

- **EVERYTHING YOU
NEED TO KNOW
ABOUT AUTISM:
PARENT'S GUIDE**

Why do children with autism need special care in the first place?



Children with autism are different. Autism spectrum disorder (ASD) is a complex developmental disability; signs typically appear during early childhood and affect a person's ability to communicate, and interact with others. Some of the behaviors associated with autism include

- delayed learning of language
- difficulty making eye contact or holding a conversation
- narrow or intense interests
- poor motor skills
- sensory sensitivities

It is not easy being the child that is always one step behind his or her peers. And for that alone they deserve a little extra support and care!

YOU ARE NOT ALONE!

SCENARIO ACROSS THE WORLD

Studies conducted in the United States has estimated an average prevalence of 1 in 68 births, (CDC, 2014). Asia and Europe have identified an average prevalence of about 1% while South Korea was reported with a prevalence of 2.6%. Not only are the present numbers alarming, but they are also progressively increasing over the time.

SCENARIO IN INDIA

According to the Autism Society of India, approximately 1 in every 250 persons (i.e., a total of nearly 40,00,000 individuals) have autism in India. The count of the incidence has only been growing in the last few years.



Let's talk science and facts now!

What is Autism?

Autism is defined as the dysfunction in the neurological network of the brain manifests into the spectrum of autism. It is a neuro-developmental disorder which leads to difficulties in speech, communication, social interaction, behaviour, sensory issue and thinking ability.

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Causes, Signs and Symptoms of Autism to Watch Out For

The very basic facts that you as parents need know that will help you understand and sometimes even identify your child's condition early on!

● CAUSES OF AUTISM

Genetics

In many families, there appears to be a pattern of autism, further supporting the theory that the disorder has a genetic basis. However, there is no one gene that has been identified as causing autism. There is intensive research which has been carried out to tap some irregular segments of genetic code that children with autism may have inherited.

The second child stands 5% chance of having autism and a twin stands 90% of having autism.

Prenatal Environment

The risk of autism is associated with several prenatal factors such as advanced age in either of the parent, diabetes, bleeding, and use of psychiatric drugs in the mother during pregnancy. Autism has been linked to birth defect agents like viral infections, tetragons and other material conditions acting during the first eight weeks from conception.

● CAUSES OF AUTISM

Postnatal environment

Many factors have been given credit for this. They include gastrointestinal or immune system abnormalities, allergies, and exposure of children to drugs, vaccines, infection, certain foods and lack of vitamin D. It could be also due to heavy metals like lead and mercury, opiate therapy or due to a mother who isn't demonstrative of her affection. The evidence for these risk factors is yet to be confirmed by reliable studies.

Perinatal Environment

Autism has also been linked to factors like low birth weight, gestation duration (development of the child in the womb during pregnancy), and lack of oxygen to the child during childbirth.

EARLY INDICATIONS OF AUTISM

New born to 18 months

- May avoid people's gaze
- Does not like people cuddling
- Prefers to be alone
- Delayed smile or does not smile
- Repetitive behaviour or actions with the body, like hand flapping or rocking
- Repetitive behaviour or actions with the objects, like with toys
- Avoids social interaction
- Has hyperactivity (excessive physical activity, restless, not sitting at one place) when there is a change in the routines
- Lack of non-verbal communication like gestures, poor facial expression and no body language

1½ years to 4 years

- May have impaired imitation
- May avoid people's gaze (not looking into person's eyes while interacting)
- Poor understanding of language and delayed language development
- Not approaching parents for comfort, even when ill, hurt or tired
- Lacking awareness of other people's existence
- Older child may exhibit a failure to greet people or take turns while playing or interacting
- Repetition of whatever is said to him /her (echolalia) and an unusual manner of talking.
- Handles objects strangely.
- Have unusual body movements, Preoccupied with parts of objects
- Unreasonable insistence on following routines to precise detail
- Have difficulty in toilet training

EARLY INDICATIONS OF AUTISM

4 years and older

- Poor Eye contact
- Lack an awareness of the existence or feelings of others
- Absence of pretend play, e.g. dressing up a doll, or pretending to be a teacher
- Increased hyperactivity
- Lack or have unusual emotional responses, e.g. crying or laughing without any reason
- Indifferent towards or responds negatively to physical affection like hugging, patting, etc.
- Poor social interaction
- Not understanding conventions of social interaction, such as turn-taking, making requests, etc.
- Show little expressive language
- Delayed language development
- 29Parent and Teacher Guide Book for Autism
- Inappropriate gestures
- Fail to initiate or sustain conversations
- Attachment to unusual objects
- Show marked distress over changes in trivial aspects of the environment,

● SIGNS AND SYMPTOMS OF AUTISM

What are the signs are symptoms you should look out for?

- **Poor social interactions:** Children have a natural tendency towards curiosity and building connections but a child with autism will find it tough to do the same.
- **Underdeveloped emotional quotient:** They fail to grasp facial expressions and have a tough time understanding emotions. They also have trouble controlling their own emotions which is associated with irrational fears at times.
- **Unusual behaviour patterns:** Autism is usually associated with some strange habits like smelling objects or people and sometimes even an unnatural obsession with objects. They have an unusal need to repeat actions. But the worst of this is when are they inflicted with the need to be aggressive towards the people around them and themselves.

● SIGNS AND SYMPTOMS OF AUTISM

- **Speech and language communication:** This condition effects the ability of a child to speak like some children would have repetative speech whereas a few other would only speak in single words and a few others would be completely non-verbal.
- **Sensory influences:** This condition causes hypersensitivity which is a reason behind avoiding physical contact and it also effects the childs mobility. They are either hyperactive or fear movement entirely.
- **Influence on cognitive abilities:** This condition again effects the cognitive abilities to a varying capacity. Some have high intelligence but have difficulty understanding others while others have a lower IQ and find learning and understanding tough. They however tend have an additional skill that is far superior to the rest of the kids in their age group and beyond too.

These are some of the most common signs and symptoms to keep an eye out for!

● ASSOCIATED PROBLEMS



What is unfortunate is that autism sometimes comes with associated troubles like OCD, seizures, mood disorders, sleep disorders, pica (hunger food items that are not edible), gastrointestinal troubles, low muscle tone, and learning disabilities.

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Assesment, Investigations and Diagnosis

Who handles the diagnosis of a child with Autism?

What are the various investigations which an autistic child undergoes?

IT IS NOT ONE PERSON BUT A TEAM OF DOCTORS WHO PLAY A PART IN THE DIAGNOSIS (Multi-disciplinary approach)

Diagnosis of autism in most cases happens much later in the formative years mostly due to lack of awareness amongst parents. Quite sometime goes by before the parent notices that something might not be right with their child. But once parents observe that their child may need a little extra attention, a number of evaluations are conducted even before testing and investigation. This usually involves the input of:

- The Developmental Paediatrician
- Psychiatrist
- The Clinical Psychologist
- The Occupational Therapist
- The Speech and Language Pathologist
- The Physiotherapist

The diagnosis is never done by one person. It involves a whole team of doctors dedicated to improving a child's quality of living.

THE INVESTIGATIONS THAT FOLLOW DIAGNOSIS

Once the diagnosis is done, investigations are conducted to ensure that the analysis is accurate. This is also done with the aim of identifying the extent of the condition. The investigations that go into this process are as follows.

- Neuro-imaging studies (MRI/CT/PET-CT/SPECT/FMRI)
- PET-CT scan
- Electroencephalography (EEG)
- Brain Stem Evoked Response Audiometry (BERA)
- Metabolic screening
- Genetic testing

Each of these tests has a specific aim that helps understand the extent of development of the brain better and gives direction to the treatment that follows.

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DETECTION DURING EARLY PREGNANCY

Is it even possible?

● PRENATAL IDENTIFICATION IS POSSIBLE!

Recent research by scientists at the Autism Research Centre at Cambridge University has identified ways by which a probable diagnosis of autism can be made prenatally (i.e. before the child's birth). There is a possibility of screening unborn babies to detect autism in the womb itself.

Chromosomal Microarray Analysis (CMA)

CMA is a novel method of analysing chromosomes for detection of autism. With a single test, CMA can detect genetic abnormalities on all chromosomes simultaneously. It has much higher sensitivity than the older chromosome test called karyotyping. It uses the amniotic fluid as sample for testing and is taken with the procedure of amniocentesis as mentioned above.

These tests are secondary to clinical screening and may not be confirmatory, but definitely aid in medical decisions.

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REDUCING THE RISK FACTORS

What can you do?

● THIS IS FOR THE PARENTS TO BE!

As 'to-be' parents or for those who are planning a sibling to their child with autism, information about the possible risk factors and measures to reduce the risk of ASDs given below are much needed.

Some of the identified factors are:

Modifiable: The following factors should be avoided

- Taking antidepressants, particularly in the first trimester (first three months of pregnancy)
- Nutritional deficiencies early in pregnancy especially folic acid deficiency
- Maternal infections
- Maternal stress
- Exposure to chemical pollutants such as metals and pesticides
- Exposure to harmful rays or extreme environmental conditions
- Exposure to some harmful drugs during pregnancy

Non-modifiable:

- Mother's autoimmune disorders such as celiac disease and rheumatoid arthritis
- The age of the mother and the father- research studies have indicated that children born to older fathers have a higher risk of suffering from autism
- A parental history of schizophrenia-like psychosis, affective disorders including depression or bipolar disorder



BUT SOMETIMES DESPITE YOUR BEST EFFORTS, THE GODS HAVE A DIFFERENT PLAN!
So what do you do then?

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WHAT CAN YOU DO AT HOME?

Symptomatic treatment

● SOCIAL RELATIONSHIPS AND RECIPROCACY

Poor eye contact:

Move flickering lights in front of the child's eyes & demonstrate how he could track the light with his eyes. Hold some glittering object near your eyes and encourage child to look in your eyes. Keep in mind their preferences when decorating and keep the amount of toys used in a room at minimum. Regular practice is a must!

Unable to respond to social/environmental cues:

Teach your child emotions using images and practice with them. Combining this with the use of social stories from a child's perspective and role play has been found to be effective.

Does not maintain peer relationships:

Provide a wide range of opportunities for your child to communicate and connect. Autistic kids tend to have poor confidence levels and their every attempt at socializing should be rewarded. Keep a track and gently keep probing them forward.

EMOTIONAL RESPONSIVENESS

Shows inappropriate emotional response:

Consistency is what they need. Whatever rules you establish must be the rules of the house. Engage them in the practice of time out to ensure they can calm down no matter where they go. And if they show signs of irritation to anything, removing it from the environment can help a lot.

Engages in self stimulating behaviour:

Has he or she been rocking or moving their hands too much? This is called self stimulation. Best way to manage this is to engage them some activity that will keep their hands busy. But make sure that it is an activity they enjoy and want to do. That will reduce the emotional stress on them.

Lacks fear of danger:

This is a result of the dysfunction and can result in hyper or hypo cases. In hyper cases, the child will make fearful movements even in normal situations and in hypo, they need additional stimulation. This can result in loss of control at times. In such situations, stop the activity and engage in simple one on one communication.

● COGNITIVE ASPECTS

Inconsistent attention and concentration:

Avoid clutter in study table and area. Use darker colours to help improve attention. Give him or her a separate room to sit and study. Ensure that this room uses soothing colours. Some children are also distracted by visuals. Do your best to ensure that distractions are minimized.

Delay in response time:

Some kids need a longer time to process information and respond. In such cases, use bright colours and visual methods. Writing skill maybe poor so make writing a fun with colours and use computers. Focus on improving concentration and eye contact. Other techniques of positive reinforcement can be really useful too.

Has savant ability:

Autism spectrum disorders may effects ones ability to learn in certain ways but it certainly doesn't make them stupid. Some children are gifted in specific skills like calculations or playing musical instruments and some with the arts. Use these talents to build their self confidence and mingle with their peers.

SPEECH AND COMMUNICATION

If your child loses the ability to speak:

Patience is imperative. Use cards to explain regular activities to him or her. Use the words that are commonly used to identify objects repeatedly. Picture cards and real objects are important because visual, auditory, tactile stimulation help children to understand concepts faster. Follow a similar pattern.

Has trouble with gestures or non-verbal language:

Improving eye contact is essential as non-verbal communication depends on it to a large extent. Encourage them to shake hands and other social gestures. Teach them to identify themselves and you in photographs. All of these put together aid in building social adaptability.

Unable to maintain conversations:

This causes one of the biggest challenges in social situations. The low attention span and reduced speech functions together pose a challenge. Encourage your child to engage in activities like craft to improve attention and also help them first use monosyllables that can then be combined.

● **SENSORY ASPECTS**

Unusual sensitivity:

This is an indicator of hypersensitivity.

Encourage bear hugs, massages with or without lotions and work on desensitizing the tactile system.

Vibrating objects including toothbrush, pens, balls, stuffed toys, etc.

"Sandwiching" between pillows, climbing under sofa cushions also aids.

Tends to space out or has unusual vision:

Work on improving eye contact as a basic foundation. Add activities like tracking objects to improve his or her ability to stay focused on a single activity. Some kids also find unusual patterns disturbing. Avoid complicated patterns in the environment in such situations.

Insensitivity to pain:

This is a result of hyposensitivity of the tactile system. The sensation of heat, cold and rough surfaces does not register well. Working on this will involve coaching of what the sensation means. The use of different fabrics and also warm towels and dry rice or beans can be of help.

● BEHAVIOUR PATTERNS

Repetitive behaviour and social interaction:

Engage the child in understanding the expressions of others. Repetitive behaviour makes those around them uncomfortable and they need to be able to read expressions. Engage them in activities that can substitute for their repetitive behaviour. Use videos and stories to repeat learning new actions.

Unable to respond to social/environmental cues:

Teach your child emotions using images and practice with them. Combining this with the use of social stories from a child's perspective and role play has been found to be effective.

Attachment to inanimate objects:

Obsessions are not exactly the best things to have but in this case, it can be used for the better. It can be used to aid in learning and can also be incorporated in extra-curricular activities that can increase the abilities to interact.

● BEHAVIOUR PATTERNS

Hyperactivity/ restlessness: :

While many of the strategies are things a parent can do to help their child, it is also important to teach your child self-regulation. Deep breathing exercises, yoga, or meditation all help a child to slow down.

Hyperactivity zooms when boredom sets in. Create a box of activities geared toward your child's interests.

Engages in self- injurious behaviour/ Throws temper tantrums:

Difficulty in expressing emotions leads to this behaviour. Help them find less harmful ways of venting like playing drums etc. time out zone is also good as it allows both of you to calm down. Learn to identify the indicators before hand.

Insists on sameness:

Prepare them as best as you can. Setting a visible time table helps. But also set aside back ups in case of changes can be predicted. This helps them manage anxiety. Slowly introduce the change to them in small manners and build on it to make them more adaptable to unpredictable situations.

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TREATMENT OPTIONS

What can you do?

WHAT CAN YOU DO ENSURE YOUR CHILD HAS A GOOD QUALITY OF LIFE?

Stem cell therapy

This is the application of adult stem cells towards the creating new cells in the body to replace the older damaged cells. This approach makes it possible to much more than manage symptoms.

Traditional

This is more geared towards the management of the symptoms to give the patient a better quality of life.

WHAT IS THE BEST SHOT YOU CAN GIVE THEM?



A combination of stem cell therapy along with traditional symptom management methods yeild far better and lasting results. It would help improve the over all quality of the life of the child and increase the level of independence.

250

That is the number of cases we have been able to treat successfully with STEM CELL THERAPY till date!

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“There needs to be lot more focus on what a child can do instead of what he cannot do.”

Dr. Temple Grandin



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