



# India International Down Syndrome Conference 2022

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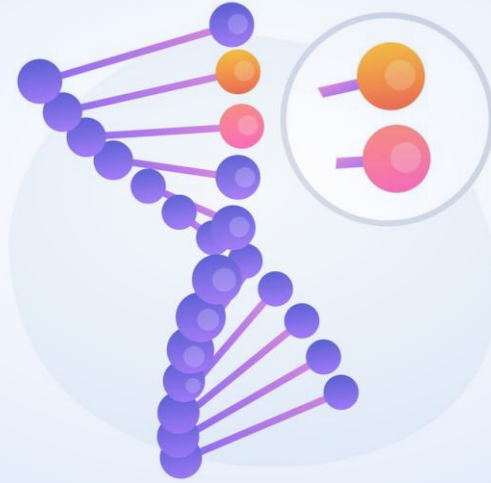
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# Index

<b>GENETICS</b> .....	<b>02</b>
- Dr. Sujatha Jagadeesh	
<b>PEDIATRICS</b> .....	<b>05</b>
- Dr. Priya Biswakumar	
<b>ENDOCRINOLOGY</b> .....	<b>08</b>
- Dr. Jayashree Gopal	
<b>ORTHOPAEDICS</b> .....	<b>11</b>
- Dr. R. Sankar	
<b>ENT SPECIALIST</b> .....	<b>13</b>
- Dr Nithya Narayanan, Consultant, Apollo Children's Hospital	
<b>PAEDIATRIC CARDIOLOGIST</b> .....	<b>16</b>
- Dr. Anuradha Sridhar, Apollo Children's Hospitals	
<b>DENTIST</b> .....	<b>19</b>
- Dr. Nidhi Gupta	
<b>VISION SPECIALIST</b> .....	<b>23</b>
- Dr. Prithie Singh Rekhi	
<b>PSYCHIATRIST (ON MENTAL HEALTH)</b> .....	<b>26</b>
- Dr. N. Rangarajan	
<b>SPEECH THERAPIST</b> .....	<b>28</b>
- Dr. Sharanya Krishnan	
<b>DEVELOPING WRITING SKILLS - TIPS</b> .....	<b>30</b>
- Ms. Hemamalini Sowmithiri & Ms. R. Srilakshmi	
<b>EFFECTIVE TECHNIQUES IN WRITING SKILLS</b> .....	<b>33</b>
- Ms. Hemamalini Sowmithiri & Ms. R. Srilakshmi	



## GENETICS

*Dr. Sujatha Jagadeesh*

### **1. What all be delayed in kids if they have genetic disorder**

Genetic disorders are many. Their presentations are varied. If a genetic disorder affects brain cells then these kids may have delay in attaining developmental milestones like head control, sitting, standing, talking, learning etc.,

### **2. Is there is any genetic treatment to reduce the effects of DS child development delays?**

At present there are only physical therapies to improve child's development. As such there is no drug which improves development. However most of the children with Down syndrome have thyroid hormone deficiency. These can significantly delay development. Hence this has to be detected early and treated. This improves development significantly. Even if thyroid function is normal initially we should not ignore it and do a 6 monthly thyroid check and see to it that things are ok.

### **3. Any treatment available for Down syndrome**

At present only physical therapies like physiotherapy, speech therapy, visual and hearing training, behavioral therapy, occupational therapy, psychotherapy (in older children and adults) may be employed based on needs of the child

**4. Is there any research which support stem cell therapy to improve brain function in kids with Down syndrome? How do I know that my kid is on which spectrum of Down syndrome?**

As of now there are lots of research going on in understanding mechanism of delayed development in children with Down syndrome and possible therapies. But none has come as an approved therapy to be used routinely in children with Down syndrome. There are developmental assessment tests which can be administered in the child to assess his or her degree of developmental lag.

**5. Is down syndrome hereditary also is it true that if 2 blood related people get married they are more likely to get a disabled child has any research been done along those lines**

Down syndrome caused by translocation of chromosome 21( which is a structural rearrangement in chromosomes) can be transmitted by one of the parents if they possess an alteration in chromosome structure. But majority of Down syndrome happens by chance due to unequal separation of chromosomes in egg or sperm during formation of embryo (non-disjunction). If one marries a relative there will be similar genetic arrangement in the couple in most areas of the genome. If both happen to carry a faulty gene and transmit to offspring then baby can be born with genetic disorder. But Down syndrome does not occur because of marrying a relative.

**6. Many siblings of the challenged are concerned about their chances of having a normal child ,what should they know**

We should understand the genetic mechanism that caused Down syndrome in that particular family. The most common mechanism - called nondisjunction variety does not increase risk in sibs. But if one parent is a translocation carrier then sibs has to check their chromosomes to see if they are also carriers. If they are not carriers then there is no increased risk. But if they are carriers there is 10-15% chances of transmitting Down syndrome to their children. They have to undergo genetic counseling to understand preventive reproductive options.

**7. What are the conditions that cause the alteration in genes? (2) Are these conditions mental, physical or environmental? And if so, what can be the preventions? (3) Since Down syndrome is genetic, are their chances of more kids with down syndrome being born to the same family?**

Genetic conditions that are caused by alteration in genes are called Mendelian disorders. The clinical symptoms depend on which organs are affected.

Prevention is by avoidance of consanguineous marriages, premarital genetic counseling and preconceptional carrier testing for genetic disorders.

Down syndrome is a chromosomal problem and not a gene problem. So usually it does not pose increased risk to other family members

## **8. which therapies are beneficial for Ds kids to recover fast? 2 .What we can do for them to live**

Please refer to answer 3

Periodic medical checkups attending to their medical needs then and there and giving them a congenial environment to grow and helping them with therapies to function better will improve their longevity

## **9. I have thought about my daughter that she may follow her aunty's (father's sister) Mental illness which was in our genetics so do you think that both downs and mental illness in heredity can happen**

Please refer to my answer 7

## **10. Should Pap smear be done to our adult ladies to rule out any complications (How do we be tkc prevention against Breast cancer uterus or other gynec problems normal ladies above 35 Get .Is there any precautionary tests ?**

PAP smear can be done annually in adults to rule out cancer cervix.

Annual self-breast examination is recommended in women to pick up lumps in the breast when they are really small

If there is family history of breast cancer annual mammogram is suggested apart from self-examination

## **11. Can a child with DS give birth to normal kids**

Usually males with Down syndrome have fertility issues. Females usually have normal reproduction There is 50% risk of transmission of Down syndrome to offspring

## **12. How can we avoid trisomy 21 in the first place itself?**

It is a by chance error that occurs during formation of an embryo So we do not know which pregnancy will be affected prior to conception Risk increases as maternal age advances

There are screening tests in I trimester of pregnancy which compute risk for Down syndrome in a particular pregnancy taking into consideration mothers age, weight, previous history of Down syndrome pregnancy, some scan measurements and findings from baby like nuchal translucency etc and some biochemical parameters from mothers blood. There is a recently available test called noninvasive prenatal testing which can test amount of fetal genetic material in mothers blood and compute a risk for Down syndrome. This test has 99.9% accuracy. Nevertheless high risk pregnancies picked up by screening need invasive tests like chorionic villus sampling or amniocentesis to confirm Down syndrome in pregnancy



## PEDIATRICS

*- Dr. Priya Biswakumar*

### **A Growth & Development :**

#### **1. How to guide him through life's journey?**

a- There is a passport available which will help guide parents and the child through every year and what needs to be done.

#### **2. Should pediatrician measure and plot child growth according to DS growth chart to the parents, which some of them don't have.**

a- Yes- the growth in terms of height, weight and head circumference should be plotted on the DS growth charts or IAP growth charts.

#### **3. I want to try every possible treatment. What can parents do to develop their child at an early age? When to start physiotherapy?**

a- The early intervention programme should be started from 4-6 months of age after consulting with the Paediatrician and Physiotherapist. Other therapies such as Speech therapy, Behavioural modification may also be needed.

#### **4. How to take care of their general health? How frequently is it necessary to do their medical checkups?**

a- Proper nutrition, vaccination, adequate play and interaction with other children, and treating infections promptly should help in maintaining good health. Medical checkups should be monthly during the first year; 2-3 monthly during the second year and thereafter 6 monthly till 5 years. After that yearly follow-ups are enough.

**5. What can professionals do to help parents develop their child while waiting for any assessment. What tools can be given to parents?**

a-Professionals can refer the child to a DSFI centre where the parent can understand all the various interventions that can be started to help the child grow well. The Passport is a tool that can help in guiding.

5. Checklists for understanding delays in growth milestones will help.

a-The illustrations that are given below can help in guiding parents in understanding developmental milestones.

**6. Children do a lot of self-talk whenever they are free, so how do we stop it?**

a-Exercise on a regular basis, yoga, music and dance can help in decreasing this.

**7. How can improve memory power for a 13 years old child? And can teach for reading?**

a-Repetitive reinforcement. cutting down screen time and play methods can help in improving memory.

**8. What counselling services are suggested for the parents of a ds child?**

a-Counselling in the DSFI centre, with a professional psychologist and establishing contact with other parents through groups will go a long way in giving the parent much needed support –physical and mental.

## **B. Infections**

**9. My son who is 5 years of age has suddenly developed fear .. His voice is lost, He was uttering few words and blabbering but since last week he is slightly whispering in low tone.. He has no fever no cold cough..What could be the reason? doctor? dr advised some medicines for five days saying he has mild chest congestion, but still his voice is not coming. He is able to shout , cry and eat. Pls help..**

A-multiple causes like a respiratory/gastro oesophageal reflex/additional speech or cognitive problems /psychological issues can be there. Once the cause is identified, appropriate therapy and treatment will help resolve the issue.

**10. How to get rid of common cold that comes in kids even in summer season.?**

a- Colds can be due to infections or allergies; Appropriate medication can be given to treat the present infection. Blood tests/X-rays may help in identifying the reason for recurrent infections which can then be resolved. Influenza and Pneumococcal vaccination will definitely help in reducing recurrent infections and preventing Pneumonias.

**11. Is it compulsory to give supplements (vitamin medicine) in growing age because they have down syndrome?**

a-Downs syndrome is not a disease and is just an associated condition. Children with this lack certain enzymes, and are also slightly immune deficient –certain supplements definitely help in overall growth and preventing infection.

**12. Any additional vaccination required for kids with down syndrome for their overall growth?**

a-Regular vaccination according to age should be given. In addition, Pneumococcal and yearly Influenza vaccines are necessary.

**13. 1.Which body parts are got effected mainly in downsyndrome? 2. In long run what extent it can be recovered? 3. What are the important things we have to care for normlling services suggest for the parents of ds child?**

a- Multiple organ systems like the heart, gastrointestinal, ,thyroid, vision, hearing, immune systems are involved and affected. A good initial assesement of all these and regular follow up for those systems affected will help in bringing the child upto his/her potential in all spheres.

**14. Though my son started speaking late he is able to have a proper conversation. However his speech is not fully clear, though it has improved a lot over the last 3 months that he going to school. Is this normal?**

a-Speech therapy may be beneficial.

**15. How to manage Constipation? Will they have poor digestion and weak health?**

a-First a proper consultation with your Paediatrician and if necessary with a gastroenterologist will help in identifying the cause of the constipation. Appropriate diet modification, and laxatives will help.

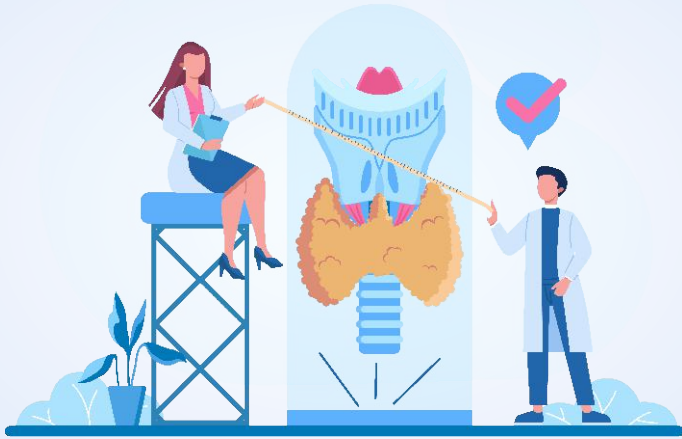
**16. How can we manage common cold and cough at home?**

a-Home remedies like Tulsi, honey, steam inhalation ,adequate fluid intake will help. In addition, antihistamines, nasal drops/sprays after consulting with your doctor may give relief.

**17. Everytime my child gets upper respiratory infection, he is given strong antibiotics, how to deal with these frequent seasonal infections?**

a-Antibiotics are given if there is a bacterial infection only. Preventing recurrent infections as advised earlier will help.





## ENDOCRINOLOGY

*Dr. Jayashree Gopal*

### 1. What is a hormone?

- A hormone is a chemical, usually a protein, made by glands in our body, secreted into the blood and which travel to other parts of the body to control various aspects of our normal functioning. For example, insulin hormone controls blood sugars, adrenaline controls blood pressure and heart rate, calcitonin controls calcium.
- There are many endocrine glands in our body, and the thyroid is one of them.
- The thyroid is a butterfly shaped gland situated in the front of the neck. It starts working even the baby is developing inside the mother's womb. It makes thyroid hormone, which is necessary for normal functioning of every cell in our body.

### 2. What are the actions of thyroid hormones?

The thyroid hormone binds with its receptor present inside every cell of our body. Depending on the organ, the thyroid has different effects. For example in the heart, it controls heart rate and the force with which the heart muscle contracts. In the brain, it is needed for normal development when a baby and for normal memory and optimal intelligence as an adult. In the liver, the thyroid hormone influences production of several proteins related to cholesterol metabolism. Normal levels are needed for regular menstrual cycles in girls. These are just a few of the essential actions of thyroid hormone.

### **3. Why do doctors measure T4 and T3? What is the difference between the two? And what is TSH?**

T4 and T3 refer to the number of iodine molecules on the hormone (T4 has 4 iodine atoms, T3 has 3). T3 is the active form of the hormone, but T4 is the main hormone made and secreted (put out) by the thyroid gland. Why is it like this? This is because T4 is more stable and this system allows each cell to make as much T3 it needs from the circulating pool of T4.

The TSH refers to Thyroid Stimulating Hormone. It is made by the pituitary gland, and as the name implies, it is a hormone that makes the thyroid gland more active and make T4 and T3. When the thyroid gland is less active, the body makes more TSH in an effort to improve the activity of the gland. And when the thyroid gland is working excessively, our body dials down the TSH production.

Hypothyroidism refers to underactivity of the thyroid gland, and hyperthyroidism refers to overactivity of the thyroid gland.

### **4. Why is thyroid testing so important in T21?**

- Normal thyroid levels are very important for growth and development
- If hypothyroidism develops, growth and development will slow and halt
- Replacement of thyroid hormone with tablets will restore thyroid status and optimize growth.
- Some studies show that by the age of 10 years, 30% of children with Trisomy 21 may have developed a thyroid problem.

### **5. How frequently should my child be tested for thyroid problems?**

- It is recommended that all children be tested at birth, and every 6 months thereafter till age of 4 years
- After age of 4 years every 6 – 12 months
- Earlier if any symptoms of hypothyroidism seen – constipation, less activity, hair fall, skin dryness

### **6. What test needs to be done?**

It is a blood test where TSH, Free T4, thyroid antibodies are checked. Sometimes your doctor may order an ultrasound of the neck.

### **7. What are thyroid antibodies?**

- These are “auto” antibodies – or proteins that the body makes against “self”
- There are 2 main types of thyroid antibodies  
Antimicrosomal & Antithyroglobulin
- High levels of antibodies ONLY mean that the thyroid gland may not function properly – it has no other significance. Even if the thyroid levels are high, as long as the thyroid levels (TSH and T4) are within the normal range, there is nothing to be worried about.

## **8. What if my doctor says thyroid levels normal but my child has symptoms that suggest a thyroid problem?**

- This is a very common issue BECAUSE symptoms of thyroid problems are not specific to thyroid alone.
- Constipation, growth restriction, and difficulty walking are common in T21 even with NORMAL thyroid function

## **9. What if thyroid levels are borderline but my doctor says it is normal for age?**

- TSH values change with age – it is highest at birth, decreases slowly over the first 10 years of life to adult levels
- At birth TSH can be up to 10 mIU/L (rarely even 20-40)
- Up to age of 10 years, levels of 8-10 mIU/ml of TSH considered “normal”
- Because of this variation in TSH with age, interpretation of thyroid test reports needs to be done by the doctor.

## **10. What is the treatment for hypothyroidism?**

- Thyroid tablet given which contains T4
- Remember the tablet is safe – only problem occurs if dosing not proper – over or under replacement
- Once on stable dose of thyroid tablet – need to check TSH and free T4 once in 4-6 months
- If levels are normal when you are taking tablets, it does not mean we can stop the tablets. The normal levels only indicate that the dose is accurate. All that we are doing with the tablet is replacing a deficiency. The gland usually continues to remain underactive, lifelong supplementation with thyroid tablets is needed.

## **11. Can I prevent thyroid problems?**

To some extent yes. Avoid weight gain, Maintain good nutrition and No Hereditary or genetic factors play a strong role

## **12. What other endocrine issues do we need to consider in children with trisomy 21?**

1. Growth restriction is common, which means adult height on an average is less than that of other family members. This slowing of growth may start becoming visible from infancy. Growth needs to be monitored using growth charts for children with Down's syndrome. This is available from CDC.gov (USA). There are currently no specific growth charts in India for T21.
2. Puberty occurs at normal age -10-14 years, If delayed or early, it should be assessed. Periods in general are regular in girls, with normal fertility potential for boys and girls.
3. If there is excess weight gain, there is increased risk for diabetes, high cholesterol and similar metabolic issues. After the age of 18-20 years, it is good practice to screen for diabetes and cholesterol problems once in 1-2 years.



## ORTHOPAEDICS

*Dr. R. Sankar*

### **1. Does Down Syndrome affect bones?**

Yes. We see lot of bone related problems due generalised ligamentous laxity and hypermobility of joints. Common conditions are neck instability, scoliosis, hip and knee instability and foot disorders.

### **2. My child, who is one and a half years old, cannot sit or stand without support. Is it normal for DS child?**

Compared to normal children, DS child will have delayed mile stones. It is normal.

### **3. How to improve muscle tone? What kind of issues will they face when they become old?**

Regular exercises keep children fit. As mentioned earlier, they will develop issues with neck, back, hip, knee and foot.

### **4. How to make bone and muscles stronger?**

To have healthy bone, child should have adequate physical activity, with calcium rich diet and sun light exposure.

### **5. Why sunlight exposure?**

For calcium to be absorbed from body, you need vitamin D. Major source of vitamin D is sunlight. So, sunlight exposure helps absorption of calcium.

### **6. Can you suggest food rich in Calcium?**

Main source of calcium rich food are milk and milk products, green leafy vegetables, soybean, nuts, lentils etc.,

### **7. What kind of physical activity is good?**

Any kind of physical activity for 30-60 minutes everyday along with adequate calcium and vitamin D will keep bones healthy.

### **8. How much calcium does a child need every day?**

Growing children will need up to 1 gram calcium every day.

### **9. How to improve muscle tone in children with DS?**

By doing regular exercises, one can expect to improve muscle tone. This can be achieved only to a certain extent as DS is associated with ligamentous laxity too.

### **10. My child is getting bone cracking sound from the knee. Why?**

Cracking sound or snapping is due to displacement of fluid in the joint. No need to worry.

### **11. Can children with DS do gymnastics or classical dance practice for long hours?**

Even though they have lax ligaments which can make them more flexible, DS children have difficulty with maintaining balance and so will find doing gymnastics and dancing for a prolonged time quite strenuous.

### **12. Do all children have flat feet? How to identify it?**

Yes, due to ligamentous laxity. Once you make them stand, the inside of the feet will be on the ground without medial arch.

### **13. Is flatfoot condition curable?**

Flatfeet are not curable, but remedies are there in the form of arch support and special shoes.

### **14. My baby's legs are twisted. Are there any shoes to keep the leg straight?**

Twisting of legs is commonly due to child sitting on their legs or W sitting. Best way to treat is to discourage them from sitting like that. Shoes or splints do not help in making the legs straight.

### **15. My 5-year-old child with DS is not walking independently yet, in spite of regular physiotherapy. How to improve?**

Usually by 5 years, a child will start walking on his/her own. If you are concerned, consult a doctor to get an advice.

### **16. My son has started walking at 2 years and six months. However, he is finding difficult to jump or climb stairs. How to help him?**

As mentioned earlier, there will be delay in milestones in children with DS. He will improve as he grows.

### **17. My child complains of leg pain. She has flat feet. How to treat?**

Leg pain in children after activity is due to fatigue of muscles. Gentle massage will help rather than giving any medication. Pain settles once they rest for some time.



## ENT Specialist

*Dr. Nithya Narayanan*

### **1. While drinking water always my baby is getting cough, will there be any issues.**

If child is not having cough while eating solid, he should be fine. However if cough is always present with drinking water, vocal cords may have to be checked.

### **2. It is right for children to have tonsils and adenoids surgery.**

Few children need surgery for tonsil and adenoids, as they may be born with big size tonsils and adenoids which obstruct the airway leading to snoring, or they may need surgery for recurrent infections which hamper growth.

### **3. Speech**

Any speech disturbance needs evaluation by Speech Therapist and speech therapy.

**4. My son Sulaiman, 5 years of age has suddenly lost voice . He has developed fear .. His voice is lost, He was uttering few words and blabbering but since last week he is slightly whisperin low tone.. He has no fever no cold cough..What could be the reason.. My doctor drdurgaorasadsir advised lanzol junior and relent plus syrup fir five days saying he gas mild chest congestion, but still his voice is nit coming. He is able to shout , cry and eat. Do i need to give any soecific medicine or treatment . Pls help..**

He may have developed infection without other symptoms due to excessive shouting or he may have psychological issues like fear. If voice doesn't improve in few weeks, he needs examination of vocal cords under short anaesthesia.

**5. What are basic routine ENT check up we do it from home.**

No need of routine ENT checkup at home. If baby is very small, parents should try to assess hearing for early diagnosis of hearing loss.

**6. If kids with Down syndrome respond to our voice, do we need to do BERA test? What kind of ENT issues can arrive in future? How frequently we need to do ENT examination?**

If child is responding to sounds at home, and starts speaking at a reasonable age, BERA test is not essential. Regular ENT examination is not essential, unless child has chronic ENT problem.

**7. Tonsil and adenoid is it safe and better to remove them to prevent infections.**

surgery for tonsil and adenoid is absolutely safe. It is never done routinely to prevent infections. Some children who have large size tonsils and adenoids or get recurrent infections needing antibiotics, do well after surgery.

**8. What to do if regular wax comes in ear little more than us?**

Better to visit ENT doctor regularly after using wax dissolving drops. Avoid ear buds.

**9. Is tonsil removal helpful to deal with frequent cold, cough , bronchitis issues**

**1) which kind of test is best to know the accuracy of deafness in our children 2) does the hole in the ear drum heal on its own 3) what causes frequent ear discharge.**

Tonsil removal will be helpful if child has infected tonsils, needing antibiotics regularly.

1) MASTER test is best to assess deafness. 2) If ear remains dry for long time, small holes can heal on their own. 3) Recurrent cold, sinusitis, tonsillitis and adenoiditis can lead to ear discharge in children.

**10. 1.Is regular ENT test required? 2.What is effective method to be taken avoid mouth breathing? 3.Reason for lack of sound sleep?**

1. Regular ENT test needed only for children with chronic ENT problems. 2. Child should sleep in lateral posture to avoid mouth breathing, can use nasal sprays. 3. Disturbed sleep in children may be due to snoring and mouth breathing.

**11. Since birth my child had discharges from her ears thrice .. Not sure what was the issue.. Anything that i should be extra careful to avoid ear discharge ?**

avoid water entering the ear while bathing. Might have been fungal infection which can happen if ear is wet.

**12. What do we need to keep in mind during a regular ENT check up.**

be sure to list out all your problems to the ENT Doctor so that he or she can sort it out.

**13. How can I take care or know if he has any ENT issues at the age of five?**

If child is hearing and speaking well, it is good. Mouth breathing is another symptom which you should look for, by 5 years.

**14. She has small nose holes so always suffering from cold.**

It may not be due to small nose holes, maybe child has nasal allergy to dust and cold.

**15. Ashritha has hearing problem .since 5 years .One ear is operated ..she doesn't like wearing aids .can we fix a permanent aid. Hearing problem is affecting her performance level. Is there in any better way of helping her other than wearing hearing aid. can we fix any.**

If child has had Cochlear Implant, nothing else has to be done. But it is also like an aid which has to be fixed. There is no other solution. Hearing is necessary for speech to improve.

**16. Can a child with DS lose his hearing at later stages in life? Is regular cleaning of ears mandate for children with DS if yes please let us know the methods.**

Children with DS don't have higher chance of losing hearing in later stages of life. It is same for all. Regular cleaning of ears at home, is not essential. If child has ear block or pain, it is better to see the doctor. Some children with DS tend to have narrow ear canals, in them, once a year visit to doctor is better.

**17. Do we need to clean our DS child's ear wax from time to time inserting an ear scratcher made of silver? 2. What can we do to stop my DS child's stuffy nose, which happens to be quite frequent?**

Never put ear bud. 2. Child may need nasal sprays. Avoid cold atmosphere, AC.



## PAEDIATRIC CARDIOLOGIST



*Dr. Anuradha Sridhar*  
Apollo Children's Hospitals

**1. If once the holes is closed, is it necessary to take cardiac checkups every year.**

Yes. It is absolutely necessary to have yearly check ups to monitor lung pressures and Heart function.

**2. My son had asd of 2.4 mm at birth. Recently we did ultrasound and got to know the asd is now 1mm or they said PFO. When should i retest him again?**

There is no need to retest for PFO. However DS children will need either yearly or once in two years cardiac review to monitor for high lung artery pressures (Pulmonary hypertension).

**3. He had Undergone an open heart surgery at the age of 2.5. we had advised to get ECG every year, apart from that is there anything else we should look forward? Now he is 16 year old.**

Following cardiac surgery child should be on yearly follow up with paediatric Cardiologist to monitor for residual lesions, lung pressures and Heart pumping function. You have to report to Cardiologist if there are any new symptoms like breathing difficulty or bluish discolouration while playing or climbing stairs.

**4. My son's is having PAH, anything that helps to control along with medicine?**

Breathing exercises (Pranayama) will help your child breathe-in more Oxygen. Oxygen will reduce lung pressures dramatically.

**5. Is there any chance that kids with no heart issues can develop them in future?**

If they are born normal, these children won't develop congenital heart defects like hole in the Heart. However they can develop high lung pressures (Pulmonary hypertension) gradually over many years.

**6. Prevalence of heart conditions in this population what is the latest research.**

Children with DS face a high rate of congenital heart defects (CHDs). About 40-60% percent of infants with Down syndrome have some form of heart condition, compared with approximately 1 percent of typical infants. It is unclear why these conditions occur so frequently in children with Down syndrome. Three of the most common heart conditions seen in children with Down syndrome are atrioventricular septal defect, patent ductus arteriosus, and tetralogy of Fallot.

**7. Time gap to repeat scans for my child ?**

Yearly once is the ideal time gap to repeat scans or earlier if advised by paediatric Cardiologist.

**8. Suggestions for healthy heart functioning?**

Regular physical exercises and maintaining a normal body weight. Strength training exercises and breathing exercises done regularly will strengthen the Heart.

**9. 1) Do all children have heart issues 2) my child doesn't have heart issues at the birth but can they be developed later in life? (3) What is the success rate of heart surgeries in down syndrome children?**

Not all children with DS have Heart issues. About 50% of them have some form of Heart diseases, especially congenital heart diseases. If your child has normal Heart at birth, chances of developing congenital heart defects is unlikely. However at any age they can develop high lung pressure (pulmonary hypertension) and secondary deterioration of Ventricular function. In adulthood they are prone for all adult Heart issues like Hypertension and Ischemic Heart diseases. Heart surgery in DS children carries slightly higher risk than general population of children. This is because of high lung pressures, airway problems and type of congenital heart diseases like AV canal defects. If the lung pressures are within normal limits the success rate of various cardiac surgeries ranges between 90-95%

**10. What would be the basic health parameters at different ages of good health in childhood, adolescence, adulthood, older adults.**

At any age good Heart health parameters are good exercise capacity, normal blood pressure and Pulse. Normal lung pressures is also a measure of good Heart Health in DS children.

**11. Can a cardiac issue come up to DS at any age?**

The only major problem for DS children during childhood is development of high lung pressures (Pulmonary hypertension) secondary to airway or lung abnormalities and subsequent Right Heart failure. During adulthood they are prone for all adult Heart problems like Hypertension and Ischemic Heart diseases.

**12. Pls share diet for maintaining healthy heart.**

Low salt diet is always good for Heart as it reduces volume load on the Heart. Minimising packed food (ready to eat including biscuits and other bakery food) and avoiding fast foods available in restaurants is good for the Heart. Eating three portions of fruits and vegetable everyday will reduce unwanted fat and helps Heart to be healthy.

**13. Would there be any issues in future for my DS child who had a PDA surgery when she was one year old?**

PDA is a communication between the body artery and lung artery and is outside the four chambers of the Heart. PDA closure (Device or surgery) has become the safest among various congenital heart correction procedures and children recover without any residual lesion. There won't be any issues in future if lung pressures were normal and in the operable range before closure. So even after good recovery from PDA surgery your child will need regular follow up in the long term for monitoring of lung artery pressures.



## DENTIST

*- Dr. Nidhi Gupta*

### **1. Upper palate is high arched, is it possible to expand the palate my baby is 4 yrs old**

In children with down syndrome, generally palate is high arched which affects speech, mouth space, positioning of tongue etc. Yes its advisable to expand the upper jaw. Its very much part of dental regime in western countries.

### **2. It is right to have RCTs for children.**

If RCT is indicated, it should be done to save the tooth if its permanent. In baby teeth if the tooth is meant to be in child's mouth for more than some months, it should be kept as it maintains the space for the eruption of permanent teeth.

### **3. Can we go for dental cleaning By professionals in interval? because sometimes I feel did he brushed his teeth properly? as he doesn't like my interference in his daily routine.**

Professional Dental cleaning is suggested if there are deposits or tartar formation or any gum disease deducted. Timely dental checkup will help understand if there is any need for professional cleaning.

**4. My son 5 yr old is always putting each n everything in mouth. Drooling always.. He does not eat while fruits nor any snacks, he chews well but eats only food.. How can i stop him from keeping items in the mouth..is he giving any tooth pain or is it a sensory issue i cant make out. Pls help.**

Sometime children put things in mouth to satisfy their sensorial needs. Exposing to wide range of textured foods do help. Timely visit to dentist helps in knowing if child is facing any kind of discomfort because of dental issues.

**5. How to introduce solid food. I can chew but i am too scared to give proper solid foods**

The readiness of the child is really important before introducing solid items. You can start with semi solids first depending on child's age. If the child can chew, you can start with his favourite flavoured food.

**6. How to take care of their oral health? Is there any special brush or paste or any other instrument I need to use for brushing?**

Oral hygiene is really very important for kids and adults with down syndrome . Good oral hygiene helps in proper nutrition intake. Brushing of teeth with soft brush is the primary requirement to ensure good oral hygiene. Mouthwashes, dental flossers are additional tools which can be used provided they are suggested by the treating doctor. If the child can spit, fluoridated toothpastes are recommended.

**7. Oral health at different stages ,a checklist and parent guide**

**(a) should we get the baby teeth removed in grown up adults**

The baby teeth should be removed but before that a full mouth x ray should be taken to understand if successor tooth is present or not.

**(b)How to work on their sensory issues as our children doesn't allow us to touch their mouth**

The sensory issues can be generalized where the child does not allow touching, combing, bathing. Proper desensitization protocol helps in such cases. If the trouble is in and around the mouth, then oromotor exercises along with different texture desensitization around the mouth helps.

**(c) is it possible to get RCT done for our children**

Yes, If the child cooperates, it can be done.

**8. What if they do chew properly even at age of 8-9 yrs?**

Chewing is an essential skill needed for proper nutritional intake, speech etc. Use of oromotor tools along with therapy plays an important role in this..But Dont neglect the dental issues. Sometimes bad bite of teeth can create abnormal chewing pattern which can be corrected by the dentist.

**9. How can it be made more easy and less frightening for our children to attend those procedure can more dentist be train in special needs requires**

Not only dentist but the caregivers at home also play a very important role in making the child aware and counselling by both the stakeholders play a vital role in easing the anxiety of the child. Regular visits from the infancy stage, along with social stories helps a lot in creating positive patterns and reinforcing the desired behaviour. Yes, there is increasing need to train dentists across the globe for catering to needs of children and adults with special needs.

**10. 1, What is the reason of uneven and double teeth? 2. How we can deal with the problem of teeth grinding? 3. How to take care of proper oral hygiene?**

Double row of teeth is common, but timely intervention should be done to extract baby teeth so that the successor teeth erupt in place. Teeth grinding is multifactorial. But if its affecting the dental structures like weakening and wearing of teeth, it should be taken care of.

The best and simple tool for oral hygiene is tooth brushing.

**11. My son's teeth came out in different order, it was late but mostly all his teeth have come. However they are not in shape, is there something to be done in order to put it back in shape?**

Its common in down syndrome to have unusual eruption pattern. If they are baby teeth, we don't recommend any build up. For permanent teeth, cosmetic make up can be done for aesthetic enhancement.

**12. Is it a must to remove retained milk teeth?**

Yes, if its successor is affected . retained baby teeth can alter the path of eruption of permanent teeth.

**13. What care need to be taken of a down syndrome 5 year old dental ?**

Pl check for any cavities, or gum swellings. Toothbrushing is mandatory and daily reinforcement is needed. Diet modification for including more fibrous diet and cutting down on refined sugary products should be taken into consideration.

**14. My daughter is 25 month old and don't have only 6-8 teeths which exercises and vitamins need to go for**

Check vit d, thyroid n parathyroid hormone level.

**15. Can A missing tooth be implanted..for our adults .Is doing it under GA is okay**  
Yes, it can be done. If child cooperated and medical history allows, it can be done in OPD too.

**16. How can we train a Downs syndrome child to brush her teeth all by herself?**  
**2. How can we make a DS child cooperate to brush her inner molar teeth? 3. How can we teach a DS child not to swallow toothpaste foam while brushing?**

Role modelling and play way learning plays an important role for picking up of any habit. Break the whole process into small steps. encourage by giving rewards. Slow but steady practice yields good results. Regular visual clues along with positive reinforcement can help from swallowing the paste. Check for any sensitive spots before introducing the brush in molar areas.

**17. Is it common in children with down syndrome to have delayed eruption of teeth?**

It is generally seen that children with down syndrome have delayed eruption of teeth. Sometimes not a single tooth might erupt even by the age of one year. The delay in eruption may be as long as two to three years.

**18. My child has not erupted all teeth even at an age of 2 years? Should I worry?**

The teeth in children with Down syndrome may erupt late. The eruption can keep happening even after 2 years of age. Sometimes eruption of all teeth may complete at 4 or 5 years of age.

**19. My child has erupted back teeth but front teeth are not erupted yet?**

Sometimes the eruption of teeth happens in unusual pattern. There is nothing to worry about it.

**20. Does any deficiency of hormone or vitamins affect the eruption of teeth?**

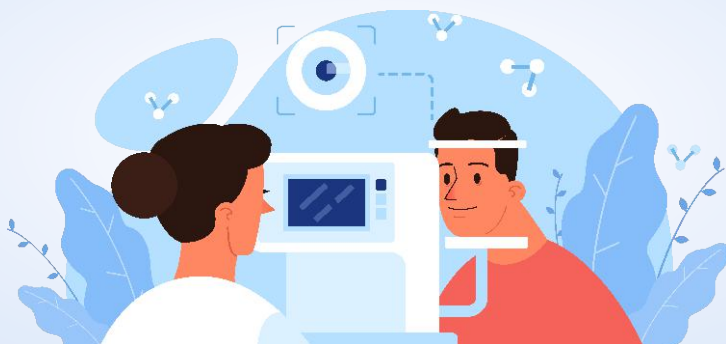
Ans— Yes, Vitamin D and thyroid hormone play very important role in the eruption of teeth so these two factors should be within normal range.

**21. My child has cut most of the milk teeth. Should I brush them?**

Its a misconception that baby teeth don't need to be brushed as eventually they will fall. But actually they are very important and due care should be taken for their hygiene. The simplest and most effective oral hygiene tool is tooth brush.

**22. When should I brush my child's teeth?**

To the child's teeth should be brushed twice daily; morning and night.



## VISION SPECIALIST

*Dr. Prithvi Singh Rekhi*

### **1. My child brings work really close and goes close to the TV.**

Going close to the TV is indicative of reduced vision or myopia or both. Having said that, I am happy he is watching TV, as that means he is using his vision.

### **2. How often should I get my child's eyes examined?**

Ideally a child's eyes should be examined at birth, six weeks, six months and yearly after that. Preferably do one test by 6 months and one definitely by two and a half years.

### **3. When we go to get an eye test done, then these children not reply correctly, so how will we know whether their glasses number is right or wrong?**

We rely a lot on objective measurements in such cases.

### **4. How can I do home testing to check my son's vision**

Cover one eye while the child is looking at a page or screen (not doing an activity in 3 dimensional space, like reaching out for a toy). This is repeated for the other eye as well. If consistently the child doesn't like one eye being covered, then the other eye has a problem.

### **5. My son has some vision issues...had eyes surgeries. I want to consult for Is there any activities which he should avoid...as swimming etc. He has glaucoma also.**

Unless specified, there are no restrictions

### **6. Food and supplements to prevent vision problems in future, I want to take preventive methods**

A good healthy diet



**7. My child using 7 & 6 size glass but he doesn't know how to read doctor can't identify correct size .what I can do to get correct size.**

The doctor will rely on objective measurements, your child doesn't have to respond.

**8. How frequently eye examinations are needed in kids with Down syndrome?**

Ideally a child's eyes should be examined at birth, six weeks, six months and yearly after that. Preferably do one test by 6 months and one definitely by two and a half years. Subsequently an exam every year.

**9. How to deal with a child that refuses to wear glasses .what effect this will have on him. My son has never wear glasses despite being told he needs them. He seems to be able to see ok**

If the glasses are helping, he will wear them. If he doesn't you need to go back to the doctor and he should have an explanation. Sometimes the glasses may be incorrectly made, or may actually make certain activities worse.

**10. How much mobile affect their eyes?**

There is some talk of blue light from mobiles affecting the retina over a period of time. Other than that, usage of the phone at night affects sleep.

**11. Some kids may not respond well to eye tests so how can their vision be monitored at childhood, adolescence, adulthood**

Quite often we don't rely on responses as much as we do on our objective measurements. A yearly check is sufficient unless otherwise specified.

**12. (a) Do all children with down Syndrome require spectacles? No**

**(b) my child is unable to read and write and is nonverbal, how will the ophthalmologist test his eyesight**

The doctor will rely on objective measurements, your child doesn't have to respond.

**(c) How do we encourage toddlers to wear glasses?**

Put the glasses on and let him do an activity he likes. If he takes off the glasses, stop that activity

**13. (a) Is regular eyes checkup required? Yes**

**(b) what regular precaution needs to be taken?**

What ever had been advised, else a check every year.

**14. Till now his vision is good, anything that we need to take care or precaution or be wary about for future?**

A routine eye checkup every year is sufficient.

**15. Had a eye checkup for my 4month old child and it was normal.. When can i repeat the eye checkup again?**

If he had achieved what is expected by 4 to 6 months, then after a year.

**16. My child was given bifocal lens because of accommodation issues. Can we do something to improve accommodation?**

Persons with DS have accommodation issues. There are some exercises that help, but needs a fair amount of time and cooperation.

**17. Plan for future that she don't have Glasses in future**

If there is no power, at some point reading glasses will become necessary. I would focus my efforts elsewhere.

**18. Ashritha complains of Eye Pain..consulted 4 Drs and all are of the opinion that it's because of Dry eyes .She had her both eyes operated for cataract.**

Constant lubrication of the eyes is necessary for her, (if it relieves the pain). I'm such situations it's better to use preservative free lubricants.

**19. My Son stands in front of TV to watch.Is this indicative of poor eyesight? He also has watery eyes which has reduced but still there**

Going close to the TV is indicative of reduced vision or myopia or both. Having said that, I am happy he is watching TV, as that means he is using his vision. Watery eyes are quite common in children with DS.

**20. (a) Is intraocular lens implantation advisable for a child with aphasia?**

Yes

**(b)What are the advantages and disadvantages of such IOL implantation?**

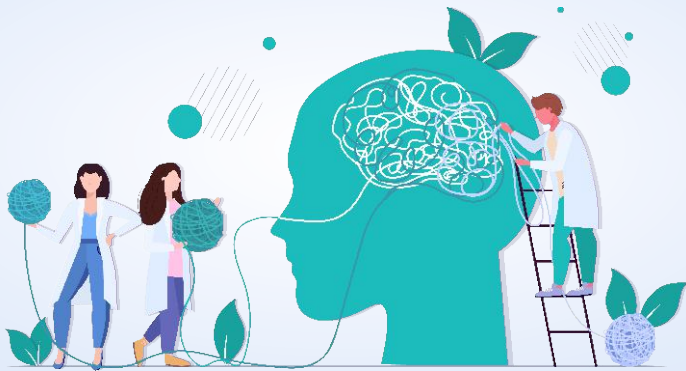
Without the IOL a person would have to wear (usually) a spectacle of +10.00 which causes a lot of magnification, fid loss and distortion. No real disadvantage.

**(c)Does a child have to wear power spectacles even after IOL implantation?**

Quite often, yes.

**21. Why does my child turs his head at angle while watching TV?**

Head turns and head tilts are an indication that the child's vision is better when the eyes are positioned that way. Most commonly this is due to a squint or nystagmus. For example if a child's vision is better in left gaze (eyes are turned to the left) he or she will have a face turn to the right. DO NOT correct the child. Instead let the doctor decide appropriate treatment. Quite often, there is no treatment, in which case we have to shift the environment for the child. For example, he will sit to watch TV in a place such that the TV is to his left.



## PSYCHIATRIST (on Mental Health)

*Dr. N. Rangarajan*

### **1. How to control the stubbornness in 4 yrs. Old. Stubbornness is a part of DS? Throwing things around? What can we do to help them have a good mental health**

- ▲ When a child wants something very badly, he will use all his “skills “ to obtain it. This can be techniques like begging, cajoling, crying, shouting etc.
- ▲ If there’s a difference between what the child wants to do and what his parents want him to do, there’s a battle on for it.
- ▲ Let’s take it for a fact that the parent is refusing to yield to an unreasonable request from the child and the child is stubbornly resisting.

The way to handle it is different in younger children, (usually less than five or six years of age) and the older ones .

- ▲ Younger kids mostly do not know “right from wrong” and can’t be reasoned with.
- ▲ This doesn’t mean one should give in to the tantrum.
- ▲ The best approach here would be to hug and pacify the kid , and gently, but firmly distract him and this will make him lose interest in what he was wanting and get involved in the new activity.
- ▲ Happy ending for all!
- ▲ With older ones, a more firm approach is needed. Stand your ground and tell the child that his demand is not right and there’s no way he will get it. Explain in a simple way, why he is wrong and what is the correct thing to do . If the child listens and stops the tantrum, hug and praise the child for being very smart and good!
- ▲ If he continues to be stubborn , then firmly put him in a corner of the room and tell him that he will remain in that corner and nobody will talk to him, till he stops the tantrum.

- ▲ The tantrum may increase immediately, but when he realises that he will not get what he is demanding, it will slowly reduce.
- ▲ Once you are sure that the tantrum is over, hug and praise again that he has understood that he was wrong and then engage him in a “happy” activity.

### **A few important things to remember:**

1. When you yield to a tantrum, you are basically teaching the child that if wants something, throwing a tantrum is a sure success! If you do so, you should be ready for more and more stubbornness and tantrums in the future.
  2. When one parent is setting the limits clear to the child, others in the family should not contradict and try to be the child’s advocate. Undermining the parent’s authority will teach the child to play one parent against the other and learn to “divide and rule”.
  3. Be consistent in the limits you have set for the child. Allowing a particular behavior at one instance and punishing the same at other times will confuse the child and he will not learn right from wrong.
  4. Verbally or physically abusing or threatening the child will not make the child understand that his tantrum is wrong. He would only think that he has not been understood and the parent is just being unfair.
  5. Praising the child and rewarding him with a positive and happy attention for stopping the tantrum is essential to shape the child’s behaviour for the future.
- And, lastly- Stop for a minute to think that the child may be right, and you may be the one who is placing an unreasonable order on him. Not at all wrong to hear the child out before you frame the rules!

### **2. Any medication to improve mental health?**

None exist. A healthy balanced diet with sufficient Omega 3 fatty acids is important. Good exercise, being actively involved in learning, and regular sleep have a positive impact on mental health.

### **3. Does teenage affect them same as Normal children?**

Yes. Same as it does anybody else. Parents have the responsibility to understand that their children are not bad, naughty, perverts etc and they are only figuring out more about themselves and the changes they are going through. Travel along with them, only being available to prevent them from major disasters.

### **4. Please elaborate on rise in cases of depression and regression in adults when they seem to lose out on all the learning in their lifetime in areas of life skills, socialization etc which is commonly seen.**

a. is self talk is normal or common in our children 2) how do we identify that my child showing signs of OCD (3)How to ensure that my teenager doesn't slip into depression



## **SPEECH THERAPIST**

*Dr. Sharanya Krishnan*

### **1. At what age should my child start talking?**

In general, communication in children begins in the form of babbling from around the age of six months and they say their first words between 10 and 15 months (most start speaking around their first birthdays). They then begin to pick up a number of words and start to combine them into simple phrases after 18 months.

### **2. My child can understand most of the things said to him but cannot talk verbally?**

It is NOT all about speech. Parents should be aware that from the earliest stages of language development, children understand more than they can communicate themselves. It is through this understanding that they build their own expressive vocabulary.

### **3. What should I expect during my first visit with a Speech pathologist?**

An evaluation is done by a speech therapist to assess your child's development. This assessment usually includes a standardized test, observation through play, medical history information, and parent report. The evaluation will help the therapist understand where the child stands with regard to language and speech skills. This will help in planning their goals and strategies for therapy.

### **4. How often does my child need to attend therapy?**

It is important that parents understand two things- One, presence and participation of the parent in the therapy session is very important in understanding the how and why of therapy strategies. Two, it is NOT necessary that you see your speech therapist EVERYDAY. Two to three days a week/ once a week depending on mutual convenience will suffice. You will need discuss and agree upon a frequency that works with your preference and lifestyle. What is important is carrying out all the activities given to your child by the therapist AT HOME.

### **5. How long does my child need speech therapy?**

It depends upon many variables like age of the child, amount of stimulation given at home and many more. Each child is different. Therefore, treatment can take a few weeks, a few months, or a few years. Therapy is a long drawn process that requires PATIENCE and PRACTICE.

### **6. When do I see a speech therapist for my child?**

As early as know that your child is having a delay, you MUST consult a speech therapist.

### **7. Will my child have a speech problem if we speak more than one language?**

No. Children who are exposed to many languages will say their first words at about the same age as those children learning only one language. Unless your child has a hearing/visual impairment you need not restrict language exposure.

### **8. Are Speech Pathologists and Speech Therapists the same?**

Yes!! The names are used interchangeably. (They hold a degree in Speech Language Pathology.)

### **9. My child can talk but his communication is not clear?**

Children with Down Syndrome commonly experience feeding and speech difficulties due to anatomical and physiological differences in their mouth area. These differences include a high arched palate, small upper jaw, bulky tongue with low muscle tone and weak oral muscles.

## DEVELOPING WRITING SKILLS - TIPS

*- Ms. Hemamalini Sowmithiri &  
Ms. R. Srilakshmi*



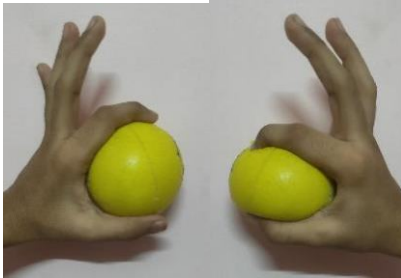
Finger Strengthening Exercises  
for Writing for children  
with Down Syndrome

Strengthening the intrinsic muscles of hand for hypotonia, involving thumb movements as it is used more in pencil grip for writing skill.

1) Make a fist – make a gentle fist by folding your thumb across the fingers



2) Ball squeeze – for grip strength, hold a soft foam ball and squeeze and hold for few seconds and release. Repeat for 10 counts.



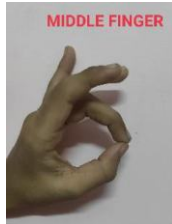
Pinch a ball - Pinch a soft foam ball between the tips of your fingers and your thumb. Hold for few seconds and release. Repeat for 10 counts.

3) Thumb sliding - Start with hand out in front, palm up. Thumb away from other fingers as far as possible. Then bend the thumb across the palm so it touches the base of small finger. Hold for few seconds. Repeat for a count of 10.





4) Thumb touch – Hold hand out in front of, with wrist straight. Gently touch the thumb to each of the four fingertips, one at a time, touching the tip making the shape of an "O.". Hold each stretch for few seconds. Repeat for a count of 10.



5) Thumb rotation (opposition movement) - Hold your hand out, with fingers close to each other except thumb. Rotate the thumb, diagonally direction to touch the base of the index finger.



## Activities related to finger exercises

- 6) Squeezing water out of a sponge.
- 7) Dropping coin in a coin box with pinch grasp between thumb and index finger.
- 8) Playing with dough / clay.
  - 1) Pop the bubbles on large or small bubble pack by pinching with thumb and index finger or by pushing down on bubbles when sheet is placed on a hard surface.
  - 2) Building towers with small Lego bricks.
  - 3) Playing with jigsaws & puzzles, develops pincer & tripod grasps.

# EFFECTIVE TECHNIQUES IN WRITING SKILLS



Pre-writing skills and  
adaptations for writing skills

compiled by  
**V S Hemamalini Special Educator  
and Srilakshmi Physio Therapist,  
DSFI, Chennai**

## Pre - Writing Skills



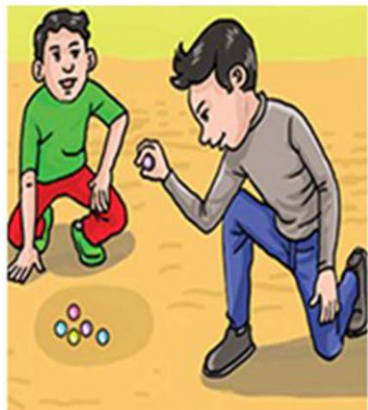
1. Use of two or one finger to squeeze a spray bottle



2. Spinning a top holding with thumb, index and middle finger.  
Note the elbow and body position



3. Roll a small clay ball with thumb and index fingers and place it.



4. Shoot marbles (complete hand mind and eye coordination)



5. Making pattern with index finger dipped in paint



6. Cutting a clay or a paper and also pasting the bits of paper

### **Transition from pre-writing to writing skills**

During the scaffolding stage - a caregiver need to sit behind the child to support their elbow enabling to function as desired.

For the skill of colouring within the lines, the pre-requisite will be the spatial awareness and hand control as part of the pre-writing skills.

# Writing Skills

## Important points to be noted before starting to write:

1. Identify the hand dominance
2. Ability of fingers to exert force
3. Steadiness of shoulders while writing
4. Awareness of letter and number formation (along with its name and sound)
5. Sensory processing in pencil control
6. Pressure applied on the surface mechanics
7. Pre-writing strokes formation
8. Stabilizing trunk and neck to maintain the posture and to ensure readiness.

Issue to be addressed	Suggested Adaptations
<b>Hypotonia at fingers leading to hyper-extension</b>	<ol style="list-style-type: none"><li>1. Use of rubber band or gripper for extra grip.</li><li>2. Use thick pencils/felt pens</li><li>3. Use wrist to pencil support</li></ol>
<b>Finger Isolation</b>	<ol style="list-style-type: none"><li>1. Use triangular pencils</li><li>2. Use socks for hand with three holes (for thumb, Index and middle finger)</li><li>3. Use soft pad to tuck in the ring and little finger</li></ol>
<b>Sitting in upright position</b>	<ol style="list-style-type: none"><li>1. Give a solid support to foot. Knee to foot at 90 degree</li><li>2. Flat seat with backrest</li><li>3. Writing desk at lower chest level</li></ol>

# **Towards Creating an Inclusive Tomorrow**



**[downsyndrome.in](http://downsyndrome.in)**