

When your doctor examined your baby he found some unusual signs. The baby was floppy and weak. There was something unusual in the baby's face; the nose looked flat, the eyes were slanted upwards, the ears were small and the baby had a tendency to keep the mouth open with the tongue protruding at times. When he looked at the baby's hands, the little finger looked very short and there was only a single crease across the palm instead of the usual two. Finally he turned to the baby's feet and found a wide gap between the first and second toes. These signs made the doctor suspicious, as these are some of the features of a baby affected with a genetic disorder called Down syndrome.

What is Down syndrome?

Down syndrome occurs due to an abnormality in the number of chromosomes. A normal baby has 46 chromosomes in every cell of the body. 23 chromosomes come from each of the father's sperm and the mother's ovum that fertilized to produce the baby. Sometimes, due to an accidental error in the production of sperms or ova, the father's sperms or mother's

ova may end up with 24 chromosomes instead of the usual 23. When such a sperm or ovum unites with a normal ovum or sperm, as the case may be, the baby will then have 47 chromosomes instead of the usual 46. A baby with 47 chromosomes is said to have Down syndrome. This can be confirmed by doing a blood test (a karyotype test) to study the baby's chromosomes. Your doctor will refer your baby to a geneticist for this test. So remember, your baby did not get Down syndrome because of anything you did or anything that happened during the pregnancy. It is simply a genetic disorder.

What does the future hold for our baby?

Babies with Down syndrome grow up to be "good babies" and happy children. They tend towards mimicry, are friendly, have a good sense of rhythm, and enjoy music. They are slow starters. As they grow older, their muscles become stronger, they will walk and talk. However, the rate of development slows down with age. As a result they remain mentally subnormal. Mischievousness and obstinacy may

also be characteristic and some of them may have emotional problems. Their adolescent sexual development is usually somewhat less complete than normal. Those who do not develop any major illness could be expected to have a normal life span.

How can we help our child?

There is no cure for Down syndrome. However, a lot of love from the immediate and extended family, dedicated support and special attention in the early years will help them improve considerably. They need special support such as speech therapy, physiotherapy, specialized educational support, and vocational training to reach their full potential and to enable them to lead independent lives.

Some Down syndrome babies may have heart defects or other congenital abnormalities. These are usually identified at birth. So if your doctor says that your baby does not have these problems then don't worry. As they grow up they may experience thyroid dysfunction, respiratory tract infections and other health problems. Regular medical checkups are useful

to detect and treat these problems early.

Will our future babies also have Down syndrome?

Most of the time, as mentioned above, the extra chromosome results from an accidental error in the production of sperms and ova. If this is how your baby got Down syndrome then the chance of recurrence is very low. However, rarely, there can be a hidden abnormal chromosome in the father or mother that could be passed down to their children. So doing a karyotype test on your baby is important if you are planning to have any more children. This test will enable doctors to determine the origin of the extra chromosome and give you more accurate advice.

How can we obtain assistance and advice to look after our child?

The social services officer in the Divisional Secretariat in your area will be able to tell you more about how and from where you could obtain help to look after your child. The **“Chitra Lane School for the Special Child”** situated at No.45/3, Chitra Lane, Colombo 5

has specially trained personnel who can advise you. You can contact them on 01-503906.

How can we meet with other families with Down syndrome babies?

The **“Parents’ Association for the Advancement of the Special Person”** situated at No. 28, De Alwis Place, Dehiwala is a support group for parents of children with special needs. They invite you to join them. You can contact them on 01-732676.

Who can give us more advice and genetic counseling?

Your family doctor, who knows you and your family, is the best person to advise you and to provide you with genetic counseling. If you do not have a family doctor you can contact any other doctor or our Unit.

**GENETIC AWARENESS PROGRAMME
(GAP)**

HUMAN GENETICS UNIT

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The doctor says that our baby has Down Syndrome



Facts YOU Should Know

