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CONTACT HOURS

Caring for a child with autism

Autism is one of the most common childhood developmental disorders, even more prevalent than Down syndrome. But because its origin is unknown and it encompasses a range of behaviors, working with a child with this disorder can be challenging. Learn what you can do provide your young patients with the care and attention they need.

*HEATHER BROWN-GUTTOVZ, RN, BSN
Head Nurse • Southfield Pediatric Center •
Southfield, Mich.*

The author has disclosed that she has no significant relationship with or financial interest in any commercial companies that pertain to this educational activity.

AUTISM IS A complicated neurodevelopmental disorder that impairs social interaction and communication and causes repetitive and stereotypical behavior patterns. In this article, I'll discuss the causes of this lifelong disorder and its effects on the individual and his family. I'll also look at current screening and diagnostic techniques. Finally, after going over current treatment modalities for autism, I'll explain how you can help children and their families learn to best cope with this all-too-common disorder.

ISABELLE ARSENAULT

Pervasive developmental disorder

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)*, under a broad category of *pervasive developmental disorders*, describes five disorders that share similar features (see *The five disorders on the autism spectrum*). Autistic disorder, or autism, is the most common one. The severity of these five disorders and their symptoms and behavioral characteristics can differ widely. Over a lifetime, someone diagnosed with one of these disorders can move along the spectrum from low functioning to high functioning.

Although race, ethnicity, and socioeconomic status don't influence the overall incidence of autism, the disorder is four times more prevalent in boys than in girls. Estimates gauge its incidence at approximately 1 in 150 births, with about 1.5 million Americans living with 1 of the 5 disorders on the autism spectrum.

Searching for a cause

The exact cause of autism is uncertain at this time, but abnormalities in brain structure and function are a probable cause (See Figure 1). As autism and other related disabilities tend to run in families, a genetic component is suspected and currently being researched.

Children who have particular medical conditions such as congenital rubella syndrome, fragile X syndrome, tuberous sclerosis, and untreated phenylketonuria have a higher risk of developing autism. Much attention and debate have focused on potential environmental causes; some theories involve vaccinations and their components, as well as diet, but these environmental causes remain unproven at this time. Increased rates of autism in recent years have amplified the environmental theory, but the

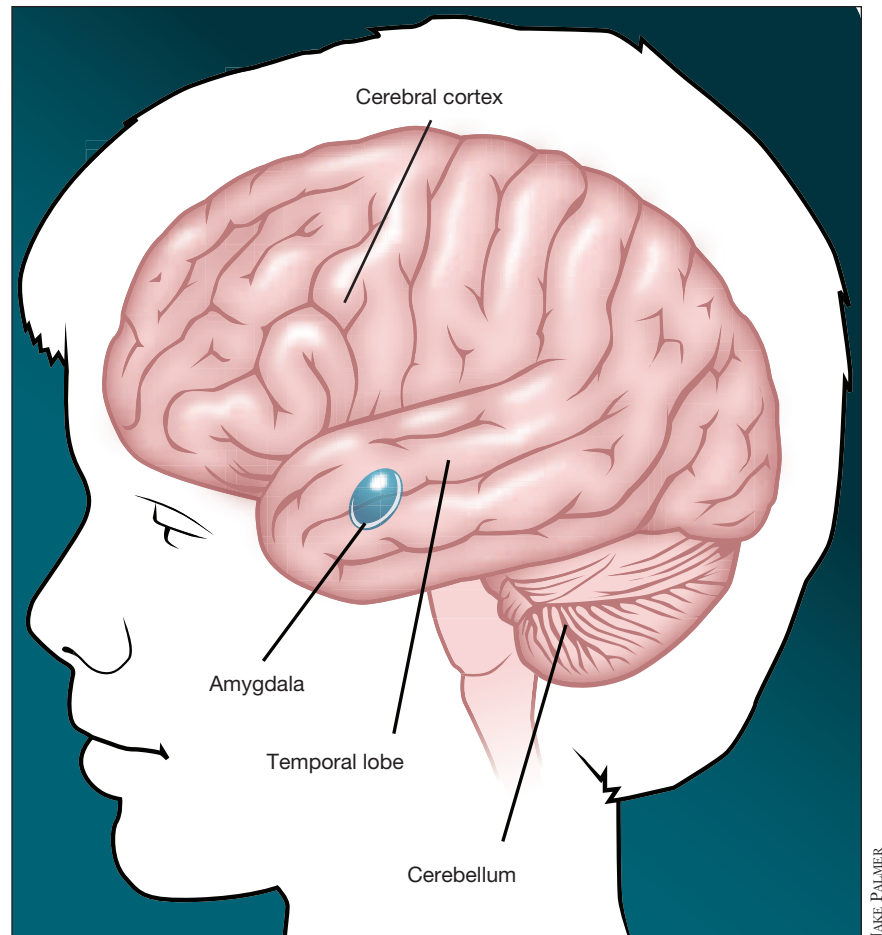


Figure 1. Recent studies and new imaging techniques have helped to identify some of the major brain areas implicated in autism. The areas include the cerebellum, cerebral cortex, and temporal lobe (particularly the amygdala). The disorder may result from the failure of various parts of the brain to work together.

increased rates may be related to better identification and diagnosis. More research is needed to identify the exact cause of autism.

Signs and symptoms

Children with autism exhibit a wide array of symptoms and behaviors that can range from mild to severe. This disorder usually presents in the first year of life and almost always by age 3.

Autism is characterized by unusual social interaction, speech and language problems, repetitive and ritualistic behaviors, and uneven intellectual performance. The atypi-

cal social interaction could include withdrawn behavior in which the child prefers to be alone, not interacting with peers, not making eye contact, and not wishing to be touched or cuddled. The child may be unable to understand or interpret social cues such as smiles, facial expressions, and tone of voice. Speech and language problems can include delayed or absent speech, communicating only with gestures instead of words, repeating specific words or phrases, not comprehending the actual meaning of some words, and having a short attention span.

JAKE PALMER

Diagnostic criteria for autism

Below are the diagnostic criteria for diagnosing autistic disorder, according to the *DSM-IV-TR*. Additional criteria are used to diagnose other disorders that are classified as autism spectrum disorders.

Autistic Disorder is diagnosed if the person has A, B, and C:

A: a total of six (or more) items from 1, 2, and 3, with at least two from section 1, and one each from sections 2 and 3:

1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (such as by not showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
2. qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (such as hand or finger flapping or twisting, or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance isn't better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Some children with autism engage in repetitive and ritualistic behaviors such as playing with the same object over and over, continuous hand-flapping, and rocking their body back and forth. These children like consistent routines and are very resistant to change. Additional behaviors may include self-injuring behaviors such as biting and head banging, aggressive behaviors, frequent tantrums occurring for no apparent reason, sensory impairment, and a decreased sensitivity to pain.

Some children with autism start out acquiring some normal developmental skills, but then the previously acquired skills regress. It's not uncommon for children with autism to experience seizures in early childhood and adolescence; 20% to 30% of children with autism develop epilepsy by adulthood.

Early identification of autism, as well as early treatment, leads to more positive outcomes for children with the disorder. So how is autism diagnosed? Let's take a look.

Diagnosing autism

Developmental screening should be performed by a child's health care provider as part of a well-child examination. Some red flags that may be seen in infants include:

- not babbling or pointing or using gestures by age 12 months
- not saying single words by age 16 months
- not verbalizing two-word phrases by age 24 months
- any loss of language or social skills at any age.

A child who has these red flags should be referred to a specialist for further investigation.

A multidisciplinary team, which may include a developmental pediatrician, child psychologist, neurologist, speech/language therapist, and a physical and occupational therapist, can further evaluate the child. A thorough medical evaluation should be performed, including a neurologic exam, formal audiology and visual exams, and serum lead evaluations on children who experience developmental delays.

Various screening tools are used to evaluate children for autism. Because there are no diagnostic tests that are definitive for the disorder, a clinical diagnosis by an expert using the *DSM-IV-TR* diagnostic criteria is the gold standard for the diagnosis of autism (see *Diagnostic criteria for autism*). Additional screening instruments used by specialists include:

- *Childhood Autism Rating Scale*, an observational screening tool
- *Autism Diagnostic Interview-Revised* and *Gilliant Autism Rating Scale*, which are based on interviews with parents
- *Autism Behavior Checklist* and *Autism Diagnostic Observation Schedule-Generic*, which are specific tests for autism in 2-year-olds.

Presently, autism has no cure and

no one specific treatment program is in place for all children with autism. Most treatment programs focus on improving the child's overall functioning. Early diagnosis and treatment focusing on language and behavior are essential to achieving this goal.

Targeting behavior and communication

A common treatment approach used for children with autism is *applied behavior analysis* (ABA) therapy. This type of therapy is based on the principle that a child will repeat positively reinforced behaviors and won't repeat ignored behaviors.

An example of ABA therapy is discrete trial training, an intensive training program that can teach basic everyday skills, correct behaviors, and work on social interaction. Tasks are broken down into small steps, with rewards offered as the child progresses through each step. Research has shown ABA therapy to be successful in teaching new tasks and behaviors to children with autism. Current scientific evidence shows that ABA therapy is the optimal treatment approach for young children with autism.

Another treatment approach that's been used for children with autism is *Treatment and Education of Autistic and Related Communication Handicapped Children* (TEACCH). The TEACCH method uses a structured teaching approach with the idea that the child's environment should be adapted to him, rather than the child adapting to the environment.

The TEACCH approach takes advantage of the child's use of visual information processing, which is a strength in children with autism. The child learns with very structured classrooms, many visual schedules, and very structured learn-

The five disorders on the autism spectrum

According to the *DSM-IV-TR*, five disorders can be classified as pervasive developmental disorders. These are often referred to collectively as *autism spectrum disorders*.

- Autistic disorder
- Rett's disorder
- Childhood disintegrative disorder
- Asperger's disorder
- Pervasive developmental disorder not otherwise specified

ing activities broken down into smaller, visually organized steps. The goal of this treatment approach is to help the child better understand the world around him and to learn to interpret other people's behavior as well.

Several other behavioral/learning approaches are sometimes recommended for children with autism. The *social stories technique* uses scripted stories about particular situations to help the child understand appropriate social responses. The *Picture Exchange Communication System* is a communication program that teaches children and adults to trade a picture for something they desire. This helps foster language development.

Sensory integration may also be used to help desensitize the child if he's having sensory difficulties, and it may help to reorganize sensory information. Speech therapists typically work as part of the treatment team to help foster the development of language and communication skills. Physical and occupational therapists help the child with gross motor and fine motor skills.

Medication management

Although no medications have been specifically developed for the treatment of autism, several medications are sometimes used to treat the symptoms and behaviors associated with the disorder. The child may receive a selective serotonin reuptake

inhibitor for treatment of depression, anxiety, and ritualistic behaviors associated with autism. Antipsychotic medications such as risperidone (Risperdal), olanzapine (Zyprexa), clozapine (Clozaril), and quetiapine (Seroquel) are sometimes prescribed to manage aggression, hyperactivity, or stereotypical or withdrawal behaviors. The child must be very closely monitored for adverse effects, such as tardive dyskinesias (involuntary movements most often affecting the mouth, lips, and tongue), weight gain, sedation, and withdrawal dyskinesias (involuntary movements that appear after the medication's been stopped suddenly).

Stimulant medications are sometimes prescribed to control hyperactivity and impulsivity in children with autism. The use of medications to treat the symptoms of autism remains controversial.

Alternative therapies

Because there's no traditional medical cure for autism, families of children with autism often turn to alternative therapies in search of a cure. When you're caring for a child with autism, you need to be aware of any alternative therapies your patient could be undergoing. One such therapy is the use of a gluten- and casein-free diet. This is based on the theory that people with autism have difficulty digesting proteins, which can contribute to behavioral issues.

Sometimes vitamin and mineral supplementation is recommended for children with autism, including the use of vitamin B₆, vitamin B₁₂, magnesium, vitamin C, and folic acid, although their effectiveness and safety haven't been established.

In addition to dietary changes and supplements for autism, multiple behavioral therapies may be offered to families but effectiveness is unproven. Counsel families on the risks associated with alternative therapies and provide them with information on effective evidence-based treatment plans, which are available through physical therapists, speech therapists, occupational therapists, and structured special education programs.

How you can help

You may encounter children with autism in a variety of health care settings including health care provider's offices, hospitals, and schools. It's vital that you understand the various behaviors and symptoms of this disorder and learn how to help children and their families get the best possible care.

Approaches to the child's care need to be tailored to his individual specific needs. If possible, try to interview the child's parents or caregiver prior to assessing the child. Learn what the child likes and dislikes and what will help keep him calm. Understand that interruptions in the child's daily routines are very stressful, so you should try to schedule appointments at a time with the shortest waiting period.

Try to limit the number of health care workers the child encounters at one time. Watch the environment you bring him into because too much sensory stimuli can exacerbate symptoms and prompt tantrums. Try to maintain a quiet, calming environment that's free of excess

equipment, lighting, and clutter.

When performing procedures, explain in simple terms exactly what you're going to do. If possible, simultaneously demonstrate what you're about to do because children with autism are visual thinkers. Have patience and give the child time to process what you're telling him. Attempt to distract him during procedures and always provide positive reinforcement. Avoid frequently saying "no" because this can sometimes lead to tantrums and aggressive behavior. Telling the child what to do rather than what *not* to do may be a better approach.

Playing it safe

A high priority when caring for a child with autism is maintaining his safety. Children with autism are at higher risk for injury due to impulsive behavior, disorganized motor skills, frequent tantrums, pica (eating nonfood items such as dirt or rocks), and altered sensitivity to pain. Provide a safe environment to prevent accidents and injuries. This is important both in the child's home, at school, in play areas, and in the health care setting.

Keep work areas free of excess clutter and stimuli. Work closely with the parents before a procedure to find out what the child's preferences are and the best approach to help keep him calm. Ask the parents how they typically handle disruptive behavior.

Perform careful pain assessments. Children with autism may show inconsistent responses to pain, such as overreacting to being touched but not reacting to having an injection. If the child throws a tantrum and becomes a danger to himself or the staff, enlist extra help from other staff members, but use restraints only when absolutely necessary. Wear personal protective equipment

for your own safety.

To help families ensure a safe home environment, educate parents about putting locks and possibly alarms on doors and windows to prevent the child from wandering off. Advise them to:

- Hide all electrical wires and cables and cover electrical outlets to avoid injury.
- Store all poisonous chemicals, cleaning supplies, and sharp objects in cabinets with safety locks.
- Arrange household furniture carefully to prevent injury.
- Use safety gates around stairwells and other unsafe areas.
- Keep all matches and lighters out of the child's reach.
- Use extra caution around grills and fireplaces.
- Place safety covers over stove burners.
- Place stop signs on dangerous objects and in areas where the child doesn't belong. These serve as a visual reminder that what the child is about to do is dangerous.
- Use social stories, which can be developed and repetitively told to children, explaining what they should or shouldn't do in easy step-by-step instructions.

Family support

Families of children with autism experience a great amount of stress. Caring for the child requires a great deal of time, routine, energy, and money. Provide families with the most up-to-date information on autism. Clear explanations of recommended treatment plans and parental involvement in decision making are essential to help the child achieve long-term goals.

Provide support by listening carefully to the family's questions and concerns. Make appropriate referrals, provide appropriate resources for educational information, and

give assistance with insurance issues if necessary. Advise families to get involved with their local chapter of the Autism Society of America (<http://www.autism-society.org>) for additional information, support groups, and help with financial assistance if needed.

Current research

The exact cause of autism remains unclear, there's no cure, and no one specific treatment program is available. Research currently under way includes a study by the Centers for Disease Control and Prevention (CDC) entitled the Thimerosal and Autism Study, which is evaluating thimerosal exposure in children with and without autism. Another CDC study, the Autism and Biopsy Study, is investigating whether the measles, mumps, and rubella vaccine may cause autism.

Become knowledgeable about current research so you can communicate this information to families and provide the best possible care to patients with autism.

You can make a difference

Although the exact cause of autism remains unclear and is still being researched, early diagnosis and treatment lead to more positive outcomes for children diagnosed with the disorder. By staying informed on the latest research into autism and taking the proper precautions when caring for children with this disorder, you can help the children and their families learn to cope with this disorder and achieve their long-term goals. **LPN**

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On the Web

AutismLink: <http://www.autismlink.com>

Autism Research Institute: <http://www.autism.com>

Autism Society of America: <http://www.autism-society.org>

Autism Speaks: <http://www.autismspeaks.org>

National Institutes of Health Autism Resource Network: <http://www.autismresearchnetwork.org>

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Caring for a child with autism

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Caring for a child with autism

GENERAL PURPOSE: To provide the nurse with an overview of autism, current screening and diagnostic techniques, and current treatment modalities. **LEARNING OBJECTIVES:** After reading the preceding article and taking this test, you should be able to: 1. Describe autism and its associated signs and symptoms. 2. Discuss current treatment approaches for autism.

1. Which of the following is *not* one of the five disorders on the autism spectrum?

- a. Attention-deficit hyperactivity disorder
- b. Rett's disorder
- c. Autistic disorder
- d. Asperger's disorder

2. Which medical condition is *not* associated with a higher risk of developing autism?

- a. congenital rubella syndrome
- b. fragile X syndrome
- c. hyperbilirubinemia
- d. untreated phenylketonuria

3. Autism usually presents in the

- a. first 6 months of life and almost always by age 1 year.
- b. first 6 months of life and almost always by age 2 years.
- c. first year of life and almost always by age 2 years.
- d. first year of life and almost always by age 3 years.

4. Autism is characterized by unusual social interaction, speech and language problems, uneven intellectual performance, and

- a. increased sensitivity to pain.
- b. repetitive and ritualistic behaviors.
- c. erratic delusional behavior.
- d. uncoordinated fine and gross motor control.

5. Which of the following describes typical social behavior of the child with autism?

- a. The child cries to demand attention when left alone.
- b. The child can only be satisfied when touched and cuddled.
- c. The child prefers to not interact with peers.
- d. The child will lock eye contact with a subject and track him or her incessantly.

6. Speech and language patterns associated with autism can include all of the following *except*

- a. delayed or absent speech.
- b. communicating only with words and never using gestures.
- c. repeating specific words or phrases.
- d. not comprehending the actual meaning of some words.

7. Which behavior may be characteristic of an autistic child?

- a. self-injuring behavior
- b. playing with an object once and then losing interest quickly
- c. dislike of consistent routines
- d. an increased sensitivity to pain

8. Further evaluation for autism should be pursued in a child who is *not*

- a. babbling or pointing by age 6 months.
- b. babbling, pointing, or using gestures by age 12 months.
- c. saying single words by age 12 months.
- d. verbalizing two-word phrases by age 16 months.

9. Which statement is correct about the treatment of autism at present?

- a. Appropriate therapy will cure the child's medical condition.
- b. One specific treatment program is effective for all children with autism.
- c. Most treatment programs focus on improving the child's overall functioning.
- d. Early treatment typically focuses on language only.

10. Which of the following is *not* consistent with applied behavior analysis (ABA) therapy?

- a. It's based on the principle that a child will repeat positively reinforced behaviors and won't repeat ignored behaviors.
- b. It's a training program for everyday skills and social interactions.
- c. It teaches clusters of tasks to help the child see the "big picture."
- d. It uses a reward system for progress gained.

11. According to current scientific evidence, what is the optimal treatment approach for young children with autism?

- a. ABA therapy
- b. Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)
- c. social stories technique
- d. Picture Exchange Communication System (PECS)

12. Which treatment uses very structured classrooms and learning activities broken down into smaller, visually organized steps?

- a. ABA therapy
- b. TEACCH
- c. social stories technique
- d. PECS

13. A class of medication sometimes used to treat ritualistic behaviors is

- a. antiepileptic medications.
- b. antipsychotics.
- c. selective serotonin reuptake inhibitors.
- d. stimulant medications.

14. Quetiapine (Seroquel) may be used to manage aggression, hyperactivity, or

- a. stereotypical or withdrawal behaviors.
- b. delusional and psychotic behaviors.
- c. psychosis.
- d. sensory impairment.

15. Discussions with families about alternative therapies should include information that

- a. gluten- and casein-free diets may help through reduction of dietary fat.
- b. supplementation with B vitamins is both safe and effective.
- c. of the alternative therapies, only behavioral therapies have been proven effective.
- d. because many alternative therapies have no established record of safety, keep your health care provider informed of any therapies you use.

16. When working with an autistic child, you should

- a. prevent inappropriate behavior by saying "no" frequently until the child is calm.
- b. quickly provide a detailed explanation of a procedure you are about to perform.
- c. ensure that there are as many health care providers as possible when the child first enters the room in case a tantrum gets out of control.
- d. attempt to distract him during procedures and always provide positive reinforcement.



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