

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Suspecting Autism and Care of Children with Autism

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Acknowledgment: Neurodevelopment and
Disability Chapter, IAP
for Detection Charts



FAQs on SUSPECTING AUTISM AND CARE OF CHILDREN WITH AUTISM

1. My son is 11 months old. He sometimes does not respond to his name when I call. Should I be worried?
2. My elder son was diagnosed with autism at 3 years of age. My younger son is going to turn 3 in another couple of months. When should I be worried?
3. My child is 2.5 years old and is obsessed with certain routines such as sleeping on the same bedsheet, wearing the same shoe color but he speaks in sentences and uses gestures to convey his needs. Is he autistic? Should I visit a pediatrician?
4. My daughter was diagnosed as an autistic child with autism at 4 years of age and now has a lot of behavioral issues. Would an early diagnosis have helped?
5. My son is 3 years old. He had normal language and speech until 2.5 years of age. However, since last 3 months after a bout of a fever he has stopped speaking and does not respond when called. I visited a physician who told me not to get worried. I am not convinced. What should I do?
6. What should I do if my child starts showing some of the signs of autism?
7. I have heard that some vaccines can cause autism. Are childhood vaccines responsible for causing autism?
8. My son has recently been diagnosed with autism. Is he likely to suffer from any other medical issues as well?
9. My child who is 2 years old does not respond when called. His pediatrician has asked for a hearing test to be done. Should I go ahead and get it done?
10. My son was diagnosed with autism at 4 years of age. Now I am pregnant. Will my next child also be autistic?
11. My son who is 2 years old holds my hand and leads me on when he wants something. I have never seen him pointing. Should I be worried?
12. My child is 3 years old and we were recently told by our pediatrician that he has autism. Who should I consult about the care of my child with autism?
13. If my child has features of autism but no diagnosis, what should I do next?
14. What should I as a parent be aware of while caring for my child with autism? Can autism be cured with medications?
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16. My child is 4 years old. He was diagnosed with autism 6 months back. At home, what all can I do to help him?
17. My child is autistic, but he is very hyperactive. Sometimes he starts hitting other people when he is hyperactive. How can one decrease this hyperactivity?
18. What type of therapies are available for children with autism?
19. I have heard about sensory integration therapy. Is it helpful in children with autism?
20. My child has autism and he keeps on playing while by lining the up toys, sometimes I have seen him spinning the wheels of cars. How do I decrease these behaviors of my child?
21. My child has autism and has been undergoing various therapies since his diagnosis. However, he is always very anxious and does not like to be touched. How do I deal with such issues?
22. Are there any ASD-specific self-help groups?
23. What are the opportunities available for adults with autism? Are there any government guidelines?
24. My daughter has been receiving intervention for Autism since the age of 5 years. How do I rate the quality of intervention, my child has been receiving?

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Suspecting Autism and Care of Children with Autism



Indian Academy of Pediatrics
Chapter of Neurodevelopmental Pediatrics



Detect Early Autism

Autism is a condition that affects three critical areas of development: Social, communication, and cognition leading to impairment in all these areas. An early diagnosis and appropriate training can show significant progress in the child's development.

1 Does not look towards pointed direction

Child may not follow pointing gestures shown by others and may not look at the object that has been pointed.



2 Does not share

Child may not comprehend the joy of sharing. He does not give or handover. Does not point.

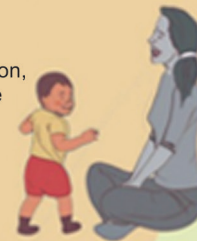


3 Does not imitate your actions

May not follow the actions or gestures shown to them.



4



Does not smile back or smiles less

Does not smile back/when smiled at; smiles less

5



Avoids Eye contact

Makes no eye contact and looks away when trying to do so

6



No response to picking up gesture or name call

Does not respond to picking up gesture. They do not seek to be hugged or caressed

7



Prefers to be alone

Prefers not to mingle/play with others

For 18 months or above infants

① ② ③ are the crucial signs which are noticeable in a child with autism

ASSAM AUTISM FOUNDATION

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Autism is not a disease, it is a condition in which the child's learning of social interaction, social behavior, and communication is impaired. There is also an innate tendency toward repetitive behaviors and restricted interests. If these deviancies are corrected early on, then child will have a good prognosis.

Q1

My son is 11 months old. He sometimes does not respond to his name when I call. Should I be worried?

Not responding to name does not necessarily mean Autism. On an average, children start responding to their name by the age of 8–9 months and by their first birthday all children should respond to their name. Not responding to name by this age can mean a number of things such as hearing loss, probable autism, and developmental delay. If your child has not started responding to name by this age you must visit a developmental pediatrician and report your concerns. At the same time, as a parent you should also look for other signs of autism such as lack of eye contact, not pointing to items and repetitive behaviors.


Q2

My elder son was diagnosed with autism at 3 years of age. My younger son is going to turn 3 in another couple of months. When should I be worried?

While having a child with autism does raise the risk of having another child with the same disease by about 15%. Boys are two to three times more likely to be at risk than girls. In case you notice loss of language skills, aloofness, not playing with other children of his age group, lack of eye contact, some repetitive behaviors in your younger son, then you should definitely visit your pediatrician for further advice. However, if you have not noticed any signs of autism in your younger son by now, it is unlikely that he will develop autism.

At the same time, it is also important to know that although sibling of an autistic child may not develop the full-blown spectrum of autism, they may still have mild subclinical traits of abnormal social behavior, language deficits, and sensory sensitivities.

Q3

My child is 2.5 years old and is obsessed with certain routines such as sleeping on the same bedsheet, wearing the same shoe color but he speaks in sentences and uses gestures to convey his needs. Is he autistic? Should I visit a pediatrician?

While repetitive behaviors and obsessions may be normal in a young child, they are expected to fade away with age. However, if these symptoms are persistent and continuously present it may indicate either an "Autism Spectrum Disorder", attention deficit/hyperactivity disorder (ADHD) or obsessive compulsive disorder. Children with high-functioning Autism who are high functioning may speak in sentences, sometimes may use gestures but may have deficits in the social communicative sphere. At the same time, you should look for other signs such as flapping of hands and rearranging objects. If these repetitive behaviors being displayed by your child are causing concern, it is best to see your pediatrician and seek answers.



Q4

My daughter was diagnosed with autism at 4 years of age and now has a lot of behavioral issues. Would an early diagnosis have helped?

About a decade earlier, autism was generally diagnosed between 3 and 4 years of age. However, with growing awareness both among parents and primary care physicians, autism can be diagnosed earliest between 2 and 2.5 years of age. The purpose of diagnosing early is dual fold. It allows children to enter into intensive therapies early in the hope that the severity of autism will lessen and also, some children may later outgrow the diagnosis of autism. Early diagnosis also allows these children to develop and enhance their skills to reach their full potential when the young brain has what is called “plasticity”, i.e., it can be molded toward achieving a better outcome. Children who are diagnosed later generally do not develop language, have secondary behavioral issues in the form of hyperactivity, sensory issues, sleep disturbances, depression, learning difficulties, and aggression. These children consequently are highly dependent on their primary caregivers for activities of daily living.



Q5

My son is 3 years old. He had normal language and speech until 2.5 years of age. However, since last 3 months after a bout of a fever he has stopped speaking and does not respond when called. I visited a physician who told me not to get worried. I am not convinced. What should I do?

Regression or loss of already developed language and social skills in a toddler is always worrisome and should never be taken lightly. This condition is also known as autism with regression or autistic regression. Usually, the loss of these skills occurs sometimes between 15 and 30 months. Your child should be evaluated for a possible autistic regression by a physician who specializes in autism spectrum disorders. It is important to test for hearing loss since some brain infections cause hearing loss as well.

Q6

What should I do if my child starts showing some of the signs of autism?

Autism spectrum disorder expresses itself in toddlerhood causing delays in basic areas of speech, language, and gestural communication along with difficulty in relating to people around them. If your child starts showing signs of autism, you should seek early diagnosis so that early and intensive intervention can be started. Do not lose hope, such early behavioral interventions can reduce the disorder's effect and also its severity.



Hyperactivity



Preferred to play alone



Depression



Built in the object in a ruler



Intolerance to sounds



Sleep problem



No Eye following



Rejecting cuddles



Delayed speech development

Q7

I have heard that some vaccines can cause autism. Are childhood vaccines responsible for causing autism?

Although the role of vaccines was speculated in the causation of autism, however, considerable research later found that these were mere speculations. Hence, it has now been concluded that childhood vaccination has *“no role in causation of autism”*. Vaccinations prevent common childhood illnesses which can otherwise have devastating consequences. Hence, there is no scope of *“Not Giving Your Child Vaccinations”*. Not vaccinating your child or delaying vaccinations can be extremely risky for your child because vaccine preventable diseases such as measles still exist. Measles is a leading cause of sickness and death in young children, especially in a country like ours. However, if you as a parent still have concerns about your child’s vaccination, then you should seek advice from your physician about the benefits and risks of vaccines.


Q8

My son has recently been diagnosed with autism. Is he likely to suffer from any other medical issues as well?

Yes, children who have autism can have a range of medical issues such as constipation, diarrhea, abdominal pain, gastroesophageal reflux, disrupted sleep, decreased appetite, restricted food habits, pica, mood disorders, headache, food allergies, anxiety, seizures, etc.

As a parent you should keep a detailed note of these health concerns and discuss with your pediatrician.

Is autism a mental disorder? Is my child going to be mocked as “mental”?

Autism spectrum disorder is a group of neurodevelopmental disorders that are neurological in origin and cause deficits in social, language, and communication spheres. Hence, it is extremely wrong to call autism ‘mental disorder’.

Q9

My child who is 2 years old does not respond when called. His pediatrician has asked for a hearing test to be done. Should I go ahead and get it done?

Children start responding to their name by 8–9 months of age. However, if your child does not seem to respond to any sound, then definitely you should get a formal hearing screening done. If your child enjoys TV, music, gets alarmed by door bells, closes ear with train whistles or any alarms and at the same time, does not seem to respond to his or her name, then he or she needs to undergo a comprehensive “autism” screening for early diagnosis in addition to formal hearing screening.

Q10

My son was diagnosed with autism at 4 years of age. Now I am pregnant. Will my next child also be autistic?

Research has indicated that if there is a couple with one child with autism, then the chances of next child having autism is 15%. If this next child is a boy, then that child is two to three times more likely to be diagnosed with autism spectrum disorders (ASD) than if this child is a girl. In families wherein there are two or more children with autism the risk of having the next child with autism increases to 30%. Hence, you should watch for early signs of autism in your child and seek early medical attention.

Q11

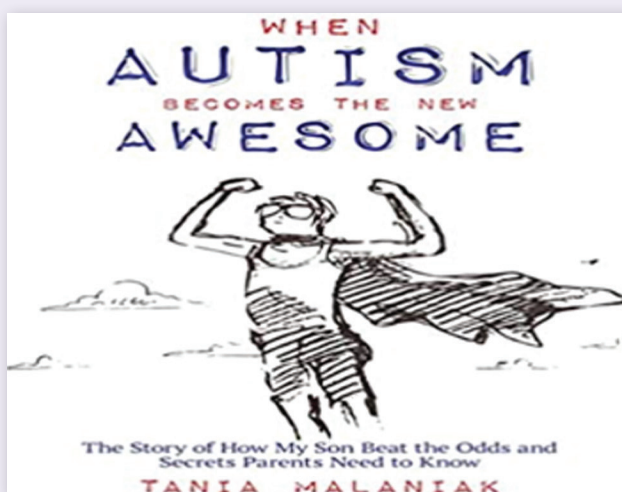
My son who is 2 years old holds my hand and leads me on when he wants something. I have never seen him pointing. Should I be worried?

Gestural pointing is a core developmental milestone that develops around 14–15 months of age. Its absence in a toddler should always be viewed with concern. Persistent hand leading beyond this age and lack of pointing with index finger *are typical deficits seen with early autism*. While it may not always indicate autism, such children should be formally screened for autism and other language delays.



Does not point with the index finger to indicate interest

Note: Parents are also requested to read this beautiful book by an international author who also happens to be mother of an autistic child.



Q12

My child is 3 years old and we were recently told by our pediatrician that he has autism. Who should I consult about the care of my child with autism?

A developmental behavioral pediatrician would be the best person to begin consultation with. He/she specializes in the assessment and evaluations of developmental and behavioral concerns in children. A developmental Pediatrician will counsel you regarding the diagnosis of your child, investigations to be planned, and also design an appropriate intervention plan. Your developmental pediatrician will also monitor the intervention process to check if the child is progressing in the best possible manner.

Q13

If my child has features of autism but no diagnosis, what should I do next?

A diagnosis is not the most important thing. Developmental interventions should be designed to get your child's development to get better—not merely to address a diagnosis. The Indian Academy of Pediatrics Guidelines (Indian Pediatrics, March 2017) state that a confirmed diagnosis is not necessary to commence interventions. Moreover, earlier the intervention, better the outcomes. So, focus on getting the child better, not merely on the diagnosis.

Q14

What should I as a parent be aware of while caring for my child with autism? Can autism be cured with medications?

As a parent, please remember that autism is a condition, not a disease. Children with autism show deviancies in their normal development. Focus on the normal development that the child has achieved. Help the child to develop further, step by step. Each step will take time, but once an improvement is seen, it usually continues. Ensure you get the appropriate and genuine professional assistance for your child. Do not fall prey to quackery. Ask for qualifications, certification, and written documentation. Do not hesitate to ask questions. Autism is not a disease to be cured. Core elements of autism are impairments in social communication and interaction and repetitive and restricted interests. These cannot be reversed with medications. But medications can help to control the comorbidities or consequences of autism such as anxiety and hyperactivity.

Q15

What do you mean by “autism-specific intervention”? When should these interventions begin?

There is no “autism-specific intervention” since autism is not one specific condition. Children who are considered to have autism have specific delays and deviancies in social and communication domains of development. Intervention is targeted at getting these delays and deviancies better. Intervention should begin as early as possible. It should begin as soon as the parent suspects delays or deviancies in the development or when the pediatrician points out certain red flags.

Q16

My child is 4 years old. He was diagnosed with autism 6 months back. At home, what all can I do to help him?

The first thing is to consult with your “developmental pediatrician” and get a good holistic program for your child. A home program is an important part of the same. This should include not only interventional activities taught by the therapy team but, more significantly, how to help your child to be involved in day-to-day activities of life like all of us normally do. Helping your child connect with family members is essential, without expecting him to do it in a certain way. For example, too much of stress on making your child have eye contact is more likely to cause anxiety rather than any benefit.

Q17

My child is autistic, but he is very hyperactive. Sometimes he starts hitting other people when he is hyperactive. How can one decrease this hyperactivity?

Hyperactivity in a child with autism is very often a consequence of his inability to participate meaningfully and satisfactorily in the surrounding environment. This inability is a result of the child’s impairment in learning of social interaction, social behavior, and communication. Thus, improving his social interaction, social behavior, and communication, as well as understanding his inabilities better and decreasing the level of challenge, he faces daily allows him to connect better with the world. Rarely, medications such as methylphenidate and atomoxetine also help.

Q18

What type of therapies are available for children with autism?

Various therapies and intervention programs such as occupational therapy, speech and language therapy, applied behavior analysis (ABA), floor time, The Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH), early start Denver model (ESDM), etc. are available. Many interventional models are established, such as behavioral models (e.g., applied behavior analysis or ABA), structured teaching (e.g., the TEACCH), developmental/relationship-based models (e.g., floor time) and integrated programs that use a combination of strategies within the treatment program (e.g., Social Communication, Emotional Regulation, and Transactional Support or SCERTS). In terms of comorbidities, cognitive behavioral therapy has shown effectiveness for anxiety and anger management in high functioning young adults with ASD. Medications may be offered to children with ASD, when there is a specific-target symptom or comorbid condition.

Q19

I have heard about sensory integration therapy. Is it helpful in children with autism?

It is believed that difficulties with sensory interaction (appropriate reception, assimilation, and modulation of the various senses) create behavioral impairments in children with autism. A well-trained and well-experienced therapist administering “sensory integration therapy” may help a child with autism in early intervention.

Q20

My child has autism and he keeps on playing by lining the up toys, sometimes I have seen him spinning the wheels of cars. How do I decrease these behaviors of my child?

Children with autism have difficulty in understanding the use of objects as designed by humans to provide certain functions in the social world. These repetitive behaviors can be decreased by, one, in the short-term, distracting the child with an equally or more attractive option and two, in the long-term, by improving the child’s social functioning so he is able to use it meaningfully in pretending to play. Medications may help.

Q21

My child has autism and has been undergoing various therapies since his diagnosis. However, he is always very anxious and does not like to be touched. How do I deal with such issues?

This clearly indicates that those “various therapies” have failed to take cognizance of or reduce the anxiety in the child. One needs to closely monitor the child to detect what provokes anxiety in the child. It could be certain sounds or smells or just unfamiliar or disliked environments and situations. Children with autism who are anxious may respond in various ways, and we may end up judging them by the behavior they exhibit, overlooking that it is anxiety that is the cause of such repetitive behavior and must be tackled—not the behavior itself. Also challenging the child with developmental expectations which may be way beyond his current developmental capacities induces anxiety. Care should be taken to prevent exposing the child to such situations.

Q22

Are there any ASD-specific self-help groups?

There are many ASD-specific self-help groups often set up by parents or nongovernmental organizations (NGOs) that offer various kinds of support to children with autism and their parents. These groups are an excellent source of support in terms of empathy as well as sharing, learning, and caring opportunities for families with autism. Care must be taken in terms of due diligence while approaching and selecting the self-help group that best serves your needs. Cross-checking and referencing with your doctor and other parents or current and ex-members of that group may help.

Q23

What are the opportunities available for adults with autism? Are there any government guidelines?

In accordance with the Constitution of India, and Rights of Persons with Disability Act 2016, there are several government schemes and programs that can be availed by a person with autism and their families. To avail these schemes, it is mandatory to have a disability certificate.

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities has several schemes and programs available for persons with autism and their families. Please see www.thenationaltrust.co.in for details of the following schemes. Besides this, there are various schemes such as *Samarth* scheme, *GHARAUNDA* (Group Home And Rehabilitation Activities for Disabled Adults), and *Niramaya* (Health Insurance Scheme) which are schemes for the benefit of children and adults with disabilities. Besides these schemes, Government of India offers *Income Tax concessions* under Section 80U, certain travel concessions in railways up to 75% in the first and second classes and hotel discounts on room rents and food in Indian Tourism Development Corporation (ITDC) hotels.

Q24

My daughter has been receiving intervention for Autism since the age of 5 years. How do I rate the quality of intervention, my child has been receiving?

Any intervention is expected to deliver an outcome, in terms of developmental improvements, as far as possible in specified time frame. Asking for written diagnosis, plans and outcomes are the most important ways to ensure quality delivery of services. Some services do provide goals—subjective or objective (many do not even do that and may escape, accountability). It is important for the parent to ask for expected outcomes, if possible, in written format, and to follow this up over the defined time frames. It is important to remember that these may not be exact and may be subjective rather than objective. However, the parent needs to note as far as possible, objective improvements in the child's level of intervention and compare with what was expected.



Indian Academy of Pediatrics Chapter of Neurodevelopmental Pediatrics



◀ Detect Autism Early

For children of 36 months and above

Autism is a condition that affects three critical areas of development: social, communication and cognition leading to impairment in all these areas. An early diagnosis and appropriate training can show significant progress in the child's development

1 Aloof in manner

Child stays withdrawn and does not interact or play with other children. They tend to spend time being alone.



5

Restricted/Repetitive attachment to objects

Child may appear to be attached to certain toys or other objects. These attachments may seem inappropriate at times.



2 Appears deaf sometimes

Child does not respond when addressed or called.



6 Exhibits unusual behavior

For instance, hand flapping or twisting, rocking, swaying, walking on tip-toes.



3 Uses adult's hand to indicate matter of interest

Takes an adult's help to indicate desired object, but mechanically or without an interaction/eye-contact.

4

Avoids eye contact

Child may avoid eye contact with the people interacting with them.



7

Prefers not to be touched, hugged or cuddled

Sometimes feels uncomfortable and prefers not to be hugged or touched by people.



9 May not respond to "normal" teaching methods

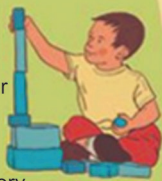
The conventional teaching methods are not effective on the child's development.



10

Peculiar/special skills

Performs certain peculiar activities or showcase special skills, such as single word reading, music, art, puzzle, memory or calculations.



8 Lacks imaginative play

Play is often solitary and passive and not creative (e.g. kitchen set, doctor patient, etc.)



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