



— KNOW —

AUTISM

What is autism?

Autism is not a disease. Autism is a neuro-developmental condition in which an individual could have communication, social skills and behaviours that are different from what is considered the norm. It is a neuro-divergent way of being which means it is a different way in which the brain functions as compared to the majority.

Some facts:

- Autism is not a rare condition. The prevalence of autism ranges from 1 in 100 children (as per Indian study) to 1 in 44 children (as per US study).
- It occurs in all racial and socioeconomic groups but is 4 times more common among boys than girls.
- It is also called a 'spectrum' as features are diverse and range from mild to severe.
- Autism is a lifelong condition. Since it is not a disease, we do not look for a cure. Instead, the focus is on helping children make progress, by providing the right interventions, support, and accommodations, so they may lead successful, independent lives.

What does autism look like?

These are some common characteristics of autistic children. (These may vary in severity and every child may not always show every characteristic)

- Limited verbal and non-verbal (eye contact, gestures, and pointing) communication.
- Difficulties or differences in social communication and interactions (e.g., starting and maintaining conversation, making friends, being in social settings).
- Unusual behaviours (e.g., hand flapping, rocking), repetitive actions, limited activities or interests and a strong preference for sticking to a routine.

Early signs of autism

A child with autism communicates, interacts, learns, and behaves differently. Watch out for these features / characteristics in early childhood. This is not meant to be a diagnostic list but merely to help identify children who may have increased likelihood of autism. Please get in touch with a specialist if you notice any of the following:

Language and communication:

- Does not respond immediately or always to own name
- Delay in speaking as per age
- Repeats words or phrases
- Does not seem to follow instructions
- Does not use language to communicate with others

Social interaction:

- Less or no interest in playing or interacting with others
- Does not have meaningful play
- Rarely looks or does not look at the person when interacting
- Does not point to show or share

Repetitive and restricted behaviours:

- Over-focused or unusual interests
- Repetitive movements such as hand flapping, body rocking, spinning, finger flicking
- Repetitive acts e.g., opening and closing doors or flicking light switches on/off
- Over or under-reaction to sensory stimuli e.g., textures, sounds, smells
- Insistence on following same routines





Who should I contact if I spot these features of autism?



Autism can be diagnosed by any specialist such as a developmental paediatrician, child psychiatrist, child psychologist or a paediatric neurologist. There is no blood or laboratory test that can diagnose autism. The diagnosis is based on detailed developmental history and careful observation of the child's behaviour.

Why did my child get autism?

The exact cause of autism is still unclear; however, it is believed to be caused by changes in the brain due to genetic and environmental factors. Genetic factors do not necessarily mean that it is inherited from any one of the parents. Changes in genes may be new and, in the child, alone. Research is still ongoing to understand more about the causes of autism.

Autism is not caused by an unhappy home environment, both parents working, mental stress during the pregnancy, poor handling by the mother, an emotional trauma, or other psychological factors.

Some people have concerns that autism might be linked to the vaccines children receive, but very reliable studies have shown that there is no link between receiving vaccines and developing autism.



I have just received an autism diagnosis for my child.

What should I do?

You are probably experiencing a whole range of emotions. Psychologists speak of the five stages of grief, which are emotions experienced by those who are undergoing any major loss, including the discovery of having a child with disability. The five stages are:

1

Denial: Trying to wish it away.

"There's nothing wrong with my child", "It's just a phase - he will outgrow it".

2

Anger: Pain and feelings of loneliness.

"Why did it happen to me?", "Why is my life so difficult".

3

Bargaining: Trying to negotiate.

"At least make him speak", "What if I take him to the best therapists, will he be ok?"

4

Sadness: Feelings of emptiness and fear.

"What did I do wrong?", "What will happen to him when he grows up?"

5

Acceptance: Accepting the new normal.

"It's OK. We know this IS autism and together, we will learn, and things will get better".



Not everyone will experience all five stages, and you may not go through them in this order. Every family's journey of acceptance of their child's condition is different. Some accept it overnight while some take more time to come to terms with it. Take your time to process all this new information. You will find acceptance at the end of it. However, do not delay in getting the necessary help for your child - the sooner a child receives interventions, the better it is for them.

What kind of interventions does my child need?

Early intervention is very effective in autism and improves the long-term outcomes. Even if not detected early, intervention is helpful for autism at any age.

Each child with autism is unique and their intervention plan is tailored to address their unique strengths and challenges. Families play an important role in a child's well-being and development and professionals must partner with families in deciding goals for the child. The initial goal for most families of young children with autism is to learn how to communicate and play with the child. The intervention plan may involve some or all the following:



Autism Intervention Therapy:

Works on social, behavioural and communication skills of a child and helps with increasing positive behaviours, understanding reasons for, and reducing unwanted behaviours.



Occupational Therapy:

Helps children develop appropriate social, play, and learning skills to help them participate and achieve independence in everyday activities (e.g., getting dressed, playing with peers).



Speech and Language Therapy:

Conventional methods of speech therapy are not always effective as professionals must have a good understanding of autism to be able to coach the family on how to use non-verbal communication, like pictures and gestures. For children who speak, a speech and language therapist helps them to increase their language skills to have conversations and social interaction.

Autistic children make significant progress if the intervention is early, appropriate, and consistent.

You may also come across many alternative treatments, diets, and therapies for autism. Please be aware that there are many prevalent therapies that lack supporting scientific evidence of any benefit. The best intervention plans are those which coach the families on how to include aspects of all the above therapies as per the child's needs and abilities.



Will my child go to school?

The Right to Education Act 2009 guarantees access to school and barrier free access for all children, including children with disability. All children, including autistic children must go to school.



Please seek the guidance of professionals and other families to help you decide the best type of school for your child. Options include a mainstream school, an inclusive school (welcomes all children irrespective of abilities), and special schools (meant specifically for children with disabilities).

Schooling and education can be a challenging phase for both parents and children with autism as inclusion isn't commonly practiced across schools in India. Once you have secured admission, it is a useful strategy for you to communicate and collaborate closely with school staff from the very beginning and advocate for the necessary support and accommodations for your child.



How can I help my child?

Understand your child's condition:

The more you learn about autism, the easier it is for you to understand your child's behaviours and the better prepared you will be to identify, work with and advocate for their strengths. Be patient with yourself, you may not have all the answers at once. It will take some time to understand your child's condition. Ask for information, speak to those who know more, learn from the professionals who are helping your child and other families who have walked this path before you.

Focus on what your child CAN do:

A child with autism may not be able to do all the things that their siblings or peers can do, but instead of focusing on that, help them realize all the things that they're able to do on their own or with some assistance. Focus on finding and building on your child's strengths, enjoy their special quirks and celebrate small successes. Feeling unconditionally loved and accepted will help your child more than anything else.

Create learning moments at home:

You know your child the best and spend the most time with them. Your child's learning is not limited to the clinic. Many teachable opportunities can be created at home to help your child learn social and communication skills. Ask your therapist how you can incorporate goals for communicating and playing with your child in activities at home. Involve other family members in the plan. However, don't try to take on too much. Do only what you can and what both you and your child enjoy.

Focus on your own well-being and mental health:

Parenting a child with autism can be overwhelming. It is important not to neglect your own needs. Get sufficient rest, take time to do activities that you enjoy (e.g. listening to music, yoga, chatting with friends etc.). Reach out to others for emotional support. Talk to your extended family and share the child's diagnosis with them. Family members can become your greatest source of support. It is also important for both parents to be involved in caring for the child, so that both of you know what to do and can give each other an occasional break. Don't hesitate to seek help if you experience anxiety, sadness or any such issues.

Connect with other families:

The most important thing you need to know is that you are not alone. There are many other families dealing with similar challenges. Get to know other families of children with autism. They can be a great source of helpful information, advice, and emotional support. Joining a parent support group, especially in the initial stages of your journey, is very beneficial.

Stay in the present:

It is impossible to predict the course of autism. Don't jump to conclusions about what life is going to be like for your child. Like everyone else, people with autism have an entire lifetime to grow and develop their abilities.



Additional Resources

Family Resource Center (FRC) at Ummeed is a team of parents of children with disabilities, who are available to offer support to families and guide on available information and resources. If you would like to talk to another parent, get suggestions, insights and advice, be a part of a parent support group or be a part of a community of families, you can connect with the FRC team via email: frc@ummeed.org or phone: 8591850804.

Training Programs at Ummeed: Ummeed conducts various workshops for caregivers on rights awareness, inclusive school experiences, toilet training, preparing for puberty, handwriting, mealtimes, behaviour management and mental health sensitization.

View on <https://ummeed.org/all-courses> or e-mail training@ummeed.org ; or send a WhatsApp message on 85912 91603 to know more.

Autism Specific Training Programs at Ummeed:

- **Let's Get Started:** For families who have received a recent diagnosis for their child. It covers what the diagnosis means and how parents can start supporting their child.
- **UPPA (Ummeed Parent Program for Autism):** is a parent training-cum-coaching program that helps parents engage and play with their children with autism.

Developmental Disabilities India (DDI)



Developmental Disabilities India is a new YouTube channel dedicated to awareness about developmental disabilities. It has informative videos on various disabilities as well as tips-based videos by parents and professionals. Scan the QR code to subscribe.

Other Organizations:

- Forum for Autism (FFA) (Mumbai)
<https://www.forumforautism.org/> 9029018100, 8080809116.
- Action for Autism (AFA) (New Delhi)
<http://www.autism-india.org/> 011 40540991, 011 40540992.
- National Institute of Mental Health & Neurosciences (NIMHANS) (Bengaluru) <https://nimhans.ac.in/> 080-26995001, 26995002.

Other Resources

- <https://www.cdc.gov/ncbddd/autism/index.html>
- www.autism-india.org
- Beyond the Blue – Book by Gopika Kapoor



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