

You and your child

This booklet is part of a series, published by Scope, called When a child has cerebral palsy. This set includes:

- What is cerebral palsy?
- How are you feeling?
- You and your child
- Playing and learning
- Professionals working with you
- A message for family and friends

To order any of the parent leaflets or for a wide range of factsheets on subjects including therapies, rights and benefits, and further resources, download them from our website at www.scope.org.uk, email cphelpline@scope.org.uk or call free on 0808 800 3333.

This information can be made available in other formats if required, such as large print or tape.

Scope is able to offer a telephone interpreting service to people whose preferred language is not English. We also have some information available in a number of languages.

For details of any of our services, call free on 0808 800 3333.

If you are dissatisfied with any aspect of our services, email complaints@scope.org.uk or write to Scope Complaints, Freepost.

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Cerebral Palsy Helpline
Whether you want to ask questions or simply talk to someone, the Cerebral Palsy Helpline offers free and confidential advice, initial counselling and information on 0808 800 3333 9am-9pm weekdays, 2pm-6pm weekends and Bank Holidays. If you wish, we can also put you in touch with your local Community Team.

Community Teams
Scope's Community Team will offer the support of a fieldworker who may visit you at home or wherever you feel comfortable. The fieldworker has specialist local knowledge and provides independent information and support.

Other parents
Visit our website discussion room at www.scope.org.uk or go to www.face2facenetwork.org.uk and contact other parents with similar experiences to yours!

To make this booklet easier to read, we have referred to children as 'he' or 'him' and 'she' or 'her'. All the information applies equally to girls and boys. References to parents can also apply to carers.

You and your child
Every child is unique. 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 first and foremost, children, individuals with their own unique personalities and potential to achieve.

It will help your child if you treat him, as far as possible, like any other child, and encourage your family and friends to do the same.

You are bound to be concerned about his future and how much he will achieve. Taking things day by day, playing with him and looking after him in the way that feels right for you, will help to give him the best possible start in life.

When you first find out
When you first discover that your child has cerebral palsy, you may feel anxious about what this will mean and how you are going to cope. Many parents feel like this at some time, especially if they have had little support and information about cerebral palsy.

Don't be afraid to ask questions – however obvious they may seem. Knowing more and realising that there are many positive things that you can do to help your child develop can help to lessen any concerns that you may have.



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

Parent

Some babies and young children with cerebral palsy may not be able to communicate with you in the same way as other children, perhaps because they cannot turn their heads or move their eyes, reach out and touch you or climb on your knee. Try to communicate with your child as often as possible. By talking, looking and touching you will learn to recognise the little signs that she is making to tell you things.

It is important to encourage your child to take part in family life in as many ways as possible.

Some parents find it tempting to over-protect a disabled child and may feel they are the only ones who can give her the attention she needs. If you can encourage other people to get to know your child, this will be a great help when she comes to settling in at nursery and later at school.

Handling a child with cerebral palsy
Handling a child means how you lift, carry, hold, position him and learn to control any muscle stiffness or uncontrolled muscle movements he may have. The best way to handle a baby or young child depends on how old he is, what type of cerebral palsy he has and how his body is affected. In general, try to position your child so he can see what is going on around him. Your physiotherapist can advise you.

As he gets older, you may find you need a special buggy or other adapted equipment such as a car seat to make sure he is safe and secure. Your occupational therapist can help you with this. For more details, see Professionals working with you.

Practical suggestions

- Try not to move your child suddenly or jerkily. His muscles may need time to respond to changes in position.
- Some children's muscles tense (spasm). Let muscles tense and relax in their own time – don't force movements.
- Fear can make muscle spasms worse, so give your child as much support as he needs when you are handling him. Be careful not to give him more support than he needs.
- Even if he is a small baby or is severely impaired, make sure that he spends time in different positions.



Scope has factsheets on the most common therapies.

Your physiotherapist can show you how to handle and carry your child in a way that will help him develop the best possible control over his body and prevent you from straining or injuring your back.

Before trying any new movements or methods always check with your paediatrician, doctor or therapist that they are suitable for your child.

Scope has factsheets on the most common therapies. Please call the Cerebral Palsy Helpline free on 0808 800 3333 or visit Scope's website at www.scope.org.uk where you can download the factsheets and share experiences with other parents.

Getting dressed

Getting dressed can sometimes be difficult for children with cerebral palsy. Make sure clothes are within easy reach when helping your child to dress.

If your child is interested, she is bound to be more cooperative. Encourage her to do things for herself, even if it takes longer, and give her lots of praise for every achievement, however small it is.

Everyday activities like dressing and feeding are good opportunities to teach her about parts of the body and how they move.

Practical suggestions

- Choose loose, comfortable clothing. Velcro and elastic can be easier to manage than buttons and zips. There are also specialist suppliers who design their clothes with the needs of disabled children in mind. Call the Cerebral Palsy Helpline for details.
- Buy well-fitting, supportive shoes. Some children with cerebral palsy need special shoes, which may be provided free through your health authority. Your doctor or therapist can give you advice about this.
- Always put the clothes on the most affected part of the body first.
- If her legs are bent before putting on socks and shoes it may help ease any stiffness in her ankles and feet and her toes are less likely to curl under.



As your child grows, encourage him to feed himself and allow him a choice about food and drinks.

Eating and mealtimes
Some children with cerebral palsy cannot suck and swallow and chew easily, so eating may be messy. It may also take longer but it is important to take time to ensure that your child has a healthy diet. Your health visitor can advise, and a speech and language therapist can give specialist help and support if your child has difficulties when eating.

Breastfeeding may be more difficult for some children with cerebral palsy though many children have no problems at all. Again, ask the advice of your midwife or health visitor.

As your child grows, encourage him to feed himself and allow him a choice about food and drinks. There are special cups and pieces of cutlery that may be helpful. Your health visitor or occupational therapist will be able to advise.

Why brushing teeth is so important
When children have eating difficulties 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 his teeth after every meal and cut down on sugary food and drinks. It is important for him to visit the dentist regularly and take dental care.

In the bath
For small children, bath time is a great time for having fun as well as getting clean. As your child gets older, special bath aids can help, or you may find using a shower easier. An occupational therapist can give you advice.

Going to the toilet
Toilet training may be more difficult for a child with cerebral palsy. For example, it may be hard for him to relax or use his muscles to empty his bowels. Continence can sometimes be a problem, too. Your therapist or health visitor can give you help and support. For specific advice about continence, you can contact the Continence Foundation Helpline via www.continence-foundation.org.uk or call 020 7831 9831. You can also call Incontact – National Action on Incontinence on 020 7700 7035 www.incontact.org.



It's normal to be concerned. Is she ill, uncomfortable or teething?

Bedtime

Having a bedtime routine to look forward to, perhaps with a drink or a bedtime story, often helps children to settle. Many children with cerebral palsy don't drop off to sleep easily or sleep for very long. They may find it difficult to get comfortable at night or change position. Some areas have sleep clinics to help with persistent problems and give specialist advice.

If a child has cerebral palsy and finds it difficult to move by himself, you may need to turn him several times during the night. Your physiotherapist can show you how to use pillows to support him when he is lying on his side. If your child needs this kind of attention you may be entitled to a higher rate of Disability Living Allowance. Ask your Citizens Advice Bureau or the Cerebral Palsy Helpline for advice.

Young children (and particularly babies) should never sleep on their tummies or be allowed to get too warm.

A child with athetoid cerebral palsy may move a lot in bed. If this is the case, your health visitor can advise about types of bedding and nightclothes to ensure your child does not get too cold.

Like many children, children with cerebral palsy often wake in the night. If your child does this, it may be that there is something worrying her. Perhaps she is afraid of the dark, or has heard strange noises, or is uncomfortable and needs to be turned. It may also be that she has found a good way of getting your attention, such as asking for food and drink.

It's normal to be concerned when your child wakes and to check whether she is unwell, uncomfortable or teething. If nothing seems to help your child to settle, ask your health visitor or sleep clinic for advice. Some parents allow their child to sleep in their bed. This may work from time to time but it could cause problems for you and your child in the long run.

Scope has a factsheet with information and advice to help with sleep problems. For a copy of this or more information please call the Cerebral Palsy Helpline on 0800 800 3333, alternatively you can download a copy from the Scope website at www.scope.org.uk

The ideas we have given here are only suggestions. Every child is unique, and you will find special ways of handling, dressing and feeding that suit you both!

