

STEP BY STEP INTO THE FUTURE An introduction to Down syndrome

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In collaboration with the
National Department of Health
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Mental Health and Substance Abuse

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INTRODUCTION

This booklet is an attempt to provide answers to questions frequently asked by parents of children with Down syndrome. Many of these questions are usually asked once the diagnosis has been confirmed. This booklet has been written by parents of children with Down syndrome in consultation with professionals working in the field of Down syndrome and it gives an introduction to Down syndrome. A short list of selected books dealing with the subject in more detail is supplied on page 54. Down syndrome occurs in both sexes. However, in this booklet the baby with Down syndrome will be referred to as "he".

SHARE THE JOURNEY -A message to parents

CONGRATULATIONS ON THE BIRTH OF YOUR NEW BABY!

Although things may not be the way you had planned, please enjoy every moment with your precious little bundle.

You will probably be feeling very overwhelmed by everything right now and at this stage might not be ready to read through this booklet. In that case, use the content page to guide you to the information you need now and after reading that, keep this booklet in a safe place for when you feel ready for the other information.

Some of these feelings may be shock, sadness and numbness. It is normal and acceptable for parents to go through a period of mourning for the imagined, or hoped-for, child they expected. Once you have said "good-bye" to the baby you expected, it will be easier for you to embrace the new baby into your heart and life.

As shock fades, you may experience other reactions such as rejection, disbelief, anxiety, anger, disappointment and denial. This too is normal. Discuss these feelings with someone you trust. You will need someone who will listen, more than someone with all the answers. Be kind and patient with yourself. Always remember that it is no-one's fault that your child has Down syndrome. It is important to remember that nothing you did before or during pregnancy caused Down syndrome. Down syndrome occurs in all races, in all social classes and in all countries throughout the world.

Do not hide the fact that your baby has Down syndrome. Tell grandparents, family and friends as soon as the diagnosis is medically confirmed and as soon as you are ready. You will benefit enormously from their support. Remember they will take their cue from you. If you are positive about your baby, they will be too. The more your child is exposed to your family and community, the sooner understanding and acceptance will occur.

Like all parents of a new baby, there is much to learn. However, you have the benefit of years of ongoing research which has been documented to help you through how and what to do. Do not be too hard on yourself or be nervous - you're certainly not alone. In fact, there's an entire organisation of people just like yourself who are willing to share your experiences. Seek information in your own time once you feel ready to cope. Don't be afraid to ask questions, it is your right! New information develops daily. Never stop reading. Never stop learning.

Children with Down syndrome can and do grow up to live long, happy and fulfilled lives. Provided they are allowed the opportunities, they will develop self-help skills and independence. They can thrive well into their fifties and beyond, facing many of the challenges we all encounter. Many children are now being integrated successfully into mainstream schools. Many individuals with Down syndrome follow high profile careers in the world of acting, modeling, music, sport, computer technology and motivational speaking. Allow your child the opportunity to develop to his full potential. Never ever let Down syndrome be the ceiling for your child's achievements. Although there might be delays in the learning process, aim high! Share his journey to independence with him and let him make you proud.

The birth of a baby is an exciting and happy time for the whole family. Rest assured that this occasion is no different. Your baby has the same needs and will require nurturing, care and love just like ALL babies. Never forget that your child is a baby first and has Down syndrome second. All our children bring much joy and love along with a measure of frustration and heartache, they teach us about patience and understanding and they love us unconditionally. Do the same for them.

You have embarked on a journey. A journey you share with your differently-abled child. Enjoy and appreciate all the wonderful things this journey has to offer. May you and your family be blessed with the new arrival and may you find much love and happiness with your child - who just happens to have an extra chromosome. Enjoy your baby!

MEDICAL QUESTIONS

What is Down syndrome?

Down syndrome is a genetic condition that is characterized by typical features. It is caused by an abnormality in the genetic material and it affects all races and all economic groups equally.

Why do they think that your baby has Down syndrome?

Babies with Down syndrome do look slightly different from other babies and therefore they can usually be identified at birth.

Some of the typical features include:

- eyes that slant upwards;
- tiny folds covering the inner corners of the eyes (epicanthic folds);
- small white flecks on the iris (Brushfield spots)
- a small nose with a broad, flat bridge;
- a small mouth which makes the tongue appear large » small low set ears;
- a single crease on the palm of the hand;
- short hands and fingers;
- inclining pinkie;
- wider gap between the big toe and second toe; and
- A slightly flattened appearance of the back of the head.

Other features

- Unusual looseness of the joints
- Poor muscle tone (hypotonia) making the baby feel and appear floppy"
- Loose skin folds at the back of the neck
- Heart defects occur in about 50% of cases
- Eye defects occur in 60% of cases
- Hearing defects may occur and can affect speech and language
- Developmental delay (intellectual disability varies from mild to moderate)

Not all these traits mentioned are found in every child with Down syndrome. Like other children, children with Down syndrome resemble their parents, e.g. hair and eye colour but they also have some of the typical features of Down syndrome. Furthermore each person with Down syndrome is a unique individual and can vary enormously in appearance, temperament and ability. It is also important to note that a person's appearance has nothing to do with his intellectual ability. Therefore a person who has more of these above mentioned characteristics is not necessarily more intellectually impaired.

Down syndrome is not diagnosed only on the basis of physical characteristics; it must be confirmed by means of a chromosome analysis. This is a special type of laboratory test performed on a sample of blood from the baby. Your doctor will be able to tell you more about this test.

Where does the name "Down syndrome" come from?

Down syndrome is named after Dr. Langdon Down, the physician who first described its features in 1866. The word "syndrome" means "a collection of signs and symptoms usually found in combination."

What causes Down syndrome?

Down syndrome is caused by extra genetic material. The genetic material is present in every human body cell and is arranged in tiny structures called chromosomes. They are the building blocks, which give us our individual characteristics. For example they determine the color of our hair and our eyes and many other characteristics.

Each human body cell contains 23 pairs (46) chromosomes, except the sex cells (egg cells of a woman and sperm of a man), which each contains only 23 chromosomes. Egg cells and sperm are formed by a special cell division process during which the chromosome pairs divide and only one chromosome of each pair is included in a sex cell. The egg cell and sperm therefore each receives only one copy of each chromosome pair.

During fertilization a sperm of the father fuses with an egg cell of the mother. The fertilized egg cell then contains 23 pairs of chromosomes (46 in total). One chromosome of each pair comes from the father and the other one of each of

the pairs from the mother. The fertilized egg cell divides rapidly in the womb and eventually the baby is formed. Each of the body cells of the baby also contains 23 pairs (46) chromosomes (see Figure 1).

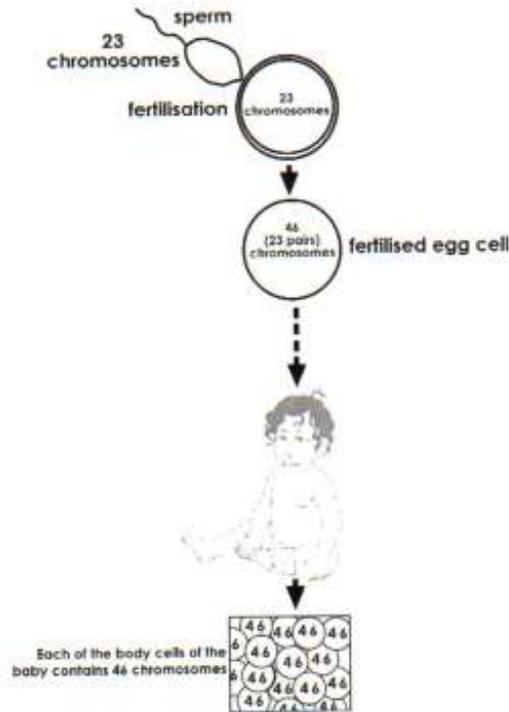


Figure 1: Fertilization and the development of a baby

When a blood sample of a baby is analysed in a laboratory, a photograph of the chromosomes is taken under a microscope. The chromosomes on the photo are then cut out, numbered and arranged according to pairs. Such a chromosome arrangement is called a karyotype. (see Figure 2).

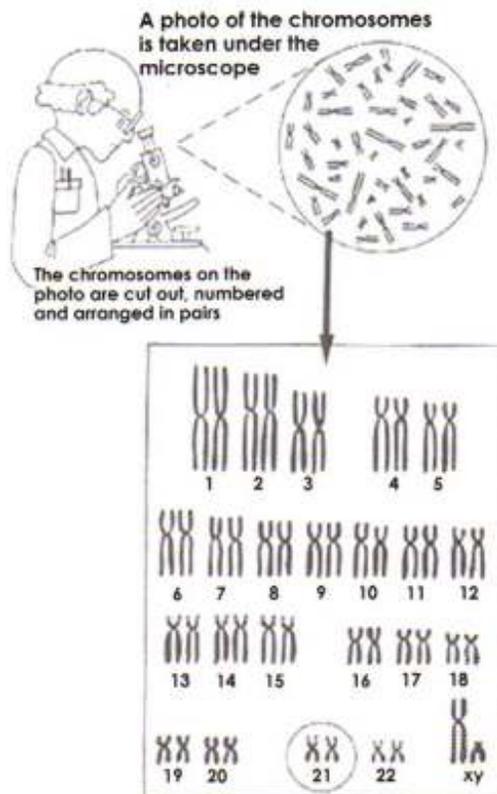


Figure 2: Karyotype of a normal male

Note that the chromosomes are arranged and numbered according to a specific pattern, namely from large to small. One of the smallest chromosomes is numbered as number 21. It is the chromosome number 21 that is involved in the origin of Down syndrome.

It is important to understand that Down syndrome is not caused by anything the mother or father did or failed to do during the pregnancy.

There are three types of Down syndrome:

1. Trisomy 21 type of Down syndrome.

Trisomy 21 is the most common type of Down syndrome and is the cause of approximately 90-95% of all cases of Down syndrome. Trisomy 21-type of Down syndrome is not hereditary!

In young mothers the chance of a second baby being born with Down syndrome is therefore very small.

Trisomy 21 (also known as non-disjunction type) occurs when the two number 21 chromosomes fail to separate and both instead of one become incorporated into either the egg cell or the sperm. This cell then has 24 chromosomes instead of the normal 23. This phenomenon of the chromosome not separating is called non-disjunction.

With fertilization, the sex cell of one of the parents (egg cell or sperm) with the two number 21 chromosomes (and therefore 24 chromosomes in total), fuses with the normal sex cell of the other parent (egg cell or sperm with 23 chromosomes) to form a fertilized egg cell with 47 chromosomes. When this fertilized cell starts to divide, it eventually develops into a baby who has an extra number 21 chromosome in each body cell and hence Down Syndrome (see Figure 3).

Trisomy 21 may be caused by non-disjunction during the formation of either the egg cells of the mother or the sperm of the father. The chances of Trisomy 21 however seem to be increased in women in their late thirties and older (see Figure 4).

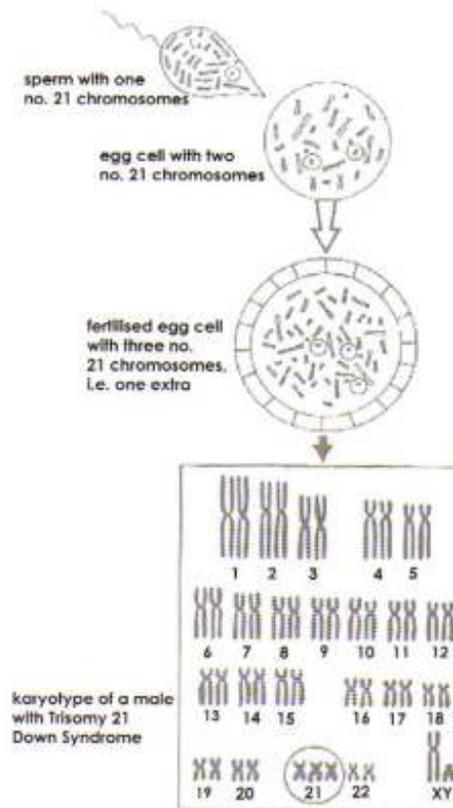


Figure 3: Fertilisation of an egg with two no. 21 chromosomes by a normal sperm (with one no. 21 chromosome) results in the Trisomy 21 type of Down Syndrome.

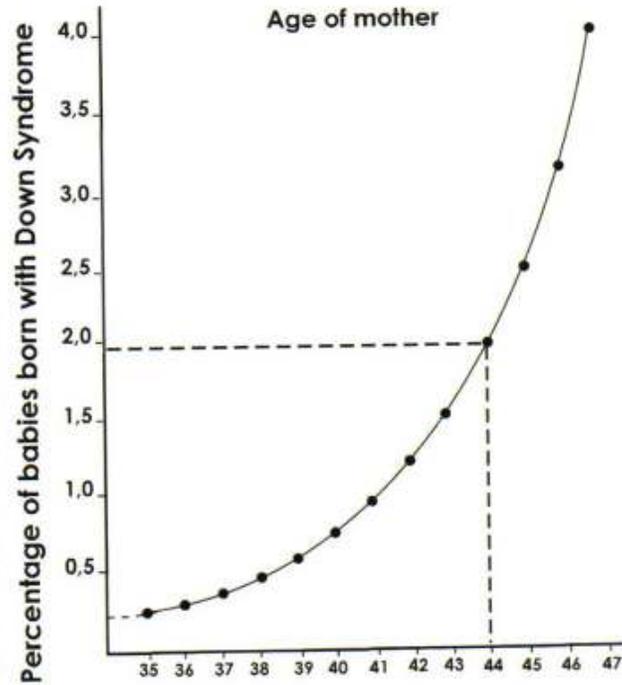


Figure 4: The mother's age and her risk of having a baby with Down Syndrome. For example, the risk for a woman that is 44 years old, is approximately one in 50 (2%)

2. The mosaic type of Down syndrome

This type of Down syndrome is very rare, not hereditary and the chance of a second baby born with it is small. Mosaic type is also known as Mosaicism. This is caused by non-disjunction of the chromosome pair number 21 shortly after fertilization. The cells of the person with this type of Down syndrome have a mosaic pattern. The result is that some cells contain an extra chromosome number 21 (and therefore 47 chromosomes) while the other cells contain only 46 chromosomes (the normal number).

Such a baby may only show partial features of the condition. Some of these babies look less affected than other babies with Down syndrome, but not all of them do.

3. The translocation type of Down syndrome

A baby sometimes has all the clinical symptoms of Down syndrome but only 46 chromosomes in every cell. With Translocation, the baby has a normal number of chromosomes but extra chromosomal material. In these cases it is found that, over and above a normal pair number 21, these babies also have an extra part of a chromosome number 21, attached to another chromosome, which usually is chromosome number 14. This is called translocation type of Down syndrome.

This type of Down syndrome can be hereditary! Either parent can carry a translocation without showing any symptoms. In this case the risk to have another child with this type of Down syndrome for the parents concerned, or for other members of the family, can be quite high. It is strongly advised that a chromosome test is done on both parents and that they seek genetic counseling if they plan further pregnancies.

It is important to remember that the type of Down syndrome that is diagnosed makes no difference to the eventual development and potential of the child.

Why did this happen to us?

Down syndrome can occur in any marriage, to people of all races and religions. It is not caused by food or medicine taken or by any other event e.g. an accident during pregnancy. Neither of the parents is to blame and therefore you have no cause to feel guilty or blame your spouse. Try not to listen to superstitions and unlikely explanations given by well intentioned people.

"My husband left me soon after they told us Thabo had a genetic condition called Down syndrome. My husband said the

ancestors were cross with me and were punishing me for something I did wrong. Today I know that that is not true and that I did not do anything wrong!"

Eveline

"I thought that our daughter had Down syndrome because of the headache and pain tablets I took during my pregnancy. Little did I know then that Down syndrome arises at conception and that nothing I did during my pregnancy could have changed what happened on the day of conception. It took time for me to explain it to my extended family members and up to today some of them still think I am to blame."

Tina

"My whole family blamed me for the thing which happened to us. They said I slept around with different men or that I laughed at a child with a disability and that that is the reason why God is disappointed in me and decided to give me a child with a disability as well. It took me a long time before I found out the real reason why Rosinah, my daughter is different from other children."

Maria

"In the beginning I kept on asking "Why has this happened", and still today, do not know the complete answer to that. A doctor told me that it might be because Steven was our third boy child, which of course is a myth and mistruth. What I do know is having Steven, has enriched our lives in so many ways and I would never change what has happened for all the money in the world!"

Vanessa

What are the chances of having another child with Down syndrome?

About one in every 600 babies born in developing countries and one in every 1000 born in developed countries has Down syndrome.

Any father's or mother's chance to have another child with Down syndrome is exactly the same as another father or mother of the same age. However, research has shown that if a couple already has a child with Down syndrome or if a mother is 35 years or older, the risk of having another child with Down syndrome slightly increases. The rise in the incidence of babies with Down syndrome in the case of older mothers is shown in Figure 4.

Why does the risk of having a baby with Down syndrome increase with the mother's age?

The most likely explanation is the following: All the egg cells of a woman have already been formed when she was born as a little girl and these egg cells are found in an immature state in her ovaries (unlike men who produce new sperm from puberty onwards). In the case of women, after puberty only one egg cell matures each month and is released at ovulation. Therefore by the time the woman is, for example, 38 years old, her egg cells are also 38 years old. Ageing is therefore likely to have had an effect on the egg cells and the way the chromosomes divide when egg cells are formed.

Today many older mothers have a prenatal test done to test for Down syndrome and other defects that can be detected before birth. Therefore, 80% of babies with Down syndrome are nowadays born to mothers younger than 35 years of age as women in this age group give birth to more babies overall and have had no reason to suspect that their babies would be affected.

Can Down syndrome be prevented?

Down syndrome itself cannot be prevented by special medicine or medical intervention since it is caused by a change in the chromosomes. Neither can this change be reversed in an individual with the disorder. Down syndrome can not be cured.

Can Down syndrome be detected?

Down syndrome can be detected during pregnancy in the fetus (unborn baby). Before a prenatal test is done it is advised that both parents seek counseling. A genetic counselor will be able to inform them about Down syndrome and the risk associated with the test. The counselor will also be able to inform them of their specific risk of having a baby with Down syndrome.

A routine maternal blood screening to determine the risk of the baby to have Down syndrome can be performed at 15 - 20 weeks of pregnancy but detects only about 60% of all cases.

Another prenatal test is called an amniocentesis and is 98% accurate. This test is usually performed at the 15th or 16th week of pregnancy, but in certain cases it is done as early as 13 weeks or as late as 22 weeks. For this test, some of the amniotic fluid that surrounds the fetus (and in which cells shed by the fetus are found), are collected and sent to a

laboratory for a chromosome analysis.

Amniocentesis involves a small but significant risk of miscarriage. For this reason an amniocentesis is usually performed only if the mother is running a high risk of having a child with Down syndrome or any other genetic disorder that is detectable before birth.

The result of the chromosome analysis after an amniocentesis may only be available after two to three weeks, since these cells must first be cultured (multiplied) before they can be analysed. In that time it is wise for prospective parents to gather information about Down syndrome in order for them to make an informed choice.

Other tests such as the Chorionic Villi Sampling and Nuchal Translucency Ultrasound can be performed earlier on during pregnancy but are not yet routinely used in our country.

If the result of any of these tests indicates that the baby might have Down syndrome, the parents are informed of this. They can then discuss the matter with their doctor or a genetic counselor.

The decision of whether to continue with the pregnancy or to have it terminated rests solely with the parents. The counselor will, however, be able to give additional information on the genetic aspects and implications of having a child with Down syndrome, and refer the couple to other sources for advice and help, if necessary.

Should we go for genetic counseling?

The following people may be at a greater risk of having a child with Down syndrome and are advised to consult their family doctor, a specialist or a genetic counselor:

- Women in their late thirties or older, who are pregnant or are planning to have a baby;
- Couples who have already had a child with Down syndrome; and
- Couples with a family history of Down syndrome.

Where can we go for genetic counseling?

There are genetic counseling clinics in all the major centers of South Africa such as certain large hospitals and Universities with a Department of Human Genetics.

The Sub-directorate Human Genetic Services of the National Department of Health in collaboration with academic centres and the provinces, train health care providers on common genetic disorders including Down syndrome. The trained health care providers should be able to advise you and arrange for you to receive further genetic counseling.

See page 49 for the addresses and telephone numbers of the Provincial Maternal Child and Women's Health co-ordinators to enquire on services available for families of children and persons with Down syndrome.

Is there a cure for Down syndrome?

Down syndrome cannot be cured! It is an irreversible condition. However there is much you can do to help your baby develop the qualities and abilities he is born with to his maximum potential.

Professionals are encouraged to refer families for necessary tests as early as possible in order to detect complications (heart, hearing and eye defects) which can be treated to improve the quality of life of the baby with Down syndrome.

Early intervention and stimulation programmes have been developed to encourage the child to reach his full potential. It is very important to realize that children with Down syndrome are born with many qualities and abilities. It is up to the parents and caregivers to see that these are developed to the fullest.

Internationally many products namely Alternative Targeted Nutritional Interventions are on the market claiming to improve the function and even in some cases cure the condition and/or the intellectual disability of the person with Down syndrome.

Down Syndrome International and also Down Syndrome South Africa and all its affiliates do not recommend the use of any treatments or substances that have not been scientifically evaluated for both safety and effectiveness.

At the time of publication of this booklet none of the products currently marketed as Targeted Nutritional Interventions, or similar, in any country, have been shown to be either effective or safe. Although intensive international research is currently undertaken none of the products have been subjected to appropriate double-blind trials. Little is known about the side-effects of these formulas and the levels of some ingredients could be dangerous, especially for infants and small children.

It is a natural response of parents to do whatever they can to better the quality of life of their children. Most of these products however are expensive and/or require intensive and time consuming efforts from the family members.

As a family we want to encourage you therefore to carefully weigh all the options, risks and implications for your family and make an informed choice when deciding on therapies and treatment for your child.

Does our baby have different needs?

In the beginning your baby will need to be cared for just as any other baby would which means that he needs to be fed, changed, bathed, loved, played with, etc. Throughout his life make sure that you treat your baby and child with Down syndrome like you would treat all your other children. Children with Down syndrome benefit from and prosper in a loving caring family environment.

Your baby will tend to be slow to respond to you. However, you will find that if you cuddle and handle your baby regularly and lovingly, he will eventually respond and you will both benefit from the contact. When your baby grows up you will need to assist him in reaching his milestones. This is discussed later in this booklet under the developmental questions.

Will our baby be healthy?

The health of babies in general differs from baby to baby. However, babies with Down syndrome seem to have an increased risk of having some congenital anomalies and developing certain medical problems. Most of these are however either treatable or correctable.

- Many children with Down syndrome have a weaker immune system and because of this, you may find that your baby is more prone to colds, infections and stomach upsets than other babies.
- The incidence of congenital heart disease is quite high among babies with Down syndrome. The mildest forms may improve with time, but corrective surgery is often necessary. Fortunately, this kind of surgery has a very high success rate.
- As children with Down syndrome often have an abnormal thyroid function, it is advisable to have your child's thyroid function checked at intervals. Routine testing should be done at birth, or soon after, at six months and then yearly after that. Thyroid treatment is usually very successful.
- The nasal passages of a baby with Down syndrome are narrow and easily blocked, Keep your baby's nasal passages clear to prevent mouth breathing. The nose, throat and chest are particularly prone to infection. In severe cases prescribed drops can be used for a while or use a saline solution twice daily (1 /4 teaspoon salt per one cup sterile water) when necessary. When dropped into his nose, it will cause your baby to sneeze, clearing the passages.
- Some degree of hearing loss is common, most often due to frequent ear infections. Adequate hearing is critical to the development of good language skills, so periodic medical check-ups are necessary. Any suspicion of an ear or eye infection, hearing loss or a squint should be treated or corrected as soon as possible.
- Your baby may also experience more skin rashes, dry skin or sore lips. If your baby's skin is dry and sensitive use a moisturizer e.g. aqueous cream, baby oil, lanolin cream, vitamin E oil or olive oil. As babies with Down syndrome often have poor circulation, a good rub with oil or cream and the bath towel after a bath is very beneficial.
- Vision problems are fairly common and an eye examination is recommended during the baby's first year. Consult your doctor immediately if your baby's eyes are sticky with thick mucus. However, if his eyes are only a little sticky, a gentle swab twice daily with lukewarm boiled water will suffice. It is important to swab his eyes from nose outwards, using each swab once only.
- Gastrointestinal abnormalities may be present at birth but can be dealt with through corrective surgery.
- A baby with Down syndrome has inefficient temperature control and does not respond well to changes in external heat. Therefore, keep your baby warm and well wrapped up in winter and cool in summer. Bath your baby daily but keep the water temperature moderate and do not leave him exposed for too long. When he is ill, a warm wipe down will suffice. When your baby gets older he may push off the blankets at night. One solution to this problem is to let your baby sleep in a warm baby grow without blankets, or to make him a warm sleeping bag with a closed hem that fits him like a dressing gown. Keep him out of draughts and winds as this kind of exposure will affect his body temperature very quickly.
- As they get older, some children with Down syndrome tend to put on excess weight. Therefore, it is good to start early with a healthy, balanced diet - avoid too many sweets and refined starches in particular.
- No individual with Down syndrome will have all the health complications, however every child needs good preventative medical care. With accurate diagnosis and appropriate interventions, most medical conditions can be easily managed.
- Teamwork between the family and doctors is vital to anticipate potential problems and provide specific and individual treatment should they occur. Families should remember that they have the right to ask a second and even a third opinion if they are not satisfied with the service of any professional working with their child.
- A regular, complete physical check-up every six months by your doctor is advisable for at least the first five years. Contact your nearest Down syndrome Association for a complete medical check list which growth charts, etc.

SOCIAL EMOTIONAL QUESTIONS

Whose advice should we listen to?

As with the birth of any baby, well meaning people will offer you all sorts of different advice. This can be rather confusing. Listen to those who have personal experience in dealing with children and people with Down syndrome and who recognize the needs of your baby. Do not hesitate to ask questions as this will help you to move towards acceptance of your baby.

Your clinic sister and doctor and your local Down Syndrome Association will help you care for your baby's health and will bring you in touch with a parent group, early stimulation center or social worker to help you cope. You have the right to choose the support system you feel most comfortable with.

If you would like more information on, or further explanations of Down syndrome, you should feel free to contact one of the genetic nurses in your region or your nearest Down Syndrome Association (see addresses on page 44 and 49).

How can we cope with our feelings?

There is, of course, no easy answer to this. You will need time to accept that your baby is different from others.

Remember that you are not alone. Many other parents have shared your shock, pain, anger, disappointment and bewilderment. Many have found within themselves unsuspected reserves of courage and faith to meet the challenge. Most parents benefit greatly in contacting other parents of a child with Down syndrome who share their interest and concerns.

Each person reacts differently in a crisis situation. You will probably experience the following range of feelings at one stage or another; sorrow, rejection, grief, denial, disbelief, disappointment, anxiety, anger and guilt. These are all normal feelings and reactions.

Try not to plan your baby's future too far ahead. This is not practically possible with any baby. Live one day at a time and deal with each problem and stage as it arises,

Try never to be so burdened with work or grief that you cannot enjoy the fact that your baby is a unique, wonderful little person with a great deal to share with you.

How do we tell our family and friends about our child with Down syndrome?

Inform yourself as fully as you can about Down syndrome by reading and through discussion, but keep your explanations to your children, family and friends simple and straightforward. Tell everyone concerned as soon as possible. The longer you wait, the more difficult and awkward it will become.

An example of a simple explanation you could give to older family members and friends is: "Our child has Down syndrome. It is a chromosomal disorder and he will be a child with a disability."

You could tell your children about the baby in the following way: "He is a baby with Down syndrome. He will learn and develop much the same as any other baby, only slower. We will have to repeat things often to him and be patient. Oh yes! The baby will smile, laugh and play and even be naughty sometimes. In the meantime we can love our new baby and play with him a lot."

Always remember that people tend to take your behaviour, reactions and attitudes as an indication of how they should react to you. Using the correct terminology will be showing that you value your child. A child is not a "Down's child" or a "Downsie" or a "Down syndrome", but is first and foremost a child, boy, girl, teenager, etc and secondly happen to have Down syndrome. Therefore you can set the example to your family and friends in using person first terminology. Speaking about a child / boy / girl / with Down syndrome is a good habit which does not give labels to people.

THINK OF ME FIRST AS A PERSON

You look at me first with pity, concern or indifference,
For I am a disabled child
But you see only the outside of me.
If I could express myself,
I would tell you that I am inside
I am very much like you!

Think of me first as a person,
Who hurts and loves and feels joy.

And know I am a child to encourage and direct.
Smile and say hello ..Even that is enough.

Author unknown

Understand that many people may feel awkward about speaking to you and will sometimes be clumsy in what they say. Sometimes you may have to correct them gently. Speak openly about your child and your friends will feel more and more at ease with the situation. You may even derive support from asking a friend to accompany you on your first outing with the baby.

Give your family and friends the opportunity to hold your baby and play with him, or ask them to baby-sit for you if necessary. It may even help to give this booklet or other literature to your friends and family to read. Grandparents are often just as distressed as you are and may try to help by making suggestions that you interpret as negative. Communication and time will help to sort out all the problems.

Your children, family and friends will mostly reflect your own attitude. If you cope with the situation effectively, most other people will to.

Will this child put a strain on our marriage?

The birth of a baby with Down syndrome may cause crisis situations in a family, but then any baby can put a strain on a marriage. Research has shown that no more marital difficulties are experienced by parents of children with Down syndrome than by the rest of the population. In fact, when asked about the effect of having a child with Down syndrome had in the family, parents often say it has brought them closer together.

Never hesitate to seek professional help if you feel unable to handle your specific situation. A balanced, happy family life should always be your ultimate, overall goal, with a reasonable amount of time being devoted to each member of the family. A united, loving family can provide the strength you need.

Private time for you and your spouse should definitely be set aside. Your marriage will benefit from a lot of time and consideration for one another. Your marriage is the foundation for the quality of life of your whole family!

Where possible, parents and children's daily routine need not be unduly disrupted by the birth of a baby. Your baby should adjust to your way of life; this should not happen the other way around. A child with Down syndrome can also participate and contribute to family life. Reports vary, naturally, but living with a child with Down syndrome is not all "give" and no "take" for parents.

The amount of time spent stimulating a baby with Down syndrome depends entirely on each family's overall situation. If exercises and games can be included in your daily routine this is preferable. However, it is important that you play and communicate as much with this baby as you would with any other baby.

The rewards and satisfaction of raising a child with Down syndrome and the sense of positive achievement gained are perhaps greater than with other children. All goals are relative after all.

You and your family may find that counseling and extra support can help you to cope with your particular situation. In this regard, you will greatly benefit by contacting professionals e.g. a social worker and especially parent groups (see addresses on page 49).

Their advice can help you to maintain a balance and ensure that you are not neglecting your children, family and friends.

Will having a child with Down syndrome impact negatively on our other children?

It is of the utmost importance not to neglect your other children or your marriage partner, since maintenance of the family unit is of vital importance to all, including your child with Down syndrome. Parents should never feel obligated to devote all their spare time to their child with Down syndrome.

Research has shown that in the majority of cases having a brother or a sister with Down syndrome does not impact negatively on a child. Children usually accept disability more easily than adults and can only benefit by developing a sensitive approach to life and people. Any hardship they may have to endure as a result of having a brother or sister with a disability can help them to mature and to face life being better equipped. As the siblings of a child with Down syndrome get older (about 10 years) they tend to need more factual answers and usually like to be involved in decisions about the child with Down syndrome.

A doctor once sympathized with me that my brother had Down syndrome. I corrected him in saying that he shouldn't be sorry, as I thought it is OK and even cool. He is after all my brother! Christopher.

DEVELOPMENTAL QUESTIONS

Introduction

Your baby has Down syndrome. Just like all other babies he can't walk, talk or feed himself yet. The fact is, when he is older, he should be able to do all those things providing he gets the support he needs. With the proper support he has a good chance to learn to read and write, go to a mainstream school, establish friendships, pursue interests, get a job and live a semi-independent adult life.

How will our child grow and develop?

Every child grows and learns. Whether a child has Down syndrome or not, children vary in their rate of development. Children with Down syndrome usually follow the same pattern of skill development, while perhaps taking longer to achieve a skill.

The process of development is divided into: gross motor, fine motor, language, cognitive, social and self help skills. All these areas are linked to one another and progress in one area affects progress in others. Factors such as muscle tone and general health may affect the rate of skills development.

The average height of a child with Down syndrome is less than that of the rest of the population. A controlled diet and regular exercise prevents any excessive weight gain. Their bodies mature in the same way however, and they too will reach puberty in their early teens.

Youngsters with Down syndrome acquire new skills and develop individual talents as they grow, benefiting from all life experiences as well as their inner abilities. People with Down syndrome can gain 73% physical and mental skills throughout their lives. The ability level of children and adults vary considerably, but the average rate of progress is slower than in ordinary people.

How can we care for and stimulate our child?

Stimulation is very important in the development of our babies. It simply means encouraging your baby to become aware of you, the rest of your family, his surroundings and the day to day household happenings.

You as the parents are usually in the best position to care for and stimulate your child, especially if you are willing to accept assistance in developing your parental skills.

Learning for the baby begins as soon as he is born. Our babies tend to be quieter and cry less than other babies. It is important not to leave him alone in his cot, staring at a featureless ceiling. When he is awake he needs exercise for his body and his mind. Make his surroundings bright, colourful, mobile and sometimes even noisy. Contact a Toy Library (numbers on page 47 and 48) for ideas.

Encourage eye contact by talking and singing to the baby during feeding, playing and any interaction.

As new parents of a child with special needs, there are a number of services available to assist your child in his development. Early stimulation (early intervention) is a good start to planned assistance for your child. These programmes could include the services of speech therapists, physiotherapists and occupational therapists.

General rules that apply to all stimulation or early intervention are:

- Readiness: Look for signs of readiness, e.g. the baby who holds toys and puts them in his mouth can be given a baby rusk to hold and chew on.
- Repetition: Whatever you're trying to teach your child will have to be repeated several times before he grasps what is expected of him.
- Praise: Be generous with your praise, especially when your baby really deserves it.
- Time: Allow sufficient time for your child to experiment. It may take him longer to get a task done on his own but trying to do something for himself is the only way a child can really learn.
- Confidence: Be relaxed when you are handling the baby.

The recommendations regarding the stimulation of the development of your baby discussed in this booklet are very brief, yet sufficient for the first few months.

The exercises are only meant as a general guide. If your child only uses the exercises in this book, it would help a great deal if his progress is assessed every three to six months by a professional working in the area of early stimulation (e.g. speech, occupational and physio-therapists).

You will be able to get practical guidance in the form of;

- A few basic exercises;
- Some toys to use constructively;
- Some games to play, with clear instructions;
- Feeding, dressing and general care tips; and
- Guidelines on how to detect any secondary disability.

How can we develop our baby's gross motor skills?

It is advisable to follow a home programme or to contact a physiotherapist who specialises in Down syndrome. If this is not possible, here are some general guidelines of the main principles of development in this area: Begin with head control, proceed down the back and to the legs, from the centre-line outwards. Generally progress from the larger to the smaller body parts (e.g. arms to fingers).

Head control

- Your baby needs to lie on his back, stomach and sides during the course of the day (from birth)
- When your baby lies on his stomach he may object, but these objections take the form of movements that are ultimately beneficial. When the baby is in this position the surface under him must be smooth and firm. If the baby lies limply, tickle him with your fingers or, if he is naked after bath time, stroke his whole body with a soft hair brush. This is good for sensory stimulation (from birth).
- Lay your baby on his back on your knees or on a smooth surface. Take him by the shoulders and raise him gently until the weight of his head can be felt. At first his head will hang limply and the lifting will have to be slow and limited. After a few days some tension will begin to show in the neck muscles and he should gradually begin to lift his head. As soon as he does this he should be laid back for a rest after which the exercise should be repeated twice more. This exercise should also be varied by holding your baby slightly to the side and getting him to lift from this position as well (from 6 weeks).
- When carrying your baby, hold him against you, facing away from you so that he must lift his head and maintain that position to see things (from 6 weeks).
- Sit your baby in front of you, holding him by his shoulders. Tilt him from side to side, back and forth and in various directions to encourage head control. As your baby's neck becomes stronger, you can rock him in different positions. You should deliberately support his head less as he grows older and stronger (from 8 weeks).
- Place your baby in the middle of the room on his stomach. Walk past and around him so that he must lift his head to see you (from 6-8 weeks).
- Lay your baby on his stomach, propped up on his forearms. Introduce a toy within his field of vision and say "look Peter", as you begin squeaking and moving the toy. Gradually raise the toy so that he will have to follow it with his eyes and lift his head. Vary the objects and give plenty of praise and reward (from 8 weeks - 3 months).
- Place a rolled towel or blanket under his chest for support, if necessary. Remove this as he becomes stronger.
- Place your baby on his stomach on a large, slightly deflated beach ball. Support him securely under his arms or at his waist and roll him gently from side to side and back and forth. A friend or family member can hold a toy in front of him to encourage him to raise his head and watch and move (from 8 weeks - 3 months).

Rolling

- Encourage your baby to turn from side to back and then from back to side again by introducing an interesting toy at his eye level. Move the toy in the direction you wish him to move and, using your free hand, physically move him by bending his leg (the leg opposite the direction in which he is turning) and turning him to assume the desired position. Once the leg and hip are in position, he will strain and move his body (4-6 months).
- Lay your baby on a blanket on his stomach, then roll him onto his back. He must push up from the forearm with his fingers open (his hands must not be clenched). Gradually lift up one end of the blanket, thus prompting him to roll over in a continuous movement. Prompt him through the entire roll from his stomach to his back. At the beginning you must have to support the back of the head so that he does not bump it when he rolls over and gets a fright (from 4 - 6 months).

Leg exercises: (best given when you change your baby's nappy)

- Lay your baby on his back. Lift his feet one by one, raising them about two inches (6cm) and letting them drop gently onto the changing towel. The aim of this exercise is to get the child to make conscious movements. Four times will suffice and as he grows stronger you may raise his feet higher before letting them drop, so that he gains practice in control (from birth).
- Hold your baby's foot around the ankle, using your thumb and forefinger. Tickle the sole of his foot from toe to heel.

As his foot draws back resist the movement by keeping your hand still. Exercise both legs (from birth).

Sitting:

- Attempt to place your baby in a sitting position. This position allows more scope for movement and play and permits him to see well in three directions. As soon as his head control begins improving, a baby relax chair will be necessary. There are various types available on the market (use from 4 months).
- Your baby can be propped up in his pram or in a corner of a lounge chair with cushions on his sides and something up against his feet to stop him from sliding down. He can begin by sitting for short periods at a time. As his neck and back get stronger, the sitting time should be increased. Small babies sometimes need a little extra support at the sides of the head. Use folder nappies or a pram cushion (from 5 months).
- Put your baby in his relax chair and inside the pram or pushchair with the canopy attached. Toys can be hung from the canopy for him to focus on and reach for. Toys that make a sound are useful. Household articles can also be used. Variety, and not the cost of an item, is important (from 3-4 months).
- To encourage your baby to kick, a string of pigeon bells or rattles on a piece of elastic may be draped across his feet while he is sitting in his chair. Two large rings (coloured bracelets), as well as other noisy objects, may be threaded onto a string. Put his feet into the rings so that the rattles make a noise when he moves his legs
- Once your baby has good head control and his back is strengthened, take a large blow-up swimming tube, sit him inside it with his hands resting on the tube and his feet pushing against it, The tube will also break his fall when he topples over.