

Getting to know a baby with **DOWN'S SYNDROME**



Information for grandparents,
relatives and friends

Down's Syndrome
SCOTLAND helping people realise their potential

When a Baby Has Down's Syndrome

In some cases, parents find out during pregnancy that their baby has Down's syndrome. In most cases however, the fact that the baby has Down's syndrome is not identified until the baby is born. Whenever the parents hear the news that their baby has Down's syndrome, they may be shocked and distressed.

Whatever the circumstances, grandparents, relatives and friends have an important role to play in supporting the parents and helping them to come to terms with the fact that their baby has Down's syndrome.

Grandparents, relatives and friends can do this by learning a little about Down's syndrome, how it affects the baby and what they can do to best support the family.

This leaflet will give you up to date information about Down's syndrome and some ideas about how to support the baby and the parents through the coming months. It will also help you to make a good start in getting to know the new baby in your life.



What is Down's Syndrome?

Down's syndrome is the most common form of learning disability, occurring in about 1 in 700 births. It occurs at random and is caused by the presence of an extra chromosome in every cell of the body.

Nothing the parents did before or during the pregnancy can have caused Down's syndrome. It is rarely hereditary and so is in no way the families 'fault'. Down's syndrome is present from before birth. It cannot be caught or passed on.

There is no cure for Down's syndrome. However, there are many things that can be done to help a child to reach his or her full potential. Today, most children with Down's syndrome lead healthy and fulfilled lives and are integrated successfully into family and community life.



HOW DOES IT AFFECT THE BABY?

Babies with Down's syndrome will have a number of physical features in common. The new baby might be quite small with arms, legs and neck possibly being floppy. The baby's eyes may slant slightly upwards.

These physical characteristics will be apparent to medical staff soon after the baby is born, although they are not always obvious to parents and family. In most

cases, the Consultant Paediatrician will be the professional who tells the parents that the baby has Down's syndrome.

Down's Syndrome Scotland have written guidelines for staff about breaking the news. Therefore, parents should have been told in a sensitive manner and given well-balanced, up to date information about Down's syndrome.

The baby will also show many family characteristics. This will be true of temperament and abilities as well as looks. It is important to remember that all babies are unique individuals and a baby with Down's syndrome is no different.

Some babies with Down's syndrome may have associated health problems, for example with their heart, ears, eyes or digestive system. These may require medical attention. Frequent health checks are offered by professionals to make sure that any problems are detected and

treated early. However, it is not true that all babies with Down's syndrome are frail and delicate. Most babies with Down's syndrome enjoy good health.

Babies with Down's syndrome gain weight and grow at a different rate to other children, for this reason a baby's weight and growth should be measured on charts that have been specifically designed for babies with Down's syndrome. Many babies with Down's syndrome do not gain weight very quickly and this can be a worry for parents. Using the specific charts will help parents and the Health Visitor to monitor how the baby is progressing.

All babies with Down's syndrome have some degree of learning disability. It is impossible to predict the extent of these difficulties at birth.

The important thing is that with care, love and attention, all babies and toddlers including those with Down's syndrome, attain all the usual developmental milestones.



What Can You Do?



FOR THE BABY?

- Don't be afraid of handling the baby, just do whatever comes naturally. Babies with Down's syndrome are not fragile and will enjoy being cuddled and played with as much as any other baby.
- Treat the baby as you would any new arrival. If there are brothers and sisters, remember that they still need your attention too.
- If you had planned to give a gift or send a card, go ahead. Babies with Down's syndrome and their parents, enjoy just the same kinds of toys and clothes as any others do.

- *Welcome the new baby.*
- *Show the parents, through your words and actions, that you value their baby as you would any other baby.*
- *Your support will be important. Offer parents as much friendship and company as you can. Don't let the baby's arrival make them feel cut off from the outside world.*
- *When they are ready, let the parents talk. A good listener can be an enormous comfort.*

TALKING TO BROTHERS AND SISTERS

Brothers and sisters are often told that babies with Down's syndrome are 'special'. However, Down's Syndrome Scotland believe that all children are special, not just those who have a learning disability.

It will be important for family life, that the baby with Down's syndrome although initially may take up more of mum's time, is not seen as being different from the other children, or treated differently.

Brothers and sisters need to understand that they are equally important to their parents and wider family.

ON THE PRACTICAL SIDE

- Offer to baby-sit. It is important for parents to get out and spend time together, and to spend time with their other children. Your offer may allow this to happen.
- If the baby has to attend frequent clinic appointments, an offer of help may be very welcome. You could look after the other children, or just go along for company.
- Learn how to join in with any developmental or early intervention programme that the parents may start with the baby. Your involvement will be appreciated and the baby will enjoy a change of face.



MORE GENERALLY...

You may wish to find out more about Down's syndrome from Down's Syndrome Scotland national office in Edinburgh. There are several local branches throughout Scotland, which many relatives and friends keep in touch with, even when the baby they care about lives far away.

Parents often find that soon after the birth, they begin to forget about the label Down's syndrome and see the baby as an individual with all the happiness this brings. It is important that parents enjoy these baby days.

You too will experience a great deal of pleasure from forming a close and loving relationship with the baby.

Living with Down's Syndrome

This booklet is one of a series produced for parents, relatives, students and professionals; in fact anyone who has an interest in Down's syndrome. They have been written largely by parents with assistance from many advisers, including doctors, teachers, therapists and staff at Down's Syndrome Scotland.

The booklets are designed to help with the thoughts and questions that occur to parents and to answer some of the general queries received about Down's syndrome.

Some points to bear in mind while you read:

- People with Down's syndrome are always described as having learning disabilities or difficulties.
- We have written from a Scottish viewpoint, but the issues covered will be of relevance to readers elsewhere.



For details of other titles in the series, names of local contacts or any further information, please contact Down's Syndrome Scotland at the address on the back page.

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SCOTLAND helping people realise their potential

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Down's Syndrome Scotland provides support, advice and information to people with Down's syndrome and their families/ carers, professionals and the general public in Scotland.

It also seeks to raise awareness and understanding of the potential of people of all ages with Down's syndrome.

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