

# Handle with Care: Top Ten Tips a Nurse Should Know Before Caring For a Hospitalized Child with Autism Spectrum Disorder

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## Case Scenario

JJ is a green-eyed, blond-haired, freckle-faced seven-year-old nonverbal boy with autism who needs to be admitted to the inpatient unit for colonic washes secondary to prolonged constipation. He walks onto the unit holding his mother's hand but upon arrival becomes agitated and stops, looks down, then starts alternately flapping his arms and chewing on his finger. Unit hospital personnel had been informed that a child with autism was being admitted and are waiting near the entrance. Multiple staff members approach the boy at once, all talking to him, calling his name, leaning down to try to make eye contact and direct him toward his room. When he does not respond, one staff member takes his shoulders and tries to gently guide him toward the room. This causes JJ to scream loudly, shrug away from those near him, and start swinging his arms wildly. He ends up grazing one of the staff members in the face with his hand.

During this encounter, JJ's mom has been standing at his side telling the staff to please back up and not touch him. However, security has been called. Once they arrive, the hospital personnel and security agents decide to physically carry JJ to his room with his mom close behind them and close the door. JJ begins banging his head on the door. His mother approaches JJ in his room but appears very distraught and is unable to comfort him. A physician is called and after

The diagnosis of autism spectrum disorder is on the rise in the United States. More children with this disorder are requiring hospitalization and have an extended length of stay once hospitalized. The pediatric nurse is often unaware of or unprepared to offer the care that this special population requires. Sharing information obtained through repeated encounters with this population may lead to a less stressful and safer hospital stay for the child with autism, the family, and the pediatric nurse. Items about which the nurse should be aware when caring for a child with autism include the symptoms of autism spectrum disorder, the importance of family involvement, identifying the best way to communicate with the child, minimizing change, incorporating the child's home routine into the stay, creating a safe environment, identifying emotional disturbances, involving a multi-disciplinary team of experts on admission, listening to the family, and creating a record of this information to be shared among staff members.

confirming with the mother that JJ has no allergies, a stat dose of risperidone is ordered. Three staff members hold JJ down and administer the dose of IM risperidone. JJ calms down enough to lie on the bed, and the admission to the hospital is able to continue.

The Centers for Disease Control and Prevention (CDC) (2014) approximates that 1 in 68 children has been identified with autism spectrum disorder (ASD). Of these children, males are almost five times more likely to be diagnosed than females (CDC, 2014) (see Table 1).

According to the national survey by the Child and Adolescent Health Measurement Initiative (2012), 839,275 children between 2 to 17 years of age have been diagnosed with ASD. There has been a 600% increase in the prevalence of ASD over the last 20 years (CDC, 2012). These seem like staggering statistics, but in actuality, only accounts for approximately 1% of the pediatric population in the United States today (CDC, 2012). The question then becomes, why is this important to the pediatric acute care nurse?

**Table 1.**  
Number of Children Diagnosed with Autism Based on Gender

Gender	Frequency
Male	1 in 42
Female	1 in 189
Combined Total	1 in 68

**Source:** Adapted from the Centers for Disease Control and Prevention (CDC), 2014.

The answer is that children with ASD are more likely to use health care services than those who do not have ASD (Atladdottir, Schendel, Lauritsen, Henriksen, & Parner, 2012). Children with such diagnoses commonly have medical comorbidities, such as Fragile X syndrome, Trisomy 21, and tuberculous sclerosis, which may contribute to more frequent hospital admission. They may also have seizure disorders, increased allergies, gastrointestinal complications, such as constipation (like JJ), and other medical complications (Myers & Johnson, 2007). All of these conditions can contribute to an increased need for inpatient hospitalization. A study by Lokhandwala,

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Khanna, and West-Strum (2012) also indicates that children with ASD are hospitalized 1.5 times longer than those without the disorder. As a pediatric nurse, do you feel that you are prepared to offer the specialized care that these children require?

The purpose of this article is to familiarize the pediatric nurse with ASD and create a resource for successful inpatient treatment of a child with the disorder. This should decrease anxiety levels of the nurse, the child, and the family while also contributing to an increase in patient and personnel safety during an inpatient hospital stay. Using Benner's Novice to Expert Theory, advancing a pediatric nurse's knowledge of ASD may facilitate his or her transition from a novice, or a nurse "entering a clinical setting where she or he has no experience with the patient population," to Benner's level of advanced beginner, where the nurse may still need guidance, but can practice safely on his or her own and prevent child self-harm or aggressive behavior (Benner, 2001, p. 21). These tips may also reduce the chance of hospital personnel injury and decrease the likelihood that the child with ASD – a child like JJ – becomes agitated.

## Top Ten Tips You Need To Know (and How to Find Out)

### Tip 1: Understand Autism Spectrum Disorder

The first step to providing the best care to children with ASD in the hospital setting is to understand the diagnosis. ASD can be defined as an array of neurobehavioral disorders that are "characterized by various degrees of impaired social interaction and communication, and repetitive, stereotyped behavior" (Rakel & Rakel, 2011, p. 445). An earlier version of the American Psychiatric Association's (APA's) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) listed six types of ASD (APA, 2000). However, in 2013, the APA released the *DSM-5*, which eliminated subtypes of autism spectrum disorder such as Asperger syndrome and pervasive developmental disorder, not otherwise specified (PDD-NOS) (APA, 2013). The *DSM-5* includes a single diagnosis, ASD, which incorporates a range of severity of the disorder.

Children like JJ have an impaired ability to communicate, are socially

**Table 2.**  
**Common Symptoms Associated with ASD**

Type	Symptoms
Behavioral	Repetitive movements Routines or rituals Constant movement Uncontrollable tantrums Obsessed with specific object Self-injurious activities Pica Heightened sensation Challenging behaviors
Communicative	Delayed speech, unable to speak Loss of language or words Abnormal tone of voice Avoidance of eye contact when making requests Difficulty initiating or sustaining conversation Echolalia Difficulty understanding questions or directions
Social	Failure to respond to name Poor eye contact Resistance to holding and touch Preference to playing alone Failure to develop peer relationships Lack of empathy

**Source:** Adapted from the Centers for Disease Control and Prevention (CDC), 2012.

challenged, and exhibit obsessive or repetitive movements or actions, behaviors, or activities. Each individual exhibits different symptoms, and symptoms may change with age (CDC, 2012; Inglese, 2009). Symptoms can be noted as early as 6 to 9 months of age, but typically manifest between 12 and 24 months of age. A formal diagnosis of ASD is typically made between the second and third year of life (CDC, 2012).

Children with autism typically exhibit some form of cognitive impairment in learning, functioning, attention, and sensory processing (CDC, 2012). Diagnostic criteria for ASD include the following: 1) persistent deficits in social communication and social interaction across multiple contexts as manifested by deficits in social-emotional reciprocity; deficits in nonverbal communicative behaviors used for social interaction; and deficits in developing, maintaining, and understanding relationships; 2) restricted, repetitive patterns of behavior, interests, or activities manifested in at least two areas; 3) the presence of symptoms in early development; 4) clinically significant impairment in social, occupational, or other important areas of current functioning resulting from symp-

toms; and 5) these disturbances not better explained by intellectual disability or global delay (APA, 2013). See Table 2 for common symptoms associated with ASD.

Social deficits are based on the assessment of age-appropriate development but may include a failure to respond to the child's name being called, resisting touch, preferring to play alone, failure to develop peer relationships, poor eye contact, no interest in sharing enjoyment or interests, lack of empathy, and general disregard when one attempts to speak to the child (Inglese, 2009).

Verbal or communicative deficits may include delayed speech or the inability to speak, the loss of ability to use words and sentences, and difficulty understanding questions or conversations (CDC, 2012). Another verbal deficit exhibited may be echolalia, or repeating words and phrases in place of normal language (Grossi, Marcone, Cinquegrana, & Gallucci, 2013). A child with ASD may also have an abnormal tone of voice or rhythm of speech. He or she may also be unable to initiate conversations or continue one. Inability to communicate effectively can lead to increased agitation in this population (Matson, Boisjoli, & Mahan, 2009).

Stereotypical behaviors may include constant motion, rocking, spinning, hand-flapping, or other repetitive movements. A child may also develop an obsession with a specific object, such as the wheels on a toy truck (CDC, 2012). If a child exhibits these symptoms, it may be a method of self-stimulation or a sign of increased agitation. JJ's arm flapping in the case scenario is an example of escalating irritation. However, had it been a method of self-stimulation, it is important to note that this behavior should not be interrupted nor should a child be restrained because this is a coping technique for some children. Abrupt or forced cessation of the behavior can also lead to increased agitation (Johnson, Lashley, Stonek, & Bonjour, 2012).

Hypersensitivity to light, sound, taste, touch, or smell is often exhibited in the child with ASD (Johnson et al., 2012). Although not a component of the standard diagnostic criteria, identifying if a child with ASD has any specific sensory alterations and the child's coping mechanism may lead to a less traumatic hospitalization. If the hospital personnel had been aware of JJ's dislike of being touched, his behaviors may not have escalated as quickly.

A concerning symptom of ASD is self-injurious behavior, which can cause increased morbidity in children with ASD (Brasic, 2012; Duerden et al., 2012). Examples of such activities may include head rubbing, skin picking, eye poking, self-biting, and head banging. Although only a minority of children with ASD exhibit self-injury, they constitute some of the most challenging patients in pediatrics (Johnson et al., 2012). The cause of such behaviors is unknown, but it may be a source of self-stimulation for these children, and it is more commonly seen in nonverbal children with impaired cognitive functioning and altered sensory processing (Duerden et al., 2012). From the case scenario, JJ notably exhibited escalating behaviors of self-biting and head banging. Increasing pediatric nurse awareness of ASD may contribute to a decrease in hospital personnel triggering such behaviors in this population.

## Tip 2: Encourage Family Involvement

ASD symptoms displayed by a child are frequently first noted and best monitored by family members

(Brasic, 2012). The caregivers of these children are the medical team's biggest allies. The second tip for successful treatment of the hospitalized child with ASD is to listen to and encourage active involvement of the family or caregiver.

Partnering with family members ensures that the health care team tasked with providing care for the child with ASD is armed with the knowledge needed to best accommodate the child's special needs. The family can readily identify a child's triggers and the best method of communication, and inform the nurse of critical details to ensure that the child is less likely to become agitated and more likely to comply with the hospital treatment plan (Giarelli & Gardner, 2012). If no parent is available, it is important to find out as much information as possible from those who work in the child's school or residential facility.

While partnering with the family, the nurse should also inquire about what elements cause the child to have increased anxiety. If hospital personnel are aware of the elements that might trigger an outburst or aggressive behavior, steps can be taken to increase child compliance with the medical plan, avoid child self-injurious behaviors, and improve staff safety (Johnson et al., 2012). If the hospital personnel in the case scenario had known that being approached by more than one person and touching JJ increases his anxiety, they may have avoided the escalation in JJ's behavior.

## Tip 3: Determine the Best Method of Communication

The third and equally critical step to successfully caring for a child with ASD includes establishing a clear method of communication with the child. Children with ASD are usually concrete thinkers, and most have expressive or receptive communication deficits (Johnson et al., 2012). It is of utmost importance to identify the manner in which the child best understands information and how the child best expresses needs. Establish if there are limitations in the child's ability to communicate. Inability to communicate or improper communication with children with ASD has been shown to increase their frustration and can potentially trigger aggressive behaviors, which could compromise the child's and hospital personnel safety (Duerden et al., 2012).

The family or caregiver should also be able to inform the nurse of the best method with which one should speak with the child. Most children with ASD respond best to short, succinct commands (Scarpinato et al., 2010). Avoiding the phrase "no" is important when communicating with this population. The use of visual aids, such as picture schedules, communication boards, and labeling of objects in the rooms, has proven to be an effective communication tool for ASD patients (Chebuhar, McCarthy, Bosch, & Baker, 2013). The pediatric nurse should also work with a child life specialist (CLS) to locate or create such items to meet the special needs of the child during hospitalization. If the hospital personnel in the case scenario had listened to JJ's mother, they would have discovered that he is nonverbal and unable to clearly communicate his needs.

## Tip 4: Challenged by Change

Children with ASD prefer routine (Chebuhar et al., 2012). A routine is a comfort mechanism for the child with ASD, and these routines are always disrupted by hospitalization. It is difficult to replicate a child's routine in the hospital setting. However, all attempts should be made to regulate the child's schedule while hospitalized and abide by as much of the home schedule as possible. Keeping meal times, activities of daily living care times, and play times the same can decrease the anxiety and agitation levels of both the child and the family (Scarpinato et al., 2010). It is important to encourage the child's family to bring in favorite objects to act as a source of comfort as well. If a patient prefers certain foods or has a hypersensitivity to smells, the family should feel free to bring in food from home to decrease the number of variations from the regular routine.

The nurse caring for the child should also advocate to minimize interruptions to the child's sleep pattern because children with ASD often struggle with sleep (Myers & Johnson, 2012). If the patient is medically stable, avoiding overnight vital signs and medication administration during established rest periods may help reduce the anxiety level of the child. If disruptions to the established schedule need to occur, informing the child of the change in concrete, simple terms should be attempted prior to performing any new tasks (Johnson et al., 2012).



**Tip 5: Use Consistent Caregivers**

While trying to encourage the use of a routine in the hospital setting, using the same caregivers may also decrease patient anxiety (Scarpinato et al., 2010). Limiting the number of clinicians that interact with the patient can present a challenge in the acute care setting because most hospital personnel work three 12-hour shifts per week (Stimpfel, Sloane, & Aiken, 2012). Some personnel may also prefer variety in their assignments, but sharing the importance of consistency to children with ASD may increase personnel's willingness to work repeatedly with this population.

Repeated hospital staff exposure to the child may improve the child's compliance with the treatment plan as well as decrease the likelihood of aggressive behavior due to the child's fear of new and different elements. If staffing allows, the designated caregiver should spend more time in the child's room; this permits the child to develop familiarity with the hospital personnel, as well as allow the caregiver to gain understanding of the child's special needs (Scarpinato et al., 2010).

**Tip 6: Create a Safe Environment**

To continue to decrease the anxiety levels of the child with ASD, it is necessary to modify the hospital environment to the best of the nurse's ability. It is not likely that a room can be rearranged; however, it is possible to decrease stimulation. The hospital is a noisy, bright place. Children with ASD are frequently challenged by sensory overload (Duerden et al., 2012). The nurse should work with the family to identify if the patient is particularly agitated by touch, sound, smell, sight, tastes, or foods. Each child is different, and identifying each one's unique agitators will help make the child as comfortable as possible while in the hospital setting.

Some general practice guidelines for children with ASD in the hospital should include keeping the lights low, decreasing noise levels in the room and surrounding areas, and decreasing stimulation (Johnson et al., 2012). It is recommended that staff members turn off cell phones and pagers when entering the room if at all possible. The nurse caring for a child with ASD should use a back-up nurse and hand

off other patients when performing care for that child to decrease interruptions. The nurse should also approach the child individually in a calm, non-threatening manner and avoid approaching the child with ASD in a group, as the personnel in the case scenario did when JJ first arrived to the unit.

Activities are important for a child while hospitalized, but a playroom may be overwhelming for the child with ASD. The nurse caring for the patient should again work with the CLS to obtain appropriate toys, games, and activities that can be used in the child's room. Specific activities should be offered at specific times, again supporting the consistent routine and reinforcing that the hospital room is a safe environment for the child.

**Tip 7: Identify Emotional Disturbances and Establish A Reward System**

It is important to determine if the child for whom the nurse is caring has any known emotional disturbances or what causes the greatest amount of aggravation for the child. Frustration for children with ASD can stem from challenges with communication, change, or overstimulation (Duerden et al., 2012). Crowds, unfamiliar environments, and illness can also cause frustration and lead to challenging behaviors in children with ASD (Scarpinato et al., 2010).

Many children with ASD respond well to reward systems, which may be a way to overcome a child's increasing frustration (Johnson et al., 2012). An example of a particularly challenging task for children with and without special needs is taking medications. The administration of a medication can lead to increased frustration, agitation, and challenging behavior in children with ASD because they may not understand what or why medications are being administered. Children with ASD have used challenging behavior to escape demands (Reese, Richman, Belmont, & Morse, 2005). Therefore, offering a reward each time a child successfully takes a medication can establish a pattern of positive reinforcement and better compliance with the therapeutic regimen.

It is also important to determine the best methods to comfort the child. Many children with ASD have limited verbal skills and may not be able to clearly communicate if they have pain. A study by Messmer,

Nader, and Craig (2008) found that the pain levels of children with ASD could be discerned from their facial activity when noted by observers. The use of nonverbal pain scales, such as the Faces, Legs, Activity, Cry, and Consolability (FLACC) scale and the revised FLACC scale, which incorporate a parent's description of individual behaviors, are recommended for children with cognitive impairments (Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006).

The nurse should also ask the family what methods work best to soothe the patient at home. He or she should then incorporate those techniques into the hospital stay and ensure that hospital personnel caring for the child are aware of appropriate pain relief methods, as well as de-escalation techniques for periods of increased agitation (Giarelli & Gardner, 2012).

**Tip 8: Get a Multidisciplinary Team of Experts Involved On Admission**

The pediatric nurse should advocate for the patient and involve the multidisciplinary team from the beginning of the admission of the child with ASD. The nurse should encourage a family meeting outside of the patient's room where physical, occupational, and speech therapists can learn the child's level of activity and assist with the creation of the schedule and plan. Nutritionists should be involved to ensure that the child is presented with foods he or she will likely eat, or encourage the family to bring in foods from home. The CLS should be actively involved in the creation of the daily schedule, the reward system, obtaining toys, and developing appropriate activities to occupy the child's time. If possible, the inpatient psychiatrist, or if available, the autism specialist, should speak with the family and provide guidelines for hospital personnel. The unit educators should also provide just-in-time education to staff to increase understanding of the child's special needs.

**Tip 9: Support the Family And Encourage Them to Stay**

Families of children with ASD have reported feeling that they are not heard (Hyman & Johnson, 2012). As a nurse, supporting the family and acting as their voice during their child's hospitalization is a critical element of patient advocacy and will likely

increase the child's and family's feeling of comfort while hospitalized (Inglese, 2009). Exhaustion, depression, frustration, and poor physical health have been noted in families of children with ASD. As a health care professional, the nurse should ensure that the family members are also able to care for themselves. The nurse should listen empathetically and acknowledge concerns expressed by family members (Giarelli & Gardner, 2012).

Chiang (2008) identified that children with ASD direct challenging behavior toward adults. Unfamiliar caregivers may exacerbate such challenging behaviors. Having a familiar face at the child's bedside during hospitalization may decrease the frequency of these behaviors, which may also increase the level of staff, patient, and family safety. Partnering with the family of the child with ASD may also increase their feelings of value and respect by the health care team. Had the hospital personnel listened to JJ's mother when he first arrived to the unit, he may have had a less traumatic initial visit.

### Tip 10: Write These Facts Down!

Communication gets lost among providers during shift change. Ineffective handoffs can place all patients at risk, not just the child with ASD (Friesen, White, & Byers, 2008). Incomplete handoffs can be particularly detrimental to the safety of the child with ASD and the personnel caring for the child if critical information on necessary methods of communication, the child's triggers that may lead to increasing agitation and anxiety, the daily schedule, and the child's preferences are not clearly or completely relayed.

The nurse admitting the child with ASD to the inpatient unit should record a patient profile to decrease the chance that the information is lost during shift change (Inglese, 2009). Recording information on a list of the "top 10 tips to know about [child]" or similar template and placing it inside the child's room or exchanging the information on a form from shift to shift may improve hospital personnel safety and decrease the child and family's anxiety levels (see Figure 1).

Successfully caring for the child with ASD requires the nurse to acknowledge that this patient population is unique and requires a thorough

**Figure 1.**  
**Template for Admission Assessment Tool for the Child with Autism Spectrum Disorder**

1. What causes your child to have increased anxiety? Please list common triggers.
2. What is the best method to communicate with your child? a. Verbal, Picture, Sign Language, Other _____ b. Are there any special communication tools (ex: spell board) that we can obtain during your child's stay?
3. How should staff members approach your child?
4. Is your child particularly sensitive to touch, sound, smell, sight, or taste?
5. Does your child have any obsessive/restrictive behaviors?
6. How does your child demonstrate if he or she is in pain?
7. What are your child's early signs of increasing frustration and anxiety?
8. What are your best methods to comfort and de-escalate your child?
9. What are your child's strengths?
10. What is your child's home routine? We welcome you to bring in clothes, belongings, and food from home to make your child more comfortable. Please feel free to stay!

assessment, multidisciplinary planning, advanced knowledge of the child's special needs, and close collaboration with the child's family. Incorporating the 10 tips above into the care of the hospitalized child with ASD may take the pediatric nurse from Benner's level of novice caregiver to an advanced beginner. This may also contribute to a safer, less stressful, and more pleasant hospital admission for the child, the family, and hospital personnel (see Table 3). If this information had been available or implemented when JJ was admitted to the hospital, he might have had a much less traumatic experience and been less aggressive upon admission.

### Case Scenario Resolution

JJ remained agitated throughout the day after his initial introduction to the hospital. He continued to bite his fingers, grind his teeth, and arm-flap, and attempted to hit if someone approached him. However, the multidisciplinary team caring for JJ contacted the autism specialist within the facility who was able to assist with the formulation of a care plan and recommended initiating medical treatment for constipation the following day. While consulting with JJ's mother, the team developed a daily picture schedule for JJ that included his normal home routine and incorporated the treatments needed during his stay. Based on rec-

ommendations from JJ's mom, the CLS created a reward chart for JJ to help with medication compliance. She also located a game system and other activities that JJ enjoyed and could complete in his room. The nurse present on the day of admission agreed to care for JJ the next two days, the nursing management team was able to decrease the patient load to 2:1, and both the nurse and management team worked with JJ and his mother to make them as comfortable as possible. The nurse also wrote down the tips she learned from JJ's mother and passed the information on to the next shift. Although JJ had a traumatic introduction to the hospital setting, he was successfully treated and discharged after three days. ■

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## Instructions For Continuing Nursing Education Contact Hours

### Handle with Care: Top Ten Tips a Nurse Should Know Before Caring for a Hospitalized Child with Autism Spectrum Disorder

**Deadline for Submission:  
February 28, 2017**

**PED 1501**

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#### Goal

The purpose of this learning activity is to provide tips on caring for hospitalized children with autism spectrum disorder.

#### Objectives

1. List 10 tips nurses can use when providing care to children with autism.
2. Explain how nurses can implement techniques for providing better care for hospitalized children with autism spectrum disorder.

**Statement of Disclosure:** The author(s) reported no actual or potential conflict of interest in relation to this continuing nursing education activity.

The *Pediatric Nursing* Editorial Board members reported no actual or potential conflict of interest in relation to this continuing nursing education activity.

This independent study activity is provided by **Anthony J. Jannetti, Inc.** (AJJ).

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This article was reviewed and formatted for contact hour credit by Rosemarie Marmion, MSN, RN-BC, NE-BC, Anthony J. Jannetti, Inc., Education Director; and Judy A. Rollins, PhD, RN, *Pediatric Nursing* Editor.

**Table 3.**  
**How to Provide Better Care to the Hospitalized Child with ASD**

Know the Triggers for Anxiety and Frustration	What the Nurse Can Do
1. Change in structure, routine	<ul style="list-style-type: none"> <li>• Conduct in-depth interview with family/care providers.</li> <li>• Keep the routine consistent.</li> <li>• Follow home schedule as much as possible.</li> </ul>
2. Poor or failed communication	<ul style="list-style-type: none"> <li>• Use literal terms and direct communication.</li> <li>• Avoid metaphors and figures of speech.</li> <li>• Use visual or appropriate communicative aids.</li> </ul>
3. Anxiety/co-morbid conditions	<ul style="list-style-type: none"> <li>• Avoid hostile body language.</li> </ul>
4. Being told “no”	<ul style="list-style-type: none"> <li>• Use short succinct commands.</li> <li>• Avoid using “no.”</li> <li>• Provide rewards for positive behaviors.</li> </ul>
5. Redirection from preferred activity	<ul style="list-style-type: none"> <li>• Identify and place toys and activities in child’s room.</li> <li>• Help child locate desired object or activity when needed.</li> </ul>
6. Unfamiliarity with environment and caregivers	<ul style="list-style-type: none"> <li>• Provide continuity of hospital personnel.</li> <li>• Encourage family to stay.</li> <li>• Label room objects with words or pictures; the child may be able to point to object of desire if nonverbal.</li> </ul>
7. Unable to get what he or she wants and acts out	<ul style="list-style-type: none"> <li>• Avoid restraining an agitated child.</li> </ul>
8. Illness and pain	<ul style="list-style-type: none"> <li>• Use the FLACC or other appropriate pain scale to identify discomfort in the child with limited verbal ability.</li> </ul>
9. Overstimulation – sensory issues such as noise, crowds, proximity of others	<ul style="list-style-type: none"> <li>• Turn off phone/pager when entering patient room.</li> <li>• Decrease environmental stimulation; keep lights, noise and monitors off if possible.</li> </ul>
10. Other	<ul style="list-style-type: none"> <li>• Contact and involve the autism specialist and multidisciplinary team when developing plan of care.</li> <li>• Stay calm!</li> </ul>

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