# 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. 1

### 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 childs 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

#### 1<sup>1</sup>/<sub>2</sub> 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 controling 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 obession 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 nonverbal.
- 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.

2

# 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.

3

## 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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