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AUTISM SPECTRUM DISORDER

Autism spectrum disorder is a serious neurodevelopmental disorder that impairs a child's ability to communicate and interact with others. It also includes restricted repetitive behaviors, interests and activities. These issues cause significant impairment in social, occupational and other areas of functioning.

Autism spectrum disorder (ASD) is now defined by the American Psychiatric Association's Diagnosis and Statistical Manual of Mental Disorders (DSM-5) as a single disorder that includes disorders that were previously considered separate – autism, Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified.

The term "spectrum" in autism spectrum disorder refers to the wide range of symptoms and severity. Although the term "Asperger's syndrome" is no longer in the DSM, some people still use the term, which is generally thought to be at the mild end of autism spectrum disorder.

The number of children diagnosed with autism spectrum disorder is rising. It's not clear whether this is due to better detection and reporting or a real increase in the number of cases, or both. While there is no cure for autism spectrum disorder, intensive, early treatment can make a big difference in the lives of many children.

Autism spectrum disorder impacts how a child perceives and socializes with others, causing problems in crucial areas of development – social interaction, communication and behavior.

Some children show signs of ASD in early infancy. Other children may develop normally for the first few months or years of life, but then suddenly become withdrawn or aggressive or lose language skills they've already acquired.

Each child with ASD is likely to have a unique pattern of behavior and level of severity – from low functioning to high functioning. Severity is based on social communication impairments and the restrictive and repetitive nature of behaviors, along with how these impact the ability to function.

Because of the unique mixture of symptoms shown in each child, severity level can sometimes be difficult to determine. However, within the range (spectrum) of symptoms, below are some common ASD actions and behaviors.

SOCIAL COMMUNICATION AND INTERACTION

- Fails to respond to his or her name or appears not to hear you at times
- Resists cuddling and holding and seems to prefer playing alone – retreats into his or her own world
- Has poor eye contact and lacks facial expression
- Doesn't speak or has delayed speech, or may lose previous ability to say words or sentences
- Can't start a conversation or keep one going, or may only start a conversation to make requests or label items
- Speaks with an abnormal tone or rhythm – may use a singsong voice or robot-like speech
- May repeat words or phrases verbatim, but doesn't understand how to use them
- Doesn't appear to understand simple questions or directions
- Doesn't express emotions or feelings and appears unaware of others' feelings
- Doesn't point at or bring objects to share interest
- Inappropriately approaches a social interaction by being passive, aggressive or disruptive

PATTERNS OF BEHAVIOR

- Performs repetitive movements, such as rocking, spinning or hand-flapping, or may perform activities that could cause harm, such as head-banging
- Develops specific routines or rituals and becomes disturbed at the slightest change
- Moves constantly
- May be uncooperative or resistant to change
- Has problems with coordination or has odd movement patterns, such as clumsiness or walking on toes, and has odd, stiff or exaggerated body language
- May be fascinated by details of an object, such as the spinning wheels of a toy car, but doesn't understand the "big picture" of the subject
- May be unusually sensitive to light, sound and touch, and yet oblivious to pain
- Does not engage in imitative or make-believe play
- May become fixated on an object or activity with abnormal intensity or focus
- May have odd food preferences, such as eating only a few foods, or eating only foods with a certain texture

Most children with ASD are slow to gain knowledge or skills, and some have signs of lower than normal intelligence. Other children with ASD have normal to high intelligence – they learn quickly, yet have trouble communicating and applying what they know in everyday life and adjusting to social situations. A small number of children with ASD are savants – they have exceptional skills in a specific area, such as art, math or music.

As they mature, some children with ASD become more engaged with others and show fewer disturbances in behavior. Some, usually those with the least severe problems, eventually may lead normal or near-normal lives. Others, however, continue to have difficulty with language or social skills, and the teen years can bring worse behavioral problems.

WHEN TO SEE A DOCTOR

Babies develop at their own pace, and many don't follow exact timelines found in some parenting books. But children with autism spectrum disorder usually show some signs of delayed development within the first year. If you suspect that your child may have ASD, discuss your concerns with your doctor. The symptoms associated with ASD can also be linked with other developmental disorders. The earlier that treatment begins, the more effective it will be.

Your doctor may recommend developmental tests to identify if your child has delays in cognitive, language and social skills, if your child:

- Doesn't respond with a smile or happy expression by 6 months
- Doesn't mimic sounds or facial expressions by 9 months
- Doesn't babble or coo by 12 months
- Doesn't gesture – such as point or wave – by 14 months
- Doesn't say single words by 16 months
- Doesn't play "make-believe" or pretend by 18 months
- Doesn't say two-word phrases by 24 months
- Loses previously acquired language or social skills at any age

Autism spectrum disorder has no single known cause. Given the complexity of the disorder, and the fact that symptoms and severity vary, there are probably many causes. Both genetics and environment may play a role.

- **Genetic problems.** Several different genes appear to be involved in autism spectrum disorder. For some children, autism spectrum disorder can be associated with a genetic disorder, such as Rett syndrome or fragile X syndrome. For others, genetic changes may make a child more susceptible to autism spectrum disorder or create environmental risk factors. Still other genes may affect brain development or the way that brain cells communicate, or they may determine the severity of symptoms. Some genetic problems seem to be inherited, while others happen spontaneously.

- **Environmental factors.** Researchers are currently exploring whether such factors as viral infections, complications during pregnancy or air pollutants play a role in triggering autism spectrum disorder.

NO LINK BETWEEN VACCINES AND ASD

One of the greatest controversies in autism spectrum disorder is centered on whether a link exists between ASD and certain childhood vaccines, particularly the measles-mumps-rubella (MMR) vaccine. Despite extensive research, no reliable study has shown a link between ASD and the MMR vaccine. Avoiding childhood vaccinations can place your child in danger of catching and spreading serious diseases, including whooping cough (pertussis), measles or mumps.

Autism spectrum disorder affects children of all races and nationalities, but certain factors increase a child's risk. They include:

- **Your child's sex.** Boys are about four times more likely to develop ASD than girls are.
- **Family history.** Families who have one child with ASD have an increased risk of having another child with the disorder. It's also not uncommon for parents or relatives of a child with ASD to have minor problems with social or communication skills themselves or to engage in certain behaviors typical of ASD.
- **Other disorders.** Children with certain medical conditions have a higher than normal risk of ASD or ASD-like symptoms. Examples of these conditions include fragile X syndrome, an inherited disorder that causes intellectual problems; tuberous sclerosis, a condition in which benign tumors develop in the brain; the neurological disorder Tourette syndrome; and Rett syndrome, a genetic condition occurring almost exclusively in girls, which causes slowing of head growth, intellectual disability and loss of purposeful hand use.
- **Extremely preterm babies.** Babies born before 26 weeks of pregnancy may have a greater risk of ASD.
- **Parents' ages.** There may also be a connection between children born to older parents and ASD, but more research is necessary to establish this link.

Your child's health care provider will look for developmental problems at regular checkups.

WHAT YOU CAN DO

To prepare for your child's appointment:

- **Bring a list of any medications,** including vitamins, herbs and over-the-counter medicines that your child is taking, and their dosages.
- **Make a list of all the changes that you and others have observed** in your child's behavior.
- **Bring notes of any observations from other adults and caregivers,** such as baby sitters, relatives and teachers. If your child has been evaluated by an early intervention or school program, bring this assessment.
- **Bring a record of developmental milestones for your child,** such as a baby book, if you have one.
- **Bring a video of your child's unusual behaviors or movements,** if you have one.
- **Try to remember when your other children began talking and reaching developmental milestones,** if your child has siblings, and share that information with the doctor.
- **Be prepared to describe how your child plays and interacts** with other children, siblings and parents.
- **Bring a family member or friend with you,** if possible, to help you remember information and for emotional support.

Make a list of questions that you want to ask your child's doctor. Questions might include:

- Why do you think my child does (or doesn't) have ASD?
- Is there a way to confirm the diagnosis?
- If my child does have ASD, is there a way to tell how severe it is?
- What changes can I expect to see in my child over time?
- What kind of special therapies or care do children with ASD need?
- How much and what kinds of regular medical care will my child need?
- What kind of support is available to families of children with ASD?
- How can I learn more about ASD?

Ask additional questions any time you don't understand something.

WHAT TO EXPECT FROM YOUR CHILD'S DOCTOR

Your child's doctor is likely to ask you a number of questions. Be ready to answer them to reserve time to go over any points you want to focus on. Your doctor may ask:

- What specific behaviors prompted your visit today?
- When did you first notice these signs and symptoms in your child? Have others noticed signs?
- Have these behaviors been continuous or occasional?
- Does your child have any other symptoms that might seem unrelated to ASD, such as stomach problems?
- Does anything seem to improve your child's symptoms?
- What, if anything, appears to worsen your child's symptoms?
- When did your child first crawl? Walk? Say his or her first word?
- Does your child have delayed speech?
- What are some of your child's favorite activities? Is there one that he or she favors?
- How does your child interact with you, siblings and other children? Does your child show interest in others, make eye contact, smile or want to play with others?
- Have you noticed a change in your child's level of frustration in social settings?
- Does your child have a family history of ASD, language delay, Rett syndrome, obsessive-compulsive disorder, or anxiety or other mood disorders?

Your child's health care provider will look for signs of developmental delays at regular checkups. If your child shows any symptoms of autism spectrum disorder, you'll likely be referred to a specialist who treats children with ASD, such as a child psychologist, pediatric neurologist or developmental pediatrician, for a thorough clinical evaluation.

Because ASD varies widely in severity, making a diagnosis may be difficult. There isn't a specific medical test to determine the disorder.

Instead, a specialist in ASD may:

- Observe your child and ask how your child's social interactions, communication skills and behavior have developed and changed over time
- Give your child tests covering speech, language, developmental level, and social and behavioral issues
- Present structured social and communication interactions to your child and score the performance
- Include other specialists in determining a diagnosis
- Recommend genetic testing to identify whether your child has a genetic disorder such as fragile X syndrome

Signs of ASD often appear early in development when there are obvious delays in language skills and social interactions. Early diagnosis and intervention is most helpful and can improve skill and language development.

DIAGNOSTIC CRITERIA FOR ASD

For your child to be diagnosed with autism spectrum disorder, he or she must meet the symptom criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published by the American Psychiatric Association. This manual is used by mental health providers to diagnose mental conditions and by insurance companies to reimburse for treatment.

ASD includes problems with social interaction and communication skills and restricted, repetitive patterns of behavior, interests or activities that cause significant impairment in social, occupational or other areas of functioning.

IMPAIRED SOCIAL AND COMMUNICATION SKILLS

To meet ASD criteria, your child must have problems across multiple situations with:

- Social and emotional give-and-take in social settings – for example, an inability to engage in normal back-and-forth conversation, a reduced ability to share experiences or emotions with others, or problems initiating or responding to social interactions
- Nonverbal communication behaviors used for social interaction – for example, difficulty using or understanding nonverbal cues, problems making eye contact, problems using and understanding body language or gestures, or a total lack of facial expressions
- Developing, maintaining and understanding relationships – for example, difficulty adjusting behavior to suit various social situations, problems sharing imaginative play or in making friends, or a lack of interest in others

RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOR

To meet ASD criteria, your child must experience at least two of these:

- Odd or repetitive motor movements, use of objects or speech – for example, body rocking or spinning, lining up toys or flipping objects, mimicking sounds, or repeating phrases verbatim without understanding how to use them
- Insistence on sameness, rigid routines, or ritualized patterns of verbal or nonverbal behavior – for example, extreme distress at small changes, expecting activities or verbal responses to always be done the same way, or needing to take the same route every day
- Interests in objects or topics that are abnormal in intensity, detail or focus – for example, a strong attachment to unusual objects or parts of objects, excessively limited narrow areas of interest, or interests that are excessively repetitive
- Extra sensitivity or a lack of sensitivity to sensory input or an unusual interest in sensory aspects of the environment – for example, apparent indifference to pain or temperature, negative response to certain sounds or textures, excessive smelling or touching of objects, or visual fascination to lights or movement

No cure exists for autism spectrum disorder, and there is no one-size-fits-all treatment. The range of home-based and school-based treatments and interventions for ASD can be overwhelming. The goal of treatment is to maximize your child's ability to function by reducing ASD symptoms and supporting development and learning. Your health care provider can help identify resources in your area.

Treatment options may include:

- **Behavior and communication therapies.** Many programs address the range of social, language and behavioral difficulties associated with ASD. Some programs focus on reducing problem behaviors and teaching new skills. Others focus on teaching children how to act in social situations or how to COMMUNICATE better with others. Though children don't always outgrow ASD symptoms, they may learn to function well.
- **Educational therapies.** Children with ASD often respond well to highly structured educational programs. Successful programs often include a team of specialists and a variety of activities to improve social skills, communication and behavior. Preschool children who receive intensive, individualized behavioral interventions often show good progress.
- **Family therapies.** Parents and other family members can learn how to play and interact with their children in ways that promote social interaction skills, manage problem behaviors, and teach daily living skills and communication.
- **Medications.** No medication can improve the core signs of ASD, but certain medications can help control symptoms. For example, antidepressants may be prescribed for anxiety, and antipsychotic drugs are sometimes used to treat severe behavioral problems. Other medications may be prescribed if your child is hyperactive.

MANAGING OTHER MEDICAL CONDITIONS

Children with autism spectrum disorder may also have other medical issues, such as epilepsy, sleep disorders, limited food preferences or stomach problems. Ask your child's doctor how to best manage these conditions together.

Keep all of your child's health care providers updated on any medications and supplements your child is taking. Some medications and supplements can interact, causing dangerous side effects.

Teens and young adults with ASD may have issues with body changes, increased social awareness and transitions. People with ASD often experience other mental health disorders, such as anxiety and depression. Your health care provider and community advocacy and service organizations can offer help.

Because autism spectrum disorder can't be cured, many parents seek out alternative and complementary therapies, but these treatments have little or no research to show that they're effective. You could, unintentionally, reinforce negative behaviors. And some alternative treatments are potentially dangerous.

Talk with your child's doctor about the scientific evidence of any therapy that you're considering for your child. Examples of complementary and alternative therapies include:

- **Creative therapies.** Some parents choose to supplement educational and medical intervention with art therapy or music therapy, which focuses on reducing a child's sensitivity to touch or sound.
- **Sensory-based therapies.** These therapies are based on the theory that people with ASD have a sensory processing disorder that causes problems tolerating or processing sensory information, such as touch, balance and hearing. Therapists use brushes, squeeze toys, trampolines and other materials to stimulate these senses and organize the sensory system. A sensory processing disorder is not an official diagnosis, and it is not clear if this is even the problem experienced by people with ASD. Research has not shown these therapies to be effective, but it's possible they may offer some benefit when used along with other treatments.
- **Special diets.** Several diet strategies have been suggested as possible treatments for ASD, but more research is necessary to see if they have any effect on ASD signs and symptoms. To find out more, talk to a registered dietitian with expertise in ASD.
- **Chelation therapy.** This treatment is said to remove mercury and other heavy metals from the body. However, there's no known link between mercury and ASD. Chelation therapy for ASD is not supported by research evidence and can be very dangerous. In some cases, children treated with chelation therapy have died.
- **Acupuncture.** This therapy has been used with the goal of improving ASD symptoms. However, the effectiveness of acupuncture for ASD has not been supported by research.

Raising a child with autism spectrum disorder can be physically exhausting and emotionally draining. These suggestions may help:

- **Find a team of trusted professionals.** You'll need to make important decisions about your child's education and treatment. A team, coordinated by your health care provider, may include social workers familiar with autism, teachers, and therapists who can help explain the resources in your area. Ask if the team includes a case manager or service coordinator who can help access financial services and government programs.
- **Take time for yourself and other family members.** Caring for a child with ASD can put stress on your personal relationships and your family. To avoid burnout, take time out to relax, exercise or enjoy your favorite activities. Try to schedule one-on-one time with your other children and plan date nights with your spouse or partner – even if it's just watching a movie together after the children go to bed.
- **Seek out other families of children with ASD.** Other families struggling with the challenges of ASD may have useful advice. Some communities have support groups for parents and siblings of children with ASD.
- **Learn about the disorder.** There are many myths and misconceptions about ASD. Learning the truth can help you better understand your child and his or her attempts to communicate. With time, you'll likely be rewarded by seeing your child grow and learn and even show affection – in his or her own way.
- **Keep records of visits with service providers.** Your child may have visits, evaluations and meetings with many people involved in his or her care. Keep an organized file of these meetings and reports to help you decide about treatment options and monitor progress.

- **Stay current on new technologies and therapies.** Researchers continue to explore new approaches to help children with ASD. See the Centers for Disease Control and Prevention website on autism spectrum disorders for helpful materials and links to resources.

There's no way to prevent autism spectrum disorder, but ASD can be treated, and children can improve their language and social skills. Children with ASD typically continue to learn and compensate for problems throughout life, but most will continue to require some level of support.

If your child is diagnosed with autism spectrum disorder, talk to experts about creating a treatment strategy. Keep in mind that you may need to try several different treatments before finding the best combination of therapies for your child.

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