



Cerebral Palsy
ALLIANCE

Early Intervention Therapy

A guide for parents of
babies and children aged
0-2 with cerebral palsy



What works and how much is needed



Babies and children with cerebral palsy deserve the best evidence-based care and support that is available.

Fortunately, we now have access to a growing library of research that identifies which therapies work, which ones don't, and how much of the right therapy is needed to really make a difference.

What is cerebral palsy?

Cerebral palsy is an umbrella term for a broad group of physical disorders that affect movement and posture due to damage to the developing brain. While it is a life-long physical disability, it can change over time.

Why is early intervention so critical?

Cerebral palsy can now often be accurately diagnosed as early as three months of age. At this time, a baby's brain is developing rapidly, which makes it ideal for harnessing neuroplasticity: the brain's ability to adapt or rewire itself.

Research shows that getting access to intervention as early as possible will give a child their best chance of learning, regardless of the condition or diagnosis. This means early diagnosis is crucial because it enables access to early intervention supports as soon as possible.

Who is Cerebral Palsy Alliance (CPA)?

CPA is recognised as the leading provider of evidence-based therapy, life skills programs and services for people living with cerebral palsy and other neurological conditions. Our research foundation supports the world's best and brightest researchers to find preventions and cures for cerebral palsy.

What's in this guide?

This guide is designed to help parents of babies and children recently diagnosed with cerebral palsy understand what key areas of development can be affected by cerebral palsy, and how early intervention can deliver improved outcomes in each of these areas.

The guide also provides important facts about the best cerebral palsy-specific early intervention supports, and how much is needed for each area of development.

Areas of development include:

- Gross and fine motor skills
- Muscles and joints
- Swallowing, eating and drinking
- Communication.

Also included is important information on self-care for you and your family.

Delivery of therapy

In-person therapy is the most common mode of early intervention delivery.

However the growth and improvement of online platforms such as telepractice means many of the interventions discussed in this guide can now be delivered in your home via telepractice.

Speak with your therapist to discuss the most appropriate way for your child to access specific interventions, whether it is via in-person, telepractice, or a combination of the two.

Key highlights



A minimum of two hours of specialised therapy interventions per week in the first 24 months is recommended to guide your child's development. Your early intervention specialist will provide coaching to support you and your child's development during this time. Your child may need additional supports, depending on which areas of their development are affected.

Find out more on page 6.



Task-specific, motor training-based early interventions are recommended as the new gold standard of care for babies and children with cerebral palsy, because they encourage neuroplasticity and functional gains.

Find out more on page 8.



Swallowing difficulties are often under-recognised and under-reported, so regular observation of your child for signs of difficulty with swallowing is recommended. Timely and effective intervention in this area can promote weight gain, reduce the risk of chest infections, improve sleeping and feeding routines, and also support parental well-being. **Find out more on page 10.**



Early communication intervention involves the facilitation of pre-verbal skills through play. Early communication intervention increases the likelihood of your child learning to communicate effectively, promotes cognitive development and minimises the development of behavioural difficulties. **Find out more on page 12.**



Active monitoring of your child's muscles and joints is best practice for the management of pain and stiffness, which can occur as a secondary condition of cerebral palsy. **Find out more on page 14.**



Accessing detailed information about your child's diagnosis can be empowering, and can help reduce stress on you and your family. **Find out more on page 16.**

Cerebral palsy-specific early intervention therapy

What will help?

Early intervention is essential.

Babies and children diagnosed with cerebral palsy, or deemed to be at high risk of cerebral palsy, will be referred to an interdisciplinary therapy team that includes occupational therapists, physiotherapists, speech pathologists, social workers, early intervention teachers and psychologists. Depending on your child's individual needs, any member of this therapy team may be involved with supporting you and your child.

Referral should be made as early as possible, and should not wait for a confirmed diagnosis or the appearance of a six-month delay.



Early access to emotional and social support is recommended for you and your family to help with any stress related to coping and adjusting to your child's diagnosis and extra caring responsibilities. Counselling can also help you navigate through the diagnosis and support you to provide an optimal caring environment for your children.



It's important to access funding supports as early as possible in order to minimise any delays to starting early intervention for your child. Your therapy team may be able to suggest where you can access additional funding support.



It's important for your child to receive interventions at home. Learning in a supported natural environment will lead to greater improvements because therapy activity is personalised to their interests and enjoyment. Delivering early interventions in your child's natural environment also enables strategies to be embedded into your child and family's daily routines.



A customised home program is designed for you to carry out with your child. This program is adjusted regularly as your child's skills develop. Your therapists will coach and support you to effectively implement the recommended program at home.



How much therapy is needed?

A minimum of two hours of specialised therapy interventions per week in the first 24 months is recommended to guide your child's development. Your early intervention specialist will provide coaching to enable you to support your child's development during this time. Your child may need additional supports, depending on which areas of their development are affected.

Additional therapy supports you and your child may need could include:

- **Feeding supports:** babies with cerebral palsy are more likely to have feeding problems and saliva management difficulties
- **Communication supports:** some children with cerebral palsy will be non-verbal, and will need early access to augmentative and alternative communication (AAC) strategies to maximise their communication skills
- **Cognition and learning supports:** some children with cerebral palsy will experience learning difficulties, and all young children will benefit from stimulating early learning opportunities
- **Family support:** parents will have different needs for emotional and social support, depending on their personal and family circumstances.



Outcomes from cerebral palsy-specific early intervention

Cerebral palsy-specific early intervention maximises neuroplasticity and minimises the development of secondary impairments related to altered muscle and bone growth.

Early intervention for babies and children with cerebral palsy is essential for developing cortical connections in the brain. Brain development continues after birth and is driven by motor cortex activity. This means the first two years of a baby's life are critical for cognitive and motor development, as their brain is undergoing constant spontaneous changes. This ability for the brain to change itself is called neuroplasticity.

Babies and children who receive cerebral palsy-specific early intervention will benefit from vital learning opportunities during this critical window of neuroplasticity.





Gross and fine motor skills

Task-specific, motor training-based early interventions are recommended as the new gold standard of care for babies and children with cerebral palsy, because they encourage neuroplasticity and produce functional gains.

What will help?

Recommended intervention includes Infant treadmill training. This training is a targeted intervention that can help improve stepping in preparation for independent walking for children with cerebral palsy, Down syndrome and motor delay. Infant treadmill training allows children to achieve more stepping practice and work towards independent walking. It is suitable for babies and children between 9–36 months of age who are starting to sit, and who show signs of walking readiness.

Babies with an injury on one side of their brain, may have reduced use of the arm and hand on the opposite side of their body.

Both constraint induced movement therapy and bimanual therapy have been shown to be effective in improving the amount of use, and quality of movement, in the affected hand and arm. Studies have shown these therapies can be used from as early as 3 months of age. It is important to be guided by your therapist about the amount of time spent each week doing this therapy.



Specialised therapy supports should also involve designing a customised home program for you to carry out with your child. This program will be adjusted regularly as your child's skills develop. Your therapists will coach and support you to effectively implement the recommended program at home.

Early interventions should take place in your child's natural environment in order to embed the interventions into your child and family's daily routines.



Outcomes from cerebral palsy-specific early intervention for gross and fine motor skills

Cerebral palsy-specific early intervention maximises neuroplasticity and minimises the development of secondary impairments related to altered muscle and bone growth.

Infant treadmill training in babies and children has been proven to accelerate the onset of walking. It has also been shown to improve endurance and speed of walking, as well as balance and mobility in toddlers.

Children need to practice at least twice a week, for seven weeks, to gain these results.



Swallowing, eating and drinking

Swallowing difficulties can affect how someone eats, drinks and manages their saliva. Swallowing difficulties are often under-recognised and under-reported. Many children with cerebral palsy can experience difficulties in this area, and may require non-oral feeding supports, such as feeding through a tube.



Feeding skills are essential for health and growth, which means babies with cerebral palsy should have regular and ongoing monitoring for swallowing difficulties to ensure they are getting the right levels of daily food intake.

What will help?

Swallowing, eating and drinking interventions can work on:

- Improving your child's drinking and chewing skills and safe swallow
- Improving attachment between you and your baby
- Providing support for managing the stress often associated with mealtimes.

If your child needs interventions for swallowing difficulties, they are best done in your child's natural environment and during their regular feeding times.



Outcomes from early intervention for swallowing, eating and drinking skills in cerebral palsy

Timely intervention on feeding skills will prevent or shorten any episodes of failure to thrive, promote weight gain, and prevent related health conditions, such as chest infections. They may also improve sleep and feeding routines, and reduce parental stress.



Communication

Babies can communicate long before they begin to speak. Communication starts in early infancy by watching and copying their primary caregivers.

Babies also learn when their attempts to communicate are acknowledged, and when they are spoken to by their caregivers. This is how babies develop their foundational communication skills, known as pre-verbal skills. These include skills such as joint attention and turn-taking. This happens before babies learn to say their first meaningful words.

Many people with cerebral palsy are unable to speak and rely on other non-verbal forms of communication.



What will help?

Timely early intervention promotes the development of these foundational communication skills. If your baby is unable to express themselves adequately, or their attempts to communicate are not recognised, both learning and behaviour can be affected.

Communication intervention involves the facilitation of pre-verbal skills through play. Parent training and coaching is an essential component of the intervention whereby you are taught how to identify and respond to your child's attempts to communicate.

Early communication intervention should take place in your baby's natural environment in order to better embed the communication facilitation strategies into you and your child's daily routines.



Outcomes from early intervention for communication in cerebral palsy

Early communication intervention increases the likelihood of a child learning to speak, promotes cognitive development and minimises the development of behaviour difficulties.

When parents are able to recognise their child's communication attempts, they are better able to recognise what their child is trying to communicate and form a closer bond and attachment with their child.



Hips, muscles and joint development

One third of children with cerebral palsy have hip displacement, where the hip joint does not develop well. The risk of hip displacement is higher in children with both sides of their body affected by cerebral palsy and who are unable to walk.

It is very common for children with cerebral palsy to have stiffness in their muscles, which can reduce the range of movement at certain joints. People with spasticity (tight muscles) are most at risk. While spasticity is not usually present in young infants with cerebral palsy, it often appears from 12 months of age.

What will help?

If cerebral palsy affects both sides of your child's body, they should receive regular monitoring of their hips, muscles and joint development, and timely intervention.

Active monitoring through programs such as *CPUP* in Sweden and CPA's *CP Check-Up™* are considered best practice.

Hip monitoring should commence with an initial hip x-ray at 12–24 months of age.

How frequently?

The frequency of repeat hip x-rays will be determined by your child's level of mobility.

Children who are not standing or walking by 18 months may need more frequent hip x-rays.

CPA offers free annual *CP Check-Up™* appointments for babies and children diagnosed with, or at risk of, cerebral palsy.



Outcomes from active hip, muscle and joint surveillance in cerebral palsy

Active monitoring (or surveillance) can prevent or minimise secondary impairments such as pain, scoliosis, severe contractures and hip dislocation.

CPA's *CP Check-Up™* program is based on the Swedish program, however it extends beyond surveillance of muscles, hips and joints and includes surveillance of cognition and learning, eating, drinking, communication, and family well-being.



Support for parents and carers

When a baby or child is diagnosed with cerebral palsy, parents may feel a range of emotions including stress and anxiety, potentially affecting their ability to participate fully in early intervention for their children. Other family members such as grandparents and siblings can also be affected. A diagnosis of a loved one with cerebral palsy can also lead to extra caring, relationship and financial worries for the family.

What will help?

If you are feeling stressed or anxious about your child's diagnosis, caring for your child, or about what the future may hold, access to emotional and social support is strongly recommended.

Counselling can help your family adjust and learn to cope with the complexities of your child's diagnosis, and also ensure you can provide an optimal caring environment.

Parents may also benefit from the opportunity to connect with other parents in similar circumstances through mutual support groups or online forums.

If you, or anyone in your family needs emotional or social supports please ask your therapist for information about how to access services and supports.



Outcomes from parent support

Having access to detailed information about a diagnosis can be empowering for parents and can help reduce distress.

Parents of children with cerebral palsy find counselling at the time of diagnosis helps to manage overwhelming feelings such as stress, anxiety or depression and to cope with the stress of extra caring responsibilities.



References



How much therapy is needed

Morgan, C., Novak, I. & Badawi, N. (2013). Enriched environments and motor outcomes in cerebral palsy: systematic review and meta-analysis. *Pediatrics*, 132(3):e735–46. doi: 10.1542/peds.2012-3985.

Novak, I., Morgan, C., Adde, L. et al. (2017). Early, accurate diagnosis and early intervention in cerebral palsy advances in diagnosis and treatment. *JAMA Pediatr*, 171(9): 897-907. doi: 10.1001/jamapediatrics.2017.1689.

Novak, I., Hines, M., Goldsmith, S. & Barclay, R. (2012). Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics*, 130(5), e1285–e1312.

Spittle, A., Orton, J., Anderson, P. et al. (2015). Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database of Systematic Reviews*, (11): CD005495.



Gross and fine motor skills

Angulo-Barroso, R., Tiernan, C., Chen, L., et al. (2013). Treadmill training in moderate risk preterm infants promotes stepping quality – Results of a small randomised controlled trial. *Research in Developmental Disabilities*, 34(11):3629–3638.

Grecco, L., Zanon, N., Sampaio, L. & Oliveira, C. (2013). A comparison of treadmill training and overground walking in ambulant children with cerebral palsy: randomized controlled clinical trial. *Clinical Rehabilitation*, 27:8: 686–696.

Mattern-Baxter, K., McNeil, S. & Mansoor, J.K. (2013). Effects of Home-Based Locomotor Treadmill Training on Gross Motor Function in Young Children With Cerebral Palsy: A Quasi-Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation*, 94:2061–2067.

Morgan, C., Novak, I. & Badawi, N. (2013). Enriched environments and motor outcomes in cerebral palsy: systematic review and meta-analysis. *Pediatrics*, 132(3):e735–46. doi: 10.1542/peds.2012-3985.

Novak, I., Morgan, C., Adde, L. et al. (2017). Early, accurate diagnosis and early intervention in cerebral palsy advances in diagnosis and treatment. *JAMA Pediatr*, 171(9): 897-907. doi: 10.1001/jamapediatrics.2017.1689.

Ulrich, D., Lloyd, M., Tiernan, C. et al. (2008). Effects of intensity of treadmill training on developmental outcomes and stepping in infants with Down syndrome. *Physical Therapy*, 88:114–122.

Eliasson, A. C., Nordstrand, L., Ek, L., Lennartsson, F., Sjöstrand, L., Tedroff, K., & Krumlinde-Sundholm, L. (2018). The effectiveness of Baby-CIMT in infants younger than 12 months with clinical signs of unilateral-cerebral palsy: an explorative study with randomized design. *Research in developmental disabilities*, 72, 191–201.

Chamudot, R., Parush, S., Rigbi, A., Horovitz, R., & Gross-Tsur, V. (2018). Effectiveness of modified constraint-induced movement therapy compared with bimanual therapy home programs for infants with hemiplegia: A randomized controlled trial. *American Journal of Occupational Therapy*, 72(6), 7206205010p1-7206205010p9.



Swallowing, eating and drinking

Bell, K., Boyd, R., Tweedy, S. et al. (2010). Prospective, longitudinal study of growth, nutrition and sedentary behaviour in young children with cerebral palsy. *BMC Public Health*, 10:179.

Dahlseng, M., Finbråten, A., Júlíusson, P. et al. (2012). Feeding problems, growth and nutritional status in children with cerebral palsy, *Acta Paediatrica*, 101(1): 92-98.

Gisel, E. (2008). Interventions and outcomes for children with dysphagia. *Developmental Disabilities Research Reviews*, 14(2): 165-173.

Veness, C. & Reilly, S. (2008). Mealtime interaction patterns between young children with cerebral palsy and their mothers: characteristics and relationship to feeding impairment. *Child Care, Health and Development*, 34(6): 815-824.



Communication

Beebe, B., Messinger, D., Bahrack, L. et al. (2016). A systems view of mother-infant face-to-face communication, *Developmental Psychology*, 52(4):556-571.

Brown, M., Westerveld, M., Trembath, D. & Gillon, G. (2018). Promoting language and social communication development in babies through an early storybook reading intervention. *International Journal of Speech-Language Pathology*, 20(3):337-349.

Harder, S., Lange, T., Hannsen, G. et al. (2015). Longitudinal study of coordination in mother-infant vocal interaction from age 4 to 10 months *Developmental Psychology*, 51(12):1778-1790.

Ravn, I., Smith, L., & Smeby, N. (2012). Effects of early mother-infant intervention on outcomes in mothers and moderately and late preterm infants at age 1 year: A randomized controlled trial. *Infant Behaviour & Development*, 35, 36-47.



Hips, muscles and joint development

Australasian Academy of Cerebral Palsy and Developmental Medicine (2014). Australian Hip Surveillance Guidelines <https://www.ausacpdm.org.au/resources/australian-hip-surveillance-guidelines/>

Häggglund, G., Andersson, S., Duppe, H. et al (2005). Prevention of dislocation of the hip in children with cerebral palsy. The first ten years of a population-based programme. *Journal of Bone and Joint Surgery*, 87(1), 95-101.

Häggglund, G., Andersson, S., Duppe, H. et al (2005). Prevention of severe contractures might replace multilevel surgery in cerebral palsy: Results of a population-based health care programme and new techniques to reduce spasticity. *Journal of Pediatric Orthopaedics*, 14(4), 269-273.

Wynter, M., Gibson, N., Kentish, M. et al. (2011). The consensus statement on hip surveillance for children with cerebral palsy: Australian standards of care. *J Pediatr Rehab Medicine*, 4(3):183-95.

Wynter, M., Gibson, N., Willoughby, KL. et al (2015). Australian hip surveillance guidelines for children with cerebral palsy: five year review. *Dev Med Child Neurol*, 57:808-820.



Support for parents and carers

Higginson, J. & Matthewson, M. (2014). Working therapeutically with parents after the diagnosis of a child's cerebral palsy: Issues and practice. *Australian Journal of Rehabilitation Counselling*, 1(20), 50-66.

Rentinck, I., Ketelaar, M., Jongmans, M. et al. (2009). Parental reactions following the diagnosis of cerebral palsy in their young child. *Journal of Pediatric Psychology*, 34 (6): 671-676, <https://doi.org/10.1093/jpepsy/jsn103>

Schuengel, C., Rentinck, I., Stolk, J. et al. (2009). Parents' reactions to the diagnosis of cerebral palsy: associations between resolution, age and severity of disability. *Child Care Health Dev*, 35(5):673-80. doi: 10.1111/j.1365-2214.2009.00951.x.

Notes

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