

Cerebral Palsy Guide



Welcome to the latest edition of RWK Goodman's Cerebral Palsy Guide, featuring content by guest authors:



Ms Caroline Barrett, Partner at Rook Irwin Sweeney, on accessing special education (page 20);



Dr Heather Epps, Paediatric Neuro Physiotherapist, sharing her experience on the benefits of hydrotherapy to children with cerebral palsy (page 22);



Ms Jo Turnbull, Occupational Therapist, describing how occupational therapy can enhance the daily life of children with cerebral palsy (page 23);



Professor Ingram Wright, Clinical Neuropsychologist, on the advantages of neuropsychology input (page 25).



We are delighted to introduce RWK Goodman's latest edition of the Cerebral Palsy Guide.

If you are reading this guide, it may be because you care for a child with cerebral palsy. As a Paralympian with cerebral palsy, I have lived experience of the additional challenges faced by those with cerebral palsy.

It has been a privilege to know the team at RWK Goodman for a number of years and it is therefore with pleasure that I recommend this guide as a practical resource for children with cerebral palsy and their families.

Within these pages, you will find information on all sorts of issues from equipment to staying active within the community (a subject particularly close to my heart!). There is advice on therapies, legal resources and getting hold of funding.

I hope this guide will give you the confidence to ask for the support you and your child need.

Take care of yourselves,

A handwritten signature in black ink, appearing to read 'K. Hart'.

GB para-athlete and 2010 Commonwealth Games women's 100m T37 Gold Medalist

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Emotional support for the whole family – Shared experience

There are some days when supporting a child with cerebral palsy can feel like an emotional rollercoaster. Psychological support can come in various forms, from talking to others who have shared experiences; reaching out to family and friends; and seeking advice from professionals. There are also charities with useful resources on getting the best emotional support.

Shared experience

Speaking to others in a similar situation can be a real comfort and reduce feelings of loneliness. Local support groups can be a good place to start and your health visitor may be able to give you some ideas of groups in your locality. Alternatively, these online groups are easily accessible wherever you happen to be:

GOV.UK

The government website has a useful search facility for finding local support groups of children, young people and their families.
[gov.uk/find-a-community-support-group-or-organisation](https://www.gov.uk/find-a-community-support-group-or-organisation)

Mind Side by Side

Mind is a mental health charity in England and Wales. Side by Side is Mind's online community where you can listen, share and be heard. The online community allows you to post, comment and private message.
sidebyside.mind.org.uk

Cerebral Palsy UK – Facebook Group

Cerebral Palsy UK is a private group on Facebook. It has 8.6K members who are affected by CP in some way and is a great way of connecting with others who can share their own experiences and advice.

Somewhere to chat for parents/family/friends of children with cerebral palsy – Facebook Group

A private Facebook group with 1,200 members and created to encourage parents in the same situation to ask questions, give advice or have a chat. Formed by the mother of a quadriplegic CP, with severe visual impairment and global developmental delay.

Charities offering the opportunity to connect with other parents:

Peeps HIE Awareness and Support

Peeps provides support to families affected by HIE. HIE stands for hypoxic-ischaemic encephalopathy where there is a lack of oxygen and blood flow to the brain. HIE can cause cerebral palsy. Peeps offer buddy support, where you can be paired up with a mum or dad who has been through a similar experience.
peeps-hie.org/hie-awareness-support

Parents Connect

SCOPE offer a support service offering parents of children with disabilities the opportunity to meet and talk with other parents.
scope.org.uk/family-services/parents-connect



Professional emotional support

Sometimes it is helpful to talk to a professional, someone who understands your situation but does not know you personally. The following charities provide mentoring and one-to-one services for parents and carers of children affected by cerebral palsy and other disabilities:

Contact

As well as providing a huge amount of advice on topics from managing money to sleep, Contact has a Listening Ear Service to provide emotional support for parents facing the extra challenges of caring for a child with disabilities. The Listening Ear Service offers one-to-one telephone appointments with a family support adviser.

[contact.org.uk/help-for-families/listening-ear](https://www.contact.org.uk/help-for-families/listening-ear)

Navigate

Navigate is a national mentoring service that is part of SCOPE, providing online emotional support for parents and carers of children who have received a diagnosis in the last year. Navigate provides up to six sessions with a personal advisor to enable you to share your feelings and concerns.

[scope.org.uk/family-services/navigate](https://www.scope.org.uk/family-services/navigate)

Caldwell Children

Caldwell Children provides a family support network which includes telephone, email and face to face emotional and practical support to families.

[caldwellchildren.com/changing-lives/how-we-can-help/family-support](https://www.caldwellchildren.com/changing-lives/how-we-can-help/family-support)

Cerebra

Cerebra is a charity set up to provide advice to children living with a brain condition and their families. They have a useful guide on managing anxiety in children with intellectual disability.

[cerebra.org.uk/download/anxiety-guide-a-guide-for-parents](https://www.cerebra.org.uk/download/anxiety-guide-a-guide-for-parents)

Carers UK

Carers UK provides expert information and advice to carers and helps carers to access the support they need.

[carersuk.org](https://www.carersuk.org)

The Brain Charity

The Brain Charity provides free support for carers, friends and family of people with any form of neurological condition, including cerebral palsy, from anywhere in the UK, offering free eight-week counselling courses to anyone with a neurological condition, as well as their carers, family members and friends.

[thebraincharity.org.uk/service/counselling](https://www.thebraincharity.org.uk/service/counselling)

Changing Faces

Changing Faces offer confidential, one-to-one social, emotional and psychological counselling and support sessions to people of all ages in the UK with a condition that affects their appearance or creates a visible difference. Appointments are carried out over the phone or via video call, which means anyone from across the UK can access the service.

[changingfaces.org.uk/services-support/counselling-support](https://www.changingfaces.org.uk/services-support/counselling-support)

Cerebral Palsy Cymru

Cerebral Palsy Cymru offer therapy and support to children and their families across Wales. Together with providing physiotherapists, occupational therapists and speech and language therapists, they also have a family support service offering a listening ear, advice and support.

[cerebralpalsycymru.org](https://www.cerebralpalsycymru.org)



Siblings & staying informed

Siblings can play an important role in looking after their brother or sister with additional needs, acting as both a vital care giver and chief playmate. It is crucial that their emotional needs are met too.

SCOPE

SCOPE is a large charity that provides a huge amount of information and advice to support people with disabilities, their families and carers. Their website contains some really useful tips on supporting the siblings of a child with disabilities.

[scope.org.uk](https://www.scope.org.uk)

Sibs Charity

Sibs Charity describes itself as the only UK charity for children and adults who are growing up with a disabled brother or sister. They provide information and support for siblings of all ages.

[sibs.org.uk](https://www.sibs.org.uk)

Staying informed

Some parents find it helpful to stay informed on their child's condition and up to date on the latest research.

Canchild

Canchild is an international resource for children with cerebral palsy and their families. Following interviews with parents on their experiences of raising a child with cerebral palsy from early childhood into young adulthood, they have prepared an excellent guide 'by parents for parents' providing tips for raising a child with cerebral palsy.

[canchild.ca/en/resources/23-if-i-knew-then-what-i-know-now-parents-reflections-on-raising-children-with-cerebralpalsy](https://www.canchild.ca/en/resources/23-if-i-knew-then-what-i-know-now-parents-reflections-on-raising-children-with-cerebralpalsy)



Respite care and short term breaks

We all need a break from time to time. Your Local Authority may be able to provide 'respite care' or 'short term breaks' for your child. Short term breaks may involve someone looking after your child in your own home or your child enjoying some time in a day care facility or residential accommodation.

Your Local Authority must set out its respite care services in a document called a 'Short Breaks Services Statement'. You can ask your Local Authority for a copy.

A little bit of respite care can have a really positive impact on the whole family so take advantage of this provision if you can.

STATUTORY SUPPORT

Getting hold of funding

Raising a child with cerebral palsy can be expensive. In addition to statutory support, there are several charities and trusts that can assist in meeting the additional costs associated with your child's particular needs:

Local Authority support

Local Authorities have a duty to provide any non-medical care services to children who are disabled.

This provision may include equipment, transport assistance, home adaptations and respite care. To access these services, ask your Local Authority for an assessment of your child's needs. After carrying out the assessment your Local Authority may identify specific needs and then must arrange for all the services to be put in place to meet those needs.

The help and support that the Local Authority decides to give your child is set out in a care plan which should be discussed and agreed with you before being implemented.

Cerebra

The charity Cerebra has useful information sheets on accessing Local Authority support in England and Wales.

cerebra.org.uk/download/social-care-in-england

cerebra.org.uk/download/social-care-in-wales

School transport

The Education Act 1996 identifies four categories of children who are entitled to free transport:

1. Children who live outside the 'walking distance';
2. Children from low income families;
3. Children who cannot reasonably be expected to walk to school because of the nature of the route; and
4. Children who can't reasonably be expected to walk to school because of their special educational needs, disability or mobility problems.

Your child may fall in categories one to four. The walking distance to school is two miles for children under the age of eight and three miles for children aged eight and over.

However, many children with cerebral palsy are likely to be eligible under category four which applies if your child:

1. Is aged between five and sixteen years old; and
2. Has special educational needs, a disability or mobility problems; and
3. Cannot reasonably be expected to walk to school because of these needs.

Each child will be assessed on an individual basis to identify their particular transport requirements.

To apply for school transport visit:

gov.uk/apply-school-transport-for-child-with-special-educational-needs-sen

The Cerebra charity has a really useful guide on accessing school transport:

cerebra.org.uk/download/school-transport-in-england

cerebra.org.uk/download/school-transport-in-wales



Personal wheelchair budget

Since December 2019, adults and children who need a wheelchair can access a personal wheelchair budget. Personal wheelchair budgets are a new provision, designed to give people greater choice over the wheelchair provided. People can add their own money or money from charities to their personal wheelchair budget to purchase their wheelchair of choice. The size of a personal wheelchair budget is assessed on an individual basis depending on a person's needs.

england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets

Disabled Facilities Grant

Your Council may be able to provide a grant of up to £30,000 in England and £36,000 in Wales to make adaptations to your home such as widening doors; installing ramps, hoists or stair lifts; or providing a downstairs bathroom. Depending on your income or savings, you may have to pay towards the cost of the work but children under the age of 18 can receive a grant without their parents' finances being taken into account.

gov.uk/disabled-facilities-grants

Disability Living Allowance for Children under the age of 16

Disability Living Allowance (DLA) for children is designed to help families with the extra costs of looking after a child with a disability. DLA is not means tested and does not have a negative effect on other benefits you may be claiming. From April 2024, you can receive up to £184.30 per week depending on your child's needs. DLA is one benefit made up of two components: A care component and a mobility component. In order to be eligible for the care component your child must need more care than a child of the same age who does not have a disability. The care component can be claimed from any age.

To be eligible for the mobility component, your child must have difficulty moving about and be at least three years old.

DLA claim forms are available by phone **0800 1214 600** or can be downloaded from the government website:

gov.uk/government/publications/disability-living-allowance-for-children-claim-form

The advantage of requesting a form by phone is that your child's DLA may be awarded from the date that the form is requested. If you download the form from the website, the DLA is only awarded from the date that the completed form is submitted.

Filling in the form can be daunting. The charity Cerebra has a really useful step by step guide on completing the questions:

cerebra.org.uk/download/disability-living-allowance-dla-vc

Personal Independence Payment for adults aged 16-64

If you or your child are over 16, you can apply for a Personal Independence Payment (PIP), a tax-free benefit known formerly as Disability Living Allowance (DLA) for adults.

gov.uk/pip

Carers' Allowance and Carers' Credit

As a carer of a child or adult with cerebral palsy, you may also be entitled to direct financial support from the Government, such as a Carers' Allowance, Carers' Credit, certain employment rights and respite care/ short breaks.

gov.uk/carers-allowance

Motability Scheme

If your child gets the higher rate mobility component of Disability Living Allowance you may be eligible for the Motability Scheme. The Motability Scheme enables people to use their government-funded mobility allowance to lease a new car, scooter or powered wheelchair.

motability.co.uk

Blue Badge Parking Scheme

Blue Badge holders can park in disabled parking spaces and other spaces. Different rules for Blue Badge holders apply in different towns. If your child receives the higher rate mobility component of Disability Living Allowance or is registered blind, they will automatically qualify for a Blue Badge. However, if your child has great difficulty walking and is not yet old enough to qualify for the mobility component of DLA, it is still worth applying because Blue Badges can be awarded on a discretionary basis.

gov.uk/apply-blue-badge



Wheelchairs and equipment

Whizz-Kidz provides a range of mobility equipment to children and young people. The mobility equipment they provide includes manual wheelchairs, powered wheelchairs, buggies, trikes and sports wheelchairs.

whizz-kidz.org.uk

Children Today provides money for specialised equipment for children and young people up to the age of 25 years old. They can provide grants for electric wheelchairs, walking aids, adapted trikes, adapted car seats, sensory equipment, hoists and sleeping equipment.

childrentoday.org.uk

The Family Fund provides grants for families in the UK who are raising a disabled child or a child who is seriously unwell. You can apply for grants for all sorts of things that you feel would make a difference to your child's life. Some popular grants include sensory toys, computers and play equipment but they also provide grants for activities.

familyfund.org.uk

Cheyne Charity for children with cerebral palsy accept requests for funding for equipment such as seats, standing frames, tricycles, powered mobility, computers and respite breaks.

cheynecharity.org

Newlife Charity can provide funding for beds, buggies, wheelchairs, seating systems and other equipment.

newlifecharity.co.uk

The Boparan Charitable Trust is a national charity and accepts applications for disability equipment, treatments, therapies, and household essentials. Further information about the items they fund can be found on their website and they are happy to discuss applications before you submit them if you are unsure about the criteria.

theboparancharitabletrust.com

Peeps is a charity dedicated to supporting families affected by hypoxic-ischaemic encephalopathy (a lack of oxygen to the brain) which can cause cerebral palsy. Peeps provides grants of up to £500 for various pieces of equipment.

peeps-hie.org/hie-awareness-support

Independence at Home is a charity that provides grants for equipment, home adaptations and essential household items.

independenceathome.org.uk

Designability is a national charity that creates innovative products and services with and for people with disabilities, helping them to live with greater independence. Based in Bath, the charity is best known for their pioneering Wizzybug Loan Scheme which provides free, fun, powered wheelchairs called Wizzybugs to very young children with disabilities across the UK.

designability.org.uk

Tree of Hope is a charity that helps children and young people with a disability by supporting families to raise the funds they need for specialist therapy and treatment that is not available on the NHS.

treeofhope.org.uk

Holidays

Kids in Action provides support to children and young adults with special needs. They have three caravans in a holiday park in Great Yarmouth, complete with wet rooms and ramps. These 'homes away from home' come with central heating and double glazing – not to mention the swimming pool, crazy golf and entertainment available at the park. Kids in Action have recently merged with Ellie's Haven, offering a fully equipped holiday home in Looe, Cornwall too.

kidsinaction.org.uk

The Kensington Foundation's Daisy Chain Project offers holidays in bright and modern accommodation in Blackpool for families caring for a child with a disability. The holiday homes come free of charge and are wheelchair accessible. There are 10 self-contained apartments and they look absolutely charming. Equipment is available to hire including portable hoists, changing mats etc.

kensingtonfoundation.com

Dream Makers provides respite holidays in mobile holiday homes in Torquay, Devon. The homes are equipped for the use of children with disabilities and their careers, with walk in showers, wheelchair ramps, hoists and much more.

dreammakerschildrenscharity.com

Bendrigg Trust is a specialist residential activity centre based in beautiful Cumbria. They offer fully inclusive accessible activity breaks for groups, families and adults of all abilities. Activities they offer include climbing, canoeing, caving and cycling. They also have a pretty magical sensory room. Check out their YouTube Channel for videos of all the action!

bendrigg.org.uk



Therapies

The Boparan Charitable Trust accepts applications for funding for therapies including speech and language therapy, occupational therapy and behavioural therapy.

theboparancharitabletrust.com

Raising Money

Some families affected by cerebral palsy have been successful in raising money for particular pieces of equipment or therapy through fundraising. There are a couple of platforms online that make this possible:

Crowdfunder aims to connect projects that matter with people who care:

crowdfunder.co.uk

Go Fund Me is a similar fundraising platform:

uk.gofundme.com



EQUIPMENT

Getting the best equipment

There is a huge range of equipment on the market designed to make life easier. Your occupational therapist and physiotherapist will be best placed to advise you on the best equipment to fit your child's specific needs and circumstances.

We work with specialist neuro-physiotherapists, occupational therapists and chartered electronics engineers in the field of assistive technology to ensure our clients receive the best possible equipment to maximise their potential.

Below you will find more information on some of the equipment available and details of the pieces of equipment that our experts are recommending.

Aids to assist mobility

Mobility aids for people with cerebral palsy range from simple orthoses and walking frames to specialist powered wheelchairs. Finding the most appropriate and comfortable mobility aids for your child is vital for their growing independence, self-esteem and quality of life. Your physiotherapist and occupational therapist will understand your child's particular needs and be able to recommend the best equipment.

Assisted sitting

Assisted sitting has the benefit of providing postural support. The right sitting support will depend on your child's individual needs, and you should always seek advice from your own therapy team, but our physiotherapy and occupational therapy experts have been recommending:

The Panda Future R82 which comes in two different versions. The standard version is for children who need support around their arms and shoulders. The active version is for children who require a little extra freedom of movement. etac.com/en-gb/uk/products/paediatrics/seating/r82-panda-futura/seating/r82-panda-futura

The P-Pod by the Specialised Orthotic Services.

This is the ultimate beanbag for children and adults and provides high levels of postural support. specialisedorthoticservices.co.uk/product/p-pod

Assisted standing

A standing frame allows a child to maintain their hips and knees in a more extended and aligned position. Standing increases load bearing through the joints and aids hip development, digestion and circulation whilst providing pressure relief. If your child is able to stand with support, your therapy team can advise you of the most suitable standing frame to suit your child.

Leckey upright standing frames

Leckey has a range of upright standing systems for all ages with different ability levels. leckey.com gives a full list of suppliers.

Assisted moving

Moving is important for exercise, exploration and fun. As cerebral palsy affects everyone in different ways, the right mobility aids will depend on your child's abilities.

Mobility aids include:

Walking sticks which can help with standing, walking and weight bearing. Some have tripod bases to provide more support, and they are available in a variety of materials and at a range of prices.

Forearm crutches can help those who need help to balance while walking.

Two-wheeled walkers (with four posts) enable slower speeds and more control for those who struggle to maintain balance. Some walkers include built-in seats to enable the user to go from sitting to standing, and others include chest supports to help control the trunk. For those who cannot support their full body weight, suspension walkers include a harness attached to an overhead frame. A motorised lift adjusts what weight is borne.

Wheelchairs are suitable if your child cannot walk, or cannot walk for sustained periods.

Manual wheelchairs are cheaper than powered wheelchairs, but require the user to have some strength in their upper body and arms.

Powered wheelchairs come with several different features depending on your needs and budget. They suit those with little upper body control or strength. They are heavier than manual wheelchairs but enable you to get about quickly and easily.

Running bikes and adapted trikes may be suitable for your child and provide a great way of getting around and having fun at the same time.

A Smile Smart Wheelchair is a wheelchair training system which enables the wheelchair user to drive and control their own wheelchair using a tracking system. The wheelchair can also be attendant controlled as needed.

smilemart-tech.com

The Zippie TS Folding and TS Rigid is a tilt in space wheelchair for children. Available with either a folding or rigid wheelchair frame, built-in growth and compatible with many seating and positioning solutions.

recare.co.uk

Everyone is different in terms of their ability to move about and your child's occupational therapist and physiotherapist will be best placed to advise you. Here is some of the equipment our experts are recommending:

A Kaye Walker can be used as both a walking training device and a community walking aid.

rms-rehab.co.uk

The Innowalk is a motorised standing device which allows children to exercise in an upright, weight bearing position.

madeformovement.com

A Petra Running Bike can be used from ages three to four through to adulthood and allows the user to propel themselves along using their feet on the ground.

Supplied by rms-rehab.co.uk

Adapted trikes

There are many adapted tricycles on the market and our physiotherapy experts recommend:

Tomcat range tomcatuk.org

RMS Rehab range rms-rehab.co.uk

An adapted trike may help your child exercise and make physiotherapy more fun. For differently-abled adventurers with a passion for the outdoors, there is a range of all terrain wheelchairs on the market. Here are just a few examples:

The Trikinetic K2 is a lightweight, all terrain manual wheelchair that has been designed for everyday use, from cobbled town streets to mud and gravel. It is pretty transportable too as it can fold down and fit into a regular car.

trekinetic.com

The Sandpiper is a manual all terrain wheelchair which is at the less expensive end of the scale. Its large balloon like tyres make it perfect for gliding over soft sand, mud and even snow.

allterrainwheelchairs.co.uk

The Mountain Trike is described as an all-terrain, self propelled, sleek and versatile all-terrain wheelchair. This wheelchair can be driven with just one hand and features hydraulic disc brakes. In terms of transportability, the chair can be folded up into a cube and easily transported in the boot of a car.

mountaintrike.com

Assisted transfers

Lifting a child can become back breaking work and a hoist to assist with transfers can make a huge difference. Hoists or lifts can come as slings, seats and platforms to help people with cerebral palsy to move around spaces where it's difficult to operate wheelchairs or walkers. Your occupational therapist will have a wealth

of knowledge on hoists to fit your child's particular needs and we recommend speaking to them about the right hoist for you. Here are some of the hoists that our occupational therapy experts recommend:

The Symmetrikit Skyframe is an ideal permanent hoisting system and can be wall or ceiling mounted although free standing options are available.

symmetrikit.com

Molift Smart Mobile Hoist. This is a hoist that is designed to be easily wheeled and transported to where it is required. It is perfect for home or travel. It folds up without using any tools.

etac.com

The ProMove Sling is an incredibly light and portable moving and handling device that provides an alternative when you cannot access a hoist.

promove.uk.com

Aids to assist with drinking

For children who have a safe swallow, some of the families we work with have got on well with the Munchkin Miracle360 trainer cup:

munchkin.co.uk

Or the Nuby Sipeez 360 degree wonder maxi cup:

uk.nuby.com

Aids to help sleep

Sleep is essential for all of us. It may be that your child would benefit from a specialist bed to help their sleep. Everyone is different and your occupational therapist will be able to advise you on the best bed for your child. Some of the specialist beds available on the market are below:

The Bakare Klearside Bed is suitable for both children and adults. It allows your child full visibility around the room and you full visibility of your child without having to look over the top of the bed rails.

bakare.co.uk



The Phippen Traveller bed is a safe portable bed which is ideal for staying overnight away from home.

kinderkey.co.uk or livingmadeeasy.org.uk

Safesides Bed Surrounds are inflatable bed surrounds which create all round protection.

livingmadeeasy.org.uk

The Symmetrisleep Sleep system enables people with movement difficulties to learn to lie straight by providing support where necessary when a person is lying down.

symmetrikit.com

If your child is having difficulty sleeping, speak to your child's paediatrician. They may be able to provide medication to relax your child's muscles; or prescribe melatonin (a naturally occurring hormone which makes you feel tired); or refer your child to a sleep specialist who could help your child develop good habits for sleep.

The charity Cerebra offers a sleep advice service for children with brain injuries.

01267 244210
sleep@cerebra.org.uk

SCOPE runs Sleep Right in East London, Northamptonshire and Peterborough. Sleep Right provides practical sleep support for families with children with cerebral palsy and other disabilities, helping to put tools and techniques in place to help your child feel calm and relaxed at bedtime; fall asleep quicker; wake up less during the night; and most importantly, get the sleep they need.

scope.org.uk/family-services/sleep-right

Aids to help bathing

Astor Bannerman provide a range of height adjustable baths and accompanying devices such as powered seats and side doors to make bathing easier.

astorbannerman.co.uk

The Jiraffe Hygiene Toileting System has been designed to solve the toileting challenge. It is a seating system that can be wheeled over a toilet to allow the user to toilet in an upright position.

jiraffe.org.uk

The Sangenic Easiseal Pad Disposal Unit provides a hygienic way of disposing of nappies and incontinence pads.

[avica-uk.com/cp/incontinence_disposal_unit_sangenic_easiseal_standard/EA502](https://www.avica-uk.com/cp/incontinence_disposal_unit_sangenic_easiseal_standard/EA502)

A WashPod is a modular wetroom that is designed specifically to meet the needs of individuals with disabilities. One of its primary benefits is that it can be installed quickly and easily.

[dignityaccess.co.uk](https://www.dignityaccess.co.uk)

Orthoses and supportive footwear

Orthoses are tailored braces that support and strengthen affected areas, such as feet, ankles and knees. They are prescribed and fitted by your child's health team.

Getting shoes and boots to fit with orthoses can be a challenge. Some of the children we work with have got on well with:

- The easy dressing range at Marks and Spencer [marksandspencer.com/l/kids/easy-dressing](https://www.marksandspencer.com/l/kids/easy-dressing)

- Pedro Boots [piedro-uk.co.uk](https://www.piedro-uk.co.uk)
- Billy Footwear [specialkids.company/collections/billy-footwear](https://www.specialkids.company/collections/billy-footwear)
- Nike FlyEase [nike.com/gb/flyease](https://www.nike.com/gb/flyease)
- Butler boots [thelakesorthotics.co.uk/our-products-butler-boots](https://www.thelakesorthotics.co.uk/our-products-butler-boots)

The London Orthotic Consultancy provides bespoke orthosis for many different conditions including cerebral palsy, with clinics in Kingston upon Thames; Bristol; Cambridge; Romford; and Manchester.

[londonorthotics.co.uk](https://www.londonorthotics.co.uk)

Aids for swimming

A Chailey Buoyancy Aid supports the head and stabilises the whole upper body. Supplied by Therapy World:

[therapyworld.org.uk](https://www.therapyworld.org.uk)

Incontinence swimwear can be essential and is supplied by Incy Wincy:

[incywincy.net](https://www.incywincy.net)

EQUIPMENT

Assistive technology

We work with chartered electronics engineers in the field of assistive technology who advise us on the best and latest technologies on the market. Such technologies include special controls for powered mobility, communication aids, environmental controls and access to computers.

The purpose of assistive technology is to help someone with physical disabilities to function in the real world at a level that their level of understanding allows. The larger the gap between a person's physical skills and their cognitive abilities then, generally speaking, the more assistive technology is needed to fill the gap and help that person to fulfil their potential.

Your child's therapy team will be best placed to answer any questions you have on assistive technology to suit your child's ability but set out below is some of the technology on the market:

Aids for communication

Communication is key to so many things we do in life. Many people affected by cerebral palsy have difficulties with communication and can benefit from technology to aid communication. Here are some of the options currently available:

Electronic communications boards: Electronic communication boards are like tablets with a choice of pictures, letters or words that a person can use to express themselves although the device does not actually produce any recognised speech.

Speech generating devices: A more advanced version of electronic communication boards are speech-generating devices. With a speech generating device, the technology translates its user's instructions into speech that others can easily understand.

Eye tracking devices: When a person is unable to use their fingers to select words or images on a communication board, eye tracking devices can come into their own. Eye tracking technology follows where a person's eyes are moving so a word can be selected without having to touch a screen.

The BIGmack communication aid is a simple device which speaks a pre-recorded phrase when hit. It is easy to record speech or music into the BIGmack.

[inclusive.co.uk](https://www.inclusive.co.uk)

The Grid Pad 12 is a computer designed for communication. It has a 15 hour battery life and straight forward controls. It is designed for Grid 3 software for communication and environmental controls.

[thinksmartbox.com](https://www.thinksmartbox.com)

Tobii Dynavox has a range of communication software packages to suit every developmental level.

SnapScene is one such package designed for young children at the beginning stages of learning communication who do not speak or who are difficult to understand.

GRID3 is a flexible piece of software which can be set up to meet the developmental level of the individual.

[tobiidynavox.com](https://www.tobiidynavox.com)

A Talking Mat is a visual or digital space made up of communication symbols and can be a great form of support to people with communication difficulties.

[talkingmats.com](https://www.talkingmats.com)



Aids for typing and writing

Many people with cerebral palsy lack the fine motor skills required to use a regular keyboard or write with a pen; and technology has been developed to make typing and writing easier.

Some writing technology is at the simpler end of the spectrum. These include steadying devices that can be attached to a pen or pencil to help a person with shaky movements; or a pen that is weighted; or a desk that can be adjusted for height or angle can help someone optimise their position for writing.

At the more advanced end of the spectrum is speech recognition typing software that can be tuned into the user's own voice or the voice generated from their speech generating device.

Environmental controls

Some people with cerebral palsy benefit from an intercom and remote latch to let people in the house and many companies such as Yale, Lock Monster or Smartlock have remote locks available.

Our assistive technology experts recommend AbleNet Powerlink Control Unit as an environmental control device which enables the user to turn mains powered devices on and off.

odelmobility.co.uk

Sensory equipment

Sensory equipment enables children to develop their senses by exploring different sounds, sights and textures. Sensory equipment may include fibre optics, bubble tubes or even a magic carpet. A magic carpet is an interactive resource which projects moving images on to any surface allowing children to engage and play.

Magic carpets are available to buy:

sensoryguru.com/product/mobile-magic-carpet

Some charities and centres have magic carpets available for use during sensory sessions including:

Dame Vera Lynn Children's Charity

dvlcc.org.uk

Gympanzees is a Bristol based charity which offers the use of sensory rooms. They also have a lending library where families can borrow sensory equipment. There is a whole range of toys and equipment available on their website which is well worth a look.

gympanzees.org/our-home/lending-library

Second-hand equipment

You may be able to find suitable second hand equipment for your child. There are a couple of Facebook groups which specialise in second hand equipment including:

Special Needs Equipment ~ Buy Sell Swap UK ONLY

[facebook.com/groups/SNEUK](https://www.facebook.com/groups/SNEUK)

Disabled Gear

[facebook.com/DisabledGear](https://www.facebook.com/DisabledGear)

Similarly, you may be looking to donate equipment that you are no longer using. The charity Through the Roof has a programme called Wheels for the World which accepts wheelchairs and mobility aids to provide much-needed mobility to adults and children across the globe.

throughtheroof.org/international-mission/wheels-for-the-world/



You can find out more on the government website:
www.gov.uk/children-with-special-educational-needs

Special education

Many children with cerebral palsy require additional support to help them learn. Guest author, Caroline Barrett is a Partner at Rook Irwin Sweeney. She shares her experience about accessing special education both during childhood and after the age of 19:

1. What should I do if my child has special educational needs?

"Special educational needs" means that a child has a learning difficulty or disability so that they require special educational provision. A learning difficulty or disability means that a child has a significantly greater difficulty in learning than the majority of others of the same age, or that they have a disability which prevents or hinders them from making use of the same facilities as others in a mainstream school. If your child meets this criteria then they will have special educational needs.

Local authorities have a duty to identify children who have special educational needs, and health authorities also have a responsibility to ensure that children with special educational needs are identified.

If a child has special educational needs, it means that they will require some additional provision in school to help them achieve their potential.

2. What should my child's school be doing to support them?

All schools need to ensure that they do not discriminate against children with disabilities. They may also need to make reasonable adjustments, such as adjustments to policies and practices within the school, to ensure that children are properly included and catered for.

Schools will also need to ensure that children receive additional support where this is required. This could be additional support from a teaching assistant, or some support from a therapy service, or some adaptations to materials and resources in the classroom. "SEN Support" is the term used to describe the support that schools must provide to children where they do not have an EHC Plan. SEN Support comes with a framework which means that schools must "Assess, Plan, Do, Review". This means that your child should have a plan which clearly sets out what support the school will provide them with, and this will be implemented and regularly reviewed.





3. What is an Education, Health & Care Plan (“EHCP”)?

An EHCP is a legal document which sets out a description of a child’s special educational needs and the provision they require to meet those needs. It also contains details about healthcare and social care support that the child needs.

EHCPs can look slightly different in different local authority areas, however all EHCPs will contain the following sections:

Section A – a description of the child’s and parent’s wishes, the child’s story, and what is important to them.

Section B – a description of the child’s special educational needs/

Section C – a description of the child’s healthcare needs

Section D – a description of the child’s social care needs

Section E – the educational outcomes that it is hoped the child will achieve within the next stage of education

Section F – the special educational provision that is necessary to meet the child’s needs as described in Section B

Section G – the healthcare provision that is necessary to meet the child’s healthcare needs as described in Section C

Section H – the social care provision that is necessary to meet the child’s social care needs as set out in Section D

Section I – the name or type of school placement that the child will attend

Section J – details of any personal budget that has been agreed

Section K – a list of important advice and documents that have been referred to in the document

An EHCP is an important document as it provides a child with legal rights to access all of the special educational provision that is set out in Section F of the plan. It is important that this provision is specific, detailed, and quantified, in order to ensure your child will have access to the provision they are entitled to.

4. How do I get an Education, Health & Care Plan for my child?

Not all children who have special educational needs will require an EHCP. Many schools can meet a child’s needs within their own financial resources. However an EHCP will be issued where it is “necessary” in order to meet a child’s special educational needs.

This is a question of degree. Where children require a high level of input which goes beyond what a school can reasonably provide, then an EHCP will be necessary. An EHCP is maintained by the local authority, rather than by the school, and the local authority will provide additional funding to the school to ensure that all of the provision can be delivered.

The first step in getting an EHCP is to make a request for an Education, Health and Care Needs Assessment (“EHCNA”). A request for an EHCNA can be made by the child’s parents or by the school. The local authority must agree to carry out an EHCNA where it thinks that it “may” be necessary for special educational provision to be made for the child in accordance with an EHCP. It is helpful to provide evidence to the local authority as to what the child’s needs are, and what kind of support you think they need, in order to show that this test is met.

If the local authority agrees to carry out an EHCNA, it will consult with parents, the child’s school, and any other people reasonably requested. It will also need to obtain relevant evidence such as a report from an educational psychologist. Once this advice has been obtained, the local authority will then make a further decision about whether it is necessary to issue an EHCP for the child. If it is necessary to issue an EHCP, the local authority will issue a version of the plan in draft for parents to provide comments on. At this stage parents can also request what school they want the

child to attend, and ask for it to be named in the EHCP.

5. How often should an EHCP plan be reviewed or amended?

An EHCP needs to be reviewed every 12 months. The school will normally make the practical arrangements for the annual review meeting. The local authority will be invited but might not always attend. Parents, teachers, and any therapists working with the child will also be invited to attend and to consider how things have gone that year. The school will compile paperwork for the annual review and will send reports and notes to the local authority following the meeting.

Following each annual review the local authority will issue a decision confirming whether it intends to make any changes to the EHCP, or whether it will not make any further changes to the EHCP that year. Parents have a right of appeal against any decision that is made.

It is sometimes necessary to hold an urgent annual review where a child’s needs have changed or there is a need to change school placement, and in those cases an additional request can be made for an urgent annual review.

6. What are my rights of appeal?

Parents will have a right of appeal against the following:

- A refusal to carry out an EHCNA
- A refusal to issue an EHCP following completion of an EHCNA
- Any final issued EHCP where you do not agree with the contents of the plan. You can currently appeal against the educational elements of the EHCP (Sections B, F, and I). You can also appeal against the social care and healthcare elements as well, although the Tribunal can only make non-binding recommendations about health and social care provision.
- A refusal to amend an EHCP following annual review; and
- A decision to cease to maintain an EHCP.

Appeals are heard by a specialist Tribunal called the First Tier Tribunal for Special Educational Needs and Disability. You will have 2 months from the date of a decision letter from the local authority in order to lodge an appeal at the Tribunal. You will also need to contact a mediation advisor in most cases before you lodge an appeal.

7. What are my options for schooling my child with special educational needs?

The majority of children with special educational needs attend mainstream schools. It is very unusual for children without EHCPs to attend special schools. For children without an EHCP, parents can apply for admission to a school in the usual way, following the local admissions procedures.

For children with EHCPs, there is still a presumption in favour of children attending mainstream school. Where a mainstream school is requested by a child's parents, the local authority must ensure that the child has access to a mainstream school unless it would be incompatible with the provision of efficient education for others and it cannot take any reasonable steps to prevent this.

When an EHCP is being finalised by a local authority, parents will be asked to put forward a choice of school. This school will then be named in Section I of the EHCP. A local authority

must follow parents' preference for which school should be named in the EHCP, unless this would be unsuitable to meet the child's needs, or it would be incompatible with the efficient education of others, or incompatible with the efficient use of resources (i.e. the parent's choice is more expensive than an alternative option which could also meet the child's needs). Parents can request either mainstream or special schools, and these can be maintained, non-maintained, or independent settings.

8. What are the education options for my child after they reach the age of 19?

EHCPs can be maintained up until the age of 25. However there is no automatic right for EHCPs to remain in place and it will need to be shown that it is necessary for the EHCP to be maintained and that there are still educational outcomes to be met.

EHCPs only apply where a young person remains in further education, and do not apply to higher education settings.

Young people over the age of 19 might attend college on a full-time or part time basis, or they might enrol in an apprenticeship scheme. Residential colleges are also an option for young people where there is evidence that this is necessary to meet needs, and this can often further independence. Courses for young people with disabilities often focus on helping them becoming as independent as possible and preparing them for adult life.

About Caroline Barrett

Caroline Barrett is a Partner at Rook Irwin Sweeney. Caroline is a public law specialist who advises on education, social care, and mental capacity law. She has significant experience in advising disabled people and their families on public law decisions that affect them, and she helps them to enforce their legal rights.

To reach Caroline Barrett, please email enquiries@rislaw.co.uk

Caroline Barrett | Rook Irwin Sweeney - Public Law. Human Rights.



Treatment and therapies

Children with cerebral palsy may benefit from a wide range of treatment and therapies to assist them in reaching their full potential. Your child's paediatric team will be able to advise you on what is best for your child. Below is a summary of some of the treatments and therapies available.

Physiotherapy

Physiotherapy can be hugely beneficial to children with cerebral palsy. It can improve motor development; ease stiffness; aid postural alignment and prevent the development of contractures.

Physiotherapists give manual therapy to affected muscles using their hands, but also teach physical exercises that stretch and strengthen muscles. Physiotherapists also offer advice on using and caring for aids and orthoses, such as special arm and leg braces that help to stretch muscles.

Your child should have access to physiotherapy through their healthcare team or through their school. Alternatively, you can find a chartered physiotherapist near you by using the search function on the Chartered Society of Physiotherapy website:

csp.org.uk/public-patient/find-physiotherapist

Heather Epps is a physiotherapist specialising in hydrotherapy and paediatric neurological physiotherapy.

aquaepps.co.uk

Lindsey Hopkinson is a paediatric physiotherapist with particular expertise in treating children with conditions such as cerebral palsy and acquired brain injury.

wanderlusttherapyforkids.com

The Movement Centre is a UK charity and specialist physiotherapy treatment centre, dedicated to supporting children and their families affected by movement disabilities.

the-movement-centre.co.uk

Hydrotherapy or aquatic physiotherapy

Hydrotherapy is a specific type of treatment conducted by trained therapists for people with cerebral palsy that takes place in warm swimming pools or specialist hydrotherapy pools.

Guest author, Dr Heather Epps, is a paediatric and adult neuro physiotherapist who specialises in hydrotherapy. She shares her experience on the benefits of hydrotherapy to children with cerebral palsy:

The Benefits of Hydrotherapy

There are many benefits of hydrotherapy for children with cerebral palsy. Muscle spasticity, dystonia and stiffness are reduced and relaxation occurs because of the pressure of the water against the body, the effects of heat on the muscles, the reduced effort required to be upright, and tone influencing physiotherapy techniques and handling whilst the body is fully supported by buoyancy. At the same time, pain is reduced as muscles are stretched and moved whilst in a relaxed state and because of the weightlessness of limbs with reduced stress and weight going through the joints.

Many children can stand and step when in water with the help of the physiotherapist with a better walking pattern than when they have to lift their body weight against gravity or are reliant on



a supportive walker. It is easier to balance without the fear of falling when seated or standing as the pressure of the water around the body and turbulent drag with movement allow more time to respond and right the body, preventing injury.

Movement can be increased, muscles strengthened and head and trunk control challenged by using the properties of water alongside physiotherapy techniques in this unencumbered environment. Children have complete freedom of movement out of their equipment without the same limitations posed on their bodies by their muscle tone and reflex activity on land. In particular, it is less effortful to initiate, maintain and sustain movement, body and limb positions and postures.

Physiotherapists use the properties of water so that it is possible to move or be moved from one position to another (e.g. rolling, sitting up from lying down, standing from sitting, step ups) in the water before these transitions can be achieved on land. Some movements and positions can be experienced in water (such as on the stomach) that are not tolerated out of the water, or are not safe.

Many parents report that their child sleeps better, has less constipation, less pain and stiffness, reduced muscle tone and dystonic movements and is easier to handle, position and move after their hydrotherapy session. The hydrotherapy pool is a multi-sensory environment and, with exercise, can be used to help children to regulate, improve their gross motor skills, muscle strength, balance and body awareness and develop confidence. As it is less effortful to move in water, children with cerebral palsy can exercise for longer than on land. There are very positive heart and lung functional effects with the increased physical activity children can undertake in water, from kicking their legs to propelling or even swimming. Breath control and coordination caused by the pressure of the water against the chest wall and the increased flexibility of the spine assist voice production and swallow with specific water confidence and breathing techniques. Most importantly, children can undertake activity and exercise that has therapeutic benefit without realising how hard they are working because it is fun.

About Heather Epps

Heather and her team provide weekly treatments and/or intensive rehabilitation blocks of hydrotherapy for children and adults with cerebral palsy in their warm-water hydrotherapy pool at Lynden Hydrotherapy and Physiotherapy Centre (LHAP) in Reigate, Surrey. The clinic has specialist equipment including poolside and ceiling track hoists and shower trolleys that can be raised and lowered to assist with changing, showering and transferring into and out of the pool. Heather also provides assessments and reports, training and advice for families, carers and professionals, and pool design and development consultation.

You can find a chartered physiotherapist specialising in hydrotherapy by using the search function on the Chartered Society of Physiotherapy website:

[csp.org.uk/public-patient/find-physiotherapist](https://www.csp.org.uk/public-patient/find-physiotherapist)

Lynden Hydrotherapy & Physiotherapy (LHAP), based in Reigate, Surrey, boasts a brand new, purpose built hydrotherapy pool with state of the art accessibility equipment which opened in 2021. Regular and intensive hydrotherapy courses are available.

For more details contact:
office@lhap.co.uk www.lhap.co.uk

Occupational therapy

Occupational therapists can help babies, infants, children and young people grow, learn, have fun, socialise and play – so they can develop, thrive and reach their full potential. Guest author, Jo Turnbull, shares her experience:

Having worked as an Occupational Therapist for thirty years I am passionate about the difference OT's can make to the lives of children and adults with cerebral palsy. An OT will work alongside other members of the therapy team to help improve a child's physical, cognitive and social skills.

'Occupation' to an OT is any activity that is meaningful to someone. OT's will help children with cerebral palsy develop the skills they need to participate in day to day life using activities, assistive devices and/or adaptations. OT's will look at all areas of daily life from self care tasks such as eating and drinking or getting washed and dressed, to improving a child's ability to play, learn at school or socialise with friends.

The types of Occupational Therapy treatment are wide ranging depending on needs but may include;

- Improving a child's fine motor skills, useful for feeding, writing or playing.
- Advice, equipment or splinting to support a child's posture when undertaking activity or to minimise discomfort and the risk of joint contractures.
- Assisting with manual handling advice and recommendations of techniques and equipment.
- Assessing for adaptations at home or school to create an accessible environment (and enabling access of statutory disabled facility grant funding).
- Sensory Integration to assist children with sensory processing issues and the provision of a sensory diet that children can use at home and school.
- Adapting tasks, teaching and training carers and school staff and providing advice and support on equipment.

Occupational Therapists can be found in the social services and/or housing departments of Local Authorities and in the paediatric teams located in the NHS. There are also a number of independent OT's that can be found on the Royal College of OT's website:

Find an occupational therapist RCOTSS-IP

About Jo Turnbull

Jo is an independent Occupational Therapist who has spent her career working with children and adults in health, social care and the private sector. Jo holds an absolute belief that Occupational Therapy makes a positive difference to both individuals and local health and social care services. Jo maintains her clinical practice alongside her consultancy work and is an associate with Bush & Company Rehabilitation and is the OT associate for West Midlands Association of Directors of Adult Social Services.

For further information Jo can be contacted at
Jo@Iotherapy.co.uk.



Speech and language therapy

A child with cerebral palsy may benefit from speech and language therapy if their condition affects the muscles in their neck, face, or mouth, or if they struggle to understand and interpret speech and language. Assessments usually take place as soon as a language or speech delay is suspected. A trained speech and language therapist can help a child with cerebral palsy to overcome the following problems:

- Coordinating and controlling speech muscles
- Difficulty swallowing (dysphagia)
- Drooling
- Reduced ability or an inability to form sounds and words
- Difficulty with speech and comprehension
- The effects of a hearing impairment.

The treatment your child will receive will depend on their specific needs as they grow and develop.

Marie Couch is a speech and language therapist who works with older children and young adults with communication difficulties.

maggiesargent.co.uk/people/marie-couch

Michelle Whitton specialises in communication problems associated with cerebral palsy and acquired brain injury.

search.bushco.co.uk/consultants/profile/96164066

Ruth Merritt is an independent speech and language therapist specialising in the field of deafness.

therapyinspiration.com

Clinical neuropsychology

Neuropsychology is about understanding the links between brain function, cognitive abilities, emotions and behaviour. Guest author, Professor Ingram Wright, Clinical Neuropsychologist, shares his experience of how neuropsychology input can benefit children with cerebral palsy:

For many children with cerebral palsy there is a risk that we might make assumptions about a young person's level of ability. This sometimes means that we pitch things at too high a level or, alternatively that we underestimate their abilities. Alongside the difficulties with movement that characterise cerebral palsy there can be additional problems with learning and memory, attentional difficulties, visual information or language processing problems. Sometimes cerebral palsy can be accompanied by difficulties that are so severe they might be considered as an additional diagnosis such as ADHD or Autism.

Clinical Neuropsychologists are skilled in undertaking assessments which children who have cerebral palsy. They will also be interested in the perspectives of parents, teachers and the young person themselves. An experienced neuropsychologist can provide advice about the best way to support a child's learning and developmental needs, help them to manage difficult feelings and give parents and teacher advice about positive approaches to managing behaviour that can be challenging. Neuropsychologists will often undertake a formal assessment of your child. Typically children enjoy the assessments which involve a variety of puzzles or mental challenges that work around the motor difficulties.

There is a register, the SRCN, that contains details of those specialists who are recognised as Clinical Neuropsychologists by the UK's professional body of psychologists.

www.bps.org.uk/specialist-register-clinical-neuropsychologists



About Ingram Wright

Professor Ingram Wright is a Consultant Clinical Neuropsychologist specialising in neonatal and childhood brain injury. He has worked in the NHS for over 25 years and in medico-legal practice for 20 years. Ingram spends the majority of his time in an NHS role as lead for Psychological Health Services at a large NHS Trust in Bristol. Ingram is also Chair of the British Psychological Society's Division of Neuropsychology with responsibility for promoting the specialist skills of neuropsychologists and ensuring that the public are informed in seeking the best quality neuropsychological advice and support.

Conductive Education

Conductive Education is a unique form of rehabilitation that helps children and adults with neurological movement disorders to overcome their physical challenges with the aim of becoming less reliant on aids.

Conductive Education is based on the concept that everyone has the potential to learn and develop irrespective of their starting point. It approaches the rehabilitation of people with motor disabilities from an educational perspective, rather than a medical perspective, focusing on the link between the mind and body and the importance of developing the motivation and confidence to achieve physical goals.

Conductive Education is available through NICE, a UK registered charity dedicated to providing services and training in the field of Conductive Education.

conductive-education.org.uk

The full guidance on the availability of SDR on the NHS can be accessed via: england.nhs.uk/publication/selective-dorsal-rhizotomy-for-treatment-of-spasticity-in-cerebral-palsy



Orthopaedic surgery

Children with cerebral palsy are often at risk of developing problems with their muscles and bones.

These may require monitoring by an orthopaedic doctor throughout a child's life, particularly until they are fully grown. The orthopaedic surgeons with whom we work often recommend review every six months.

Orthopaedic surgery is used to correct conditions that affect the musculoskeletal system (bones, joints, ligaments, tendons, muscles and nerves) and may be available to relieve the symptoms of cerebral palsy in some cases. Because of the risks associated with surgery and because its benefits may only be temporary, courses of physiotherapy and medication are usually recommended first. Surgery may be able to realign fixed joints and tendons; prevent contractures (permanently tightened muscles); correct hip dislocation and treat scoliosis (spinal curvature).

If you have concerns about your child's musculoskeletal system, speak to your child's paediatrician or orthopaedic team.

Selective Dorsal Rhizotomy

Selective dorsal rhizotomy (SDR) is a surgical procedure that could help children who have spastic cerebral palsy. Specifically, it can help children with spasticity in their lower limbs that makes walking and sitting difficult. SDR involves cutting carefully selected sensory nerves inside the spine of the lower back to ease muscle stiffness. The surgery is performed under general anaesthetic.

Following surgery regular physiotherapy is necessary to obtain the best results from SDR. Like all surgery, SDR carries specific risks and your child's treatment team will be best placed to advise whether SDR is right for your child.

NHS England has provided guidance on the availability of SDR on the NHS and children must meet the following criteria:

- The child must be aged three to nine years old
- The child must have a diagnosis of cerebral palsy with spasticity mainly affecting the legs
- The child has dynamic spasticity in the lower limbs and no dystonia
- The child functions at GMFCS level II or III3
- There is no evidence of genetic or neurological progressive illness
- The child has no significant scoliosis or hip dislocation.

Botox therapy

Botox therapy involves the injection of botulinum toxin and can be beneficial for relaxing certain muscles. When injected into the saliva glands, it can help with drooling. The injections only work for a few months at a time. Your child's doctors and therapists will advise you if botox therapy is suitable for your child.

Hippotherapy

Hippotherapy or horse therapy uses the natural movement of a horse to provide therapy to the rider. The repetitive and rhythmic movements of the horse encourage the rider to achieve balance and posture while providing sensory stimulation. The Association of Chartered Physiotherapists in Equine Activities (ACPEA) can provide details of suitably qualified therapists who can provide hippotherapy.

acpea.org

Riding for the Disabled Charity primarily provides therapeutic horse riding (see staying active on page 20) but some of their centres are also able to facilitate hippotherapy with a trained therapist.

rda.org.uk



Case management services

There is a lot to juggle when looking after a child with cerebral palsy and a case manager can be appointed to support individuals with their complex needs. They may help to provide access to statutory services; employ carers and therapists; and find suitable equipment.

Community Case Management Services Limited (CCMS)

ccmservices.co.uk

Bush & Co

bushco.co.uk

COOCI Rehabilitation Case Management Services

coociassociates.co.uk

Westcountry Case Management

Westcountry Case Management provide a specialist case management service to support people in reaching their goals, for adults and children with brain, complex physical and psychological injury.

westcountrycasemanagement.com

ILS Case Management

indliv.co.uk

Breakthrough Case Management

Breakthrough Case Management supports individuals with brain, spinal and profoundly traumatic injuries – to realise their full potential and improve their quality of life.

breakthroughcasemanagement.com

Brownbill Associates Ltd

brownbill.com

North Star Case Management

northstarcm.co.uk

Rehab Without Walls

rehabwithoutwalls.co.uk

Stanley Smith Case Management

sscmanagement.co.uk

Stokes Case Management

stokescasemanagement.co.uk

Corpore Case Management

corpore.co.uk

Carer Recruitment

Snap Care can help you recruit high calibre carers, personal assistants and buddies to support your child's needs.

snapcare.co.uk



Out and about

Getting out and about can present particular challenges to children with cerebral palsy. Here we have collated some of the activities recommended by the families we work with and also some information on accessing facilities.

Changing Places toilets

Many children with cerebral palsy cannot use a standard accessible toilet, which can make life tricky when away from home. Changing Places toilets are properly equipped to meet the requirements of those who need them. Each toilet has a height adjustable changing bench and hoist and enough space to accommodate both the individual and up to two carers.

There are over 1,000 changing places toilets in the UK, from IKEA to Galloway Forest Park. To find a toilet near your destination visit

changingplaces.uktoiletmap.org

Activities for families affected by cerebral palsy

The following locations have been recommended by families we work with as some of their favourite places to visit:

Amy recommends the Alan Shearer Centre in Newcastle upon Tyne

The Alan Shearer Centre describes itself as a highly specialist, respite, residential and social facility for people with complex disabilities and acute sensory impairments. Although the centre is currently closed due to Covid-19, the activity centre is usually open daily to children and adults, offering a wide range of therapeutic and sensory activities.

alanshearercentre.org.uk

Lorna recommends Swings & Smiles at the Phoenix Centre in Newbury

Swings & Smiles provides a fantastic place to play for children with special needs and their siblings. The centre provides soft play; a sensory room; and an art room where children can paint and draw. They are also providing one-to-one and group video calls if you would like to chat to someone.

swingsandsmiles.co.uk

Sarah recommends Gulliver's World in Warrington With over 80 rides, attractions and shows, Gulliver's World is specially designed for fun. Gulliver's World has an impressive accessibility guide with information on dining areas; toilet facilities and whether the rides require upper or lower body control. For guests who struggle with queuing, ride passes are available.

gulliversworldresort.co.uk/special-needs-guide

...and The Creative Space Centre in Preston, Lancashire...

The Creative Space Centre boasts a huge multi-sensory environment with the latest lighting, sound and projection equipment which are controlled by iPads to give maximum flexibility for anyone with any special needs of any age. The centre has excellent changing facilities including a hoist.

creativespacecentre.org

...and Withy Grove Park in Preston

Withy Grove Park has an enormous playground designed to cater for all ages across three different zones. There is a large sand area for toddlers upwards which has lots of slides, climbing and sand buckets. There are bridges to climb, tunnel slides and towers. Access to the park is free and the park has been praised for being accessible to all. The wheelchair friendly roundabouts are a particular favourite.

freeparks.co.uk/park/withy-grove-park

Sarah Jane recommends Chessington World of Adventures...

Chessington World of Adventures includes a theme park, sea life centre and zoo. Ride access passes are available for guests who struggle with queuing. Chessington has changing facilities that include an adjustable changing bench, shower, toilet and hoist.

chessington.com

...and Colchester Zoo in Essex

With over 260 species to see, set in 60 acres of beautiful parkland and lakes, there is a lot to be discovered at Colchester Zoo. The zoo has a planned pushchair and wheelchair friendly route avoiding the steepest of hills. The changing facility includes an adjustable bench and ceiling hoist, although a sling is not provided.

colchester-zoo.com

Remember to apply for your Max Card which provides discounted admission for families of children with additional needs to many venues across the UK.

mymaxcard.co.uk

Simply Emma is a UK-based travel and disabled blogger and her blog is packed with travel guides, tips and reviews. Some of her latest guides include tips for travelling to New York City in a wheelchair; and wheelchair accessible things to do in West Wales.

simplyemma.co.uk/category/travel-2

Holiday accommodation

Finding suitable holiday accommodation for the whole family can be challenging. Here are some options for all-inclusive accommodation:

Disabled Holidays describe themselves as the UK's largest accessible holiday specialist and provide advice on accommodation, flights and insurance.

disabledholidays.com

Gwel an Mor Resort in Cornwall combines luxury with practicality. A number of the Scandinavian style lodges are accessible to the differently-abled traveller. In the Assisted Residence Lodge there is wheelchair access throughout, a well equipped kitchen, a fully adjustable electric bed, a wet room and an H-hoist system between the bedroom and the wet room.

gwelanmor.com

Center Parcs offers some accommodation that is accessible to all. Their accommodation comes with a fully equipped kitchen and lowered worktops; bathrooms with walk in or wheel in showers; and a hoist for the hot tub.

centerparcs.co.uk/discover-center-parcs/lodgeholidays/accommodation-type/adapted-lodges.html

Butlin's Resorts all have a limited number of adapted rooms and apartments. You can call one of their advisers to discuss your individual needs:

butlins.com/help-contact/disability-requirements
0330 100 9732

AbleStay in South West London is London's first fully accessible single storey holiday home equipped with everything from profiling beds to ceiling hoists. It even comes with an Xbox.

ablestay.co.uk

Tash's Accessible Travels blogs the experiences and adventures of Tash Hook. Having studied tourism and hospitality at university and having used a wheelchair full time for over a decade, she is passionate about accessibility in travel and London in particular.

tashaccessibletravels.co.uk



OUT AND ABOUT

Instagram suggestions

We have had some recommendations of places to visit from our wonderful community of followers on Instagram @little__champions, who recommend:

Paultons Park in Hampshire

Paultons Park is a @little__champions favourite for family rides, splash parks and a collection of birds and animals. The Park provides queue assist passes and essential companion tickets for guests with additional needs.

paultonspark.co.uk

Yorkshire Wildlife Park

The Park offers manual wheelchairs to pre-book; mobility scooter hire; wheelchair accessible pathways; wheelchair friendly viewing platforms and a Changing Places toilet.

yorkshirewildlifepark.com

Milestones Living History Museum in Hampshire

This Living History Museum takes you from the Victorian era to the 1950s and beyond. Although wheelchair users may struggle with some of the cobbled streets, areas are equipped with drop kerbs. Wheelchair hire is also available together with a Changing Places toilet.

milestonesmuseum.org.uk

Bird World in Surrey

Alongside the opportunity to see penguins, parrots and owls, Bird World also offers wheelchairs; free entry for carers; and wheelchair accessible paths and restaurant.

birdworld.co.uk

Monkey World in Dorset

Monkey World has wheelchair swings and birds nest swings that are often popular with children with limited mobility. There are accessible toilets available and the first aid hut can be used for adult changing albeit there is no hoist available.

monkeyworld.org

Wellington Country Park in Reading

Wellington Country Park is fantastic for children, complete with a farm, lots of outdoor space, dinosaur park, soft play for babies and a sensory room for guests who need a quiet break. All buildings and most of the park are wheelchair accessible and the train has a wheelchair carriage.

wellingtoncountrypark.co.uk

Finkley Down Farm in Hampshire Finkley Down Farm is home to an array of animals, has a huge indoor play barn and an outdoor sensory music garden. The Farm provides complimentary tickets for personal assistants and a Changing Places toilet has recently been installed.

finkleydownfarm.co.uk

Legoland Windsor Resort

Whether you are behind the wheel of a LEGO car at the LEGO City Driving School, riding a Dragon through a medieval castle or discovering a lost underwater city in your very own submarine – the LEGOLAND Windsor Resort has something for the whole family. They have carer tickets available, ride access parks for those with additional needs and have recently installed a Changing Places toilet.

legoland.co.uk

Alton Towers

Alton Towers has 40 rides and attractions from adrenaline filled roller coasters to family fun. They have a full and helpful accessibility guide showing which venues and attractions have accessible toilets, level access and ramped doors. They also have a Changing Places toilet and a smaller 'Space to Change' facility.

altontowers.com

Sandcastle Waterpark in Blackpool

Sandcastle Waterpark describes itself as the UK's largest indoor waterpark with rides for thrill seekers and families alike. For guests with mobility impairments they have level access throughout the park, a Changing Places 'wet room' facility and water accessible wheelchairs.

sandcastle-waterpark.co.uk

Maritime Museum in Merseyside

The Maritime Museum is at the heart of Liverpool's historic waterfront in the Royal Albert Dock Liverpool with objects and archives connected to ships, boats, life at sea, the port of Liverpool and its connection to the world. Wheelchairs are available to borrow at the entrance to the museum, there are two lifts to all floors and there is a Changing Places toilet available on the second floor.

liverpoolmuseums.org.uk/maritime-museum



GETTING SUPPORT IN BRISTOL

Welcome to Bristol

Getting support in Bristol

Cerebral Palsy Plus is a charity in Bristol, working with children and adults, their families and their carers, creating opportunities for connection, fun and personal development

cerebralspalsyplus.org.uk

Bristol Parent Carers is made up of volunteer parents of children with additional needs. Their website is packed full of Bristol based events and information on accessing support in Bristol. Bristol Parent Carers run 'pop in' coffee mornings at different locations across the city.

bristolparentcarers.org.uk

Special Friends Club is a charity operating throughout Bristol and South Gloucestershire providing weekend and holiday activities for children with additional needs including cerebral palsy. Recent events have included trips to Westonbirt Arboretum, Cattle Country and Avon Valley Country Park. Families find that attending outings where there are a group of families facing similar challenges can be hugely supportive.

specialfriendsclub.org.uk

Khaas was set up to meet the needs of Black and minority ethnic children with disabilities and their families. Khaas provide respite care and holiday play schemes, bring families together for peer support and have a wealth of knowledge on accessing local support. Khaas staff are often multilingual speaking Urdu, Punjabi, Bangla, Somali and English.

khaas.co.uk

Playing in Bristol

Felix Road Adventure Playground in East Bristol BS5 0JW provides the perfect space for outside physical play. They hold a monthly 'stay and play' session for children with additional needs and their families on the second Saturday of the month.

Felix Road is a unique space dedicated to children's play.

eastsidecommunitytrust.org.uk

Incredible Kids provide inclusive play sessions at The Vench Adventure Playground, BS7 9TB. Play sessions take place after school on Fridays and there are family sessions on Saturdays. Whether your child likes to swing, climb, slide, trampoline, make slime or chill in their sensory room they have something for everyone.

incrediblekids.org.uk

St Pauls Adventure Playground BS2 9LN is a community play space in Bristol. The playground holds sessions specifically for children with additional needs on Wednesdays from 3.15pm to 6.15pm and on Saturdays from 10am to midday. Opening times differ during the school holidays.

stpaulsventures.org.uk

Getting out and about in Bristol

Aerospace in Patchway, Bristol provides supersonic family fun with interactive exhibits, an outdoor play area and trails for budding engineers and pilots to enjoy. The site is fully accessible to wheelchair users and there are fifteen disabled parking bays near the entrance to the museum. There is a Changing Places toilet on site too.

aerospacebristol.org

Bristol Zoo is the perfect place to meet all your favourite animals. There are six Blue Badge parking bays in their carpark with step free access throughout albeit some routes are steep and a bit uneven. Accessible toilet facilities are available in the Fun Fort and at the exit to Bear Wood but there are no full changing facilities.

bristolzoo.org.uk

Brunel's SS Great Britain, on Bristol Harbourside welcomes visitors aboard this famous ship in the Great Western Dockyard where it was built. For visitors with limited mobility, the Dry Dock, Dockyard Museum, Brunel Institute and the ship are fully accessible for wheel chair users and both levels of Being Brunel have wheelchair and step-free access following an alternative route. Although the venue doesn't have its own car park there is on street blue badge parking available. Accessible toilets are available but there are no changing facilities.

ssgreatbritain.org

M Shed on Princes Wharf is a museum on Bristol and its colourful history. For those with limited mobility there is accessible car parking near by and the level access to all galleries and lifts in between. There are accessible toilets on all floors (some with right hand and some with left hand transfer) and the toilet on the ground floor also has an adult changing bench and free standing hoist.

bristolmuseums.org.uk/m-shed

Royal West of England Academy in Clifton is an art gallery in a beautiful and historic building. The academy has level access through the main entrance, café and shop and lift access to the main galleries on the first floor and the Long Gallery. There is a Changing Places Toilet available.

rwa.org.uk

Windmill Hill City Farm in South Bristol is a 4.5 acre community farm complete with gardens, play area, café and farm shop. All public areas of the farm are on a single level albeit some of the paths can be a bit muddy when wet. There are accessible toilets on the farm. The farm also offers supported animal care and gardening placements for adults with additional needs who are keen to learn new skills and increase their independence.

windmillhillcityfarm.org.uk

Changing Places Toilets in Bristol

Changing Places toilets are designed with a centrally placed peninsular toilet, enough space to turn a wheelchair and accommodate two carers, a height adjustable washbasin, a height adjustable changing table and ceiling track hoist. There are thousands of Changing Places Toilets across Britain but here are some you will find in Bristol:

- **Aerospace**, BS34 5BZ. Open Monday – Sunday 10am to 5pm.
- **Cabot Circus**, BS1 3BX. Open Monday–Saturday 10am to 8pm and Sunday 11am to 5pm.
- **IKEA**, Eastgate Shopping Centre, BS5 6XX. Open Monday – Saturday 9.30am to 9pm and Sunday 10am to 5pm.
- **Lloyds Bank**, Harbourside BS1 5LF. Open Monday – Friday 6am to 10.30pm and Saturday 6am to 6pm.
- **Royal West of England Academy**, BS8 1PX. Open daily 10am to 5pm.

Changing Places Toilets

changing-places.org



IN CONVERSATION WITH

Martin Sinclair

“I wanted to work on people’s personal development and have always seen role models as an essential part of this. I’ve always believed that if you can see it, you can be it. If you see people with impairments like yourself excelling in the sport, it inspires you to think; I can do it too.”

RWK Goodman’s Ben Lees and Constance Moon recently had the privilege of speaking to Martin Sinclair, who played for the England cerebral palsy team for 10 years, about disability representation in football and his own organisation, the Disability Football Collective (‘DFC’).

For more details, check out the website www.disabilityfc.org

You can also find us on social media platforms including Twitter, Instagram and LinkedIn.

Can you tell us a little bit about yourself?

I am a retired seven-a-side side football player with cerebral palsy. I competed in the London 2012 Paralympics, played for the England cerebral palsy team for ten years, and have over 50 England caps. I have played around the world in World Cups and European Cups.

A particular career highlight for me was playing in front of 80,000 people in London. It was even more special to me because my brother, Scott Sinclair, was also representing Great Britain at the same games. We were the first brothers in history to represent Great Britain at the Olympics and Paralympics for the same sport!

When I retired, it was not like retirement for a normal professional footballer. I had a job already as a SaintsAbility development officer for the Saints Foundation. I saw elite disabled players going onto the Paralympic pathway, but we did not have a grass roots pathway in Hampshire. The Southampton hub was set up, aimed at seven to eleven year olds with disabilities, and focussed on personal development. We then developed the adult programme with national and international tournaments, helping players develop within the game, and onto the England pathway if appropriate.

I wanted to work on people’s personal development and have always seen role models as an essential part of this. I’ve always believed that if you can see it, you can be it. If you see people with impairments like yourself excelling in the sport, it inspires you to think; I can do it too.

Over time it became increasingly clear to me that, whilst we were making great strides in helping players into the game, there were very few disability role models in support, leadership or decision-making positions. Not all people with disabilities who love the game want to be Paralympians or even players. Where are the opportunities if you want to be in management or talent spotting? What if you want to be a groundsman, referee, or presenter? What if you want to be involved in video analysis? You’ve got to think outside the box. You have to change people’s perceptions. When I left Saints and COVID hit, James (my DFC co-founder) and I got in contact and decided to fill that gap.

Can you tell us about the DFC and what inspired you to set it up. Who is it for?

We set up the DFC to try and improve disability representation across football and inspire the next generation. We wanted to provide opportunities and pathways for people to go into different fields in football. This can be anything from being a cameraman, to presenting and working in media.

The DFC will be a unique forum. No one is really doing the same thing in this space at the moment. We’re working on documenting the lived experiences of people with disabilities, and collating data to improve disability representation across the game. We want to manage and organise a network of people with disabilities, stakeholders and allies, providing a support network and building connections.

Great things are happening in football at the moment. We see this in women’s football and in accessibility for fans, but there is a missing piece; people with disabilities wanting to work in football. Women in football are lifting the nation and have had a great impact, inspiring the next generation of female footballers. As I say, if you can see it, you can be it. I see women’s football as being ten to fifteen years ahead of football for people with disabilities. We need to be inspired by, and to emulate, this success.

How can players, families and other stakeholders keep up to date with, and sign up for, the Disability Football Collective?

For more details, check out the website www.disabilityfc.org

You can also find us on social media platforms including Twitter, Instagram and LinkedIn.



Getting active

Bristol City Cerebral Palsy Football Club provides an opportunity for young people with cerebral palsy or an acquired brain injury to play football. The club is always on the look out for new players so check out their website.

bccpfootball.co.uk

Bristol Cycling Centre is a cycle skills training facility situated on the Old Whitchurch Athletics Track in Bamfield, Bristol. The centre runs inclusive cycling sessions for riders of all ages with specialist inclusive cycles, balance bikes and two-wheelers.

betterbybike.info/cycling-centres/bristol-cycling-centre

Frenchay Falcons Disability Cricket Club welcomes children with additional needs from the ages of eight–eleven years old. They meet on Monday evenings during the cricket season at Frenchay Cricket Club.

ecb.clubspark.uk/Dynamos/Course/f72c5f70-d017-432c-a393-92ef67ca5e31

Gympanzees is a Bristol based charity which offers specialised gyms and sensory rooms to provide children with disabilities the chance to exercise and play. In September 2023, the charity secured an old service station near Bristol which will become the UK's first state of the art leisure centre for disabled children. Gympanzees also has a lending library whereby families can borrow specialist paly and exercise equipment.

gympanzees.org

Flamingo Chicks was set up to enable all children and adults to enjoy dance. It was started by Poppy, a little girl who has cerebral palsy. In Bristol they run baby sling ballet



for mums with babies who have disabilities and/or mums with disabilities themselves on Whiteladies Road; and dance classes for children from 18 months to 18 years old which take place at Briarwood School in Bristol, New Fosseyway School in Bristol, Claremont School in Bristol, Bristol Children's Hospital and numerous other locations across Bristol, England and Wales.

flamingochicks.org

All Aboard Water Sports in Bristol offers sailing opportunities for people with a wide range of abilities up to Paralympic Standard. They offer sailing, kayaking and canoeing in Bristol harbour.

allaboardwatersports.co.uk

Absolutely Karting: In the Autumn of 2023, Absolutely Karting in Bristol, BS5 7EY was able to purchase two twin-seat karts enabling the facility to launch a Together Karting programme providing children with additional needs the chance to enjoy the thrill of go karting for free every Sunday morning.

absolutely-karting.co.uk

Staying active

Cerebral palsy affects different people in different ways but regardless of a person's abilities, everyone deserves to reach their full potential. Happily, there are several UK charities dedicated to making this happen.

Whizz-Kidz provides children and young people with vital mobility equipment, opportunities to meet and have fun, and training to help them gain skills. Many of the young people Whizz-Kidz works with and supports have cerebral palsy.

whizz-kidz.org.uk

Riding for the Disabled Association delivers therapy, achievement and fun to children and adults with disabilities through riding, carriage driving and other horse activities.

rda.org.uk

CP Sport is a charity at the forefront of supporting children and young people with cerebral palsy to stay active. Their vision is "to support people with cerebral palsy to reach their life potential through sport and active recreation".

cpsport.org

WheelPower has been supporting people with physical disabilities across the United Kingdom to lead healthier and more active lives for over 75 years. The charity delivers opportunities, both in person and online, that support disabled people of all ages to discover the many benefits that come from increased participation in activity and sport.

wheelpower.org.uk

The English Federation of Disability Sport (EFDS) is the national sports body for people with disabilities in England. The principle aim of EFDS is to increase participation in sport and physical activity. Their website has lots of advice on how to access sports and activities

activityalliance.org.uk/get-active

Disability Sports Coach have a number of Community Clubs across London providing weekly sports activities for people of all abilities. The Clubs offer a whole range of activities from Basketball to Boccia and are a great place to make friends and stay active. Siblings and carers are also able to take part!

disabilitysportscoach.co.uk

Supportability, based in Stockport, provides care and support for children and adults with cerebral palsy and other learning and/ or physical disabilities, helping people to access the activities they enjoy and live life to the full. They also offer adapted cycling sessions so everyone can join in and get some exercise!

supportability.org.uk

Diverse Abilities is based in Dorset with the goal of ensuring children and adults of all abilities have an enjoyable life. They provide activities, holiday clubs, respite care, a specialist school and parent support.

diverseabilities.org.uk/children

Derby County Community Trust CP offers football training for people with cerebral palsy and compete in the National CP Football League.

derbycountycommunitytrust.com/fundraising-and-events/events/derby-county-cp-training-5



Every Body Moves is a campaign to connect people with disabilities with opportunities to be active. Their website has a brilliant search function to help you connect with inclusive sporting opportunities in your area and also has home workouts available online too

everybodymoves.org.uk

Flitwick Eagles Football Club in Bedfordshire offers frame football free of charge on Sunday mornings in the season. The club meets at Redborne Upper School and Community College.

flitwickeagles.org

Frame Football Suffolk meet at Copleston High School and is designed for all ages.

inclusive.football/places/coplestonians-fc-frame-football

Goals Beyond Grass is a Gloucestershire charity that delivers inclusive sports and activities throughout the county.

goalsbeyondgrass.co.uk

Greenbank Power Hockey Club meets on Greenbank Lane in Liverpool. The game is played in specialist electric wheelchairs and offers a fast paced contact sport to children with disabilities. You do not have to be a wheelchair user to play.

greenbanksportsacademy.co.uk/inclusive-sport/power-hockey

Leeds Powerchair Football Club meets at Bishop Young Academy in Leeds. The club has over 40 players who compete at all levels.

leedspowerchairfc.co.uk

WBB Frame Football Team in Newton Abbot train regularly and compete against other teams from different regions. The club meets on Strap Lane, Kingsteignton.

wbbfc.co.uk/teams/wbb-frame-football-team



LONDON

Accessing support

London can be a daunting place to access support. Below are details of London based charities who assist children with additional needs:

KEEN London

KEEN London provides free one-to-one support at free sports and activity sessions for children with additional needs. Their weekly sessions give athletes the chance to play games, make friends and, most importantly, have fun!

keenlondon.org

C Potential

C Potential provides rehabilitation and support that is tailored to children with movement disorders.

cpotential.org.uk

Access Sport

Access Sport is a community led charity that seeks to make sport more inclusive for those with disabilities.

accesssport.org.uk

Small Steps

Small Steps delivers group sessions for children from newborn to five years with cerebral palsy and other forms of mobility issues in London and support for parents.

smallsteps.org.uk

The Ravensbourne Project

The Ravensbourne Project, based in Lewisham/ Catford was set up to provide day care and overnight services for children and young people with special needs.

ravensbourneproject.org.uk

KIDS Charity London

KIDS Charity London provides lots of advice and support to children with special educational needs or disabilities together with drop-in nurseries for under fives and short breaks and residential stays for young adults along with support for families and home care.

kids.org.uk



The full UK guidance can be found here:
paediatriccontinenceforum.org/resources

Toilet training and continence

Continence is not everyone's favourite subject but it can have a massive impact on quality of life and all children should receive support to achieve their maximum continence potential. The UK guidance for the provision of continence products to children recommends that all children must have a comprehensive assessment of their continence.

The guidance recommends the provision of four continence products per 24 hours. It is worth mentioning that this is only a recommendation and if your child requires more than four products in 24 hours, then the guidance recommends that your child should receive the number of products to meet their assessed need.

In addition, the guidance states that products would not normally be supplied before a child has reached their fourth birthday. Again, it is still worth applying before this age because for children for whom it is anticipated that there may be difficulties with toilet training, intervention can be started earlier.

If your child struggles with continence, speak to your child's GP or paediatric team about being referred to your local continence service as they should be able to provide you with the right continence products for your child. Some continence services can be contacted by parents directly.

Please see below for contact details of some of the continence services in England and Wales:

Bath: Children's Continence Service

bathneshealthandcare.nhs.uk/services/childrens-bladder-and-bowel-service

01225 831 785

Barking & Dagenham, Havering & Redbridge

nelft.nhs.uk/services-bdhvrb-community-paediatric-continence

03003 001 618

Berkshire: Paediatric Continence Service

cypf.berkshirehealthcare.nhs.uk/our-services/other-services/paediatric-continence

01189 495 146

Bedfordshire: Children's Continence Service

cambcommunityservices.nhs.uk/Bedfordshire/services/continence

Bowel: 01234 310 847 Bladder: 01234 315 847

North Devon: Paediatric Bladder and Bowel Care Service

northdevonhealth.nhs.uk/services/paediatric-bladder-and-bowelcare-service

01392 208 044

Birmingham: Child & Adult Continence Service

www.bhamcommunity.nhs.uk/bladder-and-bowel-service

01214 663 700

Cheshire & Wirral: Paediatric Continence Service

cwp.nhs.uk/our-services/cheshire-west-chester/paediatric-continence-service

01514 888 231

Cumbria: Children's Community Nursing

ncic.nhs.uk/services/childrens-community-nursing

01228 60 8112

**Lincolnshire: Children's Continen-
ce Service**

[careplusgroup.org/services/childrens-
continen-
ce-service](https://careplusgroup.org/services/childrens-continen-
ce-service)

01472 266 999

**Liverpool: Children's Bladder & Bowel
Service**

[merseycare.nhs.uk/our-services/liverpool/
adults-bladder-and-bowel-service](https://merseycare.nhs.uk/our-services/liverpool/
adults-bladder-and-bowel-service)

01512 953 993

**London, Greenwich: Paediatric
Continen-
ce Service**

[oxleas.nhs.uk/services/service/paediatric-
continen-
ceand-enuresis-service-bexley-and-
greenwich-132](https://oxleas.nhs.uk/services/service/paediatric-
continen-
ceand-enuresis-service-bexley-and-
greenwich-132)

02083 199 973

**London, Hackney: Children's
Continen-
ce Service**

[homerton.nhs.uk/continen-
ce-service](https://homerton.nhs.uk/continen-
ce-service)

0207 014 7111

**Manchester: Children's Continen-
ce Service**

[manchesterlco.org/services/
childrenscommunity-services-citywide/
childrens-continen-
ce-service](https://manchesterlco.org/services/
childrenscommunity-services-citywide/
childrens-continen-
ce-service)

01617 412 030

**Medway: Children's Continen-
ce Service**

[medwaycommunityhealthcare.nhs.uk/our-
services/a-z-services/child-health-service/
childrens-continen-
ce-service](https://medwaycommunityhealthcare.nhs.uk/our-
services/a-z-services/child-health-service/
childrens-continen-
ce-service)

03001 233 444

**Newcastle upon Tyne: Paediatric
Continen-
ce**

[newcastle-hospitals.nhs.uk/services/great-
northchildrens-hospital/childrens-urology-and-
stoma](https://newcastle-hospitals.nhs.uk/services/great-
northchildrens-hospital/childrens-urology-and-
stoma)

01912 824 890

**North Somerset: Children's Community
Health Partnership**

**Children's Continen-
ce Service**

[sirona-cic.org.uk/children-services/services/
childrens-continen-
ce-services](https://sirona-cic.org.uk/children-services/services/
childrens-continen-
ce-services)

**Oxford: Children's Bladder & Bowel
Service**

[oxfordhealth.nhs.uk/service_description/
childrens-continen-
ceadvisory-service](https://oxfordhealth.nhs.uk/service_description/
childrens-continen-
ceadvisory-service)

01865 904467

**Plymouth: Child Development Centre
Continen-
ce Service**

plymouthhospitals.nhs.uk/cdc-what-to-expect

**Powys: Continen-
ce Community
Specialist Nursing**

[111.wales.nhs.uk/localservices/ViewLocalService.
aspx?id=7616&s=Adult%20&%20Older%20
People%20Health%20Services](https://111.wales.nhs.uk/localservices/ViewLocalService.
aspx?id=7616&s=Adult%20&%20Older%20
People%20Health%20Services)

01686 617 237

**Southampton & West Hampshire:
Paediatric Continen-
ce Service**

[solent.nhs.uk/our-services/services-listings/
community-paediatric-continen-
ce-service-
southampton-and-west-hampshire](https://solent.nhs.uk/our-services/services-listings/
community-paediatric-continen-
ce-service-
southampton-and-west-hampshire)

03001 233 797

York: York Family Information Service

yor-ok.org.uk

01904 554 444



PURSUING A MEDICAL NEGLIGENCE CLAIM

Legal resources

At RWK Goodman we primarily support families in navigating the legal process.

From time to time, a child's brain injury may be a result of receiving substandard medical care. This might include a delay in delivering a baby resulting in a shortage of oxygen to the brain; or failing to recognise and treat jaundice; or not treating infection quickly enough etc.

Through the process of instructing independent medical experts, we can determine if you or your child has received substandard care and if so, pursue a claim for financial compensation to cover the extra costs of living with cerebral palsy.

At RWK Goodman we specialise in representing children affected by cerebral palsy. We work with leading experts who advise on the standard of medical care received; and on how a child's quality of life can be maximised through the provision of suitable accommodation, therapies, equipment, assistive technology, treatment and care.

We are usually able to offer children Legal Aid Funding which will ensure your child keeps 100% of their compensation.

Five reasons to choose RWK Goodman for your claim:

1. We will listen to your story; make ourselves available to suit you; and get to know you and your child throughout the legal journey.
2. We are nationally recognised specialists in birth injury cases and have recovered millions of pounds for hundreds of children who have suffered a brain injury as a result of negligent medical care.
3. You and your child will be supported by an expert team including some of the country's leading medical, therapy and nursing experts and specialist barristers, to work towards a successful outcome and to maximise compensation.
4. Your child will have the benefit of our extensive experience not just in securing compensation but also in making sure it is protected, invested and used effectively throughout their lifetime.
5. We will ensure that compensation is secured and invested in compliance with your personal and religious beliefs.



“This settlement is absolutely life changing for L. We can now afford to purchase equipment to support him that is innovative, moulded and tailored to his exact body shape and his specific needs. L is also able to work with a team of highly specialist therapists who are brilliant and cover all aspects of his therapy requirements, in time frames that are personalised to his development. He now has a fantastic team of support workers that provide care to an exceptional standard and assist L with accessing his environment. L’s everyday life has been completely enriched and we are so excited for his future.”

(L’s Mum)

How will I pay for a claim?

There are many ways in which funding for a medical negligence claim can be secured, at no financial risk to you or your child.

Any initial enquiries you make to RWK Goodman are free of charge.

If, on review of the case, we consider there to be reasonable prospects of succeeding, we will discuss funding options with you:

- Legal Aid (public funding) is available from the Legal Aid Agency for those who have suffered a neurological injury during their mother’s pregnancy, during their birth or within the first eight weeks of their life.
- If Legal Aid funding is not available we can look at alternative forms of funding such as legal expenses insurance or “no win, no fee” funding. This would mean that if your case is not successful you will not have to pay anything towards the legal costs.

Life Changing Settlements

Meeting the practical, physical, and emotional needs of a child with Cerebral Palsy can be costly and many families struggle to afford the care, therapies and equipment their child needs. Many parents ask the question: Who will care for my child when I am no longer able? Financial compensation should provide everything your child will need for the rest of their life.

In December 2021, RWK Goodman’s Kerstin Scheel and Abigail Ringer secured a settlement of more than £10 million for a little boy, L, who suffered from a shortage of oxygen at the time of his birth at Worthing Hospital in Sussex. L has brain damage due to the shortage of oxygen and has quadriplegic spastic cerebral palsy and learning difficulties. Since L was born, his family have struggled to pay for the therapy and equipment he needed but he now has the funds to access the best equipment and therapy to maximise his quality of life.

In the last few months alone, our specialist team at RWK Goodman have secured life changing settlements for a number of families:

In February 2023, RWK Goodman’s Simon Elliman, supported by Sarah White and Abigail Ringer, secured a settlement of over £12 million on behalf of a twelve-year-old boy who

“As practicing Muslims, we had concerns regarding our daughter’s finances being invested in a Halal manner and whether it would be subject to Zakat. Respecting our faith, our solicitors got in touch with an Islamic scholar who issued a Fatwa regarding the matter. This was and will be a great help for us as we wouldn’t know where to start in getting a judgment from a renowned Islamic Scholar.”

(A’s Dad)

suffered hypoxic ischaemic brain damage and consequently from quadriplegic spastic cerebral palsy (GMFCS 5), epilepsy, visual impairment and severe learning difficulties.

In May 2023, RWK Goodman’s Kerstin Scheel and Abigail Ringer secured a settlement of more than £13.7m on behalf of a ten-year-old girl affected by developmental delay, truncal hypotonia and bilateral hearing loss due to a shortage of oxygen when she was born.

In June 2023, RWK Goodman’s Kerstin Scheel and Abigail Ringer secured a settlement of more than \$40 million on behalf of a little girl born in England but who now resides in the US, with quadriplegic cerebral palsy as a result of a failure to identify fetal growth restriction.

Following the settlements of these claims, each of these children and their families will continue to have the support of a professional team under the care of a Deputy in RWK Goodman’s Compensation Protection Team.

A now has the benefit of a professional deputy, experienced in managing compensation in accordance with Shariah Law, who is working closely with the family to administer the award and ensure A has the support she needs for the rest of her life.

Contact a member of the team on wkc.enquiries@rwkgoodman.com or 0800 923 2080 for more information.

For our readers who would benefit from information in Arabic and Urdu, please see guides on pages 48 & 49 to seeking compensation for birth injuries.

Compensation Protection

RWK Goodman provides lifelong support to children and adults who have received compensation to ensure that their compensation is managed and protected to last for their lifetime.

Compensation payments can be very large and are awarded to pay for housing, equipment, care regimes, therapies, travel, additional holiday costs, education costs and to meet lifetime needs etc. The Court of Protection must be satisfied that the funds are managed properly and where there is a large award will appoint a professional deputy to support vulnerable children and adults.

To find out more about how RWK Goodman can build a team around your child, visit: [rwkgoodman.com/injury/compensation-protection](https://www.rwkgoodman.com/injury/compensation-protection)

Professional Deputy

A deputy is appointed by the Court of Protection to manage matters on behalf of a child or adult who lacks the mental capacity to make some or all decisions themselves, either in relation to their property and affairs or their health and welfare.

When a child or an adult who lacks capacity receives compensation, a deputy is likely to be appointed to manage their property and affairs. Their duties will likely include:

- Taking formal investment advice so that the compensation fund is maximised.
- Ensuring money is invested according to individual faith and beliefs.
- Purchasing suitable accommodation and adapting it for a person's exact needs.
- Employing carers and therapists.
- Buying and adapting a suitable vehicle. Considering what tax is due on investments.
- Keeping records of all decisions.
- Reporting to the Office of the Public Guardian (OPG) on an annual basis. The OPG is responsible for the supervision of deputies on behalf of the Court of Protection.

Why choose RWK Goodman's professional deputy services?

RWK Goodman prides itself on working with families to build a team around every individual made up of legal advisors; financial advisors; therapists and case managers. This multi-disciplinary team will have your child at its centre, focusing on maximising their quality of life and empowering them to lead as independent a life as possible. The deputy team works in harmony with parents, partners and siblings in order to get to know the child/adult so as to act in their best interests. The team understand the ripple effect of brain injury on the entire family.

RWK Goodman's specialist deputies act through a Trust Corporation, Withy King Trustees Limited and have a wealth of experience in supporting children and adults all over England and Wales. Partners, Tracy Norris-Evans and Maria Meek are regularly appointed as financial deputies for children with cerebral palsy.

They understand the unique challenges faced by children and adults with additional needs and are equipped with the skills and expertise to ensure your child reaches their full potential.

rwkgoodman.com/injury/compensation-protection/deputy-role-and-changing-deputy

Personal Injury Trust

If the medical opinion is that your child will have capacity to make decisions about their financial affairs upon turning 18, then consideration should be given to the execution of a personal injury trust (PI trust); this provides protection from persons who seek to take advantage of the individual's compensation and ringfences the award for the purposes of means tested benefits and local authority funding for care.

Where the compensation is significant, a professional trustee should be appointed. Tracy Norris-Evans and Maria Meek have a long history of acting as a professional trustee in these circumstances.

The benefit of having a professional manage the compensation on behalf of your child is the freedom it provides to enable you to focus on being a parent again.

rwkgoodman.com/injury/compensation-protection/deputy-role-and-changing-deputy

The Early Notification Scheme

Since 1 April 2017, NHS Hospitals have had to report to NHS Resolution all incidents where babies (who were born at term and following a labour) had a potential severe brain injury diagnosed within the first week of life.

NHS Resolution then carries out an investigation as to what may have gone wrong. The investigation is carried out by legal case managers and clinical advisors who will decide whether you and your child have received substandard care. If they decide that your child has suffered an injury as a result of care that does not meet the expected standard then they can provide you with a written apology and offer financial support for your child. The Early Notification Scheme has the benefit of allowing families to reach some sort of resolution more quickly than in pursuing a medical negligence claim. However it is worth considering that parents cannot participate directly in the investigation and there is currently a lack of transparency in how the investigation is undertaken and the independence of the clinical advisors who decide on the standard of care received.

The Early Notification Scheme is still at a relatively early stage and it is unknown how much financial support children are recovering through this scheme. It is currently likely, however, that your child will receive a higher level of financial support if you pursue a clinical negligence claim.

Maternity and Newborn Safety Investigations (MNSI) programme

On 1 October 2023, a new statutory body, the Maternity and Newborn Safety Investigations (MNSI) programme, was formed to undertake investigations when a baby has suffered a brain injury or when a mother or baby has died.

A referral for investigation is made when a baby is born following a labour AND after 37 weeks gestation AND where the outcome is:

- The baby dies during labour and before birth; or
- The baby is born alive and dies in the first week of life; or
- The baby is born with a potential severe brain injury diagnosed as occurring in the first seven days of life.

The focus of the investigation is to look at what can be learnt from what has happened, in particular the investigations:

- Identify the factors that may have contributed towards death or harm.
- Use evidence based accounts to establish what happened and why.
- Make safety recommendations to improve maternity care both locally and nationally.

For more information on the Maternity and Newborn Safety Investigations programme, please visit:

rwkgoodman.com/info-hub/hsib-maternity-investigations-have-been-replaced-by-the-maternity-and-newborn-safety-investigations-mnsi-programme

Independent financial advice

At RWK Goodman we work with Independent Financial Advisors (IFAs) to assist our clients in maximising their compensation to meet their ongoing needs and wishes. An IFA will

balance risk and reward in advising on how to invest your money and will ensure that any compensation received does not jeopardise you or your child's entitlement to state benefits and local authority funding.

Personal Financial Planning Ltd are a team of personal injury specialist financial advisors with the goal of making an award of compensation last a lifetime.

pfp.co.uk

Frenkel Topping is a company of specialist financial advisors who provide a high level of service in financial planning.

frenkeltopping.co.uk

Brewin Dolphin describe themselves as one of the UK's leading wealth managers and can help their clients plan for the future.

brewin.co.uk

Punter Southall help people build, shape and protect their financial futures.

puntersouthall.com

Sheralee Ellis is a trusted independent financial advisor, specialising in personal injury matters.

chasedevere.co.uk





Acting for Muslim Families

In May 2022, RWK Goodman's Kerstin Scheel and Abigail Ringer recovered compensation of over £9 million for a little girl, A, with quadriplegic cerebral palsy. A's birth was complicated by compression of the umbilical cord so that she suffered a shortage of oxygen to her brain.

A and her family are Muslims and RWK Goodman's birth injury and deputyship teams are experienced in ensuring compensation is managed in accordance with Islamic Law. This might apply to how interest or Riba on compensation is paid; whether compensation is subject to Zakat; and ensuring that any compensation money is invested in a Shariah compliant investment portfolio.

RWK Goodman will ensure that compensation is secured and invested in compliance with your personal and religious beliefs, seeking Fatwas when necessary and advice from financial experts in Shariah Law.

Useful contacts

The Birth Trauma Association

The Birth Trauma Association is a charity that supports women who suffer birth trauma.

birthtraumaassociation.org.uk

Group B Strep Support

Group B Strep Support is a charity that provides information and support for families affected by Group B Strep.

gbss.org.uk

AvMA

Action against Medical Accidents (AvMA) is a UK charity for patient safety and justice.

avma.org.uk

The Erb's Palsy Group

The Erb's Palsy Group offers advice, information and support to families affected by Erb's Palsy.

erbspalsygroup.co.uk

The Disabled Children's Partnership

The Disabled Children's Partnership is a coalition of more than 70 organisations campaigning for improved health and social care.

disabledchildrenpartnership.org.uk

The Pace Centre

Pace is a family centred charity that provides innovative education for children with motor disorders based on a belief that every child has the ability to learn. They provide a range of therapy services and aim to equip parents with the necessary skills to support their child.

thepacecentre.org



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