

Fundas of Parenting

March 2021

Greetings to all. As we enter into a new month, we are ready with the March issue of our newsletter.

As we all know, March 21 st every year is observed as World Down Syndrome Day. So this March issue, we have focussed on Down syndrome. Down syndrome was discovered as early as 1866 and thereafter, many advances have been made in the understanding and management of the disease.

With early antenatal diagnosis, the incidence of Down syndrome has decreased, with the current incidence of 1 in 850-900 live-births in India. The clinical presentation is variable, across the spectrum. However, children do face issues across all age groups. Currently, with the advanced medical management by specialists across all fields, there has been an increase in the life-span of children with Down syndrome. However, a lot more focus needs to be given with respect to improving their quality of life beyond the medical perspective.

This issue is to emphasise on the need to look beyond their medical issues, from a developmental point of view. Addressing issues which have a huge impact on their quality of life across all age groups, we have focussed on their development, socio-emotional thinking, adolescent changes and relationships, behavioural challenges, sleep and nutrition.

Each child needs an individualised care plan to help improve their quality of life, and to optimise their potential. Let us pledge to understand them better , nurture their abilities and make it an inclusive society to accept them as one among us.



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Over a course of time, we will be sharing knowledge on various aspects of child growth and development. As the previous year ends with a lot of despair, we hope this new year dawns great strength and builds more confident parents.

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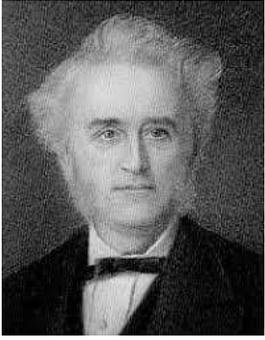
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DOWN SYNDROME- OVERVIEW

Down syndrome is the most common chromosomal abnormality and the most frequent form of intellectual disability. Down syndrome is characterised by a variety of dysmorphic features, congenital malformations and medical conditions affecting every system in the human body.



Brief history of Down syndrome

Down syndrome is named after Dr. Langdon Down, who in 1866 first described the syndrome as a disorder. Although Dr. Down made some important observations about Down syndrome, he did not correctly identify what causes the disorder. It wasn't until 1959 that scientists discovered the genetic origin of Down syndrome.

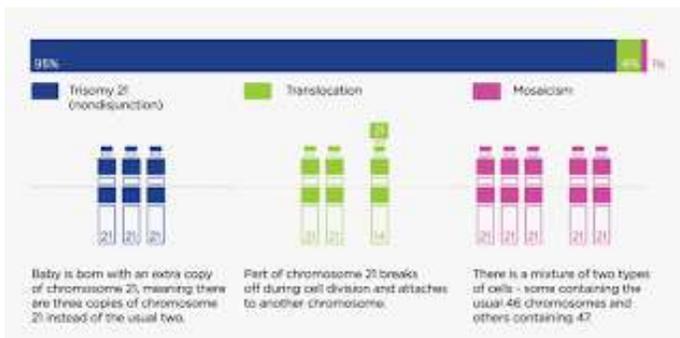
The clinical manifestations are quite variable, not all problems are present in every affected person. The impact of Down syndrome for each person is unique, some are profoundly affected whereas some are mild and able to live independently and are healthy. But Down syndrome causes varying degrees of intellectual disabilities in an affected individual.

What causes Down syndrome?

It is a chromosomal disorder, where a person has a full or partial extra copy of Chromosome 21. Typically, the nucleus of every cell in the human body contains 23 pairs of chromosomes, half of which are inherited from each parent. The additional genetic material alters the course of development and causes the characteristic features of Down syndrome.



What are the types of Down syndrome?



Down syndrome is usually caused by an error during the process of cell division called 'Nondisjunction', which results in the embryo having three copies of Chromosome 21. Prior to or at conception, a pair of 21st chromosomes in either the sperm or egg, fails to separate, due to which each cell in the body has the extra chromosome 21. This is the most common type of Down syndrome, called Trisomy 21, which accounts for 95% of cases of Down syndrome.

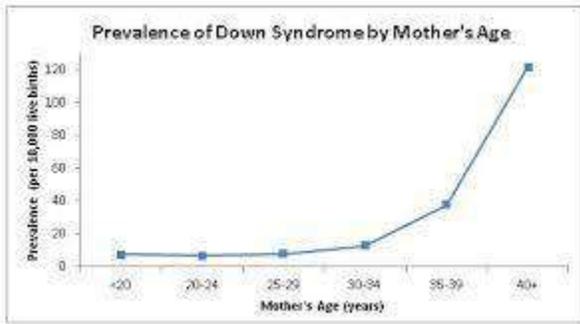
Translocation accounts for 4% of cases of Down syndrome, the total number of chromosomes in the cells is 46, but an additional full or partial copy of chromosome 21, attaches to another chromosome, usually chromosome 14. This extra full or partial chromosome 21 causes the characteristics of Down syndrome.

Mosaic Down syndrome is the least common of Down syndrome, <1% of Down syndrome, is diagnosed when there is a mixture of two types of cells, some containing 46 chromosomes and some containing 47, the cells containing 47 chromosomes contain an extra chromosome 21.

What are the risk factors for Down syndrome?

Down syndrome continues to be the most common chromosomal disorder, the incidence being about 1 in 700 livebirths. This number depends on many factors including maternal age, prenatal screening policies. This condition affects individuals across all social, racial and economic backgrounds.

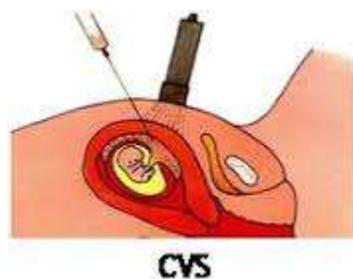
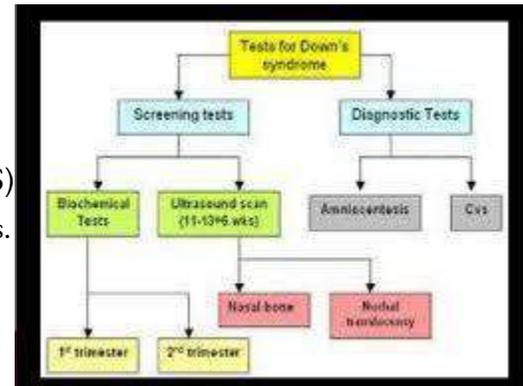
Advancing maternal age is a very well-known risk factor for Down syndrome. The risk increases from a 1 in 350 chance in a 35-year old woman to 1 in 100 by age 40 and approximately 1 in 30 by age 45.



It is important to diagnose Down syndrome early by screening tests, because in the absence of screening, the prevalence of Down syndrome is quite high. The burden of the disease for the family and individual can be significant. The success of prenatal screening lies in good, effective counselling of parents about the tests and its implications.

How is Down syndrome diagnosed?

Down syndrome can be diagnosed by prenatal tests: Screening tests and Diagnostic tests. The Screening tests are based on maternal blood tests and ultrasound testing can detect up to 95 percent of cases of Down syndrome. The definitive diagnostic procedures for the diagnosis of Down syndrome are chorionic villus sampling (CVS) and amniocentesis. These are invasive procedures and are very accurate for diagnosis. CVS is performed in the first trimester and amniocentesis in the second trimester. Prenatal screening and diagnostic tests for Down syndrome should be offered to women of all ages during early pregnancy.





After birth, Down syndrome is usually diagnosed in the neonatal period by the presence of characteristic physical features like flattened facial profile, an upward slant to the eyes, low muscle tone, a single crease in the palm, low-set ears, protruding tongue and short neck, short broad hands and hyperflexible joints.

Diagnosis can be made by chromosomal analysis, FISH and Karyotyping.



Down syndrome – facial profile.



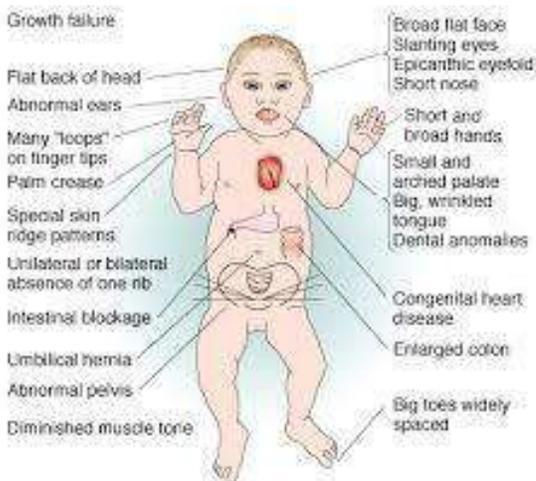
What are the problems associated with Down syndrome?

Down syndrome is the most common cause for intellectual impairment, almost all individuals have some degree of cognitive difficulties, varying from mild to severe.

This developmental impairment becomes apparent in the first few years of life, where all the milestones are delayed. For example, the average age of sitting is around 11 months and walking is about 26 months, approximately twice the typical expected age. The language development in children with Down syndrome is also delayed. Cognitive defects are also significant in Down syndrome

What are the medical conditions associated with Down syndrome?

Down syndrome affects every organ system in the body.



1. **Cardiovascular** problems occur in about 50% of individuals with Down syndrome. They can vary in severity from mild to severe. Septal defects are common in childhood and pulmonary hypertension is also common.
2. **Gastrointestinal** tract anomalies like atresia or stenosis, Hirschsprung disease and increased risk for celiac disease
3. **Ear** infections and hearing loss
4. **Eye** problems like cataracts, refractive errors, nystagmus
5. **Endocrine problems** like Hypothyroidism and type 1 diabetes
6. **Hematologic** problems like increased risk for malignancies, leukaemia, increased red blood cells and platelets

7. **Orthopedic** - Increased risk of atlantoaxial instability and hyperflexible joints
8. Impaired immune function, making Down syndrome more prone for infections, autoimmune disorders and malignancies
9. **Neurological** : Older individuals with Down syndrome have higher risk of developing dementia and Alzheimer’s disease
10. Obstructive **sleep** apnoea causing sleep problems in individuals with Down syndrome

A detailed and comprehensive management of the Down syndrome child is given by the Indian academy of Paediatrics on their website.

Can it be reversed and what is the role of intervention?

Down syndrome is a lifelong condition. Early intervention should be provided to children to improve their physical and intellectual ability. Speech therapy, occupational and physical therapy offered early will help children with Down syndrome to achieve their full potential.

The outlook for individuals with Down syndrome is improving with time. The average life expectancy has now increased up to 60 years, with more individuals leading more productive lives.



There has been a constant increasing awareness and support for parents and patients of Down syndrome which includes parent groups, internet resources like The Association for Children with Down Syndrome, National Down Syndrome Society.

There is an interview with Dr Aline Hunter, a pediatrician on world downs syndrome day 2019. She gives a brief outlook on downs syndrome and common parent questions. If interested, please go through the link: <https://cmmb.org/world-down-syndrome-day-interview-with-pediatrician-dr-aline-hutner/>

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GROWTH & DEVELOPMENT

DOWNS CHILDREN CHILD DEVELOPMENT

There is no such thing as a typical child with Down syndrome. Children with the syndrome are as different from each other as are all children. However, by and large, their development is slower than that of most children. The charts which follow give the usual developmental progress of children with the syndrome. By understanding what is usual for a child with Down syndrome you will be able to recognise any additional problems at an early stage.

Here is a gist of the milestones given in the Developmental Scale for Children with Down Syndrome by **Thomas L. Layton**.

Birth - 5 months

Typically developing children	Downs children
Reacts to sound	Reacts to sound occasionally
Turns head toward sound source	Turns head toward sound source
Watches face when parent speaks	Does not necessarily watch face when parent speaks
Vocalizes (coos, laughs, giggles, cries, fusses)	Minimal vocalization (cries, fusses)
Localizes sound source/speaker	Ceases sounds when talked too
Laughs when playing with toy	
Smiles at parent	

6-10months

Typically developing children	Downs children
Sits unsupported & Stands holding on	Sits with support
Understands some verbal commands (“no-no”, “sh”-quiet) & gestures (“come here”, “look”)	Comprehends “no-no”
Babbles (says, “ba-ba-ba”, “ma-ma”)	Does not babble until 10-12 months
Waves “bye” & Tries to communicate by action or gestures	Watches face when someone speaks
Comprehends 10-15words	Smiles at parent & Engages with parent
Recognized own name	Localizes sound source/speaker Comprehends less than 2-4 words No oral words & No signs

11-15months

Typically developing children	Downs children
Walks at 12 months	Comprehends 20 words
Comprehends 50 words	Tries to communicate by action or gestures
Produces less than 10 words	Stands holding on (at around 12 months)
Produces animal sounds	Understands some verbal commands (“no-no”, “sh” –quiet)
Recognizes family names	Understands gestures (“come here”, “look”)
Listens to simple stories	Waves “bye”
Responds to yes/no question	Limited use of manual signs
Brings object to show others	First oral word
Feeds others & imitates patting a doll	
Follows one step commands	

16-20months

Typically developing children	Downs children
Produces 10-15 words	Identifies by pointing
Produces familiar objects	Walks (at around 18 months)
Says own name on request	Seeks toy for appropriate play
Verbalizes “no”	Comprehends 40-60 words
Comprehends 50-100 words	Recognizes family names
Asks questions by raising intonation at end of phrase	Gestures and vocalizes needs
Points to toes, eyes, and nose	Points to objects and pictures
Acknowledges others by eye contact, responding, or repeating	Tries to repeat sounds 1-2 oral words & 1-2 signs

21-24 months

Typically developing children	Downs children
Comprehends 200-300 words	Comprehends 100-125 words
Produces 50 intelligible words	3-6 oral words
Beginning of two word phrases	10-15 signs
Begins to use some verbs and adjectives	Feeds others & Imitates patting a doll
Refers to self with pronoun	Follows one step command
Answers “where” and “what” questions	Gives toy or object on request
Carries out two stage command	Initiates vocalizations to others
	Imitates familiar sounds and actions
	Produces animal sounds
	Brings object to show others
	Acknowledges others by eye contact, responding, or repeating

For further milestone details refer <https://silo.tips/download/thomas-l-layton-phd>

ROLE OF EARLY INTERVENTION

- The first years of life are a critical time in a child’s development.
- All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, socio-emotional and self-help skills that lay the foundation for future progress, and these abilities are attained according to predictable developmental patterns.
- Children with Down syndrome typically face delays in certain areas of development, so early intervention is highly recommended.
- It can begin any time after birth, but the sooner it starts, the better.
- Early intervention is a systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome.
- The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, oro-motor stimulation ,occupational therapy and later on socio-emotional learning.
- Early intervention should begin any time shortly after birth, and usually should continue.
- This helps optimize the potential of the child.

Growth in children with Down syndrome

Growth in children with Down's syndrome (DS) differs markedly from that of normal children. The use of DS specific growth charts is important for diagnosis of associated diseases, such as coeliac disease and hypothyroidism, which may further impair growth.

There can be various influences on their growth.



Given below is the link for CDC growth charts for DS

<https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

It is crucial to monitor their growth and development right from birth to help optimize their potential. Growth chart is always a reflection of the child's health. This way it also helps us detect and treat the associated comorbidities early and follow up their overall health.

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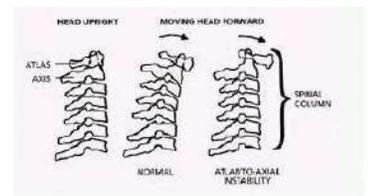
EARLY INTERVENTION IN DOWNS SYNDROME

Children with Downs syndrome are frequently referred for Physiotherapy as almost all of them suffer from motor developmental delay. Their physical development is characterised by:

1. Moderate to Severe Hypotonia
2. Increased joint mobility leading to poor joint stability
3. Abdominal weakness
4. Prominent extensor posturing (overusing upper back) leading to poor flexor patterns (forward bending)
5. Short neck leading to poor neck mobility and stability
6. Poor core strength leading to wide based sitting, standing and walking

When the diagnosis of the child is confirmed clinically, parents have to be advised regarding the clinical picture of these babies. Cautious handling due to poor joint stability especially of the atlanto-axial joint instability needs to be informed to the parents.

Although it is natural to have delayed milestones, early intervention can make a phenomenal difference in the quality and pace of motor development to make way for other aspects of development to hasten too.



Early intervention in Downs syndrome involves a combination of motor, sensory, oro-motor, visual and cognitive interventions.

Motor Intervention in Downs Syndrome involves positioning, facilitation of early reflexes, inhibition of prolonged infantile reflexes, gentle range of motion based exercises and simple stability based strategies.

Sensory interventions are aimed at exposing the baby to different forms of touch-based, movement-based and body position based stimuli to invoke natural processing of the stimuli.

Oro-motor interventions involve stimulating in and around the mouth and tongue to facilitate natural oro-motor movements and functions. Early oral-motor intervention like oral massage, lip approximation activities helps in better feeding and early motor speech development.

Visual and cognitive interventions are incorporated in our interactions with the baby to help them engage and interact with their environment.



Most babies with Downs Syndrome are cheerful and motivated by play and can be engaged in therapeutic activities actively. They would require long term physiotherapy for improving core strength, abdominal participation in maintaining their posture, balance training, lower limb and upper limb strengthening. They would continue to need assistance in attaining higher motor milestones like running, jumping and other forms of play. They would need assistance with motor coordination, fine motor skills and motor planning skills.

Children with Down Syndrome often present with persistent chewing difficulties due to low tone in the cheek muscles and poor tongue control. They need oro-motor interventions to facilitate good chewing and swallowing of food. Oro-motor interventions will also help the babies control oral behaviours like drooling, mouthing of objects and frequent tongue protruding behaviours. They would need prolonged speech therapy to improve clarity of speech.

Down syndrome is often accompanied by gastrointestinal disease, occurring mainly in early infancy and frequently requiring therapy. Early diagnosis of gastroesophageal reflux in these babies can prevent respiratory problems, nutritional deficiencies in childhood and growth retardation.

Positional and mobility based interventions help in managing the symptoms of GERD in babies and help them in prevention of pain, heartburn and frequent vomiting.



Early and consistent interventions can help babies with Down Syndrome attain optimal levels of functioning and improve their quality of life drastically.



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DOWN SYNDROME AND SLEEP

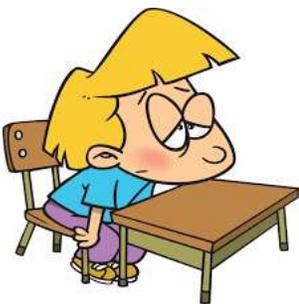
Sleep disorders are very common in individuals with Down syndrome and are often overlooked. They are present in more than 50 percent of individuals with Down syndrome.

They have obstructive sleep apnea (OSA), a condition where a person's normal breathing is interrupted due to multiple factors like large tongue, soft tissue abnormalities, low muscle tone. Symptoms include snoring, mouth breathing, frequent awakenings and intermittent restless sleep.



The brief periods of lack of oxygen during this episode is a significant cause of harmful effects on the development of the child.

OSA can cause excessive daytime sleepiness, difficulties in concentrating during school, inattention, learning problems and behavioral problems like hyperactivity, aggressive behavior, impulsivity. This can lead to a diagnosis of attention deficit hyperactivity disorder (ADHD).



All children with Down syndrome should be evaluated carefully for sleep related problems. This includes a good history and physical examination to rule out adenoid hypertrophy.

Pulse oximetry to determine oxygen saturation and Sleep study (Polysomnography) should be done in all children with Down syndrome at 4 years age and followed up regularly.

Medical management includes providing positive airway pressure, intranasal steroids, orthodontic treatment. Weight loss and environmental control measures like avoiding tobacco smoke and indoor pollutants, maintaining good position during sleep, supplemental oxygen, breathing exercises are also helpful measures to handle sleep problems in children with Down syndrome.





Surgical treatment options include removal of adenoids and tonsils(adenotonsillectomy) and reconstruction procedures of the nasal and oral airway and should be done after consultation with a multidisciplinary team that includes ENT surgeons, Facial-maxillary surgeons & Plastic surgeons.

Individuals with Down syndrome can have sleep problems due to physical causes and behavioral causes. Sleep problems due to behavioral causes can include sleep initiation difficulties and sleep maintenance difficulties. Both can cause problems in behaviour, learning and can cause worsening of cognitive abilities.

Behavioural sleep problems can be addressed by good behavioural modification, like establishing a good sleep routine, improving the physical environment, rewarding good sleep time behaviour. A combination of the above along with positive reinforcement of desirable behaviour and extinction of undesirable behaviours can help in successful establishment of good sleep routines.



Maintaining a sleep diary and regular monitoring is helpful in identifying sleep related problems and remedial measures can be initiated early.

Sleep related problems are often under-recognized and hence left untreated. There are many online resources for parents regarding sleep issues in Down syndrome.

Ensuring a good quality of sleep in Down syndrome individuals will go a long way in helping them to lead a happy and productive life.

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SHAPING SOCIALLY ACCEPTABLE BEHAVIOUR

Social reasoning lays foundation for the development of social skills and appropriate social behaviour. Social reasoning refers to the ability to analyse and reason about social situations in relation to social rules. In simpler words, it is the ability of the child to judge one's own and others' intentions and emotions, understanding social cues & selecting appropriate behavioural response to a situation. In a typically developing child & adolescents there is linear improvement in social reasoning from 6 to 20 years of age. This plays an essential role for the child's pro-social-oriented behaviours (sharing, cooperation & empathy), allowing for successful interpersonal relationships and being inclusive in the society.

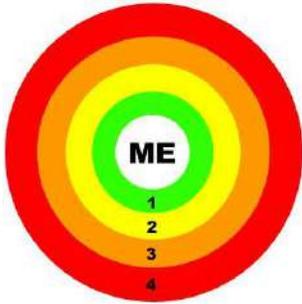
For children with Down Syndrome, because of their cognitive delays, they have difficulties in judging appropriate vs. inappropriate social behaviours and reasoning out the process of social rules. Hence, to help them overcome these deficits, we need to teach them social reasoning abilities in a way & pace they can understand.



How do we help Downs syndrome children develop these?

- Children learn through observing and imitating others and by making associations between behaviours and their consequences.
- This means that for children to learn socially acceptable behaviour they need to see other people acting in a socially acceptable way and they need to be rewarded for their 'good' behaviour and ignored for their less acceptable behaviour.
- This implies that it is the other people in the child's social world who need to carefully monitor their own behaviour and responses in order to help the child to behave appropriately.
- If, for example, you are teaching your child about appropriate physical contact with other people, it is important that the child is taught how to greet people in a socially acceptable way, e.g. shake their hand or just say 'hello'. They will need to see this modelled to them on a regular basis.
- Many parents comment on their frustrations as people continue to cuddle their older children and teenagers with Down syndrome, long after it would be socially acceptable to cuddle other people's typically developing children. This type of behaviour does not help the child to learn that it is inappropriate to greet people in this way.
- With older children, overt teaching about different types of relationships (such as family, friendship, school/work teammates and strangers/new people) will be helpful and part of this work might involve discussion of how you would greet such people and what sort of touch is appropriate.
- Teaching methods such as the use of social stories and social learning may be helpful for training in many areas.

Circle Concept and Relationships



In Preparation for teaching this important safety concept, take a picture of your child and take pictures of the following people in your child's life :

- 1 Family members and close friends (first circle)
- 2 Casual friends, acquaintances, classmates and teammates (second circle)
- 3 Doctors, teachers, social workers police officers and store clerks where you regularly shop (third circle)
- 4 Strangers (fourth circle)

“Circles and Relationships” approach to address this concern.

1

1. What are some of the feelings we have for family and close friends?

Love , trust, enjoying each other's company, dependability

2. How do we act around family and close friends?

We share personal thoughts with them

We share personal feelings with them

We trust them

We want to be together with them

We talk with them when we're upset

3. How do you touch the people in the first circle?

Handshakes, hugs, brief hugs, kisses(cheeks) , hand holding, hand on shoulder

2

1. What are some of the feelings we have for casual friends and groups we are part of?

Like, trust, enjoying each other's company, feeling of fun

2. How do we act around casual friends and groups we are part of?

We are friendly with them but we are not friends with them

We do not share personal information with them

We do not share personal feelings with them.

We feel comfortable around them but not close to them

3. How do you touch the people in the second circle?

Handshakes, high fives , first bumps

3

1. What are some of the feelings we have for helping professionals?

Friendliness, appreciation

2. How do we act around helping professionals?

We are friendly with them but we are not friends with them

We might share personal information with a doctor, teacher, social worker or police officer.

We feel comfortable around them but not close to them

We are glad we have helpers like doctors, teachers, and police officers

3. How do you touch the people in the third circle?

Handshakes, waving

4

1. Can you think of some places where you might see strangers?

On the bus or subway, on the street, in a store

2. How do we act around strangers

Be polite, but be cautious

3. How are strangers different from other people?

Some are nice and some are not nice. We just don't know.

Some strangers may offer you a ride in their car.

Some strangers may want to buy you things

4. How do you touch the people in the fourth circle?

Usually there is not touching. When you are introduced to as a stranger by someone you know and trust, then you can shake the stranger's hand (but only if you want to)

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BEHAVIOURAL CHALLENGES IN CHILDREN & TEENS WITH DOWN SYNDROME

Like any other typically developing children, children with Down syndrome also experience a wide range of emotions while attaining their developmental milestones. They try to express themselves differently when they are trying to adapt to the given situation. They tend to face a lot of different kinds of challenges while doing so.

Some of the major neurological conditions that they are prone to are:

1. Limited ability to process information from the outside world while learning particularly auditory information. (it is known that, children with down syndrome have very good photographic memory which can be considered and worked upon as their strength)
2. Decreased level of intrinsic / self-motivation
3. Problems with executive functioning
4. Poor cognitive ability due to Intellectual Difficulties

A significant proportion of children with Down syndrome (20-30%) have coexisting diagnosis such as ASD, ADHD and /or behaviour disorders, OCD and generalised anxiety (Capone et al. 2006) which may include selective mutism.

The above challenges in Down syndrome is a concern because as we all know and agree that, these difficulties will not fade away over time but in turn may get worse if not addressed at the early stage and can predict possible challenges in their future.

These problem behaviours will have a negative impact on their safety, learning, mental health, social life, inclusion, academics, family relationships, work setting and finally the overall quality of independent life.



Positive Behaviour Support strategies which helps us to identify the functions of child's unwanted behaviour, guiding him or her to communicate needs verbally or by using any other alternative methods, following structured routine, rewarding positive behaviour immediately, allowing them to have choice, skill building etc helps them to overcome some of the challenges to some extent.

Now let us try to list our challenges faced by these individuals at different stages of their lives and possible strategies to address them at the earliest:

- **At birth to toddler stage:** due to inadequate neurological support these children will have poor health conditions, delay in developing overall milestones leading to anxiety in both parents and children.

Their parents should approach professionals as soon the baby is diagnosed with Down syndrome, enrol them in early intervention program focused on overall development which include physiotherapy, Infant stimulation therapy/ sensory integration therapy and speech therapy which will help them to attain their milestones. As mentioned earlier, they have very good photographic memory so the visual schedules, consistency in parenting, positive support behaviour strategies would reduce possible development of challenging behaviour in them.



In young and early school age children: due to limitations in language and communication skills, poor cognition and problem solving abilities children with Downs syndrome might have behaviour problems. Interventions like special education, speech therapy & occupational therapy helps in addressing their deficits and improving their skills.



- ❖ Look for comorbidities and address comorbidities to avoid behavioural problems
- ❖ Increases in terms of disruptive, impulsive, inattentive, hyperactive, restlessness etc, could be due to ADHD coexistence.
- ❖ Being anxious, showing inflexible behaviour may be arising due to generalised anxiety and obsessive compulsive disorders.
- ❖ Chronic sleep difficulties leading to sleeping in school hours, feeling fatigue due to sleep deprivation etc leading to mood related problems.

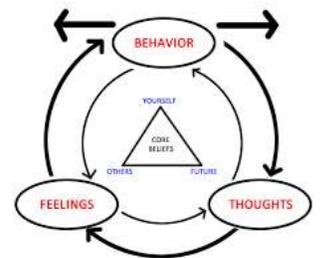
Positive Strategies to address behavioural problems:

- Having structured environment
- Using appropriate visual aids to know their schedules & predict consequences
- Social stories to teach appropriate social behaviour - explaining social rules that guide social interaction
- Social skills training to help them pick up relevant cues to support detection of social information and providing a coherent explanation of social situations that involve taking into account others' perspectives and feelings.
- More academic accommodation in school setting
- Bringing awareness about their difficulties in society

would help children with Down syndrome to face life with more confidence that may decrease challenges in them.

Adolescent, teens and adult stage: due to coexisting conditions like ASD, ADHD, OCD and sleep disorders, people with Down syndrome tend to have increased challenges in their presentation. We need to understand and be empathetic with them.

- Discuss his problems with him and his family and friends, provide multidisciplinary support - include professionals like counsellors, social workers, vocational skills trainer, health workers and psychiatrists in the team.
- Show them respect and respect their privacy, encourage them to have friends with similar interests
- Increasing their independence in self help skills and life skills will bring self-confidence and motivates them intrinsically.
- Maintaining structured routine & encouraging independence in following their routines - support such as written instructions to follow/visual reminders/ checklist to improve their organisational skills helps
- Token economy strategy to support positive behaviour
- Vocational skills training & consistent feedback on their best performance, little bit extra supervision and involving them in group activities and decision making, having realistic expectations will improve their employment skills
- Medications for comorbidities if needed will help them to have peaceful and successful independent lives.



Mrs. Savitha B S
 Special Educator, CCDD
 Msc Child Psychology,
 DSE (Autism), C/LD, MRCI

LET'S TALK PUBERTY

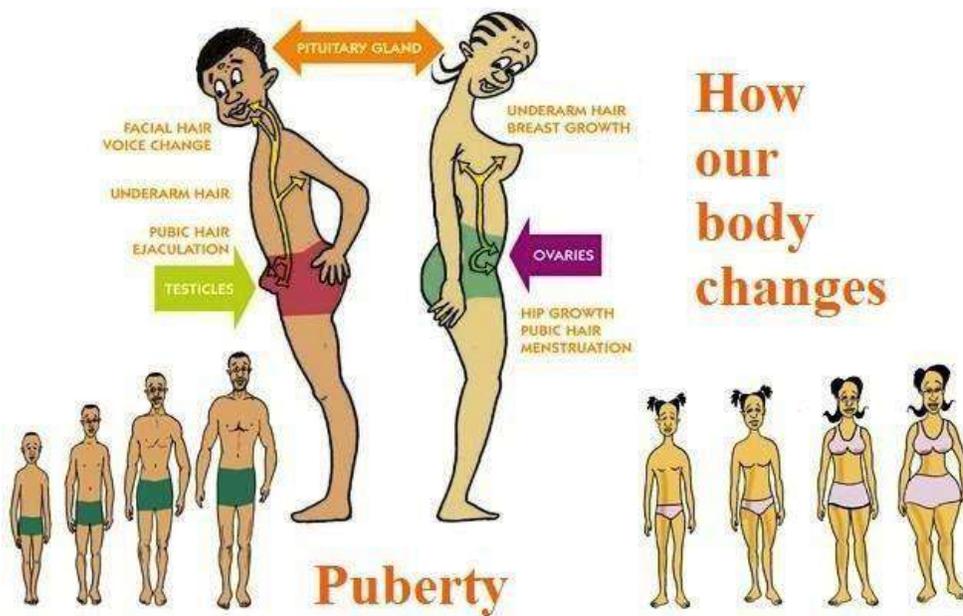
Puberty is a transition from childhood to adulthood. It is an important phase in a child's life. The changes of puberty is not just to the body, it includes social, emotional and sexual development too. For some puberty is smooth, not for all, especially with children with developmental delays. The child could go through a turbulent phase during puberty. Support provided by parents and awareness on what to expect during puberty makes a difference. Keeping aside the specific needs of a special needs child for a while, let us look into what is the development that happens to the child's body.

In girls, it starts with maturation of the ovary around 10-14 years.

In boys, release of sex hormones starts with maturation of testes. (11-13 years)

Physical changes In general

- # growth spurt (increase in height)
- # oily skin
- # oily hair
- # increased perspiration and body odour



In girls

- Breast development
- Growth of pubic hair / underarm hair
- Vaginal discharge
- Starting of menstruation

In boys

- Growth of penis and testes
- Growth of pubic hair / facial hair / underarm hair
- Sperm production starts
- Start of erection and ejaculations
- The voice break

Emotional changes

- This is the phase in which every child tries to figure out who is he/she and what matters to them
- Tries to fit in the group
- Goes through self judgment and evaluation
- Seeks for approval and appreciation

Preparation for the transition in puberty

1. Puberty & related changes

For girls

- Around the age of 6-8 years, the mother can start sharing her menstrual experience in simple language. Don't keep it as a secret. You can bring this in conversations like "hey, today i have my periods, can we play badminton tomorrow?" "Tell them what happens, not as a scary thing but as a natural development of being a woman. Let the child know, every woman has this "menstruation" as a normal development.
- Next, when you start seeing growth spurt and other developments in your child, it is time to have one to one conversation with the child. You can use pictures/ books/videos to explain what is happening to the body and what to expect next.
- Introduce concepts of Privacy- private body parts(chest/breast, genitals) & private vs. public places & rooms. Teach the rule & also model to your child- always private body parts must be covered and if a dress has to be removed/changed it has to be done in private rooms (bedroom/bathroom) by closing the doors. Child must also be modelled to ask anyone in the room to leave outside (please go out- to Dad too) before exposing their private parts.
- Even before they start menstruating, show them how to use and dispose of sanitary napkins. Provide hands on support in using napkins until the child learns to be comfortable in using and disposing of it
- Give a clear picture about what they should be doing when they get their first periods. Whom should they approach if it happens outside the home environment. Explain things in simple language or pictures / social stories. Consistent exposure and teaching according to their pace of grasping really helps.
- Also it is important to teach the child to communicate pain / discomfort during menstruation and what to do for pain - like home remedies the child can seek for etc.
- Pain relief management with medications to be done with expert guidance if required.
- Preparation to puberty prevents a lot of imagined fear and concerns for the child. When prepared, they can handle it.

For Boys

- Helping your son go through puberty is mostly about reassuring. Explain to him how his body is developing into a young adult- the changes in size of penis, testes, hair growth. Tell him ejaculation during sleep (wet dreams) and spontaneous erection are both normal.
- Kids with special needs go through the same process. Limited communication is the constraint here. The child can be prepared for puberty. Teach them about private parts and handling of private parts to be done only inside a closed private room. Teach them the hygiene aspects (washing hands, wiping genitals with toilet paper) after handling private parts. Social stories can help a lot.
- Be open to listen to the child regarding his sexuality or attraction to opposite sex. Let them know, it is not wrong.
- In the current era of online classes, children may get curious about age restricted videos. Have a conversation with them - a child can't drive a car below 18 years for obvious reasons which most of the children can relate to. Sexual content - though it is not wrong, has an age limit for the child's well being.

Things to avoid !!!

- # treating puberty as shameful / something wrong .
- # being secretive about puberty and leaving the child to discover on his own
- # presenting puberty as a painful process to go through

2. Handling personal hygiene.

Hygiene is an important component of peer acceptance, especially when your child starts puberty.

- You can help your child by establishing a daily routine to regularly tend to hygiene needs, such as showering or bathing and using deodorant.
- Start exposing your teen boys to shaving while his father is doing, gradually it can be introduced as part of his routine

- When mothers do waxing (underarms) ,include your daughters in this routine. Gradually let the teen understand removing unwanted hairs (arms, legs, underarms, genitals) is part of the hygiene routine.
- Help the child to groom themselves (Combing hair, dressing up) in a socially acceptable manner (matching with their age appropriate peers) & encourage independence.

3. Sexual activity and pregnancy.

Children with Down syndrome usually enter puberty and experience the related physical changes about the same time as other adolescents. But sexually developed teens with Down syndrome often do not have the same understanding of physical boundaries and are vulnerable to being sexually abused. Help your child avoid abuse by teaching him or her appropriate concepts of privacy, expected private behaviours and assertive behaviors

- Provide your teen with sexual education at a level he or she can understand.
- This should include ongoing discussions about love, mutual regard, kindness, and how to develop friendships.
- Your teens must know the importance of consent to touch another person's body or have someone touch them & how to keep them safe and be assertive .Teaching methods such as the use of social stories and using the circle of trust concept may be helpful for training in this area. The concepts can be introduced gradually & consistently ,at a pace your child can grasp.
- Take help of experts (gynaecologists) to prevent pregnancy
- The ability to love and feel loved, to keep safe and know how to protect to oneself physically and emotionally stems from our self-esteem . We build this knowledge from an early age and therefore our early experiences in the home will shape our development.In fact, parents are the best ones who can start to build the foundations for their child's positive transition into adult life.

So as parents-

Being Open

Being Prepared

Being Reassuring really helps

LET'S TALK PUBERTY

Compiled by :

Dr Sudha. S M.D (OBG)

Consultant Gynecologist



QUIZ TIME

Below is a quick question session.

We have made a few statements regarding down syndrome. They need to be answered if they are **true or false**.

1. Increasing Paternal (father's) age increases the risk of Down's syndrome.

- a) True b) False



2. Antenatal diagnosis can pick up Diagnosis of downs syndrome almost always.

- b) True b) False



3. Early intervention can improve the overall functioning of the child.

- a) True b) False



4. Developmental milestones may or may not be delayed in a child with downs syndrome?

- a) True b) False



5. Risk of downs syndrome increases with a previous child with downs syndrome?

- a) True b) False

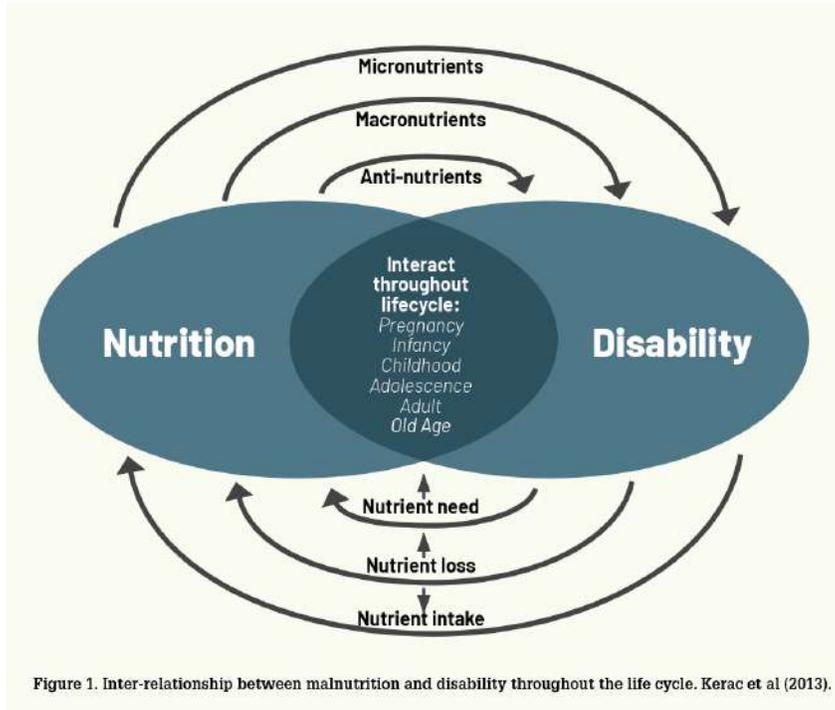


Answers:

1. True 2. True 3. True 4. False 5. True

NUTRITION & RESPONSIVE FEEDING

Down's syndrome is a genetic disorder caused when abnormal cell division results in an extra, full or partial copy of chromosome 21. This extra genetic material causes developmental challenges.



Down's syndrome and nutrition related issues can be: -

- Obesity/ overweight
- Altered Gastrointestinal (GI) functions, like constipation, celiac disease.
- Infections
- Hypothyroidism
- Nutrient deficiency
- Heart diseases
- Inadequate oral intake due to swallowing difficulty

Children with Down's Syndrome (DS) might have eating and drinking difficulties which may be because of abnormalities like smaller oral cavities, low muscle tone and larger tongue caused by a high arched palate. Infants can have difficulty in sucking, swallowing and breathing during feeds which leads

to nutritional deficiencies, delayed brain development and decreased immunity. Medical nutrition therapy along with oral motor exercises to strengthen oral motor muscles plays a major role in meeting the nutritional requirements.

WEIGHT ISSUES

It is important to design a calorie-controlled diet plan to effectively intervene obesity in children with DS. This is generally done with a diet plan based on calories per height in centimeters. Children with DS tend to increase their weight because they have decreased resting energy expenditure and tend to have less physical activity

Calorie requirements in Down's syndrome are:

Boys (5-12 years) – 16.1 kcal/ cm ht.

Girls (5-12 years) – 14.3 kcal/ cm ht.

Proteins should be based on actual weight.

In order to implant healthy eating habits in a child, special care has to be taken about consistency of food, texture, palatability and flavors. Along with a calorie controlled diet, structured physical routine (walking/cycling/swimming) as a family routine must be implemented to prevent obesity.

RESPONSIVE FEEDING

"Babies express their cues when they are hungry and when they are full" - learning and responding to their cues by the caregiver is called Responsive Feeding.

“YOU PROVIDE AND YOUR CHILD DECIDES”

Growth and development are rapid in the initial years of life and the experiences babies get with food in the early age, sets them up on healthy eating patterns later on in life. Setting up a feeding schedule makes it more likely that the child will be hungry at meal times.

It is common to encourage the baby to eat more, but ignoring their fullness cues can lead to unhealthy eating habits and lead to obesity. Trust their feeding cues. Feed the child the right food for their age and stage. Let the child stop when they are full.

Cues babies show when they are hungry can be like, moving their hand to mouth or grab food and put it in their mouth, feeling excited seeing food or leaning towards food or even crying (there can be many reasons for a child to cry and hunger is one of them, crying does not always mean that the child is hungry).

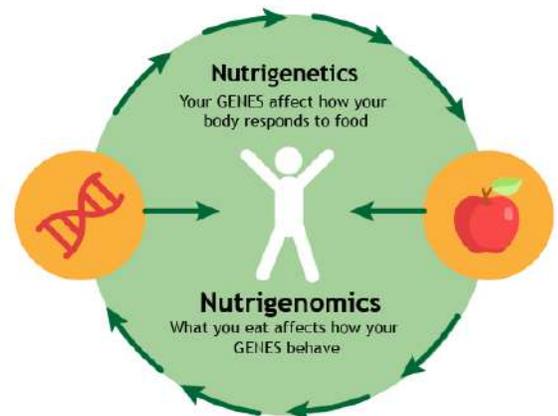
When they are full, they start ignoring food, get distracted, close their mouth, play around with food or spit out food.

Assisting and encouraging the child to eat by themselves is important but what is more important is to not force feed them, which helps in creating a healthy environment and positive feeding experience. Babies have the ability to self-regulate their eating when they are full. It is ok if the child eats only one food from a plate with many options. Let them choose what and how much to eat. Encourage responsive feeding from young age to prevent obesity in your child.

GENETIC VARIATIONS

Proteins, carbohydrates and fats are the macronutrients which need to be served in an ideal ratio, thus sparing proteins for growth and development. It is important to understand how one’s body reacts to a specific food and optimize them accordingly.

“UNSUPERVISED DIETARY RESTRICTIONS CAN AFFECT THE CHILD’S GROWTH, DEVELOPMENT AND BONE HEALTH”.



CONSTIPATION

Low muscle tone, lesser intake of fiber and fluids, low activity levels are the major reason for constipation. Fiber containing foods like fruits, whole vegetables, whole grains, have to be included.

Fiber requirement: -For children above 3 years is 5-6 grams /year of age/day.

For adults: - 25-30gms/day.

CELIAC DISEASE

Celiac disease is a condition in which, body becomes sensitive to a protein called “Gluten” and is caused by a reaction to “Gliadin” (a peptide which is a component of gluten) and damages the “villi” (small finger like projections) found along the wall of the intestinal mucosa. Gluten is a protein found in wheat, barley, oats and rye. This occurs in genetically susceptible individuals. When villi are injured, Intestine cannot absorb the other nutrients from food, leading to malnourishment, loss of bone density, and other health issues.

Manifestations observed: Diarrhea, abdominal pain, vomits, constipation and abdominal distension.

Nutritional interventions: Gluten free diet has to be followed. Foods like rye, barley, oats, wheat, have to be avoided. Reading labels is extremely important. Stay safe from cross contamination.

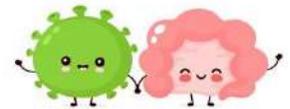
INFECTIONS

Probiotics: These are useful bacteria which play an important role in gut health. They help in the prevention of many lifestyle diseases like immunological disorders, obesity and heart diseases.

Curd and fermented foods are good sources of probiotic foods.

Prebiotics: Prebiotics are plant fibers that help probiotics grow in your gut.

Both prebiotic (foods like fruits, vegetables, whole grains) and probiotic foods (fermented foods like curd) help in gut health and preventing infections.



HYPOTHYROIDISM

This is a state of not making enough thyroid hormone, which is commonly seen in DS. This can be present at birth (congenital), or may occur later in life (acquired).

Manifestations observed: Weight gain, tiredness, high cholesterol levels, vitamin-D deficiency.

Nutritional interventions: Providing adequate nutrients to the thyroid gland for its optimal functioning by including iodine and tyrosine (amino acids) in diet which can be found in eggs, bananas, carrots, strawberries, whole pulses and dairy products.

The other nutrients needed by thyroid gland are vitamin-B complex, Vitamin C, Vitamin D and manganese.

Avoid eating processed and packaged foods, as they contain a lot of sodium, which disturbs the sodium-potassium balance in the body and interferes with iodine absorption.

Cruciferous vegetables like cabbage, cauliflower when well-cooked can be eaten occasionally.

NUTRIENT DEFICIENCIES

It is important to consume all nutrients in the right balance. Below table lists the food sources for different types of nutrients.

<i>Nutrient</i>	<i>Food sources</i>
Vitamin-A	Yellow and green color fruits and vegetables, like carrot, carrot leaves, drumstick leaves, amaranth, spinach.
Vitamin-C	Citric fruits and vegetables, gooseberries, lemon, oranges, guava, papaya, drumstick leaves, bitter gourd, capsicum. Vitamin-C maximizes the absorption of iron in the body.
Vitamin-D	Food sources are limited and available in small amounts from eggs. Ghee boosts the absorption of vitamin-D. Vitamin-D allows the body to absorb calcium.
Vitamin-E	Vegetable-oils, seeds and nuts, spinach, broccoli.
Vitamin-K	Cauliflower, cabbage, kale, spinach, mustard greens.
Choline	Sea food, apples, pumpkin, beets, green gram, cowpeas, apples.
Vitamin-B1	Nuts, oil seeds, liver.
Vitamin-B2	Green leafy vegetables, beets, carrots, eggs, liver, papaya, Colocasia leaves.
Vitamin-B3	Mutton, pomfret, sardines, peas, beans, nuts and oil seeds, rice flakes.
Vitamin-B5	Mushrooms, cauliflower, peanuts, liver.
Vitamin-B6	Sunflower seeds, yeast, walnuts, brown rice.
Vitamin-B8	Nuts.
Vitamin-B9	Green leafy vegetables, eggs, gingelly seeds.
Vitamin-B12	Liver, shrimp, meat, eggs yolk, fermented foods.
Manganese	Green gram, nuts, dry coconut, finger millet.
Omega-3 (DHA, EPA, ALA)	Human milk, avocado, walnuts, eggs, salmon, tuna, sardines.



Mrs A.S Lakshmi ,
 Clinical dietitian,
 Certified Lactation professional
 Maternal and child nutritionist.

Raising Rakshikaa...

PARENTAL PERSPECTIVE !

Blessed. Grateful. This is all I can say about having Rakshikaa in our lives. Yes, in spite of all the struggles we had, it has been an amazing journey. From the day she was born, till date – she has been a fighter and a winner.

Delayed milestones? Yes. Compromised immunity? Yes. Challenges with speech? Yes.

But, as parents, we have seen her zoom through everything with a grace. And as parents, we have been fortunate to have the front-seat view of these 7.5 glorious years. With her grit and a smile so vibrant, she has raised the bar in everything she has done so far. And in the process, has brought a lot of serene and priceless moments...that has made our lives awesome. She has always instinctively known when it's her time to do something and waited until then. She has always refused to attempt things until she is ready and when she decides to go for it, she has never left a second to doubts...until she mastered it.

This has been the story in everything - walking, running, jumping, cycling and speech. All we had to do was wait when she said No and support and encourage her attempts when she said Yes. She was walking with her cycle for eleven months and one fine day she said”mummy, kekka sit” and she took two straight weeks to comfortably ride.

I have always believed the child chooses the parent. And I have trusted her choice and never doubted that I might not be able to meet her needs. Every time there was a need, I have either known instinctively or been guided by other people...at the right time to the right place. Of course, in spite of everything, parental anxiety was also a part of the roller-coaster ride.

For me, she is the daughter I have always dreamed of. At birth, her father said, “Downs or no Downs ...she is my daughter and she is our responsibility”. The next person we informed was our friend, from whom the ‘same-microsecond’ response was “so what?” Accepting her diagnosis was something we could credit ourselves for. We never went into the “why me?” route. This sort of set the tone for the rest of the family, friends, school and community. She has not been discriminated against because of her disability - apart from a few children who had questions about the delays. To be perfectly honest, we have had a few incidents of non- inclusion - but they have not been the norm. Most of the time, she was included and received with love and joy.

We have lost count of the amazing people she has brought into our life making it richer and better. Professionals have become mentors and friends for life. Strangers have become family. We wouldn't have known any of them otherwise.

She has disproved doctors, amazed therapists, surprised teachers, mesmerised friends and connected to total strangers. I have seen her say “thank you” to a cow who moved away to give her walking space on the road. I have seen her go hug another mother in a big crowded hall who said “With that hug, your daughter wiped off all the sadness I had come with to this room. I needed it today”.

I have seen her with experts who appeared both delighted and confused that she doesn't fit the label she's tagged with. I have seen her with friends radiating such joy and walk away with grace if she doesn't fit in. I have seen her make instant connections with those individuals who are beautiful human beings.

Our little bundle of joy has changed a lot of lives already including ours. She has made us laugh and cry, driven us mad, pushed us to despair. But she has led us through all these and made miracles happen. And has thrown in a few life lessons for us too.

Fair enough to say that she turned our world upside down. But, we find, the world is wonderful when it's upside down too.

Yes, she looks different.

And she is different

- ❖ In the love that's unconditional.
- ❖ In the spirit that's unshakeable.
- ❖ In the smile that's illuminating.
- ❖ In the life that's resplendent.

She has touched many lives with her love. But never hesitated to say a well-defined yes or no. She usually chooses what she wants in life. And we have let her do that. I have seen her make many perfect choices. Lots of love and freedom to choose has made life perfect.

Down the years, I am sure she would say "Yes, I have Down syndrome. So what?" And I know she will go about changing the world in her own little ways.

Mrs Shiva Priya

Parent

SANGAMITRA

An intervention centre, located in Sahakar Nagar ,Bangalore It offers holistic programs for ASD, ADHD, LD and Down Syndrome children. Early detection and intervention is very important especially with Down Syndrome as they'll function better and will be successfully integrated into the society. Early Intervention entails a program of therapies and activities. At Sanghamitra we nurture the child, with non judgemental stimulation and help the child to reach their full potential.



PROGRAMMES OFFERED:

- Physiotherapy and Sensory Integration
- Occupation therapy– Gross and fine motor skill development
- Speech lab
- Self management skills
- Academic based skills
- Art and craft
- Preschool
- Kimochi– Social and Emotional development program
- Behavior management
- Reading and writing
- Music therapy
- Sports and games
- NIOS– Level 1

Along with an array of programs we conduct training programs, workshops and seminars and emotional counselling for the parents. The main focus is to prepare the child to be independent physically, emotionally, with self confidence to seek admission to regular school.

Contact person- **Vyjayanthi**

Contact numbers

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INSPIRATIONS - DOWN SYNDROME SOCIETY

Most people associate Down syndrome only with intellectual disability. Some equate it to Autism. Still others generally are not even aware that such a condition exists. Sadly, the most common genetic disorder in the country with 1 in every 800 live births being persons with DS remains an unknown entity in the country even today.

That was the beginning of Dr. Surekha Ramachandran's journey to help as many people with Down syndrome in the country as possible. Thus, began the **Down Syndrome Association of Tamilnadu (DSAT) and the Down Syndrome Federation of India (DSFI)**- to spread awareness amongst people about this condition and how persons with Down syndrome can lead as normal lives as possible with a little extra effort from the parents, siblings, friends and community at large.

The founder of DSFI and DSAT - Dr. Surekha Ramachandran



Dr. Surekha Ramachandran has been a visionary as far as Down syndrome in India is concerned. When Babli Ramachandran, her daughter was diagnosed as a person with Down syndrome she refused to cow down before doctors who gave Babli no hope. Inspired by her struggles, she decided to help more parents like her and more children like Babli to lead as near-normal lives as possible.

Dr. Ramachandran, decided to help others like herself get the best solutions possible. Therefore the center became a place where all the help, as in, the guidance of specialists, allied health

professionals and therapists were brought under one single roof.

Being very passionate about Down syndrome and the importance of early intervention for people with Down syndrome, Dr. Surekha Ramachandran took a Ph.D in Cognitive Deficits and Depression in Down syndrome at University of Madras. Having travelled all over the world, Dr. Ramachandran has kept herself abreast of the developments in the dynamically changing scene of Down syndrome.

Down Syndrome Federation of India (DSFI) and Down Syndrome Association of Tamilnadu (DSAT) DSAT and DSFI are organizations that offer support to individuals with Down Syndrome and their families through various Down syndrome Institutions across India. The Federation has managed to create a Parent Support Group in almost all states. This has helped parents not only connect with each other but also connect to the support system of Doctors, Therapists and other allied service providers

Established in the year 1984, with 6 children, DSFI today serves innumerable children not only around India, but also the Middle East. Dr. Surekha Ramachandran has been a constant source of support and encouragement for people who are unable to come to terms with Down syndrome. Her services include counseling distraught families, training children to overcome their shortcomings, providing therapy, and spreading awareness about Down syndrome.

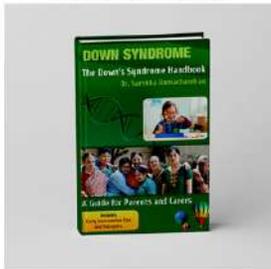
Books of Dr. Surekha Ramachandran

Dr. Surekha Ramachandran has inspired many families to cope up with Down syndrome, with love and care. She has always emphasized the need for inclusive living for these individuals with Down syndrome. She has written three books - “With love from Babli - A child with Down’s Syndrome - (A Referral Guide), Life starts at Sixteen - Down’s Syndrome” and Down but not Out – Babli’s story. All these books are an inspiration for parents and people who deal with Down syndrome. They are a simple insight into ways of making people with DS feel as much a part of society as anybody else.

Downsyndrome Parents Guide ebook



The Down's Syndrome handbook - ebook



Down but not out - Babli's Story



Nutrition Booklet for Downsyndrome Children



IIDSC – India International Down Syndrome Conference

IIDSC was started to ensure that individuals with Down syndrome in India are appreciated, integrated into society, and given the right opportunities to lead rewarding lives by providing information, networking opportunities, and encouragement.

This event brought together all stakeholders in the field of Down syndrome to bring about a positive change in the lives of persons with Down syndrome in our country.





At the UN

On the occasion of World Down Syndrome Day that falls on the 21 st of March every year, Dr. Ramachandran spoke about Down syndrome and Genetic culling, a topic that had never been discussed in the UN General Assembly. With her emphasis on inclusion, she received appreciation for bringing out this topic in the open. Like a true champion for the cause, she spoke for the rights of persons with Down syndrome to lead normal inclusive lives.

She has ensured that the voices of persons with Down syndrome also be heard by

taking along with her self-advocates who speak at the UN on the occasion about their hopes and aspirations.



Vocational Training

Vocational Training is a part of Dr. Ramachandran's plan to assist persons with Down syndrome to become independent. Keeping this in mind, the center has a Baking unit, a weaving unit and a unit for other handicrafts. Experts train these individuals and also help sell these articles. She has also helped children with Down syndrome in places like Kozhikode and Kathmandu with looms and training.

Lockdown Phase

During the lockdown while everything seemed closed and all hopes seemed lost, the Federation was there to provide support to parents and persons with Down syndrome. Through various online sessions, online courses and online consultation, the lockdown phase was a breeze. A special section called Art Bazaar was opened to highlight the art work of

persons with Down syndrome. It was a marketplace where talent was brought to the fore. The lockdown was effectively handled in such a way that parents did not feel the ill-effects of lockdown on the children to such a large extent.

HOME *ArtBazaar*
for persons with Down syndrome



DSFI as an organization is looking to support not only individuals with Down syndrome, but also their families. The core aim is to help integrate our children into this society and make our society a vibrant inclusive one.



FEEDBACK

We are delighted to share the feedback we received for the February edition of the newsletter. It gives us immense pleasure to see parental response to feeling empowered with knowledge and able to make a difference to their child. Here are some of the reviews from our dear colleagues, parents and caregivers.

- This is an awesome newsletter. Fundas. Practical and easy to read
- Awesome work by Dr Nandini and team! So much of hard work has gone into this. More Power to knowledge.
- As a parent we are always looking out for the best for our child. This is an amazing newsletter with so much knowledge and Fundamentals
- The newsletter is quite comprehensive. Looking forward for more.
- This is amazing work. Thank you team for sharing.
- Fantastic work. Congratulations to all the contributors and the editorial team.
- As much I enjoyed reading the articles, my kids enjoyed the activities.
- As a parent we are quite clueless about how are children are actually learning many a times. Beautifully written on learning and stages.
- This newsletter is flooded with knowledge. A must read for every parent.
- Thank you team FUNDAS for the wonderful work. The saying Knowledge is power holds us on to this. Much power to u all for all the efforts to empower parents, and help us be better at it.

For any support or query kindly write to us at support@totsguide.com We would love to hear from you'll about this edition too!

