

The **START** of a **JOURNEY**

A guide for parents of children diagnosed to have
Autism spectrum disorder



Developmental Paediatrics Unit
CMC Vellore



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Dear Parents,

“The Start of a Journey” is a booklet designed to assist families of children recently diagnosed with Autism Spectrum Disorder. Designed by the Developmental Paediatrics Unit, CMC Vellore, this booklet includes basic information about ASD its symptoms and, treatment, and some suggestions for families dealing with this diagnosis. We have tried to address the most frequently asked questions about ASD.

Apart from these, you may have specific questions that your doctor or therapy professional can help answer.

We hope this booklet will encourage and reassure you as you begin this journey with your child. We welcome your feedback and suggestions.

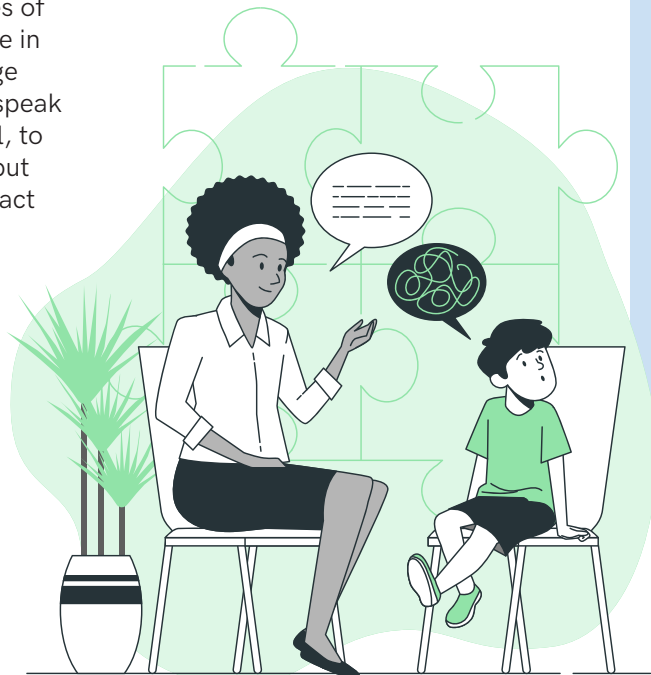
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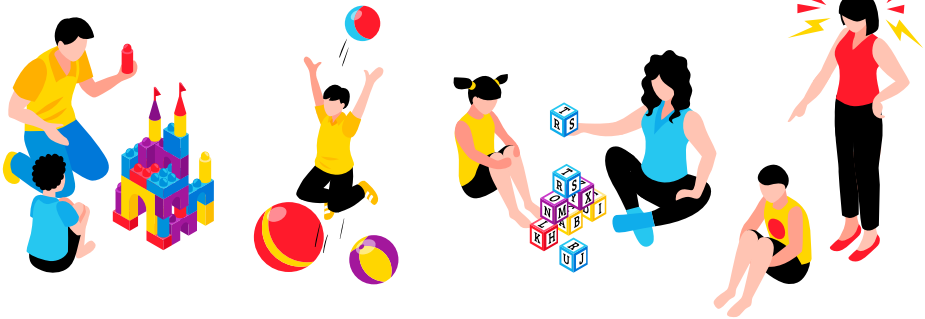
Disclaimer: The information provided is for general informational purposes only and is based on the existing medical literature. The information will be updated in subsequent versions in accordance to the emerging literature.

1) What is Autism Spectrum Disorder (ASD)?

- Autism is a developmental problem that **affects the way a person communicates and relates to the people and world around them**
- It is one of the most common developmental disorders
- 80% of those affected by ASD are boys
- Most of the symptoms begin to show when the child is around 1-2 years of age. By the time, they join a playschool, many features are noticeable.
- It is called a **Spectrum Disorder** because children can present with wide range of symptoms, which cause varying degrees of impairment and disturbance in their daily living. It can range from a child who does not speak or interact with others at all, to somebody who can speak but does not know how to interact with people.
- Each child with ASD is unique. No two children with ASD might have exactly similar symptoms and behaviour. These symptoms may be present in various combinations in a child, and it is **not necessary for the child to have all the symptoms**. Also, the **symptoms change with time and age**



2) What are the common symptoms of ASD?



Most of the symptoms of ASD may be noticed in the second year of life, when children start interacting with other children. Some common symptoms are:

- The most common presenting symptom is **speech delay**.
- Some children may speak at the right age, but they may have a monotonous, 'robotic' voice, with a tendency to keep saying things repeatedly in the same manner or repeat what is heard. They may use rote learning or memorized word chunks. They may be confused with the use of 'I', 'you' etc.
- In some children, there will be a "loss" of speech skills- they may stop using some of the words which they had previously used.
- **Using another person/parent's hands to touch something or show something**
- **Failure to respond when their name is called or when they are spoken directly to.**
- Lack of interest in interacting with other children; they **prefer to play alone**
- Lack of imaginative play/ pretend play (eg: kitchen set, dolls, teacher and student game). Their play usually consists of lining up or piling toys, stacking and disturbing, and repeating the same play pattern.
- Poor eye contact- they do not look at anyone when making a request, smiling or laughing
- Does not approach others to play or interact- they approach parents only when they have some need
- Does not follow the parent's pointed finger to a toy across the room
- Does not mime or gesture to communicate to make you understand

- Does not use gestures like nodding yes/ no, blowing a kiss, waving bye-bye
- Has unusual repetitive body movements (e.g., clapping, finger flicking, flapping, twisting, swaying, spinning in circular pattern)
- Repeats sounds or words over and over again/ repeats what is heard
- Likes carrying around or playing with things which are unusual for a child of his/ her age—e.g. a spoon, wooden sticks, a scale, a pen, a rope etc.
- Has extreme difficulty in adjusting to minor changes in routine
- **Difficulty in processing common sensory stimuli- e.g.**
 - ♣ **Significant dislike to having hair washed or trimmed, nails cut, teeth brushed etc.**
 - ♣ **Distressed by loud, common sounds like that of a pressure cooker, mixer-grinder (they may run away, tightly grasp people, close ears, cry)**
 - ♣ **Playing with shadows**
 - ♣ **Dislikes sticky sensation of some foods and wipes hand repeatedly after touching food**
- There can be associated conditions such as epilepsy, eating problems, sleep problems, constipation etc. Autism can co-exist with intellectual disability, hyperactivity, inattention, anxiety, obsessive compulsive behaviour, self-injurious behaviour, and aggressive behaviour.

3) What is the cause of ASD?

Being a diverse condition, medical research has not yet been able to identify a single cause of ASD. Current theories focus on a **combination of genetic and non-genetic factors**. Around 10% of children with ASD have an identifiable genetic cause.



Autism features



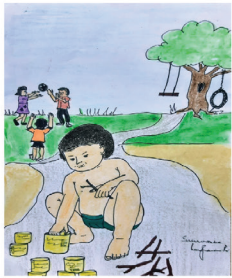
Symptom:
Not responding to name call and not looking at pointed direction



Symptom:
Using others' hands to point at something rather pointing by himself. No eye contact while requesting



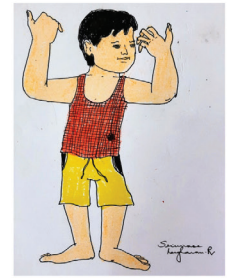
Symptom:
Repetitive spinning and toe walking



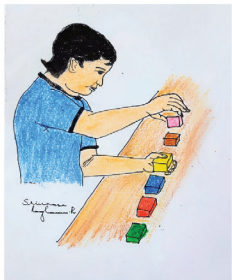
Symptom:
Not mingling with peers and prefers to play alone



Symptom:
Not involving others in play. No eye contact during play. Not sharing interests with others



Symptom:
Peculiar stereotypies keeping fingers close to face



Symptom:
Play tends to be repetitive and non imaginative like arranging all objects in a line



Symptom:
Sensory issues like getting distressed by some common sounds like mixer and cooker



Symptom:
Undue interest in watching shadows

4) How is ASD diagnosed?

ASD is quite different from most common childhood ailments. **No medical tests or brain scans can diagnose ASD. The only way to diagnose ASD is by observing the child's behaviour.** The diagnosis is usually based on parent's answers to questions regarding their child's behaviour, development, milestones achieved, and by a detailed clinical observation of the child's behaviour and development by an experienced multi-disciplinary

team of professionals (including developmental pediatricians, child psychologists, speech therapists and occupational therapists).

As mentioned earlier, there are certain conditions (epilepsy, genetic disorders, metabolic disorders) which can be associated with ASD. If such conditions are suspected, blood and urine tests, an EEG and an MRI scan will be done.



5) Is there a cure for Autism?

This is a major question on the mind of any parent- "Will my child improve with treatment?". Every parent wants to know if their child will be able to go to school and become independent. However, since the brain of the child is actively developing, it is difficult to predict the outcomes at diagnosis or during the early stages of training. Periodic follow-up with regular re-assessments is necessary.

It is estimated that 3-25% of children

with ASD move out of the spectrum with appropriate support.

ASD is a chronic condition. But, many people with this condition can lead fruitful lives, despite limitations in certain areas. The aim of the therapy is to help the child have functionally optimal outcomes. With early diagnosis, intensive multidisciplinary interventions and regular monitoring, a significant proportion of children can achieve functionally optimal outcomes.



6) What is the treatment for Autism?

Treatment of children with ASD is based on their developmental level and needs. The treatment is guided by goals. Usually, the initial goals suggested are:

- ♣ **Setting a daily routine for the child**
- ♣ **Managing a problem behaviour- to teach the child positive/wanted behaviour and reduce negative/unwanted behaviour**
- ♣ **Improving social skills and engagement in play with others**
- ♣ **Communication training, both non-verbal and verbal**
- ♣ **Independence in activities of daily living**
- ♣ **Attending to the child's sensory problems**

It is important for parents to know the therapy plan and goals as devised by the therapists working with the child. These must be practiced consistently at home.



7) Can medicines cure ASD?

Medicines cannot cure ASD. At times, medicines are prescribed for specific symptoms like aggression, hyperactivity, self-injurious behavior or anxiety. This is to ensure that the child is able to engage better and benefit from the ongoing therapies. Medicines should only be started on the advice of doctors who have adequate experience of working with children with ASD.



8) We hear about various Complementary and Alternative Medicine (CAM) therapies for ASD. Is there a role for such therapies?

You may get to read about various complementary and alternative medical practices that are suggested for ASD. There are several unsupported interventions that claim miraculous results which have led to unrealistic expectations about treatment results. As parents, you must review the scientific evidence for each of these interventions

before deciding to resort to them.

Some popular alternative therapies for ASD include Dietary restrictions like Gluten free casein free diet, Heavy metal chelation and Stem cell therapy.

Available evidence for various CAM practices:

- **Dietary restrictions (Gluten free, Casein free diet)** and vitamin supplements require more research for conclusive results and are not routinely recommended for all children with ASD.
- **Stem cell therapy and Heavy metal chelation therapy** are not recommended for treatment of ASD.

9) Is it true that vaccines cause ASD?

False. It has been scientifically proved that vaccines do not cause ASD.

Vaccines are of utmost importance to protect children from preventable communicable diseases. All children should receive vaccines as per the immunization schedule.

10) My child was able to say a few words and was quite interactive until the age of 2 years. But since then, he/ she has stopped saying those words. Why?

- This is a common feature of ASD and is called 'Autistic Regression'. It means losing a skill that the child once had. A child with ASD may learn a few words but then stop using them.
- Research has found that regression is not limited to only language, but to social communication skills at large. The child may lose interest in looking at people, even though he/she used to look at them often

We do not yet understand the biology of regression in Autism. Studies on "Autistic regression" describe one-third children losing skills between 18 - 24 months of age

11) Why my child who can switch on and off WiFi, skip videos, surf internet, and even say rhyme phrases is unable to call out to us or seek help or indicate his needs specifically?

There are things that children with ASD learn on their own, much faster than their typically developing peers. You may wonder why a child who manages to acquire some complex skills, finds it difficult to understand a simple direction like "get your ball" or is not be able to call for help.

Children with ASD are good with visual learning and grasp things that have a fixed consequence or a cause and effect response. They, therefore, can be very good at learning to operate a TV remote or browse for videos on a phone.



12) My child often looks at shadows. He/she gets distressed by certain sounds. He/she refuses to touch certain textures. Why?

Children with ASD may have a Sensory processing disorder. It affects how their brains process sensory information (stimuli) and hence, they may respond to sensations differently. Sensory information includes things you see, hear, smell, taste, or touch. Due to the sensory processing disorder, children with ASD can be overly sensitive to stimuli. It can also cause an opposite effect - in some cases,

it takes more stimuli to impact the child. What others may perceive as simple, ordinary and day-to-day stimuli, may be unpleasant or sometimes extremely enjoyable to a child with Autism. Or they may not react to the stimuli at all.



13) Why does my child have unusual physical mannerisms like flapping his/her hands, walking on his/her toes or rocking back and forth?

These unusual physical mannerisms are natural responses or methods of coping with their stress, anxiety or sensory difficulties. These behaviours may help them relax.



14) What is the role of different therapists in my child's treatment?

Multiple therapists are needed to help with various aspects of treatment of a child with ASD. It is important for parents to know the role of each therapist working with the child.

Paediatricians	<ul style="list-style-type: none"> • Identify Autism • Diagnose and treat coexisting medical disorders (sleep problems, seizures; potential genetic and metabolic disorders), behavioural comorbidities (hyperactivity, anxiety, depression) • Follow- up plan in liaison with the therapy team
Child psychologist	<ul style="list-style-type: none"> • Developmental assessment, confirmation of ASD by standardized assessment • Addressing problem behaviour- functional behaviour analysis, structuring routine, rewarding positive behaviours • Improving socialization, eye contact, joint attention through interactive play • Learning assessment and addressing learning needs
OT	<ul style="list-style-type: none"> • Assessing motor skills • Training in self-care skills, help with coordination, eye hand coordination tasks • Sensory integration therapy for sensory processing problems
Speech therapists	<ul style="list-style-type: none"> • Assess communication skills, oromotor functions- work on improving pre-linguistic and language skills- including socially appropriate expressive skills • Augmentative and Alternative Communication (AAC) use in non-verbal children
Special educator	<ul style="list-style-type: none"> • Formulating an Individualized Education Program (IEP)- work with teachers to help with the child's education



15) How do I know if therapy is helping my child?

As parents, you must maintain a baseline record of your child's behaviour and skills. Start with one intervention at a time, with specific targets, so that you know which behaviours to observe. Discuss with the therapist the current therapy goals, which will guide you to monitor changes in your child. After the therapy starts, monitor any change (positive or negative). Discuss with other people who work closely with your child (school teacher, therapist, close relative) and get their observations and feedback. These details will help you assess the effect of the therapy. Continue the treatment for at least 3 months in order to understand change or improvement in skills.

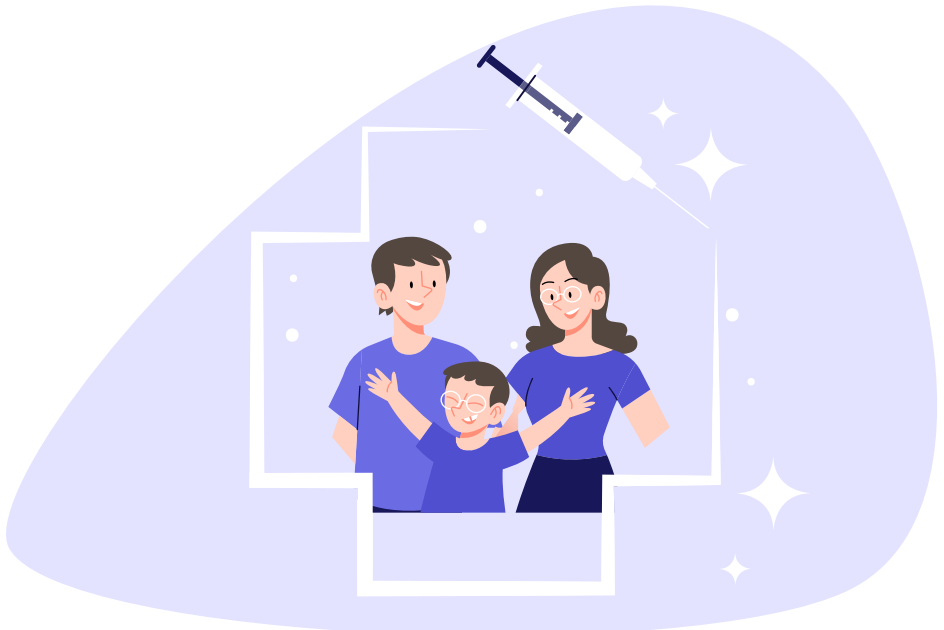


16) Besides ASD, my child has other behaviour problems like Attention Deficit Hyperactivity Disorder (ADHD), sleeping and feeding difficulties, and self-injurious behaviour. What should I do?

Children with ASD are prone to develop the above behavioural problems. There are many reasons for these problems, which require a detailed assessment and treatment plan. Often, the treatment of these behavioural problems leads to a significant improvement in the child's behaviour and reduces stress on the family's care-giving ability. So, discuss these concerns with your therapist/doctor and seek advice and treatment for them.

17) Are ASD and Intellectual Disability same?

No, ASD and Intellectual Disability/Mental Retardation are not the same. Children with ASD have difficulties in socialization and communication. The IQ of children with ASD may be above average, average, or below average.





18)) We hear that there are many other therapy modalities for ASD. What is ABA, NDBI and TEACCH?

These are different therapy modalities. Every child with ASD is unique and there is no one-fit therapy for all children. So, it is important to have an intervention program that is tailored to address the specific needs of each child. Some of the therapies are:

Applied Behaviour Analysis (ABA):

ABA is a therapy based on the science of learning and behavior. ABA-based therapies have a few basic tenets:

- ♣ They are structured
- ♣ They collect data for target skills or behaviours
- ♣ They provide positive strategies for changing responses and behaviours

In ABA therapy, the focus is on reducing unwanted behaviour and increasing desirable behaviour of the child through positive reinforcement strategies. This can help children who have difficulty in learning or acquiring new skills. It can also address problem behaviours that interfere with functioning through a process called "functional behavioural assessment.", i.e. finding out what triggered the behaviour (Antecedents) and what happened afterwards (Consequences). Understanding the triggers and the events that ensue after a problem behaviour will help devise strategies to reduce the problem behaviour.



Naturalistic Developmental Behavioral Interventions (NDBI):

NDBI is an umbrella term that includes a range of different intervention models with some underlying similarities. NDBIs combine ABA and developmental psychology. NDBIs involve incorporating learning in the context of everyday life and teaching play activities using behavioural strategies. They target core symptoms of ASD like eye contact, imitation, social attention, and reciprocal interaction. According to current research, NDBI are considered highly effective intervention programs for very young children with ASD.

Treatment and Education of Autistic and Communication-related handicapped Children (TEACCH):

TEACCH is an evidence-based academic program that is based on the idea that individuals with ASD learn better through visual cues. The key aspects of TEACCH are a modifying environment, structuring routines through sequences, and using visual cues. In TEACCH, the therapy is individualized and includes family involvement. TEACCH strategies can be used to improve motor skills, cognitive functioning, social adaptive functioning, and communication skills.



19) As parents, what can we do at home to help our child?

Parents play the most important role in a child's treatment. You should discuss the goals with your child's therapists and follow the suggested activities regularly at home. Most therapies focus on improving the child's social and communication skills. Listed below are some suggestions to follow at home:

- The first step each parent can do after diagnosis is to **reduce screen time**. It is imperative to stop all unaccompanied screen device usage, as screen devices divert your child's attention away from you.
 - Organize the day for the child- Your child will be able to do certain activities if he is taught to do it routinely. Have a specified meal-time, bedtime and activity time, and reinforce them using visual timetables.
 - Your child needs to be engaged in interactive play- social games like hide and seek, dancing together to favourite rhymes should be encouraged.
 - You are encouraged to take your child outside to play in the park and provide opportunities to interact with other people/ children. This will provide opportunities to communicate with people around.
- **Do not focus only on speech.** Communication can happen by other means as well. Encourage the child to nod yes/ no, point to things he/she needs etc.
 - It is important to teach your child to be independent in daily activities (e.g. toilet, bathing, dressing, eating).
 - Involve your child in household chores and assign roles to him/ her. Initially, your child may require help in smaller tasks (filling water bottles, putting dishes on the table, arranging shoes, etc.), but with practice the child will be able to perform these and other chores too. These tasks will make your child feel that he/she is an important and helpful member of the family.
 - As your child matures, start focusing on independent living (e.g. shopping, travelling, and finances) and vocational skills.

20) What can we do to help/empower ourselves?

After receiving your child's diagnosis of ASD, you will be confused, scared and worried. You, as parents, need to empower yourselves to help both your child and yourselves. Here are a few things you can do:

- learn about ASD
- develop the support network that you need
- concentrate on your child's capabilities
- look after yourself and your partner

Learn about ASD: One of the most important things you can do is to learn about Autism. Nobody knows your child the way you do. The more you understand ASD, the better you will know the best ways to help your child. All your family members have to support and help your child. Looking after a child with ASD requires high energy levels, which are difficult for a single person to maintain. Your child may become too attached to one person, if training is being done by a single family member. It is beneficial for your child to do activities with all the family members. Your family members should be consistent in their approach with the child. The extended family must support you in the care of your child.

Join a support network: Locate a support group in your region and connect with members of that group. Reach out to other parents and share your experiences. They can help

you with information on the school system and other services available in your community and area. Reach out to your friends and family doctor too. Remember, you are not alone.

Focus on your child's capabilities

too: Celebrate your child. Your acceptance and encouragement are essential to the child. Do not think only about your child's difficulties. Concentrate on your child's capabilities too. You must know the areas or activities where your child may need your help. But it is equally important to know their strengths and build on them.

Look after yourself: Looking after yourself is a very important part of caring for your child. It is easy to attend to all the needs of your child and your family, and forget about yourself. Do not feel guilty when you take time out for yourself. Seek help from other family members and friends.



21) Are we late in recognizing and starting treatment for our child?

It is not easy for parents or teachers to accurately recognize the early symptoms of ASD in a child. Also, it is never too late to start. Interventions are most effective if initiated at young age, but improvements are seen even if treatment is started later. The most important thing is to start treatment immediately after diagnosis and follow it consistently.



22) Was there some fault in our parenting that caused our child to have ASD? Did I/we do something wrong to cause Autism in my/our child?

ASD is NOT caused by faulty parenting. It is common for parents to feel guilty or responsible for their child's diagnosis. ASD is a neurodevelopmental disorder and is prevalent all over the world, in families from different regions and socioeconomic backgrounds.

23) We are planning to have a second child. Is there a risk that our other child will also have ASD?

In the absence of any family history of ASD, a child has 1% risk of developing ASD. There is 5 to 8% risk for the unborn child to develop ASD, if the first child has ASD. Thus, although the risk increases if a sibling has ASD, as compared to the normal population, the risk is not very high. *You have a more than 90% chance of having a typically developing child.*

As discussed before, ASD can be sometimes be due to an underlying specific genetic problem (syndrome). When the first child is diagnosed to have such genetic syndrome, the risk of ASD developing in the unborn sibling may be dependent on that syndrome. You may be advised to consult a Genetics specialist to regarding this.



24) What care should I take to prevent ASD in the next issue?

As such, there is no medical procedure to test for or prevent ASD in the developing foetus during pregnancy. Regular antenatal checkups, nutritional supplementation and a healthy lifestyle is important during pregnancy. After birth, regular developmental surveillance, and providing a stimulating and enriching environment to promote social communication is also necessary. Regular monitoring of your child's development by a professional will help in the early detection and intervention for ASD.

When your first child is diagnosed to have any specific genetic syndrome, the doctor might suggest blood tests or genetic testing of the foetus, as required.

25) Are there any governmental schemes to help our family?

The Government has recognized the special needs of children with ASD and has provided several benefits including scholarships, medical insurance, etc. under "The National Trust Act". These benefits can be availed on application in any government registered organization. More details regarding government benefits are available at the following website (www.thenationaltrust.gov.in).

26) We are worried about our child's future. What can we do to ensure proper care of our child, especially after we are no more?

All parents are worried about their child's future, and this is especially true when the child has special needs. Hence, it is important to plan for your child's future in advance rather than postponing it. Parents are natural guardians of children below 18 years of age. After the age of 18 years, it is necessary to apply for their legal guardianship to ensure proper care and supervision. Parents or siblings can become legal guardians. Parents can also form a trust (consisting of a doctor, an advocate and a government official) to manage finances and take care of the individual with disability. The application for legal guardianship needs to be submitted to the "District Social Security Office". Residential facilities like group homes are an alternative for individuals with disabilities, if their families are unable to take care

of them. It is, thus, important to discuss these concerns with other parents of individuals with disabilities and professionals and make an informed decision. Further details are available on the website www.thenationaltrust.gov.in.



General tips for **PARENTS:**

1. Regular monitoring of the child's development is imperative. Delays in development can be identified and helped early that way
2. Your child's identity is not limited to the disorder. Continue to strengthen the parent-child relationship.
3. Caring for a child with developmental problems can sometimes cause stress in the family. Hence, it is important to identify and reduce the stress
4. Take some time off from taking care of the child. Develop hobbies, have leisure time, go out and meet new people, and stay healthy.
5. Feel free to discuss your queries and concerns with the doctors and therapists
6. Share your experiences with someone close (family member, friend, other parents of children with ASD).
7. Join a parent support group. It will help you keep abreast of what is new in the field and provide you with a sense of solidarity and support.
8. Take time to enrich your marital relationship. Spend time and support each other. This is vital, as your child may have long term difficulties long term, and it is important to deal with them as a unit.
9. Read and obtain information from good and trustworthy sources that give evidence-based information. Despair sometimes leads us to believe in whatever we hear and read. As parents, you must review the scientific evidence before believing the information.
10. Every behaviour of the child may have a reason. It is easy to get overwhelmed at times by the day- to- day demands. Be patient with your child. You must always be sure never to harm to the child.
11. You might feel impatient or hopeless when you don't see changes in your child, despite intensive training. Have patience. Your child will improve gradually at his/her pace and not at your desired pace.
12. Be a strong advocate for your child. Get information about ASD by talking to professionals, reading newspaper, books or reputed websites. Network with other parents, participate/organize public events to create awareness about ASD and meet policymakers for better services.

Useful websites:

1. www.autism-india.org
2. <https://www.autism-society.org/about-the-autism-society/publications/resource-materials/>
3. www.thenationaltrust.gov.in
4. <https://www.autistica.org.uk/>
5. www.autismspeaks.org
6. www.cdc.gov/ncbddd/autism
7. www.autism.org.uk
8. www.nationalautismcenter.org
9. <https://nayi-disha.org/>

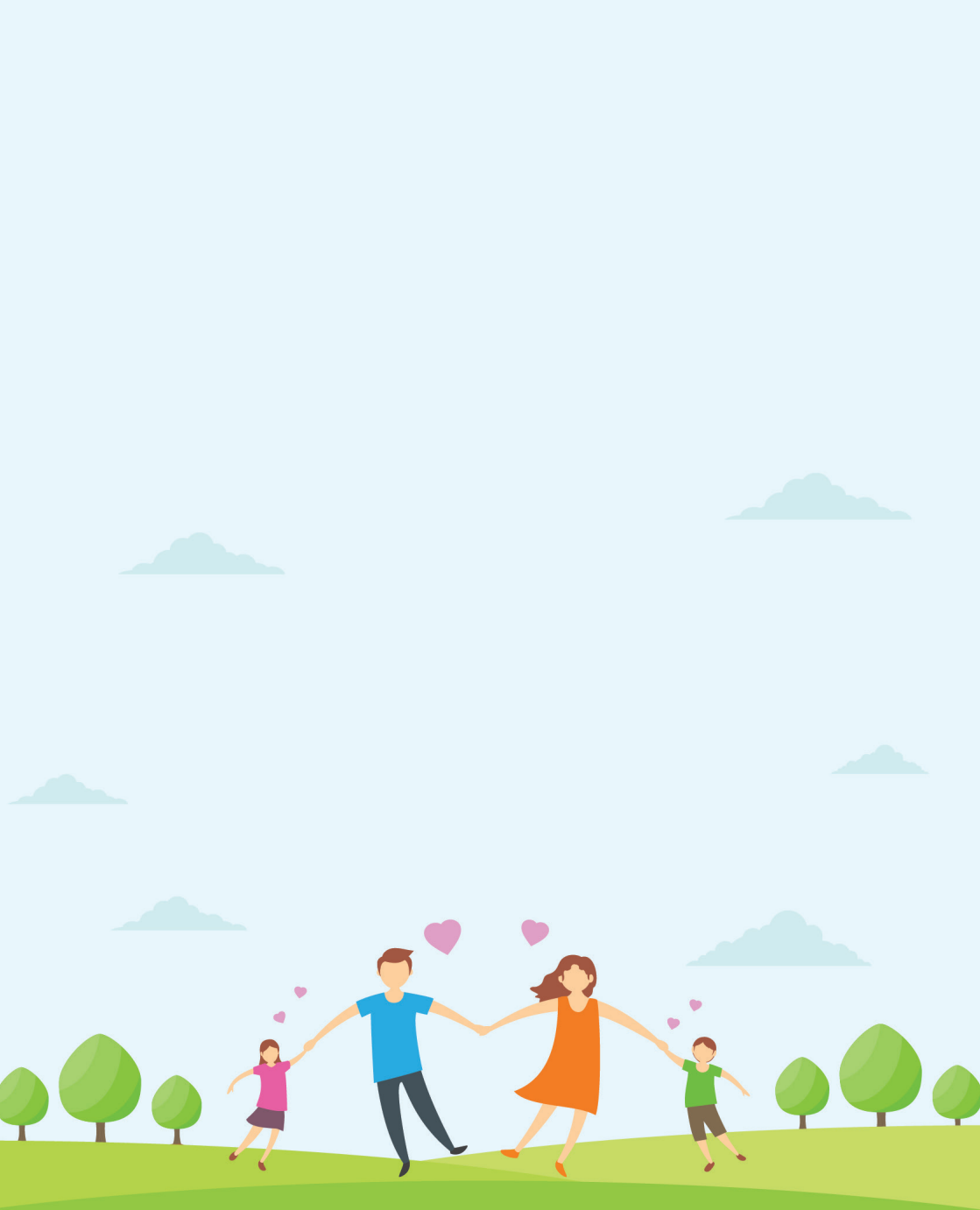
Resources for intervention

1. <https://helpisinyourhands.org/course>
2. <https://do2learn.com/>

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