

Your baby has Down's syndrome

A GUIDE FOR PARENTS

A DOWN'S SYNDROME ASSOCIATION PUBLICATION



■ YOUR BABY HAS DOWN'S SYNDROME

You may feel at this stage that you do not want to know anything more about Down's syndrome. In that case, keep this booklet in a safe place for when you feel ready.

In this booklet 'he' and 'she' are used interchangeably, but all information applies to babies of both sex.

During pregnancy most parents have hopes and dreams for their future child. When the baby is born with Down's syndrome their dreams are shattered - they are shocked and confused. The period immediately after a baby's birth is a difficult time to be given such news. Parents are not at their strongest, physically or emotionally, and many experience feelings which disturb them. This booklet is based on the writings of parents who have had the same shock, have had a baby with Down's syndrome, and have felt many of the emotions that you are going through now.

Sorrow

When you are told that your child has Down's syndrome, it would be exceptional not to feel sad. If you can express this feeling, by 'letting go' of your tears, you will find it easier to cope afterwards. There is no shame in weeping - it is a natural reaction, and crying together can help both parents bear the sadness.

Most parents need to go through a period of mourning for the imagined or hoped-for child they expected.

Anger

Most parents ask 'why should it happen to us?' There is no answer to this question, but it is all right to feel anger and no-one will blame you. If you can talk it through with a caring friend it may well be helpful.

Shock

It is quite natural after a while to feel 'numb'. This is your mind's way of protecting you from more pain than you can handle. As shock fades you may experience other reactions, which might include:

- feeling as if you are in a bad dream
- becoming forgetful and finding it difficult to concentrate
- denial

Guilt

Not all parents feel guilty, but many do. This is also a natural reaction, although the fact that your child has Down's syndrome is certainly not your fault.

These feelings are perfectly normal and, according to most parents' experience, they may never be completely eradicated but will become less prominent as time passes.

■ SUPPORT FOR PARENTS

It helps many parents to be able to talk over their feelings with others who have been through the same experience. The Down's Syndrome Association has branches and groups in most areas of the country. Getting in touch with them, when you feel ready to do so, could help you to sort out your feelings about what it means to have a baby with Down's syndrome.

Most parents have questions about Down's syndrome and what having a baby with the condition will mean to them and their family. In this booklet we shall try to answer questions that parents most often ask. The Down's syndrome Association has literature and information on almost every aspect of the condition, so if you would like more information, just contact us.



■ WHAT IS DOWN'S SYNDROME?

Down's syndrome is a genetic condition (*i.e something you are born with, which is present in the baby from the moment of conception*) caused by the presence of an extra chromosome. Chromosomes are tiny particles which are present in every cell in every tissue of our bodies. They carry the 'blueprint' for all the characteristics we inherit. This blueprint is carried in the form of a coded message in a chemical substance called DNA. There are 23 pairs of chromosomes in each cell, hence 46 altogether. One of each pair comes from the father, one from the mother.

In 1959, a French geneticist, Professor Jérôme Lejeune, discovered that Down's syndrome was caused by the presence of an extra copy of chromosome 21, making 47 chromosomes in all.

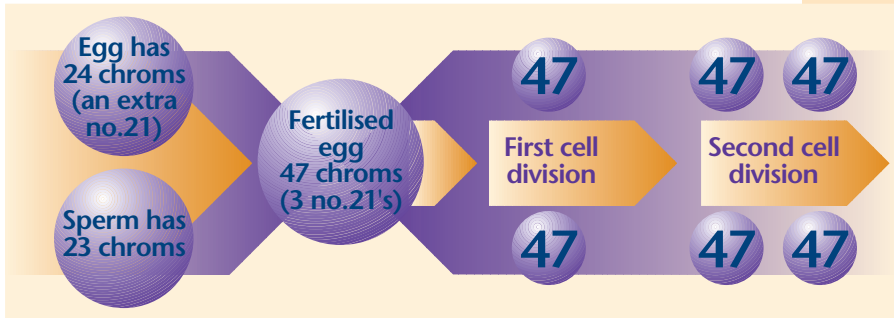
A 'syndrome' is a collection of signs or characteristics. The name 'Down' comes from the English doctor, John Langdon Down, who first described the syndrome in 1866, nearly 100 years before the extra chromosome was discovered. Every day in the UK, between one and two babies are born with Down's syndrome, which means that about one baby in 1000 has the condition.

People with Down's syndrome all have a certain degree of learning disability (mental handicap). The degree of disability varies from person to person and it is impossible to tell at birth what that degree will be.



■ WHAT CAUSES DOWN'S SYNDROME?

As yet, we do not know what causes the presence of the extra number 21 chromosome. It can come from either the mother or the father. The most common type of Down's syndrome, Standard Trisomy 21 (also known as *Primary Trisomy 21* or *Regular Trisomy 21*), occurs because of an unusual cell division which has produced either an egg or a sperm with 24 chromosomes instead of 23. When this egg or sperm fuses with an ordinary egg or sperm, the first cell of the developing baby has 47 chromosomes instead of 46, and all that baby's cells will have 47 chromosomes. There is no way of predicting whether a person is more or less likely to make eggs or sperm with 24 chromosomes. We know that babies born to older mothers have a higher chance of having Down's syndrome, but we do not know why.



■ COULD WE HAVE PREVENTED OUR BABY HAVING DOWN'S SYNDROME?

It is important to remember that you are not to blame for your baby having Down's syndrome. Nothing you did before or during pregnancy has caused it. It occurs in all races, in all social classes and in all countries throughout the world. It can happen to anyone.

■ DOES IT MEAN THAT ANY FURTHER CHILDREN WE MIGHT HAVE WILL ALSO HAVE DOWN'S SYNDROME?

Standard Trisomy 21 is not hereditary. However, once you have had one baby with Down's syndrome your chances of having another child with the condition are increased. Overall this chance is between 1 in 100 and 1 in 200 which is considerably less than the chance of, say, having twins 'out of the blue'. When thinking about your next pregnancy it would be helpful to talk to a genetic counsellor who could talk things through with you in some detail.

■ WHAT DOES THE EXTRA CHROMOSOME MEAN FOR OUR BABY?

All people with Down's syndrome share certain physical characteristics, though not every child with the condition has every characteristic. Your baby will have inherited physical characteristics from both of you, just like any other of your children, as well as sharing some of the common signs of Down's syndrome. Your baby is unique. Some parents wonder if there is a link between the number of these physical characteristics and the future development of their new baby. In fact, there is no way at this early stage of predicting the level of ability of your child.



The extra chromosome means that your baby will be slower to reach her milestones and will have a certain degree of learning difficulty, but most children with Down's syndrome do learn to walk, talk, ride a bike and read and write, in fact to do most of the things other children do. It's just that their development is usually delayed.

■ WHAT ARE THE COMMON SIGNS OF DOWN'S SYNDROME?

- Your baby may have looser muscles and joints than other babies. This will improve as she gets older.
- She may have a lower than average birth weight and put on weight at a slower pace than other babies. *(Special weight charts are available for babies and children with Down's syndrome from the National Office of the Association).*
- Babies with Down's syndrome often have eyes that slant upward and outward. Their eyelids often have an extra fold of skin (*epicanthic fold*) which appears to exaggerate the slant. This does not mean there is anything wrong with the eyes. They just look different.
- The back of your baby's head may be flatter than average.
- Many babies with Down's syndrome have a single crease which runs right across the palm of the hand. Doctors often look for this characteristic crease as a sign that a baby may have Down's syndrome. However, some babies who do not have Down's syndrome also have a crease like this.

All babies are different from each other and the same is true of babies with Down's syndrome. This means that in some babies the characteristic signs of Down's syndrome are fairly easy to recognise soon after birth, whilst others may look and behave differently from other babies. However, experienced doctors and midwives are usually very good at picking up subtle differences which suggest that a blood test should be done to check the chromosomes.



■ WILL OUR BABY HAVE HEALTH PROBLEMS?

Chest and sinus problems

Babies and young children with Down's syndrome tend to be prone to chest and sinus infections but, thanks to better medical knowledge and care, such infections are no longer as serious as they used to be.

Feeding problems

Some babies with Down's syndrome seem to lack the strength and determination to feed in the early days. Some may be slow to sort out the complicated coordination necessary to suck, swallow and breathe at the same time and they splutter and choke a bit. These problems often settle down during the first two weeks. If you want to breast-feed but find your baby can't cope in the early days it may well be that if you keep your milk going he will soon sort himself out and take to breast-feeding.



You may have chosen to bottle-feed your baby for whatever reason and many babies with Down's syndrome find it easier to feed from a bottle. It will not harm your baby to have a formula milk. The important thing is that you and your baby should be as contented as possible!

When you begin to feed your baby it is worth trying to hold her fairly upright to feed and check first that the tongue is not sticking to the roof of the mouth. For a baby to suckle and get adequate milk the nipple or teat must be ON the tongue (*not under it*). Specially adapted teats are available to help babies who have difficulty feeding.

Do not hurry the feed. Babies with Down's syndrome often feed very slowly, so do not stop too quickly. Your baby may fall asleep at intervals. If this happens in the middle of a feed, try tickling his cheeks, chin and feet.

Temperature control

The body's heat-regulating mechanism does not always work well in early life. It is therefore important that the baby's bedroom is not too cold (*18°C is ideal*), and there are no draughts. Overheating can be hazardous for all babies, however, and it is important that they do not get too hot through over-wrapping when indoors. Humidifying the air will help your baby to breathe more freely, too.

Skincare

Your baby's skin may be very dry. Massage him with a little baby oil and put some in the bath water. A little moisturising cream, for example E45 cream, unperfumed cold cream or olive oil rubbed gently on the skin every day should prevent drying and cracking. Keep an eye out for allergic reactions. Your doctor or pharmacist can help with alternatives. You may be able to obtain some creams on prescription.

Tongue control

You may need to give your baby particular attention to help control her tongue. Playing games, pulling faces and making noises etc, will assist your child to exercise face and tongue muscles and also help with early sounds and speech. Try to avoid a blocked nose which would encourage open-mouth breathing and protruding tongue. Humidifying the air in the baby's room will help prevent a dry, blocked nose. Making a game of pushing in the tongue over and over again will help!

Heart problems

About one in three children born with Down's syndrome has a heart defect. Some heart defects are quite minor, such as murmurs; some defects are severe, requiring medication and/or surgery.

Your baby's heart will be one of the things that a paediatrician will check at her first neonatal examination, and, if there is any doubt about a heart defect being present, then further tests will be made to make sure everything as it should be. However, heart defects are not always picked up by these tests when a baby is very small so your paediatrician will continue to make regular checks in the first year or so for any signs of a defect. If you are ever worried about anything - ask your doctor! *(For a detailed explanation of the more common heart defects that can affect babies with Down's syndrome, please see Appendix 1).*

If you are told your baby has a heart defect, and you would like to talk to someone whose child has a similar problem or has had heart surgery, the Down's Syndrome Association can put you in touch with parents who will understand what you are going through.

■ HOW WILL HAVING A BABY WITH DOWN'S SYNDROME AFFECT THE REST OF THE FAMILY?

Having a baby with Down's syndrome in the family will require a period of readjustment. You may feel under more pressure to do things with your baby to help her development than you would have felt with any other baby. Take time to get to know the baby as part of the family. Your baby with Down's syndrome will have his own personality and characteristics just like your other children.

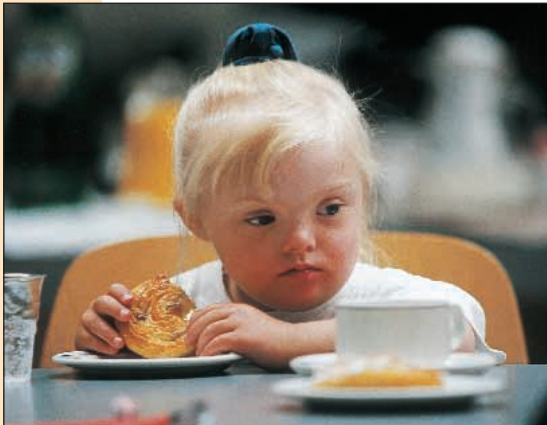


■ HOW WILL WE EXPLAIN TO RELATIVES?

Telling brothers and sisters

Children take their cue from their parents - if you can feel positive about the new baby, they will too. It is important to explain to them as soon as possible that the new baby may learn more slowly than themselves to do things and may need extra care, but that with time he will learn to do everything other babies do.

There is little reason to think that the new baby will have a bad effect on the other children's lives. Research shows that most children get on well with their sibling with Down's syndrome, are fond of him, still enjoy their own pursuits and are not embarrassed by their friends meeting him.



Many parents have felt that their other children became more compassionate, with more feeling for people with all kinds of disabilities, as a result of having a sibling with Down's syndrome.

Try to integrate your baby into the family routine as quickly as possible. It is important not to restrict the rest of the family's activities more than necessary because the baby has Down's

syndrome. Take him out and about with the family - this will help them all to come to terms with the condition and will give the baby plenty of new experiences.

Telling the grandparents

Grandparents will undoubtedly go through the same feelings as yourselves, but without being able to fill their time with the practical tasks of looking after the baby. Where possible, try to include them in doing things with and for your baby and allow them to get to know her. Grandparents and relatives or friends are always welcome to speak to someone at the Down's Syndrome Association or to attend meetings of local branches or groups.

Telling friends and acquaintances

This, too, is done best as soon as possible after the birth. Sometimes friends (*and relatives*) unwittingly say thoughtless and hurtful things out of embarrassment and even ignorance. They have pictured you with your 'normal' new baby and may have difficulty knowing how to react now that the baby is born and has Down's syndrome. If you can be positive about your baby, friends will take their cue from you.

■ WILL HAVING A BABY WITH DOWN'S SYNDROME IN THE FAMILY DISRUPT OUR MARRIAGE?

Research shows that no more marital difficulties are experienced by parents of children with Down's syndrome than by the rest of the population. In fact, when asked about the effect of having a child with Down's syndrome in the family, parents often say it has brought them closer together.

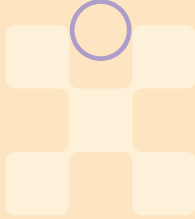
■ WHAT DOES THE FUTURE HOLD FOR OUR CHILD?

During the first weeks, the parents ask

- what will be available for my child when she is older?
- what kind of financial provision can we make for our child's future?

Children with Down's syndrome can and do grow up to live long and fulfilled lives. Provided they are allowed the opportunities they need to develop self-help skills and independence, people with Down's syndrome can thrive well into their fifties and beyond, facing many of the challenges we all encounter: school, further education, work and a home of one's own. Many children with Down's syndrome are now being integrated successfully into mainstream schools.





Available provision differs from area to area and the situation is always changing. Residential and occupational opportunities for young people and adults are being developed all the time by both statutory and voluntary agencies. Up-to-date information can be obtained from the Information Officers at the National Office of the Association. Financial provision can be made by way of a trust. In either case, it can be combined with a planned programme of saving or by the provision of a suitable insurance policy. The Association has information on these topics and can put you in touch with professional people who can help.

■ WHERE CAN WE GET HELP IF WE NEED IT?

Your midwife, Doctor, Health visitor and Specialists

Questions about health care should be addressed to your midwife, family doctor, or to your Health visitor who is generally based at the local Child Health Clinic. Your child may also be under the care of a paediatrician or some other hospital-based specialist who will also give advice. All can be useful sources of information about other services.

Social Worker

A useful starting point for help is the Local Authority or Hospital Social Worker. In many areas a Social Worker will call automatically after the birth of a child with special needs. Sometimes you may have to ask for a visit. You will find the number in your telephone directory under Local Authority Social Services Department.

Child Development Centres and Community Teams for Learning Disabilities

Child Development Centres and Community Teams for Learning Disabilities exist in many areas. They consist of professionals: psychologists, speech and language therapists, doctors etc., who can provide valuable information and assistance.

Benefits Agency (Department of Social Security)

This is the government department which is in charge of the payment of benefits to people with learning disabilities (*mental handicap*) and their families and carers. One of the useful booklets the Benefits Agency produces is updated from time to time to take account of changes in the benefits and is called 'Caring for Someone?'. Telephone your local Benefits Agency office for a copy. The DSA also has information on benefits.

Down's Syndrome Association

The Down's Syndrome Association's National Office is at:
155 Mitcham Road, London SW17 9PG.
24-hour help-line: 0181 682 4001 Fax: 0181 682 4012

We have staff who can spend time with you to help sort through some of the many questions you may wish to have answered. If you telephone in advance for an appointment we will ensure someone is free to see you.

Local Branches and Groups

The Association has a network of Branches and Groups which are run by other parents. They are mine of information and first-hand experience and will always welcome a new member.

■ SUGGESTED ACTIVITIES WITH YOUR BABY

■ Blow at all parts of your baby's body. Tickle, rub, pat and prod him. Roll him around.

■ Do not always have your baby dressed. Place the baby naked onto a scratchy woollen blanket or crackly paper so that the nerves of the body experience something quite different. The noise of the paper will be an incentive for him to move. Sounds are the baby's reward.



■ Forget about the baby's comfort now and then. Put him too near the foot-end of the cot. He may want to push against it. Place the baby on his tummy and hold some bright, noisy object in front of his eyes, but above the head. This will encourage him to lift the head and exercise the neck muscles.

■ Whistle and sing if it makes the baby stretch or arch the back. Use odd sounds which suddenly lapse into a peaceful silence. Do not be afraid to be child-like with your baby. It is surprising how aahs and oohs can provoke wriggles and happy twisting which no serious talk can ever achieve.

■ Do not place bells near the hands but put them also on and near the feet. This will make the baby kick more frequently and more purposefully. If the bells are placed on the sides, he will even learn to use alternate limbs.



■ Carry the baby around in a baby sling, In this way she gets rocked, lowered, lifted and turned without much effort on your part. This stimulates the sense of balance while she feels loved and a part of everything you do.

■ Tease the baby into turning, stretching or bending movements by holding a desired object at a slight distance. It may be good for an inactive baby to learn that effort has its reward.

■ If the baby does not attempt to crawl, give her the joy of a bath in which you lie her down on her tummy over a large rolled up towel. This comfortable bulge should support the chest and abdomen while leaving the limbs to dangle freely in the water. When splashing in this position, the baby may come very close to the mechanics of crawling.



■ It is helpful to do things together with the baby, to get down with her at times. For the baby the task at hand is gigantic. Why must we then make it harder still by standing over her like a giant? If the legs are still lifeless or weak and the knees still unused you can sit opposite your baby on the floor, with the soles of your feet touching her feet, and push against each other. You can



be the wall on which the baby gradually raises herself from crawling to a standing position. You could make a ramp with your legs on which she can learn to climb.

■ Last but not least, make your child itch with curiosity. Do something secretive nearby, or clatter about unseen so that the child will want to overcome the physical stumbling block and get up!

■ ONE PARENT'S VIEW

"For me, the beginnings of bringing up a child with learning difficulties (I prefer this more inspiring label to 'handicapped') were not so easy. Although my books on baby play helped, I still had to feel my way through, especially as my daughter was my first child.

I would let her close to me a lot:

■ *I carried her in a sling;*

■ *I wheeled her with me around the house in a small cot;*

■ *I propped her up in a slanting chair placed near me on the top of the sink or on the table (ideal for the two of us to look, listen, touch and babble).*

I would not let her doze off too much nor accept this tendency simply as a part of the 'the condition'. I found that if I made something stand out for her, if I selected for her what she might not have been able to select for herself from an overwhelming setting, she showed little sign of tiredness or switching off. Her eyes became alert, her body more tense and the little head was less likely to sink loosely into the back of her neck. I still respected, however, her need for some switching-off times which I noticed in her remote glance.

Apart from general baby care I tried to change the routine:

- *I changed her in different places. A bath could be had in a sink, with dad or in a swimming pool.*
- *Physical play could be done on a puffy eiderdown or a rough mat.*

I would ask critical questions regarding toys. Did they delight, provoke and provide enjoyment? For instance:

- *Why not fix cradle toys where the feet and knees are hopefully kicking, or where the elbows push out?*
- *Why not have a rustling paper under the shoulders?*
- *Could cradle toys be made of other materials than plastic, could they be covered with different textures?*
- *How about changing colours from baby pink to a glittering gold?*
- *How about changing from bell to beady sounds to a wooden clippety-clop, a cymbal clang, a click?*
- *Can I surprise by hanging up a fat balloon, tiny beads, a closed plastic water bag for squeezing, a piece of chocolate, a mirror? Can I cover things up suddenly and then let them reappear?*

We decided to be on her side and not make behaviour training our first concern. On looking back this seems like a daring attitude but my daughter, who is now ten years old, shows me that FOR HER this must be right."

■ PARENTS TALKING - HOW SOME PARENTS COPE

"When telling relatives and friends that our much-wanted first child had Down's syndrome we knew that they would find the news sad and we broke it to them gently. Our son has been accepted and visited by all."

"By the time the diagnosis was made, Steven was already part of the family and we could not consider anything other than keeping him with us."

"When our little girl was born with Down's syndrome, it was a terrible shock and we were very sad. Our parents and friends were very supportive, which helped enormously. One of the most helpful things was being introduced, through the local Down's Syndrome Association group, to a family with a nine-month old daughter with Down's syndrome. Meeting them showed us that we would be able to cope because they had."

■ BROTHERS AND SISTERS SPEAKING

"When my little sister was born, Mummy and Daddy told me that she would be a bit different and would need help to learn things, more than I did. She can do lots of things and I take her out to play. I think she is lovely." Angela, aged 12

"My brother can be a real nuisance. He gets everywhere and wants to play with all my books and toys but my older sister says I used to do that when I was his age so I suppose I just have to be patient with him." Simon, aged 9

■ GRANDPARENTS HAVE THE LAST WORD

"One of my friends reminded me recently that when I told her that my daughter's first child had been born with Down's syndrome, I said my life would never be the same again. After 11 years I can say that what I said then has been true, not in quite the negative sense that I might have anticipated, but in the richness of the experience we have had in watching our grand-daughter grow and develop." Lucy's Grandma

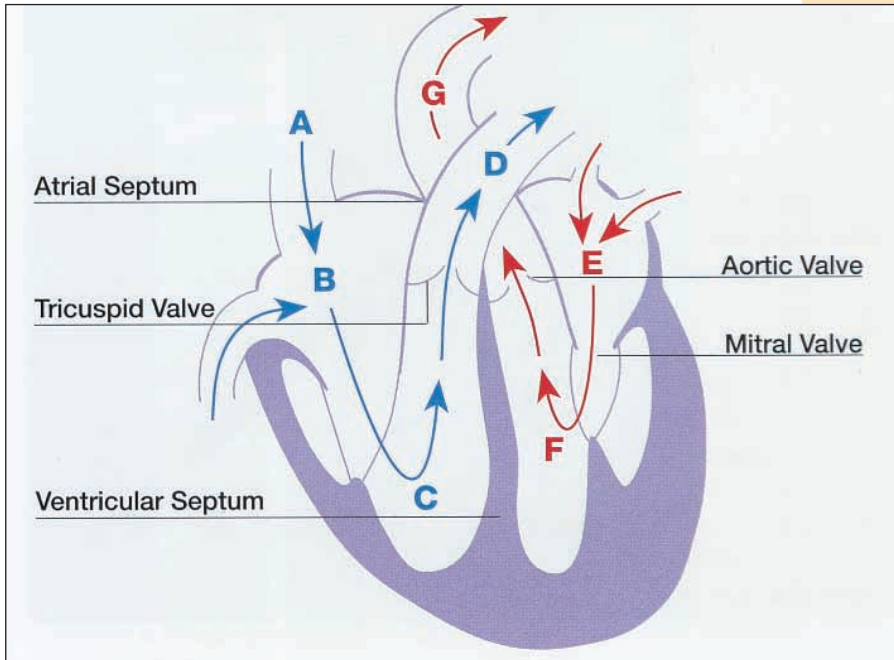
"I still feel moments of sadness when I think how much help Timmy needs compared to my other grandchildren, but bit by bit, I can see some of the tricks in him that the other children have got up to and I know I am really glad to have him as a part of our family." Timmy's Grandpa



APPENDIX I

Congenital heart defects

The normal heart is divided into four chambers. Blueish blood, low in oxygen, reaches the heart through veins (A) and enters the right collecting chamber - the right atrium (B). Blood then flows into the right pumping chamber - the right ventricle (C) - through the tricuspid valve.



The right ventricle pumps the blood through the pulmonary artery (D) to the lungs where the blood receives oxygen. After the blood is oxygenated, it is bright red. This blood returns to the heart through the left collecting chamber - the left atrium (E).

It then flows through the mitral valve into the left pumping chamber - the left ventricle (F). From there it is pumped into a large blood vessel called the aorta (G) which feeds it into smaller blood vessels which carry it around the body to supply essential oxygen to the tissues. When the oxygen has been removed the blood becomes blue again and returns to the right side of the heart.

Usually it is a heart murmur that first alerts a doctor to the possibility of congenital heart defect. However, not all children have a murmur so various other clues such as colour (pale, grey, blue), respiratory rate and effort, contours of the chest, swelling of the eyelids are looked at. On X-ray an enlarged heart and congested lungs might indicate a congenital heart defect.

An electrocardiogram (ECG) or echocardiogram (*using high-frequency sound waves*) helps provide additional information which may indicate the need for a cardiac catheterisation. This procedure requires a stay in hospital and can define precisely the extent and location of the defect. It is common for a congenital heart defect to give rise to a delay in growth and weight gain, and in children with Down's syndrome there is often also decreased muscle tone and motor delay (*i.e. they are delayed in learning skills such as crawling, standing, walking etc.*). These symptoms usually improve after surgical correction of the heart defect.



The most common heart defects among children with Down's syndrome are:

Atrio Ventricular (Septal) Defects (AV(S)D)

These involve a malfunction of the walls and the valves between the atria and the ventricles. The condition amounts to a 'hole in the centre of the heart', which can gravely affect the direction and pressure of the blood flow and impose a strain on the heart and lungs. Nowadays this can be corrected by major heart surgery in infancy, but for a few babies the operation is not medically advisable.

Ventricular Septal Defects (VSD)

These defects involve an opening in the septum or wall which separates the two ventricles. If a small opening exists, this will not cause strain on the heart and, in some cases, the opening may close itself. For large defects surgical correction may be necessary - again this is usually carried out in the first years of life.

Tetralogy of Fallot

This is a combination of four defects:

1. A large hole between the two ventricles (*ventricular septal defect*);
2. A narrowing in or near the pulmonary valve;
3. An unusually muscular right ventricle
4. The aorta receives blood from both the right and left ventricles.

This condition results in cyanosis or blueness of the lips and fingernails. Total correction is difficult in infants but an operation can be carried out to provide temporary relief.

Persistent Ductus Arteriosus (PDA)

All children are born with a ductus arteriosus - an opening between the pulmonary artery and the aorta. Normally, the passageway closes up within a few weeks of birth. When this fails to happen, some of the blood that should go through the aorta and on to the body is sent back to the lungs, thus circulating uselessly between the lungs and the heart so imposing extra strain on the heart. If this occurs the duct can be closed by a simple operation which does not involve operating on the heart itself.

Atrial Septal Defect (ASD)

These are holes in the wall which separates the two artia. They are often quite small. If large enough to allow a significant amount of blood to flow through they may need to be closed by a surgical operation. So-called *secundum* defects (*openings in the upper part of the atrial septum*) often close on their own. *Ostium primum* defects (*openings in the lower part of the atrial septum*) are very near the valves and often need surgery.

APPENDIX II

The genetics of Down's syndrome

There are three types of Down's syndrome:

Standard (Regular or Primary) Trisomy 21

About 94% of all people with Down's syndrome fall into this group. This type of Down's syndrome is always an accident of nature. It can happen to any one and there is no known reason why it occurs.

The parents have normal chromosomes, but the baby has three rather than two chromosomes of the number 21 pair.

Translocation

This type of Down's syndrome occurs in about 3% of babies with Down's syndrome. Part of the number 21 chromosomes becomes attached to another chromosome so that both parts of the new large chromosome move closer together as one. In about half of the people who have Translocation Down's syndrome, the translocation is a one-off occurrence and does not mean that it will happen again in any future pregnancies.

In the other half, however, it occurs because one or other parent, though having a normal balanced chromosomal make-up, has one of the number 21's 'stuck on' to another chromosome. In this case the chance of another child with Down's syndrome being conceived is quite high. Blood tests can be carried out to find out more detailed information.

Mosaicism

This type of Down's syndrome is also rare - only about 2-3% of people with Down's syndrome fall into this category. In Mosaic Down's syndrome the cells with the extra 21 chromosome are mixed with other 'normal' cells. In other words, only a certain percentage of the cells is affected.



New parents are entitled to one year's free membership of the Down's Syndrome Association. For details and to join, please [click here](#) to go to our membership section.

If you are looking for more information on any aspect of Down's syndrome, you can [click here](#) to go to our 'information' section.

If you would like to speak to someone our information team is available on
020 8682 4001 from 10.00am to 4.00pm
Monday to Friday
or e-mail: info@downs-syndrome.org.uk.

