Understanding Hemiplegia

Your guide to supporting your child with hemiplegia, with a focus on strategies to improve hand and arm use

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Welcome

This information is designed to provide support and understanding for parents and carers of children recently diagnosed with hemiplegia. Receiving this diagnosis can be overwhelming. The aim of this guide is to equip you with the knowledge and resources to help your child thrive.

This book has been co-designed by parents and therapists of children with hemiplegia, providing an overview of what to expect and guiding you to relevant information and therapy resources.

There are lots of different therapies out there, but it can be difficult to navigate. This guide focuses on those therapies that evidence shows will support your child to thrive. It will equip you with the terminology and information to advocate for your child's needs. This is a common challenge many parents find at the start.

Contents

"The hardest days were the early ones, when we realised Jake wasn't developing as he should be. There was so much uncertainty, and we had so many questions and worries bouncing around our heads constantly. It took time, but once we had a diagnosis and we found out what help was out there...

things got so much easier.

Talking to other parents and realising you're not alone made it even more so."

- (parent K)

About Hemiplegia

Depending on the cause, hemiplegia may also be referred to as unilateral cerebral palsy, hemiplegic cerebral palsy, or hemiparesis. Different health care professionals may use some or all of these terms.

Hemiplegia is a condition characterised by weakness (hemiparesis) or paralysis (hemiplegia) affecting one side of the body, whilst it generally affects both the arm and leg on the affected side, this booklet mostly focuses on therapies that have been proven to improve hand and arm function.

Causes and effects

Hemiplegia is caused by an injury, damage or deformity to one side of the brain. This can happen because of a stroke, traumatic injury (both of these before or after birth), brain tumours or infections which affect the brain.

The effects of hemiplegia vary significantly, from mild cases to more severe but will generally lead to difficulties in movement and coordination on the affected side of the body. However, there are really effective therapies to support your child's progress.

Furthermore the size of the area of the brain impacted does not necessarily correspond with the scale of the impact on the child" e.g. there are lots of examples of large parts of the brain being impacted but the child has a relatively mild form of hemiplegia.

There are a number of different therapies that are proven to be effective in improving your child's outcome. These are based upon neuroplasticity and motor learning theories. Neuroplasticity is the brain's amazing ability to change and reorganise itself based on our experiences and what we practice. Important principles of neuroplasticity include:

Use it and improve it: The more we use certain parts of our brain, the stronger and better they become.

Specificity: Practicing specific skills leads to improvements in those exact areas.

Repetition: Repeating activities helps reinforce and strengthen brain connections.

Transfer: Skills learned in one area can help improve abilities in other areas.

(Kleim et al 2008)

If you'd like to read more about neuroplasticity you may find this an interesting book "The boy who could run but not walk" by Karen Pape.

Motor learning theory is about how people learn and improve physical movements through practice and experience. It includes:

Learning new motor skills: Figuring out how to do new physical activities.

Improving existing skills: Getting better at activities we already know.

Optimising movement: Making our movements more efficient and effective to achieve our goals.

In essence, motor learning helps us get better at moving and performing physical tasks by practising and gaining experience.

"When my parents first found out about my disability, they didn't know anything about hemiplegia. They listened to the doctors with an open mind and made sure I worked on my weak side by doing exercises.

I saw that they were being strong for me and in turn it made me strong physically & mentally!"

- (Adult with hemiplegia)

In the UK, hemiplegia affects up to 1 in 1000 children with most of these, about 80% of cases, due to an event before or around birth and 20% acquired (post birth) (Contact,2024; Sellier et al, 2016).

The condition will often be described as right or left sided hemiplegia, depending on which side of your child's body is affected. An injury to the right side of the brain will cause left-sided hemiplegia (left side of body is affected) and an injury to the left side of the brain will cause right-sided hemiplegia (right side of body is affected).

The exact cause of this injury can be impossible to pinpoint and may never be known. You might ask yourself something like "Why did my child have a stroke?"

It is important for you to know; **you are not to blame** and research is ongoing to understand more.

"When I found out Samuel had had a stroke, immediately I blamed myself, what had I done wrong, how did I not know, over time I have come to accept that

I couldn't have known and it wasn't my fault"

- (Parent N)

Feelings and Emotions

"Trying to understand what cerebral palsy or hemiplegia means is incredibly overwhelming and to this day I don't think a doctor has actually used the word cerebral palsy with us,

so it really depends who you see and when and what information they share"

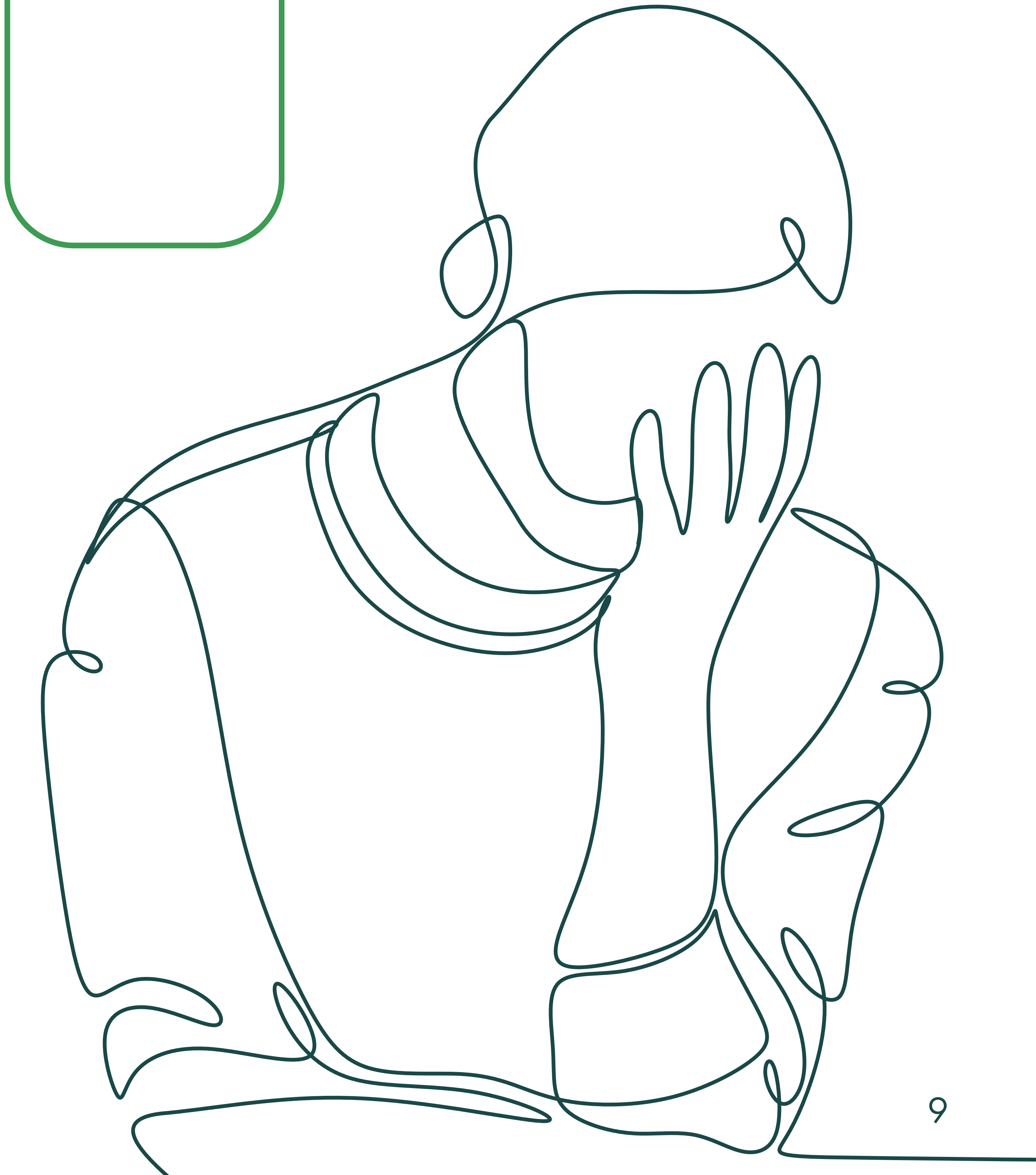
- (Parent P)

Your own journey

Everyone's journey to receiving their child's diagnosis is different and can vary greatly, which can make it challenging to access information and intervention to support your child reach their full potential – this can have a huge emotional impact or strain on you as parents and this is completely normal.

When being given your child's diagnosis, you may experience a range of different feelings. Noticing a difference in the way your child moves both sides of their body can be worrying. Finding out the diagnosis can be a relief, whereas for others it may be a big shock.

You might find it difficult to take in all the information the doctor or other health care professionals are sharing with you. Do not hesitate to ask questions when you are ready. You might find it helpful to write your questions down as they occur to you and take them to your next appointment. Charities like "The Stroke Association" have a really helpful checklist of questions to ask your doctor or specialist.



Many parents describe feelings of loss or grieving for the future you thought your child may have had. You might be experiencing this and it's common and natural, you shouldn't feel guilty. You may be worried for your child's future. It is important to know that you are not alone, and that there is a wide range of support that may be helpful to you and your family, some of which are listed below. Some families find it helpful to connect with other parents of children with hemiplegia and you can do so through some of the resources detailed on this page.

> **"Talking to another parent who is in the same boat as you is really helpful..."**
>
> (Parent K) -

Hemihelp have a closed facebook group offering peer support for parents: HemiHelp closed group for families affected by hemiplegia | Facebook

If your child has had a stroke – the stroke association also have a parent to parent offer: Parent-to-Parent Volunteer Calls | Stroke Association

What will this mean for my child?

Every child's journey is unique, but with early intervention, appropriate therapies and support, many children with hemiplegia can achieve their full potential.

The level of independence your child may achieve depends on various factors, such as;

- Cause of hemiplegia
- Effectiveness of interventions
- The child's individual strengths and abilities

There are many ways to support and advocate for a person with hemiplegia to enable them to reach their full potential. It is important to get the right professional support around you and your child. The 'where can I find support section' later in this guide contains a who's who list of professionals your child may see. The Stroke Association website also has a number of different resources including downloadable lists of questions for different medical professionals which can be found at the following link: https://www.stroke.org.uk/stroke/childhood/i-am-parent

> **"I would say our experience from that initial point was one of we didn't know what to expect. We've never been faced with this before".**
>
> - (Parent P)

What happens after diagnosis?

Therapy services

In each region in the UK you will find community therapy services that offer support and intervention to children with hemiplegia. Services do vary from region to region depending on the local NHS trust's offering and so the next few pages are designed to give you an indication of what is recommended for your child and what you should expect and request through your paediatrician or GP.

These services may provide blocks of therapy, home visits and guidance for families to support their child's development, participation in daily life and well-being. You should be referred to these now you have your child's diagnosis.

Some families may choose to pay for private therapists too. When meeting any therapist, the Stroke Association have developed a useful guide for questions to ask your therapist this may help you navigate the types of therapy they may be offering and whether they are evidence-based. This can be found at https://www.stroke.org.uk/stroke/childhood/i-am-parent or at the following link (child_stroke_therapy_q_a_v3_web.pdf).

When should we start therapy?

Research shows that getting help for your child as early as possible gives them the best chance to learn and develop their potential. Don't be afraid to seek a diagnosis (trust your instincts) and request immediate treatment after that diagnosis. Early intervention following a brain injury takes advantage of a crucial time when a child's brain and body are most able to change and adapt. We also know children can continue to learn and develop their skills as they get older.

Which therapies are effective to improve arm and hand function?

There has been a lot of research in this area, now showing what is effective in helping your child reach their potential. In particular you may hear about things like Bimanual Therapy or Constraint-Induced Movement Therapy (CIMT). For many children with hemiplegia, these have been shown to be highly effective when delivered in line with the evidence (and are on the NHS National Institute for Health and Care Excellence (NICE) recommended therapies list). These are a few of the effective interventions, more can be learned by reading the evidence summaries and material in the bibliography. All approaches start with setting goals, and the selected intervention approach should be selected based on those goals.

Constraint Induced Movement Therapy (CIMT)

There are different forms of CIMT. In younger children approaches called baby-CIMT or modified CIMT (mCIMT) are typically used. Every CIMT approach involves using a restraint on the unaffected hand e.g. with a mitt, sling or cast. The child practices carefully selected activities to improve movement, control and coordination of the more affected hand. This approach has been shown to be effective when offered at a specific dose (e.g. number and length of practice sessions) and intensive practice. It is not effective to only wear a restraint without the practice of activities.

Bimanual Therapy

Bimanual therapy focuses on activities that encourage the use of both hands together. The child practices fun, meaningful two-handed activities. This approach is effective when practice achieves a recommended dose and high levels of practice.

Both CIMT and bimanual approaches are equally effective. Your child may benefit from either, or a combination of both. More information can be found in the additional resources in this booklet.

> "I remember not knowing or understanding what to expect from my son's capability with his hand which to an extent is still true as he surprises us everyday. The therapy we have done both CIMT and bimanual has been invaluable in his progression and use of his affected arm. I remember the first time he raised his arm onto a railing when sat on a train, I cried.
>
> **He continues to do things I never thought he would."**
>
> - (Parent N)

Some key elements of these approaches include;

- You as parents are core to therapy delivery
- Set goals – this helps to measure and see progress
- Integrate practice into your child's natural environment giving the opportunity for regular practice
- Repetition and intensity are key – practice, practice, practice!
- Specificity – ensuring the practice is targeted, practicing specific skills related to the goal.

Whereas CIMT and bimanual therapy involve practising movements or skills that could be part of a task, **goal directed training** is a therapy that focuses on practicing the whole task.

Goal directed training

Goal directed training is a therapy that aims to improve independence and overall functional performance by setting clear, personalised goals and using structured practice to improve performance and skills in targeted activities.
Goals are broken down tasks into manageable steps and practicing them. Some examples of goals children have set are:

- To tie my own shoelaces
- Put on jewellery or make up by myself
- Ride a bike to my friend's house
- Use cutlery so I can eat out with friends
- Dress myself
- To hold the swing with both hands at the playground

Botulinum Toxin (Botox)

Evidence based therapies such as those described in the previous sections should be provided for children and young people under 19 years. Botulinum Toxin A (commonly known as Botox) can be used alongside therapy to help children with muscle stiffness (spasticity). Botox helps relax the muscles, which can make it easier for therapy to improve a child's abilities.

The main goal of this combined approach is to help children do everyday activities more comfortably. However, Botox injections are only effective when used with a therapy plan, which may include options like occupational therapy, physiotherapy, or putting the affected limb in a cast or splint. The effects of Botox typically last 12-16 weeks, sometimes up to 6 months, and therapy during this time can make a real difference.

It's essential to have a team of specialists keep an eye on how well the Botox works. Giving too much or too little Botox can cause problems, so careful planning is important. **Botox alone won't lead to a big improvement,** and it can also weaken muscles. The long-term effects are still unclear, and its effectiveness varies depending on where the injection is given. Before deciding on Botox treatment, talk with your therapy team and paediatrician to ensure it's the best option for your child and that they have the right support for therapy afterward.

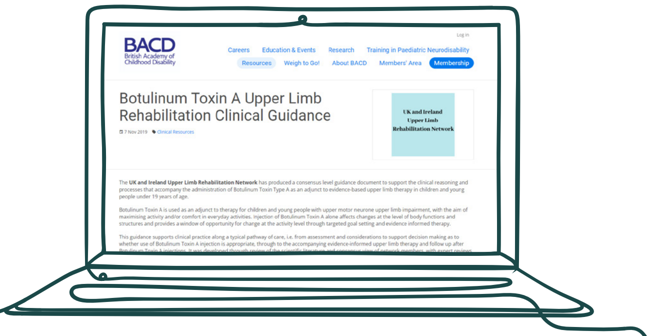
Botulinum toxin and hemiplegia

10 mins read

Botulinum toxin (also known as Botox) injections are frequently offered to children with hemiplegia as part of their movement therapy programme. They act to reduce the stiffness or 'spasticity' of the muscles, improving range and function and decreasing discomfort.

Some information can also be found at:

https://contact.org.uk/help-for-families/information-advice-services/hemihelp/how-is-hemiplegia-treated/botulinum-toxin-and-hemiplegia/



Botulinum Toxin A Upper Limb Rehabilitation Clinical Guidance

The **UK and Ireland Upper Limb Rehabilitation Network** has produced a consensus level guidance document to support the clinical reasoning and processes that accompany the administration of Botulinum Toxin Type A as an adjunct to evidence-based upper limb therapy in children and young people under 19 years of age.

Botulinum Toxin A is used as an adjunct to therapy for children and young people with upper motor neurone upper limb impairment, with the aim of maximising activity and/or comfort in everyday activities. Injection of Botulinum Toxin A alone affects changes at the level of body functions and structures and provides a window of opportunity for change at the activity level through targeted goal setting and evidence informed therapy.

This guidance supports clinical practice along a typical pathway of care, i.e. from assessment and considerations to support decision making as to whether use of Botulinum Toxin A injection is appropriate, through to the accompanying evidence-informed upper limb therapy and follow up after

Specific Botox guidance has been developed based on research and advice from experts.

https://www.bacdis.org.uk/resources/57-botulinum-toxin-a-upper-limb-rehabilitation-clinical-guidance

How to set goals

All therapies require setting goals. Goals are really important in order to measure progress and support motivation. However some families find it challenging to know what to consider or where to start with goal setting. Goals are based areas on function or activities that are important to you and your child and will likely depend on your child's age and stage. A few ideas of goal areas you might consider are below – (this is not an exhaustive list):

Grasping and holding objects: during play.

Stabilising toys: Help the child stabilise a toy with their more affected arm against a surface while playing.

Reaching for toys: reaching with the more affected arm during playtime.

Supporting a bottle with both hands to drink.

Self-feeding: Eat snacks from a container holding the container in the more affected hand, developing use of cutlery.

Hand washing: brushing teeth, washing hair.

Aspects of dressing: pushing arm through sleeves through to putting on items of clothing and fastening buttons or zips, tying shoelaces.

Household chores: carrying items in or with both hands to the table, or the laundry basket or items with both hands, helping carry items of shopping, holding and passing items e.g. when tidying up.

Sports and hobbies: goals can be set around sports and hobbies too.

These goals focus on enhancing the child's independence and ability to perform everyday tasks, facilitating their development and integration of motor skills into daily activities.

What makes therapy effective?

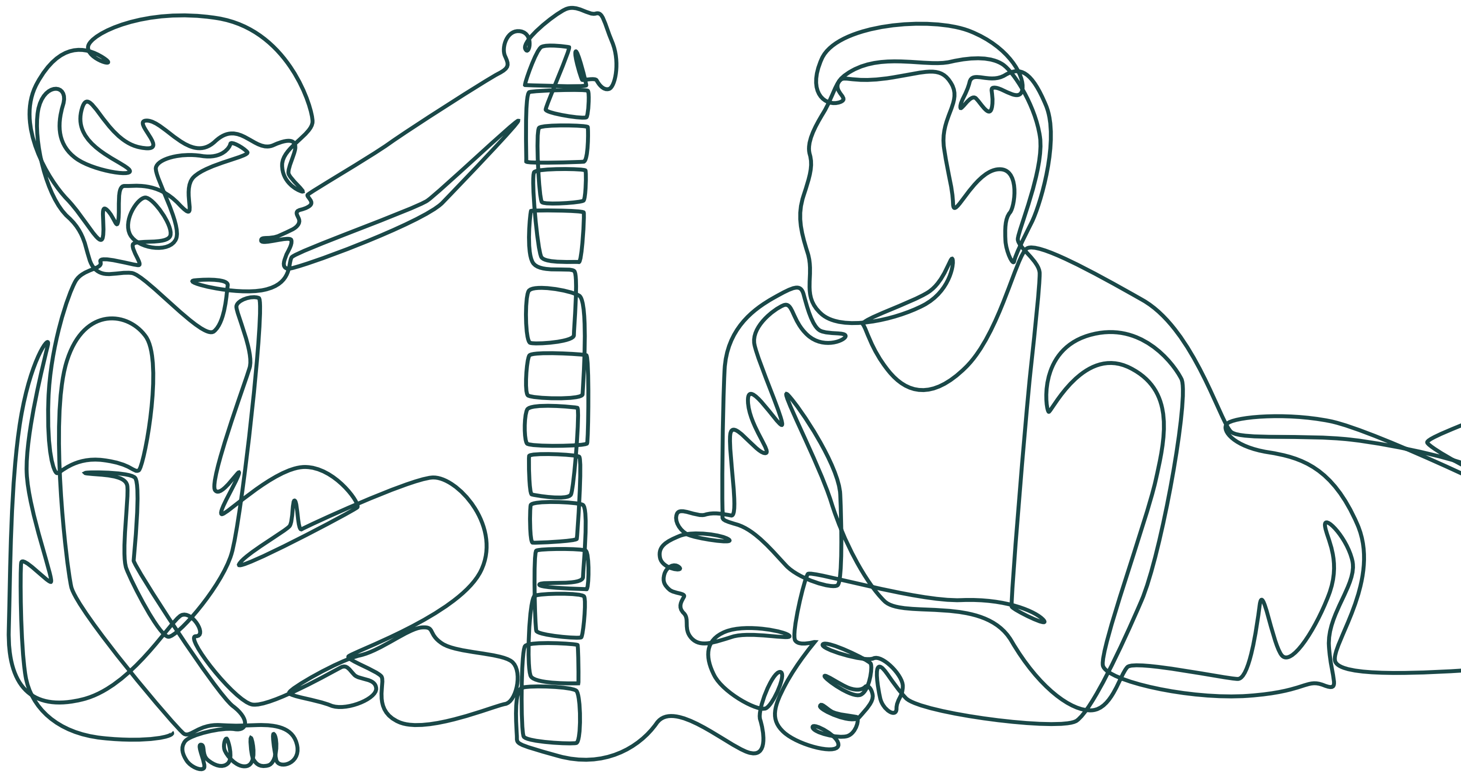
To improve function for children with hemiplegia therapy should:

- Ensure the child is active in carrying out the activity or task
- Involve practicing the whole task or set goal such as in goal directed training
- Involve practicing part of the task your goals are based on, such as bimanual or CIMT approaches
- Provide education and information to parents to enable them to deliver the therapy themselves outside of scheduled appointments.
- Work directly towards goals that are chosen by the child and family
- Ideally be in the child's environment (e.g. home / school)
- Directly involve children and families in decisions
- Always be fun!

Approaches that involve children actively practicing their goals or every day tasks, typically in their real-life environment, have been proven to be effective in improving a child's participation. For neuroplasticity to occur, the child should be actively engaged in the activity so that their brain is active. If a therapist is simply doing something for, or to the child (e.g. holding them on a ball, or positioning them in different ways), the child's brain is not doing the work. Remember the phrase "Neurons that fire together wire together!"

Everyday fun and educational activities can be therapy in themselves. It's not all about your child doing therapy all day. Having fun, going to the park or sitting and doing a craft activity can provide opportunities for your child to practice and optimise their skills. Outdoor play such as water play or sand where your child can hold an object with both hands and pour from a large container is an opportunity to further their motor skills as it is using self-initiated movement, one of the principles of neuroplasticity.

> "A therapist told me once that as adults we all have our own jobs or duties, but for a child their only job is to play. When you have a disabled child, you tend to get bogged down in therapies and appointments.
>
> **Sometimes children just need to do their job and have opportunities to play**
>
> That in itself can be the best therapy of all."
>
> \- (Parent K)



What does the research say?

There have been several studies over the years carried out to find the most effective therapy for children with hemiplegia. Research has shown that with targeted intervention children can achieve their goals.

Summaries of the research have been written to help families and therapists decide which therapies may work best for their child. These can be found below (for full research publications see also bibliography at end of this guide).

Evidence summaries written by occupational therapists
Evidence summaries written by a group of occupational therapists on a few topics, offer a practical overview and insight into the evidence for a particular intervention. Current topics include:

- Home programmes
- Family centred practice
- Occupation focussed interventions
- Parent and caregiver coaching

The Children's Trust evidence summaries. volume 3, February 2019
Summaries of the research carried out into lots of therapies, with clinical recommendations for each one.

Cerebral Palsy Alliance – Identifying the right intervention for your child
An easy to read summary of the study by Novak et al in 2020, showing which interventions have been shown to be most effective for children with cerebral palsy.

Other activities

There are a wider range of other complementary therapies or activities that some parents have shared with us that they have found useful (but there is not yet be enough evidence to determine if they are clinically effective). Many of these activities are more general and not specific to upper limb function.

Baby massage

Baby yoga

Swimming

Hippotherapy or horse riding

Martial arts

Chiropractor (regular and neurological)

Gymnastics or trampolining

Conductive Education (for example Small Steps and Dame Vera Lynn charities)

Moving around on uneven surfaces for example, at the beach, soft play or playgrounds

What can I do to help my child now?

Be an advocate

You are your child's biggest supporter and unfortunately awareness of hemiplegia varies. Learning what to advocate for, and how, might take time but gets easier as you learn more and gain confidence. You may not have all the answers now but over time you will work through it. It can be hard to navigate at times, but you may need to be proactive in finding out what is available and getting access.

> **"My paediatrician hadn't heard of CIMT, but from research I had done, she was able to make the right referral to get our child access to therapy."**
>
> (Parent N) -

Making referrals

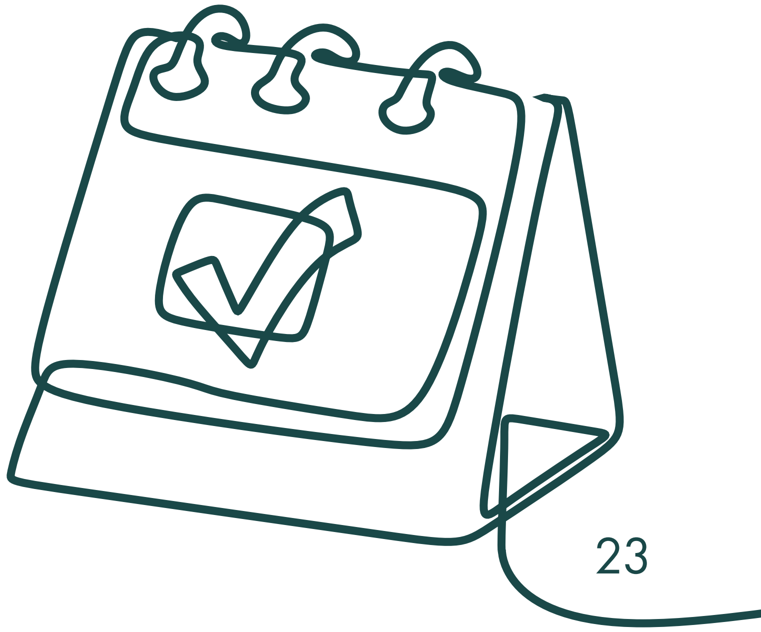
You may need to ask your GP or health care professional to refer your child to your community therapy team. Depending on your child's needs, you may be referred to physiotherapy, occupational therapy and/or speech and language therapy. In some areas, you may be able to refer your child yourself to these services. Other services may include a dietician, orthotics, opthalmology.

It is important for your child to access their community team as soon as possible, so either ask for a referral straight away or process the referral yourself.

You may be placed on a waiting list but once you get to meet your therapist, they will work with you to set goals and show you how to deliver your child's therapy for you to continue at home. Your therapist should show you how and what to do to help your child make progress towards their goals.

Things you can start today to help your child use their affected arm / hand

You don't need to wait for an appointment to get started and you don't need specialist equipment. Things you can start to do include encouraging the active use of your child's affected side and both sides together as early as you can by finding toys, activities or games that they enjoy. Don't be afraid to try. Encouraging your child to use their affected side in a fun way, through play, can help them be more aware of their arm/hand which is a great start. The simplest activities can be the most fun and effective! Social media can be useful for discovering toys, techniques etc.



Tips for getting started

General hints and tips

Always keep it fun!

Think differently! It's okay if your child does things their own way!

You know your child best, so feel confident in trying new things together.

Don't worry about stopping if your child isn't in the mood. Some days they won't feel like it and that is ok! Just leave it and try again a different day.

Ways to set up play and daily activities

Try to sit on your child's affected side and pass things in from that side or in front of them.

If your child is in supported sitting (e.g. a high chair) or leaning against a surface while playing, encourage them to keep their arm in front of their body where they can see it.

Arrange toys and tasks to promote reaching. Place toys on your child's affected side or in the middle, to prompt them to initiate movement towards them.

Switch off tv and try to minimise other distractions.

Use prompts sparingly: Set up activities so your child naturally uses both hands without needing verbal reminders. Use gentle touch or cues when necessary. When using prompts clearly say the name of the affected arm you want them to use (e.g. can you push it with your "right" arm).

For infants, vary positions: Use tummy time, sitting, or side-lying to encourage different movements. Tummy time can be across your lap to begin with. When moving onto the floor, place forearms and encourage them to lift their head initially by placing something for them to look at in front e.g. mirror.

Demonstrate first: Show your child how to perform an activity and then give them time to try it on their own without stepping in too quickly.

Find the "just right challenge" which means giving tasks that are not too easy or too hard, but at the right level to help your child succeed e.g. start by placing items within reach. As they achieve success, move items further away to increase the challenge.

Encouraging movement/use of affected arm/hand

Visual attention strategies: Place toys, objects, or even stickers, scrunchies, or bracelets on the affected arm to draw attention to it.

Encourage repetition: Find motivating activities that encourage your child to repeat movements; e.g. toys that make sounds or light up when touched, batting a balloon on a string, nudging cars down a ramp.

Provide opportunities to hold objects: Start by placing it in your child's hand. Use easy-to-hold items like cylindrical toys that fit comfortably in their hand. If they let go or drop it, place it back in their hand to practice holding.

Focus on progress, not perfection: Celebrate any movement or attempt to use the affected hand, no matter how small.

Encouraging two hand use

Choose activities that require both hands: Consider actions that require two hands then provide activities or toys that can encourage those e.g. containers (that will fit in hand), magnetic toys, springs, duplo.

Add ways to need two hands: consider adding steps to activities to encourage the use of both hands (bimanual) e.g. placing items or toys in bags boxes and containers that require two hands to open. This strategy can be used for toys or snacks that are motivating for your child. Empty kitchen packets or containers or wash bags with drawstrings can be handy!

Functional tasks: Everyday activities like cooking, gardening, and crafts are great for practicing two-hand use. For example, carrying a heavy item or stirring a bowl encourages the use of both hands.

Incorporate play at the playground: Swings, climbing equipment, and other playground features often promote the use of two hands, offering a fun way to practice.

Sensory play is a great way for your child to feel different sensations, for example, get messy with paints, sand, water, playdough, leaves, bath foam etc.

> "When I was a child, I used a controller with one hand and not to brag but I was pretty good. My point being that doing things differently is okay. There will be some trial and error, but THE most important thing is to
>
> **not give up"**

- (Adult with hemiplegia)

Where can I find further information or support?

Access Sport
A national charity who support access and inclusion in sport.

Action CP
Improving public, professional and political awareness of the issues facing children and young people with cerebral palsy.

Baby CIMT
Some educational resources for babyCIMT are shared on this website.

Breathe magic
The bimanual and goal-oriented intensive therapy program for children with hemiplegia, aimed at young people aged 7-19, is a group-based initiative that incorporates magic. Recent studies show that this program helps develop psychosocial skills and independence.

Cerebral Palsy Alliance (Australia)
An Australian based organisation with a variety of resources and useful information on their website.

Child Brain Injury Trust
Work in hospitals, schools and community and are able to offer support through face to face meetings, phone and email.

Contact/Hemihelp
Information and advice services and advice services
Part of contact with a wide range of resources to help children with hemiplegia and their families.

- Contact / Hemihelp - Guide to school and nursery specifically for children with hemiplegia.
- Contact / Hemihelp - Education information - school applications and process for Education Health and Care Plans (EHCP) in England. This page also has links to information for families in Northern Ireland, Wales and Scotland.

Council for Disabled Children
A national umbrella body that brings together a diverse range of organisations that work with and for disabled children to support development and implementation of policy and practice.

CP Toys

CP Toys is a platform that supports therapists and parents of children with cerebral palsy. They share therapeutic activity ideas, educational webinars on relevant topics and share interviews of families at different stages of their therapy journey.

CP Sport

CP Sport is a national charity that helps people with cerebral palsy lead more active lives by providing sports opportunities, support services, and advocating for positive change for disabled individuals.

Dame Vera Lynn Children's Charity

Supporting young children with cerebral palsy and motor impairments.

EISmart

EiSMART is an evidence-based framework designed to provide high-risk babies, particularly those born prematurely or with health challenges, with the best possible start in life. The framework addresses all aspects of a child's development, including sensory experiences, motor skills, attention and self-regulation, and relationships.

Evelina REACH service

A specialist (NHS) service for children with hemiplegia. Children who live in the southern boroughs of London, Kent, Surrey or Sussex are eligible for consultation and advice appointments, and where clinically indicated, offer intensive rehabilitation programmes. For children outside these areas, they can offer one-off consultation and advice appointments. The Evelina REACH service encourage local therapists to attend these appointments.

Facebook

Hemiplegia closed group. This is a closed group for families of children with hemiplegia.

Hemipower

Hemipower is a group of parents and therapists who came together through the Parents as Partners in Rehabilitation (PaPeR) research project which created this booklet. They continue to work towards supporting parents, primarily owning the content and distribution.

I can do it myself

The guide provides practical advice on dressing and other daily living skills for children with one-arm weakness, covering home activities like dressing, grooming, and kitchen tasks, as well as school and leisure activities.

Riding for Disabled Association

Charity offering fun activities including riding and carriage driving for disabled children and adults.

SCOPE
Disability equality charity in UK.

Kids - SENDIASS
Special Educational Needs and Disabilities Information Advice and Support Servicee. offers information to young people with special educational needs and disabilities (SEND) and to their parents and carers.

The Professional Conductors Association
The Professional Conductors Association website, which includes a map of all of the registered Conductive Education Centres across the UK.

Stroke Association – Childhood stroke resources
(For children who have been affected by stroke). You will also find some useful question and answer sheets that were developed by parents and professionals. These may help you to think about questions to ask at health appointments.

- Teachers Toolkit
  Resources to support you and your child if you are returning to school after a stroke.

Who's who

PAEDIATRICIAN

A paediatrician is a medical doctor specialising in the care and treatment of infants, children, and adolescents. They have expertise in child development, growth, and the management of various paediatric health conditions. Paediatricians play a crucial role in the early diagnosis and treatment of medical issues affecting children. They conduct regular check-ups to monitor a child's growth and development. When a child presents with health concerns or developmental delays, the paediatrician evaluates, diagnoses, and may refer the child to other specialists or therapists for further assessment and intervention.

NEUROLOGIST

A doctor who specialises in helping children with problems related to their nervous system, which includes the brain, spinal cord, and nerves. These doctors are experts at diagnosing and treating conditions that affect a child's brain and nervous system, such as seizures, epilepsy, headaches, developmental delays, and neurodivergence or cerebral palsy. They work closely with children and their families to provide medical care and support, aiming to improve the child's neurological health and overall well-being.

OCCUPATIONAL THERAPIST

Helps with promoting their independence and participation in everyday activities including play, dressing skills, getting washed, feeding yourself, writing, typing and participating in leisure activities. They may also provide equipment depending on your child's needs. Some occupational therapists may also advise or refer to other colleagues for home adaptations if required.

WHEELCHAIR SERVICES

Depending on your child's needs you may have a referral to wheelchair services who will assess whether any equipment they provide may be appropriate to support your child's mobility. It is important to note this is not relevant to all children with hemiplegia.

SPEECH AND LANGUAGE THERAPIST

Helps with communication, eating, drinking and swallowing.

ORTHOPAEDIC SURGEON

This is a medical doctor with expertise in the musculoskeletal system, which includes bones, joints, ligaments, muscles, and tendons. In the context of hemiparesis, an orthopaedic specialist *may* be involved in assessing and managing issues related to the child's skeletal and muscular development.

PHYSIOTHERAPIST

Helps with movement and mobility, to develop new motor skills or maintain skills and abilities and support participation in leisure, recreation and sport activities.

PSYCHOLOGIST

Helps with emotions/feelings, thinking and learning.

ORTHOTIST

An orthotist for children with cerebral palsy designs, fabricates, and fits orthotic devices such as braces and splints to enhance mobility, manage muscle tone, and prevent deformities. They work closely with a multidisciplinary team to create tailored treatment plans that promote optimal physical development and improve the child's quality of life.

Glossary

Botulinum Toxin: In some children their muscles may become very tight and stiff making it hard for them to move. Botulinum toxin injections may help muscles to relax a little. Goals should be set and injections combined with therapy to promote the best outcome.

Hemiparesis: Weakness or partial paralysis affecting one side of the body.

Hemiplegia: A form of unilateral cerebral palsy. One side of the body (arm and leg) is affected.

Muscle tone: This refers to the tension in your muscles. It is what helps your body stay steady and ready to move. If you imagine your muscles to be like rubber bands the tension varies between high (like taut rubber bands) and low tone (like stretchy loose rubber bands).

- **Dystonia:** A movement disorder that causes muscle contractions, leading to twisting or repetitive movements and abnormal postures
- **Hypertonia:** A form of high or increased muscle tone
- **Hypotonia:** A form of low or decreased muscle tone

Orthotics: Special devices that are worn inside shoes to help support the feet, improve walking, or correct foot problems.

- **Ankle Foot Orthosis (AFO):** A type of brace that supports the ankle and foot. It helps keep the foot in the right position while walking.
- **Dynamic Ankle-Foot Orthosis (DAFO):** A flexible type of AFO also designed to support the ankle and foot.
- **PIEDRO Boots:** Specially designed boots that offer extra support for the feet and ankles, often used by people who need additional stability when walking.

Spasticity: A word used to describe a form of hypertonia, where muscles feel stiff.

Unilateral cerebral palsy: A form of hemiplegia where one side of the body (one arm and one leg) is affected. Some healthcare professionals may use this term instead of hemiplegia, depending on when the brain injury happened.

Splints: Some children may be provided with a splint to help them to use their hand in activities, this may be made from neoprene or a thermoplastic. They may also have a thermoplastic night resting splint that helps to maintain their range of movement. All splints must be regularly monitored when provided.

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Notes

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This booklet has been developed by parents and therapists who know how hard it can be to find the right support for your child following a diagnosis of hemiplegia. In order to help those going through the same experiences they have founded the group "Hemipower" to manage this content and the distribution of it, to empower parents with the knowledge to best support their child with hemiplegia. This booklet can be found in digital form at hemipower.co.uk

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