

Down's Syndrome



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a new parents guide

Congratulations

on the birth of your new baby!

Most of our parents find out that their baby has Down's syndrome soon after the birth and the news is a great shock. We understand that your life is no longer following the expected route, but we want you to know that you are not alone, and we hope that we can help you celebrate your baby's life.

Finding Out

You will probably never forget the moment you were told your baby has Down's syndrome.

The birth of a baby is a time of tension and excitement for parents. New mothers can feel extreme emotions and they sometimes experience the 'baby blues' after birth. It is not surprising that in this vulnerable state, the news that your baby has Down's syndrome comes as such a shock.

Most of our families say the moment remains crystal clear in their memories. They are able to relive it many years later as though it happened yesterday.

People react in many different ways. Some may feel overwhelming sadness or an overwhelming protectiveness towards their baby or even embarrassment and some may feel too numb to react much at all.

Feelings of rejection towards your new baby can happen at first, although most people who experience this feeling realise that it wasn't the baby they were rejecting, but the condition.

Do not assume your partner is experiencing this in the same way as you. It is OK to react in whichever way you do. Your partner's way of coping is OK too. Talk to each other and talk to trusted friends.

You are not alone, other people have felt this way before you.

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'. Their baby becomes a well-loved member of their families, just part of their everyday lives.

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

There will be times in the future, perhaps when a friend has a new baby, or when you notice 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.

Although it is natural to think about planning for your child's future based on your current experiences and feelings please remember that your child, your family, society and the possibilities for your child will all change for the better in the years ahead.

Here are some words of advice from a person with Down's syndrome:

"Hello, my name is Nicholas. I am a young adult with Down's syndrome. It is important to understand that, even with their extra chromosome, babies with Down's syndrome are still normal people like you and me. Life with a child with this syndrome can be a hard job, but life with all children is hard work! All babies and children are the same, the only difference is that we need to have a bit of extra help with some life skills."

"What's Down's syndrome for me? I don't feel any different. I know it's there,

but I don't think about it. I carry on with my life. It's not going to stop me having a flat one day and getting married."

"My advice to you is to encourage children and adults with Down's syndrome with their dreams and goals and to believe that success comes from believing in ourselves."

This is one mother's interpretation of the experience of having a child with Down's syndrome:

Welcome to Holland

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.

By Emily Perl Kingsley

First questions

You may feel that you don't want to think about Down's syndrome right now. If so, just put this booklet aside until the time is right for you.

What is Down's syndrome?

Down's syndrome is a life-long condition that causes delays in learning and development.

Why does Down's syndrome happen?

Down's syndrome occurs because your baby's cells contain an extra chromosome 21.

Is it my fault?

Down's syndrome is never anyone's fault; it just happens. It has never been linked with particular foods or actions or pollution, it occurs in all races and religions. Whatever else you may feel at this time, don't feel guilty. Some mothers especially feel this way having been the ones who carried the baby.

How can doctors tell my baby has Down's syndrome?

Doctors can usually tell that our children have Down's syndrome when they

examine them and notice certain physical characteristics.

Our babies are usually floppy (have hypotonia) and have very flexible joints. This will improve as they get older. Usually our babies have a face that looks flattened, excess skin on the back of their necks and the back of their heads may be flatter than average. They 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. 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 the baby may have Down's syndrome. However, some babies who do not have Down's syndrome also have a crease like this. They may have a larger than usual gap between

the big toe and the second toe (sometimes called a 'sandal gap').

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 no differently from other babies. Your baby will look like the rest of your family, the Down's syndrome accounts for only a few of your baby's looks.

How can doctors be sure my baby has Down's syndrome?

A blood test will show for certain if your baby has Down's syndrome. This is called a chromosome analysis test and will show the extra chromosome 21 material which causes Down's syndrome.

Are the doctors ever wrong?

It is extremely rare for the blood

test to show normal chromosomes when a doctor thinks your baby has Down's syndrome. There is no need to wait for the results before telling people about your baby's Down's syndrome. Until the results come, you may find it easier to spend time getting to know your baby rather than worrying about Down's syndrome.

Can Down's syndrome be cured?

Down's syndrome is a life-long condition that cannot be cured. Like any other child, our babies vary in their abilities and achievements. It is not possible to predict your baby's abilities and achievements at birth. They are not linked to appearance. The problems can be eased if your baby has the right help and if people about you have a positive accepting attitude to Down's syndrome.

How severe is my baby's Down's syndrome?

All people with Down's syndrome will have some degree of learning disability.

What is a learning disability?

This means that it takes longer to process information, to learn new skills, and that tasks and learning may need to be broken down into smaller steps. If someone has a learning disability it means that they may not learn things as quickly as other people and they may need more help and support to learn. Learning disability is not an illness. It is a permanent condition, but with the right kind of help many people can acquire practical and social

skills even if this may take them longer than usual.

Will my baby be healthy?

Babies with Down's syndrome can be fit and healthy and have no more medical problems than any other child. However, our babies can pick up coughs more easily than other children can and their narrow ear and nose passageways may become blocked more often. Just over half of children with Down's syndrome are born with a heart or bowel problem. These require an operation which may be done soon after birth or when the baby is older and stronger.

Information about routine medical care and health problems can be found in the insert for your personal child health record. If you did not receive a copy with this leaflet, contact us on **0333 121 2300** and we will send you one. You can also find out more about health issues in our early support booklet. This list of possible medical problems can seem daunting but it is important to remember that these conditions are known to occur in children with Down's syndrome and can be looked out for and can be treated as quickly as possible.

What will my baby be like?

Like all babies, your baby will eat and sleep and cry and need nappy changes and like all babies your baby will need warmth, comfort and plenty of cuddles. Your baby will learn and develop more slowly than other babies, but by this time next year, your baby will probably be able to sit up, roll around, chuckle, charm your family and friends and enjoy playing with birthday presents.

What will my baby be like as an adult?

Your baby will grow through childhood to become an adult member of your family who reflects your interests and values. Our parents say it is better to deal with the baby you have now rather than worrying about the teenager or adult you imagine. The outlook for our children has improved greatly over the past generation. Do not base your ideas on out-dated information or the lives of older adults who have not had today's levels of health care and early intervention.

What if I don't want the baby?

Some families at first feel they don't want their baby. Usually this feeling changes as they get to know their own little baby who needs them now rather than "this baby with Down's syndrome with an unknown frightening future". Occasionally the feelings of rejection persist and parents decide to have their baby temporarily fostered to give them some time to think about what is best. Sometimes it is best for the baby to be adopted. There are many families happy to adopt a baby with Down's syndrome.

Will it happen again?

Probably not. A genetic counsellor can give you detailed figures, but for most families the chances of having another baby with Down's syndrome are about one in two hundred.

You can choose an amniocentesis in your next pregnancy to see if your baby has Down's syndrome.



Telling others

Your feelings

Brothers and sisters

As a parent, you are best placed to decide how much information is appropriate to give your children. Much depends on their age, their level of understanding and their curiosity. Don't be afraid to involve your children as soon as possible. It's OK to show them you hurt – they may well realise that already. Tell them in an honest and open way. They may not understand or remember all the information, so follow their lead, keep listening and answer their questions. Follow your children's lead in deciding what else to tell them. You may want to cover things like...

- It's not your fault the baby has Down's syndrome, it just happened by chance.
- Babies with Down's syndrome find it hard to learn new things. They will want to join in and do the things you like doing but they might take longer learning how to do it and they may not be good at it.
- The baby will always have Down's syndrome.
- You can't catch Down's syndrome.
- Brothers and sisters are very important to a baby.
- We love you very much and we love the baby too.

Your children will follow your lead. If you treat the Down's syndrome as just one aspect of your baby's life, your children will too.

The DSA has information about books that you can use with your children to explain Down's syndrome.

Other people

Telling family and friends can be very hard. Only you know when and how it is best to tell other people.

Sometimes you need to tell close friends or family so you have someone to cry with.

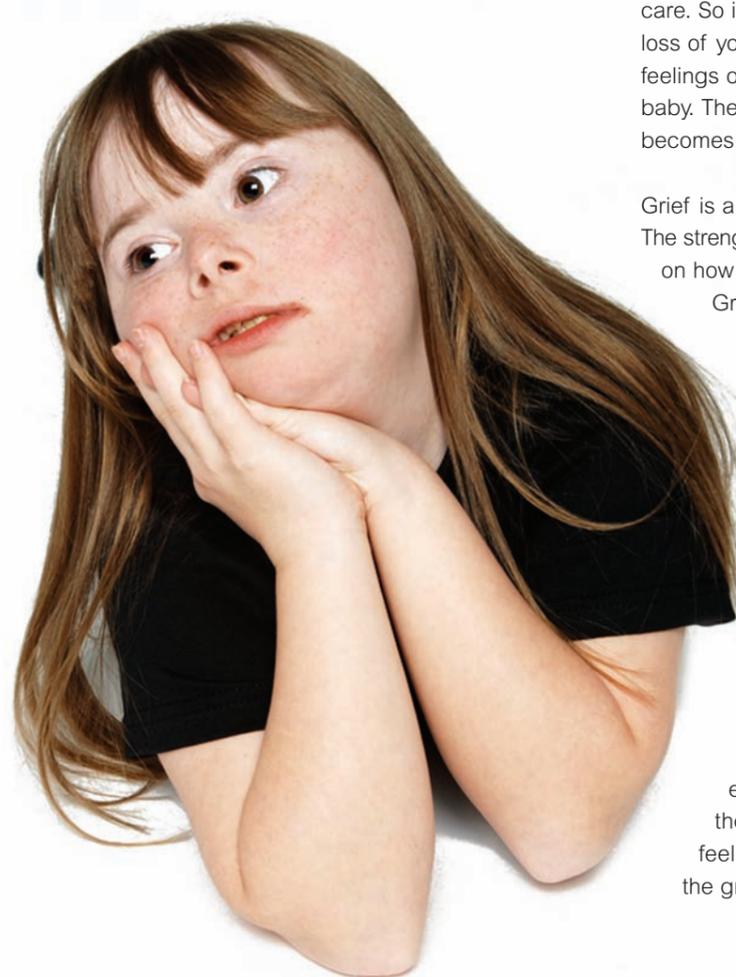
Sometimes it is easier to tell the most gossipy of your friends and ask them to pass the information around so that people know before they talk to you.

Sometimes it is best to wait until you have come to terms with the news yourself and are able to cope with the other person's reaction. Only you can decide how much of your baby's story to tell someone and which words to use.

Sometimes family, friends and people you meet say very insensitive and hurtful things. Try to ignore these comments. They are often based on misunderstandings. People will follow your lead. If you are open, honest and positive about Down's syndrome, they will be too. Give them copies of

this leaflet and the one specifically for family and friends.

You may find you are very sensitive to people you meet when you are out and about. You may not be sure if other people realise your baby has Down's syndrome. You can choose whether or not to mention it.



This is a general, simple guide. Everyone is different.

Many new parents go through a grief process as they would if their baby had died. The dream baby you imagined for nine months or more, the baby without Down's syndrome, is not there. But it is different because you still have a baby needing your love and care. So in addition to the grief for the loss of your dream baby, you develop feelings of love and joy for the actual baby. The baby who was the problem becomes the solution.

Grief is a healthy reaction to loss. The strength of your reaction depends on how big the loss seems to you.

Grief is hard work and it hurts. It can be delayed (maybe your baby is very sick and Down's syndrome seems unimportant) but it cannot be avoided.

Throughout your child's life there are likely to be times when you revisit these feelings of grief and sadness

but most parents say the pain of the early days is the hardest. Our experiences show that there are many different feelings associated with the grieving process.

Denial is a common first reaction, you hear the news and think, "this isn't really happening" "this only happens to other people". It cushions the blow and protects you for a while until your body is better able to cope with the news.

Anger may be generalised rage at the world or a more personal "Why me?" "How dare this happen to me?" You may be able to channel your anger into doing something to help your child.

Bargaining is that feeling of "If I do this I can make it better", a time where guilt and responsibility may be strongly felt. It may lead to a change in priorities in your life.

Depression is an intense and overwhelming feeling of helplessness and sadness, "My world is falling apart."

Acceptance creeps in as you start to think, "So my baby has Down's syndrome, I can live with that."

Most people don't work through these feelings in order. They may experience them all at once and revisit them time and time again. Your partner may well react differently to you.

Looking After Yourself

Your own health is vitally important. Any birth brings with it a complicated mixture of physical and emotional reactions. In addition to experiencing all of these, you are also coming to

terms with your new baby with Down's syndrome.

Expect good days and bad days and let yourself cry if you need to.

Rest. You need rest like all new parents who have just had a baby.

Spoil yourself. Enjoy your favourite treats.

Get information. Fear of the unknown may make things harder, ask questions, BUT only read information that helps you, don't get overwhelmed.

Allow yourself time to heal. Your feelings will change, things will get easier.

Get to know your baby. Cuddle your baby, breast feed, take photos.

Take time out. Visit somewhere peaceful or just forget about Down's syndrome for a while.

Talk to another parent. The DSA can give you information about your local parent support group. Picking up the phone that first time can be very hard, but it really helps to talk to someone else who's been through it.

Ignore unhelpful comments. Even if they're from people close to you!

Write a diary. Or express your feelings in art or music.

Feeding your baby

Sometimes our babies feed easily with no more problems than any other baby.

Sometimes feeding babies with Down's syndrome can be harder and needs more time, patience and perseverance.

Our babies have low muscle tone and so may have trouble latching correctly to the breast or the teat of a bottle and in coordinating sucking, swallowing and breathing. Our babies may have difficulty maintaining a seal. Gentle upward pressure on the chin may help this. Our babies may be too sleepy to feed. They may tire quickly before they have had enough milk.

Our babies may find it hard to gain weight. Like all babies our babies lose up to 10% of their birth weight in the first three or four days, but it may take them longer to regain this weight. Plot their weight gain on the special Down's syndrome growth chart, part of the insert for your personal child health record.

When should I feed my baby?

Your newborn needs at least one night feed and frequent feeds during the day. Your health visitor can give you advice. Some of our babies wake up by themselves and show obvious signs of hunger. Others will need to be woken up. Some don't cry or show you they are hungry even when they are awake. So you will need to set a routine feeding pattern.

Babies who are sleeping lightly and getting ready to feed may

- Have rapid eye movement
- Move their arms and legs about more
- Make sucking movements with their lips
- Start pulling faces

You can often wake babies by

- Removing their covers
- Talking to them
- Changing their nappy
- Gently rubbing hands and feet
- Gently moving arms and legs
- Wiping their face with a cool damp cloth
- Holding them in an upright or standing position

You may need to burp your baby and use continued gentle stimulation to keep your baby awake during the feed. If breastfeeding, try swapping to the other breast several times.

For some babies who won't wake up to feed, or don't get enough milk from the breast or bottle, milk can then be given directly into their stomach through a naso-gastric tube.

Will I be able to breastfeed?

Almost all mothers who want to can breastfeed or provide breast milk for their baby with Down's syndrome. Sometimes breastfeeding is established easily with no more problems than with any other baby. Sometimes breastfeeding a baby with Down's syndrome can be harder and needs more time, patience and perseverance. Sometimes mothers choose not to breastfeed or find that because of their circumstances breastfeeding is not right for them.

Will my baby be able to breastfeed?

Many babies with Down's syndrome are able to breastfeed successfully from birth. Other babies are not able to breastfeed fully at first, but as they grow older they usually become better at feeding and are able to be fully breast fed.

A few babies have major medical problems which affect feeding. Babies with gastro-intestinal tract (GI tract) disorders who need an operation will not be allowed to feed at first. Instead they get nutrients through a drip into their veins. Babies with severe heart

conditions may be unable to feed because they are tired or breathless.

Mothers of these babies can use a breast pump to build up their milk supply. Their milk can be given to their babies by naso-gastric tube when the babies are well enough. With patience and perseverance and following surgery for any medical disorders, these babies can often fully breastfeed eventually.

How does breastfeeding help babies with Down's syndrome?

Breastfeeding has many benefits for all babies. Some are especially important for babies with Down's syndrome.

Close body contact. This helps you bond with your baby and provides your baby with important sensory stimulation.

Less infections. Breast milk has antibodies that help your baby fight the infections that babies with Down's syndrome often pick up more easily than other babies.

Less constipation. Many babies with Down's syndrome become constipated probably due to their low muscle tone which can make their bowels sluggish. Babies who are breast fed generally don't get constipated.

Best nutrition. Breast milk provides the best possible nutrition.

How should I hold my baby to breastfeed?

Once breastfeeding is going well, you can feed your baby anywhere, in any position and with any way of holding that is comfortable for you.

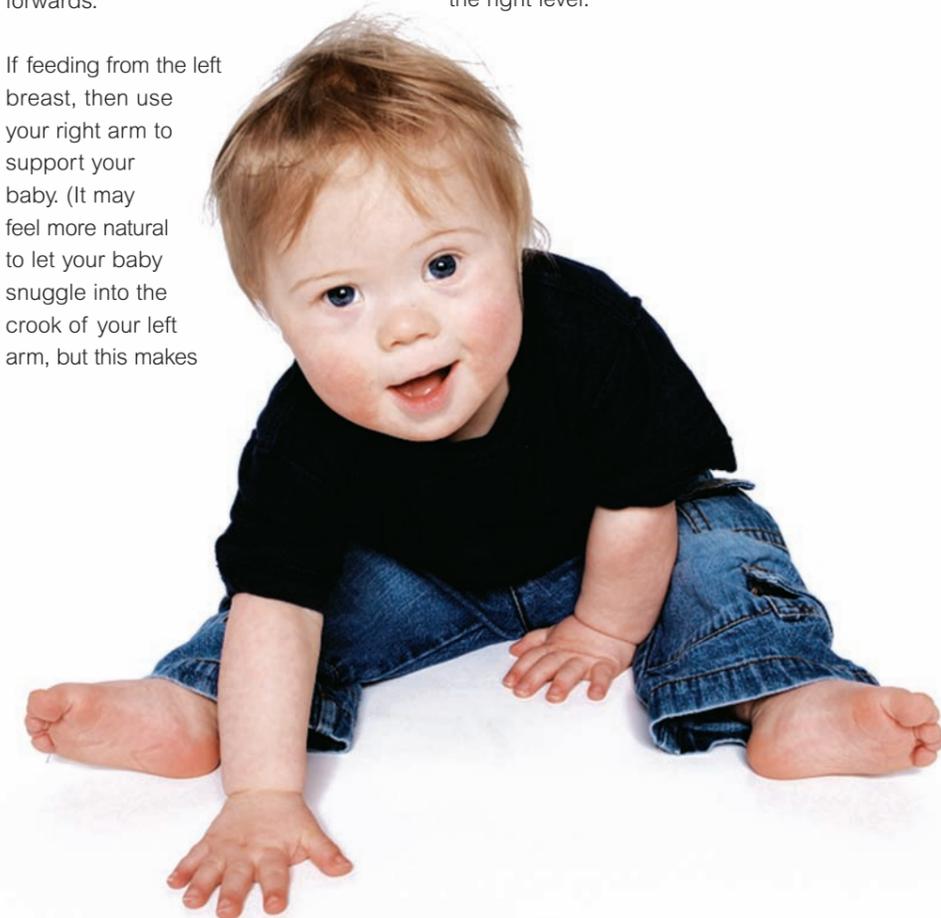
Try and find a quiet, relaxing place with a comfortable chair offering good support. Have someone nearby who can add and move around pillows for support as needed. Sit upright not slumping back or tensing forwards.

If feeding from the left breast, then use your right arm to support your baby. (It may feel more natural to let your baby snuggle into the crook of your left arm, but this makes

it harder for you to see how the baby is taking your nipple and may not offer your baby enough support at first.)

Your elbow supports your baby's buttocks. Your arm supports the back and shoulders. Your hand supports the neck and head.

Turn your baby's whole body towards your breast, baby's chest to your chest, baby's chin to your breast at the right level.



Your baby's development

How should I put my baby to the breast?

Start your milk flowing before you put your baby to the breast, by gently massaging and squeezing your whole breast.

Support your baby so that your baby's mouth is at or just above the level of your nipple.

Tickle your baby's upper lip with your nipple and wait until your baby's mouth is wide open.

Hold your left breast with your left hand in a 'C shaped' hold behind the areola (brown area around the nipple). Don't squash the areola as this can change the shape of your breast making it harder for your baby to latch on.

Put the nipple and a lot of the areola into your baby's mouth making sure your baby's tongue is below the nipple.

It may feel unusual but should not hurt. If it does hurt, gently break the suction by putting your finger into the corner of your baby's mouth, and try again.

As the milk flows your baby should begin to swallow. You can encourage swallowing by gently stroking in a downward motion on the outside of the throat.

Your baby needs to co-ordinate sucking, swallowing and breathing. This can be a hard skill to learn and at first your baby may gulp and choke.

I'm finding breastfeeding hard, what should I do?

If you are breastfeeding and your baby doesn't feed often, your breasts may not get enough stimulation and your milk supply may drop. It may be helpful to hand express a little milk after feeds or use a hand or electric pump

when your baby won't feed to keep your milk supply up.

You may need additional support and information. Many hospitals employ a lactation consultant or have midwives with a particular interest in feeding problems. A speech and language therapist may also be consulted.

Most difficulties will resolve as your baby grows stronger and learns to breastfeed. Some babies take two months or more before feeding is established but then go on to have no further problems.

Only you can make the decision whether or not to stop breastfeeding. If you find breastfeeding so difficult that it is affecting your own well-being and your relationship with your baby, then it may be best to stop. You don't need to feel guilty, you have tried your best.

The most vital part of parenting is to love your baby, breastfeeding is just one part of parenting.

When should I introduce solids to my baby?

Babies with Down's syndrome should be introduced to solids at the same time and in the same way as other babies.

It may take longer for our babies to co-ordinate the actions needed for eating solids.

How should I treat my baby?

You have a baby with the same needs as all babies; so use baby books, magazines and support from your family and friends just as you planned during pregnancy. Remember, most of your baby's behaviour is due to being a baby rather than being due to Down's syndrome!

Involve your baby in everyday family activities. Play and interact together as you would with any baby. If your baby is floppy, make sure your pushchair and car seat offer good support and don't allow legs to flop apart. Carry your baby with legs together not on your hip. Your baby may not be responsive but it is still important to respond to your baby's noises, and talk to your baby about what you are doing and where you are going.

What will my baby achieve and when?

Children with Down's syndrome do learn to walk, talk and be toilet trained but in general will meet these developmental milestones later than children who do not have Down's syndrome.

There is a wide range of ability in children with Down's syndrome just like in the rest of the population.

Each baby is different but generally our babies:

- Smile between 1 and a half and 4 months, average 2 months
- Roll over between 4 and 22 months, average 8 months
- Sit alone between 6 and 28 months, average 10 months
- Crawl between 7 and 21 months, average 12 months
- Finger feed between 8 and 28 months, average 12 months
- Say first words between 9 and 31 months, average 16 months
- Walk between 12 and 65 months, average 24 months

Like all babies, our babies learn and develop, but their development is slower than that of other children.

Like all parents we should enjoy our children and celebrate their achievements. Although much of our children's development rate depends on their individual make-up, we can help them through play, everyday activities and early intervention programs which develop their skills in small steps.

When you are ready, you can find out more information about child development and who can help your child from the DSA's early support booklet.

What learning problems do our babies have?

Our children often have short arms and legs and low muscle tone making it harder to learn the skills of moving.

Our children find it hard to learn through their ears and learn better through their eyes. They find it easier to learn to talk if their main words are signed as well as spoken. They find it hard to "just pick things up" and easily forget new skills. Patiently repeating tasks helps them learn. They may find change hard. Regular routines, doing tasks the same way can be helpful.



What is the most important thing I can do to help my child's development?

Start by loving them! Everything else comes after that. Make them feel loved and secure so that they grow up feeling good about themselves. Don't forget to look after yourself. Also it may be helpful to talk to other parents who will have been through what you are experiencing.

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. Some parents have found that their babies particularly enjoyed the sensation of lying on foil blankets and watching the light reflected on the blanket. Foil blankets can be bought very cheaply from camping shops.
- 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.
- Encourage your baby to look at your face by making funny faces and smiling. Hold objects up to your

face so that your baby looks right at you, but also hold objects in your hand and look at the object together. When you look at an object together, take time to explore it. Use sound effects and look interested in the toy. Touch the toy, smell it, look at it and comment on what you see and feel. That will increase your baby's interest in exploring.

- Do not just 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 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!

Will my child need special toys or equipment?

Some parents worry that their baby with Down's syndrome will need special equipment and toys. This is not the case!

Early intervention

Early intervention programmes which are widespread for children with learning disabilities help in all areas of child development, as well as providing support to the family. These programmes can include speech and physiotherapy as well as home teaching programmes for the child and family. Being part of an early intervention programme also provides families with opportunities to find out about the syndrome, and to meet other families in similar situations and share support. During the past 30 years, extensive research has taken place looking at how people with Down's syndrome learn, and which skills are particularly challenging. There is now plenty of information that professionals and families can use to support children with Down's syndrome to capitalise on their strengths, address areas of difficulty, develop the skills they need and to get the most out of life. Children and adults with Down's syndrome can and do continue to learn throughout their lives just like the rest of the population.

Keeping a balance

The demands of living with a young child can be overwhelming particularly when the fact that your child has Down's syndrome may lead to extra appointments with doctors

and therapists and anxiety in the early years. It's easy to become completely tied up with what is special or different about your child. It's important to strike a balance so that your needs and the needs of other family members are addressed. Remember that to some extent, all babies have to fit in with what is going on around them! While 'special' activities help, they are unlikely to be the main influence on your child's development. The most important experiences for a child with Down's syndrome come from being a member of a happy, loving and active family – and from doing all the things that families normally do. Not everything has to be educational or meaningful. Let your child and the rest of the family chill out, do something that has absolutely no educational function other than being fun.

What help is available?

Our early support booklet contains information about the professionals and agencies that can help you and it also contains information about why you may want to use their services. Services and facilities that are available for all families of young children are equally useful and relevant for children with Down's syndrome (e.g. parent and toddler groups, play schemes, movement and activity groups, nurseries and

playgroups, swimming classes, baby yoga and baby massage).

Will I be able to go back to work?

There is no reason why not, if you decide that that is what is best for you and your family! If you intend to go back to work there is no need to change these plans. The Government has recognised that families and their needs are all different! Flexible working hours, tax credits and benefits and varied childcare options all contribute to making the balance between childcare and work that much easier for individual families.

Is there any financial help available?

A range of benefits and tax credits are available to help families, which you may be able to claim if you have a child with Down's syndrome. Your entitlement will depend on the needs of your child and/or on your income. The DSA has publications about what you can claim. You can obtain advice and support from our benefits advisers.

Growing up

When most children are born, parents usually focus on the day-to-day essentials of living with a small baby and if they think of their child's future it is with big dreams. It does not need to be any different for a child with Down's syndrome.

Will my child go to school?

Most of our children start at their local mainstream school just like their brothers and sisters. Some parents choose a special school or special unit for their children as they feel this best suits their child.

Will my child make friends?

There is no reason why not. It is what naturally happens as they meet other children at mother and toddler

groups, nurseries and schools. As with other children the friendships can be lasting as they move through the school system and live in their local communities.

Some teenagers and adults with Down's syndrome find friendships with other people with disabilities easier than those with typically developing teenagers or adults.

Will my child get a job?

Some adults with Down's syndrome find a job through the open job market. Many find supported employment in part-time jobs which they combine with leisure activities and college to provide a rich life experience.

Will my child leave home?

All adults with Down's syndrome can leave home if they choose to do so and if their families support the decision. Some adults can live independently but most will need some support.

Like all adults, people with Down's syndrome have a need for loving relationships. Some get married and live fairly independently.

People with Down's syndrome today

In the past it was believed that there were many things that people with Down's syndrome could not do when in fact they had never been given the opportunity to try. Today these opportunities have never been greater with many people with Down's syndrome leading rich and varied lives. People with Down's syndrome are now leaving home, forming relationships, gaining employment and leading independent and active lives with differing levels of support. The quality of life, life expectancy and role in the community for adults with Down's syndrome has been transformed as education, support and opportunities have improved.



Useful contacts and organisations

The following organisations provide information, advice or support. Some of them may have information or services that will help you or your child. Others may not be particularly relevant for your family. Website and email groups are listed separately in the web-based resources section.

In addition to these organisations, many local and regional groups offer support and advice to individuals with Down's syndrome and their families. Contact the Down's Syndrome Association to find out if there is a group near you.

Down's syndrome organisations

The Down's Syndrome Association

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome. We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website. Printed copies are available for a small fee. Single copies of most leaflets and information sheets are available free of charge to members.

The Langdon Down Centre
2a Langdon Park
Teddington
Middlesex TW11 9PS
Tel: **0333 121 2300**
Fax: **020 8614 5127**
Email: info@downs-syndrome.org.uk
Website: www.downs-syndrome.org.uk

Down's Syndrome Scotland

158/160 Balgreen Road
Edinburgh
EH11 3AU
Tel: 0131 313 4225
Fax: 0131 313 4285
Email: info@dsscotland.org.uk
Website: www.dsscotland.org.uk

Down Syndrome Ireland

30 Mary St.
Dublin 1
Tel: 01 873 0999
Fax: 01 873 1064
Email: info@downsyndrome.ie
Website: www.downsyndrome.ie

Down's Heart Group

The Down's Heart Group offers support and information to families who have a member with Down's syndrome and heart problems.

PO Box 4260
Dunstable
Beds LU6 2EA
Tel: 0845 1668061
Fax: 0845 1668061
Email: info@dhg.org.uk
Website: www.dhg.org.uk

Mosaic Down Syndrome UK

Mosaic Down Syndrome UK has a website set up as a support tool for parents of children with Mosaic Down's syndrome.

Email: judy.green@blueyonder.co.uk
or bill.green@blueyonder.co.uk
Website: www.mosaicdownsyndrome.org

Web-based resources

The following list provides some starting points if you want to look for information about Down's syndrome on the Internet.

While the following website addresses are recommended, we are not responsible for the material on these sites or for any linked sources of information. Some linked websites may contain content that is inaccurate or misleading.

Canadian Down Syndrome Society

www.cdss.ca

Down Syndrome Health Issues – USA

www.ds-health.com

Down Syndrome Information Network – UK

www.down-syndrome.info

Down Syndrome New South Wales – Australia

www.dsansw.org.au

Down Syndrome Research Foundation – Canada

www.dsrff.org

National Down Syndrome Society – USA

www.ndss.org

Riverbend Down Syndrome Parent Support Group – USA

www.altonweb.com/cs/downsyndrome/index.htm

UK Resources for Down syndrome

www.43green.freemove.co.uk/uk_downs_syndrome/ukdsinfo.html

Email discussion lists

DS-UK discussion list

Based in the UK. Provides informal support, discussion and information for parents and professionals caring for individuals with Down syndrome.

To subscribe to the DS-UK discussion list go to:

<http://listserv.down-syndrome.net/archives/ds-uk.html>

Or send an e-mail to: listserv@listserv.down-syndrome.net with the phrase 'subscribe DS-UK' in the body of the message.

Down-syn listserv/newsgroup

The oldest and most international e-mail discussion list on Down's syndrome – based in the USA.

To subscribe to the Down-syn list, go to: <http://listserv.nodak.edu/scripts/wa.exe?SUBED1=down-syn&A=1&D=0&H=0&O=T&T=1>

If you don't want to subscribe, you can access the list archives at: <http://listserv.nodak.edu/archives/down-syn.html>

Down Syndrome Information Network discussion lists

The Down Syndrome Information Network offers a variety of e-mail discussion lists for parents, professionals, researchers, and individuals with Down's syndrome.

For more information go to:

www.down-syndrome.info/discuss

Downs-Heart mailing list

The Down's Heart Group in the UK operates the Downs-Heart mailing list. For details go to: www.yahogroups.com/subscribe/Downs-Heart/

Additional Reading

Need To Know – Down's syndrome
Kristina Routh
Heinemann Library 2005
ISBN: 0-431-18850-5

Understanding Down syndrome – A Parent's Guide
Cliff Cunningham
Souvenir Press 2005
ISBN: 0-285-63697-9

The Down syndrome Handbook – A Practical Guide For Parents And Carers
Richard Newton
Vermilion, 2004
ISBN: 0-09-188430-6

Living with Down syndrome
Sue Buckley
The Down Syndrome Educational Trust 2000
ISBN: 1-903806-01-1

Down syndrome – The Facts
Mark Selikowitz
Oxford University Press 1997
ISBN: 0-19-262662-0

Babies with Down syndrome – A New Parent's Guide
Karen Stray-Gunderson (editor)
Woodbine House 1995
ISBN: 0-933149-64-6

A Minor Adjustment
Andy Merriman
Pan Books 1999
ISBN: 0-330-36748-X

