

# Early Support

for children, young people and families

## Information about cerebral palsy



## About this resource

This guide to cerebral palsy has been produced to provide general information, guidance and sign-posting for parent carers of children and young people diagnosed with cerebral palsy, or who are in the process of getting a diagnosis.

It has been developed in response to requests from families, professional agencies and voluntary organisations for better and more useful information to enable you to provide a stable and supportive environment for your child.

This refreshed version of the guide offers a range of information, including:

- Real life perspectives based on interviews with people with cerebral palsy sharing everyday experiences.
- A range of video content, which provides additional insight.

Families, young people and practitioners have been consulted about the content of this guide, and the format reflects what parent carers and others have said they would like to have known in the early days of finding out about their child's situation.

The content is not intended to provide in-depth information about the condition, treatments, therapies and practical management of the condition, although more detail is provided for certain key areas.

This resource was developed by **Scope** for **Early Support**.

### Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled 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 disabled 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: look them up in the **Glossary** at the back of the resource; find contact details for the organisation or agency

highlighted in the [Useful organisations and websites](#) section; or find out more in the [Who can help](#) section.

### Explanation of the term parent carer

In this resource the term 'parent carer' is used. It 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.

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## Cerebral palsy

This section begins to describe what cerebral palsy is. It sets out the different types of cerebral palsy, the language used to describe it and briefly outlines how this might affect your child. The section ends with video footage of adults with cerebral palsy sharing their thoughts and experiences.

### What is cerebral palsy?

Cerebral palsy, also commonly referred to as CP, is an umbrella term that describes a group of disorders caused by damage to the brain. It results in physical impairment affecting body movement, coordination, balance and posture. Cerebral palsy is neither contagious nor progressive.

Cerebral palsy does not affect every child in the same way. It is not a specific condition and does not have a single cause. There are different types of cerebral palsy, which are related to the part of the brain that has been affected. The effects vary from child to child and some children can have a combination of one or more of the different types of cerebral palsy.

Cerebral palsy is sometimes referred to as a 'developmental condition' because damage can occur during the prenatal, natal or postnatal periods (before, during or after birth). Sometimes other areas of the brain are involved, affecting vision, communication and learning.

Cerebral palsy is sometimes visible or noticeable at around the time of birth, or during early childhood. It is a wide-ranging condition and has many complex symptoms, with various types and degrees of **motor impairment**. No two children with cerebral palsy will be affected in quite the same way – your child is an individual and their pattern of development will be their own.

Cerebral palsy cannot be cured, although early support and therapeutic interventions can help with a child's development. It does not normally affect life expectancy.

The symptoms of cerebral palsy include an early change in muscle tone. Muscle tone is measured by the amount of resistance there is to a stretch on a muscle. Low muscle tone means the affected area feels floppy. This is called **hypotonia**. High muscle tone means the muscle feels stiff – this is **hypertonia** or spasticity.

Although cerebral palsy is divided into different types, there are a number of physical symptoms that each type has in common, which include abnormal muscle tone, altered reflexes, spasticity and difficulty in muscle control. Movements may be jerky or slow.

Cerebral palsy is the most common physical impairment in childhood. Current estimates suggest that one in every 400 children is affected by cerebral palsy. This means about 1,800 babies are diagnosed with cerebral palsy in the UK every year. Cerebral palsy affects people from all social backgrounds and ethnic groups.

*“Never let having cerebral palsy get in the way of what you want to do.”* Nicolas Hamilton, racing driver

## What causes cerebral palsy?

It is often not possible for doctors to explain exactly why part of the brain has been damaged or has failed to develop, as there may be no obvious or single reason. Cerebral palsy can be caused by multiple and complex factors, although the cause in a number of cases is unknown. Relevant factors that can lead to cerebral palsy include:

- infection in the early part of pregnancy
- premature birth – pre-term babies are extremely vulnerable and at risk of haemorrhage, infection and oxygen deprivation to the brain. A third of babies born prematurely go on to develop cerebral palsy. There is also an increased risk of cerebral palsy in premature babies with a birth weight of under 500g.
- a difficult birth, which can cause injury to the baby’s head, and if a baby has difficulty breathing there is sometimes a risk that not enough oxygen reaches their brain
- illness or injury after birth – this can include the effects of other conditions or illnesses, such as meningitis and hydrocephalus, a head injury, very high fever or a lack of oxygen from choking or near-miss cot death
- genetic links, although this is very rare

## Types of cerebral palsy

Cerebral palsy affects the messages sent between the brain and muscles in the body. There are essentially four categories of cerebral palsy, which are:

- spastic
- athetoid (or dyskinetic)
- ataxic
- mixed

In general, these types relate to the part of the brain that has been damaged or affected. The effects of cerebral palsy vary enormously from one person to another, with some people experiencing a combination of two or more types, known as ‘mixed’ cerebral palsy.

### Spastic cerebral palsy

The word **spastic** really means ‘stiff’ and relates to muscle tone – i.e. the muscles are stiff with increased levels of spasm. This form of cerebral palsy can decrease the range of movement anywhere in the body, including the joints affecting walking and coordination.

**Spastic** cerebral palsy is caused by impairment of the brain. Spasticity is the most common form of cerebral palsy, occurring in 70-80% of people affected.

A child with **spastic** cerebral palsy has to work hard to walk or move. Spasticity can affect different areas of the body and, like other types of cerebral palsy, may affect how clearly children can speak. The effects may increase with anxiety or increased effort, leading to excessive fatigue.

Sometimes **spastic** cerebral palsy is grouped and described according to the parts of the body that are affected: when all four limbs are affected, this is known as 'quadriplegia'; if it affects only one side of the body, this is known as 'hemiplegia'; and if mainly the legs are affected, this is known as 'diplegia'.

The National Institute of Clinical Excellence (NICE) has produced guidelines on the management of spasticity. To download the resource please visit <http://guidance.nice.org.uk/CG145/NICEGuidance/pdf/English>.

### **Athetoid (or dyskinetic) cerebral palsy**

This type of cerebral palsy causes involuntary movements due to lack of control in the way that muscle tone changes from floppy and loose to tense and stiff. It can result in difficulty maintaining any position. Speech can also be hard to understand due to difficulty in controlling the tongue, breathing and the use of vocal cords. Hearing problems can be associated with athetoid cerebral palsy, too. This type of cerebral palsy occurs in about 15% of people affected.

A child with **athetoid** cerebral palsy is rarely still – they have too much movement. As soon as they try to initiate a movement or thought, their body will start to move. Effort or intention to move of any sort tends to increase movement.

### **Ataxic cerebral palsy**

**Ataxic** cerebral palsy affects the whole body – all four limbs and the trunk are usually affected. This results in poor spatial awareness and difficulty in judging body position in relation to the physical environment.

**Ataxic** cerebral palsy impairs coordination and balance. It is a relatively rare form, affecting about 4% of people with cerebral palsy.

Children with **ataxic** cerebral palsy find it very difficult to balance. Most children with **ataxic** cerebral palsy can walk, but they are often unsteady. They may also have shaky hand movements and irregular speech. Some of the patterns of **ataxia** can appear similar to children with **athetoid** cerebral palsy.

## Mixed cerebral palsy

The types and descriptions of cerebral palsy above do not always describe adequately the individual nature of cerebral palsy. Individuals can often experience a mix of types of cerebral palsy.

## Other terms and language

There are a number of other words that are sometimes used to describe cerebral palsy.

These include:

- **hypertonia** – high muscle tone leading to stiffness
- **hypotonia** – low muscle tone leading to floppiness
- **dystonia** – when muscle tone fluctuates between stiffness and floppiness
- **rigidity** – sustained stiffness of a limb
- **spasm** – involuntary contraction of a muscle
- **tremor** – rhythmic, uncontrolled, repetitive movements
- **minimal or mild cerebral palsy** – when there may be little obvious physical impairment, but children experience poor coordination and ‘clumsiness’ that can be associated with some learning difficulties

Cerebral palsy is sometimes grouped and described according to the area of the body or the number of limbs involved. The following terms are most commonly used:

- **Diplegia** – This describes cerebral palsy that mainly affects a child’s arms or legs. Children with diplegia may also have subtle or mild muscle tone problems in the upper part of their body, but they have sufficient control for most daily activities.
- **Hemiplegia** – This means only one side of the body is affected. Childhood hemiplegia is a relatively common condition, affecting up to one child in 1,000. For further information see below.
- **Quadriplegia** – This means cerebral palsy affects a child’s arms and legs. Quadriplegia can also affect the trunk, neck and face muscles.

It is important to remember that these categories simply describe where in the body cerebral palsy influences muscle control. They do not tell you anything about how severely the different parts of your child’s body are affected.

## Hemiplegia

Hemiplegia is a condition affecting one side of the body – it is often referred to as ‘right sided’ or ‘left sided’, depending on the side of the body that is affected. Generally injury to the left side of the brain results in right hemiplegia and injury to the right side of the brain in left hemiplegia. Sensory loss in the affected arm or leg is common in nearly half of children

who have hemiplegia and can contribute to difficulties, particularly in using the affected limb.

Parent carers usually become aware that something is affecting their child during the first years of life. 'Acquired hemiplegia' results from damage to the brain at some point in childhood. The most common cause of damage after birth is a stroke (also known as a cerebral thrombosis), but it can also result from an accident or infection.

The charity **HemiHelp** offers information and support to children and young people with hemiplegia, their families and those working with them. It produces a large range of fact sheets, many of which can be downloaded from its website, or you can call its helpline for support.

### Video link – Speaking for ourselves: interviews

Listen to the different perspectives of adults with cerebral palsy as they share their experiences and thoughts on diagnosis, education and attitudes to disability.

[www.scope.org.uk/help-and-information/education/speaking-ourselves](http://www.scope.org.uk/help-and-information/education/speaking-ourselves)



## In the beginning

In this section you will find information to help you understand the process of diagnosis and brief details of some of the other conditions and impairments that are associated with cerebral palsy.

### Finding out your child has cerebral palsy

Finding out your child has cerebral palsy is almost always unexpected and often devastating. Parent carers often say that they bounce between feeling they need to hold on to their child and never let them go, and wanting to run away. This is normal – it takes time to absorb the news. Some people take a long time to adjust to their new family situation, others do not. There is no right or wrong way to do this and no hard and fast rules for how you might or should feel.

*“It’s OK to feel completely upset, confused and angry... You have to go through an almost grieving process, as all of us have our own aspirations for our babies.”* Parent

*“My advice to other parents would be to take it one day at a time.”* Parent

What is important is that you take whatever time you need to express and work through your feelings – different people come to terms with their new situation in different ways and in their own time.

*“They said, ‘Look after yourself as well as the baby.’ Looking back now, I can see how important that advice was.”* Parent

It can be difficult for your doctor or **paediatrician** to diagnose cerebral palsy in the first months or even years of a child’s life. Parent carers are often the first to notice signs of a brain injury in their child. For example, once a baby reaches six months it usually becomes apparent that they are not picking up the usual motor skills, that they are not sitting up properly, or that they show an unusual tendency to stand on their toes.

Sometimes if you go to your consultant with these concerns, they are able to diagnose cerebral palsy straight away. However, they may not like to start talking about cerebral palsy too quickly and you may hear broader terms like ‘motor delay’ or ‘developmental delay’ being used.

This is because a young child’s central nervous system can recover after injury – the brains of very young children have a much greater capacity to repair themselves than adult brains do. When a brain injury occurs early, the undamaged part of the child’s brain sometimes develops to take over some of the functions of the damaged areas. This is often referred to as the plasticity of the brain.

The brain is ‘immature’ until around the age of five or six, so some doctors monitor the child during the early years before giving a final diagnosis of cerebral palsy. This avoids making predictions too early about the long-term effects of your baby’s impairments and the impact it could have on their lives.

However, therapeutic intervention, such as physiotherapy, can be very beneficial to young children in helping to improve muscle tone, manage movement and ensure correct positioning. This will help maximise your child's potential.

## Diagnosis

During the diagnosis, you may feel overwhelmed by the amount of new terminology you have to deal with, particularly in the early days when you are beginning to understand your child's condition. Voluntary organisations and other parent carers will be able to give you information and direct you to services that can help. You should always feel able to ask questions or seek other opinions if you feel uncertain about what's happening.

The diagnosis of cerebral palsy is made largely through clinical observations, as well as other tests and neuroimaging, such as MRI scans. The approach most widely used by clinicians is to rate activity limitation based on a standardised measure of motor function, for example, the Gross Motor Function Classification System (GMFCS). This system classifies children according to their mobility, from level one, indicating good motor skills, walking and balance, to level five, where children need to use a wheelchair in all settings and may need help in controlling posture.

To confirm a diagnosis of cerebral palsy, clinicians will use brain imaging techniques, such as an electroencephalogram (EEG) or magnetic resonance imaging (MRI), which allow them to see brain abnormalities. These tests provide clues to the pattern and severity of the brain injury underlying cerebral palsy, and the motor problems that may occur.

The particular test used will be based on an assessment of the patient's symptoms. It is important to note that in about 10% of cases, a child can be diagnosed with cerebral palsy but nothing will show on the MRI scan. Also MRI scan results do not accurately predict the level of motor ability that a child will achieve.

Debate exists over the best time to diagnose cerebral palsy. Issues surrounding the timeliness of diagnosis focus on three areas:

- **Early diagnosis** – This can lead to early intervention, treatments, therapies, funding and benefit programmes. It can also result in misdiagnosis.
- **Delayed diagnosis** – A delay in diagnosis can allow time for the family to bond before the condition is known. It allows time to observe developmental milestones, rule out other conditions and confidently confirm cerebral palsy.
- **Misdiagnosis** – This can occur if signs are not properly monitored, tested and confirmed, or when other conditions are not properly ruled out. The diagnosis of cerebral palsy may be correct, but the severity, extent, or other mitigating factors may be improperly diagnosed.

Cerebral palsy cannot be 'cured', although early support and therapeutic intervention can help a child's development. If children are positioned well from an early age and encouraged to move in a way that helps them to improve their posture and muscle control,

this support will help them to develop, achieve and become more independent. There are also a number of therapies that help some children.

## Associated conditions

Children with cerebral palsy sometimes have other associated difficulties. However, while certain conditions do occur more frequently in children with cerebral palsy, your child may not have any of the associated conditions described in this section. Some babies with cerebral palsy are born prematurely and have breathing difficulties. Most babies with cerebral palsy improve as time goes on, but these first months can be very worrying for parent carers.

You will see your [neonatologist](#) or [paediatrician](#) during this time. As your child grows, you may also be referred to other specialists, such as [physiotherapists](#), [speech and language therapists](#), [audiologists](#) or [occupational therapists](#).

## Epilepsy

Some children with cerebral palsy can develop epilepsy, which may be managed and controlled through medication and/or diet. For organisations that provide further information about epilepsy turn to the [Useful organisations and websites](#) section. The [Epilepsy Action](#) website and [British Epilepsy Society](#) offer comprehensive resources.

## Learning difficulties

Children with cerebral palsy can have associated learning difficulties. These can include the following:

- **Specific learning difficulties** – This is when a child has difficulty learning because they experience a challenge processing particular types of information. These processing difficulties may affect particular skill areas, for example learning to read or spell, however they do not affect a child's overall level of intelligence.
- **Severe learning disability** – This results from extensive damage to the brain and can lead to more general difficulties. The areas of the brain influencing the development of language and intellectual functioning may be affected, not only the areas controlling movement.

Do not assume that if your child has a severe physical impairment, they will also have a learning difficulty or learning disability; this is not necessarily the case. It is important to remember that every child is an individual and their personal circumstances will differ from others.

Environmental factors can also lead to increased challenges and difficulties for children with cerebral palsy. For example, learning opportunities may be more limited if a child has difficulty moving or speaking. They will invariably rely upon the adults around them to

create a learning environment that helps them develop and grow. There is a lot you can do to help a child in this situation.

### **Visual or spatial perception difficulties**

Although there may be nothing wrong with the vision of a child with cerebral palsy, their brain can have difficulty interpreting and making sense of the visual information it receives. We use spatial awareness to work out where we are in relation to objects and the other people around us. Visual-perceptual difficulties can affect the following:

- **Body perception** – This is the overall awareness of body parts, posture, balance and movement.
- **Vision** – The ability to focus, to follow and scan objects or text, or to give a name to what is seen can be particularly affected. This can often be mistaken for a communication or vocabulary problem.
- **Learning to read** – The words can appear backwards or with an inconsistent pattern.
- **Perceptual motor skills** – These enable children to judge where their bodies are in space and to estimate the distance, time or speed of objects moving towards or away from our bodies.

### **Visual-motor difficulties (difficulty combining movement with vision)**

Children with cerebral palsy who are affected in this way can find it more difficult to plan their movements (i.e. work out exactly which steps are needed to complete a task) or to carry out the movements needed to complete a task automatically. They may appear to be unusually slow, awkward or inefficient when they need to use fine motor movements or hand-eye coordination. Some children who are affected in this way experience particular difficulty with 'midline crossing', that is, reaching one hand to the opposite side of the body before using it.

### **Sensory impairment**

Children with cerebral palsy may have additional impairments that affect their hearing, vision, touch, taste and/or smell. In some situations, there can be damage to the visual cortex of the brain resulting in impaired vision, even though there is no damage to the eye itself. Hearing impairment can occur in around 8% of children with cerebral palsy.

For organisations offering further information about associated conditions and impairments, go to the [Useful organisations and websites](#) section in this booklet.

## Early Years

This section provides information and tips to help you build a relationship with your child, with a focus on the importance of communication. The section ends with a link to a video of a parent sharing her personal experience at the time of diagnosis.

### Understanding your child's needs

Children with cerebral palsy are children first and foremost, and it's important to remember that they are all affected in different ways. Children with cerebral palsy can have average or above average intelligence, but some have a significant learning difficulty.

Some children will learn to talk, sit up and walk, although they may take longer to develop than other children of the same age, while others will always need a high level of support in a number of different areas of their lives. The range is wide and it is important to understand that some children are very severely affected.

Injuries to the brain do not get worse as a child gets older, although some of the effects on the muscles and joints do get worse as a child grows. On the other hand, children sometimes get better at understanding and learning to deal with the effects of their cerebral palsy as they get older.

Cerebral palsy cannot be 'cured', although early support and therapeutic intervention can help a child's development. If children are positioned well from an early age and are encouraged to move in a way that helps them to improve their posture and muscle control, this support will help them to develop, achieve and become more independent.

### Building a relationship with your child

Communication is at the very centre of our lives. It expresses our identity as individuals and allows us to develop relationships with other people. Communication happens in many different ways, for example, using hands, eye contact, body language, crying and laughing. Newborn babies are already able to communicate and very soon they can tell you whether they are happy or sad, hungry or thirsty. Parent carers often understand their baby by the type of crying, body language and gestures that their child uses.

Many children with cerebral palsy experience difficulties with communication and it is good to seek advice as early as possible from a **speech and language therapist**, as well as from a **physiotherapist** and **occupational therapist**.

You can find your local speech and language therapy department here - [www.talkingpoint.org.uk/talkinglinks](http://www.talkingpoint.org.uk/talkinglinks)

## Encouraging communication

Here are some practical tips on how to encourage communication:

- Talk all the time. Tell your child what you are doing, what is happening around you, what objects are, etc.
- Hold your child's hand, touch their face, call their name and help them to turn to you.
- Encourage eye contact. Good eye contact helps your child pick up more information about meaning from your facial expressions and gestures. If necessary, gently move your child's head to look at you or towards an object you are looking at.
- Try to extend your child's attention span. A good attention span is important for learning language and for understanding.
- Talk, sing, and make faces and noises to encourage your child to do the same; respond to any sound your child makes, for example, by pausing, looking at them and imitating the sound.
- Always allow your child plenty of time to respond to your communication or express something of their own, rather than jumping in too soon or anticipating what they want.
- Praise your child when they make an attempt to communicate. Try to reward them immediately – perhaps with a cuddle or by clapping.
- Use natural gestures as much as possible when you talk to your child. Children learn simple gestures before they use words – for example, waving bye-bye.
- Above all, try to make communication fun for both of you!

## Yes and no

The ability to indicate 'yes' and 'no' is a basic communication skill that empowers a child to communicate what they want and do not want, and what they like and do not like. Some children are not able to nod or shake their head, but can make other signals to indicate their choice, for example, by sticking their tongue out for 'no'. You need a reliable and consistent method.

Learning how to indicate 'yes' and 'no' is one of the first keys to communicating with your child. Once this is established, you will find that you can begin to communicate with your child and that they will begin to be able to respond to your questions.

## Choice and control

Offering choices teaches children that they can take control of the world around them and encourages them to communicate. It is one of the most important areas of development in early communication. Try to offer choice whenever you can.

Your child may only be able to communicate choice by looking at what they want, reaching for it or pointing to it. Later on they may develop words or phrases to choose what they want. Here are some tips to encourage your child to make choices:

- Show your child the objects they can choose between and try to include choice in everyday routines. For example, when dressing your child, you might ask, “Do you want the red jumper or the blue one?” and show both.
- At first children may seem unwilling or unable to make choices. Try giving choices about something you know your child likes, for example, food or drink.
- After showing the objects, you must take whichever one your child chooses, even if you know it’s likely that they actually prefer the other one.
- Mark and reinforce the choice. For example, you might say, “Well done, you looked at the milk, so you’ll have milk today.”
- Be consistent and soon your child will learn what choice means and how they can communicate what they want.

### **Good positioning for communication**

Children need to be in a safe, supported position that helps hip, trunk, head and neck control when they are communicating with other people. For some children, this involves using specialist seating. They need to be able to see what or who they are looking at and may need to be able to use a hand to point. Check that the sun or electric lights are not shining into their eyes.

When supportive seating is being introduced for the first time, keep sessions short and fun, and gradually extend their length over a period of time. An **occupational therapist** or **physiotherapist** will be able to advise you about supportive seating, which will help your child to sit in a good position and use their limbs in the best way.

For organisations offering further information about communicating with your child, go to the **Useful organisations and websites** section in this booklet and see **Communication Matters**, **I CAN** and **Afasic**.

### Video link – Jo and Leila’s story

Jo describes her experience following Leila’s diagnosis. Find out how Jo accessed the information she needed to be able to look forward to a brighter future for her and Leila:

[www.scope.org.uk/help-and-information](http://www.scope.org.uk/help-and-information)



## General information

This section looks at everyday activities and offers some practical tips and suggestions on how you might support your child with their daily routines and activities.

### Everyday life with your child

All children need love, security, fun, encouragement and the opportunity to learn about the world around them. Children with cerebral palsy are no different and it is important to encourage your child to take part in everyday and family life in as many ways as you can.

It will help if you and your friends and family treat your child in the same way as any other child – although this may be difficult and the urge to protect them may be very strong. The more you encourage other people to get to know your child, the easier it will be when the time comes for them to settle in at a nursery or school.

Everyday life for a child with cerebral palsy can be challenging and demanding. Depending on the level of cerebral palsy the child has, handling mealtimes, dressing, toileting and bedtime can be quite exhausting and time-consuming. As hard as it may be for you, remember that your child must at all times feel and be treated like a child. Helping them to make sense of the world around them despite their additional needs is paramount.

Some babies and young children with cerebral palsy are not able to communicate easily. For example, they may not be able to turn their heads or move their eyes as other young children do, and they cannot reach out and touch you or climb on to your knee. Try to communicate with your child as much as possible. The more you talk, look and touch, the more you will learn to recognise what your child is trying to tell you. Here are some suggestions to assist you:

- Remember that children are children whatever the differences.
- Use consistent language.
- Consider how many key words a child may understand in a sentence.
- Use body language, facial expressions and so on.
- Make it a fun experience for both you and your child.
- Consider your child's attention span.
- Work on developing eye contact.

Here, young people with cerebral palsy talk about their everyday lives:

*“Having CP does have an impact. Not walking makes travelling harder. But I still choose what I want to do, how I look, what music I listen to, whether to go to college, concerts, etc.”*

*“I use a wheelchair and **Dynavox**. I use a wheelchair to get about and a Dynavox to speak. I also have a gastrostomy [PEG] to help me eat.”*

*“CP affects the left side of my body – I cannot sit up properly. My legs do not work. I use a Powerchair – it can be annoying in my manual [chair] because I feel trapped. The Powerchair makes a big difference. My wheels are my legs.”*

*“I can get fed up and down, but I just deal with it. I have had CP for so long I just live with it – try to make it not the most important thing and see myself as a ‘normal’ person.”*

*“If you’ve got CP don’t get down just carry on with normal life – just because you’ve got a disability, you are still a normal human being. Keep fighting.”*

## Speech, language and communication

Six out of 10 children with cerebral palsy will have difficulty with speech, language and communication. Children with **athetoid cerebral palsy** are more likely to have such difficulties. It is important that children’s needs are seen and treated as a priority; without any form of communication, children will have great problems with their education.

Many children with cerebral palsy will have speech difficulties. Some children have difficulty articulating particular speech sounds, while other children cannot make themselves understood at all.

Language is different from speech. Some children with a speech and associated communication problems have excellent language – in other words, they know exactly what they want to say, but have difficulty saying it. Some children understand everything that is being said to them but are unable to communicate.

Most of us communicate through spoken language. We do not use other methods of communicating, such as signs, symbols, hand-eye pointing and facial expression very much. This is called unaided communication. It does not involve any external materials or equipment, since for most of us the ability to communicate develops gradually and unconsciously.

Some children with cerebral palsy are not able to use unaided communication, but still want and need to express the same range of thoughts and feelings as other people, albeit in a modified manner. They need a reliable system to signal their own meanings and to indicate when they have understood what other people say to them.

**Augmentative and alternative communication (AAC)** describes different methods of communication which includes a whole range of ‘low-tech’ techniques, symbols and strategies that support the spoken element of communication and help children to communicate better. AAC offers a range of ways of replacing spoken words. It can range from a movement or behaviour, to the use of a more formal code agreed between people, where different items have specific meanings.

There are different vocabularies and languages to choose from, so the child can use the most appropriate system.

For more information please see **Communication Matters** in the [Useful organisations and websites](#) section.

It is really important that you think about communication as early as possible. Your child may go on to develop good speech, but anything you can do early on to ensure that they interact and communicate well with a widening circle of people will be of immense value to them later in life.

Remember also your child's impairment is only one aspect of their identity or experience. You may not have English as your home language and it is important to ensure that your child's rich language heritage is acknowledged and supported too.

## **Other forms of communication**

Finding the most suitable communication system for a child with little or no speech can be difficult. Do not assume that a child who cannot speak cannot understand you or communicate as this may not be the case.

### **Sign language**

Your **speech and language therapist** may suggest that you start to use simple sign language with your child – signing whilst speaking has been shown to encourage the development of communication and language skills. It can also help you to understand what your child wants and needs.

If the **speech and language therapist** recommends sign language, they will explain the system your child could use. Ask how they expect the signs you use will help your child. For example, will they help your child to understand more? Will the signs help them talk back to you using hands?

If the therapist is expecting the child to use signing as a way of talking, you will need to involve the **physiotherapist** to make sure that your child's hands will be flexible enough to make signs. If the therapist does not think your child's hands can be used for signing, you will need to think about using other communication methods such as using pictures instead.

### **Symbol systems**

Symbol systems that use pictures a child can point to can reduce frustration, even for children with very little control of movement. Any work done with pictures and symbols early on can be useful should the child need more advanced technological aids to communication later on.

### **Objects of reference**

This system uses objects to convey meaning. For example, a spoon attached to a photo of lunch might be used to mean 'lunchtime'. Again, a **speech and language therapist** will explain this to you if they think this would help your child.

## Communication passport

This is a simple yet effective support for children who use an alternative means to communicate independently with people. The passport introduces the child to everyone they meet and provides practical information about how best to communicate.

Communication passports are particularly useful when children get a bit older and begin to attend playgroups and nurseries, and then school.

Communication passports can be used for any non-verbal child or adult of any age. They contain personal information about your child's needs, how they indicate 'yes' or 'no', and so on. They value children and give them a voice, as well as helping other people to understand your child's needs.

They should be reviewed at least once a year, or every six months if the child is very young. The passport should go everywhere with the child, especially when they attend anywhere for the first time, such as a nursery or school.

## Technological devices

There are many different types of **voice output communication aids (VOCAs)** available. They range from equipment that will speak one response, to sophisticated displays that change when you select a button.

Your child may need a VOCA as well as signing or symbols. Careful assessment is needed to ensure your child's individual needs are met before the right device can be selected. A **speech and language therapist** will be able to offer you advice.

Please see the resource ***Other Ways of Speaking*** in the **Useful resources** section for more information on different methods of communication.

### Video link – No voice, no choice

This video clip looks at the experiences of people with additional needs who use alternative and augmentative communication (AAC), their families and the practitioners who work with them:

[www.scope.org.uk/help-and-information/communication](http://www.scope.org.uk/help-and-information/communication)



## Supporting your child with their personal care

This section describes some of the types of personal care that may be required by your child. It offers a series of tips to help you provide that extra support when necessary, whilst promoting independence and individuality.

### Handling your child

'Handling' means how you lift, carry, hold and position your child, and what you learn to do to help them with muscle stiffness, or with the uncontrolled muscle movements they experience. The best way to handle a baby or child will depend on how old they are, what type of cerebral palsy they have and how their body is affected.

**Physiotherapists** can advise you in this area. For example, they can tell you how to carry your child in a way that helps them develop more control over their body and prevents you from straining or injuring your back. It is important to build your child's exercise and positioning programme into the day; this is because frequent repetition helps them to develop and learn more controlled movement.

In general, try to position your baby so they can see what's going on around them. Before trying any new movements or methods always seek the opinion of your paediatrician, doctor or therapist. There may be some positions that are best avoided.

Here are some practical tips on handling:

- Try not to move your child suddenly or jerkily as their muscles need time to respond to changes in position. Give them time to make their own adjustments as they move; support them if necessary, but wait and give them time to do as much as possible by themselves.
- Some baby's muscles tense (spasm). Let tense muscles relax in their own time – don't force movements.
- Fear often makes spasms worse, so give your child as much support as they need when you're moving them, but be careful not to give more support than is needed.
- Even if your child is very small or has severe difficulties, try to make sure they spend time in different positions.
- Some children need to be positioned and supported in good positions throughout the day; this is called a 24 hour postural management programme. Adapted equipment is available to help with this. Your **physiotherapist** or **occupational therapist** will assess your child and advise you about this. They will work with you and other people involved with your child to find the best way to help your child's movement and posture.

## Getting your child dressed

Getting dressed can sometimes be difficult for children with cerebral palsy. Make sure their clothes are within easy reach when you help them with this. If your child is interested, they will be more cooperative. Talk to them and encourage them to do things for themselves, even if things take a lot longer. Give lots of praise for every achievement, however small.

Here are some practical tips on dressing:

- Choose loose, comfortable clothing.
- Velcro and elastic may be easier to manage than buttons and zips, and you may want to find out about clothing that is designed specifically for disabled children. [The Disabled Living Foundation](#) can help you locate manufacturers and retailers of specialist clothing and equipment.
- Put the clothes on the most affected part of the body first – for example, the most affected arm through the sleeve first.
- All children should wear well-fitting footwear. Some children with cerebral palsy need specialised supportive shoes, which are usually provided free of charge by your health authority. Your doctor or [physiotherapist](#) can advise you about this.
- If you bend your child's legs before putting socks and shoes on it may help to ease any stiffness in their ankles and feet, and make toes less likely to curl under too. Your [physiotherapist](#) will show you how to do this effectively and safely.

## Assisting your child with going to the toilet

It is difficult to provide general advice about toileting, because cerebral palsy affects children in such different ways. The degree to which children can be responsible for their own toileting varies greatly. Some children, particularly those with severe or multiple impairments, never achieve full independence in this area of their personal care. However, just mastering some of the skills needed can give children more dignity and improve their self-esteem.

Children normally achieve daytime freedom from nappies at two or three years of age. Children with cerebral palsy may experience a number of additional challenges that mean they aren't ready to start learning toileting skills until much later, but this does not apply to every child who has cerebral palsy. Some children need to have the correct type of toilet seat or support to enable them to relax and establish normal function.

Before starting on the process of trying to toilet-train your child, it is wise to talk to your doctor to see if they are aware of any aspects of your child's condition that will affect their ability to control bladder or bowel movements. If cerebral palsy affects them in ways that mean they may be unable to feel when they need to use the toilet or to control the muscles needed to regulate the passing of urine or faeces, it is best to seek specialist advice on how to manage their continence.

Some children with cerebral palsy experience problems with constipation that makes passing faeces extremely difficult or painful. In this situation, it may be wise to try to find a solution before toilet-training. Your family doctor may advise on medication or changes to diet that may help alleviate the constipation, or refer you to a **paediatrician** or **dietician**.

If there are no medical concerns about starting toilet-training, it is worth spending a few days noting when your child naturally urinates and passes faeces. For more information visit [www.scope.org.uk/help-and-information/cerebral-palsy/developing-independent-toileting-skills](http://www.scope.org.uk/help-and-information/cerebral-palsy/developing-independent-toileting-skills).

Here are some practical tips on toileting:

- It is important to ensure that your child feels safe when using the toilet or a potty.
- If your child has particular problems maintaining a sitting position, ask about specialist equipment and where you can get advice.
- An **occupational therapist** is a good source of information on suitable equipment and how to get hold of what you need.
- If other people are involved in the day-to-day care of your child, it's sensible to talk to them about how you are planning to toilet-train your child so that everyone is using the same approach.
- If after a reasonable period of trying little progress is being made with toilet-training, seek professional help. You can also contact the charitable organisation **ERIC**, which offers specialist advice and support on continence.

### **Supporting your child with their dental care**

When children have difficulties eating, food can easily get stuck in their teeth and gums, and this can lead to tooth decay and gum disease. Try to help your child brush their teeth after every meal and cut down on sugary food and drink. It's important to take your child to the dentist regularly.

If your child's condition makes brushing difficult, your dentist may be able to advise you about a special mouthwash. Here are some practical tips on dental care:

- Even before your baby's first teeth have come through, get them used to you looking in their mouth and touching their gums.
- Brush their teeth regularly, ideally after every meal.
- Give lots of praise when brushing your child's teeth to reinforce it as a positive experience.
- Ensure your child is well positioned so that you're both comfortable and your child's head is well supported.
- If possible sit your child in front of a mirror when you brush their teeth as this helps to show them what needs to be done.
- Some children much prefer the texture of an electric toothbrush.

*“People need to talk to me first and make sure I am comfortable – I need personal care in a certain way or it will hurt. I am OK telling people what I want.”* Young person

## Equipment

Many children with cerebral palsy will require equipment to support them with everyday life. This can include a wide range of aids and adaptations around the house, such as standing frames, supportive seating hoists, bath chairs, slings, walkers and communication devices. It is always best to ask for specialist advice before getting any equipment for your child; check what is most likely to help and always check if the equipment you need can be provided free of charge.

An individual assessment is essential, as the most appropriate equipment can only be provided if your child’s particular needs have been identified. A number of factors are usually considered when an assessment is made, including:

- the nature and impact of cerebral palsy on your child
- the disabling barriers facing a child in their daily life
- appropriate solutions to overcome these barriers

You might choose to buy additional equipment and aids that are not supplied by social services, health services or (later) educational services. [Disabled Living centres](#) and a number of charities operate as specialist suppliers of equipment. They can usually provide opportunities for you to see and test out equipment before you buy anything. Not all centres have equipment for children, so it is a good idea to contact your nearest centre and ask whether they can help you before visiting.

The [Disabled Living Foundation](#) helpline provides advice on equipment and gadgets, and where to find them. It can also direct you to other organisations providing related information. The Disability Equipment Register is a service that enables disabled people and their families to buy, sell or exchange equipment.

Here young people with cerebral palsy talk about their aids, adaptations and equipment:

*“In my house I have a toilet chair, a hoist and sling, and my bed can be lowered up and down. I use a communication aid and a head mouse. I use a wheelchair – one manual, one powerchair, which I prefer.”*

*“I have a chair that has head switches so I can drive myself.”*

*“I have environmental controls – automatic doors, ramps. All things to make getting around and doing things easier.”*

*“I have to wear splints at home and school. At first it was really awkward and my friends thought it strange, but they come in lots of different colours and patterns. Next time I am getting some pink ones to match my trainers.”*

## Early intervention – therapies and approaches

This section looks at the key types of practitioners that are available to support you and your child, along with approaches that may be useful in enabling you and your child to maximise choice, control and independence.

There are a number of different approaches to the physical management of cerebral palsy. Because the impact of cerebral palsy on individual children varies so widely, some children benefit from particular treatments and therapies and others do not.

Some children with cerebral palsy will receive an initial assessment through the **Common Assessment Framework (CAF)** process. For more information visit [www.education.gov.uk/childrenandyoungpeople/strategy/integratedworking/caf](http://www.education.gov.uk/childrenandyoungpeople/strategy/integratedworking/caf).

This aims to find out what families need in terms of support. The assessment of individual needs is therefore very important.

Consult the practitioners who are already in contact with your family (for example, your family doctor, health visitor, paediatrician, **neurologist** or orthopaedic team) before starting any treatment, particularly if you are thinking of paying for it.

### Orthopaedic intervention

Some children who experience tight tendons and muscles, hip dislocation and have mobility impairments may benefit from treatments from an orthopaedic surgeon or **neurologist**. Here are some of the common treatments now available:

- **Tendonectomy** – Surgical lengthening or shortening of tendons in the leg allow the child to walk more independently and place their feet flat on the ground.
- **Botulinum Toxin A** – Otherwise known as Botox™, this drug can reduce spasticity in muscles thereby giving greater range of mobility. Botox injections are usually administered every four to six months and have to be accompanied by a programme of physiotherapy. For further information visit [www.scope.org.uk/botox](http://www.scope.org.uk/botox).
- **Selective dorsal rhizotomy (SDR)** – This is a surgical technique used to relieve spasticity in lower limbs. It involves identifying and dividing or cutting nerves in the vertebral column (spine) that are causing the spasticity. This is a major operation and mostly benefits young children with spastic diplegia. For further information visit [www.scope.org.uk/help-and-information/z-therapies/selective-dorsal-rhizotomy](http://www.scope.org.uk/help-and-information/z-therapies/selective-dorsal-rhizotomy). The National Institute of Clinical Excellence (NICE) has produced guidelines on SDR, visit [guidance.nice.org.uk/IPG373/Guidance/pdf/English](http://guidance.nice.org.uk/IPG373/Guidance/pdf/English).
- **Intrathecal baclofen therapy (ITB)** – This is a method of administering the muscle relaxant baclofen internally. A pump is placed in the abdomen to release a measured dose directly into the spinal cord where it is needed. Effects can be achieved with smaller doses than oral medications and some of the potential side

effects can be minimised. For further information visit [www.scope.org.uk/help-and-information/z-therapies/intrathecal-baclofen](http://www.scope.org.uk/help-and-information/z-therapies/intrathecal-baclofen).

## Mainstream therapies

'Therapy' for cerebral palsy usually refers to three mainstream therapies – physiotherapy, occupational therapy and speech and language therapy, or forms of treatment that involve some or all of these.

Your health visitor, family doctor or **paediatrician** will refer you to therapy services if they are needed. In the early months of life the consequences of cerebral palsy on an individual child can be difficult to determine because the brain is still developing. However, therapists can play an important part in assessing your child's needs and in advising on and showing you different approaches towards promoting development. For this reason, it is often recommended that a physiotherapy assessment should be made as soon as cerebral palsy is first suspected or diagnosed.

Many children will attend a child development centre where a team of therapists can assess and review your child's needs with you.

As the nature of cerebral palsy varies immensely, therapy is adapted to the needs of the individual. **Physiotherapists**, **occupational therapists** and **speech and language therapists** often work very closely with everyone who is involved with your child to devise a treatment programme that is designed to meet the needs of your child and family.

## Physiotherapy

Physiotherapy is the treatment of disorders of movement and function in the human body caused by problems in the muscles, bones or nervous system. **Physiotherapists** who assess and work with children use natural methods like exercise, positioning, sensory stimulation and stretches.

Many of these interventions will happen through structured play sessions, ensuring that your child enjoys and is motivated to try the activities. They also advise parent carers on how to lift and position their child safely and properly. They will teach you an exercise and positioning programme that you should use regularly to help your child at home.

If appropriate, your **physiotherapist** will work with you to teach your child how to reduce spasticity (stiffness) in their muscles so that better patterns of movement can develop. This is achieved through the use of exercise, structured physical activity and, sometimes, the use of splints. They can also provide an assessment and advice on equipment and adaptations.

Your child may be offered more intensive blocks of treatment to help to establish the programme. They may also be offered hydrotherapy if available. This is the opportunity to exercise in warm water using targeted movements to aid development.

Your **physiotherapist** should always be involved if your child has orthopaedic interventions, such as Botox treatment.

They may also work with the **occupational therapist** to look at the best posture, walking pattern and seating for your child. **Physiotherapists** work in hospitals, schools, child development centres and in the community, visiting children in their homes.

### **Occupational therapy**

Occupational therapy enables children who have cerebral palsy to participate in everyday activities that are meaningful to them. A family-centred approach is used to address the most immediate concerns at the time. These may include sensory, cognitive, perceptual or motor difficulties, which can be a barrier to self-care and prevent them from enjoying leisure activities.

**Occupational therapists** also work with **physiotherapists** to encourage the development of new skills. They may work with the family to develop physical or learning skills using a variety of play equipment. **Occupational therapists** sometimes give advice about specialised seating or equipment and aids that could help your child with everyday activities, such as eating. They may work in the community or within a hospital, school or special unit.

**Occupational therapists** also work within the local authority's social services department and are responsible for the assessment and provision of equipment. They can give you advice about modifications or adaptations to your home that will help your child move about as independently as possible.

### **Speech and language therapy**

Speech and language therapy helps children to make maximum use of the communication skills they have, to express their own ideas and to understand what is said by other people.

**Speech and language therapists** may meet you very early on if your child has problems with feeding, drinking or swallowing.

If your child has problems developing speech and language, a **speech and language therapist** will work with you to promote communication and the development of speech.

Some children with cerebral palsy have delayed language because they are not able to play and explore the world in the same way that other children do. When this happens, **speech and language therapists** can work with early years practitioners, teachers, **occupational therapists** and families to plan suitable learning activities.

They may also help with alternative communication systems and devices, which help children who are having major problems with language or speech. Sign language, symbols or a communication aid can reduce the frustration a child experiences when they are

unable to communicate their wishes and desires. **Speech and language therapists** normally work in clinics, health centres, early years settings, schools and hospitals.

### **Conductive education and schools for parents**

Conductive education is a holistic learning approach for children who have physical impairments and associated difficulties. It was developed in Hungary, and British therapists and teachers have integrated the approach within early years settings and schools for over 20 years.

Conductive education is based on the theory that the disabled child develops and learns in the same way as their peers. It needs a concentrated effort over a period of time to enable the participants to achieve recognised goals and aspirations.

The key is to find ways in which the child can develop purposeful movement and therefore independence. It does not use complicated aids and equipment. The approach integrates a child's learning – communication, physical, intellectual and emotional – within the **Early Years Foundation Stage Framework** and the **national curriculum**.

### **Schools for parent carers**

These are welcoming places where parent carers can learn how to play with and support their child throughout the early years. The schools use the principles and practice of conductive education to structure active learning for children and their families.

Sessions are based on the principle that the parent carer, the practitioner and the child are a team working together and have equal parts to play in the child's development and achievements. There are a number of schools for parent carers around the country – to find out if there is one in your area contact **Scope**.

### **Bobath**

Bobath therapy is effective for children with all types of cerebral palsy and other allied neurological conditions, regardless of their associated problems or age. Early diagnosis and treatment is crucial to support these children.

Each child's problems are individually assessed by an interdisciplinary team of **physiotherapists**, **occupational therapists** and **speech and language therapists**. As each child's needs change, the treatment is regularly reassessed. For further information visit [www.bobath.org.uk](http://www.bobath.org.uk).

## Portage

Portage is a home-visiting educational service for preschool children with additional support needs, and their families. It is also sometimes used in schools, nurseries and other early years settings. Expertise and responsibility is shared between practitioners and parent carers. After an initial assessment, the 'home visitor' will work with the parent carer to prepare an individual programme for the child and set weekly goals. Parent carers then work with their child every day, supported by a weekly visit from the home visitor.

The programme is very flexible and can be used alongside other therapies. For more information about portage, contact the [National Portage Association](#).

## Complementary therapies

'Complementary therapy' is a term used to describe a number of different therapies, each with its own particular principles and practices. They can be gentle, pleasant, relaxing or stimulating, and range from acupuncture through to baby massage and yoga.

If you decide to try complementary therapies, always use a qualified therapist. Tell them exactly how cerebral palsy affects your child and about any special needs they have. As with all other approaches, an individual assessment is very important before therapy begins. Scope has brief details of a number of therapies at [www.scope.org.uk/help-and-information/therapies](http://www.scope.org.uk/help-and-information/therapies).

## Face 2 Face

This is a peer-to-peer support and parent-befriending scheme. Befrienders are volunteers who themselves have children with additional needs. They are able to share experiences, and empathise with and support other parent carers who have a child with additional support needs, special needs or an impairment. For more information visit [www.scope.org.uk/services/local-groups/face-2-face](http://www.scope.org.uk/services/local-groups/face-2-face).

## Playing and learning with your child

This section focuses on the importance of playing with your child. It offers tips and web links to other resources that may help your child to develop skills, explore capabilities and understand their environment through play.

Play is important for children. It is a means of enjoying themselves and a part of ordinary life. It is the way they explore the world and find out more about themselves. Play offers children the opportunity to learn, relax, express their feelings, experience success and failure, and experiment with physical movement.

Play is also essential for the development of communication and language skills. You know your child better than anyone else. The information given here is general so you may find some parts more useful than others.

If you are not sure what kind of play will be enjoyable and helpful for your child, or whether a toy you have in mind is suitable for your child's stage of development and ability, then talk about this with other people who know your child well. If a health visitor, therapist or teacher works with your child, ask them – they often have useful advice to share. Some children need physical help to play, and in some cases simple adaptations to toys are needed.

Some children have very little muscle strength and get tired easily. If this is true of your child, look out for toys that are lightweight and give a big reward (light, sound or movement) for a small amount of effort. Toys are not essential for play; many forms of play involve no toys – but do use empty boxes, old clothes and plastic cartons. These all add up to one important word – fun! Fun is something everyone can offer their child. You do not need to buy expensive or specialist toys.

Remember that all children dislike some activities or toys, but that your child may not be able to communicate this. The type of play that you engage in will depend on the type of cerebral palsy your child has. This doesn't mean to say that your child can't engage in lots of play and fun like other children, rather it is to make sure that all play and learning experiences are tailored to your child's needs.

Here are some practical tips on playing:

- Play somewhere quiet and turn the television off so your child can hear you clearly.
- Play at your child's pace.
- Include siblings or other children of a similar age in the games you play whenever you can.
- Fix or steady play materials by attaching them to a surface so that they do not move around.
- Make items bigger so they are easier to see, or see if you can make parts of the toys you are playing with bigger, so they are easier to grasp and handle.
- Remove distractions and simplify backgrounds – for example, place a light coloured toy on a dark cloth or towel, or a dark coloured toy against a light background to highlight the toy and help your child to focus on it.

There are a number of resources that help to ensure that children with additional needs have the same opportunities to play as everyone else. One of these resources is *Play talks*, which has been designed to help parent carers and practitioners find practical ways for a young child with movement difficulties to communicate through play. To download the information pack visit [www.scope.org.uk/help-and-information/publications/play-talks](http://www.scope.org.uk/help-and-information/publications/play-talks).

You do not need to have lots of expensive equipment; an empty box can be a toy. You may need to take the time to assist your child to play with toys that they cannot access alone. Remember to relax and have fun as, like any child, they will pick up on your anxiety.

Play is an important resource in helping children to understand their world. Play is an activity for everyone. It heightens the focus on the child's positive capabilities, skills and interests. Through play children learn about the world around them. They learn to communicate, interact with others, develop their own identity and build on their social

skills, enabling them to prepare for adulthood. For more play resources and ideas visit [www.scope.org.uk/play](http://www.scope.org.uk/play).

The resource *Games all children can play* shows how children with additional needs and children without additional needs can play together. All of the games use simple and easy-to-use equipment that can be carried conveniently in a sports bag. They are intended for families and group leaders who work in any play setting with children with additional needs and children without additional needs. To download the publication visit [www.scope.org.uk/sites/default/files/pdfs/Early\\_years/Scope\\_games\\_for\\_all.pdf](http://www.scope.org.uk/sites/default/files/pdfs/Early_years/Scope_games_for_all.pdf).

## Eating, drinking and mealtimes with your child

This section looks at some of the issues that can arise when supporting your child to eat and drink, and how you might be able to overcome these to maximise the dignity and independence of your child.

Children with cerebral palsy may have difficulties eating, swallowing, chewing and sucking. Since most children with cerebral palsy use more energy than other children because of the muscle spasms they experience, being able to eat and drink enough is very important. Some babies with cerebral palsy might have difficulty feeding from a breast or bottle; other children may experience difficulties later in life – sometimes not until adulthood.

### Sucking

Some babies with cerebral palsy experience difficulties sucking. Many new babies experience problems latching on to a nipple or teat in the early days of life and so this does not necessarily imply that a child has cerebral palsy. If your child has problems sucking, ask for advice from the nursing staff on the maternity ward. Sometimes a nurse advisor, who has specialist expertise and experience in feeding difficulties, will be on hand to help. Once you take your baby home, your **health visitor** should be able to advise you if problems with sucking continue.

### Weaning

Babies with cerebral palsy often find eating semi-solid food easier than sucking and can begin to thrive once they have been weaned. Children with cerebral palsy can usually be weaned at the same age as other children, but weaning can take a long time and persistence may be needed. It can be a frustrating process and families often need help and support at this stage. Prolonged use of bottle-feeding should be avoided, but not at the expense of reducing the amount of nutrition or fluid that a child takes in.

Your **health visitor** should be able to advise you if there are any issues, or you can ask for a referral to a **speech and language therapist**, who should also be able to offer advice and support.

## Growing up and gaining more independence

Most children with cerebral palsy will learn to feed themselves to some degree eventually. As children mature and begin to attempt to feed themselves, there are a number of utensils that may be helpful. Special plates, bowls, cups, adapted cutlery and non-slip mats to help keep the dish in place are all available. An **occupational therapist** can advise you about these. For more information on eating and mealtimes, visit [www.scope.org.uk/help-and-information/cerebral-palsy/eating-and-meal-times](http://www.scope.org.uk/help-and-information/cerebral-palsy/eating-and-meal-times).

Many people with cerebral palsy would prefer to be able to sit at the table and feed themselves, even if it takes longer or is messier than being assisted to eat by someone else. Being able to choose what you eat and when you eat is one of life's pleasures for many people. Taking the time and effort to help a child to develop these skills can also help them in other ways – for example, with language development, awareness of position and hand-eye coordination. Some children with cerebral palsy will always need help with fundamental skills, such as eating and drinking, but they can choose what they eat and how they are fed – for them, this is independence.

Using the correct supportive seating makes it much easier for a child to learn to eat, and maximises the chances of their achieving independence.

## Healthy diet

Some people with cerebral palsy experience a lot of involuntary movements. These movements can burn up energy, which needs to be taken into account when the person's diet is being planned. A person with cerebral palsy may need to consume extra calories to compensate for the additional movement. Sometimes a food supplement is suggested or prescribed to help ensure that a person's nutritional needs are being met.

Health visitors can advise you on food consistencies and suitable diets for weaning, and the advice of a **dietician** may be helpful for both children and adults. **Speech and language therapists** offer specialist help if your child has particular eating difficulties, especially in relation to the food texture and consistency an individual will find most manageable.

However long it takes, it is important to ensure that your child has a healthy diet and gets enough nourishment. It may be necessary to do some further tests to ensure food and drink is being swallowed effectively.

## Bite reflex

This is when the person being fed immediately 'locks' their mouth on to anything that is introduced into it. They have no control over this and it may only happen occasionally. Sometimes a **speech and language therapist** can advise you on techniques that may help, and demonstrate how to 'unlock' the jaw if the reflex occurs. The use of a plastic spoon will lessen the chance of injury to the mouth or damage to the teeth.

## Choking

This is often caused by poor positioning of the head and trunk, or poor control of the muscles involved in swallowing. Regular choking can cause considerable anxiety at mealtimes for both the parent carer and the child or young person with cerebral palsy.

Seeking advice on how to react to choking may help lessen any anxiety and make you feel more confident that you will know how to react in an emergency. A doctor, **physiotherapist** or **speech and language therapist** should be able to advise you. Persistent choking should always be investigated by the doctor, and a test called **videofluoroscopy** may need to be carried out to find out what happens when your child eats and drinks.

## Constipation

This is common in people with cerebral palsy, especially if they have reduced mobility. An underlying medical problem, poor diet and/or inadequate fluid intake may be the cause. Often the situation can be improved by adding more fruit, vegetables and wholegrains to the person's diet. If the problem recurs frequently, the advice of a **GP** or **paediatrician** should be sought.

## Non-oral feeding

For a very small number of people who are not able to suck or swallow adequately, non-oral feeding may be necessary to provide proper nutrition, or to avoid food passing into the lungs rather than the stomach.

The most common type of non-oral feeding is nasogastric, where a tube is inserted up the nose in order to pass food into the stomach. Some people with cerebral palsy are fitted with a gastrostomy tube (often nasogastric tube feeding will have been tried first). This tube is surgically inserted directly into the stomach through a small incision made into the abdomen.

Both nasogastric and gastrostomy tube feeding have been shown to be helpful in assisting some people with cerebral palsy to receive the nutrition they need. Tube feeding may be a short-term procedure, but occasionally it needs to be permanent. Sometimes a combination of tube and conventional feeding is recommended.

*Fun in the sun* is an illustrated early years storybook featuring Peg Ted and Mikki Dolly, showing how being tube-fed doesn't stop children having fun. To download the book visit [www.scope.org.uk/help-and-information/publications/fun-sun](http://www.scope.org.uk/help-and-information/publications/fun-sun).

However long it takes, it is important to ensure that your child has a healthy diet and gets enough nourishment. Your **health visitor** can offer advice, and a **speech and language therapist** may be able to give you specialist help if your child has particular eating difficulties.

Mealtimes are not just about eating but also about family life, communication and interaction. Eating is a social occasion.

As your child grows, encourage them to feed themselves and offer them choice about food and drink. Here are some practical tips on feeding and mealtimes:

- Getting your child into the right position to eat is very important. For example, it's difficult to eat or drink when the head is tilted back. You may need to help your child get into a good eating position several times during a meal, but the correct supportive seating helps.
- Keep to a routine. Washing hands, putting on a bib and getting into their usual chair will all help your child understand that they're going to eat soon.
- Make sure your child sees what they're going to eat, or describe it and let them smell it if they have a visual impairment.
- Give drinks in single sips to allow time for swallowing and for the drink to go down before taking more.
- Share the load – some children take a long time to feed, which can be exhausting for everyone. If possible, try to get a number of people in the family involved and trained so they're confident about feeding your child, too.
- There are special cups, plates and cutlery available to help children with additional needs. Your cultural traditions may mean that you do not use utensils, such as feeding spoons. It is worth talking this through with any cultural advisors supporting your child.
- Your **health visitor** or **occupational therapist** should be able to tell you more about feeding and drinking options. **Scope** produces an information pack called *Food talks*, [www.scope.org.uk/help-and-information/publications/food-talks](http://www.scope.org.uk/help-and-information/publications/food-talks).

Here two young people with cerebral palsy talk about eating and drinking:

*"I just have to be careful what I eat – I need my food chopping up. I need help with equipment – I can feed myself and like that I can do it myself."*

*"I used to find I choked easily on drinks, but my therapist suggested adding a thickening agent and it is now easier for me to swallow."*

## Sleep and supporting your child at bedtime

This section looks at possible causes of sleep issues and provides a range of advice, tips and sign-posting to help your child sleep well.

Having a bedtime routine to look forward to, perhaps with a drink and a bedtime story, often helps children settle. However, many children with cerebral palsy do not drop off to sleep easily or sleep for very long at night because they find it difficult to get comfortable or to change position.

Some children with cerebral palsy may find it difficult to sleep because their muscles spasm during the night and they may need turning. Your child may need a sleep system to help to support them comfortably and maintain a good posture throughout the night. Your **physiotherapist/occupational therapist** will work with you to assess whether this would help and supply detailed information about using the support. Most children have improved sleep patterns once the support is in place.

Children with **athetoid cerebral palsy** sometimes move a lot in bed. If this is the case, your **health visitor** can tell you about types of bedding and nightclothes that will help to make sure your child does not get too hot or cold.

If your child finds it difficult to move, you may need to turn them several times in the night. Young children, and particularly babies, should never sleep on their stomach or be allowed to get too warm.

It is normal to be concerned when your child wakes and to check on them. Children, including children with cerebral palsy, often wake in the night. If your child does this, it may be that there's something worrying them. On the other hand, it could be that they've found a good way of getting your attention. If nothing seems to help your child settle, ask your **health visitor** for advice.

Statistics suggest that sleep problems are more common in children who have certain disabilities or disorders:

- Forty one per cent of children aged four to 12 years in special schools have difficulty settling at night, compared with 27 per cent of children in mainstream schools.
- Children with **additional needs** have greater difficulty staying asleep – 45 per cent compared with 13 per cent of children in mainstream schools. Children with a severe learning disability are more susceptible to sleep difficulties, with over 80 per cent of children up to the age of 11 years demonstrating sleep problems.

Sleep deprivation in children with additional needs can have a distressing effect on families. But often there are simple measures that can be put into place to help overcome the difficulty.

### **Causes of sleep problems**

There are a number of reasons why your child may not be sleeping. If you can identify the cause of the problem you can then work on strategies to try to improve the situation. Consider whether your child might be:

- too hot or too cold
- hungry or thirsty
- wet or soiled
- feeling unwell
- uncomfortable in their cot or bed

- disturbed by noise
- overstimulated by their bedroom environment
- in pain
- unable to self-settle
- overstimulated before bedtime
- teething
- underactive during the daytime or having too many naps
- disturbed by enlarged tonsils/adenoids

For more information on sleep issues, visit [www.scope.org.uk/help-and-information/cerebral-palsy-and-associated-impairments/sleep-difficulties-children](http://www.scope.org.uk/help-and-information/cerebral-palsy-and-associated-impairments/sleep-difficulties-children).

You can also find more information on this area in the Early Support information resource on [Sleep](http://www.ncb.org.uk/early-support/resources) – available to download from [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

Keeping a sleep diary is a useful way of evaluating the problem. Here are some practical tips on keeping a sleep diary:

- To establish whether there is a pattern to your child's sleep disturbance you should keep a diary for at least two weeks.
- Record the diary honestly.
- If your child sleeps elsewhere, such as a respite centre or with grandparents, ask them to complete the diary too.
- Check with carers to see if your child is napping during the day.
- Share the diary with practitioners to see if they can assist you in finding a possible cause for your child's sleep difficulties.
- Keep the diary by the bed with a pencil so that you can fill it in during the night, rather than trying to remember the times and lengths of waking the next day.

### **Twelve steps to good sleep practice**

These steps may help your child to fall asleep and stay asleep:

- Make sure that your child's room is quiet and dark. No TVs or electrical items should be used; toys should be hidden or covered. Close the curtains; black-out blinds will make the room darker if necessary.
- Wake your child at a regular hour each morning so that their circadian (daily) cycle is strengthened – not before 6am!
- Keep a regular, age-appropriate bedtime for your child.
- Ensure a consistent bedtime routine is followed each night. Try making a picture, or photographic timetable of previous routine activities to highlight the countdown. This will help your child to understand the order of events and what is going to happen next.

- Keep room temperature to a comfortable level, ideally between 16-20°C. High temperatures disturb sleep.
- Keep environmental noise within the home to a minimum (for example, no loud TVs).
- Make sure that your child does not go to bed hungry – but do not give a child over six months old feeds or drinks during the night.
- Help your child to learn to fall asleep alone in their bed, without your presence. Further guidance on this is available from a sleep practitioner.
- Avoid stimulating activity in the hour before bedtime. Encourage quiet play, such as jigsaws or colouring.
- Do not let your child have prolonged naps in the late afternoon. If they still need to nap, schedule it for early afternoon.
- Include sleep-inducing foods in the last meal before bedtime. Avoid drinks like cola, chocolate, tea and coffee before bed – i.e. all drinks with caffeine and additives. Instead offer a warm, milky drink.
- Try this as an example of a good bedtime routine:
  - After teatime allow free play for an hour, followed by quiet play for 20 minutes. Offer a snack and drink. Use clues to signal bedtime, such as closing the curtains, or playing a set piece of music each time. Bath time, of around 20 minutes, should be relaxing.
  - Once you have left the bathroom to go to the bedroom, you should remain in the bedroom with your child. Read a bedtime story, but ensure that it's within a clearly defined time and does not go on indefinitely. Ten minutes is usually good for this.
  - Dim the lights. Say goodnight in the same way each night and for the same length of time (kisses and cuddles should last no longer than three minutes).
  - Then leave the child to settle alone.

Here two young people with cerebral palsy and a parent share experiences on sleep:

*“Having CP affects my sleep and I have to ask night staff to turn me.”*

*“I have to have an overnight feed at 6am, so I will be awake anyway.”*

*“Jack never slept and by the time he was three we were tearing our hair out. The sleep practitioner came to our house and was brilliant. She helped us look at how we reacted and helped us plan a bedtime routine that suited us, Jack and his elder brother. He still wakes up occasionally, but the improvement over the last six months has been tremendous.”*

## Meeting others

Learning to adjust as a parent carer of a child with cerebral palsy takes time. We have all had different life experiences and come with our own perceptions and assumptions.

It is really important not to be afraid to ask questions. If you do not understand something, ask. It takes time to become confident when talking to practitioners who support your child, but remember they are there to help you.

All home situations are different and can be complex. Try to talk openly about your feelings and concerns with family and close friends.

In time you will gain confidence to explain your situation to a wider circle of neighbours and other friends or associates, and to venture out to local groups.

Many parent carers say that having knowledge and information about how cerebral palsy affects their child empowers them to mix with other people and do everyday 'normal family things'.

Being able to explain to others how cerebral palsy affects your child and what helps will give you confidence to meet new people.

When you are ready, sign up to social media sites and web forums, for example, [www.scope.org.uk/forum](http://www.scope.org.uk/forum), where you can talk online with parent carers in the same situation as you.

**HemiHelp**, a charity for children with hemiplegia, runs 'a living with hemiplegia' campaign where families upload their stories about living with the condition. For more information, visit [www.youtube.com/user/hemihelp](http://www.youtube.com/user/hemihelp).

Your local Carers Association, [www.carers.org](http://www.carers.org), can give you support and advice and the chance to meet a whole new group of people in similar situations to yourself.

For some parent carers, the chance to talk to other parent carers for emotional support is invaluable. Scope runs a Face 2 Face service where parent carers of children with additional needs are trained to befriend and support others. For more information, visit [www.scope.org.uk/face2face](http://www.scope.org.uk/face2face).

Your local **Family Information Service (FIS)** can give you details of local support groups that can help you and your child, visit [www.familyinformationservices.org.uk/index.php](http://www.familyinformationservices.org.uk/index.php).

If you are thinking about attending your local parent and toddler group, here are some tips to consider:

- Take a close friend or family member with you for support.
- Where possible, if your child uses a walking or seating aid, take it with you so they can join in with their peers.
- Encourage people to chat about your child and what they like to do.
- If your child pals up with another child, encourage play dates at home.

Some parent carers prefer to attend groups for children with additional needs. The **FIS**, your local children's centre, **health visitor**, **portage worker** or **key worker** (if applicable) will

be able to advise you of the nearest one. Whatever you choose, children with cerebral palsy need be treated in the same way as any other child or sibling.

Some parent carers of children with cerebral palsy who use walkers or wheelchairs to get around can find stares from members of the public off-putting.

In time, families devise their own strategies to deal with those stares, from ignoring or scoring points for the degree of rudeness, to scowling or even smiling back. Most people are just curious and want to help.

The most important thing is that your child's cerebral palsy should not stop them from experiencing the world around them, having fun and enjoying life.

# Education

## Choosing a preschool

This section sets out some of the considerations and options to help you make an informed decision about the right preschool for your child and you.

Your child may be entitled to free early education or childcare. You can access further information about local preschool provision and funding arrangements from the [Family Information Service](#) at your local council. Information is available on the council website or via your local children's centre.

Children's centres and many community early years services offer a range of 'stay and play' sessions where your child can meet and play with other children. You will be able to stay with your child for the session and there will be staff trained in early language development, special needs, equalities and family support, so it is a good place to start the process of choosing a preschool that is right for your child.

You will need to consider the best option, or combination of options, for your child and family. Children under five can attend:

- home-based childcare (accredited childminder)
- daycare provided by a private, independent or voluntary provider
- a nursery or playgroup provided by a private, independent or voluntary provider
- a nursery class in a local primary school run by the local authority
- a nursery school run by the local authority

All early years providers, including childminders, will be registered and inspected by Ofsted. This ensures that everyone working with children under five has completed training and meets the statutory requirements in the Early Years Foundation Stage. For more information visit [www.education.gov.uk/early-years-foundation-stage-eyfs](http://www.education.gov.uk/early-years-foundation-stage-eyfs).

You can find copies of Ofsted reports for all early years provision at [www.ofsted.gov.uk](http://www.ofsted.gov.uk). These reports can be useful when considering the different types and the quality of preschool provision.

The best way of finding the right preschool for you and your child is to arrange a visit when the setting is open. Here are some important things to consider when you visit the preschool for the first time:

- How many children are at the setting and how are they grouped and organised?
- Would your child have access to resources and staffing appropriate for their needs?
- Would they be encouraged to play with their peers?
- Is the environment bright, welcoming and child-friendly?
- Look to see how the staff are interacting, playing and talking with the children.

- How do the children respond to the adults? Are they playing happily, confidently and independently as they move around?
- Does the setting promote a rights-based and inclusive approach?

You would expect to see a role play area, book corner, water and multi-sensory play, and there should be opportunities and space for children to enjoy both indoor and outdoor play. You might want to ask the following questions:

- What experience have you had of working with children with additional needs, or specifically cerebral palsy?
- How do you work in partnership with parent carers?
- How are different communities represented in the setting?
- Do the children have a say and influence on school practices?
- What facilities/arrangements do you have in place to support communication and language/personal care/accessibility?
- How do you work in partnership with health visitors, **speech and language therapists** and family support workers?

Every early years setting is required by law to meet the requirements of the Equality Act 2010. For more information visit

[www.education.gov.uk/aboutdfe/policiesandprocedures/equalityanddiversity/a0064570/the-equality-act-2010](http://www.education.gov.uk/aboutdfe/policiesandprocedures/equalityanddiversity/a0064570/the-equality-act-2010). This means that the setting must make 'reasonable adjustments' to meet the needs of your child. Every setting is required by law to have a special education/equal opportunities policy and this should be available for you to read on request.

Many early years settings have **equality named coordinators (ENCOs)** in place who work with the setting's **special educational needs coordinator (SENCO)** to support additional needs and other equalities needs for all the children. You may want to have a chat with these staff members on your visit to the early years setting to see how your child will be supported.

You can find lots of information about enjoying early education on the Foundation Years website, [www.foundationyears.org.uk/parents/getting\\_ready\\_for\\_school](http://www.foundationyears.org.uk/parents/getting_ready_for_school). You will also find up-to-date information about the changes to the Early Years Foundation Stage and there are parent forums if you have questions.

Once you have found the right early years setting for your child, you will need to discuss with the nursery manager, or your **key person**, how you will work together to support your child to settle. Make a list of all the information the setting will need to know about your child.

You may want to use the materials in the **Early Support Our Family**. For more information on file visit

[www.education.gov.uk/publications/standard/publicationDetail/Page1/ES1#downloadablep-arts](http://www.education.gov.uk/publications/standard/publicationDetail/Page1/ES1#downloadablep-arts).

You should also consider whether your child will need:

- a personal care plan
- a medical emergency plan
- a communication passport
- a behaviour plan
- an individual play plan
- an equalities plan (to meet your child's holistic identity needs)

You will need to make sure that the early years setting is aware of who is working with your child and, if you give your permission, set up opportunities for everyone to meet and share information. Often the early years team will be very willing to support a speech and language programme or physiotherapy programme and this may help to ensure your child gets daily input.

### Video link – In the picture

In this clip, children share their feelings and ideas on the inclusion of disabled children in books:

[www.scope.org.uk/help-and-information/families-and-parenting/disabled-children-books](http://www.scope.org.uk/help-and-information/families-and-parenting/disabled-children-books)



## Choosing a school

This section builds on the [Choosing a preschool](#) section and begins to explore the school options that are available. It also looks at how support can be put in place to allow your child to get the most out of school.

When choosing the right school for your child, you will need to go through a similar process to the one you went through to select a preschool. Take the opportunity to attend open days or special events so that you get to see the school in action.

You can make an appointment to visit the school during the school day by contacting the head teacher. It will be important to share information about your child's needs at this stage so that you can have an open, honest discussion about the difficulties and opportunities in context. Many parent carers say that the important quality to look for is a 'can do' approach from the head and staff. They must be willing to make adjustments and meet the needs of your child.

There are several options that may be available to you, including:

- mainstream primary/secondary school
- special school for pupils with severe and complex needs
- special school for moderate learning difficulties
- a residential school
- a special needs unit in a mainstream school

Further information about the options in your area can be provided by the children's services department at your local council. There is a statutory process for any child who needs a special school placement and this process should be discussed with the [Parent Partnership Service](#) at your local council. If you are unsure which option would be best for your child, arrange a visit to a special school and talk through the options with the head teacher.

If you are looking for a local placement in a mainstream school, you will need to feel confident that your child will be accepted, valued, learn and make progress. You will need to consider the following:

- What size is the school – how many pupils are there and what is the layout of the buildings and the playground?
- What size are the classes? Primary classes can have a maximum of 30 children with one teacher, but often they are smaller and the teacher is supported by a teaching assistant (TA).
- How are the classes organised? Sometimes a mixed-age class can allow for greater flexibility and personalised learning.
- Look into the quality of parental partnerships, teaching and learning, and inclusive and rights-respecting practice. You can access this information for every school by looking at recent inspection reports at [www.ofsted.gov.uk](http://www.ofsted.gov.uk) or by talking to children and parent carers at the school.

- Keep in mind the distance of the school from your home. Complicated travel arrangements could put additional strain on you and your child.

All schools will have a **special education needs coordinator (SENCO)** on the staff team who can support your child to settle into school. You can request to see the SENCO during your visit.

Some schools also have **equality named coordinators (ENCOs)** in place who work with the setting's SENCO to support additional needs and other equalities needs for all the children. You may want to have a chat with the ENCO on your visit to see how your child's multiple equalities needs will be supported. As with the preschool, you will need to check the following:

- Is the environment bright, welcoming and child-friendly?
- Look to see whether the staff are interacting, playing and talking with children.
- How do the children respond to the adults? Are they playing and learning happily? Do they look confident and independent as they move around the classroom?
- Does it promote recognition and respect for diversity?
- What is accessibility like – would adaptations be needed for your child?
- Find out what experience and training is available to staff to help them meet special educational needs.

The staffing ratios and support for children with additional needs is managed differently in each school and it is allocated according to the assessed need of each child. One-to-one support is needed at times. However, all children benefit from time away from adults to interact with their peers and to develop their own strategies. This can be achieved even with children who have the most complex needs, so long as it is well planned, the risks are assessed and the child feels safe and secure. You might encourage the school to have a key working approach to support, or to embed the Early Support approach across the school. For more information visit [www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport).

Transition into school is also managed differently by each school. Some children will start full time in the term of their fifth birthday; others will be given a part-time place. The guidance in the Early Years Foundation Stage encourages schools to be flexible. A child with special educational needs will benefit from an individual 'starting school' plan, which might involve a phased introduction through visits or part-time attendance. This plan should be agreed with the parent carer, taking into consideration the child's individual needs. Many reception teachers will carry out a home visit or invite you into school during the summer term to get to know your child.

It is important at this stage that you share information and discuss any concerns you might have with the class teacher, SENCO or the head teacher. You may want to use the materials in the **Early Support Our Family**.

[www.education.gov.uk/publications/standard/publicationDetail/Page1/ES1#downloadablep\\_arts](http://www.education.gov.uk/publications/standard/publicationDetail/Page1/ES1#downloadablep_arts)

Discuss the plan with the class teacher, SENCO and other relevant practitioners, and consider whether your child will need support with:

- personal care
- additional/specific medical needs
- behaviour strategies
- play
- physical support and positioning
- a communication passport

It is often helpful to prepare your child for starting school with a photo story about the new school, the class teacher and the classroom. Most early years settings will help you to do this and may help with visits and information.

A system for ongoing communication with the school is important and most schools will be happy to set up a home/school liaison book. Many schools will have a phone texting/email system that can be used to exchange information and reassure you in the early days.

If you have a concern about your child in school, always discuss it with the class teacher first. You can involve the **SENCO** and the head if necessary. **Parent Partnership Services** can also help by providing advice and support. Do not wait for a problem to escalate, resolve it early on. When your child is happy and settled, they are much more likely to learn and make progress.

Where there are a number of different agencies and services involved with your child's care, it is useful to have regular 'team around the child' (TAC) meetings to make sure that you are all working together. This team should always include you and might include a **physiotherapist, occupational therapist, speech and language therapist, dietician,** consultant paediatrician, **SENCO**, class teacher, a visual and/or hearing impairment specialist teacher and an **educational psychologist**.

Any plans for your child should be updated and revised as a team to ensure an integrated approach to meeting the needs of your child and family. These TAC meetings will also help ensure that any issues are dealt with early on and do not escalate. The school SENCO or class teacher can arrange these with you. The school will need to have a list of contact details of everyone who is involved with your child.

## **Fatigue management**

Fatigue is a factor in many medical and physical conditions, including cerebral palsy. If your child shows signs of fatigue it is important to exclude an underlying medical condition, such as anaemia. The school may need support in identifying the correct rest/exercise balance to ensure that they are supporting your child appropriately. All those involved with the child should contribute to the overall physical management plan, which should be reviewed regularly.

## Memory difficulties

Some children with cerebral palsy may suffer from memory difficulties, so lessons planned well in advance can ease the learning journey for your child. Planning ahead is a fact of teaching life, with the year planned in advance and the lesson details planned six to 12 weeks ahead. This commitment to planning allows teachers and parent carers to consider well in advance any particular needs your child may have with memory difficulties and how to tackle them. When planning, many factors regarding your child should be taken into account. These include:

- concentration span
- vocabulary level
- interests
- motivating factors

## Being different is OK

Throughout life children will begin to notice that people are different to them. It is important that they are told from the start that being different is a positive thing and not a negative thing.

Scope's publication *Imagine the difference* helps children at stage one and two understand that everyone is different and that being different is a positive thing. One of the primary aims of this resource is to raise the profile of people who are different because of their impairments, and to avoid stereotypical attitudes towards them in the future. To access the publication and teaching materials visit

[www.scope.org.uk/help-and-information/publications/imagine-difference](http://www.scope.org.uk/help-and-information/publications/imagine-difference).

## Meeting others – school years

As your child starts school, it is really important that you encourage them to make friends and enjoy the same social life as any other child of their age.

Children with cerebral palsy may have many clinic and therapy appointments, and it can be easy to forget to have fun.

In the beginning you may need to encourage friendships and be quite proactive as some people may be shy about including your child. Try to be confident about your child and what they can do, and welcome questions about them from other parent carers. Here are some suggestions on how to encourage social interaction:

- Find out from your child's teacher who your child likes to play with and invite that child home for tea.
- As much as possible encourage school friends to come over and play.
- Include your child in all family events, cultural and community celebrations, activities, holidays, days out, cinema trips, etc.

- Encourage sleepovers. If your child can't access stairs very well have a sleepover in your lounge or in a tent in the garden.
- Take a week or fortnight off appointments and just enjoy family time or being with friends.
- If your child tires easily from walking, take their walking aid, wheelchair or tricycle out with you.

Depending on your child's needs you may need to accompany your child to a friend's house for tea, a party or on an outing.

If your child cannot easily access certain activities, then think about how they might be involved. For example, a child in a power chair could not join in the Ladders Game at Brownies, or play Guli Danda with friends due to health and safety issues, but instead they could control the game using their communication aid.

The resource *Games all children can play* gives some ideas on inclusive play for all. To download the publication, visit [www.scope.org.uk/help-and-information/publications/games-all-children-can-play](http://www.scope.org.uk/help-and-information/publications/games-all-children-can-play).

Try to encourage your child to join a local group, such as Beavers, Rainbows, Brownies or Cubs, or specific cultural support groups, such as Chinese/Greek/Italian/Irish/black cultural heritage groups, etc. Or if they love football, basketball or another sport/leisure interest, find out about a local team they can join. Your local **Family Information Services** will have details of local groups, both mainstream and special needs services. For more information visit [www.familyinformationservices.org.uk](http://www.familyinformationservices.org.uk).

Some practical issues may need to be addressed before your child with cerebral palsy can attend certain groups. These might include:

- accessibility of the venue
- transport to and from the group
- manual handling and personal care
- use of aids, for example, walking and communication aids
- feeding issues
- completing risk assessments

### **Communication passport**

Think about making a communication passport for your child, which can go everywhere with them. This will explain all the key needs of your child to practitioners who are new to them. Go to [www.scope.org.uk/help-and-information/publications/communication-passport](http://www.scope.org.uk/help-and-information/publications/communication-passport) to download a passport template.

## Siblings

If you have other siblings in your family, think about encouraging them to join a young carers group; these groups provide activities and support. Contact the charity **Sibs** or your local **Family Information Service** for details, at [www.familyinformationservices.org.uk](http://www.familyinformationservices.org.uk).

## Choosing a secondary school

Making the transition from primary to secondary education is a crucial period in any young person's life. When that person has cerebral palsy, they are dependent on a network of support from family, teachers, specialist support workers and health practitioners.

The key to a successful transition is planning and preparation. The teachers and **special educational needs coordinator** (SENCO) at the primary school will be able to advise you about the options that are available. These options might include:

- a mainstream secondary school
- a special unit based in a mainstream school
- a pupil referral unit
- a specialist school/college
- a residential special school

To make an informed decision, it is always best to visit the different schools within your area, consider the Ofsted inspection reports at [www.ofsted.gov.uk](http://www.ofsted.gov.uk) and talk to other families. Ideally your child will accompany you on the visits and will be actively involved in making the decision, but you will need to consider what is best for your child. Some young people can become very anxious when faced with change, so you may want to wait until you are ready to offer a choice of two schools.

Arrange to visit the school during the day (so that you can see the school in operation) and ask to talk to the **SENCO** and the head. You will need to share information about your child's needs so that you can find out what adjustments would be made to accommodate those needs.

As with early years setting and primary schools, you will want staff to demonstrate a positive 'can do' approach and to listen to your concerns. They should be able to show you how they will listen and respond to the views of the young person, too. When choosing a secondary school you and your child will need to consider the following factors:

- What size is the school and how big are the classes?
- What is the layout of the buildings and how accessible are they?
- What is the age range of the school – is there a sixth form on site offering an option to stay on for A levels?
- What range and choice of subjects are on offer?

- What support options are available in the classroom – for example, communication aids, IT support, learning support assistants, a special needs department, a learning mentor and/or peer support?
- What is the journey length to school, and what transport options are available?
- Where are your child's peers/friends going?
- What is the equalities and rights-respecting approach and the ethos of the school?
- What community links does the school have?

Most secondary schools have very good websites, which can be used to support any discussions with your child and to help prepare them for the change. Brochures and prospectuses are also useful visual aids to support your discussions.

The primary school will organise a series of transition visits to local schools. If you choose a school outside the catchment area you may need to work with the school to set up these visits and arrange suitable transport. Transition visits enable young people to see the layout of the buildings, meet the staff, ask questions and prepare for the change.

It is important that information is shared between the primary and secondary schools; parent carers will need to give permission for this to happen. It is likely that the schools will want to share information about specialist educational plans, assessments, individual needs and barriers to learning. A 'team around the child' (TAC) meeting can be a good opportunity to ensure that the secondary school has all the information it needs; it establishes contact with all the support services involved with your child and allows the school staff to plan ahead with you as parent carers.

It is important that good communication channels are established early on so that concerns and issues can be dealt with before they escalate. Most schools are happy to keep in contact via text and email. Some schools have virtual learning websites with an area for parent carers to liaise with staff. Alternatively a home/school diary can be used to exchange information. Any concerns should be raised initially with the class teacher. The **SENCO** and head may get involved if the problem is not resolved. Any complaint can be made more formal if it is put in writing to the head.

Every school will have an equal opportunities policy, and all members of staff should adhere to the Equalities Act 2010 and other related legislation. Some staff will have more experience than others in overcoming barriers to learning and it is important that you work with the school staff to improve their knowledge and understanding.

Many schools are adopting the Early Support approach, which focuses on achievement for all; it is 'whole school' commitment to inclusive practice. For more information, visit [www.ncb.org.uk/early-support](http://www.ncb.org.uk/early-support).

Here, two young people with cerebral palsy share their experiences on bullying:

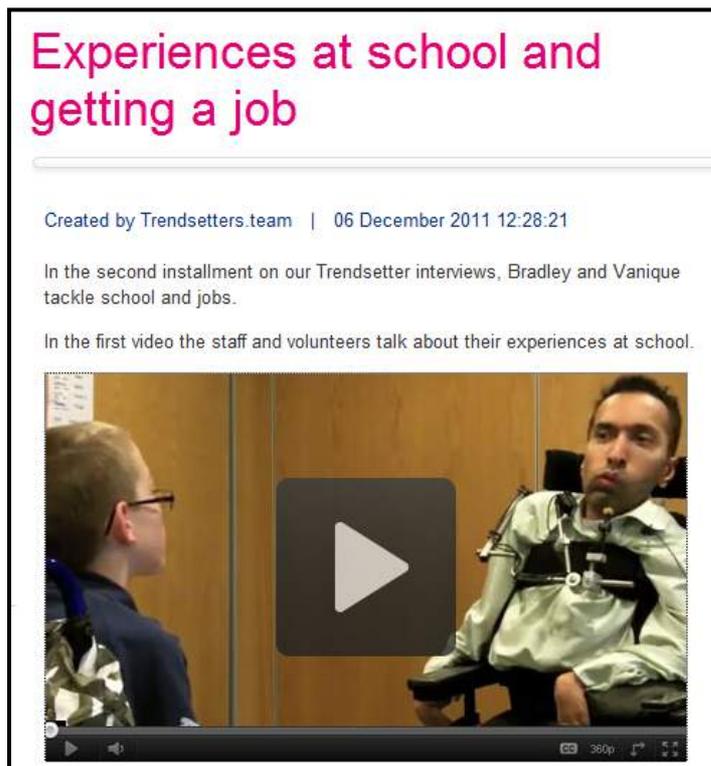
*"I was bullied. I told my dad and he sorted it out. I felt frightened and did not want to go out anymore."*

*“I have been bullied – I try to ignore it. I try to just carry on and ignore what other people say. I have got used to being insulted. I get annoyed but away from them so they do not see I am affected.”*

### **Video link – Trendsetter interviews: school experience**

Bradley talks to volunteers and staff at Scope about their experiences at school:

[www.scope.org.uk/news/blogs/trendsetters-blog/experiences-school-and-getting-job](http://www.scope.org.uk/news/blogs/trendsetters-blog/experiences-school-and-getting-job)



## Growing up

### Everyday life

This section offers a collection of comments, insights and video links that share what life is like growing up with cerebral palsy. It looks at personal experiences of cerebral palsy, describing some of the feelings and emotions towards aspects of everyday life.

Each and every person with cerebral palsy is affected in a different way and it is impossible to predict what the future will hold for your child. Children with cerebral palsy are children first, with their own personalities, cultural identities and potential to achieve. As they grow and develop into young people and adults, the questions and issues you have will change according to the life stage they are at and their individual circumstances.

*“In my experience, you cannot separate cerebral palsy from the person and vice versa! I have always been dogmatic in my approach – if I wanted to do something hard enough there is always a way round. Nothing is impossible if you really want to do it, it just may take a bit of thinking and a lot of flexibility.”* Young person

Entering adulthood can be a daunting time for many of us. Learning about and planning for the future, adapting to life in new and different ways and overcoming barriers are challenges that we all face, regardless of having an additional need.

All people should be enabled to lead a life that is meaningful within a community that acknowledges, values and supports their differences. The life stages and life changes are the same for someone with cerebral palsy as they are for everyone else.

*“My CP really doesn’t stop me doing what I want to do; it’s mainly other people’s attitudes that put limits on me.”* Young person

*“I would explain my disability as the brain working but sometimes the body doesn’t follow.”*  
Young person

There is no prescription for growing up. Every person has a right to equality in everyday life, should be treated with dignity and respect, and supported to realise their individual potential and fulfil their ambitions and aspirations.

Here two young people with cerebral palsy talk about independence:

*“College has helped me. I can now direct people to help me with my needs.”*

*“I have good independence with college helping me – moving away from home to live on my own has helped me decide what I want to do.”*

## Video link – GASP

In this film, eight young people and their colleagues from the Gasp theatre company put on an acclaimed play for a local arts festival in Bedford about transition issues:

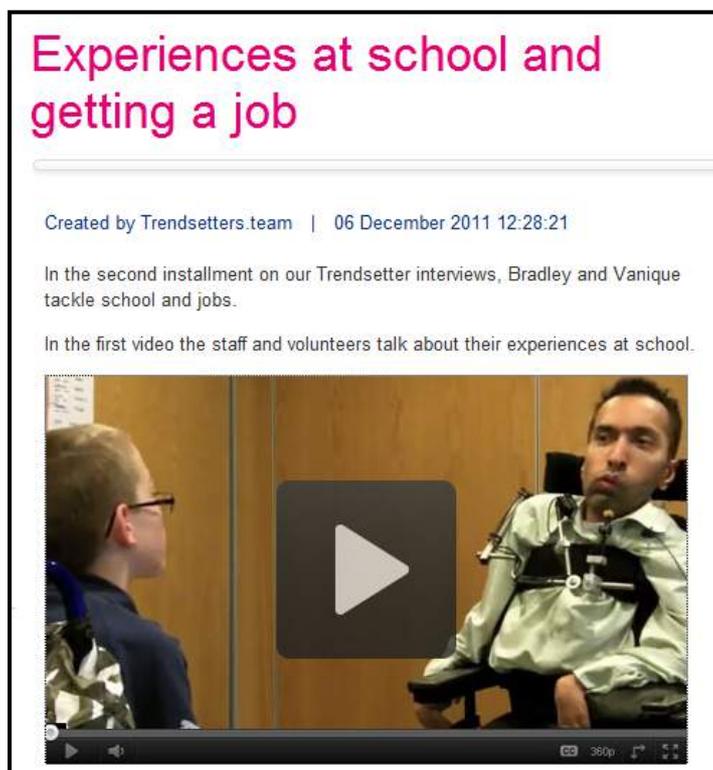
[www.scope.org.uk/help-and-information/young-disabled-people](http://www.scope.org.uk/help-and-information/young-disabled-people)



### Video link – Trendsetter interviews: plans for the future

Vanique talks to volunteers and staff at Scope to find out what jobs they do and how they got into those roles:

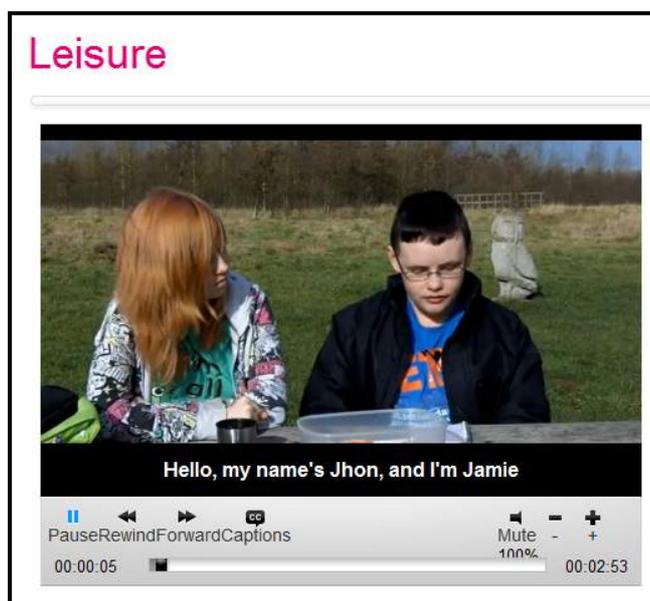
[www.scope.org.uk/news/blogs/trendsetters-blog/experiences-school-and-getting-job](http://www.scope.org.uk/news/blogs/trendsetters-blog/experiences-school-and-getting-job)



### Video link – Access to parks: John's story

John has made his own film about some of the barriers to getting out and about in the parks and countryside. He uses his film to highlight the changes that are needed:

[www.scope.org.uk/help-and-information/leisure](http://www.scope.org.uk/help-and-information/leisure)



## Video link – Trendsetter interviews: overcoming barriers

Staff and volunteers share some of the barriers they face and how they overcome these barriers:

[www.youtube.com/watch?v=3605OgKbZSA](http://www.youtube.com/watch?v=3605OgKbZSA)



Here young people with cerebral palsy talk about the importance of speaking out when things do not work in the way they would like:

*“Tell people: tutor, support staff and key worker.”*

*“I say, ‘I think its rubbish’ – I tell people. I joined the student union to make college better.”*

*“I just speak up and discuss what is wrong – I get it sorted.”*

*“Mum and Dad used to speak for me and now I speak for myself and this has boosted my confidence.”*

*“Having cerebral palsy is not a problem. The problem is finding solutions to everyday life.*

*“Anything is possible, just believe in yourself and what you want to do.”*

## Cerebral palsy and ageing

It is a common perception that growing older brings with it poor physical health, mental incapacity and an inability to function independently. Whilst physical abilities do decline with age, this happens more slowly and to a lesser degree than most people think.

The impression that older people experience severe physical decline stems partly from confusion between primary ageing (changes brought about by increasing age) and secondary ageing (changes caused by disease and disuse or abuse of our bodies). In fact, many people retain good physical health into their 70s and beyond.

However, for those who have lived a lifetime with a physical impairment, the effects of ageing can become apparent earlier than expected. Cerebral palsy is an example of a developmental disorder in which physical functioning can deteriorate with ageing as a result of poor mechanical efficiency.

Whilst there is not a wealth of published scientific evidence on the physical effects of ageing and cerebral palsy, surveys have highlighted some of the problems that people encounter. What is clear is that people with cerebral palsy age in the same way as people without cerebral palsy, but some people with cerebral palsy can also experience secondary ageing effects. These are likely to be the long-term effects of the original impairment. Common problems that people with cerebral palsy may face as they get older include:

- increased levels of pain and discomfort
- osteoarthritis (pain and stiffness in the joints)
- an increase in spasms
- an increase in contractures (shortening of muscles)
- joint problems
- tight muscles
- gastrointestinal (digestive system) problems
- new or increased back pain
- reduced energy and fatigue

*“I become tired and weary more quickly than I used to. I have many more aches and pains around my joints and back; my balance has become poorer.”*

For more information on ageing and Cerebral Palsy, visit: [www.scope.org.uk/help-and-information/cerebral-palsy/ageing-and-cerebral-palsy](http://www.scope.org.uk/help-and-information/cerebral-palsy/ageing-and-cerebral-palsy).

## Top tips

The following top tips have been put together by parent carers of children with cerebral palsy, who have 'been there'. They felt that these words of wisdom helped to make a difference:

- Make time for yourself – if you are feeling OK everything else will fall into place.
- Treat your child as you would any other. Be proud of them and celebrate who they are and what they can do.
- Talk to other parent carers with children who have similar conditions, and join social media sites and parent web forums – their experiences and advice will be invaluable. Do not be afraid of talking to parent carers about how cerebral palsy affects their child. Many parent carers welcome the chance to share their feelings and having someone who will listen can make a real difference.
- Work closely with therapists on your child's programmes and plan ahead when it comes to equipment – you can wait months to get it.
- Don't be afraid to ask for help. Ask as many questions as you want and get as much information as you can. Talking to friends and family can be helpful.
- Discuss your child's needs with your child and try to be honest. Talk to your child about what you are doing together. Encourage your child to do things for themselves, even if it takes longer. Give lots of praise for every achievement.
- Keep a list of medication dosages and contact details for your child's practitioners on a computer/phone, which can be easily printed out/accessed.
- Before a meeting or appointment, think about what you want out of that clinic. Make a list of questions to ask and store them on your phone or print them out (see the meeting tips in the [Who can help](#) section for further pointers).
- Take time off from appointments when you can and enjoy being a family.
- If your child needs to be hoisted use one. Do not be tempted to lift your child because it is easier and hope your back will be OK – you may be making yourself prone to years of back problems.

## Who can help

Receiving your child's diagnosis of cerebral palsy can be emotionally and mentally difficult. It is important to have people to help and support you on this journey. As a parent carer, you are the expert on your child – you know more about them than anyone else. However, you may need help from a range of people who have knowledge and experience of cerebral palsy and available services.

Voluntary organisations and other parent carers will be able to give you information and direct you to services that can help. You should always feel able to ask questions or seek other opinions if you feel uncertain or unhappy about what's happening.

### Practitioners you will meet along the way

You are likely to come into contact with a number of practitioners over the coming months and years. They will work in many different spheres, from health, social and educational services, to early support children's centres and voluntary agencies. They will be important partners for you and help you to get the best support for your child.

Initially you may feel overwhelmed by the number of practitioners you have to deal with, particularly in the early days when they are all getting to know your child. But gradually the appointments will become less frequent.

### Meeting a practitioner

Meetings with the relevant practitioner or multi-agency can be one to one, or include a number of practitioners involved in your child's care. You and your child should always be at the centre of the meeting. You need to be fully involved and to understand everything that is said. Sometimes that can be difficult, especially if you are anxious or upset. Here are some things to think about in advance of a meeting:

- **Timing** – Does the date and time of the meeting or appointment suit you and your family? If not, try to change it.
- **Venue** – It may be possible to change the venue for some of your appointments or meetings, for example, to your local children's centre. Ask for privacy if it makes you more comfortable. Some parent carers prefer to meet in their own home. Culturally sensitive locations may be needed for some families; if a venue presents a cultural barrier to you, make this known.
- **Planning** – Keep a calendar of appointments by the phone to help plan your time.
- **Medical appointments** – Take a list of any medication your child is taking.
- **Who's who** – Be clear who is at the meeting and what their role is. Do not be afraid to ask for everyone to introduce themselves.

Here is a list of some of the practitioners you may come into contact with:

**Audiologist** – Advises on hearing, carries out hearing tests and explains the results of those tests. If your child needs hearing aids they will establish the best type and arrange for you to get them.

**Community or district nurse** – Someone who works outside the hospital environment, visiting people at home.

**Dietician** – A health practitioner who will advise you on foods, diet and nutrition tailored to meet your child's needs.

**Educational psychologist (EP)** – Assesses your child's development and provides support and advice on learning and behaviour.

**GP** – The family doctor, who deals with your child's general health and can refer you on to most other medical services. They may also support welfare benefit applications and other types of help.

**Health visitor** – A qualified nurse who has extra training in advising parent carers with young children. They do home visits in the early years to check on the child's health and development, and provide practical advice and support, and information on local services.

**Key worker** – A public sector employee who is considered to provide an essential service.

**Neonatologist** – A paediatrician who has additional training in treating newborn babies that need special care. They are trained specifically to handle the most complex and high-risk situations.

**Neurologist** – A doctor who specialises in the brain and nervous system.

**Occupational therapist** – Helps children improve their developmental function by therapeutic techniques and advises on adaptations and the use of specialist equipment.

**Orthotist** – Measures, designs, makes, fits and services braces, splints and special footwear to help people with movement difficulties and to relieve discomfort.

**Paediatrician** – A doctor who specialises in the care of babies and children. They work in hospitals, children's assessment centres or local health clinics.

**Physiotherapist** – Specialises in helping people with movement problems. They show you exercises for your child and discuss ways of holding and positioning your child, as well as developing good movement patterns.

**Portage worker** – Portage is a home visiting service for children with complex or significant additional needs that have usually been identified in the child's very early years.

**Social worker** – Qualified practitioners who support children and families by advising on and introducing them to appropriate services. They can advise on practical and financial issues, and tell you about local services.

**Speech and language therapist** – Advises on communication issues, and eating and drinking. If appropriate, they can recommend and help you with specialist communication aids or sign language.

## Useful resources

Here is a list of publications that you may want to refer to for additional information:

- Bjorklund, R., (2006) *Cerebral palsy*. Marshall Cavendish
- Miller, F. & Bachrach S.J., (2006) *Cerebral palsy – a complete guide for caregiving*. Johns Hopkins University Press
- Stanton, M., (2002) *The cerebral palsy handbook – a practical guide for parents and carers*. Random House
- *Disability rights handbook*. Available at the Disability Rights UK website [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org). This is a comprehensive reference guide to social security benefits and services for disabled people, updated every year.
- Meleady, C., *ENCO handbook*. Early Years Equality. This handbook provides guidance and support to equality named coordinators and settings in a variety of sectors on planning for and meeting children and young people's multiple equalities needs, and the settings equalities responsibilities and duties. In regard to disability equality, the work links with and supports the role of the SENCO.
- Doherty, J., & Morris, J., *A guide to grants for individuals in need*. A regularly update guide available at the Directory of Social Change website [www.dsc.org.uk](http://www.dsc.org.uk).
- Brewis, L., (2010) *Including children with cerebral palsy in the foundation stage*. A. & C. Black Publishers Limited
- Pimm, P., (2002) *Living with cerebral palsy*. Hodder Wayland
- Meleady, C., *Single equalities strategy*. Early Years Equality. This document focuses upon the Equality Act 2010 and the various protected equalities and requirements. Disabled children and young people's equalities are included.
- Martin, S., (2006) *Teaching motor skills to children with cerebral palsy and similar movement disorders: a guide for parents and professionals*. Woodbine House
- *Other Ways of Speaking* (2011) This booklet provides information about children and young people who use a variety of different ways to communicate, how you can help support them and where to go for further information. To download please go to [www.thecommunicationtrust.org.uk/resources](http://www.thecommunicationtrust.org.uk/resources)

The National Institute for Clinical Excellence (NICE) produces a range of guidance notes and information for the public on health and surgical treatments. You may find the following helpful:

- *Spasticity in children and young people with non-progressive brain disorders.* Available to download at [guidance.nice.org.uk/CG145/NICEGuidance/pdf/English](https://guidance.nice.org.uk/CG145/NICEGuidance/pdf/English)
- *Selective dorsal rhizotomy for spasticity in cerebral palsy.* Available to download at [guidance.nice.org.uk/IPG373/Guidance/pdf/English](https://guidance.nice.org.uk/IPG373/Guidance/pdf/English)

### **Books featuring children with additional needs**

Scope has published a list of books that include images of disabled children or feature disabled characters. These can be a great source of positive imagery for your disabled child and their siblings. For more information, visit [www.scope.org.uk/campaigns/scope-campaigns/children-picture/books-list](https://www.scope.org.uk/campaigns/scope-campaigns/children-picture/books-list).

### **Trendsetters**

This is a project run by Scope for young disabled people to share information and ideas around living with a disability. It includes online videos made by young people with cerebral palsy. Visit [www.scope.org.uk/help-and-information/young-disabled-people/about-project](https://www.scope.org.uk/help-and-information/young-disabled-people/about-project).

## Useful organisations and websites

### 1 Voice

A network and support system for children and families using communication aids.

[www.1voice.info](http://www.1voice.info)

0845 3307862

### Action for Kids

Helps young people with physical and learning disabilities find independence and create opportunities through the provision of mobility aids, employability training and family support.

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

0845 3000237

### Afasic

Helps children and young people with speech and language impairments, and their families.

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

0845 3555577

### Bibic

Offers information and support to the families of children with brain conditions.

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

01278 684060

### BLISS

Ensures that all babies born too soon, too small or too sick in the UK have the best possible chance of survival and of reaching their full potential.

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

020 73781122

### Bobath Centre

Two national charities for children with cerebral palsy and adults with neurological disability improving the independence, health and wellbeing of people living with cerebral palsy.

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

020 84443355

### Brainwave

Provides home-based therapies and exercises to support disabled children.

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

Tel: 01278 429089 (Somerset); 01376 505290 (Essex); 01925 825547 (Warrington)

### British Epilepsy Society

A national epilepsy medical charity working for everyone affected by epilepsy.

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

01494 601400

### Bullying UK

Offers a helpline and support for families dealing with bullying.

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

0808 8002222

### Cerebra

Works to improve the lives of children with brain-related conditions through research and education, and by directly supporting the child and their parent carers.

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

0800 3281159

### Chartered Society of Physiotherapists

Official organisation for physiotherapists and physiotherapy. Its website allows you to search for a physiotherapist near you.

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

### Child Brain Injury Trust (CBIT)

Provides information, support and training to anyone affected by childhood-acquired brain injury.

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

0303 3032248

### The Children's Trust, Tadworth

Works with children with acquired brain injury, multiple disabilities and complex health needs.

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

01737 365000

### Communication Matters

A charitable organisation which covers the whole of the UK. Their vision is a world where all individuals have a right to a 'voice' through the provision of equipment and ongoing support services.

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

0845 456 8211

### Contact a Family

Offers support, advice and information for families with disabled children.

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

0808 8083555

### Council for Disabled Children (CDC)

A membership organisation that hosts a number of networks relating to disabled children.

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

0207 8431900

### CP Sport

Promotes and seeks to increase sport and physical recreational opportunities for people with a disability, especially those who have cerebral palsy.

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

0115 9256442

### Disability Equipment Register

A not-for-profit organisation providing a service for disabled people and their families to enable them to buy and sell items of used disability equipment on a direct one-to-one basis.

[www.disabreg.pwp.blueyonder.co.uk](http://www.disabreg.pwp.blueyonder.co.uk)

01454 318818

### Disabled Living

A charity which provides impartial information about equipment (assistive technology) and services for disabled adults, children, older people and the professionals who support them.

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

0161 607 8200

### 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 130 9177

### Dynavox

Provides communication and education solutions designed to help individuals living with speech, language and learning disabilities communicate and reach their potential.

<http://uk.dynavoxtech.com>

01926 516250

### Early Years Equality

Provides disability equality and other protected characteristic equality support, guidance, advice, discrimination casework and training to children, families, organisations, providers and policymakers across the UK.

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

0114 2700214

### Education and Resources for Improving Childhood Continence (ERIC)

ERIC provides information, support and resources to children, young people and their families and health professionals on bladder and bowel problems.

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

0845 370 8008

### Epilepsy Action

Offers information and support on all aspects of epilepsy.

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

0808 8005050

### Equality and Human Rights Commission

Promotes and monitors human rights and equality.

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

0800 444205

### Family Footings

Helps families to find a common language with practitioners through person-centred approaches.

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

01908 230100

### Family Fund

Gives grants to low-income families raising disabled and seriously ill children and young people.

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

08449 744099

### Family Information Service

Your local Family Information Service (FIS) provides a range of information on all services available to parents, including parents of disabled children.

<http://findyourfis.daycaretrust.org.uk>

020 7940 7510

### Family Lives

Helps parent carers deal with the changes that are a constant part of family life and supports them to achieve the best relationship possible with their children.

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

0808 8002222

### The Foundation for Conductive Education

Works to improve the lives of children and adults with neurological motor disorders through the system and practice of conductive education.

[www.conductive-education.org.uk](http://www.conductive-education.org.uk)

0121 4491569

### HemiHelp

A membership organisation supporting children and young people with hemiplegia, and their families.

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

0845 1232372

### I CAN

The children's communication charity. I CAN's mission is to ensure that no child who struggles to communicate is left out or left behind.

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

0845 225 4071

### Include Me Too

Supports disabled children, young people and their families from black, ethnic minority and other marginalised backgrounds, and aims to promote and support all disabled children and young people's rights.

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

01902 711604

### Institute of Child Health

Works to improve the health and well-being of children, and the adults they will become, through world-class research, education and public engagement.

[www.ucl.ac.uk/ich/homepage](http://www.ucl.ac.uk/ich/homepage)

020 72429789

### KIDS

Its vision is of a world in which all disabled children and young people realise their aspirations and their right to an inclusive community.

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

020 75200405

### Kidscape

Offers support and advice to parent carers of bullied children.

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

08451 205204

### Kidz Aware

A website for everyone who wants to make sure that children grow up in a world free from social exclusion, discrimination, bullying and racism.

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

### Mencap

Works with people with a learning disability to change laws and challenge prejudices, and supports them to live their lives as they choose.

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

0808 808111

### National Children's Bureau (NCB)

Supports children, young people, their families, and those who work with them.

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

020 78436000

**Parent Partnership Service** – Provides information to parent carers and practitioners involved with children with special educational needs.

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

### Powerpack

Devon-based support network of families, creating opportunities for disabled children in wheelchairs.

[www.powerpack.uk.com](http://www.powerpack.uk.com)

### Scope

Provides information, advice and support to disabled people and their families at every stage of their lives.

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

0808 8003333

### Sibs

Provides information and support for the siblings of disabled children and adults.

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

01535 645453

### Talking Point

Talking Point is a website all about children's speech, language and communication. It is designed for parents, people that work with children, and children and young people themselves.

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

### The March Foundation

Supports inner-city children who have learning difficulties to reach their full potential.

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

01252 810557

### The Movement Centre

A physiotherapy centre helping children with cerebral palsy and related problems of movement control.

[www.the-movement-centre.co.uk](http://www.the-movement-centre.co.uk)

01691 404248

### Wheelpower

Transforms lives through sport.

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

01296 395995

### Whizz-Kidz

A charity that is all about giving disabled children the chance to lead a more independent life. Its service meets their individual mobility needs.

[www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk)

07588 555761

### Youthnet

Online guide and support for young people, enabling them to make informed choices, participate in society and achieve their ambitions.

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

## Glossary

**Additional needs** – The term ‘additional needs’ is used in this and other Early Support resources to refer 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.

**Ataxia** – Lack of voluntary coordination of muscle movements.

**Athetoid (or dyskinetic)** – Involuntary movements resulting from the rapid change in muscle tone from floppy to tense.

**Athetosis** – A condition characterised by uncontrolled, rhythmic, writhing movements, especially of fingers, hands, head and tongue.

**Augmentative and alternative communication (AAC)** – An umbrella term that encompasses the communication methods used to supplement or replace speech.

**Cerebral palsy** – A disorder of movement and posture due to a non-progressive lesion or damage to the immature brain.

**Common Assessment Framework (CAF)** – A process to ensure children’s needs are met in the most efficient and proactive way.

**Computerised tomography (CT) scanning** – Also known as a CAT scan, this uses X-rays and a computer to create detailed images of the inside of the body.

**Conductive education** – A holistic learning approach that integrates children’s learning – communication, physical, intellectual and emotional – within the Early Years Foundation Stage Framework and the national curriculum.

**Contracture** – Permanent shortening of a muscle or joint.

**Cranial ultrasound (CUS)** – A method using reflected sound waves to produce pictures of the brain and the inner fluid chambers (ventricles).

**Diplegia** – Where both legs are affected but the arms are not (or less so).

**Early Support Our Family** – This file includes the family file, a family-held record and a number of useful publications to support better coordination of services provided for a child and family. The file is designed to encourage joint planning and partnership working between families and the practitioners who work with them.

**Early Years Foundation Stage Framework** - The Early Years Foundation Stage (EYFS) is the statutory framework that sets the standards that all Early Years providers must meet to ensure that children learn and develop well and are kept healthy and safe. It promotes teaching and learning to ensure children are ready for school and gives children the broad range of knowledge and skills that provide the right foundation for good future progress through school and life.

[www.education.gov.uk/schools/teachingandlearning/curriculum/a0068102/early-years-foundation-stage-eyfs](http://www.education.gov.uk/schools/teachingandlearning/curriculum/a0068102/early-years-foundation-stage-eyfs)

**Equality named coordinator (ENCO)** - A childcare practitioner that completes a training course to become recognised as the 'Equalities Named Coordinator' in their setting.

**Hemiplegia** – A condition affecting one side of the body only.

**Hydrocephalus** – Also known as 'water on the brain', it's a medical condition in which there is an abnormal accumulation of cerebrospinal fluid in the brain.

**Hypertonia** – High muscle tone which means the muscle feels stiff.

**Hypotonia** – Low muscle tone which means the muscle can feel floppy.

**Magnetic resonance imaging (MRI)** – Uses magnetic and radio waves to diagnose conditions affecting organs, tissue or bones. There is no exposure to X-rays or any other damaging forms of radiation.

**Meningitis** – Inflammation of the protective membranes covering the brain and spinal cord, known collectively as the meninges.

**Mixed cerebral palsy** – When children have both the tight muscle tone of spastic cerebral palsy and the involuntary movements of athetoid cerebral palsy. This is because they have injuries to both the pyramidal and extrapyramidal areas of the brain.

**Motor impairment** - A loss or limitation of function in muscle control or movement or a limitation in mobility.

**Nasogastric feeding** – A nasogastric (from the nose to the stomach) tube is used for feeding and administering drugs and other oral agents.

**National curriculum** - The national curriculum is a set of subjects and standards used by primary and secondary schools so children learn the same things. It covers what subjects are taught and the standards children should reach in each subject.

**Primary ageing** – Refers to aspects of the normal ageing process that we have no control over.

**Quadriplegia** – Where all four limbs are affected.

**Secondary ageing** – Aspects of ageing that are directly affected by lifestyle, disease and trauma.

**Spasticity** – Tightness and stiffness of muscle tone.

**Special education needs coordinator (SENCO)** – A SENCO is responsible for the day-to-day operation of a school's special educational needs policy, coordinating resources to meet the needs of each pupil identified as having a special educational need.

**Team around the child (TAC)** – Coordinates and delivers integrated services for children and young people. A TAC meeting takes place between the family and the services/practitioners to look at ways that they can support you and your child.

**Tremor** – Rhythmic, involuntary, trembling or quivering movements.

**Videofluoroscopy** - A moving X-Ray image of swallowing recorded on DVD that allows an individual's swallow to be viewed in real time, slow motion or frame by frame. It is an essential diagnostic tool for the assessment and management of people with swallowing difficulties.

**Voice output communication aid (VOCA)** – An electrical device that assists people who are either unable to speak or whose speech is unintelligible.

# Early Support

for children, young people and families

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

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**Early Years Equality**  
*removing racism • defying discrimination*

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