Tackling the challenges of

autism

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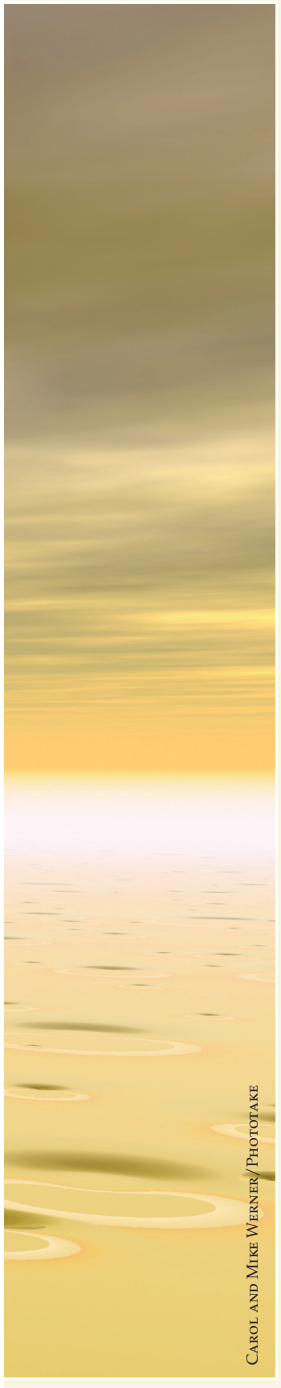

CAROL AND MIKE WERNER/PHOTOTAKE

Autism commonly refers to a collection of disorders affecting communication, socialization, and behavior. Each year, an increasing number of families hear the words "your child has autism." We help you understand these mysterious disorders and their challenging care.

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The authors have disclosed that they have no significant relationships with or financial interest in any commercial companies that pertain to this educational activity.

Meet Jeffrey. At age 2, Jeffrey was first diagnosed with pervasive developmental delays. He showed delays in typical language benchmarks, not saying his name or attempting any vocalization; avoided eye contact with everyone, even when he was being fed by his mother; didn't smile at people he knew or initiate any greetings or wave goodbye like the other kids; and wasn't interested in playing with others. Instead, he continually ran in circles while flapping his hands or stared at spinning wheels of toy cars and trucks for long periods. In fact, he played with most toys inappropriately. Jeffrey also showed an aversion to highly sensory things. He wouldn't touch toy clay, most soaps, finger paints, or even the rice in the sensory table at preschool. Common odors, such as glue, some fruits, and cooked hot dogs, offended him; he gagged when these odors were nearby. By age 4, Jeffrey was diagnosed with autism.

In this article, we'll discuss the suspected causes of and risk factors for autism, the signs and symptoms and diagnostic criteria of these disorders, an overview of available treatment options, and the nurse's role in helping families ensure the best possible outcome for their child.

Across the spectrum

Autism spectrum disorders (ASDs) represent a broad range of complex neurodevelopmental disorders affecting socialization, verbal and nonverbal communication, and behavior. Spectrum refers to the fact that these disorders affect each patient in different ways, with the degree of communication, socialization, and behavioral impairment ranging from mild to severe.

Autistic disorder, or "classic" autism, is the most severe form. Individuals usually have significant language delays, social and communication challenges, and unusual

behaviors and interests; many also have an intellectual disability.

Asperger syndrome is a milder form of autism. Individuals may experience social challenges and display unusual behaviors and interests, but they typically don't experience language problems or have an intellectual disability.

If a child has symptoms of both autistic disorder and Asperger syndrome but doesn't meet the specific criteria for either, he's diagnosed with ***pervasive developmental disorder not otherwise specified*** (PDD-NOS), or atypical autism. These individuals usually have fewer and milder symptoms than those with autistic disorder; they may only experience social and communication challenges.

Autism affects all ages, races, ethnicities, and socioeconomic groups. Both boys and girls are diagnosed with autism, but boys are four times more likely to be diagnosed than girls. Before 1980, autism was believed to be rare, affecting about 1 in 2,000 children. With revised diagnostic testing and criteria for the spectrum of disorders, the rate of ASDs has increased dramatically. The CDC reports that by age 8, 1 in 110 children in the United States is diagnosed with an ASD.

The reason for the dramatic increase in the rate of ASDs is unclear. One explanation is that the criteria for diagnosis have changed over time. There are more subgroups of autism as diagnostic categories, so more people are included in the prevalence rate. There's also a heightened awareness about ASDs. Parents, teachers, nurses, and pediatricians recognize the criteria for these disorders and the importance of early diagnosis and intervention. There's better monitoring of current cases and more data reporting of new cases.

A mysterious disorder

There's no one identifiable, specific cause of autism; researchers believe the cause is a combination of genetic and environmental factors. A number of genes associated with ASDs have been identified. Some children have a genetic predisposition to autism. For example, a child with a parent or sibling with an ASD is more likely to be diagnosed with an ASD. When one identical twin is affected with an ASD, the second twin has a 90% chance of the same diagnosis. Families with one child diagnosed with an ASD have a 5% chance that the second child will also be diagnosed, a risk that's greater than the rest of the population.

The CDC reports that about 10% of children with an ASD diagnosis have an identifiable genetic, neurologic, or metabolic disorder, such as fragile X syndrome (the most common cause of inherited mental impairment), tuberous sclerosis (a genetic disorder that causes tumors to form in different organs, such as the brain, eyes, heart, kidney, skin, and lungs), or Down syndrome. Children with autism may have Angelman syndrome (a neurogenetic disorder characterized by developmental delays, lack of speech, seizures, and walking and balance disorders), chromosome 15q duplication syndrome (a duplication of chromosome 15), or other chromosomal abnormalities.

Some drugs taken during pregnancy, such as thalidomide and valproic acid, have been associated with a higher rate of ASDs. Recent research findings confirm that children born to women over age 40

did you know?

The pattern of behavior we call autism isn't new. More than 50 years ago, Leo Kanner, a psychiatrist at Johns Hopkins, described children in his clinic who lacked attachments with others, avoided eye contact, engaged in repetitive behaviors, and displayed language disorders and significant intellectual deficits. He dubbed this pattern of behavior "early infantile autism." Before this, children who displayed these signs and symptoms were considered emotionally disturbed or "mentally retarded."

After Kanner's findings were published, Hans Asperger, a Viennese physician, described boys with normal intelligence who had social and communication deficits similar to those Kanner described. Dr. Lorna Wing, a British psychiatrist and mother of a child with autism, used Asperger syndrome in 1981 to describe individuals with the features of autism who spoke grammatically and were more socially connected. Through her publications, Dr. Wing and colleagues are credited with pioneering the autism spectrum, with classic autism on one end of the continuum and Asperger syndrome on the other.

are twice as likely to develop autism compared with children born to women under age 25. In most cases, the father's age has little relationship to the development of autism.

Specific environmental factors that cause ASDs haven't been isolated. Some factors suspected to play a role in the diagnosis include environmental mercury; exposure to other heavy metals, contaminated water, pesticides, or flame retardants; an increased reliance on antibiotics; and even some foods. In 1997, research suggesting a relationship between the MMR (measles, mumps, and rubella) vaccines and autism was published. However, the results of this study, which involved only 12 children, were refuted by a more recent study with more than 30,000 children. The relationship between MMR vaccines and autism has been retracted.

For more than a decade, scientists have tried to understand the brain pathophysiology in individuals with ASDs and how these changes affect observed behaviors. Generally, the brains of children with an ASD are slightly larger and heavier than the brains of other children. In fact, brain growth during the first few years for a child with an ASD is faster than average, detectable with head circumference measurement and brain scan. However, some areas of the brain are structurally different in autism. These areas include the amygdala, involved in awareness of emotions in oneself and others; the corpus callosum, involved in communication between the brain's hemispheres; the hippocampus, important for memory of new information; and parts of the cerebellum, important for attention and coordination. Interestingly, the amygdala is larger than average in younger children with ASDs but smaller than average in adolescents and adults with ASDs.

Brain activity during certain cognitive processes is also different in an individual with an ASD. For example, areas of the brain with heightened activity when thinking about another person's feelings, intentions, or emotions show less activity in an individual with autism compared with those who don't have the disorder.

Signs and symptoms: Mild to severe

Autism is often detectable before age 3. Some children show signs of an ASD before their first birthday; other children develop normally during the first 18 to 24 months, then development stops and no new skills are learned. The median age for an early diagnosis of an ASD is between ages 4.5 and 5.5. Other children aren't diagnosed until they're much older. Although symptoms present at one time may change or improve, autism is a lifelong disorder.

Parents are often the first to notice signs and symptoms suggestive of autism. They may report that their child doesn't respond to his name. The child may not babble, point, or make meaningful gestures, all of which a child usually does by about age 1. Some children with an ASD are still not speaking at 16 months. Others aren't combining two words together by age 2, and sometimes the child seems to lose language and social skills. Some children with autism remain language delayed well into age 5 or may remain nonverbal throughout their lives.

If a child with autism does speak, other people may have trouble understanding him. The child may repeatedly use the same words or phrases or parrot others. Sometimes language is only mildly affected. The child may have a large vocabulary but difficulty understanding common phrases or idioms used in speech. For example, a child with autism asked not to "spill the beans" misunderstands the need to keep something secret. Often the child is unable to maintain a conversation with others. Nonverbal communication may

also be challenging for a child with autism. Whether using verbal or nonverbal communication, he may misunderstand the meaning of facial expressions or changes in tone of voice.

The child with autism often avoids eye contact, even with his mother. The child may not smile or may seem hearing impaired. As he gets older and is distressed or afraid, the parents realize they're unable to comfort him with words or touch. The child may even resist his parents' hugs. Some children with autism feel the attachment to their parents, but are unable to express this appropriately.

Parents also report that their child doesn't know how to play with toys or uses toys in unusual ways. For example, the child may line the toys up in a row or play continuously with a single part, such as the wheels on a toy truck or car. Some parents describe that their child is unusually attached to a particular toy.

Children with autism are often unable to read the more subtle social cues from others, such as a smile or a wave. Most kindergarteners understand that people have different feelings and goals from their own. A child with autism may not understand this or may not be able to predict the different reactions in others. Some children with autism may not be able to adequately control their emotions or may not recognize social boundaries. For example, Jeffrey impulsively hugs children on the school bus. In some cases, the child with autism may blurt out expression or words, some that are meaningless, or give unrelated answers to questions. Children with autism often script because they've memorized something from the radio or TV. They may repeat the same sounds or words over and over. Some become physically inappropriate with their frustration, banging their head on the wall, biting their own arms, or pulling out their hair.

Despite normal physical appearance, the odd repetitive behaviors or motions of some children with autism make them look different from their peers. They might run in circles or flap their hands like Jeffrey or they may stop in a frozen position. Sometimes the child with autism becomes extremely fascinated with some unlikely object, such as the movement of a fan, the hands on a clock, or the sight or sound of a number. Interrupting the repetitive behavior may upset the child. These children need consistency; the slightest change in eating, drinking, dressing, bathing, or school rituals may cause distress.

Several physical and mental health disorders coexist with autism. About 20% to 30% of children with an ASD develop epilepsy by the time they reach adulthood. Seizure disorders are commonly seen in children with the more profound cognitive deficits associated with autism, especially children who've shown some skill

Autism indicators

cheat sheet

Early indicators include:

- no babbling or pointing by age 1
- no single words by 16 months or two-word phrases by age 2
- no response to name
- loss of language or social skills
- poor eye contact
- excessive lining up of toys or objects
- no smiling or social responsiveness.

Later indicators include:

- impaired ability to make friends with peers
- impaired ability to initiate or sustain a conversation with others
- absence or impairment of imaginative and social play
- stereotyped, repetitive, or unusual use of language
- restricted patterns of interest that are abnormal in intensity or focus
- preoccupation with certain objects or subjects
- inflexible adherence to specific routines or rituals.

Source: National Institute of Neurological Disorders and Stroke. Autism fact sheet. http://www.ninds.nih.gov/disorders/autism/detail_autism.htm.

regression. Some children diagnosed with an ASD also experience depression, anxiety disorders, or obsessive-compulsive disorders. Difficulty falling asleep or staying asleep is another common problem for these individuals.

Many children diagnosed with autism have gastrointestinal (GI) tract problems, such as gastritis, chronic constipation, colitis, celiac disease, and esophagitis. The number of children with autism affected by GI issues is unknown, but some studies suggest that between about 10% to 85% of children with an ASD are affected.

The importance of early diagnosis

The *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (*DSM-IV-TR*) outlines the standard criteria for the diagnosis of autistic disorder, Asperger syndrome, and PDD-NOS. The diagnosis of ASD includes a combination of six or more characteristics from categories one, two, and three (identified below), with at least two characteristics from category one and one each from categories two and three. The categories are:

1. ***Qualitative impairment in social interaction.*** This includes marked impairment of usual eye contact, facial expression, body posture, and gestures. A lack of age-appropriate peer engagement and a lack of shared interests or reciprocal emotional reactions are also considered.
2. ***Qualitative impairment in communication.*** Characteristics include language delay or total lack of development, or a significant inability to initiate and sustain a conversation. In individuals with adequate speech, stereotypic, idiosyncratic, or repetitive language is present.
3. ***Restricted repetitive and stereotyped patterns of behavior, interests, and activities.*** This includes unusual behavior intensity, repetitive movements such as hand flapping or twisting, or a persistent preoccupation with parts of objects.

Delays or abnormal functioning in social interaction, language as used in social communication, and symbolic or imaginative play before age 3 are also characteristic of a diagnosis of autistic disorder.

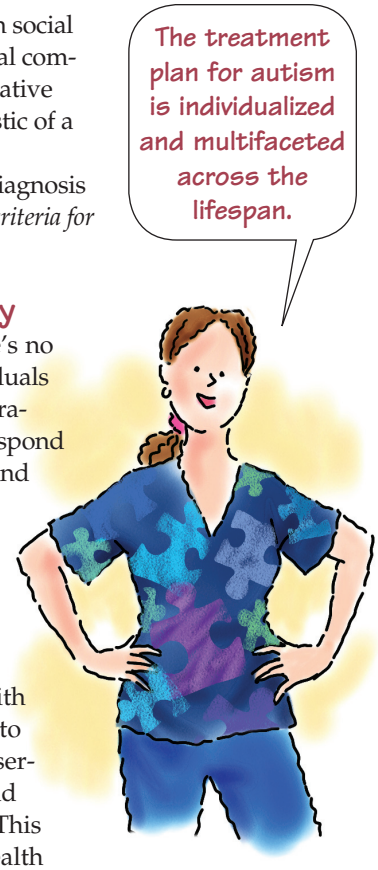
For a more complete look at the diagnosis of ASDs, see *DSM-IV-TR diagnostic criteria for ASDs.*

Multiple therapies are key

Because autism is so complex, there's no single treatment plan. Many individuals with autism receive a variety of therapies. Most children with an ASD respond best to consistent, comprehensive, and structured treatment programs.

Research shows that early intervention is the key to successful behavioral, communication, and educational progress. This includes teaching the parents successful strategies for working with their child. Parents are encouraged to keep a notebook or journal with observations of their child's behaviors and successful management strategies. This helps teachers, nurses, and other health professionals evaluate the child and match him with appropriate special programs (see *An overview of federal programs*).

The treatment regimen may include educational and behavioral interventions, pharmacologic therapy, and other nonpharmacologic therapies.



Behavioral therapies

A variety of behavioral therapies are being used to help children with autism develop social and language skills. One of the oldest and most often researched treatment methods is applied behavioral analysis. Comprehensive and assessment-driven, this method is based on an individualized reward system. Desired behaviors are broken into small steps, with positive rewards for the steps being completed appropriately. As individual steps are accomplished, they're blended together into a more

DSM-IV-TR diagnostic criteria for ASDs

Diagnostic criteria autistic disorder

- Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
  - —qualitative impairment in social interaction, as manifested by at least two of the following:
    - 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
    - failure to develop peer relationships appropriate to developmental level
    - a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (such as by a lack of showing, bringing, or pointing out objects of interest)
    - lack of social or emotional reciprocity.
  - —qualitative impairments in communication as manifested by at least one of the following:
    - 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 gesture or mime)
    - in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - stereotyped and repetitive use of language or idiosyncratic language
    - lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.
  - —restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - encompassing preoccupation with one or more stereotyped and restricted patterns of interest that's abnormal either in intensity or in focus
    - apparently inflexible adherence to specific, nonfunctional routines or rituals
    - stereotyped and repetitive motor manners (such as hand or finger flapping or twisting, or complex whole-body movements)
    - persistent preoccupation with parts of objects.
- Delays or abnormal functioning in at least one of the following areas, with onset before age 3: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- The disturbance isn't better accounted for by Rett disorder or childhood disintegrative disorder.

Diagnostic criteria for Asperger syndrome

- Qualitative impairment in social interaction, as manifested by at least two of the following:
  - —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
  - —failure to develop peer relationships appropriate to developmental level
  - —a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (such as by a lack of showing, bringing, or pointing out objects of interest)
  - —lack of social or emotional reciprocity.
- Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - —encompassing preoccupation with one or more stereotyped and restricted patterns of interest that's abnormal either in intensity or in focus
  - —apparently inflexible adherence to specific, nonfunctional routines or rituals
  - —stereotyped and repetitive motor mannerisms (such as hand or finger flapping or twisting, or complex whole-body movements)
  - —persistent preoccupation with parts of objects.
- The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- There's no clinically significant general delay in language (such as single words used by age 2, communicative phrases used by age 3).
- There's no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- Criteria aren't met for another specific pervasive developmental disorder or schizophrenia.

Diagnostic criteria for PDD-NOS (including atypical autism)

This category should be used when there's a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria aren't met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes atypical autism—presentations that don't meet the criteria for autistic disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Source: CDC. Autism spectrum disorders (ASDs): diagnostic criteria. http://www.cdc.gov/ncbddd/autism/hcp-dsm.html.

comprehensive behavior with rewards. Documentation from the therapist, including parents and teachers, is imperative to evaluate effectiveness. There are several types of applied behavioral analysis programs that are useful for a variety of behaviors, in almost any setting, and with older learners. However, critics state applied behavioral analysis is a robot-like approach and not effective in addressing negative behavior.

Other available methods of behavioral and relationship training include Treatment and Education of Autistic and Communication-Handicapped Children, which addresses unique needs through individualized teaching plans and careful organization and structure so the child can ultimately function and learn independently, and "Floortime," which allows the caregiver or teacher to use floor play with the child to develop self-regulation and appropriate expressions of loving relationships and enhance communication and emotional expression.

Various types of sensory therapies may be used, including art and music therapies, to address the enhanced sensory needs of individuals with ASD.

Pharmacologic therapies

Currently, no medications cure autism; however, several medications are used for symptom management, such as anxiety, depression, or obsessive-compulsive disorder. The FDA approved the use of the antipsychotic drug risperidone to treat severe tantrums, aggression, and self-injury in children ages 5 to 16 with an ASD. Other antipsychotic medications, such as haloperidol, thioridazine, fluphenazine, and chlorpromazine, have been used to treat behavior disorders. These medications must be monitored closely because of the potentially severe adverse reactions. Fluoxetine may be used to treat depression associated with autism. Antiepileptic drugs, used individually or in combination, have been prescribed for individuals with seizures associated with autism; monitoring therapeutic blood levels is imperative. Methylphenidate, used to treat attention-deficit hyperactivity disorder, has been used successfully in children with autism as well.

Other therapies

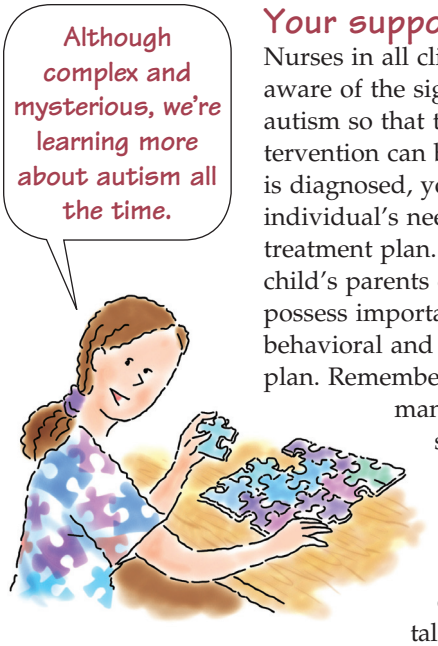
There are a number of controversial therapies or interventions available for children with autism, but few, if any, are supported by scientific studies, according to the National Institute of Neurological Disorders and Stroke. Although dietary interventions, such as a gluten- and casein-free diet, have been helpful in some children, parents should be careful that their child's nutritional status is carefully followed.

Gluten is a grain protein found in rye, wheat, and barley. Casein is a protein found in milk and cheese. Some have suggested that these proteins metabolize differently in children with ASDs. Instead of the usual allergic reaction, individuals with an ASD have physical and behavioral manifestations. Research in this area is limited, but many believe that the child with autism develops more regular bowel habits, improved sleep patterns, and better regulation of repetitive or habitual behaviors when following a gluten- and casein-free diet.

An overview of federal programs

Children under age 3 with special needs, including an ASD, are eligible for early intervention programs available in every state. Home- or community-based services are provided by multidisciplinary experts in caring for toddlers with disabilities. The care plan, called the Individualized Family Service Plan, is reviewed biannually.

School-age children with special learning needs are guaranteed education and specialized services as part of the Individuals with Disabilities Education Act. This federally mandated program ensures appropriate education and other necessary services free through public schools. Depending on need, these services may include speech therapy, occupational therapy, social workers, school psychologists, and special services from the school nurse or a teacher's aide. By law, after the child enters school, his Instructional Education Program is part of an ongoing, multidisciplinary evaluation with the teacher, representatives from all special services the child uses, and the parents or the child's representative.



Your support is requested

Nurses in all clinical areas need to be aware of the signs and symptoms of autism so that timely diagnosis and intervention can be achieved. After a child is diagnosed, your role is guided by the individual's needs, along with the specific treatment plan. Listen carefully to the child's parents or caregivers because they possess important information about the behavioral and communication treatment plan. Remember that successful symptom management depends on consistency and structure.

Health education is another important nursing role. Education needs will vary; for example, depending on developmental and skill levels, individuals with autism may need help with personal hygiene such as hand washing, toileting assistance or training, or help understanding adolescent hormonal changes. If medications are used for any reason, teach parents or caregivers about appropriate use and potential adverse reactions. Individuals with a higher functioning form of autism such as Asperger syndrome may need education about safe sexual expression or career options. You can play an important role in assessment of educational needs and the development of an appropriate teaching plan to meet those needs.

Many parents report that their child with an ASD has trouble taking oral medications. In some cases, medications may need to be taken during the school day. Open communication between the school nurses caring for the child and parents or other caregivers can make medication administration less stressful. Part of this communication should include the most successful oral medication administration strategies for the child.

The nurse must also be aware of special dietary needs or restrictions. You can remind family members and other caregivers of the potential need for dietary supplements to replace necessary nutrients from restricted foods. For example, a child on a gluten- and casein-free diet will have restricted intake of milk, cheese, and certain fiber foods. These children may need calcium and vitamin D supplements along with additional foods for dietary fiber, such as bananas, potatoes, apples, or asparagus. Children with excessive activity may also need additional calorie supplementation.

Remember that the individual with autism needs a lifetime of treatment and support. Careful observation of behavioral and communication changes is important for access to appropriate resources. Help family members or caregivers to connect with resources as their loved one's needs change. Most communities have a variety of resources and support services for individuals and families dealing with ASDs.

And, finally, stay informed about research findings and new treatment options. Future research may successfully isolate specific causes of ASDs, and new treatments may emerge to successfully manage autism as the individual ages and symptoms change.

The complex symptoms of autism demand a variety of treatments to meet the individual's needs. Although complete recovery from autism isn't realistic, with your help families will be able to implement effective interventions to ensure the best quality of life for their child. ■

Learn more about it

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DOI-10.1097/01.NME.0000386786.40862.cf

On the web

These online resources may be helpful to your patients and their families.

Autism Research Institute: http://www.autism.com/index.asp
Autism Society of America: http://www.autism-society.org/site/PageServer
Autism Speaks: http://www.autismspeaks.org/
CDC: http://www.cdc.gov/ncbddd/autism/index.html
National Autism Association: http://www.nationalautismassociation.org/
National Institute of Child Health and Human Development: http://www.nichd.nih.gov/health/topics/asd.cfm

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