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# Nursing care of autism spectrum

Successful assessment and delivery of interventions can be challenging when caring for patients with ASD. Sensitive nursing care and an understanding of sensory and communication difficulties are required.

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April is National  
Autism Awareness Month

# patients with n disorder

Autism spectrum disorder (ASD) is a complex neurobehavioral and developmental disorder characterized by deficits in three domains: impaired social interaction; impaired communication; and restricted, repetitive behaviors. In 2013, the *Diagnostic and Statistical Manual of Mental Disorders* was revised, combining the diagnosis of autism with several other previously separate conditions, such as Asperger syndrome, childhood disintegrative disorder, and pervasive

developmental disorder, to create a new diagnosis known as ASD. The term *spectrum* in ASD refers to the wide range and severity of symptoms often experienced by people with this diagnosis that primarily affect their relationships and interactions with others.

Increased ASD screening, better diagnostic criteria, and accurate behavioral and neuropsychological instruments may be contributing to the appearance of a steady rise in ASD diagnoses (see *Screening tool*

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examples). Children appear to develop normally over the first year of life with a period of regression between 18 and 24 months of age, and symptoms usually appear before age 3. ASD is four to five times higher in boys, with current estimates of about 1 in 36 children.

The exact etiology of ASD is unknown, but strong genetic and environmental influences appear to coexist and affect brain development in ways irrespective of culture, race, ethnicity, or socioeconomic group. Identical twins have a higher prevalence of ASD, and siblings have a 2% to 8% risk rising to 12% to 20% if the affected child has deficits in one or two of the three domains impaired in autism. In addition, children born to older parents, born before 33 weeks' gestation, or with low birth weight are at increased risk. Recent studies demonstrate a link with exposure to viral or bacterial infections in the first or second trimester of pregnancy, exposure to valproate for treatment of epilepsy or bipolar disorder in utero, and fetal exposure to insecticides.

### Manifestations

Social communication and interaction difficulties are often the earliest features of

ASD, which can be subtle and easily missed. Characteristics such as failure to show interest, atypical attention, atypical gaze patterns, lack of facial expression, and excessive use of gestures are highly suggestive red flags of ASD (see *Developmental red flags*).

Each person with ASD has different communication skills. Some speak well, but about 40% of children with an ASD don't talk at all. About 25% to 30% of children with ASD have some words at 12 to 18 months of age but lose them for no apparent reason. Lack of sentence use, including unusual speed, volume, tone, or pitch, is common. Some individuals with ASD communicate with only single words or repeat the same phrases or what others say, a symptom known as echolalia.

Some people with ASD may be unaware of personal space and stand too close to others when talking, yet others may not respond when their name is called or seem to be unaware of the presence of others. Most find it difficult to participate in conversations with others, particularly if uninterested in the topic. Not recognizing emotions, including problems understanding the feelings of others, prevents engagement in play, and

#### Screening tool examples

Ages and Stages Questionnaire	A general developmental screening tool, this parent-completed questionnaire contains a series of age-specific questions for children age 1 month to 5.5 years assessing communication, gross motor function, fine motor function, problem-solving, and personal adaptive skills, resulting in a pass, fail, or monitor score for domains.
Communication and Symbolic Behavior Scales	A standardized tool for screening communication and symbolic abilities up to age 24 months.
Parents' Evaluation of Developmental Status	A general parent-completed screening tool for developmental and behavioral problems needing further evaluation in children age 0 to 8 at risk for autism.
Modified Checklist for Autism in Toddlers	A test intended for toddlers between ages 16 and 30 months that uses a series of 20 questions for parents to assess if further evaluation is needed.
Screening Tool for Autism in Toddlers and Young Children	A 20-minute interactive screening tool designed for children age 24 to 36 months when developmental concerns are suspected that consists of 12 activities assessing play, communication, and imitation skills.

initiating conversation can appear awkward and thus be avoided. These factors contribute to problems maintaining relationships (see *Communication challenges*).

Mannerisms of individuals with ASD are often stereotyped or repetitive. Restrictive and repetitive behaviors are often displayed, such as hand flapping, head banging, and turning in circles (see *Restrictive/repetitive behaviors*). These usually increase when the individual is anxious or stressed. People with ASD often resist change in their routine or the way their environment is organized, which often results in acting out. These individuals may also experience sleep problems and irritability.

## Diagnosis

ASD has transformed from a narrowly defined, rare disorder of childhood onset to a well-known, relatively common, lifelong condition. There are no reliable biomarkers or specific diagnostic tests for ASD; therefore, the diagnosis must be made based on the person's behavior.

To be diagnosed, a person must show evidence of difficulties in all three of the social communication subdomains and must have or have had difficulty in two of four different repetitive sensory-motor behavior subdomains. Communication subdomains include persistent deficits in social communication, including social-reciprocity such as not sharing and lack of back-and-forth communication; deficits in nonverbal communication with mismatched verbal/nonverbal communication, poor eye contact, and body language deficits; and lack of developing and maintaining relationships described as the inability to adjust behavior to social situations and lack of interest in peers. Sensory-motor subdomains are restrictive and repetitive behaviors, such as repetitive motor movements and speech; insistence on sameness and inflexibility to changes in routine; highly fixated interests with intensity and focus on objects

## Developmental red flags

- Not responding to his or her name by age 12 months
- Not pointing at objects to show interest by age 14 months
- Not playing pretend games by age 18 months
- Avoiding eye contact and wanting to be alone
- Having trouble understanding other people's feelings or talking about his or her own feelings
- Having delayed speech and language skills
- Repeating words or phrases over and over
- Giving unrelated answers to questions
- Getting upset by minor changes
- Having obsessive interests
- Flapping the hands, rocking the body, or spinning in circles
- Having unusual reactions to the way things sound, smell, taste, look, or feel

## Communication challenges

- Delayed speech and language skills
- Repeating words or phrases over and over
- Reversing pronouns (such as saying "You" instead of "I")
- Giving unrelated answers to questions
- Not pointing or respond to pointing
- Using few or no gestures (such as not waving goodbye)
- Talking in a flat, robot-like, or sing-song voice
- Not pretending in play
- Not understanding jokes, sarcasm, or teasing
- Being able to learn things in detail and remembering information for long periods of time
- Being strong visual and auditory learners

## Restrictive/repetitive behaviors

- Repeating certain behaviors or having unusual behaviors; for example, repeating words or phrases
- Having an overly focused interest in certain topics, such as numbers, details, facts, or moving objects
- Becoming upset by slight changes in a routine
- Being more or less sensitive than other people to environmental/sensory input, such as light, noise, clothing, or temperature

and repeated behaviors; and hyper/hyporeactivity to sensory input, such as adverse reactions to textures, sounds, smells, or touching objects.

Changes in behavior may occur as a person ages, and symptoms in the early developmental period may not be evident until social demands exceed a person's capabilities. Many parents express concerns as early as age 15 to 18 months but, despite increased awareness and guidance, the average diagnosis remains between ages 4 and 5. Studies have indicated that a diagnosis of ASD at age 2 is possible, although it's less reliable for the broader autism spectrum.

### Home life

Many individuals with ASD show a need for a structured, sometimes regimented, daily schedule. The need for controlled sensory stimulation, such as decreasing noise, lights, and tactile input, is common. Families must consider each family member's personality and activities while adapting to the needs of the family member with ASD.

family members can work together to communicate honestly, accept their circumstances, and rejoice with each moment of progress.

Lack of insurance coverage for ASD care is a significant factor in the use of therapies causing financial stress. Sacrificing time, learning new skills, and paying for specific, yet often difficult to find, resources are frequent difficulties that affect the entire family. Surviving criticism from peers and even total strangers who assume that the child with ASD is out of control is also a challenge.

Communication deficits may vary over time, requiring a picture board, identifying key instruction words for redirection, and every family member recognizing when to retreat to deescalate behavior. Sensory intolerance and ongoing training/therapy support can limit having guests unless they're adapted to the home environment. However, having the support of key friends and family members can benefit the social development of a child with ASD while providing necessary breaks for immediate family members.



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Stressors related to raising a child with ASD are unique and unexpected. The physical demands are extensive, and the emotional toll is even greater. Accepting that your child may never reach a level of functioning to live independently in the everyday world is devastating. Each unmet milestone over the years is a reminder of this dilemma. With counseling, support groups, behavioral therapy, physical and occupational therapies, and ongoing reading of current literature,

Siblings experience considerable stress, with added responsibilities that may hinder their daily wants and needs. Accommodations must be made for each family member's needs while respecting that each sibling deserves parental attention and all need time for activities not focused on the individual with ASD. Changes in relationships and everyday activities may impact each sibling differently. Family members experience the new normal at their own pace.

Successful outings require finding family-friendly restaurants and stores willing to collaborate in training a sensory sensitive child into adulthood. Repeated practice trips to multiple locations for developing socially acceptable behaviors necessitate time and energy. Community involvement, including respite care, neighbors/extended family encouraging the practice of social skills, and positive mentoring from peers can help the person with ASD gain skills and increased comfort with communication.

### School experiences

Public school offers accommodations under the Americans with Disabilities Act (ADA) after the diagnosis of ASD is made. Creating an educational environment and behavior plan similar to home requires parental diligence and stamina. The school nurse has an integral role in wellness, safety, medication administration, and socialization of the student with ASD.

It isn't unusual for someone with ASD to require support for some things while excelling in other areas. Early and consistent interventions demonstrate the best results. Where the person is on the autism spectrum determines the need for therapies and accommodations and influences outcomes. Educators and parents spend considerable time working together to create the best learning environment for students with ASD.

Forging a path for correct perception of verbal and nonverbal communication paired with training on how to function and tolerate the daily environment is ongoing into adulthood. Self-awareness and self-esteem are important and differ related to where the individual is on the autism spectrum. ASD can be viewed as neurodiversity or as a disability by those with the disorder, family members, and society. Those with significant early interventions improve their behavioral skills, which influences this view.

### Quick tips card

#### Tom's "quick tips"

**How I communicate:** Signing or pictures

**What helps me understand:** Give me simple steps to follow

**What I like:** Cars and drawing

**What calms me:** A quiet area and time to answer

**Touch/sensory dislike:** Smells, too much talking, buzzing lights

**It upsets me when:** You call me "buddy" or "son"

**I'm afraid of:** Loud sounds, yelling, lots of people in one place

**Comments:** I run when I'm overwhelmed

**Caregiver requests:** I want to be involved with care and I can help

Adapted with permission from Bultas MW, McMillin SE, Zand DH. Reducing barriers to care in the office-based health care setting for children with autism. *J Pediatr Health Care.* 2016;30(1):5-14.

### Into adulthood

Ongoing positive behavioral support and working toward inclusion in the everyday world form the best plan for those with ASD. Many colleges have programs focused on success for students with ASD. Transition to living independently or with assistance, using transportation, travel, safe self-care, and career development may require special training and supervision for those with ASD to reach their full potential.

Securing disability services and health insurance into adulthood is needed. If ASD prevents the individual from holding a job or living independently, plans for assistance should include guardianship and care after parents or siblings have passed away.

### Healthcare delivery

Regular health checkups, diagnostics, health promotion teaching, and emergency situations require more time while maintaining a controlled environment



## consider this

Consider these shared examples from the mother of a now-adult son with ASD to broaden your understanding of family-centered care.

When my son was young, his environment included the quietest/darkest room in the house, blackout curtains, a bed that had pull-around curtains, no scents, no tags on clothing, a fan with just the right white noise, no fluorescent bulbs that he could hear buzzing, and minimal artwork or other visible items in the room. He had communication problems (expressive and receptive) and great difficulty understanding non-verbal cues. His food choices were very limited, mostly due to texture intolerance. Any change in these necessities could result in a meltdown, which included spinning in circles, screaming, throwing things, running away from the stimulus, and hopefully a voluntary retreat to his “cave” to roll up in a blanket in his quiet, dark, and cold room. Transitioning from meltdowns to self-care techniques took training, rehearsal, and controlled and direct verbal commands with many repetitions. He described the meltdowns as like “being on fire.” His most moving comment to me was, “Mom, when I’m on fire, your words are like gasoline.”

At school, my son spent his day in the regular classroom, in his “tent” in the special education room to refocus and limit sensory input, in gifted and talented activities, and in daily therapies after school to address symptoms and develop acceptable social behaviors. According to my son, field trips, physical education (PE) classes in the gym, and substitute teachers were the “kiss of death,” requiring

further adaptation. Use of a colored pocket card allowed him to leave any class to go to his “tent” to regroup and desensitize from over-stimulation. Obtaining approval for martial arts classes as out-of-school PE credit took considerable persistence and meetings with many administrators. He required very few educational/environmental supports in high school.

In adulthood, my son has been able to share important information about ASD. He states that it’s hard to listen to someone and maintain eye contact, especially in a sensory-rich environment, because he can’t focus on extraneous incoming information and process what’s being said. He’s learned how to correctly interpret others’ facial expressions and body language by asking and repeatedly validating his interpretation.

Today, my son is a happy, productive, employed, and active individual who brings joy to our family and friends. We appreciate his uniqueness and what he contributes to the family. We’ve shared our experiences and knowledge with others traveling the same road. As a young adult, this disorder doesn’t define my son. He’s finding his way and exploring what he enjoys, such as running marathons, metalwork, leatherwork, reading, and living independently. We celebrate his victories that have been won with hard work, persistence, great time commitment, and creative solutions. It’s been an adventure that’s kept our family focused on living one day at a time while relentlessly seeking long-term goals.

with a focus on specific communication. Barriers to care include fear, environmental issues, and healthcare providers being unaware of basic best-practice strategies for individuals with ASD.

Use of a quick tips card offers consistent information and encourages autonomy for individuals with ASD seeking medical care. The card communicates unique information not usually contained in the electronic health record (see *Quick tips card*). The healthcare team benefits from clear instructions by the parent or

individual with ASD to ensure that needs are met and reduce the incidence of creating a traumatic experience.

Based on clinical practice guidelines, use of medication when nonpharmacologic treatments fail can be beneficial. Commonly used medications, including antidepressants, antipsychotics, antiepileptic drugs, anxiolytics, sleeping pills, and sedatives, for planned procedures or travel can be helpful. Risperidone and aripiprazole have been shown to reduce irritability and are FDA approved for use in ASD.

## Best practices for nurses

Education of nurses on how to best care for patients with ASD provides an avenue for ongoing advocacy to the entire healthcare team. Each person with ASD is unique and complex, and each must adapt to the world based on his or her strengths, weaknesses, and limitations. Remember that these individuals aren't autistic, but rather they have ASD.

Key interventions for care in any setting consist of set communication methods using a card, color-code system (green, yellow, red related to pain, need, and urgency), picture board, and simple sign language (pain, water, hungry, and

In most social situations, people with ASD may interpret language literally. An example is when directing a patient to "open your mouth and say 'ah.'" Patients with ASD may open their mouth, say "ah," and close it. These patients need direct instruction, preferably with a demonstration, describing how you want to look at their throat, so they should keep their mouth open and say "ah" while you look.

Clinical practice guidelines encourage direct, clear statements beginning with the patient's name to improve information processing. Instead of completing the entire head-to-toe assessment, nurses can anticipate the need to assess one or two

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medicine) and maintaining a brief care plan for the patient with ASD, including best ways for comfort and communication. Awareness of the ADA plan can guide the nurse to deliver care that matches the patient's educational level. For school nurses, these interventions can be rehearsed early in each school year to establish rapport with the child with ASD.

Nurses can team with the family for rehearsal of planned actions with expected behaviors before appointments or procedures, and frequent reminders during postintervention care can reduce fear and outbursts while gaining patient cooperation. Tailoring care based on sensory sensitivity and the patient's ability to communicate is the primary focus. Interventions, such as dimming the lights, using a weighted blanket or vest, and allowing repetitive movement that doesn't hinder care, can soothe the person with ASD.

body systems at a time to evaluate sensory tolerance. It's recommended for nurses and caregivers to deliver clear directions to gain inclusion and participation in the actions that are needed when giving care. For example, "Tom, lift your shirt so I can listen to your chest." Creating clear goals for positive interactions while avoiding too much communication and excessive physical stimulation can prevent difficulties in accomplishing an assessment.

Nursing care is guided by translating knowledge of ASD into action and listening to the individual with ASD and his or her family members. This includes adding specific key information to the care plan, such as best ways to communicate or sensory stimulation to avoid, for continuity of care. Early diagnosis and treatment, consistent nonpharmacologic approaches, use of medication when indicated, regular use of therapies, and ongoing counseling result in the best outcomes and quality of life.

## Celebrating life

The long list of manifestations, difficulties, and barriers can paint a dismal picture of caring for someone with ASD. Raising a child with ASD to adulthood is challenging, bringing unexpected difficulties and pain but also great love and rewards. Celebrating each moment of joy and each accomplishment helps overcome the despair that can overwhelm anyone when raising a child with disabilities. Research into gene therapy is ongoing, seeking ways to deliver the necessary nonfunctioning genes while turning off overactive genes that cause symptoms. In the future, this type of therapy may further improve the quality of life for individuals with ASD. ■

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