

Early Support

Helping every child succeed

Information for parents

Down syndrome





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Down's syndrome and **Down syndrome** are different names for the same condition and you'll hear people using both terms.

For simplicity, this booklet uses one term, **Down syndrome**, throughout.

Passages that appear in italics and in colour, *like this*, are direct quotations from what other parents or people with Down syndrome have said.

Where words appear in colour *like this*, it means you can look it up in the **Glossary** or that the contact details for the organisation or agency are listed at the back of the booklet.



Introduction

This publication:

- provides information about Down syndrome
- explains what is known about how the syndrome affects progress in children
- points to ways in which you can help your child
- tells you about support and services that can help
- identifies useful sources of information and advice.

The booklet has been developed with the help of families who have a child with Down syndrome and contains the information that they say it's useful to know. If you don't feel ready to read it right now, that's fine - come back to it later. You can use it to answer questions that crop up as time goes by or to check out things as you get to know your child better

The information is free-standing. However, some people may use it alongside another Early Support publication, the Developmental journal for babies and children with Down Syndrome. The Journal helps parents and carers track and understand a child's development, celebrate achievement and find out what they can do to encourage their child to learn.

To find out more about [Early Support](#) and to download copies of other [Early Support](#) materials, visit www.dcsf.gov.uk/everychildmatters/earllysupport

What is Down syndrome?

This section provides information about Down syndrome. It also explains some of the terms you may hear being used by professionals you meet.

Down syndrome

A syndrome is a characteristic group of symptoms or features that often appear in combination with one another.

In 1866 an English doctor, John Langdon Down, described a group of people who shared a consistent pattern of characteristics. The syndrome was named after him because he discovered it and it is now called **Down's syndrome** or **Down syndrome**.

Down syndrome is a genetic condition that results in some level of **learning disability** and a characteristic range of physical features. Learning disability significantly affects a child's ability to learn, compared with other children of their age - it does not mean a child cannot learn at all. Down syndrome is one of the most common causes of learning disability.

About one baby in every thousand is born with Down syndrome.

What causes the syndrome?

The human body is made up of cells. Each cell is like a factory, which has everything needed for growth and to maintain the body. Every cell contains a nucleus in which genes are stored. Genes are grouped in thread-like structures called **chromosomes**. Usually, the nucleus of each cell contains 23 pairs of chromosomes. Twenty-three are inherited from the mother and 23 from the father. This makes 46 chromosomes in all.

In people with Down syndrome, all or some of the cells in their bodies contain 47 chromosomes, as there is an extra copy of **chromosome 21**. This additional genetic material results in the range of physical and developmental characteristics associated with Down syndrome.



Three types of genetic variation are relevant:

- **Trisomy 21** - in which all the cells in the body have an extra chromosome 21. About 94% of people with Down syndrome have this type.
- **Translocation** - in which extra chromosome 21 material is attached to another chromosome. Around 4% of people with Down syndrome have this type.
- **Mosaic** - in which only some of the cells have extra chromosome 21 material. About 2% of people with Down syndrome have this type.

The type of genetic variation that children experience does not significantly alter the effect of Down syndrome. However, individuals with mosaic Down syndrome appear to experience less delay with some aspects of their development.

Anyone can have a baby with Down syndrome

Down syndrome affects people of all races, religions and economic backgrounds and in all countries around the world. It can happen to anyone.

Although the chance of having a baby with Down syndrome increases with the mother's age, babies with the syndrome are born to mothers of all ages. Over half of children with Down syndrome are born to mothers under the age of 35 years.

As yet, no one knows what causes the presence of the extra chromosome 21. It can come from the mother or the father. There is no way of predicting whether a person is more or less likely to make an egg or sperm with an extra chromosome. What we do know is that nobody is to blame. As far as we know, nothing done before or during pregnancy causes the syndrome.

Finding out

In some cases, babies with Down syndrome are identified before birth as a result of antenatal tests (either **amniocentesis** or **chorionic villus sampling**). In most cases, however, the presence of the syndrome is indicated soon after birth because of the way the baby looks.

A range of physical characteristics indicates that a baby may have Down syndrome.

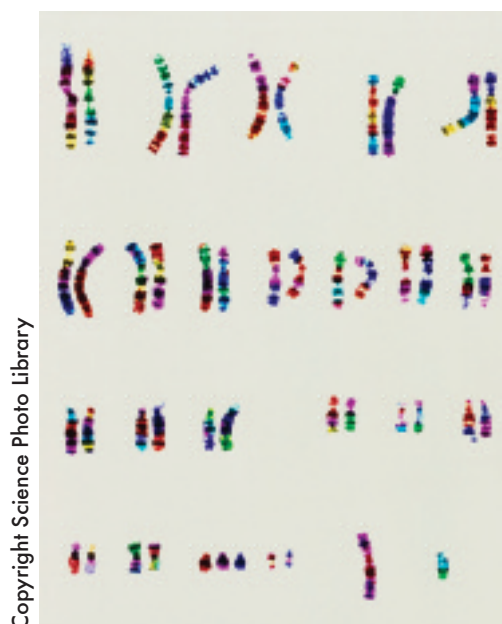
These include:

- 'floppiness' due to reduced muscle tone (**hypotonia**)
- facial features like a flat facial profile and nasal bridge, a small nose, eyes that slant upwards and outwards, and a small mouth cavity which makes the tongue appear large
- a big space between the first and second toe (**sandal gap**)
- a single crease across the palm (**palmar crease**)
- below average weight and length at birth.

However, many of these features appear naturally in the general population and not all babies with the syndrome show all of these characteristics. Individuals with Down syndrome are all different and have some of their family's physical features, just like any other child.

The only way to make a definite diagnosis of Down syndrome is to analyse the chromosomes in a sample of the baby's blood. The resulting picture of the baby's chromosomes is called a **karyotype**, and it shows the presence of an extra copy of chromosome 21 if the baby has the syndrome.

Here is an example:





Helping babies to develop and achieve their potential

At the present time, there is no 'treatment' or 'cure' to reverse the effects of the extra genetic material that causes Down syndrome. However, research over the last 20 years has taught us a great deal about how the syndrome affects individuals and about how to promote development.

The following all help children achieve as much as possible:

- effective healthcare
- good parenting skills
- an ordinary family life
- early intervention to support development
- good education.

Early intervention in this context usually means taking positive action in the first years of life.

What effect does Down syndrome have?

This section explains how Down syndrome may affect your child's health and development.

First things first

Some of the needs children with Down syndrome have are exactly the same as other children, but there are other things that are different.

Your child has the same need for love, security and stimulation as any other child. It helps if you include them in as many everyday family, learning and social experiences as possible. It's important to understand that you can positively influence your child's development simply by providing loving care and fun.

Your child is an individual

Children with Down syndrome are all individuals. The only thing they all have in common is that they have extra chromosome 21 genes. The effect that this extra genetic material has on each child's health and development varies a lot – all have some additional needs, but the pattern of impact is different for different children.

Children with Down syndrome share some common physical characteristics, but they do not all look the same. Your child may look more like you, your partner or other members of the family, than other children with the syndrome. Your child's personality is also unique. They may be sociable or shy, calm, anxious, easy to manage or stubborn – just like other children.

Children with Down syndrome also vary significantly in the progress they make with reaching, sitting, standing, walking, communicating, talking and learning to read.

Some children have a greater degree of disability and more needs than others. However good their family care, therapy and education, this is the way the syndrome affects them. No one is to blame for this variation - least of all you, as a parent.



Your child's healthcare needs

Many children with Down syndrome have associated healthcare needs, but the pattern is very varied indeed.

Children with Down syndrome are known to be at higher risk for some illnesses and sensory difficulties than other groups. Possible complications include: heart disorders, bowel abnormalities, digestive problems, hearing and vision impairments, thyroid dysfunctions, infections, cervical spine dislocation and blood disorders. Some of these conditions are serious, but most are not.

Your child may not suffer from any of these medical conditions or may experience only a few of them.

Health conditions associated with Down syndrome are a good example of the range of experience that families have. About half of babies born with the syndrome have a heart disorder - half do not. Where children do have a problem, it may be a relatively mild condition, or a serious medical complication that requires surgery.

Children are usually under the care of a **paediatrician** from birth, who will screen for heart defects and watch out for any other health risks known to be associated with Down syndrome. Your child may be checked more often than other children to pick up developing problems as early as possible.

If you have any concerns about your child's health, discuss them with your general practitioner (GP), **health visitor** or **paediatrician**.

If you are reading this soon after discovering your child has Down syndrome and you have immediate concerns about your child's medical condition, turn to the Health Issues section now. You will find more detailed information about health issues there.

You may find it useful to refer to the following health checklist, produced by the **Down's Syndrome Medical Interest Group (DSMIG)** as time goes by.

DOWN'S SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns						
	Birth to 6 weeks	6 - 10 months	12 months	18 months to 2½ years	3-3½ years	4-4½ years
Thyroid blood tests	Routine Guthrie test		Thyroid blood tests including antibodies		Thyroid blood tests including antibodies	
	If your area has introduced fingerprick blood tests these should be done every year.					
Growth monitoring	Length and weight should be checked frequently and plotted on Down's syndrome growth charts. (see page 9 onwards) Head circumference should be checked at each routine medical check.			Length and weight should be checked at least annually and plotted on Down's syndrome growth charts.		
Eye check	Visual behaviour. Check for congenital cataract	Visual behaviour. Check for squint	Visual behaviour. Check for squint	Orthoptic examination, refraction and ophthalmic examination		Visual acuity, refraction and ophthalmic examination
Hearing check	Neonatal screening, if locally available	Full audiological review (Hearing, impedance, otoscopy)	Full audiological review (Hearing, impedance, otoscopy) annually			
Heart check and other advice	Echocardiogram 0-6 weeks or chest X Ray & ECG at birth and 6 weeks			dental advice		

	FROM AGE 5 TO 19 YEARS
Paediatric review	Annually
Hearing	2 yearly audiological review (as above)
Vision / Orthoptic check	2 yearly
Thyroid blood tests	At age 5 years, then either 2 yearly venous surveillance or annual fingerprick.

Detailed recommendations for Medical Surveillance Essentials for children with Down's syndrome are available.
For further information contact your local community paediatrician.

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Your child's developmental needs

All children with Down syndrome experience some degree of learning disability. They usually make progress in most areas, but at a slower pace. Children vary widely in the progress they make with reaching, sitting, standing, walking, communicating, talking and reading. Some aspects of development progress faster than others. What's important is that your child moves forward at his, or her, own pace - not how fast this happens.

There are recurring patterns in the development of children with Down syndrome when they are considered as a group - you could think of this as a 'developmental profile' of characteristic strengths and weaknesses associated with the syndrome.

Characteristic strengths

- **Social interaction:** most children with Down syndrome enjoy and learn from social interaction with family and friends. As time goes by, they often have good social and emotional understanding and most are able to develop age-appropriate behaviour, if this is encouraged and expected.
- **Visual learning:** children with Down syndrome generally learn visually. This means that they learn best from watching and copying other people and may find it easiest to take in information presented with the support of pictures, gestures or objects that they can see.
- **Gesture and mime:** children with the syndrome are often particularly good at using their hands, faces and bodies to communicate. They often enjoy drama and movement as they get older.
- **Reading ability:** reading is often a strength, possibly because it builds on visual learning skills. Therefore, reading is sometimes used to help young children develop language.

Characteristic weaknesses

- **Learning to talk:** Many children with Down syndrome experience significant delay learning to talk. Most children become talkers, but it takes longer. There seem to be three main reasons for this:
 - it takes them longer to learn to control their tongue, lips and face muscles
 - they have more difficulty remembering spoken words
 - they often have hearing difficulties, making it hard to pick up speech.
- **Hearing and vision:** hearing difficulties are common and can contribute to speech and language difficulties. Similarly, problems with vision are also relatively common, and these can affect the ability to learn visually. However, both hearing and vision difficulties can usually be treated effectively, or managed, with appropriate medical intervention and therapy.
- **Learning to move:** the skills needed to move around and explore, like reaching, grasping, sitting, crawling, standing and walking, tend to be delayed compared with other children. However, given time, most children become mobile and learn to be independent with feeding, dressing and toileting.
- **Learning from listening:** children with Down syndrome tend to find learning by listening difficult. This may be because they have a hearing impairment or because language is developing slowly. It also reflects particular problems with short-term or working memory.
- **Number skills:** many children with Down syndrome experience difficulties with number skills and learning to calculate.

Children with **mosaic Down syndrome** may be less delayed in some areas of development, but still seem to experience a similar profile of strengths and weaknesses.



Some children have extra difficulties

Some children have extra difficulties that cause more severe developmental delay. A small proportion of children with Down syndrome have additional medical complications, which affect their development. A relatively small proportion of children also experience **autistic spectrum disorders (ASDs)**, or **attention deficit hyperactivity disorders (ADHDs)**.

These extra difficulties affect about 10% of children with Down syndrome. If, at some time in the future, you think that your child may have any of these extra difficulties, ask the professionals who are working with your family for an assessment and advice.

Times are changing

It's impossible to predict outcomes for any individual child when they are very young, but it's important to understand that children and young people with Down syndrome in general are achieving much more than they did 25 years ago.

Some of the reasons for this are:

- increased acceptance and inclusion by society
- advances in medical care
- better understanding of the developmental and educational needs of individuals with Down syndrome
- better quality education.

People with Down syndrome are living longer and are learning to read, write and achieve more than was the case even 10 years ago. They often progress more slowly than other people, but if they are given opportunities to carry on learning, they can benefit from becoming lifelong learners, just like the rest of the population.

Here is what some people with Down syndrome have to say about their own experiences:

'What's Down 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.'

'Hello, my name is Nicholas. I am a young adult with Down's syndrome. For first born babies with Down's syndrome it is important to understand that with their extra chromosome they are still normal people like you and me. Life with a child with this syndrome is a hard job, but life with all children is hard work. All babies and children are the same, only one difference is that we need to have extra help with some life skills from a young age and growing up with the help of families and support workers to be independent.'

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



Starting out

Feelings

For most parents, finding out that their child has Down syndrome is a shock.

A key priority in your baby's first few months of life is to give yourself enough time to adjust. There are no rules and no rights and wrongs here - some people adjust very quickly and others find their emotions take much longer to settle down. As time goes by, things look very different, but in the early days, it's 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 anxiety and colours the challenges and excitements that every parent faces with a newborn child.

'It's OK to have days when you are not coping. In my experience these get fewer and fewer, but it is still OK to have them.'

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 or difficulty, having a family member with Down syndrome is often described as a positive experience - particularly for other children in the family. Here's what some other parents have to say:

'We adopted our son as a very small 18 month old baby. We have never regretted it. He has given us a second life. Yes, there have been bad times ,like what school he had to go to and what college, but our family life is good and we are very, very happy as a family.'

'Our babies with Down syndrome are still just babies who need to be loved and treated normally. I adore my son, we all do - and I wouldn't change him for the world. He delights us daily and has taught us tolerance and humility.'

Finding out more

Reliable information helps. It helps to guide expectations and takes away some of the fear of the unknown. There's a whole section explaining where you might look for more information at the back of the booklet. Come back to it later if it seems too much to take on board now.

If you use the internet, lots of information about Down syndrome is available online and email discussion groups make it possible to chat with other parents across the country and around the world. However, it is important to remember that much of the information out there will not be relevant to your individual child.

Keeping a balance

The demands of living with a young child can be overwhelming, particularly when Down syndrome results in extra appointments with doctors 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 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 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.'



Involving other people

Extended family and friends are important. They're the ones everyone naturally turns to when things are difficult. They can also help in very practical ways - for example, 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 syndrome. Share useful pieces of information and any advice you receive and involve them in some of the meetings you have with professionals, if you can. 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. [The Down's Syndrome Association](#) can tell you if there is a group in your area. You can find their contact details in the [Useful contacts and organisations](#) section towards the end of the booklet. 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 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.

Helping your child

This section provides information about early development, and about how you can help your child to grow and learn. It introduces some techniques which:

- build on what is known about the characteristic learning strengths of children with Down syndrome
- address areas of difficulty
- focus on skills children need to learn.

The material reflects the experience of other families and is supported by research findings, but it is general advice, which may or may not be relevant for your child. Discuss it with any professionals who work with you regularly. You know your child better than anyone else and are best placed to consider what might work for your child, and for your family.

Early days: baby care

Growth

Babies and young children with Down 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

Check your child's weight and height gain against appropriate norms.

The **Down's Syndrome Medical Interest Group** (www.dsmig.org.uk) produces a special insert for the Personal Child Health Record which includes growth charts for children with Down syndrome and other useful health information.

Breast feeding

Many babies with Down 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 you can do

- Persevere if you want to breastfeed 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 (telephone 0300 330 0771 for free advice).



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 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 you can do

- Introduce your baby to solids and finger foods in the same way and at the same time as you would any other baby.
- 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 on liquids or sloppy food.
- If your child experiences particular problems in this area, ask to see a speech and language therapist with expertise in feeding disorders.

Teething

Children with Down syndrome tend to get their teeth later than most other babies.

What you can do

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

Skincare

Many babies with Down syndrome have dry skin.

What you can 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, general practitioner (GP)** or pharmacist for advice if there is a particular problem.

Temperature control

Many babies and young children with Down 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 you can 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 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're 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's important to resolve sleep difficulties, as broken nights adversely affect everyone in the family. Your health visitor can give advice in this area. General books on sleep issues for children may help. Many families experience difficulties in this area.



What you can do

- Ask for a specialist assessment if your child breathes noisily, is restless, wakes frequently, or you suspect they have **sleep apnoea**. Ask your **health visitor** or **GP** to refer you. Specialist sleep clinics are available in some parts of the country.
- Establish clear bedtime routines and sleep patterns and stick to them. Repeat a pattern of bath, cleaning teeth, a song or story, kissing goodnight, then into bed with a cuddle. If your child wakes at night, put them back to their own bed with the minimum fuss.

Toilet training

Most children with Down syndrome are toilet-trained during the day by four or five years of age, but there is wide variation. You may find the same approach you've used with other children is successful. However, many children with Down syndrome need more practice than other children to develop control. This is the result of learning difficulty. A consistent routine of sitting on a potty/toilet at set times in the day (for example after meals) may help.

If you need advice, ask your health visitor and local parent support group for help and ideas.

Helping your child 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 have already learnt or slow down in one area of development while pushing ahead in another. There may be unexpected spurts of development. This uneven pattern of development is characteristic of children with Down syndrome.

This section considers development under the following headings:

- Learning to interact with others
- Learning to move and explore
- Learning through play
- Developing attention and memory skills
- Learning to communicate
- Learning how to behave
- Learning how to think and learn
- Learning social and self-help skills.

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 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 you can 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, everyday, by being with their family and with other adults and children.



- Try not to 'baby' your child, but encourage age-appropriate behaviour. Over time, this will build self-confidence and prepare your child for life with other children of a similar age.
- Encourage your child to play with other children in a mainstream nursery or playgroup, if you can. Children with Down 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 (often 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 to start exploring on their own.

Your child is likely to face significant delay in developing 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 an **occupational therapist** can offer advice and pass on good ideas. Not all children with Down syndrome need professional help, but they should all be offered a 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 towel under the armpits, which lifts the upper trunk. Don't leave your baby on their own while they're lying on their front until you're 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 you can 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 your child to help them learn about body parts and to encourage them to practise movement.
- As your baby grows into a toddler and young child, use music, movement and sports activities to practise 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 syndrome learn in the same way as other children but often benefit from more support for their play.

Who can help?

Most children with Down syndrome receive support from a home visiting teacher by about 12 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 you can do

- Become your baby's 'play partner' and show your child how to play with their toys. Show them what a toy does, how to get it to make a noise or to move, how to screw or 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's helpful to have two toys, so that you can both shake a rattle or 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 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 syndrome tend to be good at learning by imitating or copying other 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 to 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 jiggling 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 to remember it. Attention and memory skills help children do these things.

The ways that babies with Down syndrome pay attention to the world around them varies a lot. Some children like to 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 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 the knock-on effect of slowing down the rate at which they learn language.

What you can do

- Encourage your baby to interact with you in the early months by being lively and responsive.
- Repeat things more often than you 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 and 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 with your child from around two years of age to help your child develop their 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 syndrome are keen to communicate. However, many 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 support and advice 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 and input 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 working with you has of Down 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 you can 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 together 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 everyday 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 syndrome are often good visual learners, and therefore you may be able to help them to understand by using signs and gestures. Many babies and toddlers understand more language than they can use (in other words, their **receptive language** is better than their **expressive language**). 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 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, by looking in the back of this booklet.

What you can 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 a child has hearing difficulties.
- Make sure that your child can see what you're doing when you're 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 syndrome when they begin to join words together - usually between two and three years of age.

Who can help?

Your **home visiting teacher** and your **speech and language therapist** can help you use reading activities and materials with your child. The **Down Syndrome Education International**, the **Down's Syndrome Association** and **Symbol UK** also provide information and DVDs about reading and language.

What you can do

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

Learning how to behave

Like all children, your child may start being difficult at about 12 months of age - demanding to be picked up, sleeping badly, or suddenly having 'faddy' preferences for foods. By two years of age, like many other parents, you may be struggling with increasing demands for independence and tantrums.

Children with Down syndrome often display more difficult behaviours than typically developing children of the same age, because they have more 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 you can do

Three simple pieces of advice can help to 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 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 most 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 life. Babies constantly watch all the activity around them and explore toys and objects within their reach. As they grow older, children continue to learn through all their everyday activities at home, when out shopping or at the park, and in playschool.

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

What you can 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 to three years, 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 syndrome are capable of behaving in an age-appropriate way - in other words, in the same way as other children of their age. Progress in this area is influenced by how much parents expect of their children, as well as by any learning difficulties children experience.

What you can 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 to do things for themselves.



Development by school age - what is it reasonable to expect?

The progress children make varies a great deal, but most children with Down syndrome can achieve a number of the same developmental goals as other children by the time they start school.

Most five year olds with Down syndrome are toilet-trained and can walk, feed themselves and change at least some of their own clothes. They know how to be part of a group of children of the same age and can conform to some of the social expectations of a nursery or infant school classroom. They are able to sit at a table, listen to stories and follow instructions from a parent or teacher. Most can control their own behaviour and can understand other people's emotions. Some children need little or no help with these things, but others need much more support to get to this point.

There are likely to be significant delays in spoken language. Children typically use single word or two to three word sentences when they start school. Some words may be difficult to understand. Despite this delay, at around five years of age some children are reading words and know letter names and sounds, and others are starting to count. Speech and language go on to develop further as children get older.

Who can help?

This section introduces some of the professionals and agencies you may meet and explains why many parents find contact with other families with children with Down syndrome helpful.

Community services

All the services and facilities that other families with young children in your area use are equally important and relevant for babies and young children with Down syndrome. These are likely to include:

- parent and toddler groups
- musical activities
- swimming classes
- movement and activity groups
- local libraries and toy libraries
- play schemes
- nurseries and play groups
- childminders.

However, there are also other services that are additional to, or different from, what other families in your area might need. Many parents of children with Down syndrome find they naturally come into contact with many more professionals and agencies than other families.



Overview of professional services

The services that are usually particularly important in the lives of families with a young child with Down syndrome are:

- healthcare services
- services that promote development in children.

Your **health visitor**, or any other professional you meet on a regular basis, should be able to tell you about what is available in your area and about how services are organised.

Any special healthcare services you need are usually coordinated by a **paediatrician** - a doctor who specialises in the care of babies and children. However, your **general practitioner (GP)** and **health visitor** will continue to cover everyday health issues. Your GP can refer you to other specialists anytime during the first few years of your child's life, if this is needed.

Early intervention services that promote development are usually provided by a number of different healthcare and education professionals or agencies. Speech and language therapy, physiotherapy and occupational therapy are normally provided by health services. **Home visiting services**, advisory and **Portage services** are usually provided by education services.

Sensory impairment teams support children who have hearing, visual or multi-sensory impairments. Children with Down syndrome who have significant vision or hearing difficulties benefit from the support of advisory teachers working for these teams.

In some areas of the country, health and other early intervention services are located in one place so that they can offer a better-coordinated service for families and children. There will be more detail about this later in the booklet.

Professionals who can help

The role of professionals is to support you and encourage your child to develop as fully and quickly as possible. If you are unsure about what anyone you meet does, ask someone to explain - if you're meeting a lot of different professionals in a short space of time it can be overwhelming, particularly if you are upset and trying to take in a lot of new information.

The following table summarises some of the people you may meet and identifies the area they may be able to help you with:

Area	Professionals who can help
Healthcare	General practitioner (GP) Paediatrician Specialist doctors and consultants Health visitor
Movement skills	Physiotherapist Occupational therapist
Equipment	Social worker
Financial help	Social worker
Learning and play	Home teacher Portage Home Visitor
Speech and language	Speech and language therapist
Hearing and vision	Sensory impairment team (teachers of the deaf, teachers of visually impaired children and teachers of children with multi-sensory impairments)



Social services

Social worker

A **social worker** is a professional who supports families by providing information and advice and introducing them to services they may need.

Social workers can provide practical help and advice about counselling, transport, home helps, and other services such as respite or babysitting services. They may also be able to help you with claiming welfare benefits or getting equipment you need at home. In some areas they help families make contact with parents' groups or local play schemes that may be particularly useful.

Services are organised in different ways in different places. Sometimes specialist social workers are available who have particular knowledge and experience of working with people with learning disabilities, including those with Down syndrome. In other places, social workers work as part of a specialist team that supports children of all ages, with a range of disabilities or special needs.

In many areas, social workers call automatically when a child with special needs is born. Sometimes you have to ask for a visit. You will find the number in your telephone directory listed as the social services department under your local authority.

Health services

General practitioner (GP)

A **general practitioner** or **GP** is a family doctor who works in the community in a doctors' surgery or health centre. They deal with general health issues and can refer you on to clinics, hospitals and specialists when needed.

Paediatrician

A **paediatrician** is a doctor who specialises in the care of babies, children and young people. They may work from a hospital, child development centre or local health or children's centre. They can offer advice, information and support about any medical condition your child has. It is usually a **paediatrician** who refers your child on to other specialists when this is needed.

Specialist doctors

Depending on your child's particular healthcare needs, you may meet some other specialists. For example:

- **ear, nose and throat consultant (ENT consultant)** - a doctor who specialises in the diagnosis and treatment of ear, nose and throat conditions
- **audiologist** - a specialist in testing hearing conditions, who prescribes hearing aids
- **cardiologist/cardiac surgeon** - a doctor who specialises in treating heart conditions
- **neurologist** - a doctor who specialises in the brain and nervous system
- **ophthalmologist** - a doctor who specialises in eye conditions
- **endocrinologist** - a doctor who specialises in conditions of the endocrine system (the glands producing hormones, including the thyroid gland)
- **gastroenterologist** - a doctor who specialises in conditions of the stomach and intestines (the gastro-intestinal system)
- **oncologist** - a doctor who specialises in the treatment of cancer.

Health visitor

Health visitors are qualified nurses or midwives with additional special training and experience in child health. They visit family homes in the early years to check on children's health and development. They give help, advice and practical assistance about the care of very young children, child development, sleep patterns, feeding, behaviour and safety.

You should automatically receive a visit from a health visitor, as all families are visited in the early years. If you don't, you can usually contact them through your GP. Health visitors can help you contact doctors, hospitals and other services in your area. In some areas, there are health visitors who specialise in providing support for children with special needs.

Speech and language therapist (SALT)

A **speech and language therapist** is a health professional specialising in communication development and disorders (and associated eating and swallowing difficulties). A speech and language therapist can offer support and advice to parents of children with any type of communication problem. This includes children with Down syndrome. They work to enable children to develop their communication skills, in sign language and/or in spoken language.



A speech and language therapist can work with you and your child at home, in nursery or school, or at a clinic or hospital. Sometimes speech therapy is offered on an individual basis and sometimes in groups.

Some speech and language therapists specialise in working with children with Down syndrome, but these specialists are not available in every area. Most speech and language therapists work for the National Health Service, but some work for voluntary sector organisations or for themselves, as independent therapists.

Physiotherapist and occupational therapist

A **physiotherapist** is a health professional who specialises in helping people with movement problems. Their work will focus on your child's **gross motor skills** - such as the skills involved in sitting, crawling, standing and walking. They may show you exercises for your child and discuss ways of developing good movement patterns. They can also offer advice on the best way to carry, hold and position your child.

Occupational therapists are experts in basic fine motor skills such as holding, grasping, picking up and manipulating objects, feeding skills and drawing/writing skills. They will be able to show you specific activities for your child and advise you on adaptations to your home and the use of special equipment.

Early years education services

Home visiting services

Home teachers or **advisory teachers** provide an education service for preschool children with additional support needs in their home.

They make regular visits to help parents support the development of their child's play, communication and relationships, and encourage children's full participation in everyday life. These services are organised differently in different parts of the country and are not available everywhere - your local Children's Centre or a practitioner will be able to advise you on this.

Sometimes home visiting or home teaching services are called **Portage services**. You can find out more about Portage and whether there is a service where you live, by getting in touch with the National Portage Association (see Useful contacts and organisations section for contact details).

If there is a service like this in your area, your child should receive regular help from about nine to twelve months to three years of age. In some places, home visiting services support children up to five.

Home visiting services can offer practical help and ideas to make learning fun for all the family. They encourage your child's interest and talk through any problems you are experiencing. A **home teacher**, **advisory teacher** or **Portage Home Visitor** can provide advice on:

- making the most of play
- developing motor skills
- promoting early language and communication
- developing social skills
- general child development issues
- suitable preschool or school settings for your child in your area
- preparing your child for preschool or school settings.

Home teachers usually coordinate their activities with any other professionals that are working with you and your child - for example, a **speech and language therapist** or **physiotherapist**.



Special educational needs (SEN) service

The Education Department is the section of your local authority that is responsible for the schools in your area. Children who need more help than other children are described by education services as having special educational needs. The **special educational needs (SEN)** service is part of your local authority. They provide extra help for children with special educational needs and their parents.

SEN services provide support for children in the family home, at nurseries and playgroups and in a range of school settings. They also offer advice and information to nurseries, playgroups, schools and colleges that teach children with special educational needs, including Down syndrome.

Your local SEN service can provide advice and support on:

- how learning disabilities affect children
- language and communication
- other support services
- parenting issues
- your child's education
- access to nurseries, playgroups and schools.

You can find out more about special educational needs in other [Early Support](#) publications, such as the [Background information booklet](#) on Statutory Assessment: Education, which is part of the [Early Support Family pack](#).

Educational psychologist

An **educational psychologist** is someone with a degree in Psychology and a doctorate in Educational Psychology. Educational psychologists specialise in children's development and learning and help children who find it difficult to learn, to understand or to communicate with others. They visit schools and nurseries, work with teachers and parents to assist children's learning and behaviour, and assess psychological development and special educational needs.

Special educational needs co-ordinator (SENCO)

A **SENCO** is a teacher in a school, or early years setting, who has responsibility for identifying children with **special educational needs** and making sure they receive appropriate support. This may involve working directly with the child, supporting mainstream staff in assessing a child's needs or a combination of both of these things.

Support assistant

Support assistants work alongside teachers in classrooms or nurseries. They support children on an individual basis, or in a small group, to reinforce lessons or help a child to develop communication skills. Some specialise in working with children with **special educational needs**, and some are qualified **nursery nurses** or may be working towards other accredited qualifications.

Integrated centres

There are **child development centres** or CDCs in many areas. These specialist centres bring together a team of professionals in one place to provide a range of health and early intervention services for children. Psychologists, speech and language therapists, doctors, specialist health visitors, advisory teachers and paediatricians work together in these centres.

In some areas, **Sure Start children's centres** are developing to provide integrated education, childcare, family support and health services in one place for young children. These centres encourage professionals from different backgrounds to work together to support all the children and families in an area, including children with disabilities or special educational needs.



Meeting with professionals

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

Professionals work in partnership with families and it's 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 a concern about
- ask the same question 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 take notes or to take someone with them to jot down important points. You could do this in the [Early Support Family file](#). Others ask to 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 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 your 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 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 if you are finding it difficult to find out what is available.

Charities and voluntary organisations

Many charities and voluntary organisations can offer support, advice, information and events for children with Down syndrome and their families. The professionals working with you should be able to tell you about any local organisations that provide support. Key national organisations that can help you include the [Down's Syndrome Association](#) and [Down Syndrome Education International](#). Their contact details are provided in the back of this booklet.



Financial help

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 syndrome. The main benefits are:

- Disability Living Allowance (DLA)
- Carer's Allowance
- Child Tax Credit
- Working Tax Credit.

You may be entitled to one or more of these benefits or tax credits. Your entitlement depends on the needs your child has as a result of disability and/or on your income.

If you would like to know more about the range of financial help that is available to you as the parent of a child with Down syndrome, contact the Down's Syndrome Association's welfare benefits advisors on 0333 121 2300 . They will be able to advise you on how to fill in your DLA form. Your health visitor may also be able to help.

- You can find out more about DLA from:
www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011925.
- Or call the Benefits Enquiry Line on 0800 882 200
- Or textphone 0800 24 33 55.
- You can download a DLA application form from
www.dwp.gov.uk/advisers/claimforms/dla1a_child.pdf

Why you should claim

You may find that having a child with Down syndrome means you spend extra time visiting hospitals or clinics, going for tests and attending therapy sessions. Your child may need more help on a day-to-day basis than other children of the same age. All this is time consuming and can cost money. It may also be important to expose your child to a wide range of experiences, to stimulate their interest and language development. Claiming benefits may allow you to make more visits and allow your child to participate in a wider range of activities than would otherwise be possible.

Other sources of financial help

There are organisations that may be able to give grants to help you meet your child's needs. One of the best known is the Family Fund, which can help with needs related to children's disabilities (including holidays).

The grants are means-tested. Children with Down syndrome and their families do receive help, but each case is considered individually.

For more information, contact:

Family Fund
4 Alpha Court
Monks Cross Drive
York YO32 9WN

Tel 0845 130 4542 or 01904 621115

Email: info@familyfund.org.uk

Web: www.familyfund.org.uk

There are several other organisations that give grants for a wide variety of reasons, though be aware that many receive far more requests for help than they are able to meet. If you need financial help for something that would make dealing with your child's disability easier, contact the welfare benefits advisors at the [Down's Syndrome Association](#). They have a computer database to help you find grant-making organisations suitable for your situation.



Looking ahead - childcare and education

Children with Down syndrome often need additional support to be able to take full advantage of education. Additional support means extra help, or help that is different from what other children need. In the first three years of life, practical advice and support is usually provided by a **Portage Home Visitor** or a **home visiting teacher**, who works with you at home.

This section explains what happens next and tells you where you can find out more about education services and **special educational needs**.

Childcare

There are many kinds of childcare. It can be formal care provided by a childminder, nursery, playgroup or crèche. It can be less formal care provided by a relative, friend or babysitter. Childcare can be for a brief period of time, or for longer, to allow you to go back to work or to study.

It's important that you feel comfortable with your childcare arrangements and that anyone working with your child is able to meet their needs. It is not always possible to find someone with experience of working with children with Down syndrome, but it is worth asking around. The most important qualities to look for in a childcare professional are an interest in your child and a desire to learn about his or her needs.

Young children with Down syndrome tend to have more appointments and clinics to attend than other children. Your child's carer needs to be aware of this and able to provide a flexible service, so discuss it with them.

There are many factors involved in deciding what kind of childcare is suitable for your child. Your **health visitor** or **Portage Home Visitor** or **home visiting teacher** may be able to tell you about the childcare options available in your area.

The following organisations can also give you information:

Daycare Trust

The Daycare Trust is a national childcare charity. They work to promote high quality, affordable childcare for everyone. They provide information about all aspects of childcare.

2nd Floor, Novas Contemporary Urban Centre
73-81 Southwark Bridge Road
London SE1 0NQ

Parent helpline: 0845 872 6251
Tel: 020 7940 7528

Email: info@daycaretrust.org.uk
Web: www.daycaretrust.org.uk

Family Information Service (FIS)

The Family Information Service can give you information about the full range of childcare and other services for children, family and young people available in your area. You can contact the FIS through your local authority offices or the National Association of Family Information Services (NAFIS). NAFIS is a registered charity that supports, links and promotes Family Information Services (FIS) in Great Britain.

National Association of Family Information Services
Grosvenor Gardens House
35-37 Grosvenor Gardens,
London SW1W 0BS

Email: info@nafis.org.uk
Web: www.nafis.org.uk



National Childminding Association

NCMA (the National Childminding Association) is a charity and professional association that aims to ensure that families in every community have access to high quality, home-based childcare, play, learning and family support so they can help their children reach their full potential.

Royal Court
81 Tweedy Road
Bromley
Kent BR1 1TG

Tel: 0800 169 4486

Email: info@ncma.org.uk

Web: www.ncma.org.uk

Education

Why should you think about education now?

The extra support that many children with Down syndrome need can be provided from a young age. There are also decisions you will have to make at different stages as your child grows. Being aware of the educational system for children with Down syndrome well ahead of time can help you gather the information you need to make important decisions later on.

Types of early education setting

Places that offer education to young children, like nurseries and playgroups are known as early education settings or early years settings.

By three years of age, your child should be able to join a playgroup, preschool or kindergarten. Children with Down syndrome often benefit greatly from the role models for social behaviour, play and language provided by other children. Many children benefit from extra support in **mainstream settings**, but some children will be able to cope without extra help.

Your child should not be 'babied' in these settings. They should be supported to learn how to conform to routines and to behave as well as other children of their age. They should be given access to the same curriculum, with appropriate adaptations. It is helpful if staff understand that children with Down syndrome often benefit from structured teaching and supported play.

In your area there may also be nurseries and preschools that are just for children with disabilities. Some children attend both **mainstream** and **special schools** in the first three years of their life. Find out about the early education settings available in your area and if possible, visit some before deciding which provision you think is best for your child.

Your **home visiting teacher** can help you choose a preschool placement, such as nursery, playgroup or childminder. They may also be able to support you later when you choose a school.

When it is time for your child to go to nursery or school your home teacher can help prepare your child. They can also help prepare the nursery or school, by offering training to staff. They should be able to give you information about the range of educational placements available in your area.

Support in early education settings

When a child starts attending an early education setting, a range of additional support can be given. The level and type of support depends on what your child needs. If a child needs extra, or different, support than other children, teachers and schools will describe him or her as having **special educational needs**. All children with Down syndrome fall into the category of having special educational needs, but the degree of support they need depends on their individual strengths and weaknesses. For many children, extra support is provided by the staff in the nursery/playgroup they attend, not by additional specialist staff coming in from outside.

If your child needs more support, then the nursery can bring in additional specialist help. A range of people work with children with Down syndrome in nurseries and schools, including: nursery nurses, teachers, teaching assistants, and **SENCOs**. The number of people involved with your child will depend on how much support he or she needs and how services are organised in your area. Specialist support for children with Down syndrome can include a visiting **educational psychologist**, a **speech and language therapist** and a **physiotherapist** or **occupational therapist** who works with nursery staff and your child to offer support.



Moving on to school

Some children receive a **Statement of Special Educational Needs** from their local authority education department before they start school. This is a document that specifies your child's additional needs and how these will be met at school.

Mainstream or special education?

Increasing numbers of children with **special educational needs** are educated in mainstream nurseries or mainstream schools with support. This policy of 'inclusion' aims to combat discrimination against people with disabilities and to include them fully in society. Most of the available evidence indicates that children with Down syndrome do well if they go to the same nurseries and schools as the other children in their neighbourhood. Studies have shown that older children with Down syndrome who attend mainstream schools tend to achieve better than comparable children educated in special schools.

Based on this evidence, recent government policy in the UK has been to encourage children with Down syndrome to attend mainstream nurseries and schools. Successful inclusion for your child depends on their needs, abilities, interests and personality, the resources provided (particularly staffing levels and staff training) and the attitudes of staff and other pupils.

However, individual needs vary and it may be more appropriate for your child to attend a 'special' school or nursery (one that only caters for children with a disability or **special educational needs**).

Some parents feel that a special school will offer the most suitable provision for their child. Others may start their children in a **mainstream** infant school and then decide that **special school** provision is more appropriate as their child gets older.

It's easier to make some of these decisions if you have visited some mainstream and special schools in your area and discussed how they might meet your child's **special educational needs**.

Choosing a nursery or school

Choosing a nursery or school for your child is a very personal decision. You might want to think about some of the following points:

- Do you feel comfortable and welcome?
- Do the staff appear to be interested in your child? Are they interested in what you can tell them about your child?
- How do they describe the main aims of the school? Does it sound as though your child will be included?
- How much choice will your child get regarding activities? Will they be included in all school activities? If not, then which areas won't they be included in and why?
- How did staff get on with your child at a first meeting? Are you happy with their attitude and style of working? How did your child react to them?
- How do they handle liaison between home and school/nursery?
- What resources does the school have? Ask about qualified specialist teachers, access to medical and therapy staff if appropriate, and other specialist resources.
- Who exactly will work with your child? If they don't yet know, how will they decide?
- How many children are there per each member of staff?
- How much, if anything, do staff members know about Down syndrome and other learning disabilities? What training or experience have they had with children with Down syndrome?



Health issues

This section provides some basic information about the range of health issues known to affect some children with Down syndrome. It is for guidance only, as it is beyond the scope of the booklet to provide detailed medical advice.

Always seek qualified medical help if you have any concerns about your child's health - the sooner any issues are detected, the sooner they can be treated to minimise their effect on your child's development.

Please remember how individual children with Down syndrome are. Your child may not suffer from any of the medical conditions discussed here or may experience only some of them.

Overview

The following health conditions are known to be more common among children with Down syndrome than other children:

- Newborn health issues:
 - heart disorders
 - bowel abnormalities
- Ongoing health issues:
 - hearing impairment
 - visual impairment
 - infection
 - digestive difficulties
 - thyroid dysfunction
 - blood disorders
 - epilepsy
 - cervical spine instability.

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 that they are present at birth.

Heart disorders

About half of babies born with Down 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 some are serious and will need surgery.

Because of the high incidence of heart defects, paediatric departments in hospitals normally operate screening programmes for newborn children with Down syndrome. Some problems will have been found on antenatal **ultrasound** before the baby is born. Newborn babies are also normally examined by a paediatric doctor, with appropriate experience. They will arrange necessary tests, which may include an X-ray, an electrocardiogram (ECG) or an **echocardiogram**.

If there are concerns that there may be a heart problem they will refer your child to paediatric **cardiologists** or paediatric **cardiac surgeons** for further diagnosis and treatment.

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. Find out more at www.dhg.org.uk

Bowel abnormalities

Around 10% of babies with Down 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 (**duodenal or jejunal atresia**) or where the anus is not present (**anal atresia**). These problems may have been diagnosed antenatally, or the baby could develop problems within the first day or two of life. Surgery in the newborn period will be necessary to correct them.



Hirschsprung's disease is a relatively rare condition among the general population but it's more common in children with Down syndrome (affecting approximately 2% of them). When this occurs, part of the wall of the lower part of the large bowel has nerve cells missing. This means the bowel cannot do its normal work of pushing stools along to the anus. **Hirschsprung's disease** may be diagnosed in the newborn period because the baby does not pass any stools, or it may become apparent weeks or months later when it causes **chronic constipation**. Diagnosis is by a combination of medical examination, X-ray and biopsy of the bowel.

Ongoing health issues

There are several health issues that you need to be aware of throughout your child's early years.

Hearing impairment

It is quite likely that your child will be affected by hearing impairment or deafness at some stage, as over three-quarters of children with Down syndrome experience problems hearing at some point. The hearing loss may be mild and temporary or a more long-term problem – the different types of hearing loss are discussed below. You can read more about hearing loss in the [Early Support Information for parents booklet on Deafness](#).

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 usually considered serious in other children, it may have a significant effect on learning for children with Down syndrome. Where children are having difficulty learning to talk because of the hearing loss, signing may help.

Glue ear

Glue ear is a particularly common condition in children with Down syndrome. The condition is called **Glue ear** because a thick secretion that looks like glue, builds up in the middle ear cavity, causing **conductive hearing loss**. Glue ear has a greater incidence and impact on children with Down syndrome compared with other children, because:

- the 'glue' is stickier
- the ear is more likely to become infected
- the **Eustachian tubes**, which connect the middle ear to the upper part of the throat, are often not as effective in draining fluid out of the middle ear in these children.

There are various treatments, including **antibiotics** and the insertion of **grommets** or the use of hearing aids. Grommets are tiny tubes that are inserted through the eardrum under general anaesthetic. They improve hearing by allowing the 'glue' to drain out. This form of treatment is effective as long as the **grommets** remain in position in the eardrum. Because children with Down syndrome tend to have small ear canals, **grommets** may be difficult to insert or may need to be replaced frequently. For some children, hearing aids may be a better option. Removing tonsils and/or adenoids sometimes helps. An ear, nose and throat (ENT) consultant will advise on treatment options.

Middle ear infections

Middle ear infection, or **otitis media** is also quite common. The treatment of middle ear infection usually involves the use of **antibiotics**.

Sensori-neural deafness and hearing aids

Some children with Down syndrome have a **sensori-neural** hearing loss that is permanent. When this happens, hearing aids are normally used. Digital hearing aids are now able to compensate accurately and effectively for many different types of hearing loss. Traditional behind the ear aids may be prescribed or increasingly ones that are worn on a head band (BAHA soft bands) are being used.

Getting used to wearing a hearing aid may be difficult in some cases.

More information is available in the booklet Down's Syndrome and Childhood Deafness published by the National Deaf Children's Society - see www.ndcs.org.uk

Children need to learn that the aid is helpful and a period of training may be necessary. A specialist teacher of the deaf may be particularly helpful here.



Visual impairment

Children with Down syndrome are more likely to suffer from vision disorders such as **short sightedness**, **long sightedness** and **astigmatism**.

These are all known as 'errors of refraction' and distort the image upon the **retina** - the light-sensitive surface at the back of the eyeball. They are also more likely to have squints and to experience delays in developing effective focusing, depth perception and sharpness of vision. Research into all these issues is ongoing and the use of bifocal lenses appears to benefit many children.

As children with Down syndrome tend to rely heavily on visual information, any eye problems can have a major impact on their development. Your child should have a routine eye test at least once a year through childhood, and as soon as possible, if their behaviour indicates a deterioration in vision.

Many of these difficulties can be corrected to give good vision with the use of spectacles. If your child needs spectacles, make sure that they are properly fitted, especially on the bridge of the nose and on the ears.

You may find that your child initially refuses to wear their spectacles and need to ask for some help from a specialist teacher to establish use.

Some parents recommend fitting elasticised bands to the ear-pieces (like the ones used by some sportsmen/women) to stop spectacles falling off. Try to keep glasses as clean as possible, so that your child is always aware how they make the world around them clearer and easier to see and check that they are kept clean by staff in preschool and nursery situations. Other parents also recommend keeping a spare pair of glasses - to avoid the disruption of waiting for a new pair if spectacles are lost or damaged.

For more information about vision disorders in children with Down syndrome, visit the website for the **Down's Syndrome Group**, based at Cardiff University - www.cardiff.ac.uk/optom/eyeclinic/downssyndromegroup/downssyndromemain.html

Infection

Children with Down syndrome generally have an increased susceptibility to infections. It's thought that this may be due to differences in their immune systems. Children are prone to more frequent infections and these infections are sometimes more difficult to treat.

If your child seems below par for no obvious reason, they may have a hidden infection or occult infection. Common sites for infection are:

- bladder (urinary)
- throat
- tonsils
- teeth
- middle ear
- skin

Some infections can be treated using **antibiotics**. Your child may need antibiotics more frequently than other children and they may be given earlier in the course of an infection. The number of infections should go down as your child gets older.

Childhood immunisations

It is important that children with Down syndrome receive standard childhood immunisations in the normal way (i.e. all vaccines that are part of the universal UK schedule).

Additional immunisations, including seasonal influenza vaccines, may also be advised each year, particularly for those with heart or respiratory problems. Other immunisations such as Hepatitis B may be suggested in some circumstances. You should discuss these additional immunisations with your GP.

For more details about immunisations for children with Down syndrome, contact the **Down's Syndrome Association**. For more information about standard childhood immunisations visit the NHS website: www.immunisations.nhs.uk

Sleep related breathing disorder (SRBD)

SRBD (also known as sleep apnoea or sleep related upper airway obstruction) occurs in children with Down syndrome more frequently than other children. It can occur in those with large tonsils or adenoids, particularly floppy tongues, or a chronic blocked nose. When the child is asleep, their airways become partly blocked making



breathing more difficult. Children with this condition may snore, be very restless during sleep, or adopt unusual sleeping positions. In the day they may be sleepy or overactive. It can have a long-term effect on their growth and health.

Your doctor may suggest a simple test to measure oxygen levels during sleep. If there is a significant problem, further tests will be suggested. The first step in treatment is often removing the tonsils and adenoids, or a specialist referral may be needed for the consideration of other treatments

Digestive difficulties

Children with Down syndrome may be more prone to digestive difficulties including **constipation**, **diarrhoea**, and **gastro-oesophageal reflux**.

It's important that any signs of digestive difficulties are investigated thoroughly as they are sometimes associated with bowel abnormalities. Picking up on the signs, and addressing underlying problems, will make sure that your child gets the nutrition needed to grow and develop, and will minimise any discomfort and distress associated with digestive problems.

Constipation

Constipation (difficulty passing stools) is a common problem in children with Down syndrome and in most cases it is not due to underlying disease. It can be due to a combination of poor mobility in the gut, diet and inadequate fluid intake. Giving your child extra fluid, fruit and cereals may solve the problem, or it may be necessary for your doctor to prescribe a stool-softening laxative.

If **constipation** is severe, or persists, then other causes should be considered.

Hypothyroidism and **Hirschsprung's disease** are both possible causes. If your child has had a severe problem with constipation since they were born that has not responded to simple measures, ask your GP about these possibilities.

Diarrhoea

Diarrhoea is the frequent passage of loose stools. It's not possible to specify how loose or how often is abnormal, as every child is different. Many infants and toddlers (and some adults) pass several loose stools everyday, others do not. What your child eats and drinks also has an effect.

The important thing is to notice when there is a significant change from your child's normal pattern that lasts more than a few days.

Sometimes stools may be particularly bulky, foul smelling or look frothy or greasy and this may be a sign that food is not being absorbed properly.

One condition where this happens is **coeliac disease**, which is more common in children with Down syndrome.

In some circumstances, **diarrhoea** can be associated with chronic constipation. If this is the case, you may see an 'overflow' of small, gritty pieces of solid in a straw-coloured liquid.

Gastro-oesophageal reflux

Gastro-oesophageal reflux occurs when food, which has already passed into the stomach and into the bowel, comes back up into the **oesophagus** and is vomited up. Most healthy children experience this from time to time. It is more common in babies because:

- their food is liquid and therefore more easily brought back
- they spend less of their time upright
- the muscle at the top of the stomach that should prevent this is not yet well established.

Some babies also have a **hiatus hernia** - where the top part of the stomach is pushed up into the chest.

Babies with Down syndrome are more likely to have reflux, probably because the muscles of the stomach and **oesophagus** that work to push the food along, seem to work less effectively. Symptoms may be mild and some children gag rather than vomit, making diagnosis more difficult. However, vomiting may be severe enough to stop a child gaining weight. The contents of the stomach are acid and can irritate the lower **oesophagus**, causing discomfort and sometimes bleeding from the oesophageal wall, which can cause **anaemia**. In these cases, medical treatment is necessary.



Thyroid dysfunction

The **thyroid** is a small gland in the neck that produces **thyroxine** - a **hormone** that helps control the body's metabolism and growth. Activity of this gland is controlled by **thyroid stimulating hormone (TSH)**, another **hormone** produced in the brain.

Hypothyroidism, or underactivity of the thyroid gland, is more common in people with Down syndrome than in the population as a whole, and affects around 10% of children with Down syndrome. In hypothyroidism the levels of **thyroxine** are low, and **thyroid stimulating hormone** high.

The signs and symptoms of **hypothyroidism** vary a great deal between individuals. Some of the signs are subtle, and can be attributed to Down syndrome itself. Common symptoms are:

- feeling tired or sluggish
- feeling cold
- hair loss
- constipation
- dry skin
- a hoarse voice
- poor growth.

Hypothyroidism is diagnosed by taking a blood test to measure the levels of **thyroxine** and **thyroid stimulating hormone**. Anti-thyroid antibodies can be measured on the same sample - if these are raised it can be an early warning that **hypothyroidism** is likely to develop.

Because the signs and symptoms can be subtle, but the impact on health and development significant, it is recommended that these blood tests are done regularly. The first test is done for all babies in the first week of life (as part of the **heel prick** or **Guthrie test**). The current recommendation is that this should be repeated at one year of age for children with Down syndrome and then repeated at least every two years. To do all the tests mentioned above requires a proper blood test. It is possible to measure just **TSH** with a finger prick. However, this test by itself, gives less information. If this screening method is used, it should be repeated every year. Your **GP** or **paediatrician** can arrange the tests.

If your child does develop **hypothyroidism**, treatment is straightforward, with **thyroxine** tablets (which contain the **hormone** that the **thyroid** produces naturally). These tablets need to be taken regularly, usually daily, and treatment is long-term. Regular blood tests are needed to check that your child is getting the right amount of medication.

Blood disorders

Children with Down syndrome are at increased risk of a number of disorders affecting blood cells. One of these is **leukaemia**, which affects around one in a hundred children. Response to treatment is usually good.

Epilepsy

Children with Down syndrome are more likely to have epilepsy than other children. This can occur at any age. One particular type of epilepsy that occurs in the first year of life is more common. It causes brief episodes of body, arm and leg stiffening. These are known as **infantile spasms**, as the body seems to fold forward. Each episode lasts only a few seconds, but they occur in clusters, which may be repeated many times through a day. The condition can be treated with medication and response to treatment is usually good.

Cervical spine instability

A small minority of children are affected by **atlanto-axial instability** - difficulties at the top part of the spinal column, or cervical spine. In very rare cases, **cervical spine instability** can cause damage to the spinal cord. However, as this condition is rare, the current opinion of most Down syndrome specialists is that there is no good evidence that any form of exercise carries a particular additional risk for people with Down syndrome.

Although **cervical spine instability** is very uncommon, given its potential seriousness you should watch out for any of the following early warning signs that might indicate a problem: weakness, new difficulties in walking, not lifting the feet properly, unsteadiness, pain or discomfort in the neck, holding the neck in an unusual position. Bladder and bowel function may be affected and problems with hand and arm function can be a later sign that something is wrong.

If you notice any of these possible warning signs in your child it's a good idea to ask for medical advice as soon as possible.



Further information on health issues

If you have any questions or concerns about your child's health, talk to your midwife, family doctor, or to your **health visitor**. If your child is under the care of a **paediatrician** or some other hospital-based specialist, they can also give advice.

You can obtain further information about medical issues from the **Down's Syndrome Association's** medical advisory service and on their website.

The Down's Syndrome **Medical Interest Group** provides comprehensive information resources on the healthcare of individuals with Down syndrome, including growth charts, developmental milestones and guidance for parents, doctors and healthcare professionals.

One of the most informative international websites on health and medical issues is that provided by Dr Len Leshin, a US paediatrician and father of a child with Down syndrome - www.ds-health.com

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.

We have listed Down syndrome organisations first. Other organisations are presented in alphabetical order. Additional websites 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 syndrome and their families. Contact the [Down's Syndrome Association](#) to find out if there is a group near you.

Down syndrome organisations

Down's Syndrome Association (DSA)

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome. They 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 their 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 Down's Syndrome Association
The Langdon Down Centre
2A Langdon Park
Teddington
Middlesex TW11 9PS

Helpline: 0333 121 2300 (open Monday to Friday, 10:00 am to 4:00pm)

Email: info@downs-syndrome.org.uk

Web: www.downs-syndrome.org.uk



Down Syndrome Education International (Downsed)

Down Syndrome Education International (Downsed) is focused on the education and development of individuals with Down syndrome. It undertakes innovative scientific research, publishes practical information, organises conferences and workshops, and provides advice and consultancy services. Downsed has specialist knowledge in early years intervention and inclusive education.

Down Syndrome Education International also operates a specialist mail order service selling a comprehensive range of books and teaching resources for children with Down syndrome.

Downsed
The Sarah Duffen Centre
Belmont Street
Southsea
Hampshire PO5 1NA

Tel: 023 9285 5330
Fax: 023 9285 5320

Email: enquiries@downsed.org
Web: www.downsed.org and www.down-syndrome.info

Down's Heart Group

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

Down's Heart Group
PO Box 4260
Dunstable
Bedfordshire LU6 2ZT

Tel: 0844 288 4800
Fax: 0844 288 4808

Email: info@dhg.org.uk
Web: www.dhg.org.uk

Down's Syndrome Medical Interest Group (DSMIG)

DSMIG is a network of doctors whose aim is to ensure equitable provision of medical care for all people with Down syndrome in the UK and Republic of Ireland. The organisation provides information for healthcare professionals and may be contacted through the Down's Syndrome Association.

Web: www.dsmig.org.uk

Down's Syndrome Vision Research Group

A specialist group of researchers based at Cardiff University studying eye defects and visual development in individuals with Down syndrome and their effect on learning.

Down's Syndrome Vision Research Group
School of Optometry and Vision Sciences
Maindy Road
Cathays Park
Cardiff CF24 4LU

Tel: 029 2087 6163

Email: Downssyndrome@cardiff.ac.uk

Web: www.cardiff.ac.uk/optom/eyeclinic/downssyndrome/mgroup/downssyndromemain.html

Mosaic Down Syndrome UK

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

Email: judy.green@blueyonder.co.uk or bill.green@blueyonder.co.uk

Web: www.mosaicdownsyndrome.org



Other organisations

Association of Speech and Language Therapists in Independent Practice (ASLTIP)

ASLTIP is a professional body for speech and language therapists working independently. All members are registered and qualified therapists.

ASLTIP
Coleheath Bottom
Speen
Princes Risborough
Buckinghamshire HP27 0SZ

Tel: 01494 488 306 (answerphone); Fax: 01494 488 590

Email: asltip@awdry.demon.co.uk
Web: www.helpwithtalking.com

Contact a Family

Contact a Family provides support, advice and information for families with disabled children, no matter what their condition or disability.

Contact a Family
209-211 City Road
London EC1V 1JN

Helpline: 0808 808 3555
Textphone: 0808 808 3556 (Free for parents and families 10am-4pm, Mon-Fri)
Tel: 020 7608 8700
Fax: 020 7608 8701

Email: helpline@cafamily.org.uk
Web: www.cafamily.org.uk

Family Fund

The Family Fund is an independent organisation funded by the government administrations of England, Scotland, Northern Ireland and Wales. The Fund provides grants and information to families caring for a severely disabled child under 16.

Family Fund
4 Alpha Court
Monks Cross Drive
York YO32 9WN

Tel: 0845 130 4542
Textphone: 01904 658 085
Fax: 01904 652 625

Email: info@familyfund.org.uk
Web: www.familyfund.org.uk

Family Information Service (FIS)

The Family Information Service can give you information about the full range of childcare and other services for children, family and young people available in your area. You can contact the FIS through your local authority offices or the National Association of Family Information Services (NAFIS). NAFIS is a registered charity that supports, links and promotes Family Information Services (FIS) in Great Britain.

National Association of Family Information Services
Grosvenor Gardens House
35-37 Grosvenor Gardens,
London SW1W 0BS

Email: info@nafis.org.uk
Web: www.nafis.org.uk



Family Action

Family Action provides a wide range of support to children and families living with poverty, ill health and social isolation. It undertakes specialist work with children with disabilities and provides financial support to families.

Family Action
501- 505 Kingsland Road
London E8 4AU

Tel: 020 7254 6251
Fax: 020 7249 5443

Email: info@family-action.org.uk
Web: www.family-action.org.uk

Home-Start UK

Across the UK more than 15,000 Home-Start volunteers visit families at home each week, supporting parents in situations as diverse as isolation, bereavement, multiple births, illness, disability or who are just finding parenting a struggle. They provide non-judgemental practical and emotional support and help build the family's confidence and ability to cope. Home-Start runs more services, and has more volunteers supporting more families, than any other family support charity in the UK.

The Home-Start Centre
8-10 West Walk
Leicester LE 1 7NA

Tel: 0116 2587900
Freephone information line: 0800 068 63 68
Fax: 0116 2582901

Email: info@home-start.org.uk
Web: www.home-start.org.uk

Independent Panel for Special Education Advice (IPSEA)

An independent organisation, providing free advice to parents on local authorities' duty to assess and provide for children with special educational needs.

IPSEA

6 Carlow Mews
Woodbridge
Suffolk IP12 1EA

Helpline: 0800 018 4016

Tel: 01394 446 575 (General enquiries)

Fax: 01394 446 577

Web: www.ipsea.org.uk

KIDS

A national charity dedicated to helping children and young people with disabilities and special needs develop their skills and abilities and realise their potential. It works with parents, carers and children to deliver a wide range of services.

KIDS

49 Mecklenburg Square
London WC1N 2NY

Tel: 020 7520 0405

Email: enquiries@kids.org.uk

Web: www.kids.org.uk

The Makaton Charity

Offers materials and training in the use of Makaton sign language.

The Makaton Charity
Manor House
46 London Road
Blackwater
Camberley
Surrey GU17 0AA

Tel: 01276 606760

Email: info@makaton.org

Web: www.makaton.org



Mencap

Royal MENCAP Society is a registered charity that offers services to adults and children with learning disabilities. They offer help and advice on Benefits, Housing and Employment. They also offer help and advice to anyone who has any other issues or they can signpost them in the right direction. They can also provide information and support for leisure, recreational services (Gateway Clubs) residential services and holidays.

Mencap

4 Swan Courtyard

Charles Edward Road

Birmingham B26 1BU

(please note, this address is due to change towards the end of 2010 – contact the office for further details)

Tel: 0121 707 7877

Fax: 0121 707 3019

Helpline: 0808 808 1111

Typetalk: 18001 0808 808 1111

Learning Disability Freephone Helpline: 0808 8000 300

Learning Disability Freephone Minicom Helpline: 0808 808 8181

Email: helpline@mencap.org.uk

Web: www.mencap.org.uk

The National Deaf Children's Society (NDCS)

The NDCS supports families of deaf children. It provides clear and balanced information on all aspects of childhood deafness, including temporary conditions such as glue ear. It also campaigns on behalf of deaf children and their families.

NDCS

15 Dufferin Street
London EC1Y 8UR

Tel: 020 7490 8656
Minicom: 020 7490 8656
Fax: 020 7251 5020

Web: www.ndcs.org.uk
Email: helpline@ndcs.org.uk or ndcs@ndcs.org.uk

National Portage Association (NPA)

A registered charity established in 1983 to offer support and information to parents and professionals involved in Portage- a home visiting educational service for pre-school children with additional support needs and their families.

NPA

Kings Court
17 School RD
Hall Green
Birmingham B28 8JG

Tel: 0121 244 1807

Email: info@portage.org.uk
Web: www.portage.org.uk

Network 81

A national network of parents, working towards properly resourced inclusive education for children with special needs.

Network 81

1- 7 Woodfield Terrace
Stansted
Essex CM24 8AJ

Helpline: 0870 770 3306
Fax: 0870 770 3263

Email: info@network81.org
Web: www.network81.org



Parents for Inclusion (Pi)

A network of parents of disabled children and children with special needs. It aims to help parents so their children can learn, make friends and have a voice in ordinary schools and throughout life.

PI
336 Brixton Road
London SW9 7AA

Freephone helpline: 0800 652 3145

Email: info@parentsforinclusion.org

Web: www.parentsforinclusion.org

Royal College of Speech and Language Therapists (RCSLT)

The professional association for speech and language therapists. RCSLT produces leaflets, runs an information service and offers individual advice to members and to the general public.

RCSLT
2 White Hart Yard,
London SE1 1NX

Tel: 020 7378 1200

Fax: 020 7403 7254

Email: info@rcslt.org

Web: www.rcslt.org

The Signalong Group

The Signalong Group is a charity providing publications, research, training and advice in sign-supported communication. Signalong publishes a wide range of British Sign Language based vocabulary resources.

The Signalong Group
Stratford House
Waterside Court
Neptune Close
Rochester, Kent ME4 4NZ

Tel: 0845 450 8422
Fax: 0845 450 8428

Email: info@signalong.org.uk
Web: www.signalong.org.uk

Symbol (UK) Ltd

Symbol's private speech and language therapy service provides specialist services to both children and adults who have learning disabilities.

Symbol (UK) Ltd
Newington Manor
Callaways Lane
Newington, Kent ME9 7LU

Tel: 01795 844440
Fax: 01795 844414

Email: info@symboluk.co.uk
Web: www.symboluk.co.uk



Web-based resources

The following list provides some starting points if you want to look for information about Down syndrome on the internet. While the following websites 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
www.ds-health.com

Down Syndrome New South Wales - Australia
www.dsansw.org.au

Down Syndrome Medical Interest Group (DSMIG) - UK
www.dsmig.org.uk

National Down Syndrome Society - USA
www.ndss.org

UK Resources for Down syndrome
www.zen123082.zen.co.uk/uk_downs_syndrome/index.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 email 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 email discussion list on Down 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 email discussion lists for parents, professionals, researchers, and individuals with Down 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: <http://groups.yahoo.com/group/Downs-Heart>



Additional resources

Activities for babies with Down syndrome (DVD)

The Down Syndrome Educational Trust (2006)

<http://www.downsed.org/en/gb/in-practice/baby-activities/>

Babies with Down's Syndrome - a new parent's guide

Susan J. Skallerup (Ed)

Woodbine House (2008)

ISBN: 978-1-890627-55-3

Down's Syndrome – A New Parent's Guide & Information for Families and Friends

Stuart Mills

The Down's Syndrome Association (2007)

Available free of charge from the Down's Syndrome Association

info@downs-syndrome.org.uk or 0333 121 2300

Down Syndrome – An Introduction for Parents and Carers

Cliff Cunningham

Souvenir Press (2006)

ISBN: 0-285-63697-9

Down Syndrome - the facts

Mark Selikowitz

Oxford University Press (2008)

ISBN: 0-19-923277-2

The Down Syndrome Nutrition Handbook - a guide to promoting healthy lifestyles

Joan E Guthrie Medlen

Woodbine House (2002)

ISBN: 1-89062-723-2

Early Communication Skills for Children with Down Syndrome - guide for parents and professionals

Libby Kumin
Woodbine House (2003)
ISBN: 1-890627-27-5

Fine Motor Skills in Children with Down Syndrome - a guide for parents and professionals

Maryanne Bruni
Woodbine House (2006)
ISBN: 1-890627-67-4

Gross Motor Skills in Children with Down Syndrome - a guide for parents and professionals

Patricia C. Winders
Woodbine House (1997)
ISBN: 0-9331149-81-6

Living with Down syndrome

Sue Buckley
The Down Syndrome Education International (2000) ISBN: 1-903806-01-1
This publication can be viewed free of charge at
www.down-syndrome.org/information/development/overview/

An Overview of the Development of Infants with Down Syndrome (0- 5 years)

Sue Buckley and Ben Sacks
The Down Syndrome Education International (2001)
This publication can be viewed free of charge at
<http://www.down-syndrome.org/information/development/early/>

Understanding Down Syndrome - a parent's guide

Cliff Cunningham
Souvenir Press (2005)
ISBN: 0-285-63697-9



Glossary

adenoids: enlargement of the glandular tissue between the back of the nose and the throat.

amniocentesis: a diagnostic test performed at around the 16th -18th week of pregnancy to check for abnormalities in the developing foetus. It involves the insertion of a fine needle through the mother's abdominal wall, into the womb, to remove a sample of the amniotic fluid for testing.

anaemia: medical condition resulting from a deficiency of red blood cells or haemoglobin (the protein in red blood cells that carries oxygen around the body).

anal atresia: a rare but serious **congenital** bowel abnormality where the bottom opening (anus) is not present.

antibiotics: medicines used to treat infections caused by bacteria and other micro-organisms. Penicillin is one of the commonest antibiotics.

astigmatism: distortion of vision resulting from light rays not meeting at a single point in the retina.

atlanto-axial instability: see **cervical spine dislocation**.

attention deficit hyperactivity disorders (ADHDs): a range of behavioural disorders occurring in children. Symptoms include poor concentration, hyperactivity and learning difficulties.

audiology: the study and measurement of hearing and deafness.

autistic spectrum disorders: autistic spectrum disorders (ASDs) are complex lifelong, developmental disabilities that affect the way a person communicates, relates to people around them and uses language.

British Sign Language: the sign language used by Deaf people in the UK.

cardiac: relating to the heart.

cervical spine dislocation or atlanto-axial instability: a very rare condition where the top two vertebrae (bones in the spine) dislocate in such a way as to compress and damage the spinal cord.

chorionic villus sampling (CVS): a diagnostic test performed after the 10th week of pregnancy to check for abnormalities in the developing foetus. It involves the removal of a tiny piece of chorion - part of the developing placenta.

chromosomes: thread-like structures carrying **genes**. They are contained within each cell of the body. The nucleus of each cell usually contains 23 pairs of chromosome - 46 in total. In Down syndrome, some or all of the cells in the body have 47 chromosomes as there is an extra copy of chromosome 21.

chromosome 21: the chromosome associated with Down syndrome. Individuals with Down syndrome have an extra copy of chromosome 21 in all, or much less commonly some, of the cells in their body.

cochlea: part of the inner ear. It is filled with fluid and contains many thousands of specialised cells that convert vibrations from the **middle ear** into nerve messages.

coeliac disease: inability to digest food caused by sensitivity of the small intestine to gluten, which is found in wheat products and some other foods.

cognitive development: the processes involved in thinking, reasoning, learning, and processing and remembering information.

conductive hearing loss: deafness caused when sounds cannot pass efficiently through the outer ear (the part of the ear you can see) and middle ear to the cochlea.

congenital disorders: conditions that are present at birth.

constipation: difficulty in opening the bowels to pass a stool when going to the toilet.

CVS: abbreviation for **chorionic villus sampling**.

decibels (dB): measurement unit for sound (used in hearing tests).

diarrhoea: a condition in which faeces are passed frequently and in a liquid/loose form.

Disability Living Allowance (DLA): the main financial benefit for disabled children.

duodenal atresia: a rare but serious **congenital** bowel abnormality where part of the small intestine, just after the stomach, is not continuous. The condition can be corrected with surgery.

early intervention: activities and support to promote children's development during their early years.



echocardiogram: a test that uses **ultrasound** waves to produce a visual image of the heart's action.

ENT: medical abbreviation for ear, nose and throat.

Eustachian tube: a narrow tube which connects the **middle ear** to the upper part of the throat.

expressive language: what a child says or signs.

fine motor skills: movement skills such as reaching, grasping, holding and manipulating objects (see also **gross motor skills**).

gastro-oesophageal reflux: a medical condition that occurs when food, which has already passed into the stomach and into the bowel, comes back up into the oesophagus and may be vomited up.

gene: a sequence of DNA on the **chromosome** responsible for passing on specific characteristics from parents to their children. Genes are arranged on the **chromosomes** in the nucleus of each cell.

glue ear: a medical condition in which a mucous-like secretion builds up in the middle ear and reduces hearing levels, causing **conductive hearing loss**.

grommets: a treatment for glue ear. Grommets are tiny tubes with flanges at each end that are inserted through the eardrum under general anaesthetic. They allow the 'glue' to drain away, therefore improving hearing.

gross motor skills: movement skills such as sitting, rolling, crawling and walking (see also **fine motor skills**).

Guthrie test: another name for **heel prick test**.

Health visitor: a qualified nurse or midwife with additional special training and experience in child health.

heel prick test or Guthrie test: a blood test carried out on all babies to check for a number of conditions. The test involves your midwife or health visitor taking a small blood sample from your baby's heel when your baby is six to ten days old. This blood sample is then sent to a laboratory for analysis.

hiatus hernia: a medical condition where the top part of the stomach is pushed up into the chest.

Hirschsprung's disease: a rare medical condition in which part of the wall of the large bowel has nerve cells missing, resulting in obstruction to the passage of the bowel contents.

hormone: a chemical messenger used by the body to stimulate activity in specific cells.

hypermetropia: another name for **long sightedness**.

hypothyroidism: underactivity of the **thyroid gland**.

hypotonia: 'floppiness' due to reduced muscle tone. This physical characteristic is common among many, but not all, babies with Down syndrome, and affects every baby differently.

inner ear: the part of the ear that is inside the skull and that includes the **cochlea**.

jejunal atresia: a rare but serious **congenital** bowel abnormality, where part of the small intestine is not continuous. The condition can be corrected with surgery.

karyotype: a picture of the **chromosomes** in a cell, obtained by analysing a sample of blood.

learning disability: any cognitive development that is significantly behind what is expected for a particular age. Learning disability may occur on its own or in addition to sensory or physical impairments or medical conditions. Down syndrome is one of the most common causes of learning disability.

leukaemia: a cancer of some white blood cells. White blood cells are part of the body's defence against infection.

local authority: the local government body that provides services for people living in an area.

long sightedness: things seen more clearly in the distance than close up. Also known as hypermetropia.

long-term memory: the part of the memory involved in storing information over the longer term (eg for days, weeks, months or years).

mainstream education or mainstream settings: schools and early years settings, like state primary and secondary schools, that are used by all children.



Makaton: a form of signing that uses signs based on **British Sign Language**. It can be used alongside speech to support communication, language and literacy skills. Makaton is used by children and adults with a range of communication and learning difficulties.

metabolism: the biochemical processes that take place in the cells of the body.

middle ear: the part of the ear that transmits sound between the eardrum and **cochlea**.

mosaic Down syndrome: an uncommon form of Down syndrome in which only some of the cells have extra chromosome 21 material.

motor skills: the skills involved in moving and exploring, such as reaching, grasping, holding, sitting, crawling, standing and walking. Often divided into **fine motor skills** and **gross motor skills**.

myopia: medical term for **short sightedness**.

occult infection: the medical term for an infection which is difficult to detect.

oesophagus: the tube connecting the throat to the stomach.

otitis media: medical term for infections of the **middle ear**.

paediatrician: a doctor who specialises in the care of babies and children.

palmar crease: a single crease across the palm. This physical characteristic is common among many, but not all, individuals with Down syndrome. It is also found in the general population.

Portage services: a home-visiting educational service for preschool children with additional support needs and their families.

receptive language: the language that a child understands.

retina: the light sensitive surface at the back of the eyeball.

sandal gap: a big space between the first and second toe. This physical characteristic is common among many, but not all, individuals with Down syndrome. It is also found in the general population.

SEN: abbreviation for special educational needs.

SENCO: abbreviation for **special educational needs coordinator**.

sensori-neural hearing loss: hearing impairment caused by malfunction of the **cochlea** or nerves running from the **cochlea** to the brain.

sensory impairment team: a team of professionals supporting children who have hearing, visual or multi-sensory impairments.

short sightedness: things seen more clearly close up than in the distance. Also known as **myopia**.

short-term memory: the part of the memory involved in processing information and storing information for short periods (for no longer than a few seconds). Also known as **working memory**.

Signalong: a form of signing that supports spoken language. It uses some signs taken from British Sign Language. It was developed for children (and adults) who experience language difficulties associated with learning disabilities.

sleep apnoea: a medical condition in which breathing temporarily stops for short periods while sleeping.

special schools: schools or early years settings that provide services only for children with learning disabilities and/or physical disabilities (children with special educational needs).

special educational needs: the common term for the additional or different help that some children need to learn in an educational setting.

special educational needs (SEN) service: the part of your local education authority that provides services to children with special educational needs and deals with **Statements of Special Educational Need**.

special educational needs coordinator (SENCO): a teacher in a school or early years setting who has particular responsibility for identifying children with special educational needs and making sure they receive appropriate support.

speech production skills: how a child produces and pronounces words.

Statement of Special Educational Needs: a document produced by your local education authority that specifies your child's additional needs and how these will be met at school. Often referred to as a 'statement'.



structured play: a way of helping children to learn by breaking activities into small steps and incorporating more demonstration (or modelling), repetition and practice than ordinary play.

thyroid: a gland in the neck that produces a hormone which helps control the body's metabolism and growth

thyroid stimulating hormone (TSH): a hormone produced in the pituitary gland (situated at the base of the brain) that controls the activity of the **thyroid** gland.

thyroxine: a hormone produced by the **thyroid** gland.

tonsils: two small glands in the throat at the root of the tongue.

translocation Down syndrome: a form of Down syndrome in which the extra chromosome 21 material is attached to another chromosome.

trisomy 21 Down syndrome: a form of Down syndrome in which all the cells in the body have an extra chromosome 21 - the most common form of Down syndrome.

TSH: abbreviation for **thyroid stimulating hormone**.

ultrasound: high frequency sound waves used to produce images of the inside of the body.

vertebrae: the bones which form the spine or vertebral column.

working memory: another name for **short-term memory**.

Early Support

Early Support is the Government's programme to improve the quality, consistency and coordination of services for young disabled children and their families across England. **Early Support** is funded and managed by the Department for Children Schools and Families (DCSF) and is an integral part of the wider Aiming High for Disabled Children (AHDC) programme, jointly delivered by DCSF and the Department of Health. The AHDC programme is seeking to transform the services that disabled children and their families receive.

Early Support is targeted at families with babies or children under five with additional support needs associated with disability or emerging special educational needs although the principles of partnership working with families can be applied across the age range. This partnership working between families and professionals means that families remain at the heart of any discussions or decisions about their child – their views are listened to and respected and their expertise is valued by the professionals working with them.

To find out more about the **Early Support** programme and associated training or to view or download other materials produced by the programme, visit www.dcsf.gov.uk/everychildmatters/earllysupport

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. This is the third edition of the booklet, which up-dates information and incorporates comments from those who used the material in 2004-2009. The other titles in the series are:

Cerebral palsy (ES10)

Autistic spectrum disorders (ASDs) and related conditions (ES12)

If your child has a rare condition (ES18)

Learning disabilities (ES15)

Deafness (ES11)

Speech and language difficulties (ES14)

Multi-sensory impairment (ES9)

Visual impairment (ES8)

When your child has no diagnosis (ES16)

Three additional Information for parents booklets, one on Sleep, one on Neurological disorders and one on Behaviour will be available by Spring 2010.

Other [Early Support](#) information about services is available separately, or as part of the Early Support [Family pack](#). The Family pack helps families who come into contact with many different professionals to co-ordinate activity and share information about their child through the first few years of life, using a [Family file](#).

These are resources that families say make a difference. If your family is receiving regular support from professionals, please feel free to ask them about the [Early Support family pack](#). It may help and is available free of charge.

[Early Support](#) would like to thank the many families and professionals that have been involved in the development of these resources, and to thank the Down's Syndrome Association and Down Syndrome Education International and all the parents and families who were involved in producing this material for their help in writing this booklet. We would like to thank the Down's Syndrome Association for revising this booklet in 2010.

[Down Syndrome Education International](#)

Down Syndrome Education International (formerly the Down Syndrome Educational Trust) (Downsed) is a leading international charity focused on the education and development of individuals with Down syndrome. Since 1979, researchers at Downsed have undertaken pioneering research into the development and education of individuals with Down syndrome. This research has helped identify a range of practical strategies to promote the development of children with Down syndrome. All of Downsed's services and publications draw on the evidence of this research as well as extensive practical experience.

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Down's Syndrome Association

The Down's Syndrome Association is a national charity that has been helping people with Down's syndrome live fulfilling lives since 1970. They provide information and support to individuals with Down's syndrome and their families. They strive to improve knowledge and understanding of the condition amongst Government agencies, interested professionals and the general public. They campaign for social equality and fair treatment for people with Down's syndrome in the areas of health, education and social care.

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DCSF Publications
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Please quote ref: ES13

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3rd edition

www.dcsf.gov.uk/everychildmatters/earllysupport

We acknowledge with thanks the contribution of the following organisations in the production of this resource.

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