

When a Baby has **DOWN'S SYNDROME**



Information for
new parents

Down's Syndrome
SCOTLAND helping people realise their potential

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The EARLY days

HEARING THE NEWS

The birth of any baby is a time of tension and excitement. Changes within the mother's body can also bring feelings of extreme tiredness and occasional 'baby blues' after the birth.

It is not surprising that in this vulnerable state, the news that your baby has Down's syndrome seems too much to bear.

"I just felt disbelief, how could this have happened to me? Like everyone else, we had been expecting to have the perfect baby. At my age, the last thing I ever expected was to have a baby with DS. How would we tell everybody?"



You may be shocked and a bit concerned by your own reactions, or your partner's, but don't worry: anger, grief, shock, rejection, feelings of overwhelming protectiveness, embarrassment – these are all common reactions. Other parents have felt like you:

"It's difficult for fathers. I kept my innermost feelings just clamped down because I had to get on with other things."

"I felt a tremendous sense of failure, and of letting people down."

"I didn't want her to be mine. I hoped that someone would come along and say that there had been a mistake, and that the nice baby over there was mine instead."

"I felt numb. I don't think I took in what DS was. I felt frightened about how I would cope, but I felt I would just do the best I can."

"With all the to-ing and fro-ing after Eoin was born, I knew that something was wrong. When I was told he had DS, I thought, well is that all. I was just relieved that he was well."

Whatever else you may feel at this time, don't feel guilty. Mothers especially feel this way, having been the ones who carry the baby.



Nothing you did or did not do during pregnancy can have caused Down's Syndrome (DS). DS is caused by a chromosomal accident at conception. No one knows why it happens, or can predict who will be affected.

YOUR FEELINGS

Many parents feel it is helpful to find out as much as they can about DS. Learning the facts can help get rid of some of the fears and uncertainties that buzz around in your head.

While you are in hospital, ask the medical and nursing staff for answers to any questions you might have. Another good way can be to talk with the parents of another child with DS.

Ask the Ward Sister to put you in touch with a parent visitor from Down's Syndrome Scotland; or you can do this later, once you are home, if you prefer.

“Mary came to see me bringing some family snaps. This was the most reassuring thing that could have happened... to see a happy family doing normal family things together. The photos helped my husband too. Those that he'd seen previously had been so old-fashioned.”

“When Liz brought Andrew to see me I thought, if my baby's like him I'll manage fine, because he was running about and playing with bricks.”

Down's Syndrome: the FACTS

'WHAT IS DOWN'S SYNDROME?'

Down's syndrome was first described in detail by an English doctor, John Langdon Down, in 1886. It is a congenital condition which randomly affects about 1 in every 700 babies born throughout the world, male and female alike.

A 'syndrome' means a group of recognisable characteristics occurring together. A 'congenital' syndrome is one present at birth, one which cannot be 'caught' later on.

The name 'Trisomy 21' is also used, and will be explained later. However, Down's syndrome or DS is the most widely known term.

Chromosomes are tiny components within the cells in our bodies. They carry the blueprint for all the characteristics that we inherit, such as the colour of our hair and eyes.

We have 46 chromosomes per cell, half from our mother and half from our father. The baby with DS in nearly all cases has one extra chromosome (number 21) making a total of 47 instead of the usual 46. This is why DS is sometimes called Trisomy (three copies) 21.

WHAT DOES THIS EXTRA CHROMOSOME MEAN?

DS is one of the few genetic conditions that is recognizable at birth. There are many different physical characteristics linked with DS, but your baby will only have some of them.



Remember, while children with DS do share some common characteristics, they more closely resemble their parents, brothers and sisters, in both appearance and personality. For further information see *What is Down's Syndrome?* in this series.



At birth, your baby's muscle tone was probably rather poor, making him appear somewhat floppy. Tone is always lowest during the early years and improves as the baby grows older.

Babies with DS tend to weigh less than others at birth and do not gain weight as quickly in the early weeks. It is important that you do not feel under too much pressure because of this. Your baby's height and weight should be plotted on a chart that is specifically designed for babies with DS. Down's Syndrome Scotland can provide you with this and would be happy to talk to your Health Visitor if necessary.

Doctors monitor babies born with DS very carefully for any heart problems. All new babies with DS will be given a heart scan.

Up to 40% of babies born with DS have heart defects, ranging from quite minor problems to more serious defects which may benefit from surgery. However, the majority of babies with DS do not have any heart problems.

Visual, hearing and thyroid problems may develop in childhood and require medical attention. Most of the other physical characteristics of Down's syndrome have no adverse effects on the child.

YOUR BABY'S DEVELOPMENT

All children with DS have some degree of learning disability. This is mild in some, and more marked in others. It is impossible to predict at birth the extent of your baby's learning difficulties.

Be assured that babies and toddlers with DS will benefit from appropriate care, attention and stimulation. Some will go on to attain developmental milestones as in walking, communication, feeding, dressing and toilet training. There will however, be a range of individual differences. Parents should aim to help their child develop to their own greatest potential.

In time, your baby should walk, talk, feed himself, dress himself and be toilet trained. Parents' should aim to help their children develop to their full potential.

COMING to TERMS with the situation

Most parents find that once the early stages are over and their baby starts to be more responsive, giving them winning smiles, they then get to know an individual character and forget the 'label'.

“At first whenever I looked at Stuart all I saw was DS. Gradually things changed. It was such a lovely feeling the day I realised that I was no longer looking at DS, I was looking at my lovely little boy, Stuart.”

By then parents 'wouldn't change things for the world'. They begin to enjoy seeing their baby grow and learn. They often discover strengths in themselves, their family and friends that they had not known about before.

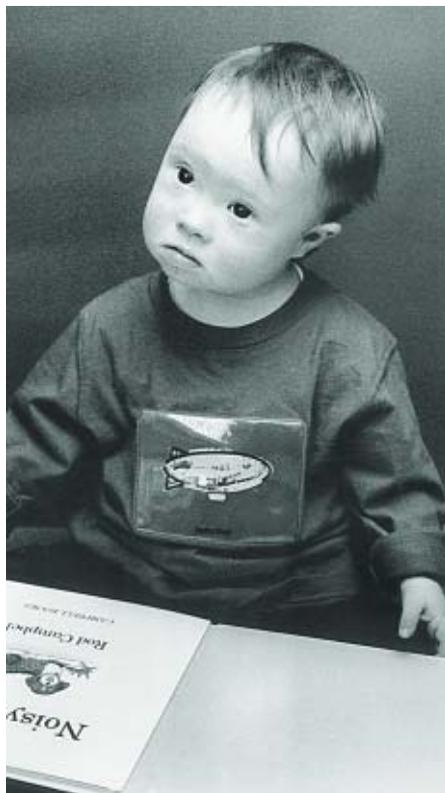
“My only concerns have been about attitudes towards disabilities, and how society fails so miserably to prepare any of us to love, to live with and to provide for anyone who is anything other than 'normal'.”

There will be times in the future, perhaps when a friend has a new baby, or when your baby is a little slower in reaching a milestone than someone else's – when some of the old feelings will reappear.

However, they will not hit you quite so hard as at the beginning. Sometimes if you try to look into the future and plan ahead, you may feel apprehensive or despondent. Try instead to take each step as it comes and enjoy your baby at that particular stage.

“Every hurdle we cross prepares us for the next.”

Although it is natural to think about planning your child's future, please remember that things will change with time, just as they do for any family.





Don't bottle up your feelings. Share them with your partner, a friend, or the parent of another child with DS.

Make use of your health visitor, paediatrician, GP, or other professionals. They will be happy to listen, as well as giving you advice. For further information see *The Professionals and how they can help*.

Your partner's feelings won't always coincide with your own. You will probably work through things at different speeds, and have ups and downs at different times. Try to be sensitive to each other's feelings.

Make time for yourself, to do something you enjoy. All parents need this, and you'll find yourself better able to cope once you've had a break. Unless your baby has severe health problems, there is no reason not to leave them in the care of others.

Make sure that you and your partner also find time to spend together, away from your children. Make use of friends, family and baby-sitters.

If you intend to go back to work there should be no need to change these plans.

If you are a single parent, use the support offered by family and friends, and take professional advice where appropriate.

TELLING other PEOPLE

YOUR OTHER CHILDREN

Try to tell all your children together that their new baby brother or sister has DS. How to tell them will depend on their age, but whatever the circumstances, be open with them. The new baby will then be seen as a loved and valued family member.

Children from the age of about three will need some explanation. Using the terms 'Down's syndrome' and 'learning disability' is preferable to words like 'different' and 'wrong with'. It is not always helpful to refer to your baby with DS as 'special' when talking to your other children. Remember that all children are special. Teenagers will want more detailed information, and may wish to read about DS.

Make sure that the baby with DS does not become the sole focus of your attention. Share your time and energy with all your children, and let each one have some special time alone with you.

Be prepared for brothers and sisters in all age groups to express strong emotions, just as you did.

Most children respond well to being the brother or sister of a child with DS and develop strong bonds.

"When my little sister was born, Mummy and Daddy told me she would need help to learn things, more help than I did. She can do lots of things and I take her out to play. I think she is lovely."

Explain the facts about DS – this way children will be better able to cope with ignorant and hurtful remarks from their peers. Listen sympathetically if they are being teased.

Down's Syndrome Scotland may be able to go along or to talk to staff and children at school to explain more about Down's syndrome.





TELLING RELATIVES AND FRIENDS

It's not always easy to break the news to relatives and friends, especially when you are perhaps feeling vulnerable yourself. People's reactions can be hurtful, born from their own shock and ignorance about DS. You might find it helpful to give copies of *Getting to know a child with Down's syndrome*, in this series, to friends and relations.

Try to remember that when someone says something inappropriate, they are really feeling awkward and don't know what to say. Sometimes they will look to be led by you.

Grandparents may be particularly upset. They are distressed not only for their grandchild but for you, their own child.

“My mother wanted to make things right for me... because she's my mother.”

Try to involve people in caring for your baby. Practical tasks can help both them and you. Reassure friends that your baby is not fragile, and needs to be treated like any other baby.

Remember, people will take their lead from you. If they see you treating your baby as a valued and loved individual, that will greatly influence their response.

“We never tried to cover up the fact that Stuart had DS. We soon found that other people coped better by us being open with them and showing that we were not embarrassed.”

When you describe your baby's condition, remember to say that he is a baby who has DS and use his name. The child is more important than the syndrome.

Show your baby off to relatives and friends as soon as possible. When they see how delightful he is, many of their concerns will disappear.

If you feel you CANNOT COPE

Some parents have great difficulty accepting that their new baby has DS. Don't be afraid to voice your feelings, whatever they are.

Parents may feel rejection towards their new baby at first, although most come to realise that it wasn't the baby they were reacting to, but the condition.

"I could not face up to things at first. I rejected my baby, but I am glad I have her now."

"I couldn't see the baby, all I saw was DS, and that was the worst thing that could ever have happened to me. Now I know and love him for who he is."

Don't make any decisions in a hurry, just try to understand your real feelings. Bounce these thoughts off a health visitor or doctor. They should act as a sounding board but should not try to make decisions for you.

You may want to leave your baby behind in hospital for a while, where he will be well cared for, to give yourself time and space to think.





Some parents may continue to feel that they can't face the prospect of bringing up a child with DS.

"I feel sorry for her, but I don't love her".

"I knew I couldn't cope, and we decided on adoption. I'm sure it was the best thing for all of us."

In these circumstances, there are a number of options. Foster or respite care is available, and there are always families keen to adopt a baby with DS.

"As a foster parent, I'm there at the drop of a hat, and parents know that their child is in a safe and loving home."

"We felt we could give a child with DS the special love and encouragement that's needed. Fiona has enriched our family life more than we ever expected."

"Our other children totally accepted Ian as their brother from the day he came to live with us and absolutely adore him. We are very proud of him, and very happy we decided to adopt a baby with DS."

Giving up your child is not an easy decision to make. Parents who know they will never be able to love or care for their child deserve understanding and compassion, not criticism.

Helping your baby to GOOD HEALTH

The idea that all children with DS are frail and delicate is false. On the contrary most children enjoy good health.

Don't be worried by medical problems which can sometimes be associated with DS; these can cause unnecessary anxiety. Here are some hints.

FEEDING

Breastfeeding is a good way of giving your baby extra protection against infection. Mothers are sometimes told that they cannot breastfeed simply because their baby has DS. Babies with DS can be successfully breastfed.

“Breastfeeding Lucy was so important to me in the early days. My feelings of inability to cope disappeared whenever I fed her. I felt I was doing something which was giving her the best possible start in life.”

If bottle feeding does turn out to be the best thing for you and your baby, make sure that feeds are still intimate times.

Babies with DS can take a long time to feed, so you may have to use all sorts of methods for keeping baby awake. Stroke his cheeks, tickle the soles of his feet, unwrap him slightly, or even change his nappy.

Don't worry if your baby vomits a little after feeds. Babies with DS are more likely to do this than others. It is thought to be due to floppy stomach muscles. As these strengthen, the vomiting gets less, and by six months it has usually disappeared.

It is important that your new baby sleeps for no more than 4 hours at a time without being woken for a feed.

This may be different advice to that given to you with your other children.





TEMPERATURE CONTROL

Any new baby's heat regulating mechanism may not always work well in early life. It is important to keep checking that your baby is comfortable, and never gets too hot or cold. Babies can become dehydrated quickly so offer sterile water regularly.

SKINCARE

Your baby's skin can get dry and flaky. Massaging his body with baby oil following the bath can help. You can also obtain creams to apply which will prevent drying or cracking. Ask your health visitor or doctor.

TONGUE CONTROL

Young babies often stick out their tongues, and babies with DS may initially seem to do so more. This is partly because of their poor muscle tone. To help your baby, try to avoid a blocked nose which encourages an open mouth and protruding tongue.

Whenever you notice his tongue sticking out, pop it back into his mouth with your finger. Even if muscle tone is poor, your baby will soon learn to do this for himself.

IMMUNISATIONS

Children with DS should follow the usual immunisation schedule.

HEALTH CHECKS

Try to attend all the health checks arranged for your baby. They give you confidence that your baby is healthy and developing well. They also make sure any possible problem is detected early, when treatment is more likely to be effective.

Eyes

It is sensible to make sure that your child is seen regularly by an eye specialist – an ophthalmologist. Your paediatrician will arrange this. The first visit should be made at about nine months. Thereafter, routine annual checks are important.

Ears

Hearing will be tested by your health visitor at about nine months. Routine tests are important as children with DS are susceptible to a condition called 'glue ear'.

'Glue ear' can result in hearing loss and delay learning ability. However, treatment can be extremely effective. Look out for signs of hearing difficulty, or a persistent blocked nose and ears.

Teeth

The teeth of children with DS often erupt later, so milk teeth stay longer and can suffer more wear.

Dental care is important. Brushing should be started when the first tooth appears. Regular visits to the dentist should be made from an early age.

General physical examinations

Every child with DS should be examined by a doctor annually. This allows growth to be monitored, and any health problems to be detected.



PLAYING with your BABY

'Early stimulation' of babies with DS helps their development. Don't let yourself be worried by this phrase, and plunge into an intensive training regime which will exhaust both of you, and upset family life.

Let your instincts guide you: cuddle and speak to your baby when he's awake. Provide interesting sights and sounds, introduce a wide variety of experiences – just as you would for any baby. Also respect his need for sleep in between feeds.

SUGGESTED ACTIVITIES WITH YOUR BABY

Carry your baby around with you in a baby sling. Not only do your movements stimulate his sense of balance, but he will feel close to you, and content.

String cradle toys across his cot within reach of his kicking feet. Turn bath time into play time by tickling, blowing, kissing and singing. You'll find it fun too!

When changing nappies, place bright objects beside the mat to catch your baby's attention. Later he'll try to reach and grab them. Better still, ask an older child to provide the entertainment while you work on the nappy end!

As he gets bigger, prop him in a bouncing cradle beside you as you work. Talk, whistle and sing to him as you get on with things. Play games like 'This little piggy' and 'Round and round the garden', and teach older children to do the same.

Remember – during the first year you are the most important person in your baby's life. Your attention and involvement will help your child's development more than anything else.



Future PREGNANCIES

However much you love your child, you may be concerned about the possibility of having another baby with DS. Perhaps you are also wondering whether your other children have an increased chance of having a child with DS.

There are three kinds of DS: Trisomy 21 DS (found in about 95% of cases), Translocation DS and Mosaic DS. For more information about these look at *What is Down's Syndrome?* in this series.

Chromosome analysis performed on a blood sample from your baby shortly after birth will show which type your baby has. If the results of this test are not automatically given to you, ask the paediatrician in hospital for them.

The chances of having another child with DS depends upon the type that your baby has. Around 95% of babies have Trisomy 21 DS and this is not carried by the parents.

About 4% of babies have Translocation DS. This usually occurs at random, but in one third of cases it has been inherited from either mother or father. Parents whose infant has Translocation DS should have a blood test to see if they are 'carriers'.

A very small number of children have mosaic DS. In this case, only a percentage of cells carry the extra chromosome. If your baby has mosaic DS, your chance of having a second child with DS is likely to be the same as the usual risk factor, which is dependent on the age of the mother.

At present there is no treatment which will prevent the occurrence of DS. Once pregnant, 'screening' tests available to pregnant women will indicate whether there is an increased chance of the baby having DS. Currently to confirm or exclude DS, the mother has then to go on to have amniocentesis.

Amniocentesis and chorionic villus sampling (CVS) are antenatal diagnostic tests which will detect whether or not the baby has DS. These then leave the parents with the difficult decision of whether or not to proceed with their pregnancy.

Research is advancing all the time into non-invasive testing for DS. However some women choose not to have any testing during pregnancy.

Looking to the FUTURE



Today, children with DS are healthier, more able and more integrated into the community than ever before. People with DS now have many more opportunities to realise their potential.

Thankfully today the negative attitudes people once held towards disabilities are disappearing.

It is important to remember that a baby with DS is first and foremost a baby, a unique individual full of potential.

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 we often receive about Down's syndrome.

Some points to bear in mind while you read:

- The term Down's syndrome has been shortened to DS.
- People with DS are described as having learning disabilities or difficulties, rather than as having a mental handicap.
- In some of the booklets we refer to the person with DS as 'she' or 'her', while in others we refer to 'he' or 'him'. All the information applies equally to both sexes.
- 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.



Down's Syndrome

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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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