

DOWN SYNDROME – ALL YOU WANT TO KNOW ABOUT

DOWN SYNDROME

Q: What is Down Syndrome?

A: Down syndrome is the most commonly occurring chromosomal abnormality, resulting when an individual possesses three, rather than the usual two, copies of the 21st chromosome. This excess genetic material affects a person's physical and cognitive development. People with Down syndrome will have some degree of Intellectual Disability, usually in the mild to moderate range. There are many characteristics associated with Down syndrome, including low muscle tone, an enlarged tongue, a flat facial profile, and increased risk of related medical conditions.

Q: What are some basic facts about Down syndrome?

A: The medical name for Down syndrome is Trisomy 21. Down syndrome occurs at conception and is not because of something the mother did during pregnancy at all. It is a random occurrence. It does not matter race, religion, socio-economic level, etc.

Q: What cause Down syndrome?

A: It is stated that 95% of all cases is caused by an error in cell division called nondisjunction. Few cases are caused by two other chromosomal abnormalities: mosaicism and translocation. The additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. One in every 800-1,000 live births is a child with Down Syndrome, representing approx 30,000 birth per year in India.

Q: What is down syndrome diagnosed?

A: The diagnosis of Down syndrome is usually picked up soon after the birth of the baby because of the way it looks. There are many physical characteristics associated with the condition, which may lead a parent, or medical professional to suspect that the baby has Down syndrome. Many of these features are found in the general population. Therefore a chromosome test would need to be done on the baby before a positive diagnosis could be made. Taking blood from the baby and then analyzing the chromosomes does this. The result is called a karyotype.

Q: Is there a vaccine you can take to cure for prevent Down syndrome?

A: No, there is not a vaccine to prevent or cure Down syndrome. However, medical advances have lessened the impact of medical conditions, while early intervention, therapy, education, and support from family and friends, assist the person in leading a productive life.

Q: Is there a cure for Down syndrome?

A: Currently, there is no cure for Down syndrome. However, researchers are exploring a number of ways to address and correct many aspects of the syndrome including research.

Q: Why the myth that more children are born to mothers over the age of 35 years of age?

A: Actually, 85% of children born with Down syndrome are to mothers under the age of 35 years of age. The reason the greater risk over age of 35 is because the statistics are higher in that age group because there are not as many women having babies over the age of 35 years of age.

Q: What is the risk of parents of a child with down syndrome having another child with down syndrome?

A: In general, for women under 40 (after having one child with Down syndrome), the chance of having another baby with Down syndrome is 1 percent. The chance for Down syndrome is also

known to increase with the mother's age and, after age 40, a mother would simply have the risk based on her age at delivery.

EDUCATION

Q: What is the type of education received by children with down syndrome?

A: Children with Down syndrome have been included in typical 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 degree of mainstreaming is based on the abilities of the individual; but the trend is for full inclusion in the social and educational life of the community.

Q: Should all children with down syndrome be placed in special education classrooms?

A: Children with Down syndrome can and have been included into a regular classroom. They can be integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The current demand has been 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.

EMPLOYMENT

Q: Are there employment opportunities for adults with down syndrome?

A: Yes, businesses are seeking young 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, and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

SUPPORT GROUPS

Q: Why is it so important to get involved in a support group?

A: Becoming involved in a support group allows you the opportunity to fellowship get resources and get questions answered by people that are in similar situations. There is nothing better than being surrounded by people that understand what you are going through. We encourage everyone to attend a support group.

Q: How can parents and providers help teens and young adults with down syndrome transition into adulthood?

A: In foreign countries, more and more youth and young adults with Down syndrome are achieving some of the same milestones as other young people, such as driving a car and finishing high school. As they start to live more independently, young people with Down syndrome get jobs, move into group homes or individual housing, or pursue further education, often at community colleges. Families may need to be advocates to ensure that their young adult children don't "fall through the cracks." Sometimes, young people with Down syndrome in the midst of these transitions start to do worse in school or undergo major mood changes. In these cases, additional school assistance or evaluation for hypothyroidism or depression may be appropriate.

Many adolescents and adults with Down syndrome find success in jobs. When considering whether their child with Down syndrome might be ready to look for work, parents should keep several factors in mind: Success depends on a healthy sense of self-esteem, the ability to complete

tasks without help, a willingness to separate emotionally from family, and access to personal recreational activities.

Adolescents often switch from care by a pediatrician to adult care, and this change can be difficult for young people with Down syndrome. Families and young people with Down syndrome often have strong bonds of trust with their pediatricians, and adult health care providers may be poorly prepared to meet the needs of maturing patients with Down syndrome. Individuals who receive care at special Down syndrome clinics that provide lifelong care might prefer to stay with the providers at these clinics as adults.

Teenagers with Down syndrome undergo hormonal changes like any other teen. Parents should encourage their teenagers with Down syndrome to develop independent skills in hygiene and self-care, to be aware of privacy issues, and to manage their behavior appropriately. Teenagers with Down syndrome also should be educated about puberty, sexuality, sexual activity, and the consequences of such activity. Males with Down syndrome generally have a reduced sperm count and are usually unable to father children. In contrast, females with Down syndrome have regular menstrual periods and can get pregnant and carry a baby to term. Therefore, health care providers and families should consider having discussions with their teens with Down syndrome about birth control and preventing sexually transmitted diseases (STDs).

HEALTH

Q: What are the health issues for adult with down syndrome?

A: The life expectancy for people with Down syndrome has increased substantially in the last few decades, to an average age of 50 years and beyond. In addition to living longer, people with Down syndrome now live fuller, richer lives than ever before as family members and contributors to their community. Many adults with Down syndrome form meaningful relationships and eventually marry. Now that people with Down syndrome are living longer, the needs of adults with Down syndrome are receiving greater attention. With assistance from family and caretakers, many adults with Down syndrome have developed the skills required to hold jobs and to live independently well into later adult life.

Increased life expectancy in individuals with Down syndrome puts them at risk as they age for developing mental health issues, such as depression. Death of parents, changes in caregivers, and medical issues often contribute to such changes in mental health. Individuals with Down syndrome seem to respond well to treatment with medication, but it is important that they follow instructions for taking these medications closely.⁶

Premature aging is a characteristic of adults with Down syndrome, as is dementia, memory loss, and impaired judgment similar to that occurring in individuals with Alzheimer disease.⁶ Although much has been learned about Alzheimer disease as it affects individuals with Down syndrome, effective treatments and diagnostic tools that can identify early stages of dementia or the symptoms of mild cognitive impairment are still needed. Currently, changes in behaviour may be the best indicators of dementia in people with Down syndrome. Families should look for associations between the type of behaviour, how often the behaviour occurs, when the behaviour occurs, and the persistence of specific behaviours as a way to check for dementia and memory loss in a person with Down syndrome.^{6,7} Family members and caretakers may need to step in if the individual begins to lose the skills required for independent living.

Other medical issues associated with aging in individuals with Down syndrome include high cholesterol (which can be treated with medications), obesity, metabolic syndrome, diabetes, cataracts and other visual problems, and early menopause. In contrast, individuals with Down

syndrome appear to be "protected" from certain diseases that are common in the elderly: they do not develop hardening of the arteries; they have fewer solid tumor cancers (for example, breast cancer), and they have low blood pressure.

Longitudinal studies of aging in Down syndrome (some ongoing for more than 25 years) reveal that healthy aging occurs in most individuals with Down syndrome if they continue to receive routine medical care and attention to their special needs.

Q: What are the physical characteristics of a person with down syndrome?

A: Flat appearing face

Small head

Flat bridge of the nose

Smaller than normal, low set nose

Small mouth, which causes the tongue to stick out and to appear overly large

Upward slanting eye

Extra folds of skin located at the corner of each eye, near the nose

Small, misshapen ears

Small, Wide hands

An unusual, deep crease across the centre of the palm (simian Crease)

A malformed fifth finger

A wide space between the big and the second toes

Unusual creases on the soles of the feet

Overly flexible joints(sometimes being referred to as double jointed)

Shorter than normal height

Q: What is the life expectancy for someone with down syndrome?

A: Once the life expectancy of a person with Down syndrome was under 25. Due to an increased understanding of Down syndrome and advances in medical care the current life expectancy for a child born with Down syndrome is 60.

SOCIETY

Q: Can people with down syndrome be a productive member of society?

A: People with Down syndrome attend schools, live independently, make decisions that affect them, work, volunteer and contribute to society in many ways.