sup> These records include information on specific behaviors diagnosed individuals may exhibit in emergent situations (such as hand-flapping) and direct EMS providers on specific approaches to care.

EMS personnel may want to consider hosting special events for those in the community with autism where autistic individuals can interact with EMS personnel in an “autistic friendly” environment. During these times, the autistic individual can meet the providers and become familiar with some of the basic equipment used in emergency situations. Conversely, EMS providers may want to invite parents of autistic individuals to speak on their experiences as caregivers.

#### ***Responding to an Emergency***

When responding to situations involving an autistic patient, there are specific adjustments EMS providers can make in the delivery of care. The following should be considered if appropriate:

- Avoid the use of lights and sirens when possible. This will help reduce the anxiety of those who are hypersensitive to external stimuli.
- Limit the number of caregivers, allocating a key individual to the patient so the patient can better understand what is happening to them.
- Provide direct requests using simple language. If you say, “Can you move over here?” the autistic patient may not understand you are actually asking them to move. Instead say, “Please move over here.”
- If transporting the patient, consider the response autistic individuals may have to the safety straps on a stretcher. Explain the purpose of the straps before application.
- Inform the receiving facility of the patient’s diagnosis. A “hallway” bed may be unbearable for the autistic patient. Be sure to communicate any specific approaches that have proven successful with your patient.

- Look for the less obvious. Remember that autistic individuals may be less aware of danger, may give misleading statements or may not be able to communicate the extent of the trauma. Use clues from the patient's environment and bystanders' accounts to obtain a complete picture of the situation.
- Minimize distractions, providing very deliberate care with a distal to proximal approach. Explain each move before proceeding.
- Recognize that although the individual may be non-verbal, autistic patients often have remarkable and intact receptive abilities. Remember, too, that they are literal thinkers. Avoid idioms or other figures of speech such as, "This will only hurt for a minute."
- Allow the patient to perform self-stimulating activities unless it would otherwise compromise care. These activities may be patients' ways of calming and comforting themselves.
- Remember that autistic patients may be hyper- or hypo- sensitive to tactile stimuli. EKG patches, tape or gauze pads may be an added discomfort to them. Oral medications may be especially repugnant to them. Consider using pediatric medications for adults when possible.
- Assess for pain, recognizing that autistic individuals may not respond to commonly used instruments such as the Wong-Baker FACES pain rating scale, due to their inability to read facial expressions. Commonly used modalities used to relieve pain such as hot and cold therapy may not be tolerated by the individual.
- Utilize the patient's caregivers whenever possible, allowing the caregiver to accompany the patient during transport. In essence, they can be used in the role of an interpreter.

#### *Autism and Aggressive Behavior*

Research indicates that those on the autism spectrum are 20 to 30% more likely to exhibit aggressive behavior than the general population.<sup>6</sup> These aggressive behaviors are often escalated when the individual is distressed due to feeling unwell or uncomfortable. This aggressive or violent behavior must be thought of differently than as an act of violence that is planned and purposeful. Aggression in autistic individuals is often due to their inability to communicate verbally, and rather than an intentional act, it is a reaction to pain, irritability or fear. Recognizing this behavior as a form of communication and altering approach accordingly is important for the safety of the emergency responder and patient.

To decrease the likelihood of the autistic patient becoming violent, the emergency responder should first try to determine what the patient is trying to communicate. Understanding the behavior will better enable the emergency responder to provide proper help. Utilizing the caregiver to help decipher and assist EMS to respond to the patient's aggressive behavior is the most important tool the EMS provider has at his disposal. Caregivers know what words, actions or stimuli can calm a child and which could have the opposite effect.<sup>7</sup>

Performing only those procedures that are absolutely vital to the patient's well-being and eliminating those that can be delayed until after transport will also help lessen anxiety-based behaviors. If time permits, demonstrating any procedures that must be done first on a stuffed animal or toy may help alleviate some of the patient's fear.

As always, the safety of the provider and the patient is of the utmost importance. Backing away and telling the patient who is becoming aggressive to “stop” in a clear, authoritative voice may help curb the aggressive behavior.<sup>8</sup> The use of restraints should only be considered if there is imminent danger to the patient or others.

## Conclusion

Autism is the fastest-growing serious developmental disability in the United States. Prevalence rates continue to increase by 10 to 17 percent annually.<sup>9</sup> Therefore it is crucial for EMS personnel to educate themselves on the disorder and to familiarize themselves with techniques that will ease delivery of care in emergent situations. Online resources such as Autism Speaks and The Autism Society provide useful, current information that can be utilized by the EMS provider as they continue to educate themselves on autism.

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