

Early Intervention Therapy and Support for Pre-Schoolers

A guide for parents of
children aged 3-6 years
with cerebral palsy



What works and how much is needed



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 injury 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 ways to improve current interventions and search for ways to prevent and cure cerebral palsy.



What's in this guide?

This guide helps parents of children aged 3-6 with cerebral palsy understand what areas of development can be affected, and how early intervention can improve outcomes in each of these areas. Children with cerebral palsy usually continue to learn and refine their motor skills up until the age of 7, so we recommend that early interventions addressing all affected developmental domains be undertaken until children start primary school. Attention to learning, behaviour, communication and social skills are also vital for this period as children prepare for school.

This guide also provides important facts about the best cerebral palsy-specific early intervention therapies and supports. It covers:

- Task-specific training
- Gross motor skills such as walking and mobility
- Hips and musculoskeletal development
- Management of muscle tone
- Hand function and fine motor skills
- Swallowing, eating and drinking
- Communication
- Self-care skills
- Learning
- Behaviour
- Social skills and friendships
- Support for parents and carers.

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 from the guide



Task-specific training

- Age 3–6 is an important time for skill development in children with cerebral palsy and customised intervention programs based on their goals should be available for every child
- Task-specific training aimed at a particular goal is more effective than therapy that is generalised
- Children need at least 14 hours of intervention per goal. If your child has two identified goals, they will need at least 28 hours of intervention. If they have three goals, then 42 hours at least.

Find out more on page 5



Gross motor skills such as walking and mobility

- Motor training-based early interventions that are goal-directed and task-specific are recommended as the gold standard for children with cerebral palsy, because they induce neuroplasticity and produce functional gains
- Gait training, treadmill training, and hydrotherapy, are additional interventions that may support your child develop their gross motor skills
- Assistive technology and ankle foot orthoses can enable your child to optimise their independence.

Find out more on page 7



Hips and musculoskeletal development

- Children with cerebral palsy are at risk of hip displacement and joint contracture as they grow. These conditions can be painful
- Children with cerebral palsy should receive regular surveillance of their musculoskeletal development and timely interventions
- Interventions such as serial casting can have short-term benefits
- Sometimes orthopaedic surgery is needed to keep bones and muscles aligned.

Find out more on page 10



Management of muscle tone

- Altered muscle tone such as spasticity can affect a child's control of movements, contribute to the development of muscle contractures, and can also cause pain
- Botulinum toxin can help reduce spasticity in injected muscles in the short term
- Some oral medications can also help muscle tone.

Find out more on page 12



Hand use and fine motor skills

- Task-specific, motor training-based early interventions are recommended as the gold standard for children with cerebral palsy, because they induce neuroplasticity and produce functional gains
- Children need at least 14 hours of intervention per goal. If your child has two identified goals, they will need at least 28 hours intervention. If they have three goals, then 42 hours at least
- Setting a goal and actual practice of those goals requires less hours to make improvements in goals than generalised upper limb training
- Discuss with your therapist the best way to structure training.

Find out more on page 14



Swallowing, eating and drinking

- Swallowing problems are common and often not recognised
- Children with cerebral palsy should have regular check-ups for swallowing problems
- Adjusting what and how your child eats or drinks can help.

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Communication

- While problems with communication are common, there are many ways to support the development of your child's ability to communicate
- These include expressive and receptive language therapy, speech therapy and assistive technologies
- Communication partner training can help too.

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Self-care skills

- Task-specific, motor training-based early interventions are the gold standard for children with cerebral palsy, because they induce neuroplasticity and produce functional gains
- Sleep issues are common. If left untreated, they can have a significant impact on your child and family
- Health professionals should work closely with you and your family to identify the most appropriate options to help with sleep difficulties.

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Learning

- Children with cerebral palsy may experience difficulties with specific areas of their thinking and problem-solving skills. Issues can include difficulties controlling or maintaining their attention, difficulties holding things in mind momentarily, being unable to control inappropriate behaviours, or difficulties in planning, organising or thinking of solutions to problems
- Supports are available for assessing, assisting and making adaptations for your child's needs, both at school and at home.

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Behaviour

- Maintaining the wellbeing of the family unit can help families stay together
- Parenting programs can reduce any problematic behaviours and emotional issues your child may experience, and can improve parents' confidence, wellbeing and relationship with each other.

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Social skills and friendships

- Pre-schoolers are encouraged to have regular, weekly contact with other children to support their social development
- Supporting the development of social skills involves understanding the developmental level of the child and their current patterns of social interactions
- A program can then be developed to teach children to better understand social situations and acquire new skills.

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Support for parents and carers

- Parents of children with cerebral palsy find counselling and social support helpful to manage overwhelming feelings such as stress, anxiety or depression and to cope with the stress of extra caring responsibilities.

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Task-specific training

Task-specific, motor training-based early interventions are the gold standard for children with cerebral palsy because they induce neuroplasticity and produce functional gains.

Task-specific practice is also useful for the development of other skills such as thinking and language skills.

These approaches are also called child-active approaches, because the child actively practices real-life tasks, usually in real-life environments, for the purpose of gaining or consolidating real-life skills that they want to learn. Traditional approaches have relied on specific techniques where the child is often a passive recipient, but it is now clear that traditional approaches don't help children learn new skills.

Child-active therapy approaches should:

- Be goal-based
- Involve practice of the actual task
- Involve high amounts of repetition.

Practice can be organised over either a short intensive period, or it can be distributed over a number of weeks or months. The type of practice will vary according to the goals identified, and each child's and family's individual preferences.

Types of task-specific motor training

Goal-directed therapy

Goal-directed therapy (GDT) involves the child and family setting goals that are needed for everyday life, then the child practising specific activities to reach those goals.

The goal might need to be broken down into parts or modified to start with. As the child's skill level improves, the task can be made harder and should be practiced in real life as much as possible. For example, practising climbing stairs that are in the child's home is more beneficial than practising climbing stairs in a therapy room. The task/s and the environment are often changed to help the child better learn skills.

GDT should be offered to all children who have motor goals, at the just right challenge for their level of ability. GDT may be carried out in individual or group sessions as well as intensive camp models. Regardless of the way GDT is conducted, all children should have individually identified goals to work on and the goals and activities should be motivating and fun for the child.

Depending on the specific goals chosen, weekly access to physiotherapy and/or

occupational therapy is recommended. While the number of hours of practice per goal has not yet been established for all gross motor goals, for goals involving the upper limbs (arms and hands), between 14 and 25 hours is needed to achieve a goal using GDT. The time taken for a child to reach goals will vary.

Support typically involves designing a customised home program for parents to carry out with their child. This program should be written down and adjusted regularly as the child's skills develop. Therapists should ensure the home program can be implemented by the child's carers using a parent coaching framework.

How quickly a child is able to learn a new task or movement skill using GDT will depend on many different factors including age, type of cerebral palsy, individual motivation and understanding of the task/skill (cognition), as well as opportunities to practice the task/skill.

GDT can also be used for non-motor-based goals such as play, self-care, communication, cognitive and school-based activities.

Cognitive orientation to occupational performance

Cognitive orientation to occupational performance (CO-OP) is a goal-oriented intervention which uses specific cognitive strategies to enable a child to learn or improve important skills. The aim is for the child to improve their motor and/or self-care skills, as well as improve their ability to plan and work out the steps needed to learn new skills. This learning process can be applied in different contexts, and also to learn other new skills and activities.

Children are introduced to a strategy called GOAL, PLAN, DO, CHECK, which will be used to help their motor learning. CO-OP is suitable for children aged 5 or more who have the thinking ability needed to identify possible solutions to achieving goals. Therapists must have specialised training to use this approach.



How much and how often?

Interventions that focus on functional goals and involve actual practice of the goals need less hours of practice than therapy that is generalised (not goal-directed).

There are two 'models' of motor-based therapy practice that can be used.

A distributed practice model involves a lower duration and frequency of practice delivered over a longer time period, for example goal-directed training.

A massed practice model includes high duration and frequency of therapy over a shorter period of time, for example an intensive therapy camp.

Both types of practice are effective.

Age 3-6 is an important time for skill development in children with cerebral palsy, and customised intervention programs based on their goals should be available for every child.

Task-specific training aimed at a particular goal is more effective than therapy that is generalised.

Children need at least 14 hours of intervention per goal. If a child has two identified goals, at least 28 hours intervention will be needed. If they have three goals, then 42 hours at least.



Gross motor skills such as walking and mobility

Gross motor skills are those that require use of the larger muscles of the body. They are needed for everyday activities such as holding up the head, sitting and standing and walking.

Cerebral palsy nearly always impacts gross motor skills, which affects a child's mobility. Many children will walk without any assistance, while some will use a wheelchair. And there is much variety in between, where some children may have difficulties with slopes, uneven surfaces and stairs, while others may have difficulties with balance activities such as running, hopping and jumping. Other children may walk with the assistance of a walking aid such as a walking frame or crutches and use a stroller or wheelchair for longer distances.

By age 5, most children with cerebral palsy will have reached 90% of their gross motor skills however the quality of their movement can change as they get older. Children with more severe cerebral palsy will reach their gross motor skill potential at a younger age. For these children, accessing assistive technology, for example early powered mobility such as a Wizzy Bug, as early as possible is recommended.

What will help?

In addition to GDT and CO-OP (described above), the following interventions can help children achieve their gross motor goals.

Gait training

- Gait training is specific practice of walking, in a range of contexts, to improve either the quality of the walking pattern or endurance
- Gait training can improve walking speed, but is less effective in improving other gross motor skills. Gait training should be implemented with a GDT approach.

Treadmill training

- Treadmill training can improve speed of walking, walking endurance and, to a lesser extent, gross motor function in children with cerebral palsy
- Treadmill training can be done with the support of a harness if a regular treadmill can't be used
- Treadmill training is most effective when the child is actively using their muscles
- Overground walking training should always be used alongside treadmill training, so that gains in walking can be transferred to real-life situations.

Hydrotherapy

- Hydrotherapy is an activity or exercise that is performed in warm water
- For some children, hydrotherapy may be a useful addition to their GDT program while for others it may provide a freedom of movement not easily achieved in other programs.

Assistive equipment for walking and mobility

- Some children will need specialised devices to assist with walking
- Assistive equipment includes walking frames, crutches and walking sticks. Some children will use different equipment for different activities, such as crutches to walk inside and a wheelchair to move much longer distances. Children start to show their own preferences for which equipment works in which situations
- Some children will need walking devices for a short period before independent walking develops, while others will always need a frame to move (or mobilise) in different environments
- Even children who may not achieve independent walking will benefit from mobilising in a supportive walker for fun, fitness and socialisation.

Assistive equipment for physical activity

- Some children will need specialised devices or adaptations to participate in physical activity
- Assistive equipment includes adapted tricycles, bikes and other devices
- Learning to use these devices should be part of a GDT program.

Ankle foot orthoses

- Ankle foot orthoses (AFOs) are plastic splints commonly used for children with cerebral palsy to improve the position of the foot for standing and walking
- AFOs can make small improvements to walking and gross motor abilities
- It is not clear whether wearing AFOs can prevent the development of permanent contractures, that is, the shortening or tightening of muscles
- If a child uses AFOs, there should be an appropriate GDT program
- There are several different types of AFOs. Usually the best fit is achieved by having them custom-made, although off the shelf AFOs are available. Technologies for AFOs are advancing, with 3D-printed AFOs being tested
- Cost, pain, skin irritation and the cosmetics can influence a child's choice of whether or not to use an AFO, and which one.





Assistive technology for early mobility

- Ride-on cars and powered mobility will support social-emotional and mobility skills
- Children who need assistive technology such as a Wizzy Bug should use it as early as possible
- Active robotic gait training (eg using an exoskeleton) in young children with mild to moderate gross motor impairment can improve the distance the child is able to walk independently. Some robotic devices passively move the child's legs, and are less likely to be effective
- Specific computer games have been designed for people with cerebral palsy and can be used to promote engagement and participation as part of a therapy program.

How much is needed?

The amount of intervention needed to support mobility outcomes will depend on the goals and the type of intervention. We don't have enough evidence to be sure how much therapy is enough to achieve mobility goals. In line with research on motor disorders, we recommend 14 hours as a minimum per goal. These hours can be carried out at home or in a clinical environment.

Outcomes from specific interventions for gross motor skills

Children with cerebral palsy continue to learn new motor skills during early childhood. A sufficient amount of motor training will assist children to maximise their movement potential and promote independence in daily activities that require mobility.

Motor training-based early interventions that are goal-directed and task-specific are recommended as the gold standard for children with cerebral palsy, because they induce neuroplasticity and produce functional gains.

Gait training, treadmill training, hydrotherapy, assistive equipment, assistive technology and ankle foot orthoses can all help children develop their gross motor skills.





Hips and musculoskeletal development

Some children with cerebral palsy have hip displacement, in which the hip bone doesn't sit properly in the hip socket. This can cause pain and make walking difficult.

Many children with cerebral palsy have contractures, in which the muscles are shorter and tighter than usual. Contractures are most likely to occur in joints where the muscles around them are affected by spasticity.

Hip displacement and contracture can cause pain and loss of function. Frequent monitoring and early use of evidence-based treatments is essential to minimise these problems. This approach lasts for life. Different interventions will work at different times for different people.



What will help?

Active surveillance

- Children with cerebral palsy should receive regular surveillance of their musculoskeletal development and timely intervention
- Active surveillance and monitoring through programs such as CPUP in Sweden and CPA's *CP Check-Up*™ are considered best practice.

Serial casting

- Serial casting might be considered when a shortened muscle is stopping a child achieving their goal, such as reaching or walking, or to make dressing easier. It can increase the range of movement of a muscle, and may improve a child's function for a short time after the casts are applied. As it has a short-term effect casting may need to be repeated, especially during growth spurts
- Serial casting involves putting a plaster and/or synthetic cast on the arm or leg for a short time, then replacing it with another. This is repeated several times, and helps to gradually stretch muscles
- Serial casting may be recommended to coincide with another intervention such as botulinum toxin therapy to help minimise any discomfort that may otherwise arise due to the presence of spasticity. Serial casting four weeks after botulinum toxin improves the length of the muscle more than serial casting alone
- After serial casting, active strength and goal-directed training are recommended to make use of the functional range gained.

Orthopaedic surgery

- Orthopaedic surgery might be considered for some children in the early primary school years if serial casting is not effective, to align muscles and joints to help children maintain function and prevent pain. Orthopaedic surgery is more common in later primary than early primary years.



Outcomes from active musculoskeletal surveillance

Active surveillance and the interventions that follow can prevent problems such as pain, scoliosis, severe contractures and hip dislocation.

In Sweden, active surveillance has led to almost complete prevention of hip dislocation and has reduced the number of children with severe contractures by about two-thirds. Orthopaedic surgery for severe contractures, rotational deformity, foot deformity and salvage surgery for dislocated hips has also decreased from more than one in three, to less than one in six.

CPA's *CP Check-Up™* program is based on the Swedish program, however it extends beyond surveillance of the musculoskeletal system and includes surveillance of cognition, learning, eating, drinking, communication and family wellbeing.

How frequently?

Hip surveillance should start with a first hip x-ray at 12-24 months of age, then every year after that. Infants who are not standing or walking by 18 months need more frequent hip x-rays.

CP Check-Up™ appointments should be offered annually.

It is likely that serial casts are most effective when reapplied every three days, usually with three or four casts in a row.

Children with cerebral palsy are at risk of hip displacement and joint contracture as they grow. These conditions can be painful.

Children with cerebral palsy should receive regular surveillance of their musculoskeletal development and timely intervention.

Interventions such as serial casting can have short-term benefits.

Sometimes orthopaedic surgery is needed to keep bones and muscles aligned.



Management of muscle tone and spasticity

Many children with cerebral palsy have problems with muscle tone and movement.

The most common problem is spasticity, in which stiff muscles make movement difficult.

Some children with cerebral palsy have dyskinesia, which means involuntary movements. These can be:

- Twisting and repetitive movements known as dystonia
- Slow, 'stormy' movements known as athetosis
- Dance-like irregular, unpredictable movements known as chorea.

Both spasticity and dyskinesia can affect a child's performance and control of movements, can contribute to the development of muscle contractures and bone problems, and be a cause of pain.

What will help?

There are treatments that can help reduce the effects of spasticity and dystonia in children with cerebral palsy. There is very little known about treating chorea and athetosis.

Assessment and selection of these treatments is done by a multidisciplinary team including rehabilitation physician, orthopaedic surgeon, neurologist, neurosurgeon, physiotherapist and occupational therapist.





Outcomes from interventions to manage muscle tone

Appropriate treatment can reduce spasticity, dystonia and pain in children with cerebral palsy. Botulinum toxin combined with other interventions is effective in improving function and reducing spasticity.

Altered muscle tone such as spasticity can affect a child's control of movements, can contribute to the development of muscle contractures, and can cause pain.

Botulinum toxin can help reduce spasticity in injected muscles in the short term.

Some oral medications can also help muscle tone.

Botulinum toxin

- Botulinum toxin is given by injection into a muscle or muscles, temporarily reducing spasticity. The effects wear off over 4 months, so it is common for young children to have a series of botulinum toxin injections
- Botulinum toxin in combination with other interventions (e.g. serial casting, occupational therapy, physiotherapy, electrical stimulation, orthoses) can help improve range of motion, hand function, gross motor function and goal attainment.

Selective dorsal rhizotomy

- Selective dorsal rhizotomy is a surgical procedure where sensory nerve rootlets in the spinal cord that contribute to spasticity in the lower limbs are cut. This causes a permanent reduction in lower limb spasticity and improvements in walking
- Some children with spastic diplegic cerebral palsy may benefit from this procedure
- Rehabilitation after selective dorsal rhizotomy is long and intensive.

Intrathecal baclofen

- Baclofen is a medication that can help muscles with spasticity or dystonia to relax. It can be given intrathecally, which means the medication is given into the space around the spinal cord via a thin tube (catheter) attached to a pump
- This needs a surgical procedure to insert the pump and catheter, but it means baclofen can be used often in small doses
- Intrathecal baclofen may be considered for children with spasticity or dystonia affecting most of their body, and that significantly affects personal care and comfort (usually children functioning at GMFCS levels IV and V – see appendix).

Oral medications

- Some oral medications can reduce spasticity and dystonia
- Diazepam is effective for the short-term treatment of spasticity
- Oral baclofen reduces spasticity and dystonia, but can cause side-effects such as drowsiness and seizures
- There are other oral medications that can be considered in particular situations.



Hand function and fine motor skills

Some children with cerebral palsy have difficulties using one hand (unilateral) or both hands (bilateral). Others have no problems with their hands.

Towards the end of early childhood years, goals relating to hand function become focused on getting ready for school.

Ideally, children would have their classroom support needs assessed before starting school. They may also receive and be trained in the use of assistive technology, especially if writing by hand is challenging.

What will help?

In addition to GDT and CO-OP (described above), the following specific interventions have also been shown to improve hand function and fine motor skills.

Constraint-induced movement therapy

- Constraint-induced movement therapy (CIMT) is useful for children with unilateral cerebral palsy. It involves constraining the unaffected hand with a mitt, sling or cast. At the same time, the child practises carefully chosen activities to improve the control and coordination of the affected hand
- CIMT has been shown to improve hand function, activities and participation when offered at a specified dose. It is not effective to only wear a restraint, without the exercises.

Bimanual therapy

- Bimanual therapy focuses on a child's ability to use their two hands together to carry out everyday activities
- It involves the use of specific verbal instructions and behaviour prompts to teach the child how the two hands can work together.

Hand therapy home programs

- Hand therapy home programs are an important part of therapy. They usually involve designing a customised home program that includes written instructions and photographs for parents to carry out the intervention with the child in their natural environment
- A home program can be used in conjunction with a specific motor training intervention approach.

Hand/arm orthoses/splints

- Orthoses or splints for the hand and arm can be used to support functional activities or to optimise hand position for stretching
- Using splints might give small extra benefits when used in conjunction with a motor training-based approach
- Many children find hand splints uncomfortable and this can affect their willingness to wear them. It is not clear whether wearing hand splints can prevent a contracture from developing

- Splints are usually prescribed as part of a therapy program addressing a variety of goals. They are usually used in combination with other therapy interventions such as GDT.

Taping therapy

- Taping aims to support or stop muscles turning on, to support joints, and to optimise the position of the hand and thumb so they can function more effectively
- Taping might be useful for children with tightness or weakness in their hand
- Taping should be combined with task-specific motor training such as GDT
- Therapists will recommend taping where appropriate.

Handwriting therapy

- Some children with cerebral palsy will write by hand
- The best therapies need children to practice handwriting while using their thinking skills. A minimum of 20 hours is needed to achieve significant improvement.



Assistive technology for hand function

- Children who have significant difficulty using their hands should have options to access computers and toys. This can be a specialised keyboard, mouse or joystick, using eye-gaze technology or using a switch
- This can improve participation in a range of activities such as mobility, play and accessing a computer or iPad
- Customised mounting arms and systems can be explored to provide the best position for the assistive technology to be effectively used
- Specialised seating systems are important in the daily life of children with more severe cerebral palsy, as good positioning helps children use their hands to their maximal capacity
- Access to assistive technology can also improve cognitive and social skills.

How much is needed?

It depends on the goals and type of intervention. We don't have enough evidence to be sure how much therapy is enough to achieve goals. But current research suggests that a total of 14–25 hours of practice is needed, combining therapy with home practice.

The exception is children with unilateral cerebral palsy, where one side of the body affected, who aim to improve general upper limb function through CIMT and bimanual therapy. These children need 30 to 40 hours of intervention.



Outcomes from interventions for hand function and motor skills

For children with hemiplegia, GDT, CIMT and bimanual therapy provide similar outcomes when delivered in equal amounts. The decision of what to use and when needs to take into account the child's age, hand function ability, motivation, environment and goals.

For children with both hands affected, GDT can enhance goal attainment, self-care skills and quality of upper limb movement.

For children who need the use of assistive technology, there is research to suggest that accessing adapted computers can improve play skills. For example, GDT using adaptive videogames and a modified joystick may increase visual-motor coordination and further improve motor skill development.

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

Children need at least 14 hours of intervention per goal. If a child has two identified goals, they will need at least 28 hours intervention, while for three goals, they will need at least 42 hours.

Setting a goal and actual practice of those goals requires less hours to make improvements in goals than generalised upper limb training.

Therapists can discuss the best way to structure training that suits both the child and their family.



Swallowing, eating and drinking

Swallowing problems (known as dysphagia) affect how someone eats, drinks and manages their saliva. Swallowing problems are common in children with cerebral palsy and are often not detected or discussed.

What will help?

Regular check-ups for swallowing problems are essential.

If a child grows slowly, loses weight or has frequent chest infections, we recommend they see a GP and/or go to a specialised hospital-based feeding clinic. Some children will benefit from seeing a dietitian.

Management involves adjusting what and how the child eats or drinks. Options may include:

- Making fluids thicker or solids smoother
- Positioning the child for optimal posture and head control
- Teaching carers to use physical prompts around the child's lips and jaw to promote better control and movements, e.g. mouth closure
- Parent education about how to manage the amount of food and the pace of feeding and oral hygiene
- Gradually increasing the child's tolerance of certain types or textures of foods
- The SOS approach to feeding, which integrates motor, oral, behavioural/ learning, medical, sensory and nutritional factors and approaches
- Assistive technology such as specialised cups and spoons, and appropriate and customised seating
- Surgical interventions, which may be needed when feeding problems are severe and long lasting:
 - Fundoplication is a surgical procedure to strengthen the barrier to acid reflux
 - Gastrostomy is the surgical placement of a non-oral feeding tube to prevent or reverse growth failure, and to prevent aspiration pneumonia.

How much is needed?

This depends on the goals and the type of intervention. We don't have enough evidence to be sure how much therapy is enough to achieve goals. In line with research on motor disorders, we recommend 14 hours as a minimum per goal.



Outcomes from intervention for swallowing, eating and drinking skills

Timely intervention to improve feeding skills can prevent or shorten the episodes of poor growth, promote weight gain and prevent chest infections. They might also help to improve behaviour, sleep and feeding routines, and reduce parental stress.

Swallowing problems are common and are often not detected or discussed.

Regular check-ups for swallowing problems are essential.

Adjusting what and how the child eats or drinks can help.



Communication

Communication is complex and involves different modes such as speaking, vocalising, use of gestures, and facial expressions. There are also augmentative and alternative communication systems (AAC), which allow people to communicate using technology in a variety of ways.

Communication is complex and two-way. Children can have a range of skills in expressing themselves, to understand others, and be understood. Some of these skills may be affected by cerebral palsy more than others.

It is very common for children with CP to have speech difficulties. Some are unable to speak and rely on non-verbal forms of communication.

Communication difficulties are more commonly associated with children with the type of CP that affects their whole body or the dyskinesia type. Associated impairments such as intellectual disability and epilepsy are also commonly associated with communication difficulties. Children who do communicate verbally may have difficulties with receptive language (understanding others), expressive language (expressing intention or using words and grammar), speech sounds and intelligibility or social communication.

Speech and language pathologists provide comprehensive assessments to identify key areas to work on and will recommend interventions to support the most effective communication for each individual child.



Interventions to support communication goals may focus on strategies to develop speech, strategies to develop alternative methods of communication or a combination of both. Therapy should take place in the environment where the child needs to communicate, which typically includes both home and pre-school.

Expressive language therapy

- Expressive language therapy is a general term that encompasses therapy focusing on developing language skills such as sentence structure, grammar and vocabulary
- Expressive language therapy can include verbal and AAC strategies. This is referred to as multimodal communication. Children with cerebral palsy with speech difficulties and delayed language development are typically encouraged to use multimodal communication
- Expressive language therapy typically includes practising the intervention goal in daily routines and in play, such as with shared reading, frequent modelling and feedback.

Receptive language therapy

- Receptive language therapy refers to therapy to improve the child's ability to understand when others speak. This may include understanding meanings of words, instructions, concepts, stories and idioms
- Receptive language therapy typically includes use of multiple strategies such as visual schedules and gestures.

Speech therapy

- Speech therapy specifically targets speech sounds and the components of speech production in order to improve speech intelligibility
- Speech therapy is based on principles of motor learning and involves repetitive practice.

Stuttering therapy

- Stuttering therapy aims to lengthen the stutter-free speech through graded activities.

Assistive technology for communication

- Assistive technology for communication can be low-tech, such as communication boards, or high-tech, such as computers and speech-generating devices. Software options range from play to communication solutions that can 'grow' with the child

- Alternative and Augmentative Communication (AAC) is an intervention approach that uses manual signs, communication boards with symbols or pictures, and speech generating devices to augment or replace the individual's speech
- AAC employs the child's full communication abilities that the child may not be able to use with speech alone
- AAC systems can be used by a child pointing using their hands, eyes or head movement, as well as other methods such as a mouse or a switch
- AAC intervention might focus on learning new sentence structures, operating the AAC system, finding symbols using AAC to communicate, and taking turns in conversation
- Aided language stimulation promotes language development by combining the use of speech and AAC, which include the designated AAC system, gestures and signs
- AAC promotes speech and language development. AAC allows the child to communicate more widely, and take part in conversation and activities more meaningfully. AAC also improves the child's ability to understand others, and to follow instructions and routines. It does not inhibit the development of speech.

Multimodal communication

- Multimodal communication (MMC) is a mode of communication that simultaneously engages in the use of several communication modes such as speech, signs and gestures, pictures, symbols and speech generating devices. MMC facilitates functional communication development and the understanding of words, instructions and events.

Communication partner training

- Communication partner training (CPT) is a component of AAC intervention where people the child sees often are taught strategies to support and model AAC use. Typically this means, parents, siblings and teachers
- CPT involves training the communication partners to support the child in a range of ways – by using AAC themselves, by helping them use the AAC system and by creating an environment where AAC is used freely.

How much is needed?

The amount of intervention needed will depend on the goals and type of intervention. We don't have enough evidence to be sure how much therapy is enough to achieve communication goals. In line with research on motor disorders, we recommend 14 hours as a minimum per goal. This is in addition to the time spent trialling speech generating devices or other AAC systems.



Outcomes from intervention for communication

Expressive language therapy results in the child being able to use longer sentences, more accurate grammar and a larger vocabulary in verbal speech and/or with AAC. Receptive language therapy results in the child being able to better understand instructions and more complex concepts, which may impact positively on the child's ability to follow rules and routines.

AAC promotes speech and language development. AAC allows the child to take part in conversation and activities more meaningfully. AAC also improves the child's ability to understand others, and to follow instructions and routines.

Coaching parents or carers to be communication partners promotes the child's communication skills by learning to recognise when and how the child communicates and how to respond to these consistently and appropriately. Communication partner training supports the child's successful use of AAC and ensures the device will be used rather than abandoned.

While problems with communication are common, there are many ways to support the development of a child's ability to communicate.

They include expressive and receptive language therapy, speech therapy and assistive technologies.

Communication partner training can also be helpful.



Self-care skills

All children with cerebral palsy will have some level of difficulty managing their daily self-care activities. Self-care skills include independence with sleeping, toileting, bathing, moving between positions, dressing, eating and drinking. Understanding a child's MACS and GMFCS levels (see appendix) will help focus goal setting and skill development for success with daily self-care activities.

Some children with cerebral palsy have difficulties settling and getting to sleep, or wake in the night or have breathing problems. Some are sleepy or overly energetic during the day because they are over-tired.

What will help?

In addition to GDT and CO-OP (described above), the following specific interventions have also been shown to improve goal achievement with self-care skills. Sometimes intervention focuses on the child's independence and sometimes on improving safety and efficiency for parents and carers who may be supporting these activities.

Assistive technology for self-care skills

- Assistive technology includes equipment that can help children to be more independent. This can include a range of devices for bathing, showering and changing, and a wet bed alarm.

Assistive technology for changing positions

- Some children need equipment for moving between positions, such as for bathing and toileting. This equipment could include a hoist and sling, a transfer board, a lift and home modifications.





Outcomes from interventions for self-care skills

The ability to carry out self-care activities independently is influenced by gross and fine motor function, swallowing function, vision and cognition. Classification systems such as mini-MACS, MACS and GMFCS (see appendix) are useful for understanding a child's potential to learn these skills.

Improvements in the ability to self-care can mean less parental or carer assistance is needed. Children can maintain the gains made by using the new skills in everyday life. Extra practice will be needed, however, to improve on the goals or achieve new goals.

Some research supports the use of wheelchairs and some sleep equipment to improve independence and mobility, improve sleep position and reduce the load on caregivers. The use of pressure care mattresses and cushions reduces the likelihood of pressure sores.

Task-specific, motor training-based early interventions are the gold standard for children with cerebral palsy, because they induce neuroplasticity and produce functional gains.

Sleep issues are common. If left untreated, they can have a significant impact on the child and their family.

Health professionals should work closely with children and their families to identify the most appropriate option to help with sleep difficulties.

Sleep interventions

- It is relatively common for children with cerebral palsy to have sleep difficulties. The most common sleep problems for children with cerebral palsy include difficulties settling and getting to sleep, waking up during the night, breathing problems, and being sleepy or overly energetic during the day because they are over-tired
- Sleep routines and behaviour interventions are the first line of treatment for children with cerebral palsy. This includes establishing consistent sleep routines
- A therapist might recommend a referral to a specialised sleep clinic or service
- Medical interventions for sleep include melatonin to reduce the time taken to fall asleep, analgesics to help manage pain and breathing equipment for obstructive sleep apnoea
- Selecting the right sleep intervention should be considered as part of a multidisciplinary approach including both therapy and medical teams. Further research is needed to understand the effectiveness of sleep interventions for children with cerebral palsy.

Assistive technology for sleep

- Various equipment options are available to support sleep. Specific equipment can be trialled and prescribed based upon each child's individual needs. The types of available equipment include height adjustable beds, body position supports, a pressure relieving mattress, night CPAP mask, bed pole and grasp bar. More research is needed to understand whether sleep systems improve sleep quality.

How much is needed?

The amount of intervention needed to support independence with self-care outcomes will depend on the goals and type of intervention. We don't have enough evidence to be sure how much therapy is enough to achieve self-care goals. In line with research on motor disorders, we recommend 14 hours as a minimum per goal.



Learning

Some children with cerebral palsy may experience difficulties with learning and thinking. There can be difficulties with controlling or maintaining their attention, with memory, with behaviours, with planning, or with being able to think of solutions to problems.

Other conditions associated with cerebral palsy, such as epilepsy, pain and poor sleep, can also affect a child's learning and thinking.

Early intervention might help the development of young children at high risk of learning difficulties.

What will help?

A cognitive/neuropsychological assessment for any child with suspected learning difficulties will help to identify specific strengths and weaknesses, provide an understanding of their abilities relative to their peers, and provide an overall idea of intellectual abilities.

From this, interventions and strategies may be found that use the child's strengths to compensate for areas of difficulty. These strategies can often also be transferred to the classroom.

Keeping on top of issues like pain, poor sleep and epilepsy will help children best meet their learning potential.

Interactive reading and literacy programs

- An interactive reading program involves supporting parents or carers to select and access children's books and reading materials appropriate for their child, and guiding them in reading with their child
- Interactive reading is not just about learning to read. It also helps with attention, memory, pointing, thinking skills and language skills, as well as promoting a rich parent-child relationship. Groups such as 'Reach Out and Read' and 'Let's Read' provide good tips for how to engage children in reading. For a tip sheet specifically designed for children with cerebral palsy, see www.readingrockets.org/article/reading-together-tips-parents-children-cerebral-palsy
- A number of early literacy programs are available – one example is MultiLit. This is an evidence-based literacy program which focuses on phonological awareness and oral language development for pre-school and school-aged children. It can be undertaken one-on-one or in the classroom. While research shows that these are effective literacy programs, there is little research specifically around children with cerebral palsy, so it would be best to speak to the program administrators about the best format for your child.

Cognitive play

- Cognitive play supports parents to support their child to develop their play skills
- It may involve providing toys and enriched learning experiences that match the child's ability level, creating play spaces and environments, providing equipment, using prompts and expanding play sequences.

Getting ready for school

- Children who have not been in formal day care or pre-school can benefit from transition to school or school readiness programs
- They help children with skills like sitting and listening in a group.

Compensation strategies

- General compensation strategies can help maximise a child's learning potential
- They include things like reducing background noise while a child is trying to concentrate, breaking complex questions or sentences down so that there is only one thought or one step per request, providing visual and verbal prompts when necessary, and seating a child near the front of a classroom.



Outcomes from interventions for learning

Approaches should focus on helping the child to overcome or adapt to relative weaknesses by using their strengths.

Preparing a child with the skills needed to start formal education (e.g. sitting, listening, maintaining attention and comprehension etc) will support their transition to school.

In particular, giving the child additional support in the area of literacy, so that they can read and write, and encouraging the development of skills such as problem-solving and planning through structured play, are important.

Assistive technology-based programs can help enhance the academic performance of children with cerebral palsy. Their inclusion in daily settings itself provides a favourable outcome.

Medication

- At times, medication can help children with diagnosed attentional difficulties such as attention deficit disorder. Medications need to be carefully discussed and managed by the child's treating doctor (usually a paediatrician).

Assistive technology for learning

- Software and e-books are available to help with reading and numeracy skills. These usually have a range of access options such as switch, keyboard and trackball. Literacy interventions tailored for children with cerebral palsy using communication devices can be effective in improving cognition.

How much is needed?

The amount of intervention needed to support pre-schoolers with their learning will depend on the type of learning difficulties the child has, the learning goals and the types of educational or compensatory intervention.

As yet, there is not enough evidence to be sure how much therapy is enough to achieve learning goals.

For children to maximise their potential in these areas daily exposure to books, reading and literacy activities is recommended.

Children with cerebral palsy may experience difficulties with specific areas of their thinking and problem-solving skills. Issues can include difficulties controlling or maintaining their attention, holding things in mind momentarily, being able to control inappropriate behaviours, or difficulties in planning, organising or thinking of solutions to problems.

Supports are available for assessing, assisting and making adaptations for a child's needs, both at school and at home.



Behaviour

Some children with cerebral palsy experience difficulties at times with their behaviour or emotional wellbeing.

What will help?

There are a number of options.

Behaviour therapy

- Positive behaviour support, behavioural interventions and positive parenting are approaches that involve carers changing their interaction style with the child, so as to promote positive relationships and behaviours in the child.

Play therapy

- Play therapy is a powerful means of joining with the innate, creative, non-verbal capacities of children in order to engage and work therapeutically with them. It is a developmentally appropriate, evidence-based method of counselling younger children.

Parenting programs

- Stepping Stones Triple P is a parenting program for parents of children with disability aged 2 to 12. The Stepping Stones program is based on the Standard Triple P program and provides families with the necessary skills and strategies to address parenting concerns. It can reduce children's problem behaviour and emotional problems, and can improve parents' confidence, wellbeing and relationship with each other
- The Mindful Parenting Program supports parents and carers to be present at the given moment. This presence can take many forms: paying attention to the child, awareness of own feelings when in conflict with the child, pausing before responding, and listening to the child's viewpoints, even if they differ from a parent's. Mindful parenting promotes secure attachments and emotional wellbeing in children, parents and carers.

Social stories

- Social stories are individualised, visually displayed stories that are developed to help a child prepare for and understand social situations. Social stories have been shown to improve behavioural outcomes and social relationships and skills.

Assistive technology for behaviour

- Educational software addressing safety skills and social skills, such as 'Coping with Chaos', are commercially available for children with behavioural difficulties and/or learning difficulties.



Outcomes from interventions for behaviour

Maintaining the wellbeing of the family unit can help families stay together. Building resilience and skills in children and parents to cope with daily stressors and adapt to developmental transitions can lead to improved quality of life for the child and parents.

Maintaining the wellbeing
of the family unit can help
families stay together.

Parenting programs can reduce children's problem behaviours and emotional problems, and can improve parent confidence, wellbeing and relationships with each other.

How much is needed?

The amount of intervention needed to support pre-schoolers with their behaviour will depend on the nature of the behaviour of concern, the goals and types of intervention used.

Both behaviour therapy and parenting programs typically involve at least 6 to 12 sessions with a therapist, the child and the parents and/or carers.



Social skills and friendships

There are ways to help children better understand social situations and acquire skills that will help their relationships with their family and friends. These approaches always include parent/carer training and coaching to support the child's use of new strategies.

A therapist will first conduct an assessment, which includes observing a child across a range of settings. After this assessment, they will then recommend a therapy program that will help the child develop and practice these strategies. They will also support and encourage the use of these skills in family and community settings



What will help?

Social stories

- Social stories are individualised, visually displayed stories that are developed to help a child prepare for social situations. Social stories have been shown to improve behavioural outcomes and social relationships and skills.

Group-based early learning programs

- Early education groups and pre-schools help children, especially those who have not previously been to day care, develop social skills such as turn-taking and sharing.

Planned social activities

- Weekly library rhyme or singalong groups where other children are present give the child the opportunity to interact with children and watch other children interact together. This supports social skill development.

Assistive technology for social skills and friendships

- Educational software addressing safety skills and social skills, such as 'Coping with Chaos', are commercially available for children with behavioural difficulties and/or learning difficulties.



Outcomes from interventions for social skills and friendships

Social stories have been shown to improve behavioural outcomes and social skills

Pre-schoolers are encouraged to have regular, weekly contact with other children to support their social development.

Supporting the development of social skills involves understanding the developmental level of the child and their current patterns of social interactions.

A program can then be developed to teach the child to better understand social situations and acquire new skills.

How much is needed?

The amount of intervention needed to support pre-schoolers with their social skills will depend on the goals and types of intervention used. Pre-schoolers are encouraged to have regular, weekly contact with other children to support their social development.



Support for parents and carers

Caring for children with cerebral palsy comes with extra responsibilities. Parents of children with cerebral palsy report feeling higher levels of stress, anxiety and depression than parents who do not have a child with a long-term health condition. Parental stress is often highest among those whose children have a communication or intellectual disability, or who experience pain.

What will help?

We recommend customised emotional and social support for parents. Recommended interventions can include the following:

- Stepping Stones Triple P Parenting program (SSTP) can increase parents' confidence, wellbeing and relationship with each other
- Acceptance and Commitment therapy (ACT) is a cognitive behavioural therapy program that incorporates mindfulness, experiential acceptance and engagement in deliberate actions to improve psychological flexibility. Parenting ACT (PACT) aims to boost parents' ability to use parenting strategies in complex situations
- SSTP + ACT combined is more effective in reducing parental psychological symptoms than SSTP alone
- Solution-focused brief therapy is future-focused, goal-directed and focuses on realistic solutions. This is a flexible intervention offered across multiple contexts
- Respite provides families with a short break from the extra responsibilities associated with caring for a person with cerebral palsy
- Assistive technology lightens caregiver assistance needed in the areas of mobility, self-care and to a lesser extent social function. Receiving information and training from early intervention providers and information from other sources such as libraries, workshops and other parents will provide parents feeling more confident and competent using the assistive technology.

How much support is needed?

Parents should be offered counselling at various important family transition times, such as when a child is starting school. Most parents will benefit from the opportunity to discuss their concerns, fears, emotions and the impact of having a child with cerebral palsy on the whole family. Others will benefit from the opportunity to connect with other parents in similar circumstances through mutual support groups or online forums.

A proportion of parents may need referral for psychological interventions for depression or anxiety conditions. All families need to be provided with information about how to access services and supports for their child.

There is insufficient evidence to recommend specifically how much support is needed, as family situations vary considerably.



Outcomes from parent support

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

Classification systems

Researchers and therapists use a number of classification systems to help understand the ways in which children with cerebral palsy are affected, and what may help. You may hear these terms used.

Gross Motor Function Classification System

The Gross Motor Function Classification System (GMFCS) is a scale used to broadly classify the severity of mobility in children with cerebral palsy. The GMFCS level is helpful to guide the focus of gross motor skill training for children. The child who is:

- **GMFCS Level I:** Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited. (Children who are GMFCS 1 walk by 2 years.)
- **GMFCS Level II:** 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 used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping. (These children might transition from a walking device to independent walking, or start to walk between 3 and 6 years.)
- **GMFCS Level III:** 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. (Children at this level may transition to new mobility devices and become more competent and independent with their device in a range of environments between 3-6 years.)
- **GMFCS Level IV:** Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility. (Children at this GMFCS level may become independent in powered mobility and be using a walking device to improve participation and maintain strength and fitness.)
- **GMFCS Level V:** Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. (Children at GMFCS V are prescribed wheelchairs specifically modified for their needs in all environments.)

Manual Ability Classification Scale

The Manual Ability Classification Scale (MACS) and mini-MACS level is helpful to guide the focus of goals relating to hand function training for children. The child who is:

- **MACS I** handles objects easily and successfully
- **MACS II** handles most objects, but with some reduced quality and/or speed
- **MACS III** handles objects with difficulty, and needs help to prepare and/or modify activities
- **MACS IV** handles a limited selection of easily managed objects and always requires help from others
- **MACS V** isn't able to handle objects and isn't able to complete simple actions with hands.

Eating and Drinking Classification Scale

The Eating and Drinking Classification Scale (EDACS) describes the functional eating and drinking skills of children with cerebral palsy. This scale is helpful to guide the focus of goals relating to swallowing, eating and drinking. The child who is:

- **EDACS I** eats and drinks safely and efficiently
- **EDACS II** eats and drinks safely but with some limitations to efficiency
- **EDACS III** eats and drinks with some limitations to safety; maybe limitations to efficiency
- **EDACS IV** eats and drinks with significant limitations to safety
- **EDACS V** is unable to eat or drink safely – tube feeding may be considered to provide nutrition.

Communication Function Classification System

The Communication Function Classification System (CFCS) broadly describes the different communication levels for people with cerebral palsy. It takes into consideration all modes of communication, not just verbal speech. This system is helpful to guide the focus of goals relating to communication. The child who is:

- **CFCS level I** independently and effectively alternates between being a sender and receiver of information with most people in most environments
- **CFCS level II** independently alternates between being a sender and receiver with most people in most environments, but the conversation may be slower
- **CFCS level III** usually communicates effectively with familiar communication partners, but not unfamiliar partners, in most environments
- **CFCS level IV** is not always consistent at communicating with familiar communication partners
- **CFCS level V** is seldom able to communicate effectively, even with familiar people.

Viking Speech Scale

The Viking Speech Scale helps to classify the speech performance in children with cerebral palsy aged over 4. The child who is:

- **Viking level I** has speech that is not affected by motor disorder
- **Viking level II** has speech that is imprecise, but is usually understandable to unfamiliar listeners
- **Viking level III** has speech that is unclear and not usually understandable to unfamiliar listeners out of context
- **Viking level IV** has no understandable speech.

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Notes

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