

Information for parents

Cerebral palsy



About this publication

This is a guide for parents with young children who have recently been told that their child has cerebral palsy, or who are in the process of getting a diagnosis.

It was developed in co-operation with families and this edition is an updated version based on the original information for parents booklet 'Cerebral palsy', adapted by kind permission of **Early Support**, a UK government initiative. It was originally developed by **Early Support** in partnership with **Scope**, in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content and the text reflects what parents who have 'been there before' say they would have liked to have known in the early days of finding out about their child's situation. This updated version of the publication was adjusted by the Early Support Wales team and **Scope Cymru** using feedback from parents and practitioners and in response to changes in the Welsh context.

To find out more about **Early Support** and to download copies of other **Early Support** materials, visit www.earlysupportwales.org.uk

Where words are printed in colour and italics, *like this* it means that a parent of a child with cerebral palsy said it.

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 booklet, that the contact details for the organisation or agency identified are listed in the **Useful contacts and organisations** section or that you can find out more in the **Who can help?** section.



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Introduction

Cerebral palsy is an umbrella term for a range of non-progressive conditions that affect a child's ability to move and to maintain posture and balance. It's a complex condition that can be very mild or severe, with no two people being affected in quite the same way.

This booklet has been written in partnership with parents of children with cerebral palsy to provide general information for families and carers. It aims to answer some of the questions you may have in the early days and to explain where you can get more information and help.

If you feel you don't want to read all the information now, that's fine - come back to it later when you have particular questions in mind or want to check up on things as your child develops.

Everybody reacts differently to the news that their child has a problem that they were not expecting. Most people feel anxious about what it will mean and how they will cope when they first discover that their child has cerebral palsy.

Don't be afraid to ask as many questions as you like - no matter how simple or trivial they may seem. It helps if you understand more, and realise that there are positive things you can do to help your child develop.

'My advice to other parents is don't sit and worry. There's lots that can be done. It's just a matter of finding out what.'

If you would like to find out more about cerebral palsy or talk through anything you read in this booklet, ring **Scope Response Free helpline - 0808 800 3333**. They will be more than happy to help.

What is cerebral palsy?

Cerebral palsy is an umbrella term for a non-progressive condition within the brain that affects movement, posture and co-ordination. Problems may be noticed around the time of birth or may not become obvious until later. It's a wide-ranging condition and no two children with cerebral palsy will be affected in the same way. Cerebral palsy does not normally affect life expectancy.

If a person has cerebral palsy it means that the part of the brain that controls muscles and movement has been affected or damaged. Sometimes other areas of the brain are involved, affecting vision, communication and learning. Cerebral palsy is sometimes referred to as a 'developmental condition' because damage can occur during the prenatal, natal or postnatal periods - that is, before birth, at birth or after birth.

The brain impairment that causes cerebral palsy is non-progressive i.e. it does not get worse. However, the effects on the body may become more (or less) obvious as time goes by. Cerebral palsy, therefore, is a general term for a wide range of non-progressive cerebral (brain) disorders, which result in some sort of movement impairment, that become apparent during early childhood.

It is important to remember that no two people with cerebral palsy are affected in the same way. Your child is an individual and their pattern of development will be their own.



How many children have cerebral palsy?

Cerebral palsy is more common than is generally realised. Currently, an estimated one in every 400 children is affected by the condition - 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.

What causes cerebral palsy?

It is often not possible for doctors to explain exactly why part of a baby's brain has been injured or has failed to develop, as there may be no obvious or single reason. Cerebral palsy can be caused by multiple and complex factors and the cause of about 40% of cases is unknown. However, sometimes causes can be identified and some relevant factors are:

- Infection in the early part of pregnancy (7% of cases).
- Premature birth - 33% of babies born prematurely go on to develop cerebral palsy. Pre-term babies are extremely vulnerable and at risk of **haemorrhage**, infection and oxygen deprivation to the brain. The risk of cerebral palsy is 60 times higher if the baby's birth weight is below 1,500g.
- A difficult birth (10% of cases) 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.
- After birth (7% of cases) - this category can include the affects of other conditions or illnesses such as **meningitis** and **hydrocephalus**, a head injury, very high fever or a lack of oxygen from choking, near miss cot death etc.
- 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 three types of cerebral palsy:

- spastic
- athetoid (or dyskinetic)
- ataxic

In general, these three 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.

Spastic cerebral palsy

Spastic means 'stiff'. This form of cerebral palsy causes the muscles to stiffen and decreases the range of movement in the joints. It is the most common form of cerebral palsy and occurs in three-quarters 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 may have an effect on how clearly children can speak.

If only one side of their body is affected, the term used to describe this is **hemiplegia**. Read more about hemiplegia at the end of this section.



Athetoid (or dyskinetic) cerebral palsy

Children with **athetoid cerebral palsy** make involuntary movements, because they can't control the way their muscle tone changes from floppy and loose to tense and stiff. Their speech can be hard to understand as they may have difficulty controlling their tongue, breathing and using their vocal cords. Hearing problems are commonly associated with **athetoid cerebral palsy**.

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 of any sort tends to increase **athetosis**.

Ataxic cerebral palsy

Children with **ataxic cerebral palsy** find it very difficult to balance. They may also have poor spatial awareness, which means it's difficult for them to judge their body position relative to the things around them. **Ataxia** affects the whole body. 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 mild **athetosis**.

Mixed

The descriptions above don't always describe individual children with cerebral palsy. People often experience a mix - for example **athetosis** with **ataxia**, **athetosis** with **spasticity** etc.

Some other terms you may hear people using

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

- **hypertonia** - too much muscle tone leading to stiffness
- **hypotonia** - too little 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 no obvious physical impairment, but children experience poor coordination and 'clumsiness' that can be associated with some learning difficulties.

Another way of describing cerebral palsy - the limbs affected

Cerebral palsy is sometimes grouped and described according to the area of the body or the number of limbs involved.

Monoplegia means only one limb (arm or leg) on one side of the body is affected - this is very rare.

Diplegia describes cerebral palsy that mainly affects a child's 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 means only one side of the body is affected. Childhood hemiplegia is a relatively common condition, affecting up to one child in 1,000.

Triplesia means three limbs are affected - usually one upper and two lower.

Quadriplegia means cerebral palsy affects a child's arms and legs. Quadriplegia can also affect the trunk, neck and face muscles.



It's important to remember that these words only give some simple categories to describe where in the body cerebral palsy is influencing muscle control. They don't tell you anything about how severely different parts of your child's body are affected.

Hemiplegia

Hemiplegia is a condition affecting one side of the body - it's often referred to as 'right' or 'left sided' depending on the side of the body that's 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 arm.

The causes of **hemiplegia** are mostly unknown, and usually parents become aware that it is affecting their child gradually 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 organisation **HemiHelp** offers information and support to children and young people with **hemiplegia**, their families and those working with them. They produce a large range of factsheets many of which can be downloaded from their website or you can get support by telephoning their Helpline on 0845 123 2372. The helpline is open from 10:00-13:00, Monday to Friday during term time. If you call outside these times, you can leave a message and one of Hemihelp's helpliners will call you back. Or if you prefer email, you can contact them at helpline@hemihelp.org.uk.

Starting out

Finding out your child has cerebral palsy

Finding out your child has cerebral palsy is almost always unexpected and often devastating.

Parents often say that they bounce between feeling they need to hold onto their child and never let them go and wanting to run away. This is normal - it takes time to take in and 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.'

'My advice to other parents would be to take it one day at a time.'

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.'



Why can it take so long to get a diagnosis?

It can be difficult for your doctor or paediatrician to diagnose cerebral palsy in the first months of a child's life.

Parents 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 aren't picking up the usual **motor skills**, or that they aren't sitting up properly, or that they show an unusual tendency to stand on their toes.

Sometimes if you go to your doctor 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 so you may hear broader terms like 'motor delay' or 'developmental delay' being used.

The reason for 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 why doctors tend to avoid making predictions about the long-term effects of your baby's disability and the impact it could have on their lives too early.

Children's motor symptoms normally stabilise by two to three years of age.

How will it affect my child?

Children with cerebral palsy are children first and foremost, and it's important to remember that they're all affected in different ways.

Children with cerebral palsy can have average or above average intelligence, but some have a significant learning difficulty. So, some learn to talk, sit up and walk, although they may take longer to develop than other children of the same age, while others 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 don't get worse as a child gets older, although some of the effects of muscle weakness and **spasms** do get worse as a child grows. On the other hand, children sometimes get better at understanding and dealing with the effects of their cerebral palsy as they get older.

Is there a cure?

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, they can be supported 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 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 parents. You'll be seeing your paediatrician during this time and your health visitor will advise you on any medical matters.

Epilepsy

Some children develop epilepsy. Medication is often used to control this. Generalised seizures occur when unusual electrical activity involves both sides of the brain at once. Partial seizures occur when unusual electrical activity starts in only one of the brain's hemispheres. **Epilepsy** is usually controlled by anticonvulsant drugs, which may have a sedative side effect. Other ways of managing the condition include special diets or complementary therapies.

Epilepsy Wales was set up as a charity in 1986 to help people with epilepsy in Wales, their families and carers. They have a helpline - 0800 228 9016. They can also be contacted by fax, post or email. Their contact details are:

Epilepsy Wales
PO Box 4168
CF14 OWZ

Email: helpline@epilepsy-wales.org.uk
Web: www.epilepsy-wales.org.uk

Administration Tel: 07432 640056
Email: weabradbury@btconnect.com

Epilepsy Action is a UK organisation which provides information about epilepsy - you can download information from their website - www.epilepsy.org.uk - or telephone their Helpline on 0808 800 5050.

Learning difficulties

It's helpful to think about a number of different factors that can affect a child's ability to learn when they have cerebral palsy:

- Environmental factors, where children experience difficulty because they don't have the same learning opportunities as others. If a child can't move or speak, they rely on adults around them to create a learning environment that helps them develop. There's a lot you can do to help a child in this situation. *'You are the best game in the town and the best toy in the house.'* Monty Ball, parent and psychiatrist
- Specific learning difficulties, where a child has difficulty learning because they have a problem processing particular types of information - for example, integrating spatial (where things are in relation to the body) or auditory (listening to and understanding sound) information. These processing difficulties may affect particular skill areas, for example learning to read or spell. They do not affect a child's overall level of intelligence.
- Severe learning difficulties, that are the result of extensive damage to the brain bring 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.

Don't assume if your child has a severe physical impairment they also have a learning difficulty - they may well not. It's important to keep remembering that every child is different, so they may have a particular problem with, say, mathematics, but find reading relatively easy.

Difficulties with eating

These include 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. Sometimes babies with cerebral palsy have difficulties feeding from a breast or bottle that are obvious soon after birth and difficulties continue throughout life. Others experience difficulties later in life, sometimes only in adulthood.



Sucking

Some babies with cerebral palsy experience difficulties sucking. Many new babies experience problems latching onto 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 there's a nurse advisor with specialist expertise and experience of helping with feeding difficulties who can help. Once you take your baby home, your **health visitor** should be able to advise if problems with sucking continue.

Weaning

Babies with cerebral palsy often find eating semi-solid food easier than sucking and they thrive better once they've 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 if there are any issues. If you're in contact with a **speech and language therapist** ask them, as well.

Growing up and gaining more independence

Many children with cerebral palsy prefer to be able to sit at the table and feed themselves, even if it takes longer and is messier than being helped to eat. Most children learn to feed themselves to some degree eventually. Taking the time and effort to help a child to develop these skills can sometimes 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.

Visual or spatial perception difficulties

Although there may be nothing wrong with a child's vision, their brain may 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:

- Body perception, that is, the overall awareness of body parts, posture, balance and movement
- Vision, in particular, the ability to focus, to follow and scan objects or text or to give a name to what is seen. This last difficulty can often be mistaken for a communication or vocabulary problem
- Learning to read, because words appear backwards or with an inconsistent pattern
- Perceptual motor skills that 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 affected 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 (the ability to link these two areas when planning activity). Some children who are affected experience particular difficulty with 'midline crossing', that is, reaching one hand to the opposite side of the body before using it.



Sensory impairment

Sometimes hearing, vision, touch, taste and smell are affected in children with cerebral palsy if other areas of the brain are involved in the injury that led to the cerebral palsy.

Sometimes there is damage to the visual cortex of the brain resulting in impaired vision, even though there is no damage to the eye itself.

Hearing impairment is another common associated disability.

For more information about deafness or hearing impairment, contact the [National Deaf Children's Society](#). For more information about visual impairment, contact the [Royal National Institute of the Blind \(RNIB\)](#) or the [National Blind Children's Society](#). The organisation Sense is for children and adults who have multiple or complex sensory impairments. Contact details for all of these organisations are provided in the [Useful contacts and organisations](#) booklet in the [Family pack](#).

Speech and language difficulties

Speech can be affected in children with cerebral palsy, although the range of impact is very wide. 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.

There are many alternatives to verbal communication - these are known collectively as **augmentative or alternative communication systems**. Some people use sign language, for example British Sign Language, the language used by deaf people, or Makaton. Some other systems to support communication are based on pictures and symbols - for example, Rebus and Bliss.

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 he or she interacts and communicates well with a widening circle of people, will be of immense value later on.



Helping 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's important to encourage your child to take part in family life in as many ways as you can.

It will help if you treat your baby as much like every other child as you can and if you encourage your family and friends to do the same - 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 it comes to settling in at a nursery or school later on.

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 your knee. Try to communicate with your child as much as possible. The more you talk, look and touch, the more you'll learn to recognise what your child is trying to tell you. **For more information, visit www.scope.org.uk/services/early-years.**

This section runs through some everyday activities and offers some practical tips and suggestions for how you might use daily life to encourage development.

Playing and learning

Play is important for children. It's the way they explore the world and find out more about themselves. Play offers children the opportunity to 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 and so you may find some parts more useful than others.

If you're not sure what kind of play will be enjoyable and help your child, or whether a toy you have in mind is suitable to 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 other cases simple adaptations to toys are needed.

Some children have very little muscle strength and get tired easily. If this is the case with your child, look out for toys that give a big reward (light, sound or movement) for a small effort and for lightweight toys.

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!

Remember that all children dislike some activities or toys, but that your child may not be able to communicate this.

Practical Tips

- 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 the same 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're easier to see - or see if you can make parts of the toys you're playing with bigger, so they're 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.

If you would like to find out more, Scope produce a pack called 'Play Talks' and a factsheet called 'Play and learning'. RNIB, in association with Scope, produce a series of simple play activities that support the development of spatial awareness called 'Play with a Purpose'. These sheets are available from Scope and RNIB (contact details at the end of this booklet).



Handling your child

'Handling' means how you lift, carry, hold, position your child and what you learn to do to help them with muscle stiffness or with the uncontrolled muscle movements they make. The best way to handle a baby or child depends 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.

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 opinion from your **paediatrician, doctor or therapist**.

Practical Tips

- 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, supporting 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.

Getting 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'll 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.

Practical Tips

- 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 with children with cerebral palsy in mind. Scope may be able to help you find places that sell these (Scope's contact details are at the end of this booklet)
- Put the clothes on the most affected part of the body first
- Buy well-fitting, supportive shoes. Some children with cerebral palsy need special shoes, which are usually provided free of charge by your health authority. Your doctor or physiotherapist can advise 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.

Eating and mealtimes

Some children with cerebral palsy find it difficult to suck, swallow and chew, so eating may be messy and take a long time. They may have trouble feeding soon after birth or later on in life.

However long it takes, it's important to take the time 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 difficulties eating.

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.

Practical Tips

- Getting your child into the right position to eat is very important - for example, it's difficult to eat or drink with the head tilted back. You may need to take the time to help your child get into a good position several times during a meal.
- 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 let them smell it and describe 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 disabled children. Your health visitor or occupational therapist should be able to tell you more about this if you think they might help. If you would like to find out more, Scope produce a pack called 'Food Talks' and a factsheet called 'Mealtimes'.

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 drinks. 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.

Practical Tips

- 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.

Going to the toilet

It's 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 be important because they 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.



Practical Tips

- Before starting on the process of trying to toilet train your child it might be a good idea to talk to your doctor to see if they think any aspects of your child's condition will affect their ability to control their bladder or bowel movements. It may be best to seek specialist advice about how to manage your child's continence. Your family doctor should be able to refer you to a suitable health professional.
- It's 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. There is also a specialist organisation called **ERIC** (see Useful contacts and organisations section) that can advise and support you.

Bedtime

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 don't drop off to sleep easily or sleep for very long because they find it difficult to get comfortable at night or to change position.

If your child finds it difficult to move, you may need to turn them several times in the night. Your **physiotherapist** can show you ways to use pillows to support your child when they're lying on their side. Young children, and particularly babies, should never sleep on their stomach or be allowed to get too warm.

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 doesn't get too cold.

It's 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.

Practical Tips

- Develop a bedtime routine that your child will look forward to. It should be an opportunity for them to have your undivided attention for at least half an hour. Avoid stimulating activity in the hour before bedtime - a bedtime routine should be a quiet, relaxing time without noisy games, rough play or frightening fairy tales.
- Make sure your child doesn't go to bed hungry, but avoid stimulating drinks that have a high sugar or caffeine content before bedtime.
- Help your child become accustomed to falling asleep alone in their own bed, without you being there.



Communication

Communication is at the very centre of our lives. It expresses our identity as individuals and allows us to have relationships with other people.

Communication happens in many different ways, 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're happy or sad, hungry or thirsty. Parents 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's good to seek advice as early as possible from a **speech and language therapist** as well as from a **physiotherapist** and **occupational therapist**.

Types of communication

Most of us communicate through spoken language and 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, as 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 want, and need to express, the same range of thoughts and feelings as other people, in a modified manner. Others have a more limited range of ideas and feelings to communicate but need a reliable system to signal their own meanings and to indicate when they've understood what other people say to them. Augmentative communication is aided communication that includes a whole range of 'low tech' techniques, symbols and strategies that are used to help children communicate better.

Augmentative and Alternative Communication (AAC) offers a range of ways of replacing spoken words. It can range from a movement or behaviour that's interpreted as meaningful, to the use of a more formal code agreed between people where different items have specific meanings.

A speech and language therapist can give you advice about all these methods.

Encouraging communication

- Talk, talk, talk all the time - tell your child what you're doing, what's 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, make faces and noises to encourage your child to do the same; respond to any sound your child makes e.g. by pausing, looking at them, imitating the sound etc.
- 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 it fun for both of you!



Other communication methods

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

Sign language

Your **speech and language therapist** may suggest you start to use simple sign language with your child (such as Makaton or Signalong). 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 this is the case, the **speech and language therapist** will explain the system your child could use. When talking to the therapist, find out how they expect the signs you use will help your child. For example, will they help them to understand more? Will they help your child 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 the hands will be flexible enough for making signs. If the therapist does not think your child's hands will be useful for signing you will need to think of using switches or pictures instead.

Symbol systems

Using pictures that a child can point to can have a very good impact on reducing frustration even for children with very little control of movement. Any work done with pictures and symbols early on can be useful if the child needs more advanced technological aids to communication later on.

Objects of reference

Objects of reference use 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** can explain this to you if they think this would help your child.

Communication passports

Where children are using alternative means to communicate, a 'communication passport' introduces children 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 play groups, nurseries and then school.

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, at the same time as helping other people understand your child's needs. [Find out more and download a template from www.scope.org.uk/services/early-years/products/communication](http://www.scope.org.uk/services/early-years/products/communication)

Technological devices

There are many different types of 'higher tech' '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.

The importance of yes and no

The ability to indicate yes and no is a basic communication skill that empowers a child to indicate what they want and don't want, like and don't 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'll find you can begin to communicate with your child and they'll begin to be able to respond to your questions.

Offering choices

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



Practical Tips

- 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 e.g. food or drink.
- After showing 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.

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 the length over a period of time. An **occupational therapist** will be able to advise you about supportive seating.

Early intervention - therapies and approaches

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. This aims to find out what families need in terms of support. The assessment of individual needs is therefore very important. Consult the professionals who are already in contact with your family (for example, your **family doctor**, **health visitor** or **paediatrician**) before starting any treatment, particularly if you're thinking of paying for it.

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

Your **family doctor** or **paediatrician** refers you to therapy services if they are needed. Referral is always necessary to **physiotherapy** and **occupational therapy** services (unless you decide to go privately). You may be able to contact the speech and language therapy department in your local hospital directly.

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 talking through different approaches towards promoting development. For this reason, therapists often like to see children when cerebral palsy is first suspected or diagnosed.

Your **doctor** or **paediatrician** may well refer you to a child development centre or paediatric assessment unit 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 together to devise a treatment programme that's 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 assess and work with children using natural methods like exercise, manipulation, heat, as well as electrical or ultrasonic procedures. They also advise parents and carers on how to lift and position their child safely and properly. They may teach you a series of exercises that you can use regularly to help your child at home.

A **physiotherapist** may work with you on teaching 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 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 therapists work as part of local authority social services departments 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.

They also work with **physiotherapists** to encourage the development of new skills. An **occupational therapist** may work with you to develop physical or learning skills, using special play equipment. They can also advise on equipment to help mobility, like tricycles and trolleys. They sometimes give advice about equipment and aids that could help your child with everyday activities, like eating.

An **occupational therapist** may work within the community, a hospital, school or a special unit.

Speech and language therapy

Speech and language therapy helps children 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 language and speech, 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're 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 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, symbol speech or a communication aid can reduce frustration that a child experiences when not able to communicate their wishes and desires.

Speech and language therapists normally work in clinics, health centres, schools and hospitals.

More information

If you want to know more about physiotherapy, occupational therapy or speech and language therapy services, here are some professional organisations to contact:

- **The Chartered Society of Physiotherapy**
- **The College of Occupational Therapists**
- **The Royal College of Speech and Language Therapy**
- **AFASIC**
- **Association of Speech and Language Therapists in Independent Practice**



Bobath therapy

Bobath therapy is a form of physiotherapy that aims to improve a child's posture and movement.

Through specialised ways of handling, stiffness can be reduced, muscle control against gravity can be increased and fluctuating muscle activity can be stabilised.

Positioning is very important to Bobath treatment. A child's position is frequently changed to improve movements by handling the child using key points on the body.

A Bobath therapist works with a child's family to teach them how to handle and position the child properly at home. The therapy works through play, so any treatment is fun for the child..

For more information, contact the **Bobath Centre** (contact details at the end of this booklet).

Conductive education

Conductive education is a holistic learning approach designed to help disabled children become more independent. It was developed in Hungary, but British therapists and teachers have used elements of the system for over 20 years.

Conductive Education is not suitable for everyone and it isn't a cure. It may, however, enable children to develop more independence. If you're interested in using the approach, it's advisable to begin Conductive Education as early as possible.

Conductive Education is concerned with a child's development throughout the day. A child's daily routine will include several series of tasks carried out in different positions, for example, lying, sitting and standing-walking positions. It's important to understand that these are all inter-linked. Skills that are learnt in these various positions are applied during other activities throughout the day.

A 'conductor' is a person specially trained in Conductive Education. They set tasks in partnership with families. A child's peer-group and parents are all encouraged to become involved in the process.

It's also important to realise that this is not just a physical programme. The conductor also uses activities to develop age-appropriate cognitive, social and emotional skills, for example learning colour, names, numbers, directions, etc.

You can find out more about Conductive Education by contacting the [Foundation for Conductive Education](#). Scope also supports an associated national network of pre-school services called the National Network of [Schools for Parents](#).

Schools for parents

Schools for parents are welcoming places where parents can learn how to work and play with their child. They use the principles of Conductive Education to offer active learning to children and families. Sessions are based on the principle that the parent, the professional and the child are a team working together and have equal parts to play in the child achieving success. There are over 30 Schools for Parents around the country - to find out if there is one in your area contact Scope.

Portage

Portage is a home-visiting educational service for pre-school children with additional support needs and their families. It is also sometimes used in schools and nurseries. Expertise and responsibility is shared between professionals and parents.

After an initial assessment a 'Home Visitor' will prepare an individual programme for children with parents and sets weekly goals. Parents then work with their child everyday, 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](#) (contact details in the Useful contacts and organisations booklet in the Family pack)



Complementary therapies

'Complementary therapy' is a term used to describe a number of different therapies, each of which has 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 with your child, always use a qualified therapist and tell them exactly how cerebral palsy affects them and about any special needs they have. As with all other approaches, an individual assessment is very important before therapy begins.

Many doctors will prescribe alternative or complementary therapies on the NHS. Ask them what they think before you begin

Other useful information

Meeting with professionals

Your family should be fully involved in any meetings involving therapists and professionals that are about your child, and your views should be taken into account. It's important that you understand everything that is said, although sometimes this can be difficult, if a lot of technical language is used or if you're anxious or upset.

Other parents have found it helpful to:

- Plan beforehand and be clear about what you hope to achieve. It may be helpful to make a list of questions before the meeting to take with you.
- Take someone with you if you can - a family member or friend.
- Ask for honest straightforward answers to your questions.
- Ask questions about anything you don't understand, disagree with or have a concern about.
- Ask for copies of any written reports or assessments that are discussed.

Sometimes it's hard to remember what's been said at key meetings. If you can take some notes or have someone with you who will note down important points, it can help. If you're not comfortable doing this, you could ask if you can make a recording of what's said. The [Family file](#) is a good place to keep notes and can be taken with you and shared at meetings.

Financial help

A range of benefits and tax credits are available to help families with disabled children. The main ones are:

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

Entitlement to some benefits can be triggered by a person's care needs - for example, the 'care component' of the Disability Living Allowance, and the Carer's Allowance, which is a benefit for carers. Sometimes it is mobility that triggers the benefit - for example, the 'mobility component' of Disability Living Allowance. Read more about this in the booklet on [Financial help](#) in the [Early Support Family pack](#).



Other benefits are not specific to disability, but are designed to help those on low incomes.

It's not possible to write about benefits in detail in this booklet, but it is important that you check whether you're receiving all the state benefits you're entitled to. Failing to claim one benefit can sometimes mean that you miss out on additional state benefits and money from other sources.

If you want to find out more about the benefits you are entitled to, you can ask your **social worker**, visit the Beginner's guide to benefits section of the **Directgov** website (<http://tiny.cc/X2PEg>) or telephone the Freephone **Benefits Enquiry Line** on 0800 882 200, open Monday to Friday 8am til 6pm, Textphone 0800 243 355.

Direct Payments

Direct payments are a way for parents and carers of disabled children to organise and pay for the support they are entitled to from social services themselves. Instead of getting services that are arranged by social services (such as an overnight stay with another family, or someone coming to your home to help out), an equivalent amount of money is paid to you each month. You can then use this to buy in the support you and your child need.

Everyone eligible for social care services, such as respite care or help in the home, is entitled to direct payments. Direct payments will not affect your benefits, as they are not extra money to spend on things as you want - they replace help from social services.

To get direct payments you first have to get an agreement from your local social services that your family is eligible for help. Because of the limited resources available to social services departments, those thought to be most in need are given priority.

Scope has produced a guide to direct payments, called 'In the driving seat'. You can download a copy from their website or telephone the **Helpline** for a copy.

The **Disability Alliance** can offer advice on benefits and direct payments, they also publish a Disability rights handbook annually. **Contact details are at the back of this booklet.**

Some other sources of financial help

- The **Family Fund** - the Government finances this fund and the Joseph Rowntree Foundation administers grants. The Fund is for families with a severely disabled child up to the age of 18.
- VAT Relief - you may be entitled to tax relief when buying items that are intended exclusively and specifically for the use of disabled people - for example, a wheelchair or an adapted computer keyboard. Most suppliers of specialist equipment for disabled people can advise on this.
- Voluntary organisations - if you decide that you need the assistance from a charity or grant-giving trust, you will need to find out which ones you could apply to. You can obtain a list from your **social worker**, a local advice organisation (such as the Citizens Advice Bureau) or from disability organisations, like **Scope**.
- It's possible to access similar information via **Funderfinder**, which is a computer database which filters through the details of hundreds of different grant givers and selects those that will be the most appropriate. You can access **Funderfinder** via one of the many voluntary sector organisations that subscribe to it. **Scope Response** is one such organisation.

Equipment and aids

It's best to ask for specialist advice before getting any equipment for your child. Check if the equipment you need can be provided free of charge and which equipment is most likely to help.

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:

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

For more information about assessment, contact your **social worker**, **occupational therapist** or **physiotherapist**.

Buying equipment

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's 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. They can also signpost you to other organisations providing related information. Contact details are at the back of this booklet.

The **Disability Equipment Register** provides a service for disabled people and their families, to enable them to buy, sell or exchange equipment.

Borrowing equipment

Your local social services department or **Disabled Living Centre** may be able to put you in touch with organisations in your area which loan out specialised equipment.

Throughout the UK there are toy libraries that offer local families regular toy loans for a nominal fee. Toy libraries can also act as informal meeting places for parents and carers and currently serve over 250,000 children. To find your nearest toy library, contact the **National Association of Toy and Leisure Libraries**. Contact details are in the **Useful contacts and organisations booklet in the Family pack**.

Childcare

There are many different kinds of childcare. Sometimes it's provided by a childminder or nursery and, sometimes less formally, by a friend or relative. Scope and HemiHelp have produced an information pack for childminders, available from Scope.

Choosing the right childcare is important, because you need to be happy and confident that your child is safe, secure and happy.

It may not be possible to find a childcare setting where they have experience of looking after children with cerebral palsy, but you could try asking other parents or your **social worker** or **health visitor**.

Every local authority has an **Information Service** that provides information about the complete range of childcare available in your area. It is usually called the **Family Information Service**. Read more about this in the booklet on **Childcare** in the **Family pack**.

Education in the pre-school years

Parents are the main educators in the early years of a child's life and learning at this stage often takes place through play.

The way that early education settings such as nurseries and playgroups are organised is different in different parts of the country. However, by the time your child is three years old they should be ready to join a playgroup or preschool. Read more about this in the booklet on [Education](#) in the [Early Support Family pack](#).

Some areas have nurseries and preschools specially for disabled children in addition to other early years settings. Ask your [health visitor](#) about what's available in your area and try to find out as much as you can. If possible, visit a few different places before deciding what's best for your child.

It can be helpful to ask other parents in your area about what's available and to ask yourself:

- What specialist support or therapy is available in this setting and what does my child actually need?
- Does anyone in the nursery or early years setting I'm thinking about have any previous experience of working with a child with cerebral palsy? If not, are they willing to adapt and who can help them find out what they need to know?
- How welcome do we feel?
- What about communication? If my child is using a sign system or VOCA, how will this be managed?
- If my child needs 1:1 support, how much support from an adult can be provided?



Looking ahead and understanding the special educational needs system

When your child enters the education system, you'll begin to hear teachers and other people talking about 'special educational needs'.

Children with **special educational needs (SEN)** are children who have learning difficulties or disabilities that make it harder for them to learn than other children of the same age. Sometimes people will refer to these as Additional Learning Needs and Disabilities (ALN). When they go to school, they need more or different help than other children of the same age.

Every mainstream school has a member of staff called a **SENCO** (a special educational needs co-ordinator), who is there to make sure that appropriate provision is made for children with **special educational needs**. Schools take a graduated approach to providing different levels of additional educational support and intervention.

Cerebral palsy affects different children in very different ways and as they get older, individual children have different kinds and levels of **special educational needs**. They therefore need different levels of support.

The levels of additional support that are available are:

Early Years Action or School Action - additional help and support is provided for a child by the school or early years setting

Early Years Action Plus or School Action Plus - additional help and support is given to a child by the school or early years setting, but with the help of other professionals brought in from outside. Read more about this in the booklet on [Statutory Assessment - Education](#) in the [Family pack](#)

Statement of SEN - where extra resources are required to support a child that cannot be provided at Early Years Action, then their support needs may be assessed. This assessment makes sure that a child's support needs can be agreed. The agreed support needs are set out in a document called a **statement of special educational needs**. A statement can be requested at any age, although it is not common for them

to be issued for children under three years of age. Parents may start the process themselves by requesting an assessment and they can do this as early as they feel it's appropriate

Normally other professionals that have been working with you in the early years, such as **therapists**, are involved in the planning of support for your child.

You can read more about this in Information for Parents and Carers of Children and Young People who may have Special Educational Needs. This booklet can be downloaded by visiting www.wales.gov.uk and putting the title of the booklet in the Search field, or it can be ordered from The Publications Centre, Room 3.022, Welsh Assembly Government, Cathays Park, Cardiff CF10 3NQ; Tel: 029 2082 3683; E-mail: publication-fpcc@wales.gsi.gov.uk

Ring **Scope Response** if you need help with this when the time comes as they produce a range of factsheets about education. You may also find it helpful to contact the **Advisory Centre for Education** who run an independent advice line, or the **Alliance for Inclusive Education**. Contact details for all these organisations can be found in Useful contacts and organisations.

Support for you as you make choices

All local authorities provide a Parent Partnership Service to give objective information and advice about **special educational needs**. **SNAP Cymru** provides advice across Wales through a telephone helpline service. **SNAP** also provides an Independent Parental Supporter (IPS) to help families going through the statementing process. Independent Parental Supporters are often parents who have personal experience of children with special educational needs, or retired professional people who want to continue to help parents. If you need advice on how to make your contribution to the statementing process or would like someone to go with you to meetings, your local Parent Partnership Service should be able to help.

To find out how to contact your local Parent Partnership Scheme, ask a professional who works regularly with your family, or ring **Contact a Family Wales**.

Scope also have a network called **Face 2 Face**. Face 2 Face is a network of trained volunteer befrienders who can help parents make positive adjustments to the news that their child has a disability. Every Face 2 Face befriender is a parent too – someone whose own child has a disability. They know what it's like to cope with a new diagnosis and can offer support parent-to-parent.



Face 2 Face (F2F) is free and confidential. A befriender can either visit you at home or you can agree another convenient location. It is an informal and flexible arrangement designed to suit you. Scope support parents of children with any type of disability or special need.

Face 2 Face Cymru
4 Ty Nant Court
Morganstown CF15 8LW

Tel: 029 2081 5455

Web: www.scope.org.uk/services/face-2-face-cymru
Email: maizie.elfin@scope.org.uk

Finding a school

Finding the right school for your child will take time and you may need to visit more schools and consider more options than other parents do. It's a good idea to start on this as soon as possible and to talk to as many people as you can about it.

The following questions can help to build up a picture of each school you visit to help you compare the different options that are available in your area:

- How many pupils are there in the school?
- What's the physical layout of the school like? Is it all on one level or are there several buildings?
- What's physical access like? Are there any ramps, lifts or handrails?
- How many pupils are there in each classroom?
- Is there space in the classroom for any equipment that your child needs - for example, their wheelchair or standing frame?
- Has the school had experience of supporting pupils with cerebral palsy before?
- What facilities do they have or will they provide to support your child's needs?
- How will the planning to meet your child's needs be handled and how will you be involved in discussions?

Who can help?

As a parent, you're the expert on your child - you know more about them than anyone else. However, you may need help from a range of people from health, social services and education who have more knowledge and experience of cerebral palsy and services in the coming months and years.

Voluntary organisations and other parents can also give you information and signpost you to services you may need. These are all important partners for your family and they can help you get the best support for your child. You should always feel able to ask questions, or seek other opinions, if you feel uncertain or unhappy about what's happening.

These are some of the professionals you may meet:

Audiologist

An 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. They will also monitor your child's hearing, to make sure that any hearing aids they supplied are appropriate.

Community or district nurse

A community nurse is someone who works outside hospital and visits people at home.

Dietician

A dietician is a health professional who will advise you on foods, diet and nutrition tailored to meet your child's needs.

Educational psychologist (EP)

Educational psychologists assess your child's development and provide support and advice on learning and behaviour.

Genetic counsellor

It's very rare for cerebral palsy to be inherited, but, if you're worried that this may be the case, you may find it helpful to talk to a genetic counsellor.

General practitioner (GP)

A GP is your 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 health visitor is a qualified nurse who has extra training in advising parents of young children. They visit family homes in the early years to check on children's health and development. Health visitors can help with practical advice and support on day-to-day matters such as feeding or sleeping. They may also be able to tell you about local services.

Key worker

In some areas, key workers are available to help families that receive support from a lot of different agencies. They act as a link person between families and professional services.

Neurologist

A neurologist is a doctor who specialises in the brain and nervous system.

Nursery nurse

A nursery nurse is trained to understand children's development and works in a variety of settings.

Occupational therapist

An occupational therapist helps children improve their developmental function by therapeutic techniques and advises on adaptations and the use of specialist equipment.

Ophthalmologist

An ophthalmologist is a doctor who deals with the anatomy, functions and treatment of the eye.

Orthopaedic consultant

An orthopaedic consultant is a doctor who specialises in bone and soft tissue development.

Orthoptist

An orthoptist is a health professional who works with people who have visual problems. Orthoptists specialise in correcting vision by non-surgical means. They often work with **ophthalmologists** in hospitals, but may also work in a health clinic or visiting a school. They can test children's sight, look at eye movements, assess how well both eyes work together and check for squints or turning eyes.

Orthotist

An orthotist measures, designs, makes, fits, or services braces, splints and special footwear to help people with movement difficulties and to relieve discomfort.

Paediatrician

Paediatricians are doctors specialising in the care of babies and children. They work in hospitals, children's assessment centres or local health clinics.

Physiotherapist

A physiotherapist specialises in helping people with movement problems. They may show you exercises for your child and discuss ways of developing good movement patterns. They can also offer advice on the best way to carry, hold and position your child.

Portage worker

Portage is a home-visiting educational service for pre-school children with additional support needs and their families. Portage Home Advisors are specially trained in understanding child development and come from a variety of professions, ranging from nurses or other health professionals to teachers. The success of Portage depends on the partnership that builds up between you and your Portage worker.

Social worker

A social worker is a qualified professional who supports children and families by advising on appropriate services and introducing families to some of the services they need. They can advise on practical and financial issues, tell you about local services and sometimes arrange the support you need. They provide practical help and advice about counselling, transport, home help and other services. They may also be able to help you with equipment at home.

Speech and language therapist

A speech and language therapist can advise on communication issues and about eating and drinking. If it is appropriate, a speech and language therapist may recommend and help you with specialist communication aids or sign language.

Voluntary groups

Many districts have local voluntary groups that can give advice and support to families with disabled children. Your social worker, health visitor or other professional working with you should be able to give you information about these.



Looking to the future

Each child 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 and potential to achieve.

As your child grows and develops the questions and issues you have will change according to the life stage they are at.

The aim of this booklet is to answer some of the questions you may have in the early days, when you first find out your child has cerebral palsy. However, there are many organisations that can offer you information and support throughout your child's life and into adulthood.

A good starting point to further information would be to visit the websites of some of the organisations listed at the end of this publication or call their Helplines - if they can't help you they are more than likely to know someone who can.

Useful contacts and organisations

Action on Hearing Loss Cymru

Free phone helpline: 0808 808 0123
Textphone: 0808 808 9000
Email: informationline@hearingloss.org.uk
Web: www.actionhearingloss.org.uk

ACE Education Advice and ACE Education Training

Advice Line: 0300 0115 142
Web: www.ace-ed.org.uk

Afasic Cymru

Cardiff office
Tel: 029 2046 5861
Fax: 029 2046 5854
Email: jeannette@afasiccymru.org.uk

North Wales office
Tel/Fax: 01745 550461
Email: yvonne@afaisiccymru.org.uk

Web: www.afasiccymru.org.uk

The Alliance for Inclusive Education

Tel: 020 7737 6030
Web: www.allfie.org.uk

Assist UK (formerly the Disabled Living Centres Council)

Tel: 0161 832 9757
Email: general.info@assist-uk.org
Web: www.assist-uk.org

Association of Speech and Language Therapists in Independent Practice

Tel: 01494 488 306 (answerphone)
Fax: 01494 488 590
Web: www.helpwithtalking.com

Benefit enquiry line

Tel: 0800 882 200
Textphone: 0800 243 355
Web: www.gov.uk/benefit-enquiry-line



Bobath Wales

Tel: 029 2052 2600
Email: info@bobathwales.org
Website: www.bobathwales.org

British Association of Occupational Therapists and College of Occupational Therapists

Tel: 020 7357 6480
Email: reception@cot.co.uk
Web: www.cot.co.uk

Cerebra

Helpline: 0800 328 1159
Tel: 01267 244200
Fax: 01267 244201
Email: info@cerebra.org.uk
Web: www.cerebra.org.uk

The Chartered Society of Physiotherapy

Tel: 020 7306 6666
Web: www.csp.org.uk

Children in Wales

Head Office
Tel: 029 2034 2434
Fax: 029 2034 3134

North Wales Office
Tel: 01286 677570

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

Contact A Family Cymru

Helpline: 0808 808 3555

Tel: 029 2039 6624

Web: www.cafamily.org.uk/advice-and-support/in-your-area/offices/cardiff

Email: wales.office@cafamily.org.uk

Conductive Education Wales

Craig-y-Parc School

Tel: 029 2089 0397

Disabled Living Foundation

Helpline: 0845 130 9177

Helpline email: helpline@dlf.org.uk

General email: info@dlf.org.uk

Web: www.dlf.org.uk

Disability Equipment Register

Tel: 01454 318818

Email: disabreg@blueyonder.co.uk

Web: www.disabilityequipment.org.uk

Disability Rights UK

Tel: 020 7250 3222

Fax: 020 7247 8765

Email: enquiries@disabilityrightsuk.org

Web: www.disabilityrightsuk.org

Education & Resources for Improving Childhood Continence (ERIC)

Helpline: 0845 370 8008 (10am-4pm Monday-Friday)

Sales and Customer Service: 0117 301 2100

Fax: 0117 960 0401

Web: www.eric.org.uk

Epilepsy Action

Tel: 0113 210 8800

Fax: 0113 391 0300

Email: epilepsy@epilepsy.org.uk

Web: www.epilepsy.org.uk



ERIC - Education & Resources for Improving Childhood Continence

Helpline: 0845 370 8008
Sales and Customer Service: 0117 301 2100
Web: www.eric.org.uk

Family Fund

Tel: 08449 744 099
Textphone: 01904 658085
Fax: 01904 652625
Email: info@familyfund.org.uk
Web: www.familyfund.org.uk

The Foundation for Conductive Education

Web: www.conductive-education.org.uk

HemiHelp

Office: 0845 120 3713
Helpline: 0845 123 2372
Fax: 0845 120 3723
Email: helpline@hemihelp.org.uk
Web: www.hemihelp.org.uk

The Makaton Charity

Tel: 01276 606 760
Email: info@makaton.org
Web: www.makaton.org

National Association of Family Information Services (NAFIS)

Email: membership@daycaretrust.org.uk
Web: www.daycaretrust.org.uk/nafis

National Deaf Children's Society Cymru

Tel: 029 2037 3474
Minicom: 029 2023 2739
Fax: 029 2037 9800
Email: ndcswales@ndcs.org.uk
Web: www.ndcs.org.uk

National Portage Association

Tel: 0121 244 1807
Email: info@portage.org.uk
Web: www.portage.org.uk

The Royal College of Speech and Language Therapists

Tel: 020 7378 1200
Web: www.rcslt.org

Royal National Institute of Blind People (RNIB) Cymru

Tel: 029 2045 0440
Fax: 029 2044 95500
Email: cymruevents@rnib.org.uk
Web: www.rnib.org.uk

Scope Cymru

Tel: 029 2081 5450
General Scope Helpline: 0808 800 3333
Text: SCOPE plus message to 80039
Email: response@scope.org.uk
Web: www.scope.org.uk/about-us/scope-wales

Sense

Tel: 0845 127 0060
Tel: 0845 127 0061
Textphone: 0845 127 0062
Email: cymruenquiries@sense.org.uk
Web: www.sense.org.uk

United Cerebral Palsy

An American organisation providing information and advice for people with cerebral palsy, their parents and carers. The website has recent research and information sheets to download.

Email: info@ucp.org
Website: www.ucp.org



Additional Reading

Cerebral palsy - a complete guide to caregiving

Miller F. & Bachrach S.J.
S.J. John Hopkins University Press (1995)

Cerebral palsy handbook – a practical guide for parents and carers

Stanton M.
Vermillion (2002)

Disability rights handbook

A comprehensive reference guide to social security benefits and services for disabled people. It is updated every year and is usually available in May. You can order a copy from the Disability Rights UK website.

A guide to grants for individuals in need 9th Edition

Directory of Social Change (2004)
Web: www.dsc.org.uk

Including Children with Cerebral Palsy in the EYFS

Brewis L.
Featherstone (2009)

Living with cerebral palsy

Pimm P.
Wayland Publishing (1999)

Working with Parents: of Children with Additional Needs

Brewis L.
Featherstone (2009)

Glossary

Aphasia - general term for language disorders affecting reading, writing, speaking or comprehension of written or spoken words

Ataxic cerebral palsy (Ataxia) - a form of cerebral palsy characterised by problems with balance, co-ordination, shaky hand movements and jerky speech

Athetoid cerebral palsy (Athetosis) - a form of cerebral palsy characterised by involuntary movements resulting from the rapid change in muscle tone from floppy to tense

Audiologist - a professional who tests hearing, explains the results and fits hearing aids

Augmentative or alternative communication system - methods of communication that supplement or replace speech and handwriting with signs, symbols and/or voice output communication aids

Bobath therapy - physical therapy that aims to improve posture and movement

Central nervous system - the spinal cord and the brain. The brain receives and processes signals delivered through the spinal cord, and then sends signals and instructions to the body

Cerebral palsy - a disorder of movement and posture due to non-progressive damage to an immature brain

Cerebral cortex - the outer layer of the brain

Cerebral thrombosis - formation of blood clot in an artery of the brain

Chorea - uncontrollable, small, jerky movements, usually of the toes and fingers

Conductive education - a holistic learning system which enables some children with cerebral palsy to function more independently

Congenital - present at birth

Diplegia - where both legs are affected but the arms are not (or less so)

Dysphasia - the same as Aphasia (above) but less severe

Dyspraxia - difficulty in planning and carrying out purposeful movements that is not related to muscle weakness

Encephalitis - inflammation of the brain, usually resulting from a viral or bacterial infection

Epilepsy - abnormal electrical activity in the brain that causes seizures



Fine motor movements - small muscle movements, often of the hand (e.g. the movements needed when writing)

Flexion - bending of parts of the body

Function - a clinical term usually referring to an ability or skill required to carry out an activity of daily living

Gross motor movements - large muscle movements (e.g. the movements needed for walking)

Haemorrhage - uncontrolled bleeding

Hemiplegia - where one side of the body is affected

Hydrocephalus - water on the brain

Hyperkinesia - incessant, restless activity

Hypertonia - too much muscle tone leading to stiffness

Hypotonia - too little muscle tone leading to floppiness

Hypoxia - term used when the brain or other tissue is not receiving adequate oxygen

Meningitis - inflammation of the lining of the brain and/or spinal cord

Monoplegia - impairment of one limb

Motor - movement

Muscle tone - the amount of tension or resistance to movement in a muscle

Neonatal - newborn (the first four weeks of life)

Neurologist - a doctor who specialises in the brain and nervous system

Object of reference - an object used to represent a familiar routine or activity - for example, a spoon used to represent 'dinner time'

Orthoptist - professional working with people who have visual problems and abnormal eye movements

Orthotist - professional who specialises in the supply and fitting of aids and equipment to help improve mobility and provide support e.g. wheelchairs, special shoes, splints

Paraplegia - impairment of legs only

Paediatrician - a doctor who specialises in working with babies and children

Perinatal - referring to the period from 28th week of pregnancy to 28th day after birth

Quadriplegia - all four limbs affected

Range of motion - refers to the flexibility of joints such as elbows and ankles

Seizure - a sudden burst of excess electrical activity in the brain that results in a temporary disruption in the normal messages passing between brain cells. The disruption causes the brain's messages to be halted or become mixed up

Sensory - referring to those parts of the nervous system that receive and interpret signals received from the senses

Spasm - involuntary contraction of a muscle

Spastic cerebral palsy (spasticity) - the most common form of cerebral palsy, where some muscles become very stiff and weak

Spatial - relationship of one thing to another in space, learned through vision and movement

Spatial perception - appreciation of size, distance and the relationship between objects

Special educational needs (SEN) - children with special educational needs require extra or different help than that given to other children of the same age in order to learn and participate

Special educational needs co-ordinator (SENCO) - a person in a school or early years setting who has particular responsibility for identifying children with special educational needs and making sure they receive support

Statement of special educational needs - a document which describes a child's learning difficulties and the help they will be given to help them learn

Tremor - rhythmic, uncontrolled, repetitive movements of parts of the body

Triplegia - impairment of three limbs

VOCA - a Voice Output Communication Aid - a technical device that helps children to communicate by speaking for them

Early Support

Early Support in Wales is the Welsh Government's mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across Wales.

Early Support builds on existing good practice. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children.

To find out more about **Early Support** and associated training opportunities and to view or download other resources produced by the programme, visit www.earlysupportwales.org.uk

This information resource is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. The other titles in the series are:

Autistic spectrum disorders and related conditions

Behaviour

Deafness

Down Syndrome

If your child has a rare condition

Learning Disabilities

Multisensory impairment

Neurological disorders

Sleep

Speech, language and communication needs

Visual impairment

When your child has no diagnosis

Other Early Support information about services is available separately. To download any of the **Early Support** materials mentioned here, see www.earlysupportwales.org.uk



Ynghylch parlys yr ymennydd.
Dros gydraddoldeb i bobl anabl.
About cerebral palsy.
For disabled people achieving equality.

Scope Cymru is led by the lived experience of disabled people and their families.

The Cardiff office is responsible for promoting the Time to get Equal campaign in Wales, recruiting and supporting volunteers to become Time to get Equal campaigners and developing various models of engagement for our supporters to get involved.

There are 18 **Scope** members and 134 Time to get Equal campaigners in Wales, and about 500 people subscribe to Disability Now in Wales.

Wales has a degree of political autonomy with the establishment of the National Assembly in Wales in 1999. Scope Cymru works with Welsh political parties to banish disability and help make equality for disabled people a reality.

Scope Cymru
Unit 4
Ty Nant Court
Morganstown
Cardiff CF15 8LW

Tel: 029 2081 5450

To find out more about Scope's work, visit www.scope.org.uk

Scope Response
PO Box 833
Milton Keynes
MK12 5NY
(Please include SAE for a reply)

Tel: 0808 800 3333
Text: SCOPE, plus your message to 80039
Fax: 01908 321051

Email: response@scope.org.uk

Copies of this resource can be
downloaded from
www.earlysupportwales.org.uk

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Ynghylch parlys yr ymennydd.
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Llywodraeth Cymru
Welsh Government