



Cerebral Palsy

Information, advice and support
for parents during the early years

scepe

About cerebral palsy.
For disabled people achieving equality.

What is cerebral palsy? Section 1

This section introduces cerebral palsy and offers information, tips and support.

You and your child Section 2

From when you first find out that your child has cerebral palsy to your daily routines, this section will guide you through the early years of your child's life and give you practical tips.

Professionals you may meet Section 3

There are lots of professionals who will be able to support you and your child. This section identifies and explains some of the people you may come across, what their role is and some tips for when you meet them.

Glossary of terms Section 4

There can be a lot to take in and understand when your child has been newly diagnosed with cerebral palsy. This section is your A – Z guide to defining the jargon, terms and medical language.

CD on Play Talks and Games all children can play

What is cerebral palsy?

“The most important thing to remember is that as the parent you are the expert about your child.”

Cerebral palsy is a wide ranging condition. This section explains what it is, defines the three main types and gives an overview on the facts about cerebral palsy. It also offers tips on practical ways that friends and family can support you and your child.

What causes cerebral palsy?	1.1
Facts about cerebral palsy	1.2
What are the main forms of cerebral palsy	1.3
Information to share with friends and family	1.6



Cerebral palsy is an umbrella term used to describe a group of conditions which affect movement, posture and coordination. This may be seen around the time of birth, or may not become obvious until particular motor developmental stages in early childhood.

Cerebral palsy is a wide ranging condition and can affect people in many different ways ranging from mild to profound. Children with mild cerebral palsy may demonstrate only slight awkwardness in movement and may require no special assistance or intervention; whereas other children may benefit from therapy and structured support from various professionals.

Before making a firm diagnosis, doctors normally wait to see how a child develops. Therefore, parents may not get a firm diagnosis until a child is around two or three years of age; or a number of other medical terms may be used. Please do not worry, ask the doctor or consultant to explain, or contact Scope Response.

What causes cerebral palsy?

There may be no obvious single reason why a child has cerebral palsy and it is often not possible for doctors to give an exact reason why part of a baby's brain has been injured or failed to develop. Causes of cerebral palsy can be multiple and complex. Studies suggest that cerebral palsy is mainly due to factors affecting the brain before birth.

If you're unsure what a medical term means, ask the doctor or consultant to explain. You can also look it up in the glossary in Section 4 of this guide or get in touch with us to discuss it further.

1.2

“Support from friends and family can make a great difference to a family of a child with cerebral palsy.”

Grandmother

Cerebral palsy is not caused by problems in the muscles or nerves, but by impairment or lesions in areas of the immature brain which control muscles and movement.

Known possible causes of cerebral palsy can include:

- an infection in the early part of pregnancy
- a cerebral (brain) bleed – this is more likely following premature birth or infection
- abnormal brain development
- a difficult or premature birth
- genetic link – though it is quite rare for cerebral palsy to be inherited
- lack of growth support during intrauterine (in womb) life
- blood type incompatibility
- an infection or accident affecting the brain in the early years of a child’s life
- multiple births, where the incidence of cerebral palsy can be more common.

However in many cases there is no obvious cause.

Facts about cerebral palsy

- Children with cerebral palsy are children first and foremost.
- Cerebral palsy is the most common physical impairment in childhood.
- Cerebral palsy affects each child differently.

- Cerebral palsy is a condition ranging from mild to profound.
- Cerebral palsy does not normally affect life expectancy.
- Cerebral palsy is non-progressive but some effects of cerebral palsy on the body may change through life stages.
- Cerebral palsy cannot be cured although early support and therapeutic intervention can help children's development.
- Many children with cerebral palsy show average or above average intelligence.
- Many children with cerebral palsy attend mainstream schools.
- Approximately one child in 400 has cerebral palsy.

What are the main forms of cerebral palsy?

Cerebral palsy is frequently classified into three main types, although it is often difficult to classify exactly what type of cerebral palsy a child may have. It is not unusual for a child to have a combination of any of the following:

Spastic cerebral palsy

'Spastic' means 'stiff' and is the most common form of cerebral palsy, where children have muscle stiffness (or hypertonia) and muscle weakness, which can affect the range of movements in their joints.



Bilateral spastic cerebral palsy may be diagnosed if limbs on both sides of the body are involved. Unilateral spastic cerebral palsy may be diagnosed if limbs on only one side of the body are involved.

Ataxic cerebral palsy (Ataxia)

Children with ataxic cerebral palsy often find balance difficult and generally have uncoordinated movements. Ataxia affects the whole body. Usually children are able to walk, but may be unsteady and have shaky hand movements and irregular speech.

Dyskinetic or Athetoid cerebral palsy (Athetosis)

Children with athetoid cerebral palsy tend to make involuntary movements because their muscles change from floppy to tense in a way that is difficult for them to control. This may also affect the child's speech and hearing.



Cerebral palsy is also often described according to which parts of the body are affected, for example hemiplegia (where either the right or left half of the body is affected); diplegia (where both legs and arms are affected, though arms generally less so); and quadriplegia (where both legs and arms are equally affected).

For more information about treatments and therapies often used with children who have cerebral palsy, contact Scope Response.

Are there associated conditions?

Whilst certain conditions do occur more frequently in children with cerebral palsy, every child is individual and will not necessarily have any of the following:

- difficulty with swallowing, feeding and speech
- difficulties with going to the toilet, bladder and bowel control
- visual or spatial perceptual difficulties, where a child has difficulty processing information about shapes, speed and spatial relationships
- learning difficulties, or a specific learning difficulty, for example difficulty in one particular type of activity – such as reading, drawing or maths
- some children with cerebral palsy may develop epilepsy, though medication is often used to control this.

How can I help my child?

Although there is no cure for cerebral palsy, with appropriate early support and intervention many children develop their practical skills and improve

“It gets easier as you build up your network of support.”

Parent

muscle control and coordination. Treatments can include physiotherapy and occupational therapy; speech and language therapy and/or medication to relax muscle spasms and lessen discomfort.

Information to share with friends and family

- Caring for a child who has cerebral palsy can be very tiring for parents, especially in the early days, as it is with any young child. Don't wait to be asked – offer to help if you can. If you are babysitting, make sure you know what their child's routine is and their likes and dislikes. Try and keep to their normal routine.
- Offer friendship and support. Parents of any child with additional needs often feel 'cut off' at a time when they need lots of support from friends and family.
- Don't be afraid of talking to parents about how cerebral palsy affects their child. Many parents welcome the chance to share their feelings with people close to them and having someone who will listen can make a real difference.
- Play and talk to their child as you would any other child and encourage any other children to do the same.
- Information can be helpful, but do not be tempted to show parents everything you see on cerebral palsy. Give them time to sort out for themselves what is right for their child and their individual circumstances and what they feel they need more information about.

You and your child

“You are the best game in town and the best toy in the house.”

From when you first find out that your child has cerebral palsy to your daily routines, this section will guide you through the early years of your child’s life and give you practical tips.

When you first find out	2.1
How we can support you	2.2
Handling	2.4
Dressing	2.5
Mealtimes	2.6
Brushing teeth	2.6
Going to the toilet	2.6
Bedtime	2.7
Play	2.8
Special Education	2.9



Every child is unique. All children need love, security, fun, encouragement and the opportunity to learn about the world around them. A child who has cerebral palsy is no different; they are first and foremost a child who has their own individual personality and potential to achieve.

Treat your child like any other child and encourage your friends and family to do the same. You may be concerned at times about their future, but taking things day by day, playing and looking after them in a way that is right for both of you will help give your child the best possible start in life.

If your child needs additional attention or care, they may be entitled to Disability Living Allowance (DLA). This is a benefit in your child's name, but paid to the parent and gives increased financial support for disabled children that have additional care or mobility needs.

When you first find out

It is natural to feel anxious around the time of diagnosis and you may find it quite a stressful time.

- Ask as many questions as you want and get as much information as you can. Talking to friends and family can be helpful.
- There may be a local parent befriending scheme, where you can chat to other parents. Scope Response can give you details of our local Face 2 Face parent

You can find out more about DLA from Scope Response, your Citizens Advice Bureau or Contact a Family who have an excellent leaflet on benefits – www.cafamily.org.uk or call 0808 808 3555.

befriending schemes but other agencies / charities may run similar opportunities.

You know your child better than anyone and there are many things that you can do to help your child develop their full potential.

Talk to your child throughout the day, enjoy touching, playing and having cuddles. Some children may have difficulty making eye contact, turning their head, reaching out for objects or have specific mobility difficulties. By playing and making eye contact whenever possible, you will soon learn the little signs that your child is making to communicate with you.

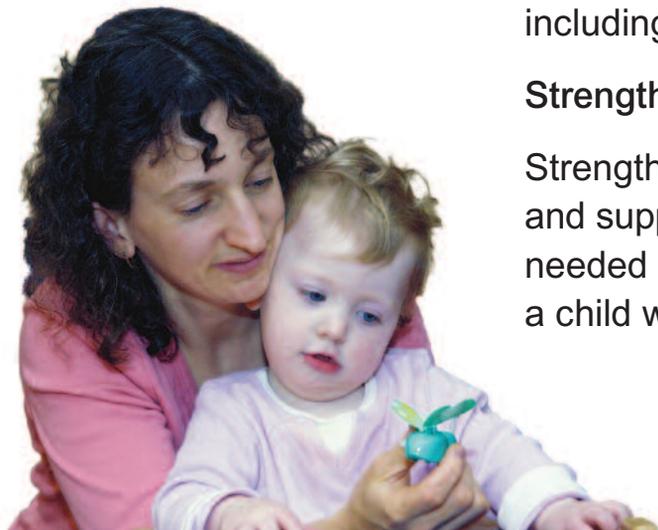
How we can support you

Scope Response

Provides information, advice and support on all aspects of cerebral palsy and disability. We are a national pan-disability service with regional staff who can support people with cerebral palsy, including home visits for newly diagnosed children.

Strengthening Families

Strengthening Families training offers professionals and supporters key training in the additional skills needed to work with parents and families who have a child with additional support needs or an impairment



The aim is to help support families and parents through emotional times and to help build stronger relationships within the family.

Face 2 Face

Local projects offering parent befriending schemes. Befrienders are volunteers who themselves have disabled children and are able to share experiences, empathise with and support other parents who have a child with additional support needs, special needs or an impairment.

Sleep Solutions

Provides support to families of children and young people with additional support needs, special needs or an impairment and severe sleep problems.

Schools for Parents

This is a network of local services providing Conductive Education for children aged under five. Parents are taught exercises and routines which mean you can continue the programme with your children at home.

Scope Website Forum

Share experiences with a range of people, including parents and disabled people in Scope's forum at www.scope.org.uk/forum. Please note our forum is premoderated to ensure website safety for children and vulnerable adults.

For details of any of the services in this section or any other Scope services, please contact Scope Response or visit our website www.scope.org.uk

“I really wish that something like this had been around when my son was very little – it's fantastic. Other parents are the best source of information on everything to do with having a child with cerebral palsy.”

Parent talking about Scope's Forum

2.4

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

Parent

Handling a child with cerebral palsy

Handling a child means how you hold, lift, carry and position them to control any muscle stiffness or uncontrolled movements. You will learn the best way to handle your child that is comfortable for both of you. Your Physiotherapist can advise further – depending on how old your child is and what sort of cerebral palsy they have.

In general, try to position your child so he can see what is going on around them. If you are unsure, you can check with your child’s doctor, paediatrician or therapist about the best way to handle your child. This will aid development and prevent back strain.

Whilst it is natural to be protective of your child, parents may become over protective of a child who has cerebral palsy. As cerebral palsy affects the muscles and motor control functions, it is important to ensure your child is as active as possible within their capabilities.

Practical suggestions

Everyday activities are good opportunities to teach your child about parts of the body. Here are some practical suggestions:

- Talk to your child about what you are doing together.
- Encourage your child to do things for themselves, even if it takes longer. Give lots of praise for every achievement.

- Keep movements smooth, as their muscles may need time to respond to changes in position. Let muscles tense and relax in their own time.
- Uncertainty can make muscle spasms worse, so support and reassure your child when moving or handling.
- Young babies or children with complex needs benefit from spending time in different positions, for example, lying on their tummy or back, side lying and so on.

Dressing

- Getting dressed can sometimes be time consuming – it can also be fun!
- Everyday activities such as dressing and feeding are good play opportunities to teach your child about parts of the body and how they move. If you have time, siblings can also join in.
- Bending legs before putting on shoes or socks can ease any stiffness in the ankle and foot and make it less likely for your child to curl their toes.
- Choose loose, comfortable clothing with Velcro or elastic ties. You should be able to find a good range of clothes on the high street to suit your child, but there are also specialist suppliers who make clothes to meet the needs of disabled children if required.
- As with any child, well fitting and supportive shoes are essential. Some children with cerebral palsy may

“Siblings are important too.”

Parent



require special shoes or boots (these can be quite trendy). Your Doctor or Physiotherapist can advise further.

Eating and mealtimes

You may not experience any problems with breastfeeding or feeding your child. However, some children with cerebral palsy may have difficulty in eating, sucking, swallowing or chewing and you may need to allow more time for this.

Your Health Visitor can offer advice and a speech and language therapist (SaLT) can give specialist support if your child has difficulties eating or swallowing. An Occupational Therapist can advise on a feeding programme and special equipment.

Brushing teeth

Children with cerebral palsy may be more prone to getting food stuck in their teeth which can lead to tooth decay. Brush teeth daily and visit the dentist regularly. Again your Health Visitor may be able to advise on specific techniques for brushing. It can also be another opportunity to have fun and play with your child.

Going to the toilet

Some children with cerebral palsy may take longer to toilet train. Your child may have no problems or may be encouraged by having a special toy whilst on the potty or a potty that plays music. You could sing songs

Scope has more information on feeding in the booklet *Food Talks*. Contact us for a copy.

Scope has a factsheet on going to the toilet. Contact Scope Response or ask your Health Visitor for advice.

whilst they are on the potty or use a reward system like a star chart.

For some children, it may be hard to relax on the potty or use muscles to empty their bowels. Continence can sometimes be a problem.

Bedtime

Some children with cerebral palsy may find it difficult to sleep because they cannot get comfortable, or their muscles spasm during the night and they may need turning.

If you are concerned, you can ask your Health Visitor, Physiotherapist (PT) or Occupational Therapist (OT) about cushions to support your child.

Babies and young children should never be placed on their tummies to sleep or be allowed to get too warm. Room thermometers may be useful and most children's bedding and sleep wear will carry advice on room temperatures and layers of clothing.

Like many children, your child may often wake at night. Perhaps something is worrying them or they are afraid of the dark, heard strange noises or are just uncomfortable. Your child may also have discovered it is a good way of getting your attention.

If your child continues to wake at night, seek advice from your Health Visitor or there may be a local sleep clinic where you can get advice.

You can also contact the Bladder and Bowel Foundation on 0870 770 3246 (Counselling Helpline) or 0845 345 0165 (Nurse Helpline) or check their website www.bladderandbowelfoundation.org

Scope also has a factsheet on sleep. Contact Scope Response for a copy.



“I’m usually one of the first non-medical people that parents meet. I’m there to provide support and advice and help them in any way I can.”

**Scope Regional
Response Worker**

Play

Play is vital for all children. It is the way we explore the world about us and our place in it. Play offers opportunities to relax, express feelings, experience success and failure, to learn about communication and our physical capacities – the list is endless. Sometimes the demands of life squeeze out play.

- Some children may need your help to play, to reach out and touch or hold toys. Often how a child is positioned can make a big difference in accessing toys.
- Sometimes simple adaptations to everyday toys can make a big difference. Ask your Occupational Therapist for advice on the best ways to help support your child.

Other play opportunities

Your Local Family Information Service should have information and services such as: baby and toddler groups, playgroups and opportunity groups, soft play areas, baby swimming groups and toy libraries.

Other useful information and resources are available:

- Pick & Mix – A selection of inclusive games and activities (Di Murray – 3rd Edition 2008). This popular publication from Kids NDD, includes a wealth of practical ideas, games and activities to help promote inclusion in any play, holiday or childcare setting. Cost: £10 for the voluntary sector / individuals, plus postage and packaging. Kids NDD, 6 Aztec Row, Berners Road London N1 OPW. www.kids.org.uk

- Best Play – What play provision should do for children (2000). Available to download from Play England at their website:
www.playengland.org.uk/resources/best-play.pdf
- Children’s Play Council: www.ncb.org.uk/cpc
- Everybody Here? – Play and Leisure for Disabled Children and Young People (Contact a Family, 2002). Available to download from
www.cafamily.org.uk/leisure.pdf
- Asian Children Play – working towards equal opportunities in play provision for Asian children – Second edition. Haki Kapasi’s research into barriers in accessing play provision for Asian children. Available from Community Insight, visit:
www.communityinsight.co.uk
- Inclusive Play – Practical Strategies for Working with Children Aged 3 to 8 (Theresa Casey 2005). This book makes practical suggestions and uses tested approaches to show how to help children feel included and involved in play opportunities. Available from Paul Chapman publishing, visit:
www.paulchapmanpublishing.co.uk

There are lots of ideas and tips for play and toys contained in the CD at the back of this booklet.

Special educational needs for the under fives

Many children with cerebral palsy experience some difficulties with learning, for example, special educational needs. Special Educational Needs (SEN) are defined in S312 of the Education Act 1996 as arising when a child has a learning difficulty which

2.10

requires special educational provision. A child is any person under the age of 19. A learning difficulty is where a child:

- has a significantly greater difficulty in learning than the majority of pupils of their age
- has a disability which either prevents or hinders them from making use of educational facilities generally provided for pupils of a similar age in schools in the local authority
- is under compulsory school age and is (or would be if special educational provision were not made for them) likely to fall into one of the above categories.

Schools, nurseries and other educational establishments are expected to be able to help most children overcome their difficulties. There are two nursery / school based stages of support for children who have special educational needs, Early Action and Early Years Action Plus.

An early years setting or school has a duty to inform you if there are concerns about your child's progress or other signs of learning difficulties. Your child's teacher or SENCO (Special Educational Needs Coordinator) may start giving extra or different support to them because of their special educational needs. However, in the case of many children with cerebral palsy, the need for additional support within their nursery or school may have already been discussed with you

and relevant professionals prior to their attendance. There is a graduated response in place to support your child via Early Years Action, where they receive support or interventions in addition to, or different from, those provided as part of the schools usual 'differentiated curriculum'. Early Years Action Plus support may be sought from external professionals, for example, Physiotherapists who will usually visit the setting and provide advice on strategies, new or different materials or particular activities that may enable your child to gain greater access to the curriculum.

Your child may need this type of support for only a short time or for several years. The nursery / school should consult with you on a regular basis regarding your child's progress and the type of intervention that they are receiving.

The strategies that are employed to enable your child to gain greater access to the curriculum are generally recorded within an Individual Education Plan (IEP).

For a few children, the support provided through Early Years Action or Early Years Action Plus may not be sufficient to enable the child to progress satisfactorily.

In such cases, the Local Authority should conduct a Statutory Assessment of a child's special educational needs and following this assessment, the Local Authority should consider whether or not to make and maintain a Statement of Special Educational Needs.



A Statutory Assessment is a multi-disciplinary appraisal of all your child's special educational needs and is carried out by therapists working with your child, an educational psychologist, other relevant professionals and you.

Parents, early years settings and schools can make a formal request to the Local Authority for a statutory assessment. If you are making the request, the letter should include the reasons why you want an assessment and any supporting information.

A Local Authority is required by law (Education Act 1996 S321 and S323) to carry out a statutory assessment if it considers that a child has (or probably has) special educational needs which require special provision. The Local Authority must inform the you of its intention to carry out such an assessment. Alternatively, if the Local Authority considers it is not necessary to assess your child, they must notify you of the decision and of your rights of appeal to the Special Educational Needs and Disability Tribunal (SENDIST).

A Statement of Special Educational Needs is produced if the Local Authority considers that the special educational provision that your child requires cannot reasonably be provided within the resources normally available to mainstream schools and early years education settings within the area.

A Statement of Special Educational Needs will:

- set out the child's special educational needs, what the child can and cannot do
- set out the SEN provision that is required to address these needs
- name a school or type of school or provision.

A number of parents are concerned about not being granted a statement of Special Educational Needs for their children, or that the statement is inadequate and does not meet their child's needs. There are organisations which can help if this is the case.

Statements are rare for children under two, and when a child under two is referred to the Local Authority, it is likely that they will have a particular condition or a major health problem that has caused concern at an early stage. Assessments for children under two need not follow the statutory procedures that are applicable to assessment of children aged two and over.

For very young children access to a home based learning programme or the services of a peripatetic teacher, may provide the most appropriate support or advice. For some children it may be more appropriate to transfer to a specialist provision. In most instances, children will continue to attend mainstream early provision with additional support or resources. You should be kept informed and consulted throughout the process of such decisions.



Further help and specialist SEN organisations:

IPSEA – Independent Panel for Special Educational Advice

Free support and advice to parents of children with special educational needs.

0800 018 4016

www.ipsea.org.uk

ACE – Advisory Centre for Education

Guidance on all aspects of school education.

0808 800 5793

www.ace-ed.org.uk

Network 81

Practical help and support to parents throughout all stages of educational assessment and statementing.

0870 770 4055

www.network81.org

Professionals you meet along the way

“With hindsight I realise how important it is for parents to make time for themselves and each other – it’s easy to get swamped with too many appointments which take over your life.”

There are lots of professionals who will be able to support you and your child. This section identifies and explains some of the people you may come across, what their role is and some tips for when you meet them.

Tips on meeting professionals	3.1
People you may work with	3.4



As a parent, you know more about your child than anyone else. You are an expert about your child's life, their growth and their development – it is important to remember this.

However, a range of other professionals from health, social and educational services to early support children's centres and voluntary agencies, may have contact with you over the coming months and years. They will be important partners for you and will help you to get the best support for your child.

Initially you may feel overwhelmed by the number of professionals you have to see and deal with, particularly in the early days when they are all getting to know your child. Gradually the appointments will become less frequent and more spaced apart.

You should always feel able to ask questions or seek other opinions if you feel uncertain or unhappy with what is said.

When you meet a professional

Meetings may be one to one with the relevant professional or multi agency, where a number of professionals involved in your child's care will attend.

You and your child should be at the centre of the meeting. You need to be fully involved and to understand all that is said. Sometimes that can be difficult especially if you are anxious or upset.

“Joining a support group is a valuable way of meeting families in similar situations who will understand how you feel.”

Parent

3.2

“Planning before appointments and writing down the questions I want to ask really helps me.”

Parent

The following suggestions may help

- Timing – does the date and time of the meeting or appointment suit you and your family? If not, try to change it.
- Venue – it may be possible to change the venue for some appointments or meetings, for example, your local children’s centre. Ask for privacy if it makes you more comfortable. Some parents prefer to meet in their own home.
- Planning – keep a calendar of appointments by the phone to help plan your time.
- Medical appointments – take a list of any medication your child is taking.
- All professionals – take a list of other professionals involved with your child and their contact details with you.
- Support – some families have the support of a key worker or advocate. Ask a friend or family member to attend with you – a second person can be invaluable for support at the meeting and later on to talk things through.
- Getting there – plan ahead. It might sound obvious, but ensure you have change for parking costs if applicable.
- Who’s who – be clear who is at the meeting and what their role is. Do not be afraid to ask for everyone to introduce themselves.

- Purpose – be clear about the purpose of the meeting. Ask what can be achieved and what the options are. Think about what you want from the meeting.
- Participation – make sure the professionals involve you in the meeting. Ask them to clarify if you do not understand anything. You might want to make notes. Don't be afraid to ask questions or to clarify any points, terminology or jargon used.
- Challenging contentious points – try to raise any concerns in a calm precise manner. If you think it's needed, ask for a second opinion.
- Next steps – make sure you are clear on what happens next.
- If the meeting makes you feel emotional, ask for a break.
- Information – ask for a copy of any written information or minutes and make sure you have contact details of everyone involved.
- Follow up – sometimes parents need time to reflect on what has been said. Ask for another meeting or appointment, if you feel you need to follow up issues.
- Take a break – plan some time when your diary is clear of meetings and appointments.

See Section 4 in this guide for definitions of some of the more common jargon.



People you may work with

Here are some people who may be working with you to help support your child or who are involved in their care:

Audiologist – An Audiologist works with people who have hearing difficulties and can advise on hearing.

Community or District Nurse – This is a nurse who works outside hospital and treats people in their homes.

Conductor – This is an educator who is trained and qualified to deliver Conductive Education programmes that incorporate all developmental areas in an integrated and unified way.

Dietician – A Dietician will advise on foods, diet and nutrition tailored to meet individual needs.

Educational Psychologist – An Educational Psychologist is available to visit schools and advises on learning and behaviour. He or she will be involved if the Local Education Authority makes an assessment of your child's educational needs – usually called 'Statementing'.

Genetic Counsellor – It is quite rare for cerebral palsy to be inherited but, if you are worried, you may find it helpful to talk to a genetic counsellor. They are based at genetic advisory centres which are usually attached to large hospitals. Ask your Doctor, Paediatrician or Child Development Centre to refer you.

Neurologist – Neurologists are doctors who specialise in impairments of the brain and nervous system.

Occupational Therapist – Occupational Therapists identify how a child's strengths and difficulties affect their activities. Occupational Therapists will assist with independence by adapting the activity or environment, whether it is at home or at school / nursery or through the provision of specialist equipment.

Orthopaedic Consultant – An Orthopaedic Consultant is an expert on bone and soft tissue development.

Orthoptist – An Orthoptist works with people who have visual problems and abnormal eye movements.

Paediatrician – Paediatricians are doctors who specialise in the care of children. They are based in hospitals, children's development centres or local health clinics.

Physiotherapist – A Physiotherapist specialises in helping people who have problems with movement. They use natural methods such as exercise, manipulation, heat, ultrasound and massage to help improve muscle tone and develop good patterns of movement. They can also advise on the best ways of carrying, holding and positioning a child. Physiotherapists work in hospitals, schools and child development centres and sometimes with people at home. You can be referred to a Physiotherapist through your Paediatrician or Doctor.

There are people who can help you if you are worried or anxious about what has been said to you.

In many areas, it is possible to make contact with other parents who have had similar experiences and can offer reassurance and support.

3.6

Ask your Health Visitor or contact Scope Response for details of Scope's Face 2 Face Parent Befriending Scheme. Scope Response may also be able to put you in touch with other local and national agencies that can help.

Portage Worker – Portage is an educational programme for children who have difficulty in learning basic skills, due to either physical or behavioural difficulties. Portage is not available in all areas so ask your Health Visitor for more information.

Social Worker – A Local Authority Social Worker can advise you on practical and financial problems (including Care in the Community Assessments) to identify the needs of you and your child; tell you about local services and help and support you in arranging services. In most areas, social workers have a budget for providing short breaks and services to you as a carer, so it is always worth enquiring about these. You can contact a social worker via your local Social Services department. In some areas, there will be a specific child disability team. However, you may not be assigned a named social worker but may have to speak to the duty social worker.

Speech and Language Therapist (SaLT) – If your child has difficulty with eating, drinking or communication, he may be referred to a Speech and Language Therapist. The therapist can advise on eating and drinking problems and can assess and treat communication difficulties. If appropriate, the therapist may recommend specialist communication aids or sign language training. Most SaLTs are based at schools, clinics and child development centres. If you are concerned about your child, you can approach a SaLT directly or ask your GP or Health Visitor for a referral.

Understanding all the terms

“I spent several long phone calls discussing educational needs for my son and Scope’s help and advice was marvellous.”

There can be a lot to take in and understand when your child has been newly diagnosed with cerebral palsy. This section is your A – Z guide to defining the jargon, terms and medical language.



This glossary is intended as an introductory guide to some of the terminology used by medical and other professionals in the field of cerebral palsy. Scope does not, however, endorse the use of medical terminology as a labelling device.

This list is a condensed version of Scope's full Glossary of Terms. If you wish to have a copy of a fuller version, please contact Scope Response or view our website www.scope.org.uk

Abduction

Movement of a limb outwards and away from the midline of the body.

Adduction

Movement of a limb inwards and towards the midline of the body.

Ambulatory

Able to walk.

Ankle-foot Orthosis (AFO)

A brace used to stretch the Achilles tendon worn on the lower leg and foot to support the ankle, hold the foot and ankle in the correct position and correct foot drop. It is a thin, light plastic material. This is individually moulded and needs replacement as the child grows.

Aphasia

General term for language disorders (reading, writing, speaking or comprehension of written or spoken words) due to cerebral dysfunction.

Apraxia

Inability to perform purposeful movements where muscle weakness is not apparent.

Ataxic Cerebral Palsy

A form of cerebral palsy characterised by problems with balance, co-ordination, shaky hand movements and jerky speech.

Bobath Therapy

Physical therapy which aims to improve posture and movement.

4.2

Botulinum Toxin A

Drug which can reduce spasticity (tightness) in muscles.

Central Nervous System

Consists of the spinal cord and the brain. The brain receives and processes signals delivered through the spinal cord, and then sends directive signals to the body.

Cerebral Palsy

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

Cerebellum

Area of the brain which controls balance and muscle tone.

Conductive Education

A holistic learning system which can enable some children with cerebral palsy to function more independently.

Congenital

‘Present at birth’, for example, a condition which originates prenatally.

CT / CAT Scan

Diagnostic technique using a combination of computer and X-rays (Computed Axial Tomography). This provides cross-sectional images of tissue which are clearer and more detailed than X-rays alone with minimal exposure to radiation.

Diplegia

Paralysis affecting symmetrical parts of the body. Can refer to any area such as face, arms or legs. Should not be confused with paraplegia which is a form of paralysis affecting the lower limbs.

Dyskinetic CP

See athetoid cerebral palsy.

Dysphagia

Difficulty in swallowing.

Dyskinetic or Athetoid Cerebral Palsy

A form of Dyskinetic cerebral palsy characterised by involuntary movements resulting from the rapid change in muscle tone from floppy to tense.

Dyspraxia

Difficulty in carrying out purposeful movements to order, which is not related to muscle weakness (or comprehension).

Dystonia

Muscle tone fluctuates between stiffness and floppiness / slow twisting repetitive movements of arm, leg, trunk.

Fine motor movements

Small muscle movements, often of the hand (for example writing).

Function

A clinical term usually referring to an ability or skill required to carry out an activity of daily living.

Gait

How an individual walks.

Gastrostomy

Surgical procedure to allow insertion of tube for feeding purposes.

Hip dislocation

In children with spasticity, the thigh bone (femur) can gradually be pulled out of its socket where it connects with the hip – this is treated surgically.

Hemiplegia

Where one side of the body is affected by paralysis.

Hydrocephalus

Water on the brain.

Hypertonia

Increased muscle tone leading to stiffness.

Hypotonia

Decreased muscle tone leading to floppiness.

Hypoxia

Term used when the brain or other tissue is not receiving adequate oxygen.

Intrathecal Baclofen

Method of administering Baclofen (a muscle relaxant) internally. This is used to treat spasticity.

Ischaemia

When the amount of blood flowing through the brain or other tissue is diminished.

Lycra Dynamic Splinting

A material suit that supports the body, while allowing function.

Meningitis

Inflammation of the lining of the brain and / or spinal cord.

Monoplegia

Impairment of one limb.

4.4

Motor

Movement.

MRI

Diagnostic technique (Magnetic Resonance Imaging) providing cross-sectional / three-dimensional images which are more detailed than CT / CAT Scans – uses electro-magnetic field and radio waves (no X-rays or other radiation involved).

Muscle tone

The amount of tension or resistance to movement in a muscle.

Neonatal

Newly born (first four weeks of life).

Neurosurgery

Surgery to the nervous system and its supporting structures, for example, brain, spinal cord or nerve.

Paraplegia

Impairment in the motor and / or sensory function of lower extremities. Usually the result of spinal cord injury or a congenital condition.

Perinatal

Referring to the period from 28th week of pregnancy to 28th day after birth.

Quadriplegia

All four limbs affected.

Selective Dorsal Rhizotomy

A neurosurgical technique used in the treatment of spasticity in the lower limbs.

Spastic cerebral palsy

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.

Tenonectomy

Surgical cutting of a segment of tendon to relieve spasticity.

Tetraplegia

Impairment of all four limbs and body (as in quadriplegia).

Triplegia

Impairment of three limbs.

All Scope publications and factsheets are available to download from our website. This information can be made available in other formats and languages.

Scope Response offers a telephone interpreting service to people whose preferred language is not English.

Scope Response is a member of the Telephone Helplines Association and is working towards the Customer Service Excellence Charter Mark.



References to parents can also apply to carers.

© We are happy for you to make photocopies of any part of this document. However, we would be grateful if you would acknowledge Scope as the source of any copies.

Call 0808 800 3333
Visit www.scope.org.uk
Email response@scope.org.uk
Text SCOPE plus your message
to 80039

We would like to thank the many parents, professionals and disabled people who have helped with the updating and production of this pack.

PO Box 833, Milton Keynes, Bucks MK12 5NY

Scope Response is open from 9am – 5pm weekdays.
Closed weekends and Bank Holidays.

Scope Response offers free information, advice and support to disabled people, families and professionals across the whole disability spectrum.

The service comprises experienced multi-disciplinary staff who will receive your telephone calls, answer your emails, provide written leaflets and send publications to you; and regionally based staff whose focus is on cerebral palsy and can provide additional support and local information.

Supported by



scope

About cerebral palsy.
For disabled people achieving equality.