

Help and Support

Useful Organisations

Cerebra - www.cerebra.org.uk

Services available include:

Grants for equipment

Sleep service

Postal lending library – books, resources and toys

Telephone counseling service

Disability Living Allowance guide

Adapted Holiday home for hire

Challenging Behaviour Foundation - www.challengingbehaviour.org.uk

The Challenging Behaviour Foundation (CBF) is a charity specialising in severe learning disabilities and behaviour described as challenging. They can provide DVDs and information leaflets.

Contact a Family - www.cafamily.org.uk

Has a range of booklets available including:

Understanding your child's behaviour

Making GP practices more welcoming

A checklist for parents - detailing benefits that may be available

Feeding and eating

Helping your child's sleep

Potty/ toilet training

Mencap - www.mencap.org.uk/

Mencap offer advice and information for parents, carers and family members of someone with a learning disability. Local branches may also run nurseries, holiday clubs and youth clubs.

Net Buddy - www.netbuddy.org.uk

Practical tips from people with first-hand experience of learning disability, autism and special needs.

Parent Partnership Services

Every local council has to provide a Parent Partnership Service (PPS) by law. PPS offer information & advice to families of children and young people with additional needs. PPS are at 'arm's length' from the local authority and the advice they offer is confidential and impartial.

Patient Advice and Liaison Service (PALS)

Every hospital should have a Patient Advice and Liaison Service. The service aims to help patients and carers with any questions and problems they may have.

PALS will:

- Provide information for patients, their families and carers about health and local health services.
- Put people in touch with voluntary organisations and support groups.
- Help people sort out problems and concerns quickly, before they get more serious and cause anxiety.
- Advise on how to make a complaint if that becomes necessary.

Scope - www.scope.org.uk

Offer families and parenting advice including:

Developing independent toileting skills

Sleep support

Eating and meal times

Disabled children in books

Sure Start Children's Centres - www.gov.uk/sure-start-contact

The centres are open to all parents, carers and children and many of the services are free. You can get help and advice on child and family health, parenting, money, training and employment.

Support for parents

Carers Trust - www.carers.org

Offers help and advice on caring for a disabled child along with a link to find local support services.

Homestart - www.home-start.org.uk

Homestart help families that are struggling and need some help by providing a volunteer to visit the family's home for a couple of hours every week. The youngest child in the family needs to be under 5 to qualify. They also run family groups and social events for families.

Direct Payments

Direct payments are payments from the local council for people who would like to arrange and pay for their own care and support services. These payments are made directly to the disabled person (or to someone acting on their behalf), to arrange their own care package.

There are a number of different ways direct payments can be used such as:

- To access shortbreaks to provide respite for the whole family
- To buy specific equipment for your child
- Employing a personal assistant or agency to provide support with your child's personal care
- To help your child access leisure facilities or attend a particular activity

To receive direct payments you will need a social worker to complete a core assessment and as a result be assessed as needing help from social services.

Professional you may come into contact with

Speech & Language Therapist (S<)

Children are seen by this service when they have difficulties with interaction, understanding and use of spoken language. S< also help with eating, drinking and swallowing problems. Therapy is set up to suit the child's individual needs and delivered individually, in a group or through a programme.

Paediatric Physiotherapists

Paediatric Physiotherapists evaluate and treat children with varying conditions. Children are seen in various settings including home, clinics, at Child Development Centres, in nursery or at school. They work with the child's parents in a way that will empower the parents to become significant partners in their child's development . Wherever possible, physiotherapists work through play and activities of daily living.

Paediatric Occupational Therapists (OT)

OT's who specialise in working with children have a wide range of knowledge in children's development, illnesses and conditions/disorders. They pay particular attention to hand and eye coordination, perception and manipulative skills. They can advise and provide suitable aids for feeding, dressing, toileting, bathing and play in younger children and writing skills in older children.

Community Dental Services

The CDS provide treatment to patients who find it difficult to access dental care, including disabled children. You can ask a health visitor or gp for a referral.

Multi-Disciplinary Teams

These are teams which include health professionals with specialist knowledge and expertise. Examples of multi-disciplinary teams/multi-agency teams include:

Team Around the Child (TAC)

This is where all of the professionals involved with your child work together, share information and support.

Child Development Team/Centre

This is a healthcare team specialising in working with children with disabilities or where there are concerns about a child's development.

Child and adolescent mental health services (CAMHS)

CAMHS teams promote the mental health and psychological wellbeing of children and young people.

Help with Toilet training

Education and Resources for Improving Childhood Continence - www.eric.org.uk

Toilet Time Resource Pack from Sense Toys - www.sensetoys.com/OF53CN850621

Help with children's communication

Gilligan Games www.gilligangames.co.uk

Tom Tag www.orkidideas.com

Clickety Books www.clicketybooks.co.uk

Hanen Programme www.hanen.org

Talking Point www.talkingpoint.org.uk

I Can www.ican.org.uk

Benefits & Financial Help

Disability Living Allowance

This is a non-means tested benefit for children with disabilities. To claim for a child, they should be one or more of the following:

- Aged 3 months or over and needs extra help or looking after
- Aged 3 years or over and has severe difficulty walking
- Aged 5 years or over and needs extra help getting around out of doors

There are two components to this allowance:

Care Component

Payable at 3 rates depending on how much care is needed:

Highest rate - For extra help during the day and night

Middle rate - For extra help during the day or night

Lowest rate - For extra help during part of the day or part of the night

Mobility Component

Payable at two rates depending on how much help is needed with getting around:
Higher rate - for children 3 years and over who are unable to walk or have severe difficulty in walking; children who are deaf and blind; those whose health might suffer from the exertion of walking; those claiming the highest rate care component that have severe mental impairment or severe behaviour problems.

Lower rate - for children 5 years and over: for a child who can walk but may need someone to supervise or guide them.

Cerebra and Contact a Family both produce a comprehensive guide to completing the application forms for DLA.

Carer's Allowance

This is a taxable benefit to help people who look after someone who is disabled. You do not have to be related to, or live with the person that you care for. You may be able to get Carer's Allowance if you are aged 16 or over and spend at least 35 hours a week caring for a person who gets DLA at the middle or highest rate for personal care

Tax credits

You may be entitled to get extra Child Tax Credits if:

- the child gets Disability Living Allowance or Personal Independence Payment
- the child is registered blind (or was within 28 weeks of your tax credits claim)

Check the website for more details - <https://www.gov.uk/browse/benefits/tax-credits>

Council Tax Reductions

If your home has been specifically adapted to meet the needs of a disabled resident who is substantially and permanently disabled, you may be entitled to a reduction in your council tax band. Adaptations that qualify are either:

- A room (not kitchen or bathroom) mainly used by the disabled person
- An extra kitchen or bathroom to meet their needs
- Enough floor space for a wheelchair used indoors

Water Meter Charges

Some people who have a water meter can request a capped bill if they receive specific benefits and cannot avoid using a lot of water because they have three or more dependent children under 19 (in full time education). This also applies if you have a medical condition specified by the government - contact your water company for more details.

Cinema Exhibitors Association Card

Free tickets for a person to accompany a child to the cinema, if they receive DLA or are registered blind. You just need to complete a form and pay the £5 administration charge.

Family Fund

They give grants to families raising disabled and seriously ill children aged 17 and under. They can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together.

Turn 2 Us - www.turn2us.org.uk

Charity that offers a benefits calculator, grant database and help managing money.

Nappies and incontinence pads

If your child is incontinent you will be eligible for free nappies/incontinence pads from your local Primary Care Trust. In terms of what age the child needs to be to qualify and the number of pads/nappies allocated a day, this differ from trust to trust. You can get a referral to your local primary care trust's continence service through your GP, health visitor, paediatrician or school nurse.

Transport and getting out and about

Blue Badge Scheme

If you are disabled, you may be able to park in restricted areas under the blue badge scheme. The scheme is for drivers and passengers.

You are automatically eligible to apply for a badge if you are over two years old and either:

- receive the higher rate of the mobility component of DLA or
- are registered blind

You may also be eligible for a badge if:

- you are applying on behalf of a child over two with a permanent or substantial disability which means they can't walk or find walking very difficult.
- you are applying on behalf of a child under three with a medical condition that requires them to be close to a vehicle for emergency medical treatment or transporting bulky medical equipment.

Contact your local authority for details of how to apply.

Motability

The Motability Scheme allows you to use the higher rate mobility component of your child's Disability Living Allowance (DLA) towards hiring a new car. You can apply after your child is 3 years old. You may have to make an advance payment towards the car.

Under the contract hire scheme you contribute the higher level mobility component of your DLA to Motability for a period of 3 years or 5 years if you take a Wheelchair Adapted Vehicle (WAV). In return, you obtain a new vehicle which is insured, maintained and serviced without further charge. The vehicles also have full RAC Breakdown Assistance.

Exemption from Road Tax

If your child gets the higher rate DLA mobility component, you should automatically be sent a road tax exemption form (DLA 403) from the DLA unit. It is important that you complete and return the exemption form to the address stated on the letter enclosed with the form. The vehicle must be registered in the disabled person's name or their nominated driver's name. It must only be used for the disabled person's personal needs. It can't be used by the nominated driver for their own personal use.

Fares to Hospital

If you are on Income Support, income-based Job Seekers Allowance or Pension Credit, you can claim help with travel costs to and from hospital for NHS treatment when escorting your child. You can obtain a refund of your fares directly from the hospital if you produce proof that you are in receipt of benefits. Ask for form HC5.

Toll exemptions

If you have a valid blue badge, you do not have to pay tolls at certain road bridges and tunnels. You can find the latest information about where you are exempt from tolls by contacting the local council at www.gov.uk.

National Key Scheme (NKS) - www.radar.org.uk

Radar keys allow access to locked public toilets around the country. Toilets fitted with National Key Scheme (NKS) locks are often found in shopping centres, bus and train stations etc. Other places that may require a Radar key include disabled changing facilities at swimming pools and leisure centers, park gates and playgrounds with wheelchair accessible equipment.

Rough Guide to Accessible Britain - www.accessibleguide.co.uk

This gives reviews, hints and tips by disabled visitors and accessibility information including disabled parking.