

Information for parents

Cerebral palsy





Introduction

Cerebral palsy is an umbrella term for a condition that affects children in different ways. 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 explain where you can find more help and information.

At the back of the booklet it tells you how to get hold of information sheets on particular issues which may affect your child.

'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.'

(Parent)

Each person reacts differently to the news that their child has a condition they were not expecting. When you first discover that your child has cerebral palsy, you may feel anxious about what this will mean and how you will cope. Most parents feel like this at some time. Don't be afraid to ask questions – however simple or trivial they may seem. Understanding more, and realising there are many positive things you can do to help your child develop, may help to reduce your concerns.

What is cerebral palsy?

Cerebral palsy is a non-progressive condition that affects posture, movement and co-ordination. It does not normally affect life expectancy. It's a wide-ranging condition that affects children in different ways and is as individual as children are themselves.

Sometimes there is no obvious reason why a child has cerebral palsy. Studies suggest it's mostly due to factors affecting the brain at birth. Some known possible causes include:

- an infection during the early part of pregnancy
- a difficult or premature birth
- a cerebral (brain) bleed
- an infection or accident affecting the brain in the early years of a child's life
- abnormal brain development
- a genetic link, although this is rare.

Cerebral palsy is often categorised into three main types, although it can be difficult to classify exactly what type of cerebral palsy a child has.

The three types are:

- spastic cerebral palsy
- athetoid cerebral palsy
- ataxic cerebral palsy.

Sometimes a child shows signs of more than one type of cerebral palsy. This is sometimes called **mixed cerebral palsy**.

Spastic cerebral palsy is the most common form. Children with spasticity will have muscle stiffness that may affect the range of movement in their joints.



Children with **athetoid cerebral palsy** tend to make involuntary movements, because their muscles change from floppy to tense in a way that is hard for them to control. This can also affect the child's speech or hearing. This type of cerebral palsy is sometimes also called **dyskinetic cerebral palsy**.

Children with **ataxic cerebral palsy** often find balance difficult and generally have unco-ordinated movements. Ataxia affects the whole body. Usually, children with ataxia can walk but may be unsteady, have shaky hand movements and irregular speech.

The organisation **Scope** can provide you with a glossary of terms that are used when cerebral palsy is discussed and also with more in-depth information on cerebral palsy. Contact information is given at the back of this booklet.

What does this mean for my child?

Children with cerebral palsy are children first and foremost, and are all affected in different ways. Some children can talk, sit up and walk – although they may take longer to develop these skills. Other children may require a high level of support in various areas of their lives. Many children with cerebral palsy have average or above average intelligence.

Children with cerebral palsy may have other difficulties such as sight problems, epilepsy or difficulty processing information about shapes, speed and space – this may be referred to as a **visual or spatial perception difficulty**.

Some children have eating or sleeping difficulties. If you need support helping your child in these areas, help and information is available. See **Where to find out more**, at the end of this booklet, for how to get leaflets on particular issues that may affect your child.

It's often very difficult for doctors to say exactly how a child will be affected, particularly when they are very young. Always discuss any concerns you have about your child with your **GP, health visitor** or consultant – and remember that you, as the parent, know your child better than anyone else.

Cerebral palsy cannot be cured. However, with appropriate early support and therapeutic intervention many children with cerebral palsy develop new skills and improve their muscle control and co-ordination, which helps their development.



Read more in **Where to find out more**

You and 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. They are individuals with their own personalities and potential to achieve.

You might find it helpful to talk to other parents of children with cerebral palsy or discuss your feelings and concerns with one of Scope's **community fieldworkers**. **Scope** fieldworkers have specialist local knowledge and can provide independent information and support. Referrals to your local team can be made through the **Cerebral Palsy Helpline**.

Scope's leaflet *How are you feeling?* passes on tips and advice from other parents of children with cerebral palsy.

Who can help?

You know more about your child than anyone else. However, some of the professionals you meet will become important partners and can help you to get the best support for your child. 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 supplied are appropriate.

Community nurse

A **community nurse** is a nurse who visits people at home.

Community fieldworker

A **community fieldworker** is a member of Scope's Community Team who can visit you at home.

Dietician

A **dietician** is a health professional who can advise on food, diet and nutrition.

Educational psychologist

An **educational psychologist** is a qualified teacher who has additional training as a psychologist. Educational psychologists can assess your child's development and provide support and advice on learning and behaviour.

General practitioner (GP)

A **GP** is your family doctor, who can refer you on to most other medical services and may also support welfare benefit applications and/or other types of help.

Health visitor

A **health visitor** is a 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 other local services.

Key worker

In some areas, **key workers** are available who offer support to families and act as a link person between families and other professionals.

Neurologist

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

Occupational therapist

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

Orthoptist

An **orthoptist** is a health professional who works with people who have visual problems. Orthoptists specialise in correcting vision by non-surgical means (especially by exercises to strengthen the eye muscles). 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.



Paediatrician

A **paediatrician** is a doctor who specialises in the care of babies and children. They can offer advice, information and support about any medical condition(s) your child has. It's usually a paediatrician who refers your child to any specialists they need to see.

Physiotherapist

A **physiotherapist** is a health professional who 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.

Social worker

A **social worker** is a 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 help to arrange the support you need. They provide practical help and advice about counselling, transport, home helps 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 on eating and drinking.

Meeting with professionals

You and your child should be fully involved in meetings with professionals, and your views should be taken into account as much as possible. It's also important that you understand everything that is said. Sometimes this can be difficult, particularly if you are anxious or upset.

Other families 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 has been said at key meetings. If you can take notes or have someone with you who will note down important points, it can help. If you are not comfortable doing this, you could ask if you can make a tape-recording of the meeting.

What can I do to help my child?

Every child is unique, but it will help your child if you treat them, as far as possible, like any other child and encourage your family and friends to do the same. It's important to involve your child in all aspects of family life. A positive attitude towards your child influences the attitudes of other people and will help your child to grow into a confident adult.

It may be tempting to overprotect your child and feel that you are the only person who can give them the attention and support they need. Try to involve as many other people as possible in your child's life, as this will help them to settle when it's time for them to attend nursery and, later on, school.

In daily activities, it helps if your child's posture is correct. You may want to ask for advice from a **physiotherapist** about this. The best way to handle a baby or young child depends on how old they are, what type of cerebral palsy they have and how their body is affected. Here are some practical suggestions that might be helpful:



- Try not to move your child suddenly or jerkily – their muscles may need more time to respond to changes in position than other children.
- Don't try and force movements. Let muscles tense and relax in their own time. This is important when children's muscles spasm or are tense.
- Give your child as much support as they need when you are handling them, because fear can make muscle spasms worse – but be careful not to give more support than is required.
- Even if your child is a small baby, try to make sure they spend time in a variety of different positions.

Children with cerebral palsy often use a lot of energy and so a well-balanced diet is particularly important. Some children cannot suck, swallow or chew easily, so eating may take longer than you expect.

Dental hygiene is important for all children but particularly so when children have difficulty eating, because food can easily become trapped in their teeth and gums. Help and encourage your child to brush their teeth after every meal and cut down on sugary food and drinks as much as possible.

As your child grows, try to encourage them to feed themselves. You can get advice on this from a range of professionals including **dieticians**, **occupational therapists** and **physiotherapists**.

Encourage your child to use their hands as much as possible. When they are very young, give them mobiles and dangling toys to follow and reach out to. Try to have interesting toys with a range of bright colours, different textures and noises.

Everyday activities can provide excellent learning and play opportunities for you and your child and can be fun. Dressing is a good opportunity to teach your child about parts of the body and how they move.

Encouraging your child to do things for themselves and praising their efforts helps to develop independence and confidence.

Where to find out more

For more information, contact **Scope**, the disability organisation whose focus is people with cerebral palsy. Whether you want to ask questions or simply to talk to someone, their **Cerebral Palsy Helpline** offers free confidential advice, initial counselling and information from 9am to 9pm weekdays, and from 2pm to 6pm at weekends. Scope can provide individual support and information specific to your child. They may also refer you to one of Scope's community fieldworkers, who have specialist knowledge and can provide independent information and support. All Scope's information leaflets and factsheets can be ordered from their Helpline or downloaded from their website.

Contacts details for **Scope** are given at the back of this booklet.



You may find the information in Scope's *Playing and learning* leaflet helpful when looking for ideas to help develop your child's experiences of life through play.

You and your child offers advice and tips on daily routines such as mealtimes, toilet training and bedtime.

An introduction to therapy gives an overview of what different therapists do and how they can help your child. Information about particular therapies, like conductive education, is also available.

As part of the National Childcare Strategy, every local authority has a *Children's Information Service* that provides details of all registered childcare provision. A national Freephone Helpline can give you information about registered childcare provision in your area and about play opportunities at baby and toddler groups, soft play areas, baby swimming groups and toy libraries. For further information ring **0800 0960 296** or visit www.childcarelink.gov.uk.

Scope supports a national network of *School for Parents* and *Face2Face schemes*. These are free services. *School for Parents* offers a supportive learning environment for pre-school children and their supporters. *Face2Face* is a confidential befriending service offering support to parents by other parents who have had a similar experience. To find out more visit www.face2facenetwork.org.uk.

Additional reading

Cerebral Palsy: A complete guide to caregiving

Miller F & Bachrach S J

John Hopkins University Press

1995

Cerebral Palsy Handbook: A practical guide for parents and carers

Stanton M

Vermillion

2002

Living with Cerebral Palsy

Pimm P

Wayland Publishing

1999

Handling the Young Cerebral Palsied Child at Home (3rd edition)

Finnie N

Heinemann Medical Books

1997

*Health Options: Complementary therapies for cerebral palsy
and related conditions*

Vickers A

Element

1994



Useful organisations and contacts

AFASIC – Overcoming Speech Impairments

Tel: 020 7490 9410

Helpline: 0845 355 5577

Fax: 020 7251 2834

Email: info@afasic.org.uk

Web: www.afasic.org.uk

www.talkingpoint.org.uk

Bobath Centre

Tel: 020 8444 3355

Web: www.bobath.org.uk

Capability Scotland

Tel: 0131 337 9876

Web: www.capability-scotland.org.uk

The Chartered Society of Physiotherapy

Tel: 020 7306 6666

Web: www.csp.org.uk

College of Occupational Therapists

Tel: 020 7357 6480

Web: www.cot.co.uk

Contact a Family

Helpline: 0808 808 3555

Textphone Helpline: 0808 808 3556

Web: www.cafamily.org.uk

Epilepsy Action (formerly the British Epilepsy Association)

Helpline: 0808 800 5050

Web: www.epilepsy.org.uk

Foundation for Conductive Education

Tel: 0121 449 1569

Web: www.conductive-education.org.uk

Hemi-help

Information and support for children with hemiplegia.

Helpline: 0845 123 2372

Tel: 0845 120 3713

Web: www.hemihelp.org.uk

Royal College of Speech and Language Therapy

Tel: 020 7378 1200

Web: www.rcslt.org

United Cerebral Palsy Association

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

Web: www.ucpa.org



The **Early Support Pilot Programme (ESPP)** is a Government programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. ESPP promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit www.espp.org.uk

ESPP is putting into practice the principles outlined in the Government guidance document *Together from the Start* which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

This booklet is one in a series produced by ESPP in response to requests from parents and voluntary organisations for better information for parents. ESPP has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles are currently available:

Autistic spectrum disorders (12)	Cerebral palsy (10)
Learning disabilities (15)	Down's syndrome (13)
If your child has a rare condition (18)	Multi-sensory impairment (9)
Speech and language difficulties (14)	Visual impairment (8)
When your child has no diagnosis (16)	Deafness (11)

Copies of these booklets can be obtained from:

DfES Publications
PO Box 5050, Sherwood Park,
Annesley, Nottingham NG15 0DJ
Tel: 0845 602 2260 Fax: 0845 603 3360
Textphone: 0845 605 5560 Email: dfes@prolog.uk.com

Please quote the appropriate reference number.

ESPP has also produced a **Family Pack**, which supports families through the first years of their children's lives. The Pack contains background information about the services you may need, the help you are entitled to and a **Family File** designed to help co-ordinate any support being provided for your family. They are resources that other families have said would make a difference. If you and your child are receiving regular support from a professional or range of professionals, please feel free to ask them about the **Early Support Family Pack**, which may help and which is available free of charge.

ESPP would like to thank all the parents and families involved in the production of these resources.

ESPP would also like to thank **SCOPE** for their help in writing, consulting upon and producing this resource.

SCOPE is a national disability charity for cerebral palsy. Scope's work is focused on four main areas: Early Years, Employment, Education and Daily Living. They provide a range of national and local services, and organise local groups. Information and advice is provided on all aspects of cerebral palsy and disability issues. A team of trained counsellors provide clients with emotional support and initial counselling.

Cerebral Palsy Helpline
PO Box 833
Milton Keynes MK12 5NY

Tel: 0808 800 3333 (Helpline)
Fax: 01908 321051

Email: cphelpline@scope.org.uk
Web: www.scope.org.uk



Copies of this booklet can be obtained from:
DfES Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ
Tel: 0845 602 2260
Fax: 0845 603 3360
Textphone: 0845 605 5560
Email: dfes@prolog.uk.com

Please quote ref: ESPP10

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