



Cerebral Palsy Guide

Edition 4



A practical guide for children with cerebral palsy and their families

Raising a child affected by cerebral palsy can be daunting at times. At RWK Goodman we have the privilege of supporting families affected by cerebral palsy as they navigate the legal process. In doing so we benefit from the expertise of some of the country's leading experts on cerebral palsy and we wanted to share some of our experience with you.

Did you know?



30,000

There are an estimated 30,000 children with cerebral palsy in the UK.



100:135

There are more boys born with cerebral palsy than girls. For every 100 girls with cerebral palsy, there are 135 boys with cerebral palsy.



1 in 3

One in three children with cerebral palsy is unable to walk.



1 in 4

One in four children with cerebral palsy cannot feed or dress themselves.



1 in 11

About one in eleven children with cerebral palsy is blind.



1 in 50

About one in fifty children with cerebral palsy is deaf.¹



41%

41 per cent of parents of disabled children were not offered any emotional support during the diagnosis journey for their child.



+£583

Families raising a disabled child face extra costs of £583 a month.²

¹ Life expectancy in severe cerebral palsy. J L Hutton et al. <https://ncbi.nlm.nih.gov/pmc/articles/PMC2065925/>

² SCOPE Impact Report 2021



Support you and your family deserve

P4. Getting the right support

P5. Accessing support in London

P7. Getting hold of funding

Statutory Support

- Local Authority support
 - Respite care and short term breaks
 - School transport
 - Personal wheelchair budget
 - Disabled Facilities Grant
 - Disability Living Allowance for Children under the age of 16
 - Personal Independence Payment for adults aged 16-64
 - Carers' Allowance and Carers' Credit
 - Motability Scheme
 - Blue Badge parking scheme
-

P9. Charities and trusts

- Wheelchairs and equipment
-

P10. Holidays

- Therapies
- Raising money

P11. Getting the best equipment

Aids to assist mobility

- Assisted sitting
 - Assisted standing
 - Assisted moving
 - Assisted transfers
 - Aids to assist with drinking
 - Aids to help sleep
 - Aids to help bathing
 - Orthoses and supportive footwear
 - Aids for swimming
-

P14. Assistive technology

- Aids for communication
 - Aids for typing and writing
 - Environmental controls
 - Sensory equipment
 - Second hand equipment
-

P16. Toilet training and continence

P18. Special education

P19. Out and about

- Changing Places toilets
 - Activities for families
 - Holiday accommodation
-

P21. Staying active

P22. Treatment and therapies

- Physiotherapy
 - Hydrotherapy or aquatic physiotherapy
 - Occupational therapy
 - Speech and language therapy
 - Conductive Education
 - Orthopaedic surgery
 - Selective Dorsal Rhizotomy
 - Botox therapy and hippotherapy
 - Case managers
-

P25 Legal resources

- Pursuing a clinical negligence claim
- The Early Notification Scheme
- Healthcare Safety Investigation Branch
- Professional deputy and IFAs



Getting the right support

A good support network is essential. There are a number of groups and organisations that provide a forum for connecting with others and offer advice on living with cerebral palsy:

SCOPE

SCOPE is a large charity that provides free information and advice along with support services to people with disabilities, their families and carers.

Website: scope.org.uk

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.

Website: scope.org.uk/family-services/navigate

Cerebral Palsy UK – Facebook Group

Cerebral Palsy UK is a private group on Facebook. It has 7.7K 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

This is another private Facebook group with 1,200 members. It was created in 2015 by a lady whose son has quadriplegic CP, severe visual impairment and global developmental delay. The group was created to encourage parents in the same situation to come and ask questions, give advice or just have a chat.

Cerebra

Cerebra is a charity set up to provide advice to children living with a brain condition and their families. It is packed full of information on everything from toilet training to accessing public services.

Website: cerebra.org.uk

Parents Connect - Leeds

SCOPE offer a support service in Leeds, offering parents of disabled children the opportunity to meet and talk with other parents.

Website: scope.org.uk/family-services/parents-connect

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.

Website: peeps-hie.org/hie-awareness-support

Contact

Contact is a charity supporting families with disabled children by providing an advice service covering all aspects of raising a child with additional needs and family workshops on Money Matters, sleep, positive behaviour, speech and language, and more.

Website: contact.org.uk

Carers UK

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

Website: carersuk.org

Adult Cerebral Palsy Hub

Adult Cerebral Palsy Hub has been established to create a home for adults with cerebral palsy, campaign for better support and services, and raise the profile of adults living with cerebral palsy in our communities.

Website: adulcphub.org

Supportability - Stockport

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!

Website: supportability.org.uk

Diverse Abilities - Dorset

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.

Website: diverseabilities.org.uk/children

Accessing support in London

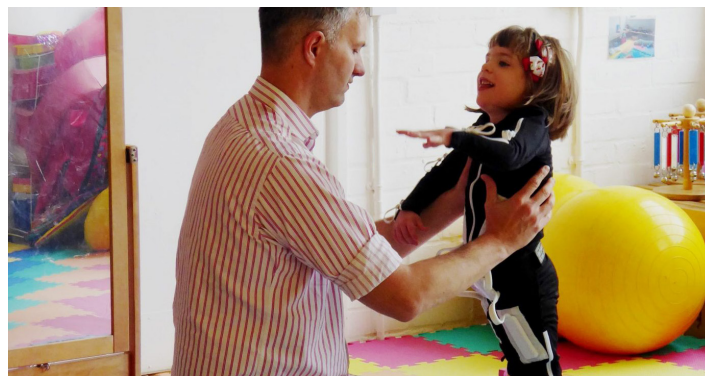
London can be a daunting place to access support. Below are details of London based charities who assist children with additional needs:



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!

Website keenlondon.org



C Potential

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

Website cpotential.org.uk



Access Sport

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

Website accesssport.org.uk



Small Steps

Small Steps delivers group sessions for children from newborn to 5 years with cerebral palsy and other forms of mobility issues in London and support for parents.

Website 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.

Website 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 5s and short breaks and residential stays for young adults along with support for families and home care.

Website kids.org.uk



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:

Statutory support

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/

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.

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 1 to 4. 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:

- Is aged between 5 and 16 years old; and
- Has special educational needs, a disability or mobility problems; and
- 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:

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

Website: 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.

Website: 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.

Website: 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. You can receive up to £156.90 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 3 years old.

DLA claim forms are available by phone 0800 121 4600 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.

Website: 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.

Website: 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.

Website: 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.

Website: gov.uk/apply-blue-badge



Charities and trusts

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.

Website: 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.

Website: 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.

Website: familyfund.org.uk

The Nihal Armstrong Trust provides grants of up to £1,000 for children with cerebral palsy to purchase essential pieces of equipment, communication aids and activities. Some of the equipment and activities that the Trust provides include: iPads, lycra suits, riding lessons, trikes, walking frames, and buggies.

Website: nihalarmstrongtrust.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.

Website: cheynecharity.org

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

Website: newlifecharity.co.uk

The Boparan Charitable Trust accept applications for funding for powered and manual wheelchairs, specialist trikes, buggies, car seats, walkers, standing frames, sensory toys, hoists, beds, and P Pod chairs.

Website: 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 £400 for various pieces of equipment.

Website: peeps-hie.org/hie-awareness-support

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

Website: independenceathome.org.uk

Designability is a Bath-based charity, centred on improving the lives of differently-abled individuals through medical engineering. In the 1970s their inventors created the world's first spring assisted armchair. In recent years they launched their first wheelchair baby carrier and established a Wizzybug loan scheme – Whizzybugs are fun little powered wheelchairs designed for children under five.

Website: 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.

Website: 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.

Website: 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.

Website: kensingtonfoundation.com

The Dream Makers Children's Charity grants wishes and dreams to children with disabilities. The wishes could be a holiday at Disney World, a trip to Lapland or the opportunity to swim with dolphins. They also have a number of large mobile holiday homes in Devon for children who are unable to travel further afield.

Website: 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!

Website: bendrigg.org.uk

Therapies

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

Website: 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:

Website: crowdfunder.co.uk

Go Fund Me is a similar fundraising platform:

Website: uk.gofundme.com



© Image by Bendrigg Trust

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. Visit r82.org for more information.

- The P-Pod by the Specialised Orthotic Services. This is the ultimate beanbag for children and adults and provides high levels of postural support.

Website: specialisedorthoticservices.co.uk/product/p-pod for more information.

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.

Website: leckey.com for 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.

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. Supplied by quest88.com

- The Innowalk is a motorised standing device which allows children to exercise in an upright, weight bearing position. Supplied by 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 quest88.com.
- Adapted trikes. There are many adapted tricycles on the market and our physiotherapy experts recommend the Tomcat range (tomcatuk.org) or the Quest88 range (quest88.com). 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.

Website: 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.

Website: 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.

Website: 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.
Website: symmetrikit.com for more information.
- 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.
Website: etac.com for more information.
- The ProMove Sling is an incredibly light and portable moving and handling device that provides an alternative when you cannot access a hoist.
Website: promove.uk.com for more information.

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:

Website: munchkin.co.uk

- Or the Nuby Sipeez 360 degree wonder maxi cup:
Website: nuby-uk.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.
Website: bakare.co.uk for more information.
- The Phippen Traveller bed is a safe portable bed which is ideal for staying overnight away from home.
Website: kinderkey.co.uk or livingmadeeasy.org.uk for more information.
- Safesides Bed Surrounds are inflatable bed surrounds which create all round protection.
Website: livingmadeeasy.org.uk for more information.
- 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.
Website: symmetrikit.com for more information.



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:

Cerebra Sleep Service
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.

Website: 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.

Website: astorbannerman.co.uk for more

information.

- 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.

Website: jiraffe.org.uk for more information.

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

Website: gompels.co.uk for more information.

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
Website: marksandspencer.com/l/kids/easy-dressing
- Pedro Boots
Website: pedro-uk.co.uk
- Billy Footwear
Website: specialkids.company/collections/billy-footwear
- Nike FlyEase
Website: nike.com/gb/flyease
- Butler boots
Website: 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

Aids for swimming



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

- Incontinence swimwear can be essential and is supplied by Incy Wincy: incywincy.net

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. Visit inclusive.co.uk for more information.
- 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. Visit thinksmartbox.com for more information.
- 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 – a flexible piece of software which can be set up to meet the developmental level of the individual. Visit tobiidynavox.com for more information.

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. Available from 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/services

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.

Website: 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
Website: [facebook.com/groups/SNEUK](https://www.facebook.com/groups/SNEUK)
- Disabled Gear
Website: [facebook.com/DisabledGear](https://www.facebook.com/DisabledGear)

Similarly, you may be looking to donate equipment that you are no longer using. The charity Wheels for the World accept donated wheelchairs and mobility aids which then provide much needed mobility to adults and children across the globe.

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



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.

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

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/childrens/bladder-and-bowel-service

01225 831785

Barking and Dagenham, Havering & Redbridge

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

0300 300 1618

Berkshire: Paediatric Continence Service

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

01189 495146

Bedfordshire: Children's Continence Service

cambcommunityservices.nhs.uk/Bedfordshire/services/continence

Bowel: 01234 310847 Bladder: 01234 315847

North Devon: Paediatric Bladder and Bowel Care Service

northdevonhealth.nhs.uk/services/paediatric-bladder-and-bowel-care-service

01392 208044

Birmingham: Child & Adult Continence Service

bhamcommunity.nhs.uk/patients-public/adults/continence

0121 466 3700

Cheshire & Wirral: Paediatric Continence Service

<https://www.cwp.nhs.uk/our-services/cheshire-west-chester/paediatric-continence-service>

0151 488 8231

Cumbria: Children's Community Nursing

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

01228 608112

Lincolnshire: Children's Contenance Service

careplusgroup.org/services/childrens-contenance-service

01472 266999

Liverpool: Children's Bladder & Bowel Service

<https://www.mersecare.nhs.uk/our-services/liverpool/adult-bladder-and-bowel-services>

0151 295 3993

London, Greenwich: Paediatric Contenance Service

<http://oxleas.nhs.uk/services/service/paediatric-contenance-servi-1/?q=contenance>

0208 319 9973

London, Hackney: Children's Contenance Service

homerton.nhs.uk/contenance-service

020 7014 7111

Manchester: Children's Contenance Service

<https://www.manchesterlco.org/services/childrens-community-services-citywide/childrens-contenance-service/>

0161 741 2030

Medway: Children's Contenance Service

medwaycommunityhealthcare.nhs.uk/our-services/a-z-services/child-health-service/childrens-contenance-service

0300 123 3444

Newcastle upon Tyne: Paediatric Contenance

newcastle-hospitals.org.uk/services/childrens_departments-and_paediatric-contenance-and-stoma.html

0191 282 4890



North Somerset: Children's Community Health Partnership Children's Contenance Service

cchp.nhs.uk/node/11310

Oxford: Children's Bladder & Bowel Service

oxfordhealth.nhs.uk/service_description/childrens-contenance-advisory-service/

01865 904467

Plymouth: Child Development Centre Contenance Service

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

Powys: Contenance Community Specialist Nursing

powysthb.wales.nhs.uk/contenance-community-specialist-nursing

01686 617237

Southampton & West Hampshire: Paediatric Contenance Service

<https://www.solent.nhs.uk/our-services/services-listings/community-paediatric-contenance-service-southampton-and-west-hampshire/>

0300 123 3797

York: York Family Information Service

<https://www.yor-ok.org.uk/families/Local%20Offer/health-services.htm>

01904 554 444

Special education

Many children with cerebral palsy require additional support to help them learn. If you think that your child may have special educational needs, speak to your child's paediatrician or GP and they will ensure that your Local Authority is aware.

Your Local Authority will have an information and advice service and will be best placed to advise you on the most appropriate school and educational setting for your child. Together you can make a decision that is in their best interest.

If your child is entitled to special provision, an Education, Health and Care Plan (EHCP) will be drawn up by the Local Authority. An EHCP will describe a child's needs and make proposals for educational and associated provision and cover the years up to age 25.

An EHCP will set out your child's short term and longer term goals in relation to their cognitive learning; social and emotional wellbeing; physical abilities; communication skills; health outcomes; and social support.

The plan will also set out the support that will be put in place to achieve these goals. This may be in the form of one-to-one adult support; small class sizes; provision of speech and language therapy and educational psychology; access to sensory equipment; behavioural support and provision of respite care.

You can find out more on the government website: gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities



Challenging your child's EHCP



An EHCP should be reviewed every year and any necessary adjustments to the document made.

If you are unhappy with your child's EHCP, it is possible to negotiate changes to the document with your Local Authority. Your Local Authority will have an internal complaints procedure and you can ask your Local Authority for details of this procedure. Alternatively you may consider seeking legal advice. Either way, it is best to act promptly as there are strict time limits involved.

If the negotiations with the Local Authority are unsuccessful, then an appeal can be made to the First Tier Tribunal (Special Educational Needs and Disability). Appeals must be made within two months of the date of your Local Authority's final decision letter.

Depending on your financial circumstances, legal aid may be available for legal advice up to a hearing, but not for the hearing itself.

Find out more on the government website:

gov.uk/courts-tribunals/first-tier-tribunal-special-educational-needs-and-disability

Special Educational Need Consultancy

The journey through education can be challenging for everyone, let alone for those with special educational needs. Happily, expert guidance is available to advise on the legal rights of a child and how to ensure a child receives the best opportunity to grow and achieve their potential.

Jenny Hooper Consulting

Jenny Hooper is an independent SEN consultant who advises and supports families in relation to education and EHCPs. She is a qualified teacher and special education needs co-ordinator (SENCO).

Website: jhoopersenconsulting.com

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.

Website: 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.

Website: 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.

Website: gulliversworldresort.co.uk/special-needs-guide

- **...and The Space Centre in Preston, Lancashire...**

The 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.

Website: 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.

Website: 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

- And don't forget 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. **Website:** 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.

Website: gwelanmor.com/cornwall-holidays/breaks-in-cornwall/accessible-breaks

- 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. **Website:** centerparcs.co.uk/discover-center-parcs/lodge-holidays/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: 0330 100 9334

Website: butlins.com/help-contact/disability-requirements

- 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.

Website: 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.

Website: tashaccessibletravels.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.

Website: 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.

Website: 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".

Website: cpsport.org

- WheelPower provides a range of activities from angling to ice sledge hockey; powerchair football to karate; wheelchair dance to wheelchair fencing; there is something for everybody. Each year, WheelPower supports over 62,000 differently-abled people to participate in sport and activities across the country

Website: wheelpower.org.uk

- Gympanzees is a Bristol based charity which offers specialised gyms and sensory rooms to provide the chance to exercise, play and build friendships. They also have a lending library whereby families can borrow specialist play and exercise equipment which can be delivered directly to your home. Gympanzees are currently running zoom sessions run by specialist paediatric therapists which are free to attend. The sessions cover practical topics from complex feeding difficulties to high tone and spasticity.

Website: gympanzees.org

- 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

Website: activityalliance.org.uk/get-active

- Flamingo Chicks was set up to enable all children and adults to enjoy dance. It was started by the mother of Poppy, a little girl who has cerebral palsy. Flamingo Chicks now has 3000 dancers participating each year. Classes take place in Bristol, London, Cardiff and West Yorkshire but are currently taking place by zoom which means we can get involved wherever we live.

Website: flamingochicks.org

- All Aboard Water Sports in Bristol offers sailing opportunities for people with a wide range of abilities, from children with complex needs to a development pathway up to Paralympic standard.

Website: allaboardwatersports.co.uk

- 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!

Website: disabilitysportscoach.co.uk



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.

Weightlessness in the water enables people with cerebral palsy to enjoy a range of motion that they may struggle with on land. Movement in the water can improve balance and postural control and increase core strength. The warmth of the water can also help to ease muscles and reduce pain.

Hydrotherapy pools are available on the NHS and most hospitals have access to hydrotherapy pools. Any member of your child's healthcare team can refer you to an NHS physiotherapist for hydrotherapy.

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

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

Occupational therapy



Occupational therapists give practical help and advice on carrying out everyday tasks. For instance, an occupational therapist can assess your home and advise on adaptations or specialist equipment that will make it easier for your child to use the shower, get in or out of bed or go to the toilet. Occupational therapists can also advise on better ways to carry out self-care tasks such as eating, brushing teeth or getting dressed. At school or in the community, they can advise on sitting at desks, using private or public transport and computers. They can also help children with cerebral palsy to access their interests, hobbies and activities.

The Royal College of Occupational Therapists website provides useful information on finding an Occupational Therapist and has an online directory:

rcotss-ip.org.uk/find

Jo Turnbull is an occupational therapist with in depth experience of working with children and adults with complex physical or learning disabilities

iotherapy.co.uk/therapists.htm

Access to Rehab offers specialist treatment in neurological rehabilitation accesstorehab.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.

Website: helpwithtalking.com/Member/Miss-Marie-Couch

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

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

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

Website: therapyinspiration.com

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

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.

³ GMFCS level II describes a child who can walk without assistive devices. "Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping."

GMFCS level III describes children who walk with assistive devices: "Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances."

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 3 to 9 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 III⁵
- There is no evidence of genetic or neurological progressive illness
- The child has no significant scoliosis or hip dislocation.

The full guidance can be accessed via:

england.nhs.uk/publication/selective-dorsal-rhizotomy-for-treatment-of-spasticity-in-cerebral-palsy

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.

Website: www.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.

Website: rda.org.uk

Bobath Approach to Therapy

The Bobath Approach to Therapy is a form of therapy which brings together physiotherapy, occupational therapy and speech and language therapy and is designed for children and adults affected by cerebral palsy. The National Bobath Cerebral Palsy Centre is based in Watford and provides both regular therapy and intensive therapy blocks.

Website: bobath.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)

Website: ccmservices.co.uk

Bush & Co

Website: bushco.co.uk

COOCI Rehabilitation Case Management Services

Website: coociassociates.co.uk

Westcountry Case Management

Website: westcountrycasemanagement.com

ILS Case Management

Website: indliv.co.uk

Breakthrough Case Management

Website: breakthroughcasemanagement.com

Brownbill Associates Ltd

Website: brownbill.com

North Star Case Management

Website: northstarcms.co.uk

Rehab Without Walls

Website: rehabwithoutwalls.co.uk

Stanley Smith Case Management

Website: sscascasemanagement.co.uk

Stokes Case Management

Website: stokescasemanagement.co.uk

Corpore Case Management

Website: corpore.co.uk

Carer recruitment

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

Website: snapcare.co.uk



Legal resources

Pursuing a medical negligence claim



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.

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.

“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)

Following the settlement of his claim, L and his family will continue to have the support of a professional team under the care of a deputy in RWK Goodman’s Compensation Protection Team.

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.

“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)

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.

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/

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.

[Guide to deputyship and changing deputy | RWK Goodman](#)

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.

[Personal Injury Trusts and Court of Protection | RWK Goodman](#)

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.





Healthcare Safety Investigation Branch



There is a second scheme in place run by the Healthcare Safety Investigation Branch (HSIB) which, in effect, runs concurrently with the Early Notification Scheme. The programme started in 2018 and investigates stillbirths, neonatal deaths, maternal deaths and cooled babies or those diagnosed with brain injuries. 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.

HSIB is changing its maternity investigation section into a separate Strategic Health Authority. It will become the Maternity and Newborn Safety Investigations Special Health Authority (MNSI). This is due to become operational from April 2023 and will likely operate on the same parameters as the current HSIB system.

Our team have drafted an in-depth guide to the HSIB on our website: [rwkgoodman.com](https://www.rwkgoodman.com)

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.

Website: [pfp.co.uk](https://www.pfp.co.uk)

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

Website: [frenkeltopping.co.uk](https://www.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.

Website: [brewin.co.uk](https://www.brewin.co.uk)

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

Website: [puntersouthall.com](https://www.puntersouthall.com)

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

Website: [chasedevere.co.uk](https://www.chasedevere.co.uk)



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



Our team



SIMON ELLIMAN
Partner & Head of Clinical
Negligence | 07818 451 354
simon.elliman@rwkgoodman.com



TRACY NORRIS-EVANS
Partner and Head of Injury Division
07717 358 058
tracy.norrisevans@rwkgoodman.com



RICHARD COLEMAN
Partner | 01865 268 631
richard.coleman@rwkgoodman.com



KERSTIN SCHEEL
Partner | 07827 920 973
kerstin.scheel@rwkgoodman.com



PAUL RUMLEY
Partner | 07810 553 609
paul.rumley@rwkgoodman.com



LUCY NORTON
Senior Associate | 01865 268 612
lucy.norton@rwkgoodman.com



HANNAH BLACKWELL
Senior Associate | 01225 730 280
hannah.blackwell@rwkgoodman.com



LUCY CRAWFORD
Senior Associate | 01865 268 647
lucy.crawford@rwkgoodman.com



ABIGAIL RINGER
Senior Associate | 01225 730 163
abigail.ringer@rwkgoodman.com



SARAH WHITE
Senior Associate | 01225 730 194
sarah.white@rwkgoodman.com

rwkgoodman.com/medical-negligence



RWK Goodman LLP is a limited liability partnership registered in England and Wales with registered number OC361361. RWK Goodman LLP is authorised and regulated by the Solicitors Regulation Authority. The term partner is used to refer to a member of the RWK Goodman LLP or an employee or consultant with equivalent standing and qualification. A list of members is available at the registered office 5-6 Northumberland Buildings, Queen Square, Bath BA1 2JE. Information contained in this communication does not constitute legal advice. All statements are applicable to the laws of England and Wales only.



RWK Goodman is committed to the environment. This document is printed using processes that are:



Renewable energy
Vegetable oil based inks
Recycled FSC® stock
Recyclable

Printed with care by Walls Printing. An ISO14001 Accredited & FSC® Certified Company

