

DOWN SYNDROME

The Down's Syndrome Handbook

Dr. Surekha Ramachandran



A Guide for Parents and Carers

Includes
Early Intervention Tips
and Therapies.





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The Down's Syndrome HANDBOOK

A Guide for Parents and Carers

Dr. Surekha Ramachandran has set up a centre in Chennai called **Down syndrome association of Tamil Nadu** where children with Down syndrome are offered a wholistic developmental programme and integrated into normal schools wherever possible.

Today, parents of Down syndrome children need not despair like Dr. Surekha Ramachandran did, seventeen years ago, for they can get their all the information at the centre. Dr. Surekha Ramachandran exhorts that Down syndrome children need to receive early intervention as early as possible for the best results, and incidentally, all this is offered, free for the under privileged.

Mere words cannot describe this intrepid lady. She has created an oasis in the desert of ignorance. For the benefit of mankind, she runs the rehabilitation centre, so that parents of Down syndrome children do not face the difficulties she had to face. She has provided this **Down's Syndrome Handbook** as a guide for Parents and Carers, which includes Early Intervention Tips and Therapies.



A Foreword By Shri C. Subramaniam
Philosopher, Statesman, Philanthropist
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What is Down Syndrome ?



These 7 exceptional people share one common condition...they were all born with Down Syndrome. However, there the similarity ends. They come from very different backgrounds and upbringing. They have been determined not to be typecast by the others as a result of their outward appearance or by the label of this particular form of learning disability. All of them are high achievers. This has come as a result of hard work by the families and enlightened professionals. They have set an example that many could follow. Today, we live in a world that offers people with Down Syndrome many opportunities than ever before.



[Indelible - The Film \(India's Official Film For The World Down Syndrome Congress\)..](#)

Down syndrome is a naturally occurring chromosomal arrangement that has always been a part of the human condition, being universally present across racial, gender or socio-economic lines, and affects approximately one in 800 births worldwide, causing intellectual and physical disability and associated medical issues.

Down syndrome, is a condition that is present at birth, which affects the body's physical and mental development.

While no two people with Down syndrome are exactly alike, they do share some common physical features. Babies with Down syndrome have similar facial features, tend to have lower muscle tone, and typically learn to walk and talk slightly later than other children.

A person with Down syndrome typically has a slightly small head that is flattened in the back; up-slanted eyes; extra skin folds at the inner corners of the eyes; small ears, nose and mouth; short stature; small hands and feet...and some degree of intellectual disability.

Normally, a child inherits two copies of chromosome 21 - one from each parent. If a child inherits an extra chromosome 21, the child will have Down syndrome. Because Down syndrome usually affects every cell in the body, people can have a variety of medical problems. For example, about 40% of children with Down syndrome are born with a heart problem. This can range from a very small hole between two heart chambers to a very large hole that requires surgery.

Is there a cure?

No, but the medical complications associated with Down syndrome can be treated and managed. Treatment for Down syndrome is specific to an individual's needs. For example, a child or adult may need heart surgery to correct a heart defect.



Should you have a test for Down syndrome?

Anyone can have a baby with Down syndrome. You might like to know, during the pregnancy, if your baby has Down syndrome. The most recent ACOG (American College of Obstetrics and Gynecology) guidelines say that prenatal screening for Down syndrome should be offered to all women - not just women over age 35. There are two categories of tests:

- 1) **Screening tests** try to identify babies that might have Down syndrome, but these tests cannot tell for sure, they can only tell if your baby is at increased risk of Down syndrome. Screening for Down syndrome should occur before the 20th week of pregnancy. Screening tests include:
 - Second trimester (serum) screening (sometimes called a “triple screen” or a “quad screen”) to check for certain substances in the mother's blood.
 - First trimester screening (early ultrasound and serum screening).
 - Second trimester ultrasound.

- 2) **Diagnostic tests** used to be offered mainly to women who will be over age 35 at delivery, who received an abnormal result on a screening test, or who are anxious due to a prior pregnancy. The newest ACOG guidelines recommend that all pregnant women, regardless of age, should have the option of diagnostic testing. Diagnostic tests require a sample of cells from the fetus. Tests include:
 - Chorionic villus sampling (CVS), usually performed between 10 and 12 weeks, involves taking a sample of chorionic villus cells from part of the placenta that contains fetal cells.
 - Amniocentesis, usually performed after 15 weeks, requires the removal of fetal cells from the amniotic fluid that surrounds the baby. In both cases, the cells are sent to a lab for analysis.



Congratulations on the birth of your baby !



If your baby is healthy, her needs will be just like other babies. You don't need to be doing anything different or special at this stage. We know that it can be difficult at first to see past the Down syndrome to your baby's individual personality.

Take time to listen to her, get to know her and enjoy her. A loving secure environment is the most important thing that you can give your baby at this time.

New parents are often concerned that their baby will miss out if they are not immediately providing some form of regular stimulation. We understand this feeling, it is very natural, but, don't be hard on yourself. **Give yourself time to adjust to your new baby, interact with her. The rest can come later !**

FREQUENTLY ASKED QUESTIONS

Q: How have doctors made the initial diagnosis of Down syndrome?

A: Doctors make an initial diagnosis because of the way a baby looks. If a collection of certain physical characteristics are present, an initial diagnosis of Down syndrome is made (e.g. floppiness due to reduced muscle tone, flat facial profile and nasal bridge, a small nose, eyes that slant upwards and outwards)

Q: Is the initial diagnosis of Down syndrome ever wrong?

A: It is extremely rare for a chromosome test to subsequently show normal chromosomes after an initial diagnosis has been made.

Q: My baby doesn't have many of the physical characteristics of Down's syndrome, does this mean that the learning disability will be less?

A: There is no connection between the absence or presence of certain physical characteristics and the level of a person's learning disability.

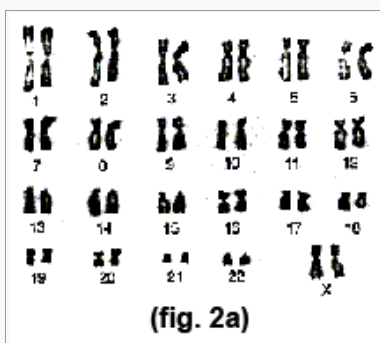


Q: How do doctors make a definite diagnosis of Down's syndrome?

A: Because not everybody with Down syndrome share the same physical characteristics and because the physical characteristics exist in the general population (singly rather than as a collection), a sample of the babies blood needs to be taken for chromosomal analysis. The picture of the baby's chromosomes, which shows the extra copy of chromosome 21, is called a Karyotype.

Q: What causes Trisomy 21?

A: Chromosomes are thread-like structures composed of DNA and other proteins. They are present in every cell of the body and carry the genetic information needed for that cell to develop. Human cells normally have 46 chromosomes that can be arranged in 23 pairs. Of these 23, 22 are alike in males and females; these are called the "autosomes." The 23rd pair is the sex chromosomes ('X' and 'Y'). Human cells divide in two ways. The first is ordinary cell division ("mitosis"), by which the body grows.



In this method, one cell becomes two cells that have the exact same number and type of chromosomes as the parent cell. The second method of cell division occurs in the ovaries and testicles ("meiosis") and consists of one cell splitting into two, with the resulting cells having half the number of chromosomes of the parent cell. So, normal eggs and sperm cells only have 23 chromosomes instead of 46. This is what a normal set of chromosomes looks like (fig.2a). The test in which blood or skin samples are checked for the number and type of chromosomes is called a karyotype.

Down syndrome, also called Trisomy 21 is the most common cause of mental retardation and malformation in a newborn. It occurs because of the presence of an extra 21st chromosome. Each person inherits 23 chromosomes from their mother and 23 chromosomes from their father. Sometimes an accident occurs and one of the parents gives an extra chromosome.

The extra chromosome could have come from either parent - so, neither the mother nor father should carry any 'blame' for their child's condition. When the extra chromosome happens to be chromosome number 21, Down syndrome occurs (fig.2b).



Q: Does Down Syndrome Run in Families?

A: All 3 types of Down syndrome are genetic conditions (relating to the genes), but only 1% of all cases of Down syndrome have a hereditary component (passed from parent to child through the genes). Heredity is not a factor in trisomy 21 (nondisjunction) and mosaicism. However, in one third of cases of Down syndrome resulting from translocation there is a hereditary component - accounting for about 1% of all cases of Down syndrome.

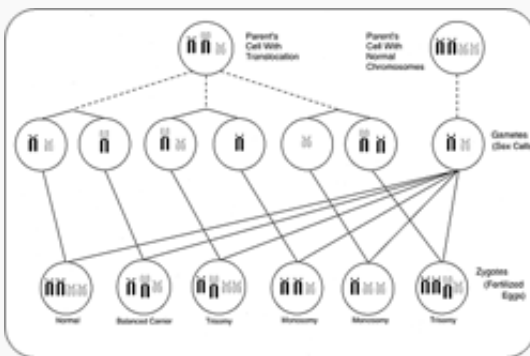
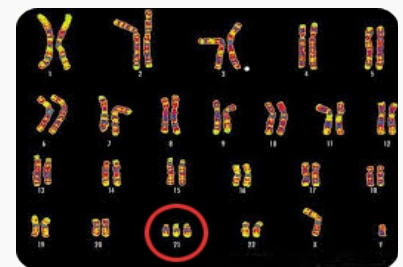
The age of the mother does not seem to be linked to the risk of translocation. Most cases are sporadic - chance - events. However, in about one third of cases, one parent is a carrier of a translocated chromosome.

Q: What Is the Likelihood of Having a Second Child with Down Syndrome?

A: Once a woman has given birth to a baby with trisomy 21 (nondisjunction) or translocation, it is estimated that her chances of having another baby with trisomy 21 is 1 in 100 up until age 40. The risk of recurrence of translocation is about 3% if the father is the carrier and 10-15% if the mother is the carrier. Genetic counseling can determine the origin of translocation.

Q: What are the different types of Down Syndrome?

A: Trisomy-21: The vast majority of children with Down syndrome (approximately 95 percent) have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, the individual with Down syndrome has 47 chromosomes. These children may only have triplication of part of the 21st chromosome instead of the whole chromosome, which is called a Trisomy 21.

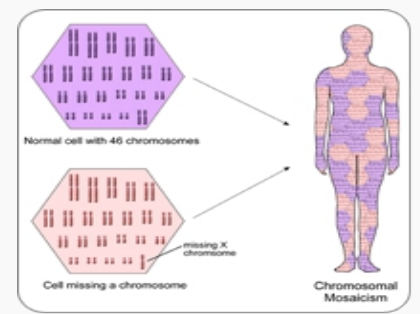


Translocation: Three to four percent of all cases of trisomy 21 are due to Robertsonian Translocation. In this case, two breaks occur in separate chromosomes, usually the 14th and 21st chromosomes. There is rearrangement of the genetic material so that some of the 14th chromosome is replaced by extra 21st chromosome.

The extra 21st chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21 or 22. Translocations resulting in trisomy 21 may be inherited, so it is important to check the chromosomes of the parents in these cases to see if either may be a "carrier."

Mosaicism: The remainder of cases of Down syndrome (one percent) is due to Mosaicism. In this case, some cells have 47 chromosomes and others have 46 (normal) chromosomes. Mosaicism is thought to be the result of an error in cell division soon after conception.

In cellular mosaicism, the mixture is seen in different cells of the same type. In tissue mosaicism, one set of cells, such as all blood cells, may have normal chromosomes, and another type, such as all skin cells, may have trisomy 21.



Q: Is Down Syndrome contagious?

A: Down Syndrome is not contagious. It is not a disease, and cannot be cured by medicine or surgery.

Q: What are the characteristic of people born with Down Syndrome?

A: Although not all Down syndrome infants share the same distinguishing physical characteristics, some may have traits to a larger or lesser degree. A preliminary diagnosis can usually be made at birth just by looking at the baby. If the attending physician suspects Down syndrome, a karyotype - a blood or tissue sample stained to show chromosomes grouped by size, number, and shape - will be performed to verify the diagnosis.



The most familiar physical traits of Down syndrome include:

- Low muscle tone (muscle hypotonia).
- Flat facial profile, including a somewhat depressed nasal bridge and small nose.
- Upward slant to the eyes (oblique palpebral fissures).
- Abnormal shape and small size of the ears (dysplastic ears).
- Single deep crease across the center of the palm (simian crease).
- Excessive ability to extend the joints (joint hypermobility).
- Fifth finger has one bending joint instead of two (dysplastic middle phalanx).
- Small skin folds on the inner corners of the eyes (epicanthic folds).
- Excessive space between large and second toe (sandal gap).
- Enlargement of tongue in relationship to size of mouth.

Children with Down syndrome can exhibit these traits in varying degrees. In addition to the characteristics above, half of the children born with Down syndrome have congenital heart defects. **The majority of these defects can be corrected, resulting in long-term health improvements.**

Children with Down syndrome also tend to have increased susceptibility to infection, respiratory problems, eye problems, thyroid dysfunctions, obstructed digestive tracts (early in infancy), and childhood leukemia. **Recent medical advances have made most of these health problems treatable,** however, and people born with Down syndrome now have an average life expectancy of 55 years.

While children with Down syndrome continue to acquire physical and mental skills throughout their lives, their ability levels vary considerably. In general, their average rate of progress will be slower than ordinary children. Because speech may also be delayed, careful attention should be paid to a child's hearing. Retention of fluid in the inner ear is a common cause of hearing and speech problems.

Q: How can Down syndrome be prevented?

A: Although there is no way to prevent Down syndrome, there is less than a 1% chance (depending on the age of the mother) that parents who have a child (or other relative) with Down syndrome will have another baby with the same genetic abnormality.

When there is an increased risk because of a mother's age (35 years or older) or a history of genetic defects in a family, parents may want to use screening and diagnostic tests.

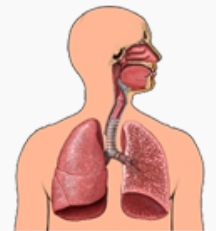
Q: What are the common Health and medical issues?

A: Some health problems are more common among people with Down syndrome than among the general population. However, given knowledgeable and well-resourced medical care, most of these can be successfully treated or managed.

Virtually all of the health issues that occur in people with Down syndrome also occur throughout the wider population. Therefore, general advances in medical care for all children and adults have also benefited those with Down syndrome. General medical advances and equal access to them are the main reasons for the increased life expectancy observed for people with Down syndrome in developed countries.

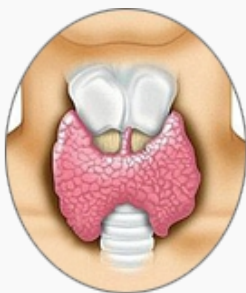
Infections :

Respiratory infections are more common among people with Down syndrome, especially during the first five years of life. Infections of the skin and the bladder also tend to be common. There is evidence that people with Down syndrome have this increased susceptibility to infection because their immune systems have some abnormalities, though the mechanisms involved remain unclear.



Heart defects :

Heart defects occur in around 47% of individuals with Down syndrome and 10 to 15% of babies with Down syndrome have a severe heart defect that requires surgical intervention during the first few months of life. The ability to repair major heart defects has had a major impact on infant survival for children with Down syndrome in countries with appropriate facilities and expertise.



Thyroid :

Thyroid disorders are more prevalent among individuals with Down syndrome. The exact extent and mechanisms of thyroid abnormalities, effective screening regimes and treatment approaches remain an area of active research and debate.

Once diagnosed, hypothyroidism can be simply and effectively treated, though this treatment and further monitoring is required throughout the individual's life.

Hearing :

Up to 80% of children with Down syndrome experience hearing loss, sometimes severe. Even mild hearing loss will lead to difficulties in speech and language development. A number of factors have been identified as contributing to hearing loss among people with Down syndrome, including increased incidence of chronic ear diseases, partly due to anatomical differences and also exacerbated by weaker immune systems. Common problems include wax in the external ear canal, conductive loss due to 'glue' in the middle ear, middle ear infections and sensori-neural hearing loss.

Hearing is vital for mental development and learning, especially for the development of speech and language and social skills. Although a mild hearing loss is not usually considered serious in other children, it may have a significant effect on learning for children with Down syndrome.. Hearing loss will also interfere with the accurate perception and subsequent production of speech sounds. In other words, hearing loss will delay vocabulary acquisition and compromise clear speech.



A variety of interventions are now available to treat or ameliorate the effects of hearing loss. Where children are having difficulty learning to talk because of hearing loss, signing may also help.

Vision :

People with Down syndrome are more likely to experience vision disorders such as short sightedness, long sightedness and astigmatism. They are also more likely to have squints and to experience delays in developing effective focusing, depth perception and sharpness of vision. Many of these problems can be corrected to give good vision with the use of spectacles.

Oral Health Problems :

People with Down syndrome have no unique oral health problems. However, some of the problems they have tend to be frequent and severe. Early professional treatment and daily care at home can mitigate their severity and allow people with Down syndrome to enjoy the benefits of a healthy mouth.



Sleep disturbance :

Studies have reported a high incidence of sleep disturbance among children and adolescents with Down syndrome. Poor sleep can lead to behaviour problems and impair learning. Unfortunately, we do not understand enough about diagnosing or treating sleep problems in children with Down syndrome.

Hypotonia (poor muscle tone) :

Poor muscle tone and low strength contribute to the delays in rolling over, sitting up, crawling, and walking that are common in children with Down syndrome. Despite these delays, children with Down syndrome can learn to participate in physical activities like other children.

Early Intervention of Downsyndrome and Therapies.

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, social 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 anytime 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 - with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children.

The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.

Physiotherapy

Children with Down syndrome want to do what all children want to do, they want to sit, crawl, walk, explore their environment, and interact with the people around them. To do that, they need to develop their gross motor skills. Because of certain physical characteristics, which include hypotonia (low muscle tone), ligamentous laxity (looseness of the ligaments that causes increased flexibility in the joints) and decreased strength, children with Down syndrome don't develop motor skills in the same way that the typically-developing child does.

They find ways to compensate for the differences in their physical make-up, and some of the compensations can lead to long-term complications, such as pain in the feet or the development of an inefficient walking pattern.



The Goal of physical therapy for these children is not to accelerate the rate of their development, as is often presumed, but to facilitate the development of optimal movement patterns. This means that over the long term, you want to help the child develop good posture, proper foot alignment, an efficient walking pattern, and a good physical foundation for exercise throughout life.

Occupational Therapy

When your child is an infant, your immediate concerns relate to his health and growth, development of the basic motor milestones, social interaction with you and others, interest in things going on around him, and early speech sounds and responses.

At this stage an OT may become involved to:

- **Assist with oral-motor feeding problems** (this can also be addressed by Speech Pathologists). Due to hypotonia and weakness of the muscles of the cheeks, tongue and lips, feeding is difficult for some infants with Down syndrome. OTs suggest positioning and feeding techniques, and can be involved in doing feeding studies, if necessary.
- **Help facilitate motor milestones, particularly for fine motor skills.** Occupational therapists and Physical therapists work closely together to help the young child develop gross motor milestones (eg: sitting, crawling, standing, walking). OTs work with the child at this stage to promote arm and hand movements that lay the foundation for later developing fine motor skills. The low muscle tone and loose ligaments at the joints associated with Down syndrome are real challenges to early motor development and occupational therapy can help your child meet those challenges.

Speech & Language Therapy

Most children with Down syndrome learn to speak and will use speech as their primary means of communication, they will understand language and have the desire to communicate well before they are able to speak. Total communication, using sign language, pictures can serve as a transitional communication system.

Parents are the primary communicators interacting with their babies and young children; thus, parents can do a great deal to help their children learn to communicate. Many of pre-speech and pre-language skills are best learned in the home environment. To help their children develop those skills, parents should:



- Remember that language is more than spoken words. When they are teaching a word or a concept, they should focus on conveying meaning to the child through play or through multisensory experiences (hearing, touch, seeing).
- Provide many models. Most children with Down syndrome need many repetitions and experiences to learn a word. Adults should repeat what a child says and give him or her a model to help reinforce a word.
- Use real objects and real situations. When teaching a concept, parents can use daily activities and real situations as much as possible. They can teach the names of foods as their toddler is eating, names of body parts while bathing the child, and concepts such as under, in and on while the child is playing.

Communication is part of Daily Life.

- Read to their child. They should help their child learn concepts through reading about them, field trips in the neighborhood and daily experiences.
- Follow their child's lead. If a child shows interest in an object, person or event, parents should provide him or her with the word for that concept.

There are many milestones as the child progresses toward using speech. The child responds to a familiar voice, recognizes familiar faces, experiments with many different sounds, produces strings of sounds over and over and makes a sound to refer to his or her parents (dada, mama).

Many children enjoy looking in a mirror, and increase their sound play and babbling when vocalizing in mirrors. Effective ways to work on these skills at home can be learned through early intervention sessions, through books, workshops and speech and language professionals.

If you are struggling with your child's speech development then please have a look at the following website to give you some tips. It has even got worksheets which you can print. [Mommy Speech Therapy](#) Hope it helps.

Using Everyday Activities for Language Teaching :

It's important to use simple language and familiar phrases. The following are some ideas on how you can utilize daily routine activities to encourage your child's language development.

- 1) **Washing:** You could play with a doll at bath times and as you wash the child's face he/she could do the same to the doll. Ask the child to wash his/her face and hands etc. and encourage him/her to tell you what you are washing.
- 2) **Dressing:** Place his/her clothes out in the morning and ask him/her to find her socks, shirt, trouser etc. and once he/she has selected an item correctly, tell him/her to put his/her trousers on, socks on, etc. Encourage him/her to name the items of clothing. Perhaps when you have asked your child to select one, try asking him/her to tell you what he /she is going to put on next.
- 3) **Mealtimes:** Lay the table, talk about the knives, forks, spoons, plates and ask him/her to put them on the table, perhaps saying whose spoon it is e.g. "that's mummy's spoon-put it in mummy's plate." Encourage him/her to name the cutlery. Talk about the food that you are going to eat and encourage him/her to make a choice between the items if possible. Use simple language, "eat potatoes up", and "dinner all gone".
- 4) **Housework and washing up:** Talk about what you are doing and how your doing it and encourage the child to describe what your doing and ask him/her what your going to do next.
- 5) **When on an outing:** Point out the things of interest and get him/her to talk about them, e.g. if you see a bus, a big bus, a red bus, a cat, if you meet people talk about them.
- 6) **Bedtime:** When getting undressed ask which clothes is he/she going to take off, talk about them as he/she takes off and whether they are going to be washed or worn again. Talk through his/her bedtime routine. Bedtime is also very good time for having a story.



Reading :

The invaluable gift of books : I introduced books to my daughter at an early age. She is two years old now and already has some favourite books. Infact, I make it a point that when I read a story to my 5 year old son, I always have Shreya around.

Even though some stories are longer and books have smaller prints for Shreya but she learns a lot from the pictures. For example, it is thanks to the many Dinosaur stories that I have read to my son that Shreya can identify a Dinosaur and even loves to roar like one.



One of the most important activity to assist a child's language learning from the first year of life, is reading books together. Books provide pictures to help you to teach new words and ideas but they also give practice at sentences. As you read even short stories you are using grammatically correct sentences with expression and intonation. Favourite stories are read over and over, allowing your child to learn from the repetition. Stories in books provide another opportunity for learning in a situation of emotional warmth, closeness and sharing enjoyment of the story together.

Please find time to read with your baby and young child daily. If you can, join a library. Your child will probably have preferences, but it is an idea at first to choose books that are not too long and have clear simple pictures.

To help maintain your child's interest in reading here are some suggestions:

- Choose books that have large print and colourful. Interesting illustrations.
- Follow your child's lead and interests. Let him choose books.
- Make visits to the library a regular part of your weekly routine.
- When your child has a favorite library book, purchase the book for your own home library.
- Choose books with thick pages that your child can turn himself.
- Make reading a special time. Try not to have interruptions. Sit in a favorite chair.
- Children love repetition. If your child asks you to read the same book again and again, read that favorite book.
- Read dramatically with expression and show that you are enjoying reading with your child.
- If your child points to a picture or a word, follow his lead and talk about it.
- Point to the name of the object on the book, then point to the picture that represents the object.
- In addition, you could try asking him/her to point to people, events or activities in the pictures.
- Many children with DS enjoy books about activities they can do themselves.

After you finish reading a paragraph or a page, ask questions. Ask your child to show you who is jumping or where is the character going. Have him point to the pictures in the book that answer the questions. If your child cannot answer the question give him the answer. Remember, you are reading with him and teaching him, not testing him. Emphasize the important word in your question "WHERE is Ravi going?" Once you have given answer on several different occasions, try providing cues instead of giving the answer. You might have the initial sound of the answer or give the phrase that will help your child say the answer. For example, say "J" or "He ate the bread and" to stimulate the word "jam".

You can teach vocabulary from books but do not do this instead of reading the story together or your child may miss out on the pleasure of the story, and the flow of the language as the story is read.

Happy Reading !!

Parents Can be the Best Therapists.

General Tips that Parents should keep in mind when working with their child during Therapy.



Children with Down syndrome have a unique learning style, and we need to understand and respect it -

- Determine what motivates your child.
- Treat it as a game.
- The quality of time you spend practicing the skills is much more important than the quantity.

Toilet Training Children with Down Syndrome.

Determining A Child's Readiness :

1. Many parents are eager to start a toilet training program for their children. However, some parents may be ready to start before their children are ready.
2. Starting before a child displays the necessary readiness signs will most likely increase the amount of time it takes for the child to learn this skill as well as decrease the amount of success he or she child experiences.
3. Starting too early can also lead to other problems, such as an increase in undesirable behaviors related to toilet training and high frustration levels in the parent. To ease the toilet training process and ensure that it is a positive experience for everyone involved, it is recommended that parents assess their child's toilet readiness skills.

Important signals of readiness are as follows:

- **Age** - The child has reached an appropriate age. It is recommended to wait until after the second birthday to begin considering toilet training. For children with Down syndrome, it has been found beneficial to wait until after the third birthday to begin the process. While age is an important component of readiness, parents should consider other factors as well when considering toilet training.
- **Bladder Control** - The child completely empties his or her bladder and remains dry for at least one and one half hours during the day.
- **Predictable Stooling Patterns** - The child's bowel movements follow a regular and predictable pattern.
- **Motor Skills** - The child demonstrates the abilities to walk to and from the bathroom independently and to pick up objects.
- **Behavior** - The child can sit on the toilet (or potty chair) comfortably for two to five minutes. He or she may be allowed to look at preferred books or play with preferred toys while sitting on the toilet.
- **Instructional Readiness** - The child can follow a few simple directions (e.g. sit down).
- **Indicates Needs** - Through facial expressions, posturing, gestures, pictures or words, the child indicates needing to go to the toilet.

Get Set, Go!

- Your days should look like this: Wake up, take off wet diaper, go to the bathroom. Put on big boy underwear or big girl panties.
- Go to the bathroom when you anticipate need to urinate or to stool.
- Make it fun! Allow your child to read a favorite book or play with a favorite toy while sitting on the toilet.
- Use a visual schedule to reinforce verbal directions to child.
- Use a reinforcer.
- Change your reinforcers from time to time.



Development in People with Down Syndrome

Children with Down syndrome usually learn and progress more slowly than most other children therefore their development tends to be delayed in relation to chronological age. However, not all areas of development are equally affected.

There is a specific pattern of cognitive and behavioural features that are observed among children with Down syndrome that differs from that seen in typically developing children and children with other causes of intellectual disability. We refer to this pattern of characteristic strengths and weaknesses as a 'Developmental Profile'.



Socially appropriate behaviour should be encouraged & expected right from the beginning.



- Children with Down syndrome benefit from boundary setting in the same way as other children.
- Parenting a child with Down syndrome will, in many ways, not be very different from parenting any other child.
- Good parenting practices apply to all children.
- And for all children, consistency of approach is important.

There are no behaviours specific to children with Down syndrome. However, sometimes the inability to express themselves with words can lead to frustration. Instead, children with Down syndrome will try to express themselves through behaviours – sometimes undesirable ones..

What social challenges do kids with Down syndrome face?

Children with Down syndrome are usually very friendly. However:

- Kids with Down syndrome can feel socially isolated due to their differences.
- Most are socially immature and find it difficult to keep up with other children their age physically, emotionally and cognitively.
- **Relationships with kids who don't have Down syndrome are often lopsided, not equal, as the kids with Down syndrome want more from the friendships than the other kids do.**



Early Childhood - Daycare and Preschool.

Introduction



Children with Down syndrome are like all children in their need to make friends, to explore their environments, to gain confidence and self esteem, and to learn.

In recognition of these needs, opportunities are provided for children with Down syndrome now that are very different to those available to their counterparts of 15 to 20 years ago..

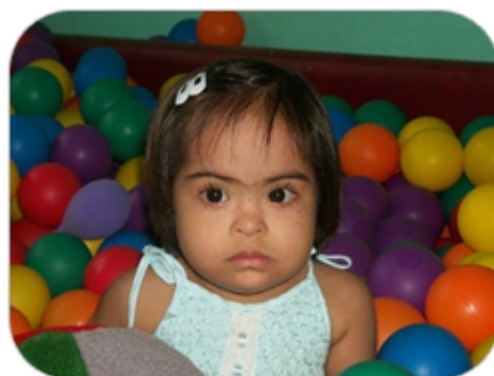
Along with other, they are encouraged to join in the full range of activities within the community - preschool, school, dance, gymnastics, music, team sports and so on.

Preschool and other community activities are excellent preparation for the integration of children with Down syndrome into their local school whether in a regular class or in a special class attached to a regular school - which for most children is a realistic goal.

Most babies and young children with Down syndrome can and do attend childcare centres, playgroups and preschool alongside children of the same age. They will learn a great deal from joining in with other young children.

Early learning and intervention specialists work with families to encourage learning and development in the daily life of the child.

Children with Down syndrome can be included in all activities and should have the same expectations placed on them for good behaviour and responsibility as other children do.



Also, preschool nurseries play an important role in the young child's life since exploring the environment beyond the home enables the child to participate in a broader world.

Later, the school can give the child a foundation for life through the development of academic skills and physical as well as social abilities. Experiences provided in school assist the child in obtaining a feeling of self-respect and enjoyment. School should provide an opportunity for the child to engage in sharing relationships with others and help to prepare the child to become a productive citizen.

Contrary to some views, all children can learn and they will benefit from placement in a normalized setting with support as needed.

Schools need not be Special !

School Years



Children with Down syndrome can attend the school of their parents' choice. In the past, many young people with Down syndrome have attended separate schools for students with intellectual disabilities.

However, research shows that the majority of children with Down syndrome make the best progress when they are educated in mainstream schools alongside their peers.

A student with Down syndrome is more likely to experience success in a school where inclusion is embraced and supported as part of the school culture, and where the different learning needs of all the students are acknowledged and properly addressed.

The best outcomes are achieved when appropriate support is provided to teachers to fully include the student in the class.



From the DSE archive:

The Early Reading Skills of preschoolers with Down syndrome <http://www.down-syndrome.org/updates/157/>



Self Help Skills and Independence.

Importance Of Self - Help Skills

- To become as independent as possible
- These skills are the daily challenges we all face
- When children can do things for themselves it helps them feel good about themselves
- When children can do things for themselves it helps others to view them in a positive light

It is important for parents and educators of young children to realise, that just like numbers, colours, and shapes, self-help skills deserve to be included in the curriculum. Self-help skills need to be introduced and reinforced through a wide variety of hands-on, developmentally appropriate activities.



Tips for Teaching Self Help Skills:



Self help training should be on-going. Whether it is learning to walk side by side without holding some one's hand, or dressing independently, you should always be thinking about developing your child's independence.

Don't baby your child. Parents sometimes feel they are helping their child, but really you are not helping them if you keep them from learning to do things for themselves. Self help skills are usually 'time sensitive'- you get dressed in the morning, you take a bath at night, etc.

Caregivers need to become consistent at practicing skills throughout the day at appropriate times. This way your child not only learns how to do skills but when they should be performed.

Observe when your child has mastered a skill and move on. If a child has mastered a skill, don't help them; you can make them dependent on your support and prompts. Something as simple as always asking a child, "Do you need the toilet?", can become a prompt. You have to fade that prompt as soon as possible.



Observe typical children. Make a list of independence skills you see in typically- developing children. I know this can be upsetting but it can serve as a wake up call that more self help needs to be focused on, not that your child can't do it. Self-help has to be consistent. Once a target is established, you can't target it half of the time. You have to target their independence every time they engage in that activity.

Remember that just teaching beginning self help skills is not enough. You have to continue to add targets e.g. once your child can dress himself, can he dress himself with you out of the room? Can he dress quickly? Can he pick out his own clothes? Can he independently change out of those clothes, take a bath and get and put on pajamas?

Acquisition of self-help skills in children:

These are all tested at the centre and remember every child is an individual

	D.S.Children	Other Children
Responsive Smile	1.5 - 5 months	1 - 3 months
Finger Feeds	10 - 24 months	7 - 14 months
Drinks From Cup (Unassisted)	12 - 32 months	9 - 17 months
Uses Spoon	13 - 39 months	12 - 20 months
Bowel Control	2 - 7 years	16 - 42 months
Dresses Self (Unassisted)	3.5 - 8.5 years	3.25 - 5 years

Social development for individuals with Down Syndrome - An overview

Table 1. Achieving independence in self-help skills

Meals

Feeds self with biscuit	10 months (range 6 - 14m)
Drinks from a cup	20 months (range 12 - 30m)
Uses spoon and fork	20 months (range 12 - 36m)
Can make a sandwich	50% at 11 - 20 years
Can make a cup of tea/coffee	46% at 11 - 20 years
Can use microwave	24% at 11 - 20 years
Can lay and clear table	80% at 11 - 20 years
Can eat in a restaurant	100% at 11 - 20 years

Toileting

Dry during the day	36 months (range 18 - 50m)
Bowel control	36 months (range 20 - 60m)
Dry at night	60% at 7 - 14 years
Use toilet/potty without help	4 - 5 years
Fully continent, day and night	98% at 11 - 20 years
Washes unaided	60% at 12 - 20 years
Can brush hair	95% at 8 -14 years
Does brush own hair	45% at 12 - 20 years
Can wash hair	34% at 14 - 22 years
Can have a bath	50% at 12-20
Can cut toe and fingernails	9% at 16-24

Motor skills

Walks alone	23 months (range 13 - 48m)
Climbs/descends stairs unaided	81 months (range 60 - 96m)
Can ride a bike	35% at 11 - 20 years
Can throw and catch a ball	98% at 11 - 20 years
Dressing	
Dresses self partially (not fastenings)	4 - 5 years
Dresses without help	80% at 11 - 20 years
Chooses appropriate clothes	70% at 11 - 20 years
Practical/Social	
Can tell the time	20% at 11 - 20 years
Can count simple amounts of money	40% at 11 - 20 years
Can go to shop alone	26% at 11 - 20 years
Crosses road alone	40% at 11 - 20 years

It is important that parents allow children do as much as they can for themselves. There is always the temptation to help the child because it is quicker and often the end result is more polished. Practice is needed in order to carry out tasks competently and promptly. It is also important that children take responsibility for themselves for the sake of their sense of control over their lives and their self-esteem.

Many young people continue to develop independence in their early adult years. Like most other young adults, they often take major steps in taking charge of more aspects of their daily lives.

Transitional stage :

Individuals with Down syndrome can benefit from an expanding environment. School can teach a child with Down syndrome the necessary academic, physical and social skills to lead a productive life within the community, instead of excluded from it. Prevocational training is also important, so that those with Down syndrome can learn important job training which will lead to meaningful employment.

Prevocational skills are skills needed to prepare for the work place. In conjunction with the vocational high school class, occupational therapists are able to help students refine physical skills and learn new skills needed to be successful for a job.

Life After School.

We are all constantly transitioning throughout our lives. We go from one grade to the next, from one job to another, or from living at home to living on our own. With that in mind, it is important for individuals with Down syndrome and their families to begin thinking about one of the most important transitions of all - the move from school to life after high school - and **to encourage them to start making plans as early as possible**. Planning for this transition from an early age can help the individual with Down syndrome mature into an adult who is as independent as possible. A well-developed transition plan ensures that the student has steps in place to reach his or her goals after high school.



Transition planning involves looking towards the future and envisioning all the skills and preparations that will be needed to lead the most fulfilling life possible. Looked at in this way, all training and education received during childhood and adolescence are part of transition planning. Transition planning is, therefore, a right that exists for all students with disabilities. It is important that individuals with Down syndrome be as involved as possible in making decisions about their future.

Transition goals should reflect a student's interests, abilities and dreams, and the plan should outline specific objectives to help him or her achieve those goals.

There are no hard and fast rules regarding transition plans, but in general, the transition team should set out to achieve the following:

- Assess, or identify the student's strengths, needs and preferences in terms of post-secondary education, employment and housing;
- Develop an awareness of various options in these areas and of the skills needed;
- Match the student to a desired post-secondary educational program, job and/or living arrangement;
- Train and prepare the student for the planned course of action;
- Help the student achieve a successful placement and ensure that appropriate support services are in place.

To accomplish all of this, the transition plan needs to describe specific long-term goals and identify smaller, measurable steps that will help achieve each goal.

A good plan will include strategies to learn specialized skills such as operating a particular piece of equipment or completing a certain course, as well as basic skills such as punctuality and working well with others. Transition plans also identify who is responsible for each step and set target dates for each objective.

Who Is Responsible for Developing the Transition Plan?

Because parents are in the position to know their child best, and to be their child's greatest advocate, ultimate responsibility for good transition planning falls on them. However, since the transition plan is part of the educational plan, the entire IEP team works together to develop the document.

The IEP team includes the student, teachers, parents (or legal guardians), school administrators and representatives of any other agency that may be responsible for providing transition services.



The process of developing a transition plan requires both creativity and coordination. It is a cooperative venture that requires input and participation by the entire team.

While the role of each team member is important, the individual with Down syndrome should be as involved as possible in all decision-making, and efforts should remain focused on his or her needs and desires.

What General Skills Should the Transition Plan Address?

Four skills are critical for individuals making a successful transition to life after high school:

- The ability for self-assessment.
- An awareness of the accommodations that they need because of their disability.
- Knowledge of their legal rights to these accommodations.
- **Self-advocacy skills to express their needs in the workplace and the community.**
(This is the most important point)

Parents can get their children off to a good start by helping them begin to develop these general skills at an early age. The transition plan should reflect specific strategies for further strengthening the skills the individual has developed over time, and for helping him or her acquire those missing or underdeveloped skills.

Transition Skills Checklist

Vocational Skills :

Can your child :

- Get to and from work, on time
- Perform work satisfactorily
- Work cooperatively with others
- Take break or lunch appropriately
- Wear suitable clothing
- Use appropriate safety procedures
- Follow directions
- Accept supervision
- Community Skills



Can your child :

- Use public transportation
- Shop for groceries, clothing
- Make necessary appointments
- Use a phone
- Use bank accounts, use an ATM



Domestic Skills :

Can your child :

- Plan menus
- Make shopping list from menus
- Prepare breakfast, lunch, snack, or pack a lunch
- Wash dishes, pots, and pans
- Clean up apartment (bathroom, living areas, kitchen, and so on)
- Clean own room
- Do laundry: use washer, dryer, and iron

Social & Personal Skills :

Can your child :

- Supply appropriate personal identification
- Greet people appropriately
- Use contemporary style of dress, hair, make-up
- Use good grooming, hygiene skills consistently
- Talk with friends and co-workers
- Be courteous
- Be responsible
- Be happy



Recreation & Leisure Skills :

Can your child :

- Use free time for pleasure
- Choose reasonable activities
- Pick a hobby
- Perform required activities
- Use community resources
- Call friends to make plans with them



VOCATIONAL TRAINING

What Is Vocational Training?

It is a process to develop occupational competence and adjustment & prepare an individual for working & living in the community.

Achieving Maximum Personal Autonomy :



An individual with Down Syndrome should be given:

- The right to the best health possible.
- The right to improve their image & social acceptance.
- Work as a source of equilibrium.
- The right to a dignified old age.

What are the changes in persons with Down Syndrome after they secure a gainful employment?

- Self-confidence
- Self-esteem
- Adjustment with peer groups
- Punctuality

Employment

In general, there are three types of employment options available to individuals with Down syndrome:

- **Open Employment**
- **Supported Employment**
- **Sheltered Employment**

In open employment, the individual secures employment in the community - for example, by responding to ads or job postings or proactively approaching businesses and works independently without any support services.

More common is supported employment, in which the individual works in an integrated setting and receives support services from a trainer. The trainers accompanies the individual to the workplace to enable him or her to learn the necessary job skills and to prepare to work independently.

Usually, the trainer with the individual full-time at first, and moves toward the goal of providing only periodic support such as visiting the job site to assist in training the individual for new assignments.

In addition to these types of employment, there are also many innovative programs that focus on business ownership and entrepreneurship for individuals with disabilities. These businesses may include artistic or creative ventures that allow the individual to focus on a specific talent or ability, such as photography or public speaking.



Puberty

You may be thinking about issues around puberty. The physical changes of puberty happen within the same age range as children without Down's syndrome and they follow the normal pattern. Remember that emotional and social development may not develop at the same rate as the physical changes in your child. Start talking to your child about growing up and the physical changes before they happen.

Puberty and sexual health



Teenagers with Down syndrome experience the same physical and emotional changes during adolescence as other teenagers.

The majority of teenagers with Down syndrome cope well with the changes. Most girls learn to take care of their own hygiene needs effectively during their periods.

Research into fertility, sexuality and pregnancy in individuals with Down syndrome is limited. It seems that both girls and boys are fertile though fertility may be lower than is typical in the general population.

The sexual and emotional needs of teenagers and young people with Down syndrome are the same as those of the rest of the population. Some young people appear to be more sexually aware and active than others, and this is also true of the rest of the population.

The opportunity for teenagers with Down syndrome to have a boyfriend or girlfriend and to establish a meaningful relationship may be reduced as their social lives are usually still controlled by their parents.

However, increasing numbers of teenagers and adults are forming close relationships, with some establishing permanent partnerships or getting married.

It is important that all young people with Down syndrome learn as much as possible about the ways in which their body is changing and about taking care of their personal hygiene. It is also important that they have good and accurate sex education, which includes all the basic biological facts and includes discussion of relationships, how sexual relationships develop and how people love and care for each other.

Sex education can take place in small steps over a number of years, in a way that is judged to be appropriate for each individual, especially as the personalities and abilities of individuals with Down syndrome varies so widely. Teenagers with Down syndrome should receive the same health care as other teenagers, as appropriate for their sexual development and experience.

Obesity, healthy eating and exercise

The risk of becoming overweight seems to increase for young people with Down syndrome after puberty. This means that parents of teenagers need to be particularly aware of encouraging healthy eating and sufficient exercise for their sons and daughters.

A balanced diet containing a proper mix of the four key food groups (meat and fish, vegetables and fruit, bread and grains, and dairy products) needs to be encouraged while limiting the intake of foods high in fats and sugars. This is not easy given the kinds of foods encouraged in fast-food outlets and even school canteens.

Down Syndrome Federation of India

We, here at the Down syndrome Federation of India, offer day-care services to individuals with special needs, more specifically, to those born with Down syndrome. The variety of support services provided by us includes counseling distraught families, medical support, training children to overcome their shortcomings, providing physiotherapy, and speech therapy, and spreading awareness about Down syndrome.

Down syndrome Federation of India was established in 1984 with just 6 children. Today, it provides services to innumerable children not just from our country but also to those from the Middle East. We have not only grown as day-care centre, but have also achieved milestones, touching lives and making a difference to thousands of children who now find themselves leading a better quality of life.

Way back in the 1980's, there were no specific centres for those born with Down syndrome. These people were just grouped with the intellectually challenged, or with people with cerebral palsy, for both therapy, and rehabilitation. Experts in this field were limited, guidance and counseling was sparingly available, and topping it all, parents with such children did not come out to share their experiences.

Help and intervention from abroad, obviously could not be afforded by one and all, and by the time help actually reached the child, the opportunity to develop the child to the best potential was lost.

Visit DSFI at www.downsyndrome.in



Down Syndrome Association of Tamilnadu

The Therapy services we provide are mentioned below :

- Speech Language Therapy
- Special Education
- Physical Therapy
- Occupational Therapy
- Audiology and Vision
- Psychological Services
- Counseling, family training, home visits and parent support groups
- Medical Services for Diagnostic or Evaluation Purposes
- Nutrition Services
- Transportation to and from Early Intervention Services
- Service Coordination

Down syndrome federation of India, the Tamilnadu chapter, an organization dedicated to the rehabilitation of those with Down syndrome, was established in 1983 by Dr. Surekha Ramachandran, a parent of a person with Down Syndrome. "Health care and a better understanding of the condition have helped us. Now we are moving in a different direction," she informs. Towards that, her organization is conducting many activities to help children with the syndrome - such as special training sessions, parental education and counseling.

"We provide family counseling since this challenge has to be properly understood and addressed not just by the parents alone, but all others in the family," she says.

Down Syndrome Myths & Truths

www.ndss.org

Myth : Down syndrome is a rare genetic disorder.

Truth : Down syndrome is the most commonly occurring genetic condition. One in every 800 babies in India is born with Down syndrome.

Myth : People with Down syndrome have severe cognitive delays.

Truth : Most people with Down syndrome have cognitive delays that are mild to moderate. Children with Down syndrome fully participate in public and private educational programs. Educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth : Most people with Down syndrome are institutionalized.

Truth : Today people with Down syndrome live at home with their families and are active participants in the educational, vocational, social, and recreational activities of the community. They are integrated into the regular education system and take part in sports, camping, music, art programs and all the other activities of their communities. People with Down syndrome are valued members of their families and their communities, contributing to society in a variety of ways.

Myth : Parents will not find community support in bringing up their child with Down syndrome.

Truth : There are support groups. Find them at the end of the book.

Myth : Children with Down syndrome must be placed in segregated special education programs.

Truth : Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The current trend in education is for full inclusion in the social and educational life of the community. Increasingly, individuals with Down syndrome graduate from high school with regular diplomas, participate in post-secondary academic and college experiences and, in some cases, receive college degrees.

Myth : Adults with Down syndrome are unemployable.

Truth : Businesses are seeking adults with Down syndrome for a variety of positions. They are being employed in small and medium-sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions, childcare, the sports field and in the computer industry to name a few.

Myth : Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth : People with Down syndrome have meaningful friendships, date, socialize, form ongoing relationships and marry.

Myth : People with Down syndrome are always happy.

Truth : People with Down syndrome have feelings just like everyone else in the population. They experience the full range of emotions. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

- **Karishma Kannan** the Artist who raises funds for the differently abled through her art works in Veitnam.
- **Pranay Burde** works for Hotel Leela Mumbai.
- **Ashwin Kumar Poddar** enjoys acting.
- **Archana Jayaraman** Special Olympics World Games Cycling Gold Medalist.
- **Babli Ramachandran** an Inspiration to families of individuals with Down Syndrome, teaches Yoga.



**Karishma
Kannan**



**Pranay
Burde**



**Ashwin Kumar
Poddar**



**Archana
Jayaraman**



**Babli
Ramachandran**

Our support is available in all parts of the country.

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Down Syndrome Support Group India

Community

PODS (PARENTS OF DOWN SYNDROME)

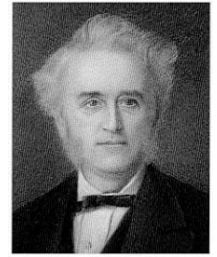
A3,Kherwadi Housing Society,
RTO Road,
Near 4 Bungalows,
Andheri (West), Mumbai.
Ph:020 26301393.

Down Syndrome Association of Tamil Nadu

New No:11 Old No:6,
Justice Sundaram Iyer Road,
Mylapore.
Chennai 600 004.
Ph: 044 24986824.

When Was Down Syndrome Discovered?

For centuries, people with Down syndrome have been alluded to in art, literature and science. It wasn't until the late nineteenth century, however, that **John Langdon Down**, an English physician, published an accurate description of a person with Down syndrome. It was this scholarly work, published in 1866, that earned Down the recognition as the "father" of the syndrome. Although other people had previously recognized the characteristics of the syndrome, it was Down who described the condition as a distinct and separate entity.



In recent history, advances in medicine and science have enabled researchers to investigate the characteristics of people with Down syndrome. In 1959, the French physician **Jérôme Lejeune** identified Down syndrome as a chromosomal condition. Instead of the usual 46 chromosomes present in each cell, Lejeune observed 47 in the cells of individuals with Down syndrome.

It was later determined that an extra partial or whole copy of chromosome 21 results in the characteristics associated with Down syndrome. In the year 2000, an international team of scientists successfully identified and catalogued each of the approximately 329 genes on chromosome 21. This accomplishment opened the door to great advances in Down syndrome research.



www.downsyndrome.in

Thank You