

# Information for Parents

## Down's Syndrome



### Feelings

For most parents, finding out that their child has Down's Syndrome is a shock.

A Key priority in your baby's first few months is to give yourself enough time to adjust. There are no rules and no rights and wrongs here – some people adjust very quickly and other find their emotions take much longer to settle down. As time goes by, things look very different, but in the early days, it is important to be able to express negative emotions and to be sad, if that is what you need to do; this takes time.

Many families say it's like setting out on a journey into the unknown. Having no idea about what to expect increases the anxiety and colours the challenges and excitements that every parent faces with a newborn child.

It's also important to know that most parents find that they grow to enjoy their child and go on to lead ordinary family lives. Although there are times of stress and difficulty, having a member with Down's Syndrome is often described as a positive experience – particular for the other children in the family

### Finding Out More

Reliable information helps. It informs expectations and takes away some of the fear of the unknown.

If you use the internet, lots of information about Down's Syndrome is available online and email discussion groups make it possible to chat with parents across the country and around the world. Local support groups are a great way to find help and support within your local community. They are a great way to meet families and share experiences and share information.

### Keeping A Balance

The demands of living with a young child can be overwhelming, particularly when Down's Syndrome results in extra appointments with doctors and anxiety in the early years. It's easy to become completely tied up in what is special or different about your child. It's important to balance all this with other things and to remember that to some extent, other babies have to fit in with what is going on around them and what other family members need.

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. Remember, not

everything has to be educational. Let your child and the rest of the family relax and do something that has absolutely no educational function other than being fun.

## **Involving Other People**

Extended family and friends are important. They're the ones everyone normally turns to when things get difficult. They can also help in very practical ways e.g. by looking after your child every now and again, so you can take a break with your partner. Some members of your family and friends may need your help to get used to the fact that your child has Down's Syndrome. Share useful pieces of information and any advice you receive and involve them in some of the meetings you have with professionals. You can also involve them in helping your child to learn from early on.

## **Other Parents Can Help**

You are not alone. There are many parent run support groups dotted around the country and most families find contact with other parents helpful. Other families who have lived through similar experiences can:

- Understand how you might be feeling and anticipate some of the questions you might want to ask.
- Explain how their feelings have changed over time.
- Tell you about their child's development and achievements and help you to meet older children with Down's Syndrome.
- Share their experience of professional support and local services.
- Alert you to common problems that you may not be aware of and suggest useful ways of managing difficult situations.
- Tell you about the organisations and contacts they found useful.

## Newborn Health Issues

There are two significant health issues that are usually identified in the first few days of life, if they affect your child – heart disorders and bowel abnormalities. These are both called Congenital disorders, which means they were present at birth.

### Heart Disorders

About half of babies born with Down's Syndrome have a disorder of the heart. These heart or cardiac disorders vary enormously in type and severity. Many are relatively mild and do not need surgical intervention, while a few are serious and do need surgery.

Because of the high incidence of heart defects, paediatric departments in hospitals normally operate screening programmes for newborn children with Down's Syndrome. Using ultrasound makes it easier to detect heart abnormalities and allows earlier and more effective treatment. Newborn babies are also normally examined by a Paediatric doctor with appropriate experience. An echocardiogram (ECG) records the result of early tests.

The diagnosis and treatment of cardiac disorders in young children is usually undertaken by doctors called Paediatric Cardiologists or Paediatric Cardiac Surgeons.

The Down's Heart Group provides detailed information on the different types of cardiac disorders and their treatment as well as general support and advice. ([www.dhg.org.uk](http://www.dhg.org.uk))

### Bowel Abnormalities

Around 10% of babies born with Down's Syndrome have problems with the structure of their bowel from the time they are born.

These abnormalities vary in their seriousness. Less severe abnormalities include bowel narrowing, which can lead to vomiting and problems with feeding. The most serious abnormalities include cases where the bowel is not continuous or where the anus is not present. These are diagnosed by ultrasound before birth or within the first day or two of life and require surgery to correct them.

Hirschsprung's Disease is a relatively rare condition among the general population, but it's more common in children with Down's Syndrome (affecting approx. 2% of them) when this occurs, part of the wall of the lower part of the bowel cannot do its normal work of pushing stools along to the anus. Hirschsprung's disease is usually obvious in the newborn period because the baby does not pass stools, or the baby would have chronic constipation. Diagnosis is by a combination of medical examination, x-ray and biopsy of the bowel.

## Hearing Impairment

It is quite likely that your child may be affected by hearing impairment or deafness at some stage, as over three quarters of children with Down's Syndrome experience problems hearing at some point. Deafness may be permanent (sensori-neural) or temporary, but recurring – due to Glue Ear or Middle Ear Infection. Conductive hearing loss can be associated with colds and runny noses and low dose antibiotics may be helpful in winter to prevent infections.

Hearing is vital to your child's intellectual development, especially the areas of speech and language and social skills. So it's important that your child has regular hearing checks at an audiology centre both in the early months and throughout childhood.

Although a mild hearing loss is not considered serious in other children, it may have a significant effect on learning for children with Down's Syndrome. Where children are having difficulty learning to talk because of the hearing loss, signing may help.

# Helping Your Child

## Early Days – Baby Care

Babies and young children with Down's Syndrome tend to gain weight and height more slowly than other children. Like all babies, they lose up to 10% of their birth weight in the first few days of life, but it may take them longer to regain this weight.

What you can do?

- You can check your child's weight and height gain against appropriate norms. The Down's Syndrome Medical Interest Group produces a special insert for the Child Personal Health Record Book which includes growth charts for children with Down's Syndrome and other useful health information.

## Breastfeeding

Many babies with Down's Syndrome are able to breastfeed successfully from birth, although you may experience some difficulty holding your child to the breast if they have very low general muscle tone.

What can you do?

- Persevere if you want to breast feed and remember, it can take a couple of weeks to establish feeding with any baby.
- Seek further advice from your Health Visitor or from one of the National Childbirth Trust's breastfeeding advisors

## Weaning

Feeding your baby is likely to be much like weaning any other child but sometimes babies are slower to learn how to suck, chew and swallow. Some babies with Down's Syndrome are particularly sensitive to different textures and prefer smoother foods and familiar flavours. As with any child, the priority is to provide a healthy and balanced diet. Ask your Health Visitor if you are worried or need advice on weaning and feeding.

What can you do?

Introduce your baby to solids and finger foods in the same way and at the same time as you would any other baby (4 – 6 months old).

- Encourage your child to learn to chew, as this is important for muscle development and speech development later on.
- Offer food with different tastes and textures, so that your baby doesn't get stuck liquids or sloppy food.
- If your child experiences particular problems in this area, ask to see a Speech & Language Therapist with expertise in eating disorders.

## Teething

Children with Down's Syndrome tend to get their teeth later than most other babies.

What can you do?

- It can be helpful to massage your child's gums
- Introduce a soft toothbrush at 12 months as it is sometimes more difficult to introduce a brush later when teeth appear.

## Skincare

Many babies with Down's Syndrome have dry skin.

What can you do?

- Gently rub your baby's skin all over with baby massage oil, or put a few drops of baby oil into bath water. Join a local baby massage group if the two of you particularly enjoy massage. It provides general stimulation as well as helping with dry skin and can be fun.
- Rub a little moisturising skin cream into your baby's skin every day. This should prevent drying and cracking. Ask your Health Visitor, GP or pharmacist for advice if there is a particular problem.

## Temperature Control

Many babies and young children with Down's Syndrome experience problems regulating their body temperature. This means that they overheat or get too cold more quickly than other children. It's important to take extra care over this.

What can you do?

- Dress your child in layers of clothing that you can take on or off quickly.
- Use a special thermometer for your baby's bedroom and/or cot and adjust their bedding appropriately.

## Sleep Problems

Many children with Down's Syndrome are restless at night and have problems sleeping. There are two main reasons for this.

Physical reasons – some children have restless or disturbed sleep because they can't breathe properly. They may have a blocked nose, enlarged tonsils/adenoids or a small mouth cavity. In a very small number of cases, children stop breathing for short periods when they are sleeping; this is called

Sleep Apnoea and it can be alarming for parents. The condition sometimes improves if a child's tonsils and/or adenoids are removed.

Behavioural reasons – your child may not want to go to bed, won't settle on their own and may wake in the night or very early in the morning. Lots of children are like this, they simply aren't very good at going to bed and staying there.

It is important to resolve sleep difficulties, as broken nights adversely affect everyone in your family. Your Health Visitor can give advice in this area. General books on sleep issues for children may help but many families DO experience difficulties in this area.

## Helping Your Child To Develop and Learn

All children learn a lot in the early years of life and every child learns at his or her own pace. At times, your child may appear to lose skills that you know they already learnt or slow down in one area of development while pushing ahead in another. There are many unexpected spurts of development; this uneven pattern of development is characteristic of children with Down's Syndrome.

## Learning To Interact With Others

In the first year of life, your baby's social development is likely to progress relatively well. He or she will probably smile, coo, babble and respond to you. Most infants with Down's Syndrome are only slightly delayed in their social development and early communication skills and are usually sensitive to emotional cues.

This is a strength, because the ability to make good relationships with other people has a direct effect on happiness, friendship and inclusion later on.

What can you do?

- Enjoy cuddles and social games with your baby as you encourage eye contact, smiling and cooing in the early months of life. Your baby is beginning to learn to communicate through these games.
- Include your child in family activities and create as many opportunities for them to play with other children as possible. Children learn social skills all day every day, by being with their family and with other adults and children.
- Encourage your child to play with other children in a mainstream nursery or playgroup, if you can. Children with Down's Syndrome are particularly good at learning by watching and imitating others and this makes it easier to learn from other children of the same age and about how to get on with other people.

## Learning To Move and Explore

Reach, grasping and holding (known as fine motor skills) are important for all babies. These skills allow young children to explore toys and objects in their world and to develop self help skills such as feeding and dressing.

Movement skills like sitting, rolling, crawling and walking are known as gross motor skills. They help babies and children start exploring on their own.

Your child is likely to face significant delay in development of motor skills, which makes it harder to explore and move around. The best way to encourage your child is through play and by motivating them to move, explore and copy other people.

Who can help?

A physiotherapist or occupational therapist can offer advice and pass on good ideas. Not all children with Down's Syndrome need professional help, but they should all be offered paediatric physiotherapy assessment in the first three months of life and an occupational therapy assessment at a later stage.

If you feel that your baby is making progress and you are giving them lots of play and stimulation, you probably don't need much input from a therapist. However, if you feel your baby is not progressing – ask for help.

For example

- If your baby is Hypotonic (floppy) with poor head control in the early months, ask for ideas on how to handle them and how to improve head control.
- If your baby needs help to play comfortably on his or her tummy, ask for some tips. It sometimes helps to provide more support by putting a rolled up towel under the armpits, which lifts the upper trunk. Don't leave your baby on their own while they are lying on their front until you are sure they can get out of this position safely and without help. Playing on the tummy can help your baby develop a strong neck and back and help towards sitting and crawling.

What can you do?

- Give your baby the chance to play in different positions during the day and help them to feel and explore toys that they are not yet able to pick up.
- Sing action songs with our child to help them learn about body parts and to encourage them to practice movement.
- As your baby grows into a toddler and young child, use music, movement and sports activities to practice and develop skills. Music dance and yoga all provide opportunities for children to have fun at the same time as learning to control movement. You might go along to local toddler activity groups, music classes, baby swimming classes, preschool ballet classes, ball pits and soft play areas.

## Learning Through Play

Play is the first and perhaps the most important way to help your child learn. All children learn through play and exploration. Children with Down's Syndrome learn in the same way as other children but often benefit from more support in their play.

Who can help?

Most children with Down's Syndrome receive support from a home visiting teacher by about twelve months of age. Practical advice and help is usually provided by a home teaching service or by a Portage service. Home visiting teachers can help you break down activities and teach your child through structured play as well as advising on other things. They work with you to:

Make learning fun for all the family

Encourage your child's interests

Address problems

What can you do?

- Become your baby's play partner and show your child how to play with their toys. Show them what the toy does, how to get it to make a noise or to move, how to screw and unscrew it, how to hide and find a toy. By demonstrating to your child how to do more interesting things with toys, you can prevent your child getting stuck on repetitive patterns of play.
- Take turns with your baby as a means to demonstrate how to do something. Sometimes it is helpful to have two toys so that you can both shake a rattle and bounce a ball.
- Later on, join in with imaginative play to show your child what to do. Imaginative games provide valuable opportunities to teach new language to children. Help your child to link two or three words together as you say "Can you wash dolly's face?" or "watch me put dolly in the bath"
- Use structured play. Children with Down's Syndrome usually need more repetition than other children before they are able to remember and master a task. Your child will benefit if you break down tasks and games into small steps and show them how to complete each step.
- Use imitation as much as possible. Children with Down's Syndrome tend to be good at learning by imitating and copying people.
- Praise your child and avoid frustration by making sure that most of the time your child gets satisfaction from playing and from toys. It can be very frustrating trying to do things that are beyond your ability. Your child is likely to experience this when they try and play with toys that need precise finger movements – they will express frustration by throwing or banging. When a young child gets frustrated, it can be quite hard for him/her to get over it. Music, holding hands and jigging or dancing are all good ways of getting over upsets.

## Developing Attention and Memory Skills

In order to learn, children have to take in information about their surroundings, usually by looking, listening or touching....and pay attention long enough to take in information and remember it. Attention and memory skills help children to do these things.

The ways babies with Down's Syndrome pay attention to the world around them varies a lot/ some children look at things, especially people's faces for quite long periods of time, but at other times they may seem to find it hard to maintain attention.

Children with Down's Syndrome tend to have relatively good long term memory, so they often retain the information and skills they have learnt very well. However, their short term or working memory usually doesn't develop at the expected rate. Children may experience particular difficulty with short term storage of information that they hear. This can have a knock on effect of slowing down the rate at which they learn language.

What can you do?

- Encourage your baby to interact with you in the early months by being lively and responsive.
- Repeat things more often than you would usually do. Games like peek-a-boo help, because they naturally build repetition into play and they are fun.
- Encourage your child to develop 'Shared Attention' where you both focus your attention on the same thing, like shaking a rattle or (later) looking at a picture book together.
- Imitate your child's actions or sounds. This is a good way to get communication going and can turn into a fun game as well as holding a child's attention and encouraging them to learn by imitation.
- Take advantage of your child's strength as a visual learner by using pictures, signs, print and other visual cues to support what you say.
- Use memory games from around two years of age to help your child develop memory skills.

## Learning To Communicate

Learning to communicate is one of the most important things that children do. Talking is a powerful tool for learning and communicating with other people and it supports thinking, remembering and reasoning. Learning language benefits all other areas of development. Each new word that a child acquires is a new concept or piece of information about the world.

Most children with Down's Syndrome are keen to communicate. However, may find it hard to learn to talk. They may experience difficulty with receptive language (what they understand), expressive language (what they say or sign) and/or speech production skills (how they pronounce words).

Who can help?

- Your child is likely to benefit from a speech and language therapist. They can give you practical ideas and advice on how to develop your child's communication skills.
- Regular advice from a speech and language therapist is desirable from six months of age or earlier, but this level of service is not currently available in every part of the country. If you do receive help, it's useful to ask what prior knowledge and experience the therapist has working with Down's Syndrome.

Children are learning language all the time and you are in the best position to develop your child's skills. Part of the therapist's role is to give you ideas and activities that you can incorporate into your daily routines and communication with your child.

What can you do?

- Make sure your child's hearing is checked regularly – many problems with learning to talk are associated with hearing difficulties.
- Talk to your child as you engage in daily activities such as dressing, bathing, going shopping, playing and going to the park.
- Name and talk about the things your child is looking at and is interested in.
- Read books together, pointing to the pictures.
- Encourage your child to make lots of meaningful simple sounds such as animal noises and every day noises.
- When your child makes a sound, imitate it and show him/her how pleased you are.
- Encourage your child to play games with his/her lips and tongue by showing them licking up and down and in and out movements.
- Play games to teach vocabulary and sentences – your home visiting teacher or speech and language therapist can give you some ideas.
- When your child starts to say words, try not to correct your child's speech – say the word correctly and clearly yourself instead.

## Using Signing

Children with Down's Syndrome are often good visual learners and therefore you may be able to help them understand by using signs and gestures. Many babies and toddlers understand more language than they can use. For this reason, learning to sign and using signs at the same time as you speak can help children communicate and get their message across. It can reduce frustration.

Signing can give your child a way of communicating before they are ready or able to use speech. It does not discourage children from talking – the evidence suggests that children who use signing go on to use spoken words earlier than those who don't.

The most common signing systems used with children with Down's Syndrome are Makaton and Signalong.

- Makaton uses signs based on British Sign Language alongside speech, together with symbols to support communication, language and literacy skills. Makaton is used by children and adults with communication and learning difficulties.
- Signalong is used by children (and adults) who have language difficulties associated with learning disabilities. The signs are mostly based on British Sign Language and are used in spoken word order. Signalong is designed to support spoken language.

Who can help?

Your speech and language therapist can give you advice about signing. You can also contact Makaton and/or Signalong direct to find out more.

What can you do?

Always use speech at the same time as you sign to help your child develop spoken language.

Use signs yourself, as well as teaching your child to sign. When you use signs in everyday life it helps understanding, particularly if the child has hearing difficulties.

Make sure that your child can see what you're doing when signing. The best way of doing this is to use sign when you are next to something your child is looking at or to sign when your child is looking at you.

Sign the information in picture books by putting your child on your lap with their back towards you and signing in front of them, with your hands above the pages of the book.

Make sure you teach lots of different types of signs – for actions and describing as well as the names of everyday things in your child's world.

## Using Reading Activities

Reading is fun and useful in its own right, but it can also be a powerful way to develop spoken language in children with Down's Syndrome when they begin to join words together – usually between two and three years of age.

Who can help?

The home visiting teacher and your speech and language therapist can help you use reading activities and materials with your child. The Down's Syndrome Educational Trust, Down's Syndrome Association and Symbol UK also provide information and DVD's about reading and language.

What can you do?

- Make your own simple books of photographs / pictures of every day objects, family members and every day events to introduce early words and sentences into print.
- Play word and picture matching games to teach word recognition. Your home teacher should be able to help you develop these activities.

## Learning How To Behave

Like all children, your child may start being difficult at about twelve months of age – demanding to be picked up, sleeping badly or suddenly having 'faddy' preferences for food. By two years of age, like many other parents, you may be struggling to meet with increasing demands for independence and tantrums.

Children with Down's Syndrome often display more difficult behaviours than typically developing children of the same age, because they have limited communication skills. However, you and your family can avoid much of this difficult behaviour if you aim to prevent these behaviours from developing in the first place, by adopting deliberate 'management strategies' early on.

What can you do?

Three simple pieces of advice can help avoid behaviour problems:

- Establish settled routines from an early age - all babies and children feel more secure in an environment of order, where they can anticipate what is going to happen next.
- Be in control as a parent – routines and set times for getting up, mealtimes and going to bed mean that you are in control – you and not your child, determine their behaviours.
- Expect your child to behave well and remember to recognise and praise any behaviour you want to see repeated. Show your child how pleased you are, every time they do what you want.

Remember that children with Down's Syndrome are often unusually good at picking up both positive and negative emotions. If they sense that the people around them are anxious or cross, this can lead to difficult behaviour as a reaction. Like all children, they need to feel secure and to know what is expected of them; they also need to be praised for good behaviour.

## Learning How To Think and Learn

Learning how to think, reason, learn, process and remember information is crucial in any child's development. Cognitive Development is the term often used to describe all these processes.

For most babies and children, cognitive development takes place all day every day without any deliberate teaching by their parents or anyone else. They pick up knowledge and understanding of the world around them through their senses, with vision and touch being the most important in the first year of a baby's life. Babies constantly watch all activity around them and explore toys and objects within their reach. As they grow older, children continue to learn through all their every day activities at home, when out shopping or at the park and in playschool.

Your child will develop some cognitive skills in the same way. However, they are also likely to need more deliberate teaching to help them develop these skills through daily activity and structured play sessions.

What can you do?

- Help your child understand how to reach the next step in their play by talking about what to do, demonstrating how to do it and by being interested and joining in.
- From two or three years of age, consider giving your child the opportunity to join a playgroup or nursery to learn with and from other children of the same age.

## Learning Social and Self Help Skills

During the second and third years of life, children develop social skills as they learn to mix with a wider range of adults and children. Their behaviour changes as they gradually learn to control their impulses better.

The more you're able to look ahead and prepare your child for life at school, the more they will be able to join in with other children. Key skills at this stage, which teachers and others will continue to encourage once your child goes to school are:

- Behaving as part of a group
- Sharing
- Taking turns
- Following instructions

It's important to remember that most children with Down's Syndrome are capable of behaving in an age-appropriate way. Progress in this area is influenced by how much parents expect of their children as well as by any learning difficulties children experience.

## **What can you do?**

**Give your child the opportunity to mix with as many children as possible and to learn how to be part of a group by attending a preschool nursery or playgroup. Play with other children can help your child learn by watching and imitating other children and can also help to develop spoken language.**

**Encourage your child to be as independent as possible from an early age with feeding and dressing, preparing to go out, getting ready for bed, brushing teeth, going to the toilet and so on. If you continue to help your child too much, they may come to depend on this help too much and be less likely to try and do things for themselves.**

## Meeting With Professionals

It's important to remember that you know your child better than any professional who meets them every now and again.

Professional work in partnership with families and it is important that your views are taken into account as much as possible when you attend appointments and meet with professionals. It's also important to understand what is being said. Sometimes this is difficult, particularly when you are dealing with a difficult situation.

Other people have found it helpful to:

- Plan ahead for key meetings or appointments and be clear about what you hope to achieve.
- Make a list of questions before each meeting to take with you.
- Take someone with you if you can – a family member or friend.
- Ask for honest, straightforward answers to your questions.
- Ask questions about anything you don't understand, disagree with or have concerns about.
- Ask the same questions again if you need further clarification or information – or just a simpler explanation without the jargon.
- Ask for copies of any written reports or assessments that are discussed.
- Ask for time to read the reports and consider their implications.

Sometimes it's hard to remember what has been said at a meeting when it's over. Some people find it helps to make notes or to take someone with them to jot down important points. Others ask for make a tape recording of what is being said – so that they can pass it on to other members of the family when they go home.

## Other Parents

- Other families with a child with Down's Syndrome can help by:
- Sharing their experiences of professionals and services
- Telling you about organisations, people and sources of information that they have found useful.
- Understanding their feelings.
- Sharing their feelings and explaining how their attitudes and experiences have changed over time.
- Arranging opportunities to get together, so that you and your child can meet other children with Down's Syndrome and hear about their achievements.

You can meet other parents at local or national events or through groups around the country. Some of these groups are set up by local services, others are run by parents themselves.

The Down's Syndrome Association can provide you with information about groups in your area. NORTHUMBERLAND Down's Syndrome Support Group leaflet is enclosed in this pack for your information.



**0845 230 0372 during office hours (Monday to Friday)**

Or write:-

**Down's Syndrome Association  
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