

# Early Support

for children, young people and families

## Information about Down syndrome



## About this resource

This is a guide for parent carers with children and young people who have Down syndrome. In this guide you will find information on:

- Down syndrome
- how Down syndrome may affect you and your child
- where to go for further support and information

You may not want to read this guide all at once; you may find it more useful to refer to different sections over time. This information is freestanding, but you may want to use it alongside other Early Support resources.

The guide was developed by the [Down's Syndrome Association \(DSA\)](#) for Early Support, in consultation with families and practitioners. The original version was developed by Down Syndrome Education International and the Down's Syndrome Association in consultation with families and professionals.

Down's syndrome and Down syndrome are different names for the same condition and you will hear people use both terms. For simplicity, this resource uses Down syndrome throughout.

### Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in *Support and aspiration: a new approach to special educational needs and disability*, the government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of children, young people and their families.

Early Support helps local areas implement the government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about [Early Support](#), please visit [www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport).

Where a word or phrase appears in colour, [like this](#), it means you can: either look them up in the [Glossary](#) at the back of the resource or in the [Who can help](#) section; or find contact details for the organisation or agency highlighted in the [Useful contacts and organisations](#) section.

### Explanation of the term parent carer

Throughout this resource the term 'parent carer' is used. This means any person with parental responsibility for a child or young person with special educational needs or a disability. It is intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

# Contents

<b>Down syndrome</b> .....	<b>Page 6</b>
What is Down syndrome?.....	Page 6
How Down syndrome may affect your child’s development.....	Page 7
How Down syndrome may affect your child’s health.....	Page 10
Early Support developmental journals.....	Page 11
<b>In the beginning</b> .....	<b>Page 12</b>
Diagnosis.....	Page 12
Feelings.....	Page 12
Telling others about your child’s differences.....	Page 13
Early relationships and bonding.....	Page 14
Looking after yourself.....	Page 14
Looking after your baby.....	Page 14
Benefits.....	Page 15
<b>Early years</b> .....	<b>Page 17</b>
Getting started.....	Page 17
General information.....	Page 21
Meeting others.....	Page 29
Choosing a preschool.....	Page 30
Choosing a school.....	Page 32
<b>School years</b> .....	<b>Page 36</b>
General information.....	Page 36
Choices and challenges.....	Page 43
Choosing a secondary school.....	Page 46
Meeting others.....	Page 47

<b>Into adulthood</b> .....	<b>Page 50</b>
Thinking about the future.....	Page 50
Leaving school.....	Page 51
Developing independence.....	Page 56
Letting go.....	Page 60
Meeting others.....	Page 61
<b>Health issues</b> .....	<b>Page 63</b>
Newborn health issues.....	Page 63
Ongoing health issues.....	Page 64
Further information on health issues.....	Page 70
<b>Top tips</b> .....	<b>Page 72</b>
<b>Who can help</b> .....	<b>Page 73</b>
<b>Resources</b> .....	<b>Page 74</b>
<b>Useful organisations and websites</b> .....	<b>Page 77</b>
<b>Glossary</b> .....	<b>Page 82</b>

# Down syndrome

## What is Down syndrome?

Down syndrome is a genetic condition that results in some level of **learning disability** and a particular range of physical characteristics. The condition is caused by the presence of an extra copy of **chromosome 21** in a baby's cells.

In 1866 an English doctor, John Langdon Down, published a paper that 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**.

Approximately one baby in every thousand in the United Kingdom is born with Down syndrome.

## Anyone can have a baby with Down syndrome

Down syndrome affects people of all races, religions and economic backgrounds 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. About half of children with Down syndrome are born to mothers under the age of 35.

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.

## What is Down syndrome?

The human body is made up of cells. Each cell is like a factory that has everything it needs 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 – 23 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 can cause Down syndrome:

- **Trisomy 21** – This is when all the cells in the body have an extra chromosome 21. About 94 per cent of people with Down syndrome have this type.
- **Translocation** – This is when extra chromosome 21 material is attached to another chromosome. Around 4 per cent of people with Down syndrome have this type.
- **Mosaic** – This is when only some of the cells have extra chromosome 21 material. About two per cent of people with Down syndrome have this type.

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

## How Down syndrome may affect your child's development

### 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 each child.

Children and young people with Down syndrome share some common physical characteristics, but they do not all look the same. Your child's personality is also unique. They may be sociable or shy, calm or anxious, easy to manage or difficult to manage – just like other children.

Children and young people with Down syndrome also vary significantly in the progress they make with walking, talking, learning at school and moving towards living independently.

Some children and young people have a greater degree of disability and more needs than others, however good their family care, therapy and education. No one is to blame for this variation – least of all you, as a parent carer.

### Your child's developmental needs

All children and young people with Down syndrome experience some degree of learning disability. They usually make progress in most areas, but at a slower pace. Some aspects of development progress faster than others. What's important is that your child moves forward at their 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 call this 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 and young people with Down syndrome generally learn visually. This means that they learn best from watching and copying other people, and may find it easier to take in information if it is presented with the support of pictures, gestures, objects and written words.
- **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.

Characteristic weaknesses:

- **Learning to talk** – Many children with Down syndrome experience significant delay learning to talk. Most children and young people learn to talk, 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.
- **Learning to move** – The skills needed to move around and explore tend to be delayed compared with other children. However, over time many children and young people develop good motor skills and can become good at all types of sports.
- **Learning from listening** – Children and young people 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** memory, also known as **working memory**.
- **Number skills** – Many children with Down syndrome experience difficulties with number skills and learning to calculate.



## **Mosaic Down syndrome**

Children and young people 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.

## **Helping children and young people 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 past 25 years has taught us a great deal about how the syndrome affects individuals and about how to promote development.

Children and young people achieve their potential with:

- effective healthcare
- good parenting skills
- everyday family activities
- early intervention in their first years of life to support development
- good education at primary school, secondary school and in further education
- sports, recreation and community activities
- vocational training and work

## **Some children and young people have more complex needs**

Some children have extra conditions that result in them having more complex needs. A small proportion of children with Down syndrome have additional medical complications, which affect their development. A relatively small proportion of children also experience **autism spectrum disorders (ASDs)**, or **attention deficit hyperactivity disorders (ADHDs)**.

These extra difficulties affect about 10 per cent of children with Down syndrome. If you think that your child or young person may have any of these extra difficulties, ask the practitioners who are working with your family for an assessment and advice.

## **Times are changing**

It is impossible to predict outcomes for any individual child when they are very young, but in general, children and young people with Down syndrome are achieving much more than they have ever done. In the past it was believed that there were many things that people with Down syndrome could not do, when in fact they had never been given the opportunity to try. Today

these opportunities have never been greater, enabling many people with Down syndrome to lead rich and varied lives.

With differing levels of support, people with Down syndrome are now leaving home, forming relationships, gaining employment and leading independent and active lives. Their quality of life, life expectancy and role in the community has been transformed as healthcare, education, support and opportunities have improved.

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 syndrome. For first born babies with Down 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.”*

Contact the [Down’s Syndrome Association \(DSA\)](#) and [Down Syndrome Education International](#) for further information about education and development.

## How Down syndrome may affect your child’s health

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 of developing 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.

The health conditions associated with Down syndrome are a good example of the range of experiences that families have. About half of all 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 GP, health visitor or paediatrician.

All new babies are issued with a *Personal child health record (PCHR)* or 'red book'. The **UK Down Syndrome Medical Interest Group (DSMIG UK)** has produced an insert with extra pages for babies born with Down syndrome. If you have not been given a copy of the insert, contact the **Down's Syndrome Association (DSA)**.

For more information about health, turn to the **Health issues** section in this resource.

## Early Support developmental journals

Many parent carers find the Early Support developmental journals very helpful to facilitate their understanding about their child's development and to celebrate small steps in progress. You might find it helpful to share your developmental journal with practitioners, particularly those involved in your child's education.

The developmental journals can be used to share your child's progress with the practitioners working most closely with your child and family, particularly those practitioners who are providing key working support.

The Developmental Journal for babies and children with Down syndrome is available at [www.ncb.org.uk/early-support/resources/developmental-journals](http://www.ncb.org.uk/early-support/resources/developmental-journals). You may also be interested in the Early Years Developmental Journal and developmental journals for children with multiple needs, for deaf babies or for babies and children with visual impairments.

## In the beginning

### Diagnosis

In some cases, babies with Down syndrome are identified before birth as a result of antenatal tests (either **amniocentesis** or **chorionic villus sampling**). Some new antenatal blood tests are currently being piloted, but are not available in the UK at present. 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**)
- certain facial features, including 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. Each individual with Down syndrome is different and has 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.

### 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.

Many families say it’s like setting out on a journey into the unknown with little idea about what to expect and this may colour the challenges and excitements that every parent carer faces with a newborn child.

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 parent carers 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 to guide expectations and takes away some of the fear of the unknown.

Lots of information about Down syndrome is available online, and email discussion groups make it possible to chat with other parent carers across the country and around the world.

## **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 increased 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, 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 significant 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."*

## **Telling others about your child's differences**

There are a number of ways you can help your family to get used to the fact that your child has Down syndrome. These include:

- sharing useful pieces of information
- sharing advice you have been given
- involving them in your activities with your child

You can contact the [Down's Syndrome Association \(DSA\)](#) for recommended resources on informing relatives, siblings and friends.

## Early relationships and bonding

Little is known about the effects of a diagnosis of Down syndrome at birth on early relationships and bonding. Most parents say they wish they had worried less and enjoyed their baby more. You will have time to learn about Down syndrome and seek information – it doesn't have to happen all at once. It will help if you try not to worry and enjoy the time you spend with your baby.

Remember that your baby has the same needs as all babies. Your baby will develop by being cared for and interacted with in the same way all babies do.

## Looking after yourself

You need to look after yourself so that you can look after your child.

Use baby books, magazines and support from your family and friends just as you had planned to before the birth.

Ask for help and support from family and friends if and when you need it and accept any offers of help, as long as you feel comfortable with this.

You can find out about help and support for you and your child at [www.gov.uk](http://www.gov.uk). For example, a social services assessment may give you access to respite services, if it is assessed as a need for your child. You are entitled to a separate carer's assessment of your needs if you provide regular and substantial care to your child with Down syndrome. Contact the [Down's Syndrome Association \(DSA\)](#) for more information about these assessments.

## Looking after your baby

### Breastfeeding

Many babies with Down syndrome are able to breastfeed successfully from birth.

Persevere if you want to breastfeed and remember it can take a couple of weeks to establish feeding with any baby.

For further advice, talk to your health visitor, one of the [National Childbirth Trust's](#) breastfeeding counsellors on 0300 3300700, or call the [National Breastfeeding Line](#) on 0300 1000212.

## Weaning

Weaning your baby is likely to be much like weaning any other child, but sometimes they can be 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. Here are some practical tips on feeding:

- 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.
- Offer food with different tastes and textures.
- If your child experiences particular problems in this area, ask to see a **speech and language therapist** with expertise in feeding.

## Skincare

Many babies with Down syndrome have dry skin. These practical tips may help:

- Gently rub your baby's skin with baby massage oil or put a few drops of baby oil into bath water.
- Rub a little moisturising cream into your baby's skin every day.
- Ask your health visitor, 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. These practical tips may help:

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

## Benefits

When your child is born, you may find that your family is affected financially. Perhaps you can't go back to work in the way you had planned to or want to work part-time, resulting in a reduction in your household income.

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.

To stimulate their development, it helps to expose your child to a wide range of experiences. Claiming benefits may allow your child to participate in a wider range of activities more frequently than would otherwise be possible. Benefits for your child can include:

- disability living allowance
- child benefit
- child tax credit (part of universal credit from April 2013)

Benefits for you as a parent carer can include:

- carer's allowance
- working tax credit (part of universal credit from April 2013)

When your child turns three, remember to check whether they are entitled to the higher rate of the mobility component of disability living allowance. When they turn five, they will be entitled to at least the lower rate of the mobility component.

Benefit entitlement will depend on your circumstances. The benefits system is very complicated, so it is always a good idea to get advice about your own situation, so that you don't miss out.

The **Down's Syndrome Association (DSA)** provides detailed guidelines about disability living allowance, carer's allowance and tax credits at [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk). Or you can call a **DSA** benefits advisor for information and advice about claiming benefits on 0333 1212300.

The government's information website, [www.gov.uk](http://www.gov.uk), has useful, basic information on benefits.

## Grants

There are organisations that may be able to give grants to help you meet your child's needs:

- **The Family Fund** give grants to families raising disabled and seriously ill children aged 17 and under.
- **Cerebra** awards grants for equipment and services.

Contact the **DSA** for further information about grant-making organisations.



## Early Years

### Getting started

#### Being together

If your baby has an early period of ill health or hospitalisation you may not be able to be together as much as you would like. It may take a little longer to get to know your baby. Here are some practical tips to encourage the bonding process:

- Make eye contact with your baby. This is really important for young babies and helps them to develop. Babies like to look at people's faces.
- Talk to your baby. Parent carers naturally use a 'sing-song' voice and often say their baby's name repeatedly.
- Make skin to skin contact with your baby. Touch your baby as you interact and care for them. Baby massage may help you to do this.

Remember that all babies are different. If you find it difficult to spend time with your baby, tell a friend or a practitioner about how you are feeling.

#### Building relationships

Relationships provide the foundation for all areas of children's development. Good relationships, affection and clear and consistent discipline set children up for managing challenges throughout their lives.

Interacting in ways that are warm and accepting, and that show your delight in interacting with your baby will help build your relationship. You can do this by:

- responding affectionately to cries and needs for attention
- comforting your child when they are irritable
- turning care routines into games
- repeating activities your baby enjoys

#### Interaction and communication

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).

In the first year of life, your baby's social development is likely to progress relatively well. They 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.

Here are some practical tips to encourage your child's communication skills in the early years:

- Play social games that encourage eye contact, smiling and cooing in the early months of life.
- Respond immediately to your child's behaviours, no matter how small.
- Imitate your child's facial expressions, their actions and the noises they make. 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.
- Accompany your communications with intonation, pointing and gestures.
- Repeat activities your child enjoys. Games like peek-a-boo help because they naturally build repetition into play and they are fun.

## Learning about speech

All babies listen to speech and speech sounds from an early age before they understand the meaning of spoken words. Research indicates that parent carers may be able to increase their child's awareness of speech sounds by saying sounds and words to their babies in a more deliberate way than they might do for another child. This approach may help children to speak more clearly when they are older.

Here are some practical tips to help develop your child's speech and language skills:

- 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.
- When your child makes a sound, imitate it and show them how pleased you are.

- Encourage your child to make lots of meaningful, simple sounds, such as animal noises and everyday noises.
- Play sound games, so your child hears a range of sounds for speech. Ask your child's [speech and language therapist](#) about how to do this.
- Encourage your child to play games with their lips and tongue. Ask your [speech and language therapist](#) about activities to develop oro-motor skills, such as drinking through a straw, blowing and chewing.
- Read books together, pointing to and talking about the pictures.
- 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 their speech – say the word correctly and clearly yourself instead.

## Speech and language therapy

Your child will 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 good to check what prior knowledge and experience the therapist 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.

Your child will be referred to your local NHS speech and language therapy service. For an NHS appointment, or to check this is underway, you can either contact your local speech and language therapy department yourself or your GP can refer you.

If you would like to contact a speech and language therapist without going through your GP, speak to the [Royal College of Speech and Language Therapy](#). For a private appointment that you pay for, contact the [Association of Speech and Language Therapists in Independent Practice](#), which can send you details of therapists working in your area. Some speech and language therapy services specialise in the needs of children with Down syndrome, for example, [Symbol UK](#).

For further information contact the [Down's Syndrome Association \(DSA\)](#) and [Down Syndrome Education International](#).

## Using signing

Children with Down syndrome are often good visual learners, therefore you may be able to help them to understand by using signs and gestures. Learning to sign and using signs at the same time as you speak can help your child to communicate.

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 most common signing systems used with children with Down syndrome are **Makaton** and **Signalong**. Your speech and language therapist can give you advice about signing. You can also contact **Makaton** and/or **Signalong** to find out more.

Here are some practical tips on incorporating sign into your day-to-day communication:

- 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 example, for action words and describing words, as well as the names of everyday things in your child's world.

## Using reading activities

Reading can be fun and used to support language and communication in children with Down syndrome.

Your **home visiting teacher** and your **speech and language therapist** can help you use reading activities and materials with your child. *See and Learn Language and Reading* resources from Down Syndrome Education International (see the **Resources** section) can also guide you.

You can try:

- making your own simple books of photographs/pictures of everyday objects, family members and everyday events to introduce early words and sentences in print
- playing word- and picture-matching games to teach word recognition.

## General information

### Making sense of the world

All children learn a lot in the early years of life and every child learns at their own pace.

Learning how to think, reason and learn, and process and remember information is crucial for 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 parent carers or anyone else. They pick up knowledge and understanding of the world around them through their senses – 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, such as daily activities and structured play sessions, to help them develop these skills.

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.

### 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 remember it. Attention and memory skills help children do these things.

The ways in which babies with Down syndrome pay attention to the world around them can vary 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 a relatively good long-term memory, so they often retain the information and skills they have learnt very well. However, their **short-term memory**, also known as **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.

Here are some practical tips on developing attention and memory skills:

- Show your child you are interested in what they are interested in. You will know what your child is interested in by following their focus of attention – what they are looking at, listening to or touching. This will help your child to develop ‘shared attention’ where you both focus your attention on the same thing, such as shaking a rattle, or (later) looking at a book together.
- Sing songs and play listening games to familiarise them with sounds and words.
- Play memory games with your child from around two years of age to help them develop their memory skills.

## Learning to move

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

Movement skills, such as 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 experience a 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.

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. A **physiotherapist** or an **occupational therapist** can offer you advice and pass on good ideas.

Here are some examples:

- If your baby has poor head control in the early months, ask for ideas on how to handle them and improve head control.
- If your baby needs help to play comfortably on their 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.
- Give your baby the chance to play in different positions throughout 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 then a 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 dance classes, ball pits and soft play areas.

## Playing

### *Learning through play*

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 with their play.

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**.

Here are some practical tips to support your child to learn through play:

- Become your child's 'play partner'. Show them how to play with their toys – what a toy does, how to get it to make a noise or to move, how to hide and find a toy, how to screw or unscrew it, etc.
- Notice what interests your child. Follow their interest and copy their play. Allow them lots of practice at each stage of play by playing in ways that interest them. They need to do this to learn. You can find out more about how children play from Early Support development resources available at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).
- As well as playing in ways that interest your child, demonstrate how to do more interesting things with toys. This will help your child to progress when they are ready. It can prevent them getting stuck on repetitive patterns of play.
- Take turns with your child to demonstrate how to do something. Sometimes it's helpful to have two toys so that, for example, you can both shake a rattle, roll a ball, push a toy car or cuddle teddy.
- Later on, join in with pretend play to show your child what to do. Help them to build a sequence of two or more actions in their play. For example:
  - put a toy man ('daddy') in the car and then push the car
  - give dolly ('baby') a drink and then put dolly to bed
  - 'feed' a toy farm animal and then make him run or jump
- Pretend games provide valuable opportunities to teach new language to children. Help your child to link two or three words together by saying, for example, '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 may express frustration by throwing or banging. When a young child gets frustrated, it can be quite hard for them to get over it. Music, holding hands and jiggling or dancing are good ways of getting over upsets.

### **Understanding your child's behaviour**

Most children with Down syndrome are capable of behaving in an age-appropriate way. You can have high expectations for your child's behaviour, provided you:

- help and support your child to behave in the ways you want them to
- praise your child when they do

You can also encourage them to use their natural capability to learn by watching others.

Progress in this area is influenced by how much parent carers expect of their children as well as any learning difficulties children experience.

Some children with Down syndrome are easy-going and others react strongly to novelty, change or sensations, and may be more likely to communicate through difficult behaviour.

### **Preventing difficult behaviour**

You and your family can help to avoid difficult behaviour if you aim to prevent it from developing in the first place. You can do this by adopting the following positive management strategies:

- Establish settled routines from an early age – all babies and children feel more secure when they can anticipate what is going to happen next. Routines and set times for getting up, mealtimes and going bed will help to determine your child's behaviour at these times.



- 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.
- Share information with your family and preschool staff for a consistent approach.

## Managing difficult behaviour

Children sometimes behave in ways that parent carers find difficult to manage and that can cause stress. Understanding your child's behaviour and the reasons behind it will help you develop strategies to deal with it where necessary.

Children with Down syndrome may display more difficult behaviour than other children of the same age because they have more limited communication skills.

By observing how your child responds to people and in particular situations, you will be able to anticipate your child's reactions. You will be prepared and better able to manage their behaviour in a calm, supportive way. Here are some practical tips on managing behaviour:

- Identify when difficult behaviour occurs and help your child learn new ways to behave in these situations. For example, if your child repeatedly drops things on to the floor at mealtimes, offer your hand for the child to give you the item, or provide a container for them to place the item into, and praise them when they do so.
- Think about how you react to behaviour you do not want, as children can learn behaviour depending on how people react to them.
- Consider what your child may be trying to communicate to you through their behaviour. Help them learn a better way of communicating – a word, gesture or sign, or a picture to point at.

Remember that children with Down syndrome are often good at picking up on 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.

If you are concerned about your child's behaviour, ask a practitioner for advice or talk to other parent carers who have experienced similar problems and developed ways to help their child.

The following resources by Kathleen Feeley and Emily Jones may help you to understand your child's behaviour:

- *Preventing challenging behaviours in children with Down syndrome: attention to early developing repertoires* provides detailed information and recommendations. To download the resource, visit [www.down-syndrome.org/reviews/2076/](http://www.down-syndrome.org/reviews/2076/).
- Case studies that show how young people with Down syndrome have been helped to change their behaviour are described in *Strategies to address challenging behaviour in young children with Down syndrome*. To download the resource, visit [www.down-syndrome.org/case-studies/2008/](http://www.down-syndrome.org/case-studies/2008/).

## Social experience

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.

Include your child in family activities and create as many opportunities for them to play with other children as possible. Children learn social skills all day, every day, by being with their family and with other adults and children.

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

## Health and behaviour

If there is a sudden change in your child's behaviour, check their health – your child could be unwell but be unable to tell you. Poor sleep at night is related to daytime behavioural difficulties. If poor sleep has become a regular occurrence seek advice about how to improve your child's sleep health. Contact the [Down's Syndrome Association \(DSA\)](#) for more information.

## Sleep

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 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, may not 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.

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.

Here are some practical tips to help minimise sleep issues:

- 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 practitioners are available in some parts of the country.
- Establish clear bedtime routines and stick to them. For example, each night give them a bath, clean their teeth, sing a song or read a story, kiss them goodnight and put them to bed with a cuddle. If your child wakes at night, put them back in their own bed with the minimum of fuss.

## Personal care

### *Brushing teeth*

Children with Down syndrome tend to get their teeth later than most other babies. You can introduce a soft toothbrush at around 12 months, as it is sometimes more difficult to introduce a brush later, when teeth appear.

### *Toilet-training*

Most children with Down syndrome are toilet-trained during the day by four or five years of age, but there is a wide variation. A consistent routine of sitting them 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. There may also be support at a local level from a continence nurse based in your local

hospital. Contact the [Down's Syndrome Association \(DSA\)](#) for advice and to access a specialist continence advisor.

## Developing the senses

We receive and process information from our senses; we have seven sensory systems, which are:

- sight
- hearing
- taste
- smell
- touch
- balance and movement (vestibular sense). This sense is based in the inner ear. It tells us where our body is in space, and its speed, direction and movement. It helps us keep our balance and posture.
- muscle and joint sense (proprioception). This sense is situated in our muscles and joints. It tells how different parts are moving and the strength being used for each movement.

Our senses work together to provide our brains with information about what is going on around us. When we need to perform a task, our brain receives the information from our senses, processes it, and sends back the necessary information to allow us to complete the task. This process is called sensory integration. For most people, this process happens automatically and without any problems.

Some children experience sensory differences during their development. For example, they may show a heightened sensitivity to some sounds or the way things feel, or they may show reduced sensitivity to temperature or pain.

Sensory differences can have a significant impact on behaviour and communication. If your child has sensory differences you may be able to make adjustments for these or introduce games and activities that can help.

If you notice sensory differences, discuss these with your practitioners or contact the [Down's Syndrome Association \(DSA\)](#).

## Independence

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 and be less likely to try to do things for themselves.

## Meeting others

### Parent and toddler groups

Attending local parent and toddler groups can be a really useful way to help your child socialise, become familiar with and learn from other children. You can find out more by contacting:

- children's centres
- Sure Start children's centres
- local playgroups

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

- musical activities
- swimming classes
- movement and activity groups
- local libraries and toy libraries
- play schemes

### Support groups

There are many parent support groups around the country and most families find contact with other parents helpful. The [Down's Syndrome Association \(DSA\)](#) can tell you if there is a group in your area. 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 experiences of practitioner 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

Many support groups also provide:

- social activities for your family – for you, your child and your child's brothers and sisters
- support and activities for your child with Down syndrome – including early development and communication groups
- information and training for you and local practitioners

## Choosing a preschool

There are a variety of childcare opportunities available for younger children, including preschool, day nurseries and childminders. Contact your [Family Information Service](#) for a list of local providers.

Choosing a preschool is a personal decision and you might like to consider the following questions:

- Do you and your child feel welcome and comfortable?
- Do the children seem happy? Are the staff warm and engaging? Is there lots of interaction between staff and children?
- How will the staff support your child to follow routines and join in with activities? How much individual attention will your child receive?
- Will they provide any individual activities your child needs? Do they seem flexible?
- How will you communicate with each other about your child's experiences? Do they offer a home/school communication book?
- What are the noise levels like? Is the environment likely to support your child's need to hear without too much background noise?
- Do the staff know your child's sign language; will they send key staff on training?

## Support in preschool

When a child starts attending a preschool, a range of additional support can be given. The level and type of support depends on what your child needs. All children with Down syndrome fall into the category of having additional 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 preschool 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 they need 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 preschool staff and your child to offer support.

You can find out more about extra support at [www.gov.uk](http://www.gov.uk), from your local authority, through your local Down syndrome support group, or from the **Down's Syndrome Association (DSA)**.

## Starting preschool

Every preschool setting will have its own policy on helping new children to settle in. It will be experienced at including children with different temperaments and needs, and is likely to be flexible. For many children, it is easier to start as you mean to go on, with sessions scheduled in the same way as for the majority of children.

The staff should be made aware of the learning strengths associated with Down syndrome and plan lessons accordingly. For example, they should support children to practise the skills they want them to learn rather than waiting for 'readiness', make expectations clear, give praise and rewards, and use visual supports for learning.

Visual supports include:

- photographs of key people, activities and a visual timetable
- using signs/gestures
- creating personal books that, for example, record activities that the child has done using photographs and words/sentences written in black felt pen
- using pictures, words or symbols to help teach language and support remembering
- using pictures and letters that illustrate sounds

You can read case studies for children's preschool placements in the *Celebrating success* series at the **Down's Syndrome Association (DSA)** website

[www.downs-syndrome.org.uk/images/stories/DSA-resources/education/Early\\_Years\\_DSA\\_Celebrating\\_Success.pdf](http://www.downs-syndrome.org.uk/images/stories/DSA-resources/education/Early_Years_DSA_Celebrating_Success.pdf).

## Choosing a school

### Mainstream or special school?

Most children with **special educational needs** are educated, with support, in mainstream schools. The available evidence indicates that children with Down syndrome do well if they go to the same schools as other children in their neighbourhood. Studies have shown that older children with Down syndrome who attend mainstream schools tend to achieve better language and academic outcomes than comparable children educated in special schools.

However, individual needs vary and some parents feel that a special school will offer the most suitable provision for their child. Others may start their children in a mainstream 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 with staff how they might meet your child's **special educational needs**.

Ask to see each school's most recent Ofsted report or look them up online at [www.ofsted.gov.uk/inspection-report](http://www.ofsted.gov.uk/inspection-report). You might also 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?
- Does it sound as though your child will be included?
- How did the 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?
- What resources does the school have? Ask about access to medical and therapy staff if appropriate, and other specialist resources.
- Who exactly will work with your child?
- How much do staff members know about Down syndrome? What training or experience have they had? Will they arrange training if they need it?

### Extra support

Most children with Down syndrome receive extra support from their local authority before they start school; however this process is currently changing. For up to date information, visit [www.downs-syndrome.org.uk/information/for-familiescarers/3-5/education.html](http://www.downs-syndrome.org.uk/information/for-familiescarers/3-5/education.html) or contact the DSA Education helpline advisor.



The **Down's Syndrome Association (DSA)** can provide an individual assessment that may help you and provide education and legal advice. Find out more at [www.downs-syndrome.org.uk/support-services/assessment-and-advice-services.html](http://www.downs-syndrome.org.uk/support-services/assessment-and-advice-services.html).

## Starting school

In the term before your child starts school, a transition meeting should be arranged by practitioners working with your child. This is an opportunity for everyone to share information and any concerns so that strategies can be put into place for a successful placement. A transition plan will be drawn up to enable a smooth transition into school.

Schools will have a settling in plan for all children, but you should discuss an individual transition plan for your child if you think it is needed. This may involve:

- more frequent visits to school before your child starts there
- a meeting with the **special educational needs coordinator (SENCO)** and teachers
- a home visit
- a transition book for your child with photo's of the school, their classroom and their teachers – the photo's should each have a sentence written underneath, for example, 'This is my teacher. She is called...'

The **DSA** offers further information in its *Primary education support pack for pupils with Down's syndrome* at [www.downs-syndrome.org.uk/information/for-professionals/education/primaryeducation-support-pack.html](http://www.downs-syndrome.org.uk/information/for-professionals/education/primaryeducation-support-pack.html).

This information is relevant for children attending both mainstream and special schools. There is also the *Education support pack for special schools*, for children who may have complex additional needs.

To download the pack please visit [www.downssyndrome.org.uk/information/for-professionals/education/special-schools-education-supportpack.html](http://www.downssyndrome.org.uk/information/for-professionals/education/special-schools-education-supportpack.html).

## Home/school communication

In all types of schools, good communication between home and school is essential. Your child may not yet be able to tell you or their teachers about things they have done or things that matter to them. Your child will benefit from:

- a communication book for you and the school to share information that may affect your child's well-being, for example, about their health and things they need for school
- an agreed way for you and your child's teacher or **SENCO** to arrange to talk about any concerns

- a 'conversation diary' (see below) to support your child's communication and help to develop meaningful reading and writing over time

You may also find this website useful [www.specialiapps.co.uk/en\\_gb/SpecialStories.html](http://www.specialiapps.co.uk/en_gb/SpecialStories.html) where you can create your own stories, containing text, pictures and sound.

### **Conversation diary**

Here are some practical tips on how to use a conversation diary:

- Towards the end of the day your child's teacher places a photo taken during the day or draws a picture accompanied by a simple, written sentence (in black felt pen) to illustrate an activity your child has enjoyed.
- Your child takes the book home so that you can talk about the picture and read the sentence with them. You can add your own sentence and picture for your child to take back into school.
- The idea for the diary page will come from your child. The teacher can talk with your child about their day and what they liked. For example, if your child says or signs 'football', the picture would show a sketch of this. The sentence might say 'I played football'. As your child's ideas develop, the sentences will become more complex and the page might show a series of pictures, each with a sentence underneath.
- The conversation diary can be created on an iPad or a similar portable computer.

### **Working with practitioners**

Children with Down syndrome may have complex health and educational needs, therefore a number of different practitioners may be involved in working with your family. Working together across the disciplines is essential. You can find out more about the different types of practitioners you may come across in the [Early Support](#) resource *People you may meet*, available at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

Services need to coordinate the way they work to ease the pressure on families, for example, by arranging for hospital appointments and therapy visits to take place in the home in the early years and at the school later on.

In some areas, key workers coordinate services and arrange support in the way that suits families best. Meetings where everybody is present can be beneficial. You may find 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
- ask for honest, straightforward answers to your questions
- ask questions about anything you don't understand or have a concern about
- ask the same question again if you need further clarification or a simpler explanation
- ask for copies of any written reports or assessments that are discussed
- ask for time to read the reports and consider their implications

Some families make a communication passport about their child, which helps to avoid repeating the same information to every practitioner involved. It's a very simple way of summarising aspects of a child's life and emphasising the best way to communicate using the child's preferred communication method. For further information, visit [www.communicationpassports.org.uk/Home](http://www.communicationpassports.org.uk/Home).

Many areas will be using Early Support approaches, working in an integrated way around the child or young person and family. You may have a team of practitioners working together with you and your family at the centre, possibly with some key working support. For more information about such approaches, see [www.ncb.org.uk/early-support/key-working](http://www.ncb.org.uk/early-support/key-working).

# School Years

## General information

### Everyday life

Day-to-day life with a school child with Down syndrome can be similar to that with a younger child. You may need to keep your child occupied and safe more than you might another child of a similar age. You will need to be patient with them and give them more time to learn skills.

As your child develops, you may notice certain recurring behaviours. These are quite normal for someone with Down syndrome:

- You may notice repetitive play happening at times when they are playing on their own.
- Your child may like to watch the same films or TV programmes again and again, or to read the same books over and over.
- They may re-enact things that have happened or scenes from films they have watched.
- You may notice them talking to themselves or to an imaginary friend.
- They may like their things arranged or placed in particular ways.

Engaging your child in play and practical activities at home will support their development.

### Supporting positive behaviour

Children learn social skills all day, every day, by being with their family and with other adults and children. It is important to include your child in family activities and create as many opportunities for them to play with other children as possible.

Most children with Down syndrome are capable of behaving in age-appropriate ways. Their progress is influenced by how much parent carers expect of them as well as by any learning difficulties they experience.

However, they may display some behaviour that is more difficult to manage than other children of a similar age because they have more limited communication skills. Common challenging behaviour may include:

- not doing as they are asked, sometimes described as 'refusing' or 'avoidance' (of something they don't understand or don't want to do)
- interacting with other children or siblings physically rather than by communicating in language
- behaviour learned at an earlier stage in their development that has become a habit

For most children, difficult behaviour improves during the primary years, but for some it doesn't. Positive behaviour management can help all children learn to behave well.

Children with Down syndrome are often good at picking up on 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. Here are some practical tips on supporting positive behaviour:

- Clearly explain expectations – what the rules are in your home or at school. You can use pictures and photographs for this.
- Make a 'social story' book or a short film that shows your child how to behave in the ways you expect. Reading the book or watching the film before your child enters a situation will help your child remember how to behave.
- Use praise and rewards.
- Provide additional ways to help them discuss their likes, dislikes and feelings. With a little help, your child can sort through and choose photographs and they can pick pictures and words to communicate their preferences. Even children who speak clearly may not yet be able to talk about things that worry them.

If you are concerned about your child's behaviour, ask a practitioner for help. You can also contact the [Down's Syndrome Association \(DSA\)](#) for further advice.

## Health and behaviour

If there is a sudden change in your child's behaviour, check their health – your child could be unwell but be unable to tell you. Poor health may manifest itself in various ways, including non-cooperation or withdrawal. Poor sleep at night is related to daytime behavioural difficulties. If poor sleep has become a regular occurrence, seek advice about how to improve your child's sleep health.

## Speech, language and communication

For most children with Down syndrome, spoken language begins to take over from sign language from around four or five years of age. They will continue to use signs for words they cannot yet say and to support their communication. Signs may also help them learn new vocabulary.

Some children need to use sign language as their main form of communication for longer. There are two reasons for this:

- They are developing their speech, language and communication skills more slowly.

- They have particular speech production difficulties that make their spoken language difficult for others to understand.

Some children have an additional communication difficulty and may use **PECS** or other systems to support their communication.

Children will be improving their speech, language and communication skills throughout childhood and into adulthood. They will be learning the meaning of new words through their experiences at home and school, from reading books and watching television. They will also be developing their understanding of sentences and grammar, for example, understanding about the past and future tenses.

They will show their good understanding (**receptive language**) through their responses to your spoken language. They may not yet be able to show they understand you by answering questions, as this requires good **expressive language**, which is often an area of specific difficulty.

**Speech and language therapy** will help your child by providing exercises that they can practise every day, as well as some targeted activities.

Memory games may help to develop your child's short-term memory skills. Your **speech and language therapist** and other practitioners can advise you about memory games. Activities may include:

- memory pairs
- repeating lists of information or instructions with your child to help them remember them
- learning how words go together based on their meaning (categories)

Pictures and written lists can act as memory aids for your child. They will also promote their independence. Visual schedules can be useful at home as well as at school.

For further information about speech and language therapy, services and resources, you can contact the **Down's Syndrome Association (DSA)**. You could also contact **The Communication Trust**, **I CAN**, **Symbol UK** and **Down Syndrome Education International** for more information.

## Reading activities

Children with Down syndrome can make good progress with their reading and spelling during their school years. They can learn about language by seeing printed words and sentences, and by reading with the help of others. Like other children, they need to:

- be taught to read at school, with support at home to practise their skills
- learn from whole word teaching methods
- learn about letters and sounds (phonics)

- read with comprehension – i.e. to understand what they read about

An evidence-based teaching programme for primary school age children with Down syndrome has been developed. The programme is for teachers to use, focused on individualised reading and language instruction. If you would like to know more about this please go to [www.dseinternational.org/resources/teaching/rli/](http://www.dseinternational.org/resources/teaching/rli/)

All school-age children with Down syndrome are likely to enjoy and benefit from a daily 'conversation diary'. For more information on conversation diaries, turn to the [Choosing a school](#) section.

## Number skills

Children with Down syndrome also benefit from using visual supports to learn about numbers, including:

- learning to recognise numerals
- learning about the sequence of numbers on a 'number line'
- understanding about quantities using visual equipment and images

For further information about teaching and learning resources, contact the [Down's Syndrome Association \(DSA\)](#) and [Down Syndrome Education International](#).

## Developing the senses

We receive and process information from our senses; we have seven sensory systems, which are:

- sight
- hearing
- taste
- smell
- touch
- balance and movement (vestibular sense). This sense is based in the inner ear. It tells us where our body is in space, and its speed, direction and movement. It helps us keep our balance and posture.
- muscle and joint sense (proprioception). This sense is situated in our muscles and joints. It tells how different parts are moving and the strength being used for each movement.

Our senses work together to provide our brains with information about what is going on around us. When we need to perform a task, our brain receives the information from our senses, processes it and sends back the necessary information to allow us to complete the task. This process is called sensory integration. For most people, this process happens automatically and without any problems.

At present we know little about how children with Down syndrome develop all of their senses. We do know that:

- they may not process sounds they hear as well as other children and that listening activities may help them
- they make excellent use of visual feedback (sight) to learn, even if they may not see as well as other children
- wearing bifocal glasses may improve their learning at school

Here are some practical tips to support your child's vision:

- Teaching and learning materials should be clearly presented in black felt pen.
- Give your child a black pen to help them see what they write clearly.
- Check they can see the words in their reading books. (As their reading skills develop the size of print on the page gets smaller.)
- Avoid yellow highlighter, faint lines and poorly photocopied sheets as these may not be seen.

For more information on visual impairment, see the Early Support resource *Visual impairment* at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

## **Sensory differences**

Some children experience sensory differences during their development, which can have a significant impact on behaviour and communication. Here are two examples of sensory differences:

- Children with auditory processing difficulties may find it hard to filter out background noise in the classroom, making it difficult to attend to what the teacher is saying.
- Children who have difficulties processing tactile information may overreact to touch or avoid certain materials.

Processing and regulating sensory information can be challenging for some children, and they may find it difficult to decide which sensory information is important and which is irrelevant. Sometimes your child may not be happy to explore or may play in a repetitive way. They may



seek excessive sensory input. **Occupational Therapists** can help with assessing these types of difficulties, and may use a variety of techniques to assist your child.

## Playing

Children's play skills and interests vary. Encourage your child in active as well as passive play. Try to strike a balance between TV/computer/iPad/iPod viewing, etc., and interaction with adults, siblings and friends, so your child spends time watching, listening to and communicating with others.

All types of play – solitary, imaginative, cooperative, free and organised – offer scope for promoting your child's development, so remember to make them fun.

Find out about local activities your child could join, such as swimming, football, gymnastics, dance and drama.

If your child likes football, contact the **Down's Syndrome Association (DSA)** for information about the DSActive football programme, or visit [www.dsactive.org](http://www.dsactive.org).

Contact your local parent support group and your local authority for information about clubs and activities in your area.

## Sleep

Many children with Down syndrome are restless at night and have problems sleeping. Children with Down syndrome may be particularly prone to developing certain types of sleep disturbance.

Some sleep problems have a physical cause, others have a behavioural basis, and treatment will depend on the underlying cause.

### *Behavioural sleep issues*

Behavioural sleep problems are among the most common sleep problems associated with Down syndrome. They include difficulty in settling the child to sleep, repeated night-time waking, early morning waking and sleeping with parent carers.

### *Obstructive sleep apnoea*

Children with Down syndrome are more prone to obstructive **sleep apnoea** than other children. **Sleep apnoea** occurs as a result of the upper airway at the back of the throat becoming repeatedly blocked during sleep. Each time this occurs, breathing stops for a time and the child wakes up to breathe. These interruptions in breathing ('apnoeas') may occur many times during the night, causing sleep disruption and poor quality sleep.

Broken nights adversely affect everyone in the family. Your health visitor can offer advice in this area.

Evidence suggests that parent carers under-report sleep problems in their children with Down syndrome. Sleep problems during the school years can negatively impact upon a child's development, behaviour and ability to learn.

General books on sleep issues for children may help. Ask your GP for a specialist assessment if your child breathes noisily, is restless, wakes frequently, or you suspect they have sleep apnoea. You can also contact the [DSA](#) for further information.

## Eating and drinking

Learning to make healthy food choices and maintaining a physically active lifestyle are important issues for children who have Down syndrome. They learn about these from their experiences at home during childhood.

If you are concerned about your child's diet, speak to your GP about a referral to a dietician.

If your child has feeding or drinking difficulties, or you have concerns, ask your child's practitioners. Your GP, speech and language therapist or a dietician may be able to help. You can also contact the [Down's Syndrome Association \(DSA\)](#) for further information.

## Growing pains

Children with Down syndrome experience puberty at the same time as other children, sometimes a little earlier. You will notice changes towards the end of primary school. By this time your child should know about some of the changes they have begun to experience. They should be educated at school about relationships, health and sexuality appropriate to their chronological age. This should be made accessible for them with pictures and language they can understand.

The book *Teaching children with Down syndrome about their bodies, boundaries and sexuality: a guide for parents and professionals*, by Terri Couwenhoven, addresses these issues. For further information on this subject, you can also contact the [DSA](#).

## Personal care

Children will be improving their personal care throughout their school years. They need to practise tasks to continue to get better so let them try doing things for themselves.

Night-time continence usually develops after daytime toilet-training and you should aim for your child to master both daytime and night-time continence during their school years.

If your child is experiencing continence difficulties, ask your GP or health visitor for help. You can also contact a continence advisor at the [DSA](#) or get in touch with [ERIC](#) (Education and Resources for Improving Childhood Continence).

## Home environment

As they develop their independence during their school years, some children with Down syndrome may copy behaviour that is not safe for them. For example, they may go outdoors without asking before they do so. If your child does this, you may need to make temporary adjustments at home, for example, by installing high door handles or outer door locks they cannot reach. Keep your car keys in a safe place. Teach your child to ask permission before they go off exploring and encourage them to talk about their ideas.

## Equipment and aids

For advice about safety equipment and aids for daily living and to encourage independence, contact the [DSA](#) or visit [The Disabled Living Foundation](#) website.

A health and social care assessment, carried out by social services, will assist you in finding out about the help and support available for you and your child. For further information, visit [www.gov.uk/apply-needs-assessment-social-services](http://www.gov.uk/apply-needs-assessment-social-services).

## Choices and challenges

### Friendships

Children make friends with people they spend time with. They make friends by doing things together:

- at home
- at school
- after school, at after-school clubs or in childcare
- in their community, through sports, dance, drama and at social clubs

### At home and out of school

When you invite your child's friends home, it may help to have play activities planned in advance.

When your child is invited to play with others, provide relevant information and keep the time short at first so everything works out well. Make sure you go to collect your child at the time you said you would.

If you don't know who your child gets on well with at school, ask your child's teacher.

Your child will make friends more easily when they play games they know well and are good at. Games and activities don't need to be complicated for children to have fun together.

Your child will make friends with children who have additional needs and those who do not, provided they have opportunities to do so.

### **At school**

Provide your child's teacher with information about the activities your child enjoys. This will help them to plan for interaction at playtime and in lessons.

Children with Down syndrome are often good at practical tasks and they usually like to help. Giving them jobs to do with other children will help develop their friendships. The more you value the jobs they do and the ways they help, the better. Your child will feel good about themselves and other children will see how competent they are.

How children experience their lessons at school will affect their friendships. If they spend a lot of their time out of class working individually, their friendship opportunities are reduced.

Your child may benefit from planned peer support at school, for example, from 'buddies' or a 'circle of friends'. These are methods to help all children make friends if they need help to do so.

### **Coping with differences**

Children with Down syndrome are often more aware of their condition than people think. It will be difficult for your child to develop their own talents and skills, and to advocate for themselves later on if they cannot accept Down syndrome.

You can approach this by making a personal book with your child about their interests and strengths. Personal books are better than general books as every child with Down syndrome is different. Use simple and honest statements appropriate for your child's age and development. You should use the term Down syndrome.

Your child will need to know they have some differences when compared with most other children, and what these differences are. These will vary from one individual to the next.

They may need:

- more time for certain activities
- people to listen carefully to what they are saying
- more help with certain tasks

Siblings and friends will also benefit from information about Down syndrome. The **Down's Syndrome Association (DSA)** can direct you to resources created by parents, and books for children with Down syndrome and their friends.

### **Developing independence**

Children with Down syndrome want to do the same as others of their age. They may surprise you by preparing food and drinks or going out of the house without asking permission before they do this. Be prepared for this. Encourage your child to talk about what they want to do and help them to behave safely. Provide clear rules for activities they can do on their own and for those they should check with you first.

Encourage practical independence at home, for example, for domestic tasks and personal care as these are strengths for people with Down syndrome.

### **What if things aren't working?**

Talk with your child's teachers and **SENCO**. Do they know how to meet the needs of children with Down syndrome? Is there anything you can do to help?

Like all children, children with Down syndrome get on better in some years than in others and there may be temporary difficulties. If you face a difficulty, don't immediately think your child must change school as there may be simple solutions.

If you are concerned about your child's development or education call the **DSA's** advice helpline. The **DSA** also provides an individual assessment and advice service. For more information, visit [www.downs-syndrome.org.uk/support-services/assessment-and-advice-services.html](http://www.downs-syndrome.org.uk/support-services/assessment-and-advice-services.html).

## Choosing a secondary school

Whether your child attends a mainstream or a special school, the essential elements needed for a successful transition are a positive attitude and a carefully prepared transition plan.

Transition to secondary school can be difficult for many pupils, but particularly for those with additional needs. In contrast to primary school, pupils have to relate to many teachers and find their way to and from different classrooms.

Pupils with Down syndrome are likely to find adapting to new surroundings and adjusting to new expectations difficult, and most of them will need extra preparation and help. During the final primary year it is vital that plans are made to make this transfer as smooth and as positive as possible.

There may be one main school that most of the pupils from the primary school (mainstream or special) feed into. Socially this is the most sensible option as the child will be well supported by familiar friends. However, if the school does not welcome the child, it may be better to look elsewhere.

It is essential that the parent carer and both the primary and the secondary school are involved in the planning process. It should start early to allow liaison between schools and relevant practitioners. Here are some transfer guidelines:

- Visit local secondary schools during the autumn term of year five. You are likely to have some choice about the most suitable mainstream or special school for your child. Contact your local authority for advice. You can also contact the [Down's Syndrome Association \(DSA\)](#) or [IPSEA](#) for information about your child's rights to attend a school that can meet their educational needs.
- Make an appointment to meet the [special educational needs coordinators \(SENCOs\)](#) of likely secondary schools. Which schools are able to include your child positively? Which schools offer activities your child will enjoy? Are the schools flexible and willing to work with you? Ask other parent carers of young people with Down syndrome about their experiences.
- Your child should be involved in the decision as well. When you have narrowed down the choice to a few schools, take your child with you. Find out what they thought about each school. You can help them to express this by sorting through and choosing from a selection of words and pictures about their visit, to tell you what they liked and what they didn't like. (This approach is called '[Talking Mats](#)'.)
- Practitioners from likely secondary schools and relevant support services will be invited to attend your child's year five review.
- Your child's primary school SENCO will probably arrange a transfer planning meeting with the secondary SENCO to decide who will do what when.

- It will help if the schools arrange exchange day visits for key staff, allowing them to get a better understanding about what is required to meet your child's needs at secondary school.
- An early year six review (autumn/spring term) will clarify the support and training needed, and set the targets for transition.
- Your child will experience transfer visits to familiarise them with aspects of the secondary school.
- The secondary school should find out about good practice guidance for educating young people with Down syndrome. This is relevant for staff in special schools as well as for staff who may not have taught a young person with Down syndrome before. This may include, for example, raising the awareness of the whole school and identifying staff training needs.
- The school should prepare visual resources – for example, a 'personal profile', photographs of the school and key people, a visual timetable, a list to help them pack their own bag and so on. School staff should prepare these but you may like to help.
- There should be a final meeting between you and key staff from the primary and secondary schools to tie up previous planning work.
- Use resources provided for parents of all children at this stage in their lives. These will help to address some of your child's worries.

For further information about choosing a school and supporting transition you can contact the [Down's Syndrome Association \(DSA\)](#). You can also refer to the [DSA's Secondary education support pack for pupils with Down's syndrome](#) at [www.downs-syndrome.org.uk/information/professionals/education/158-information/professionals/education/1245-secondary-education-support-pack.html](http://www.downs-syndrome.org.uk/information/professionals/education/158-information/professionals/education/1245-secondary-education-support-pack.html).

## Meeting others

### Parent support groups

There are many parent support groups around the country. Most families find contact with other parents helpful. The [DSA](#) can tell you if there is a group in your area.

Many support groups provide:

- social activities for your family
- activities for your child with Down syndrome – from communication groups to swimming or drama

- information and training for you and local practitioners

Other families who have lived through similar experiences can:

- share their experiences of practitioner 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

## Going out with your child

Most children with Down syndrome enjoy time with their families and lead active lives. They enjoy the same leisure activities as other children. Some children with Down syndrome find this more difficult.

You will know if your child dislikes loud noises or crowded places and can be prepared for these situations with, for example, earplugs or ear defenders.

If you go to places that are not interesting to your child, take activities with you to keep them busy. Reading books, activity books and pens for colouring, writing and word search games, and all types of electronic games are popular. Giving them a special job or responsibility while you are out will also help to keep them entertained.

If your child dislikes visiting the hairdresser, dentist or hospital, remember to reward them afterwards. You can prepare them for the visit with discussion, pictures or a social story that shows your child how to behave in the ways you expect. Be aware that too much discussion may worry them more than a calm, matter-of-fact approach. Try to keep visits short where you can.

If your child has a dual diagnosis of Down syndrome and an autism spectrum disorder, follow advice from the [National Autistic Society](#) and see the Early Support resource for autism at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

## Short breaks

There are several ways to access short breaks or respite services. Most short break and respite services will have certain criteria, the most common being that your child is receiving specific rates of benefit and that they have had an assessment from social services.



## Benefits

During your child's school years, you may be claiming several benefits for your child; you may be claiming some benefits for yourself.

The benefits system is complicated and is currently changing. It is sensible to check now and again that you are getting everything you are entitled to.

For detailed guidelines about benefits, visit the [Down's Syndrome Association \(DSA\)](https://www.downs-syndrome.org.uk) at [www.downs-syndrome.org.uk](https://www.downs-syndrome.org.uk). Or call a [DSA](https://www.downs-syndrome.org.uk) benefits advisor on 0333 1212300. The government's information website, [www.gov.uk](https://www.gov.uk), has useful, basic information on benefits.

There are also organisations that may be able to give grants to help you take holidays, including the [Family Fund](https://www.familyfund.org.uk).

## Into adulthood

### Thinking about the future

#### Helping young people choose what they want out of life

Typically, students with Down syndrome find it hard to think ahead and imagine what life might be like after they leave school. They will need the chance to try different experiences before they can make decisions about their future.

People with Down syndrome and their families should request to talk in person to an advisor about future education, training, work and apprenticeship opportunities. Careers services may be delivered through the school or via an outside organisation. They should also expect careers education about the world of work and have access to work experience.

Thinking about the future begins with the **14+ Transition Review**, which is first held at school in year nine, and then reviewed each year, usually at the same time as the annual review. The local authority or school will write to families informing them of a forthcoming review. In addition to previous topics, this review addresses planning for transition into adult life.

It is a key meeting that should cover all aspects of a young person's life and be attended by all those involved in their care, including health and social care practitioners. If it is likely that the young person will require support from adult services in the future then a representative from adult services should attend.

Certain documents may help provide the evidence to determine the level of support needed through the transition to adulthood. These include:

- a learning difficulty assessment (see below)
- the student's most statement of SEN if they have one from the outgoing system or from September 2014 the student's Education, Health and Care Plan
- the student's most recent school report and transition plan
- a relevant and up-to-date social care report
- a relevant and up-to-date medical and psychological report

These documents should relate clearly to the identified needs of the young person, the support necessary to develop their independence, as well as the person's aspirations.

Guidance for local authorities states that, 'Successful transition depends on early and effective planning, putting the young person at the centre of the process to help them prepare for transfer to adult services.' The full document, called *Prioritising need in the context of putting people first: a whole system approach to eligibility for social care*, can be found on the Department of Health website at

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113154](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154).

This is an important document, which provides the criteria that local authorities use to decide if an adult is eligible for support.

Helpful information about the transition process can be found on [The Transition Information Network](#), which is part of the [National Children's Bureau](#) – visit [www.transitioninfonet.org.uk](http://www.transitioninfonet.org.uk).

Preparing for Adulthood (PfA) is a two-year programme funded by the Department for Education. It is developing lots of information to help support young people and their parent carers throughout the transition to adulthood. For resources and tips, visit [www.preparingforadulthood.org.uk/resources](http://www.preparingforadulthood.org.uk/resources).

To find out about new funding arrangements to support the government's plans to introduce a single approach to assessment and planning for young people with special educational needs from birth to 25, visit [www.gov.uk](http://www.gov.uk).

The [Down Syndrome Association \(DSA\)](#) also provides information on looking for employment opportunities, please visit [www.dsworkfit.org.uk](http://www.dsworkfit.org.uk).

## Leaving school

Every year, there are more accounts of young adults with Down syndrome working, living independently and gaining more experiences and qualifications. Many attend a local college course at 16 or 19. If local colleges cannot offer the right support or course, there is the possibility of a specialist residential college placement.

The case for such a placement must be very strong as the cost is high – the education information officer at the [Down's Syndrome Association \(DSA\)](#) will be able to discuss this with you. For further information, visit [www.downs-syndrome.org.uk/support-services/information-team/education-advisers.html](http://www.downs-syndrome.org.uk/support-services/information-team/education-advisers.html).

Most people with Down syndrome receive some level of support from their local Adult Learning Disability Team. Information officers at the [DSA](#) can provide further details about this.

Some young people move on to voluntary and paid work. If they are thinking about getting a job, it's a good idea for them to talk to family and friends. They can get help from:

- the local careers guidance service – available through your school or college
- the Access to Work scheme
- the disability employment advisor (DEA) at your local Jobcentre Plus office

The Employment Project, launched by the [DSA](#), hopes to improve access to mainstream employment and other meaningful activities for people with Down syndrome. Visit its WorkFit website for further information on how to get involved, at [www.dsworkfit.org.uk](http://www.dsworkfit.org.uk).

## School college options

It is time to begin thinking about college options at the year nine review. You will need to find out:

- about local colleges
- about the courses they offer
- about the support they can provide
- if the local college provides opportunities for day release in years 10 and 11
- if they provide vocational tasters to help the young person make decisions about their future

If there are any concerns about local colleges being able to meet the needs of a young person, then parents should request information from the school or local authority representative about specialist provision.

If a young person is leaving school to go to college the statement of special educational needs will cease. The local authority must then carry out a **Learning Difficulties Assessment (LDA)**.

Local authorities are responsible for making sure that a LDA takes place *before* leaving school. It is an assessment of education and training needs, and a written report should be produced in the last year of compulsory school. This is sometimes called a Section 139a assessment and should help the young person and parent carer to think about possible education and training options. The LDA report:

- must be specific about the level of need and the support and learning provision required to meet those needs
- should have a specific focus on the learning programme that is required to enable the young person to progress towards greater independence and where appropriate employment
- should take account of the young person's aspirations and views
- should build on the views and expertise of other people who have already supported the person being assessed

Unless the young person or parent carer has refused permission, the local authority should share the LDA with the college, or other education or training provider, and do so in sufficient time to make sure provision and support are in place from the outset.

The local authority should also make sure that the young person and the parent carer understand the LDA process and the decisions that are made as part of that process.

The local authority must identify the representative responsible for the LDA. The representative should get to know the young person well, so they can work with them, their family and (where applicable) other practitioners to make sure an accurate assessment of the

training and education needs of the young person is available on leaving school. This is not something to be left until the last minute.

From September 2014 the law will be changing and statements and LDAs will be replaced by a single Education, Health and Care Plan which will apply to children and young people aged 0-25. It will still be important to ensure the plan is properly reviewed when the young person leaves school.

If you disagree with the decision made in the LDA report there are rights of review and complaint. The new Education, Health and Care Plans will carry a statutory right of appeal.

Information on residential provision is given in the *COPE directory: compendium of post-16 education and training in residential establishments for young people with special needs*. Your local careers service should have a copy and should be able to help you find the best option.

You can also search the directory of colleges providing further education and training for students with learning disabilities at [www.natspec.org.uk](http://www.natspec.org.uk).

## **PCP planning/process**

Person centred planning (PCP) can help people to work out what they want out of life. It is not the same thing as assessing someone for services – it is concerned with the whole of someone's life, not just their need for services. However, it can also be used by practitioners to help work out how to provide support and services.

The young person should be given the opportunity to create a person centred plan, which can be updated as they mature and can form part of the transition review. The plan will reflect what matters to the young person and will include their future aspirations, as well as the support necessary to achieve those aspirations. Person centred planning has five key features:

- The person is at the centre of the plan.
- Family and friends are partners in the planning process.
- The plan reflects what matters to the individual (both now and in the future), their capacities and the support they require.
- The plan reflects what is possible, not just what is available.
- The plan results in continued listening, learning and further action.

There are four main approaches to person centred planning. These are:

- Essential Lifestyle Planning
- PATH (planning alternative tomorrows with hope)
- MAPS (making action plans)

- Personal Futures Planning

Further information about person centred planning can be found on a number of websites, including: [www.gettingalife.org.uk](http://www.gettingalife.org.uk); [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk); and [www.preparingforadulthood.org.uk/resources/videos/person-centred-reviews-planning-for-the-future-a-parents-experience](http://www.preparingforadulthood.org.uk/resources/videos/person-centred-reviews-planning-for-the-future-a-parents-experience).

## Work options

Schools are responsible for providing a careers service. Details for this can be found in the document *Statutory guidance for schools: careers guidance*, which can be found on the Department for Education website at

<http://www.education.gov.uk/aboutdfe/statutory/g00205755/statutory-careers-guidance-for-young-people/statutory-guidance-for-schools-careers-guidance-for-young-people>.

Careers guidance must:

- be presented in an impartial manner
- include information on the full range of post-16 education or training options, including apprenticeships
- promote the best interests of the young person to whom it is given

There are a range of options for people with Down syndrome who want to explore the workplace, including:

- work placements
- paid work
- volunteering
- apprenticeships

Many people with Down syndrome rightly have concerns about what will happen to their benefit payments in each of these situations – the **Down's Syndrome Association (DSA)** offers a helpline service where you can receive advice on the individual's personal financial situation, or you can email [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

The **Down's Syndrome Association (DSA)** has a dedicated website for jobseekers with Down's syndrome at [www.dsworkfit.org.uk](http://www.dsworkfit.org.uk).

You might be interested in the *Visual timetable for working life*, a CD that can be used to help people with Down syndrome plan their day. For further information, visit [www.downs-syndrome.org.uk/shop/publications/education/further-education/1133-interactive-visual-timetable-for-working-life.html](http://www.downs-syndrome.org.uk/shop/publications/education/further-education/1133-interactive-visual-timetable-for-working-life.html).

## Living options

Many young people with Down syndrome will want to continue to live with their families, but others may have ambitions to live more independently. Sometimes this is what a young person will want and may be appropriate but others may find this a very lonely option.

Young people are advised to go on the housing register as it makes the local authority aware of the level of need in the area.

There are many options available to people with Down syndrome, including:

- home ownership
- renting privately, from the local authority, or via social landlords
- adult family placement, supported accommodation/lodging, or Homeshare schemes
- using support organised by social services, or the person with Down syndrome employing their own staff or using an agency
- residential care – where the accommodation and care are arranged together
- self-contained, shared or single independent housing options

You may need information on rights to housing and support, as well as welfare benefits advice. Housing and Support Alliance is an organisation dedicated to helping people with housing issues. For further information, visit [www.housingandsupport.org.uk](http://www.housingandsupport.org.uk).

## Other options

There will be many young people who do not have or want a job, and will need other things to do. Those who are working are more likely to work part-time and will want other activities to do during the week. Young people need to maintain their current friendships as well as make new friends. You will need to consider:

- the kind of activities that are available within the community
- opportunities to try out new things
- that some young people with Down syndrome may not have the skills or initiative to attend social or recreational activities if they are responsible for organising them; this can lead to isolation and risk of depression

## Developing independence

### Everyday life

Young people with Down syndrome need opportunities to develop their lifestyle. As an adult they will thrive physically and mentally from the following experiences. Things you can plan for as your young person moves towards adulthood include:

- acceptance as an individual
- being given choices
- expectations that are neither too low or too high
- regular exercise
- support for their preferred routine, with flexibility encouraged
- emphasis on communication skills from a young age
- vocational training as part of schooling
- an enjoyable, stimulating job that uses their strengths
- being part of a supportive community
- having opportunities to help others
- being included in society with people who do not have disabilities and also having opportunities to be with people who have disabilities
- to be heard – when they express their concerns people should listen

You can read more about how to support young people and adults with Down syndrome in *Mental wellness in adults with Down syndrome: a guide to emotional and behavioural strengths and challenges*, by Dennis McGuire and Brian Chicoine. You can also contact the [Down's Syndrome Association \(DSA\)](#) for further information about books and resources.

### Independent travel training

Local authorities will have their own schemes to provide independent travel training to young people with special educational needs, aged 14 to 19, in full-time education.

Travel trainers may work on a one-to-one basis with students, helping them develop independent travel skills and problem-solving skills, as well as providing general support.



## Sleep

Your teenager may be tired and grouchy just because they are a teenager and they have been up late watching TV, on the phone, or playing with their iPad. Teenage years can bring with them increased confusion, introspection and anxiety, which may impact on sleeping patterns. If your teenager uses **self-talk**, it can be useful to discreetly eavesdrop to find out if anything is worrying them. Recent studies show that adolescent sleep patterns actually differ from those of adults or kids. These studies show that during the teenage years, the body's biological clock is temporarily reset, telling a person to fall asleep later and wake up later.

Good sleep is a vital part of a healthy lifestyle. The exact number of hours of sleep needed varies from person to person, but enough sleep to feel energetic throughout the day is the ideal. As with all people, different activities will help or hinder sleep, depending on the individual. Lack of sleep can have a big effect on a person's ability to function and it can result in various problems, such as difficulty controlling emotions, loss of concentration and the loss of skills.

Some sleep problems can be reduced by following a scheduled sleep routine, cutting down on distractions in the surrounding environment, increased levels of exercise, dietary changes, or weight loss. Apart from the usual teenage sleep-related issues already mentioned, there are some sleep problems that are more common in people with Down syndrome. One of these is **sleep apnoea** – a condition in which breathing stops, or is greatly reduced during sleep.

If sleep disturbances continue for weeks, it is time to get help. Talk to your family GP; it may be that your teenager needs a referral to a specialist sleep practitioner.

## Eating and drinking

It is easy for people with Down syndrome to become overweight because they burn fewer calories than others. Learning to make healthy food choices and maintaining a physically active lifestyle are issues for some young people.

Low fat, healthy eating rather than 'diets' should be encouraged, along with regular activity and exercise. People with Down syndrome are also at greater risk of thyroid problems, so checks should also be carried out to exclude or monitor **hypothyroidism**, which can result in weight gain.

The majority of young people with Down syndrome will eventually need to make their own food choices, and unless they are guided by principles of healthy eating they risk becoming, and remaining, overweight. This has both health and social implications.

Some adults with Down syndrome will continue to need guidance on healthy eating. Visual recipes and cooking with others can reinforce good eating habits, as well as taking an active role in menu planning and shopping for food.

## **Personal care**

Most young people with Down syndrome master their basic personal care, such as washing, dressing and toileting needs during the day and at night. They might not do these perfectly but they need to care for themselves as often as possible to improve. Young people may need help rinsing their hair thoroughly, tying laces or doing up small buttons. If your young person needs help with their personal care, remember to respect their privacy. For example, keep doors closed and knock on the door before going into a private space.

## **Growing pains**

Mood swings, pushing the boundaries, tiredness, confusion, crushes, first loves, introspection and spending ages in the bathroom – these may occur a little later and last longer in some people with Down syndrome, but your teenager will essentially be like other teenagers. Some of the issues that need to be thought about at this point in your child's life include: a desire for greater independence; a need for more personal space; encouraging good personal hygiene; sexuality; explaining and facilitating relationships; and fostering self-esteem.

Most teenagers with Down syndrome go through the same physical and hormonal changes at around the same time as other teens. This is a time when your child will want to be doing more for themselves.

Skills and level of development vary greatly from one person with Down syndrome to another. Some teenagers with Down syndrome will try to do things at roughly the same time as other teenagers, but the majority of teenagers with Down syndrome will be at a different level of skill to other teenagers of a similar age. Both you and your child will be testing the water as to what is possible and when.

You can help your young person by arming them with information about their condition and emphasising their strengths and skills. We all need to feel good about ourselves. Help them to develop confidence by focusing on what can be done rather than what cannot because of their condition.

## **Relationships**

Relationships – starting them, enjoying them and maintaining them – are an essential and complex area of all our lives. For young people with Downs' syndrome, growing up and being part of the adult world of exciting, yet often confusing, relationships is particularly hard. Adolescence is a time of great change and the young person will need considerable support to help them embrace these changes with confidence and enable them to be as independent and socially successful as possible.

The book *Teaching children with Down syndrome about their bodies, boundaries and sexuality: a guide for parents and professionals*, by Terri Couwenhoven, addresses these issues.

*Talking together about sex and relationships*, by Lesley Kerr-Edwards and Lorna Scott, is a practical resource for schools and parents working with young people with learning disabilities.

You can also contact the [Down's Syndrome Association \(DSA\)](#) for further information on this area.

## Home environment

Living environments should promote independence, pride and self-esteem. People with Down syndrome need to be given autonomy to do what they are able to do and should receive help and guidance when needed.

Problems can develop when the person is given too little or too much independence. Careful attention must be paid to the assessment of the individual for more independent living options. Assessing the need for supervision on the ability to do general tasks rather than on their level of maturity around certain key issues can lead to difficulties. People with Down syndrome can often perform personal care and housekeeping activities, but may make poor decisions in other areas, for example, regarding sleeping, eating and leisure activities. Getting these wrong can be harmful to health, well-being and self-esteem.

Local authorities are responsible for the assessment of need under the NHS and Community Care Act 1990. You can keep updated on any changes in the law at [www.gov.uk](http://www.gov.uk).

The [DSA](#) can also provide an additional assessment that focuses on the specific areas of strengths and weaknesses associated with the condition, and can help avoid the problems associated with overestimation or underestimation of need. For more information, visit [www.downs-syndrome.org.uk/support-services/assessment-and-advice-services.html](http://www.downs-syndrome.org.uk/support-services/assessment-and-advice-services.html).

## Health checks

Many young people with Down syndrome are under the care of GPs and paediatric services. As they approach 18, they will be expected to access other adult health services, although the GP should provide some continuity. Some GP practices are now funded to provide annual health checks for people with learning disabilities. Adults with Down syndrome are advised to take advantage of this.

The [Down's Syndrome Association \(DSA\)](#) is in the process of designing a health book specifically for people with Down syndrome, which highlights the areas that GPs should target each year.

People with Down syndrome are predisposed to certain medical conditions, including cardiac disease, thyroid disorders, hearing impairment, sleep disorders, visual problems and coeliac disease – most of which are treatable.

Depression is not part of the condition, but it is one of the most frequently diagnosed psychiatric disorders for those with Down syndrome. Many people will experience depression at some time in their lives. Depression can occur as a result of an upheaval in a person's life, such as bereavement or as a result of disappointment, stress or illness. Depression can also occur for no apparent reason.

Publications covering different areas of health are available at [DSA's website](#).

## Letting go

### **Supporting choice and autonomy**

Whenever possible, people with Down syndrome should be involved in making their own decisions and allowed to learn from their mistakes. Choosing what to wear, what to eat, where to shop and who to meet, as well as bigger issues, such as where to live and who to live with, are an important part of development.

Choice and autonomy can be encouraged by family members and by support staff, but it is important that guidance is available to ensure safety. Sometimes people are put in situations where they are being overloaded with too much choice and independence within a relatively short time period. This, perhaps coupled with an inability to self-initiate tasks and difficulties describing feelings of anxiety and stress, can very quickly lead to crisis situations. With the right environment and an understanding of the individual, many such situations can be avoided.

### **Developing self-awareness**

Young people with Down syndrome are often already aware of their condition. They will ideally have learned about having Down syndrome in their younger years. The process of coming to terms with identity starts in childhood and continues into adulthood. This subject will need to be revisited, with information updated, during their teenage years.

As children with Down syndrome grow into adolescents and adults, many become more aware of the discrepancies in skills and abilities and the opportunities available to them. The difference may become more noticeable as their peers get jobs, learn to drive and get married, although some people with Down syndrome do all of these things. Young people with Down syndrome may need to discuss their condition in order to develop a positive and realistic view of themselves. It may be helpful to point to other people of different ages and levels of skill in the community who are good models and have Down syndrome.

People with Down syndrome need friends who also have the condition so that they are able to be with others who experience the world as they do. By being with others who experience the world as they do, they can gain a strong sense of support and identity.

*Mental wellness in adults with Down's syndrome*, by Dennis McGuire and Brian Chicoine, has some useful tips on supporting young people to develop self-awareness. Please see the [Resources](#) section for more information.

## Supporting positive risk-taking

'Nothing ventured, nothing gained' – unless someone takes a risk and tries new activities, they will never know of the positive benefits that might result. In our society, people are encouraged to travel widely, take part in regular leisure and sporting activities, go to college, develop careers and have families. These are all activities that don't just happen; people have to take risks to achieve their aspirations.

For many people, taking risks is an accepted part of life. Young people with Down syndrome also need these opportunities to develop as individuals. A person centred plan will help to achieve safe risk-taking for the individual by identifying the wishes of the person with Down syndrome and the support needed to achieve them.

## Meeting others

### Parent groups

The [Down's Syndrome Association \(DSA\)](#) is the only organisation in Britain focusing solely on all aspects of living successfully with Down syndrome. Since 1970, the organisation has grown from a local parent support group into a national charity with over 20,000 members, a national office in Teddington, Middlesex, and offices in Northern Ireland and Wales.

There are many local support groups offering services to families and parents across the nation. The [Down's Syndrome Association \(DSA\)](#) works closely with over 130 local parent support groups and can put you in contact with your local group.

### Social activities

People with Down syndrome need interaction with family, friends, peers and others just like everyone else. They need opportunities to participate in the life of their community through hobbies and community events, as this will boost their self-esteem and help develop and improve social skills. Interaction with others through physical activity, social events and travel, as well as learning new ideas and having a fulfilling job, all provide the social connection necessary for the well-being of people with Down syndrome.

The **DSA**, local groups and your local authority will all be able to offer information on available activities in your area.

## Short breaks

Short breaks provide opportunities for young people with Down syndrome to develop their independence and have a break from their parent carers. They can take different forms depending on the needs of the individual. They can include time away from parent carers in residential homes or with other families, or days out to enjoy leisure activities. The time available for short breaks will be determined by the community care assessment.

Short breaks are also available for parent carers who need time away from their caring responsibilities. These are determined by a **Carers' Assessment**, which can be requested from your local **Adult Services Department**. If the young person receives social care services, their social worker can carry out the **Carers' Assessment**.

Each local authority will have its own policy with regard to short breaks and you should look on its website or talk to social services for further information.

There is also information about the Carer's Assessment in *Prioritising need in the context of putting people first*. To download the resource, visit [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113154](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154).

## Benefits

When your child turns 16, their benefits will change. The benefits system is complicated and is currently undergoing major changes. Get advice about your own situation before making a claim and check to make sure you're getting everything you are entitled to.

For more information on benefits, visit the **Down's Syndrome Association (DSA)** website at [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk) or call one of its benefits advisors. The **DSA** has detailed guidelines about disability living allowance, carer's allowance, tax credits and benefits at 16.

The government's information website, [www.gov.uk](http://www.gov.uk), has useful, basic information on benefits.

## Health issues

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

Health care guidelines for GPs and parents are available on the UK Down Syndrome Medical Interest Group (DSMIG) website, [www.dsmig.org.uk](http://www.dsmig.org.uk).

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 that children with Down syndrome are all individuals. Your child may not suffer from any of the medical conditions discussed here or may experience only some of them.

### 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 all 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 before the baby is born, during an antenatal ultrasound. 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 your child may have a heart problem, they will be referred to a paediatric **cardiologist** 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.



## Bowel abnormalities

Around 10 per cent 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 is more common in children with Down syndrome (affecting approximately two per cent 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**. A medical examination, an X-ray and a biopsy of the bowel are used to make a diagnosis.

## Ongoing health issues

### 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 hearing problems 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.

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

Although mild hearing loss is not usually considered serious in other children, it may have a significant effect on learning for children with Down syndrome.

#### *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

There are various treatments, including **antibiotics**, the insertion of **grommets** or the use of hearing aids. Grommets are tiny tubes that are inserted into 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. Children with Down syndrome tend to have small ear canals, therefore 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 you on treatment options.

#### *Middle ear infections*

Middle ear infection (or **otitis media**) is also quite common. The treatment of middle ear infections 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.

More information on this is available in the booklet *Down's syndrome and childhood deafness*, published by the **National Deaf Children's Society**, and available to download on the **Down's Syndrome Association (DSA)** website at [www.downs-syndrome.org.uk/images/stories/DSA-documents/Publications/health/Downs\\_Syndrome\\_And\\_Childhood\\_Deafness\\_2011.pdf](http://www.downs-syndrome.org.uk/images/stories/DSA-documents/Publications/health/Downs_Syndrome_And_Childhood_Deafness_2011.pdf).

You can also find further information in the Early Support resource *Deafness and hearing loss* at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

Children need to learn that the hearing aid is helpful. A period of training may be necessary. A specialist teacher of the deaf helps children learn to use their hearing aids.

### **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' because they distort the image upon the **retina** – the light-sensitive surface at the back of the eyeball.

Children 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. 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 throughout childhood and as soon as possible if their behaviour indicates deterioration in vision.

Many of these difficulties can be corrected 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. Try to keep them as clean as possible, so that your child is always aware that glasses make the world around them clearer and easier to see. Check that they are kept clean by staff in school, too.

For more information about vision disorders in children with Down syndrome, visit the website for the [Down's Syndrome Vision Centre](#), based at Cardiff University, or contact the [Down's Syndrome Association \(DSA\)](#).

For more information on visual impairment, you can also refer to the Early Support resource *Visual impairment* at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

## Infection

Children with Down syndrome generally have an increased susceptibility to infections. It is 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. Common sites for infection are the bladder (urinary), throat, tonsils, teeth, middle ear and 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

Children with Down syndrome should 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 **DSA**. For more information about standard childhood immunisations visit the NHS website at [www.immunisation.dh.gov.uk](http://www.immunisation.dh.gov.uk).

## Sleep-related breathing disorder

Sleep-related breathing disorder (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 is 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 an 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 birth that has not responded to simple measures, ask your GP about these possibilities.

## *Diarrhoea*

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

When there is a significant change from your child's normal pattern that lasts more than a few days, seek advice.

Sometimes stools may be particularly bulky, foul smelling, or look frothy or greasy. This may be a sign that food is not being absorbed properly. One condition that can cause this 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 pieces of solid stools in a straw-coloured liquid.

## *Gastro-oesophageal reflux*

Gastro-oesophageal reflux occurs when food that has already passed into the stomach and into the bowel comes back up into the **oesophagus** and may be vomited up. Most healthy babies experience this from time to time. It is more common in babies because some of them 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)**, a **hormone** produced in the brain.

**Hypothyroidism**, or under-activity of the thyroid gland, is more common in people with Down syndrome and affects around 10 per cent of children with Down syndrome. In hypothyroidism, the levels of **thyroxine** are low and **TSH** high.

The signs and symptoms of hypothyroidism vary greatly from one individual to another. 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 **TSH**. Anti-thyroid antibodies can be measured using 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, 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 12 months 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 **thyroid stimulating hormone (TSH)** with a finger prick, but 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. Your child will be given **thyroxine** tablets (which contain the **hormone** that the **thyroid** produces naturally), which will need to be taken regularly, usually daily. The 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 developing 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 throughout a day. The condition can be treated with medication and response to treatment is usually good.

### **Neck instability (Craniovertebral instability)**

In people with Down syndrome ligaments tend to be lax and muscle tone is often low. In a small number of people with Down syndrome certain vertebra in the neck are able to move more than is seen in other people. This may lead to slippage of the vertebra.

If the vertebra slips far enough, it can cause bruising of, and pressure on, the spinal cord. Bruising can occur gradually or as the result of a sudden trauma. Mild symptoms occur in most people before dislocation of the vertebra occurs, so it is important to be on the lookout for these so that preventative action can be taken if necessary.

Here are the signs to look out for:

- Pain at a spot near the hard bump behind the ear.
- A stiff neck which doesn't get better quickly.
- Unusual head posture.
- Changes in the way a person walks so they may appear unsteady.
- Deterioration in a child's ability to manipulate things with their hands.
- Incontinence developing in a child who has previously had no problems.

If any of these occur the person should be seen by a doctor. If the onset of symptoms is sudden, an emergency appointment is needed. If there is no obvious alternative explanation for these symptoms they may be related to neck instability. An X-ray and specialist referral may need to be arranged. Guidance for doctors about assessment and management can be found at [www.dsmig.org.uk](http://www.dsmig.org.uk).

### **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.

Adults with Down syndrome will generally be under the care of their GP, unless they have been referred to an adult medical specialist for a specific health issue. The GP should carry out an annual health check. The Down's Syndrome Association (DSA) is currently piloting 'My Health Check', a book that people with Down syndrome keep themselves and which highlights areas GPs should target each year.

You can obtain further information about medical issues from the medical advisory service provided by the [Down's Syndrome Association \(DSA\)](#), or on its website.

You can also find further information on health and medical issues at [www.ds-health.com](http://www.ds-health.com), created by American paediatrician Dr Len Leshin.

## Top tips

- Take time to get to know your new baby. You don't need to be doing anything special or different at this stage.
- While 'special' activities help, they are unlikely to be the main influence on your child's development. It is important to strike a balance, so that your needs and the needs of other family members are addressed.
- Seek information about Down syndrome and services that can help your child. If you are refused services ask for an explanation in writing and don't be afraid to challenge the decision.
- Join a local parent-led support group.
- People with Down syndrome are predisposed to certain medical conditions, most of which are treatable. The [Down's Syndrome Association \(DSA\)](#) helpline can answer your health questions and suggest resources that might be useful. Find a GP who will treat your child or young person's health issues quickly and follow up on health checks.
- Help to develop your child's communication skills throughout their life.
- Adopting behaviour management strategies as early as possible is a good way to lessen the likelihood of behavioural problems. Consistency is the key to managing behaviour. You should always expect your child to behave well and reinforce this with what you say and do.
- People with Down syndrome are visual learners. Use this strength to help them. Tell your child's school about the [DSA's visual timetable](#) and also about its *Education Support Packs*.
- Ask about benefits. The [DSA's](#) benefits advisors are specialists within the field of Down syndrome and can provide detailed information and advice on all aspects of entitlement within the benefits system. They can help with information on what benefits to claim, do 'better-off' calculations to ensure you are receiving the correct amount of financial support, as well as support you through the appeals process where necessary. Call 0333 1212300 or email [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).
- Work with practitioners and your child to plan their future lifestyle and the support required to achieve it.



## Who can help

You will come across many practitioners over the years, some of whom are listed below. For a comprehensive list, refer to the Early Support resource *People you may meet* at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

**GP** – A family doctor who deals with general health issues and can refer you on to clinics, hospitals and specialists when needed.

**Health visitor** – A qualified nurse or midwife with special training and experience in child health.

**Home visiting teacher** – Someone who visits young children with additional needs and their families in their home. Parent carers are given advice and support to help their child's development. They aim to work in close partnership with parents, teachers, playgroup leaders and other related professionals.

**Occupational therapist** – A health practitioner who can identify activities that are causing difficulties and advise on specific activities, adaptations to the home and the use of special equipment.

**Paediatrician** – A doctor who specialises in the care of babies and children.

**Physiotherapist** – A health practitioner 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 ways to carry, hold and position your child.

**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 and language therapist** – A practitioner who guides your child's communication development.

## Resources

- Please see below a list of resources you might find useful. Woodbine House publishes practical books for families and practitioners to help children and young people with Down syndrome. Some of these may be available to borrow from your local support group. The books include:
  - Skallerup, S., *Babies with Down syndrome: A New Parents' Guide* (2012)
  - Kumin, L., *Early communication skills for children with Down syndrome* (2003)
  - Levine, S., and Skotco, B., *Fasten your seatbelt: a crash course on Down syndrome for brothers and sisters* (2009)
  - Bruni, M., *Fine motor skills for children with Down syndrome* (2006)
  - Winders, P., *Gross motor skills in children with Down syndrome* (1997)
  - Chicoine, B., and McGuire, D., *Guide to good health for teens and adults with Down syndrome* (2010)
  - Kumin, L., *Helping children with Down syndrome communicate better, for children aged 6-14* (2008)
  - Chicoine, B., and McGuire, D., *Mental wellness in adults with Down syndrome* (2006)
  - Couwenhoven, T., *Teaching children with Down syndrome about their bodies, boundaries and sexuality* (2007)
  - Horstmeier, D., *Teaching math to people with Down syndrome and other hands-on learners* (2004)
  - Froehike, M., and Zaborek, R., *When Down syndrome and autism intersect: a guide to DS-ASD for parents and professionals* (2013)
- *Celebrating success*, a series providing children's case studies on early years, primary, secondary and further education, which are free to download. Down's Syndrome Association (DSA), [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)
- *Development in practice: activities for babies with Down syndrome* DVD. Down Syndrome Education International, [www.dseinternational.org](http://www.dseinternational.org)
- *Development in practice: speech and language activities for pre-school children with Down syndrome* DVD. Down Syndrome Education International, [www.dseinternational.org](http://www.dseinternational.org)
- *Down Syndrome education online*, a website offering information from a number of Down Syndrome Education International books, journals and past newsletters, much of which is freely available. Down Syndrome Education International, [www.down-syndrome.org](http://www.down-syndrome.org)

- *Down syndrome issues and information*, a series offering practical and informative books and ebooks on development, education and adult living for people with Down syndrome. Down Syndrome Education International, [www.dseinternational.org](http://www.dseinternational.org)
- Mills, S., *Down's syndrome – a new parent guide*, offering information for families and friends. Down's Syndrome Association (DSA), [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)
- Selikowitz, M., *Down syndrome – the facts*. Oxford University Press
- Education series of booklets. Down's Syndrome Association (DSA), [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk) or call 0333 1212300
- *Education support packs*, covering primary, secondary, further and special education, which are free to download. Down's Syndrome Association (DSA), [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk), or call 0333 1212 300
- Practical tools for a quality life for people with Down syndrome, by Joan Guthrie Medlan, [www.downsyndromenutrition.com](http://www.downsyndromenutrition.com)
- The *See and Learn* series, offering early teaching activities for language, reading and speech. Down Syndrome Education International, [www.dseinternational.org](http://www.dseinternational.org)
- Kerr-Edwards, L., and Scott, L., *Talking together about sex and relationships*. (2003) FPA, [www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships](http://www.fpa.org.uk/professionals/publicationsandresources/peoplewithlearningdisabilities/talkingtogetheraboutsexandrelationships)

### For siblings

- Levine, S., and Skotko, B., (2009) *Fasten your seatbelts: a crash course on Down syndrome for brothers and sisters*. Woodbine House
- For more recommendations on resources for siblings, contact the Down's Syndrome Association (DSA) at [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

### Parent discussion lists

DS-UK Email Forum - An email forum that provides an informal support network where parents of people with Down syndrome may exchange information and ask other parents for advice.

To subscribe to the DS-UK discussion list please go to: <http://listserv.down-syndrome.net/archives/ds-uk.html>

Or send an email to: [listserv@listserv.down-syndrome.net](mailto:listserv@listserv.down-syndrome.net) with the phrase 'subscribe DS-UK' in the body of the message.

DS-AUTISM-UK Email Forum - An email forum that provides an informal support network where parents of people with a dual diagnosis of Autism Spectrum Disorder and Down syndrome may exchange information and ask other parents for advice.

To subscribe to the DS-AUTISM-UK discussion list go to: <http://listserv.down-syndrome.net/archives/ds-autism-uk.html>

Or send an email to: [listserv@listserv.down-syndrome.net](mailto:listserv@listserv.down-syndrome.net) with the phrase 'subscribe DS-AUTISM-UK' in the body of the message.

Future of Downs Chat Forum - A forum set up and moderated by a parent with discussion boards covering different aspects of living with Down syndrome. To find out more please go to: [www.futureofdowns.com](http://www.futureofdowns.com)

Down's Heart Group Online Community - A contact point for families worldwide who have a member with Down Syndrome and associated congenital heart disease. This online community is linked to Down's Heart Group, a UK charity which provides support and information related to the cardiac issues associated with Down Syndrome. To find out more please go to: <http://groups.yahoo.com/group/Downs-Heart/>

### **Medical information**

- Medical information resources produced by Down Syndrome Medical Interest Group UK (DSMIG UK) – including the insert with extra pages for babies with Down syndrome to go in the parent held *Personal child health record* (PCHR) – are available from the Down's Syndrome Association, [www.down-syndrome.org.uk](http://www.down-syndrome.org.uk)
- A medical information series, written by DSMIG UK for the Down's Syndrome Association (DSA), is also available on the DSA website, [www.down-syndrome.org.uk](http://www.down-syndrome.org.uk) or call 0333 1212 300

## Useful organisations and websites

Please see below a range of organisations and their websites that you might find useful. There are a range of local organisations focused on Down syndrome that can be accessed, you could ask the practitioners you are working with what is available locally or contact the **DSA** for a full list.

### Association of Speech and Language Therapists in Independent Practice

Provides details of speech and language therapists in the UK who are in independent (private) practice.

[www.helpwithtalking.com](http://www.helpwithtalking.com)

### Carers UK

An organisation for carers in the UK.

[www.carersuk.org.uk](http://www.carersuk.org.uk)

0808 8087777

### Cerebra

Helps improve the lives of children with brain related conditions through research, education and directly supporting the children and their carers.

[www.cerebra.org.uk](http://www.cerebra.org.uk)

012 67244200

### Citizens Advice Bureau

Provides assistance with a variety of issues, including rights and entitlements, such as benefits, and debts.

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

08444 772020 (Wales)

08444 111444 (England)

### Citizens Advice Scotland

Provides assistance with a variety of issues, including rights and entitlements, such as benefits, and debts.

[www.cas.org.uk](http://www.cas.org.uk)

0808 8009060

### The Communication Trust

A coalition of nearly 50 voluntary and community organisations with expertise in speech, language and communication.

[www.thecommunicationtrust.org.uk](http://www.thecommunicationtrust.org.uk)

020 78432526

### Contact a Family

Support the families of disabled children whatever their condition or disability. They offer support, information and advice to over 340,000 families each year and campaign for families to receive a better deal.

[www.cafamily.org.uk](http://www.cafamily.org.uk)

0808 8083555

### Disability Rights UK

An organisation that offers information and advice to students with disabilities.

[www.disabilityrightsuk.org/disabledstudents.htm](http://www.disabilityrightsuk.org/disabledstudents.htm)

0800 3285050

### The Disabled Living Foundation

A national charity that provides impartial advice, information and training on daily living aids.

[www.dlf.org.uk](http://www.dlf.org.uk)

0845 1309177

### Down's Heart Group

A charity offering support and information relating to heart conditions associated with Down syndrome.

[www.dhg.org.uk](http://www.dhg.org.uk)

0844 2884800

### Down's Syndrome Association

A charity providing information and support on all aspects of living with Down syndrome in England, Wales and Northern Ireland.

[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

0333 1212300

### Down Syndrome Education International

UK-based international charity focused on scientific research and evidence-based advice and information to support effective early intervention, therapies and education for children with Down syndrome. [www.dseinternational.org](http://www.dseinternational.org)

0300 3300750

### Down Syndrome Health Issues

US website with medical information for parents on Down syndrome, by Dr Len Leshin.

[www.ds-health.com](http://www.ds-health.com)

### Down Syndrome Medical Interest Group UK

A medical group with members who share and disseminate information about the medical aspects of Down syndrome.

[www.dsmig.org.uk](http://www.dsmig.org.uk)

(Parent carer contact is by referral through the Down's Syndrome Association)

### Down's Syndrome Vision Research Unit

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

[www.cardiff.ac.uk](http://www.cardiff.ac.uk)

029 20876163

### ERIC

An organisation providing advice, support and resources around incontinence.

[www.eric.org.uk](http://www.eric.org.uk)

0845 3708008

### Family Fund

Provides financial help and grants for families with children who have additional needs.

[www.familyfund.org.uk](http://www.familyfund.org.uk)

0845 1304542

### Family Information Service

Provides a range of information for parents, including up-to-date details of local childcare and early years provision. You can find details about your local Family Information Service on the Daycare Trust website.

[www.daycaretrust.org.uk](http://www.daycaretrust.org.uk)

### Foundation for people with learning disabilities

Provides information for people with learning disabilities, their families and carers.

[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

020 78031100

### Handsel Trust

An independent organisation working to promote effective support for the families of children who have disabilities or additional needs. Their current focus is on sleep issues.

[www.handseltrust.org](http://www.handseltrust.org)

0212 3732747

### I CAN

Provides resources and information to support children's communication.

[www.ican.org.uk](http://www.ican.org.uk)

020 78432552

### IPSEA

Provides advice and support on all aspects of educational issues, including tribunal support.

[www.ipsea.org.uk](http://www.ipsea.org.uk)

0800 0184016

### The Makaton Charity

A charity providing information and training on the use of Makaton sign language.

[www.makaton.org](http://www.makaton.org)

01276 606760

### Mosaic Down Syndrome UK

Provides information and support for families with children who have mosaic Down syndrome.

[www.mosaicdownsyndrome.org](http://www.mosaicdownsyndrome.org)

### The National Autistic Society

Provides services, information, advice and support on all issues relating to autism spectrum disorders.

[www.autism.org.uk](http://www.autism.org.uk)

0808 8004104

### National Breastfeeding Line

A service connecting mums to other mums who have experience of breastfeeding and are able to offer information and support.

[www.nationalbreastfeedinghelpline.org.uk](http://www.nationalbreastfeedinghelpline.org.uk)

0300 100212

### National Childbirth Trust

Supports parents and gives accurate, impartial information so that they can decide what's best for their family. It also introduces parents to a network of local parents to gain practical and emotional support.

[www.nct.org.uk](http://www.nct.org.uk)

0300 3300700

### National Children's Bureau

Provides information and resources for supporting families, children and young people.

[www.ncb.org.uk](http://www.ncb.org.uk)

020 790891730

### National Deaf Children's Society

A charity for deaf children, young people and their families.

[www.ndcs.org.uk](http://www.ndcs.org.uk)

0808 8008880



### Parent Partnership Service

Provides impartial support for families with children with additional needs, particularly around educational issues.

[www.parentpartnership.org.uk](http://www.parentpartnership.org.uk)

020 78436058

### Pyramid Educational Consultants UK

An organisation providing training in the use of PECS.

[www.pecs.org.uk](http://www.pecs.org.uk)

01273 609555

### The Royal College of Speech and Language Therapists

Provides information about speech and language services in the UK.

[www.rcslt.org.uk](http://www.rcslt.org.uk)

020 73781200

### SALT independent practice

An organisation providing details of private speech and language therapists.

[www.helpwithtalking.com](http://www.helpwithtalking.com)

01494 488306 (answerphone)

### Scope

Works with disabled people and their families, they offer practical support – from information services to education and everyday care.

[www.scope.org.uk](http://www.scope.org.uk)

0808 8003333

### The Signalong Group

Provides information about the use of signing.

[www.signalong.org.uk](http://www.signalong.org.uk)

0845 4508422

### Special iApps

A non-profit social enterprise, dedicated to helping children learn.

[www.specialiapps.co.uk/en\\_gb/](http://www.specialiapps.co.uk/en_gb/)

### Symbol UK

An independent speech and language therapy service.

[www.symboluk.co.uk](http://www.symboluk.co.uk)

01795 844440

### Talking Mats

An organisation providing training and resources for using 'Talking Mats'.

[www.talkingmats.com](http://www.talkingmats.com)

01786 479511

## Glossary

**Additional needs** – The term used in this and other Early Support resources refers to any child or young person who has a condition, difficulty, challenge or special educational need, whether diagnosed or not, who is likely to need additional support beyond universal services.

**Adenoids** – The enlargement of the glandular tissue between the back of the nose and the throat.

**Amniocentesis** – A diagnostic test performed at around the 16th to 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** – A 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 that are used to treat infections caused by bacteria and other micro-organisms. Penicillin is one of the more common antibiotics prescribed.

**Astigmatism** – The distortion of vision resulting from light rays not meeting at a single point in the retina.

**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.

**Autism spectrum disorders (ASDs)** – 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.

**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, which is part of the developing placenta.

**Chromosome** – A thread-like structure carrying **genes**. They are contained within each cell of the body. The nucleus of each cell usually contains 23 pairs of chromosomes – 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** – An 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 and 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.

**Craniovertebral instability** – where certain vertebrae (bones in the spine) dislocate in such a way as to compress and damage the spinal cord. ‘

**Diarrhoea** – A condition in which faeces are passed frequently and in a liquid/loose form.

**Disability living allowance (DLA)** – A financial benefit available for disabled children (DLA is being replaced for people of working age 16 – 65 with the Personal Independence PIP – there are no current plans to replace DLA for 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.

**Electrocardiogram** – Is commonly used to detect abnormal heart rhythms and to investigate the cause of chest pains

**Eustachian tube** – A narrow tube that 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**).

**14+ Transition Review** – A school review meeting that coordinates planning for transition to adulthood.

**Gastro-oesophageal reflux** – A medical condition that occurs when food that 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** that is 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 mucus-like secretion builds up in the **middle ear** and reduces hearing levels, causing **conductive hearing loss**.

**GP** – A family doctor who deals with general health issues and can refer you on to clinics, hospitals and specialists when needed.

**Grommets** – A treatment for glue ear. They are tiny tubes with flanges at each end, which are inserted into the eardrum under general anaesthetic. They allow the mucus-like substance that causes glue ear 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** – See **heel prick test**.

**Health visitor** – A qualified nurse or midwife with 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 they are six to 10 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.

**Hypothyroidism** – Under-activity 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. It affects every baby differently.

**Infantile spasms** – A type of epilepsy in early childhood.

**Inner ear** – The part of the ear that is inside the skull and that includes the **cochlea**.

**Jejunal atresia** – See **duodenal atresia**.

**Karyotype** – A picture of the **chromosomes** in a cell, which is 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.

**Long-term memory** – The part of the memory involved in storing information over the longer term (for example, for days, weeks, months or years).

**Mainstream school** – Schools and early years settings, for example, 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**.

**Occupational therapist** – A health practitioner who can identify activities that are causing difficulties and can advise on specific activities, adaptations to the home and the use of special equipment.

**Oesophagus** – The tube connecting the throat to the stomach.

**Otitis media** – The 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.

**PECS** – An augmentative and alternative form of communication. Originally devised to teach people with autism the basic concept of communication, the system is built on established psychological principles (ABA – Applied Behaviour Analysis) which include shaping and reinforcement. Find out more information here: [www.communicationmatters.org.uk/page/pecs](http://www.communicationmatters.org.uk/page/pecs)

**Personal child health record (PCHR)** – The Personal Child Health Record (also known as the PCHR or 'Red Book') is a national standard health and development record given to parents/carers at a child's birth. This is the main record of a child's health and development; the parent carer retains the PCHR and health professionals should update the record each time the child is seen in a healthcare setting. Find out more information here: [www.rcpch.ac.uk/PCHR](http://www.rcpch.ac.uk/PCHR)

**Physiotherapist** – A health practitioner 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 ways to carry, hold and position your child.

**Portage service** – 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.

**Self talk** – When people talk to themselves out loud. This can be used to direct their own behaviour, think out loud, let off steam or entertain themselves.

**Sensori-neural hearing loss** – A hearing impairment caused by malfunction of the cochlea or nerves running from the cochlea to the brain.

**Sensory impairment team** – A team of practitioners who support children with hearing, visual or multi-sensory impairments.

**Short-sightedness** – Things seen more clearly close up than in the distance.

**Short-term memory (or working memory)** – The part of the memory involved in processing and storing information for short periods (for no longer than a few seconds).

**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 educational needs (SEN)** – The common term for the additional or different help that some children need to learn in an educational setting.

**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.

**Special educational needs (SEN) service** – The part of your local authority that provides services to children with special educational needs and deals with statements of special educational needs.

**Special schools** – Schools or early years settings that only provide services for children with learning disabilities and/or physical disabilities.

**Speech and language therapist** – A practitioner who guides your child's communication development.

**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. It is 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.

**Talking Mats** – A method for sorting through and choosing from a selection of words and pictures, to help a child tell you what they liked and what they didn't like.

**Thyroid** – A gland in the neck that produces a hormone that 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** – The most common form of Down syndrome in which all the cells in the body have an extra chromosome 21.

**Ultrasound** – High-frequency sound waves used to produce images of the inside of the body.

**Vertebrae** – The bones that form the spine or vertebral column.

**Working memory** – See **short-term memory**.



# Early Support

for children, young people and families

[www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport)

Funded by



Department  
for Education

We acknowledge with thanks  
the contribution of the  
following organisation in the  
production of this resource:



Co-producers of the original version:



© Crown copyright 2012

The text in this document (excluding the Royal Arms and other departmental or agency logos) may be reproduced free of charge in any format or medium providing it is reproduced accurately and not used in a misleading context.

The material must be acknowledged as Crown copyright and the title of the document specified.

Where we have identified any third party copyright material you will need to obtain permission from the copyright holders concerned.

For any other use of this material please contact the Office of Public Sector Information, Information Policy Team, Kew, Richmond, Surrey TW9 4DU or email: [licensing@opsi.gsi.gov.uk](mailto:licensing@opsi.gsi.gov.uk)

2<sup>nd</sup> edition