



Rights & Benefits

A range of help is available to parents of children with cerebral palsy

The kind of help you need will depend on your child, and your own personal circumstances. You might need help with equipment, help at home or holidays.

You might get help from:

- the government
- your local authority (social services, education and housing departments)
- the health service (your doctor or hospital)
- charities and voluntary organisations

Some help is statutory – which means you are legally entitled to it. Other types of help are discretionary or means-tested – whether you get them depends on your circumstances.

The range of help can also vary from area to area – it is worth asking your Citizens Advice Bureau (CAB) what is available locally.

Help with money

There are two main ways to get help with the extra costs involved in looking after your child:

- You can claim regular benefits and one-off payments from the government (see page 3).
- You might also be able to apply for help from some of the charities and voluntary organisations (see page 4).

Help with equipment and services

There are many other kinds of practical help you can find:

- There are aids and equipment to help you and your child (see page 5-6).
- There are people who can support you too (see page 7).

Government Benefits

Disability Living Allowance

All parents of children with cp, regardless of their financial status, can claim Disability Living Allowance (DLA). For parents on low income, an award of DLA can lead to an increase in means-tested benefits via the disabled child premium.

Care component

This is payable at three rates to children with attention and/or a supervision needs during the day, night or both. There is no lower age limit.

Some parents, particularly those of very young children, have experienced difficulty obtaining the care component because of a special rule, which requires that a child's care or supervision needs must be 'substantially in excess' of the normal requirements of a non-disabled child of similar age.

It is important to emphasise that even children who have been diagnosed as having only mild cerebral palsy often do qualify (if not on a first claim then on a review) when developmental needs such as physiotherapy and any extra personal care and handling are taken into account.

Mobility component

Children can now be paid the higher rate of the mobility component from the age of three. Children usually qualify for the higher rate of the mobility component if

they are either unable or virtually unable to walk, or if they have a severe mental or sensory impairment. When a child is able to walk but has a need for guidance or supervision, the lower rate may be payable. Unfortunately, the lower rate is still payable from the age of five.

Invalid Care Allowance (ICA)

This is payable to carers of children on the middle or higher DLA care rates. ICA is of greatest benefit if you have a working partner and no income of your own. Recent reforms extend entitlement to the allowance to carers over 65 and allow carers to have a higher level of part-time earnings while retaining entitlement. Receipt of ICA can affect other benefits so it is best to seek advice before claiming.

Income Support (IS)

Income support is means-tested (although DLA is disregarded). Out of work parents may be able to claim IS, benefitting from the inclusion of significant disabled child and carer's premiums. Similar child disability allowances are payable as part of the new Working Families Tax Credit.

For more detailed advice contact your local benefit agency or ring 0800 882200. For independent advice, contact your local CAB or ring the CP Helpline on 0808 800 3333. You can also ask a Scope fieldworker to help you with the forms.

More help with money

There are a number of organisations outside of the government that can help you with money or in other ways.

The Family Fund

This is an independent organisation, set up by the government to help families caring for a child with a very severe physical or learning disability, who is under 16 and living at home.

The fund can either give you something specific that you need or financial help. For example, it could help pay for:

- a washing machine and dryer to help cope with incontinence
- holidays and outings to give you or your child a break
- driving lessons if you can't drive and need a car
- a fridge/freezer to reduce problems with shopping

You can apply directly or through someone like your social worker.

Contact The Family Fund Trust,
PO Box 50, York, Y01 2ZX.

Telephone 01904 621115.

Website www.familyfundtrust.org.uk

Welfare rights advisers

Welfare rights advisers work at welfare rights units, Citizens Advice Bureaux and independent advice centres. You can find out whether there's one in your area by asking at your local town hall or looking in the phone book.

Disability Law

This is a free law and advisory centre for people with a disability and their families. You can make an appointment by ringing 020 7791 9800 (minicom: 020 7791 9801) or you can write to Disability Law, Ground Floor, 39-45 Cavell Street, London, E1 2BP.

Email advice@dls.org.uk

Help with aids and equipment

The Health Service

The National Health Service may supply you with aids and equipment to help you care for your child at home. This could be a special bed or protective pants.

They may be provided free of charge, or you might be asked to pay towards the costs. If this happens, you might be able to get a grant from a charity.

The health service may also help people who are severely disabled by supplying them with extra equipment. Contact your family doctor, health visitor, district nurse, occupational therapist or social worker.

Hospitals

It is vital for any aids and equipment to be fitted to your child's individual needs, and these should be properly assessed by a physiotherapist or occupational therapist. As a temporary measure, however, hospitals may be able to arrange for you to borrow equipment free of charge if they think your child needs it. To find out more, talk to your paediatrician, GP, health visitor, district nurse or social worker. Also some Red Cross branches lend or hire equipment. Look in your local phone book under Red Cross.

Your local authority

Your local authority may help you with aids for daily living such as a bath seat, special cutlery or a telephone.

To find out what is available, contact your social services department. You may be asked to pay towards the cost.

Other help

There are several ways to get the aids or equipment that you feel your child needs.

- If you can afford it, you can buy direct from one of the manufacturers. For a small charge, the Disabled Living Foundation will send you lists of companies that supply, lend or hire equipment. Call 0845 130 9177 weekdays 10am to 4pm or visit www.dlf.org.uk
- Some organisations' newsletters have small ads for second-hand equipment.

Saving on VAT

Equipment specifically designed for use by someone with a disability may be exempt from VAT. If you are thinking of purchasing any equipment it may be helpful to talk to a professional. If you would like to check if it may be exempt, contact your local VAT office – in your phone book under Customs and Excise.

Advice about aids and equipment

To find out more about help with aids and equipment, talk to your doctor, health visitor, district nurse or social worker. Your occupational therapist is likely to be the best person to help.

The Government publishes a useful free booklet called *Caring for Someone* (code SD4). Copies of the leaflet are available from local Benefits Agency Offices.

If you have access to the internet, you can get more information from the Benefits Agency website. The address is www.dss.gov.uk/ba

To find out about voluntary organisations that might be able to help you, ask your local library for a book called *A Guide to Grants For Individuals in Need* (published by the Directory of Social Change, London). It has a section on charities for people with a disability.

Disabled Living Centres

Disabled Living Centres give free advice and information to people with a disability and their carers. The centres are in many areas of the UK where you can have a look at what equipment is available and talk to specialist staff.

To find out if there's one near you, ask the occupational therapist at your social services department or contact the Disabled Living Centres Council on 0161 214 5959. Website www.dlcc.co.uk

If your child has severe hearing difficulties

Hearing aids are available free from the health service, which also services and maintains them.

You can also contact The National Deaf Children's Society, 15 Dufferin Street, London, EC1Y 8UR.

Telephone 020 7250 0123 (voice and minicom) 10am-5pm weekdays
Website www.ndcs.org.uk

If your child has difficulties being understood

A speech and language therapist can advise or refer you to a communication aids centre. These are listed in the free government leaflet *Equipment and Services for People With Disabilities*.

If your child is blind or partially sighted

Hospitals can let you have equipment to help your child if she is blind or partially sighted. Your family doctor can make an appointment for you at the hospital. You might also like to contact the Royal National Institute for the Blind (RNIB) which has a range of services for young children. For more information write to them at 224 Great Portland Street, London, W1N 6AA.

Telephone 0845 766 9999.
Website www.rnib.org.uk

Help at home

Looking after a child with a disability can be exhausting. You may want help with certain tasks, and you are bound to need some time off. You might want to start working again or there might just be odd times when you have to go out and need someone to help while you're away.

Nursing help

Your social services department might be able to provide a home help. You usually have to pay towards this, depending on your circumstances and the number of hours of help you need.

You might also be able to get help with laundry if your child is incontinent. In some cases the refuse service can collect soiled incontinence pads and dressings for disposal.

Help from your local NHS Trust

A district or community nurse can visit you if you need help with nursing tasks like bathing your child. To find out more, ask your doctor or contact the district nursing service.

Paying for help

You might be able to afford to pay for your own help. The easiest way to find someone is through an agency (in the Yellow Pages under Home Help).

UK Home Care Association (UKHCA) is an organisation for agencies providing paid care. For agencies in your areas, write to UKHCA Office, 42B Banstead Road, Carshalton Beeches, Surrey, SM5 3NW. Telephone 020 8288 1551. Website www.ukhca.co.uk


Association for Crossroads Care Attendant schemes

This is a voluntary organisation which can provide 'care attendants' to help you at home if your normal care situation collapses. The attendants are not professionals, but they are fully trained.

If you need emergency help and the local authority cannot provide it, contact the Association for Crossroads Care Attendant Schemes, 10 Regent Place, Rugby, Warwickshire, CV21 2PN. Telephone 01788 573653. Website www.crossroads.org.uk

Carers UK

Write to Carers UK, 20/25 Glasshouse Yard, London, EC1A 4JT for a free factsheet on help in the home. For advice about what is available in your area, please telephone 0808 808 7777. Website www.carersuk.demon.co.uk



For **information and support** on all aspects of cerebral palsy and Scope, call the **Cerebral Palsy Helpline** on 0808 800 3333 9am-9pm weekdays, 2pm-6pm weekends and Bank Holidays. Calls are **free and confidential**. You can email **cphelpline@scope.org.uk** or visit our website **www.scope.org.uk**

This information can be made available in other formats if required e.g. 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.

Please contact the Cerebral Palsy Helpline for more details of these services.