

Therapy and support for school-age children

A guide for parents
of children aged 7-12
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.

Who is Cerebral Palsy Alliance (CPA)?

Cerebral Palsy Alliance (CPA) is a leading provider of evidence-based therapy, life skills programs and services for people living with cerebral palsy and other similar disabilities. 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 you, as parents of children aged 7–12, to understand therapy and support approaches that are available to help your child achieve their goals. These approaches are supported by research evidence, underpinned by neuroscience, and can be individualised and tailored to the needs of your child and family.

Throughout this guide, we refer to six words that are important to consider when planning your child's services. The six words can be used to start a conversation with your service providers. These words are:

- **Fun:** activities that your child enjoys
- **Function:** the activities and tasks that your child does
- **Family:** ways to involve your family, as they know your child best
- **Friends:** friendships and the opportunity to develop social skills
- **Fitness:** staying physically active and healthy by participating in exercise and other recreational activities
- **Future:** yours and your child's dreams for the future.

This guide provides general information only. It is not intended to replace specific advice offered by your doctors or other health professionals. Please consult with your doctor or health team for advice personalised for you and your circumstances.

Contents

Highlights	2
Best practice therapy approaches	5
How therapy works	7
Fun	8
Function	10
Family	32
Friends	34
Fitness	36
Future	38
Classification systems	39
What does that word mean?	40
References	41

Highlights



Fun

Children participate more in life if they enjoy what they are doing. In turn, participating more helps their physical and emotional development.



Function

Under this heading, there are many areas that may be relevant to your child. Many of them involve development of motor skills. Motor interventions that are goal-directed, task-specific, motivating and enjoyable are the gold standard because they can help your child's brain and nervous system change and adapt. They also can produce improvements in how your child's body functions.



Walking and gross motor skills

- There is good evidence about what works and what doesn't work for improving function and performance of motor-based tasks
- Intervention is more effective when a child and family has a goal to work towards (goal directed) than general training approaches
- At least 14 hours of intervention is needed per goal. For example, if a child has three identified gross motor goals, then at least 42 hours of goal-directed motor training intervention will be needed.



Hand function and fine motor skills

- Assessment of your child's hand skills is recommended before and after commencing upper limb interventions
- Your child needs 14–25 hours of practice, including therapy such as goal-directed training, to reach hand function and fine motor skills goals
- If your child has unilateral cerebral palsy, they need 30–40 hours of practice and therapy, through bimanual therapy or CIMT, to improve their general upper limb function.



Hips and musculoskeletal development

- Your child should have a CP Check-Up™ appointment each year.



Muscle tone and spasticity

- Botulinum toxin combined with other interventions can improve function and reduce spasticity.



Swallowing, eating and drinking

- Children with swallowing problems need regular and ongoing monitoring to ensure they stay healthy and grow.



Communication

- Learning to communicate with others is vital to any child's development
- Communication interventions work best in real-life situations
- Communication partner training and involvement contributes to the success of communication interventions.



Learning and school

- Planning for your child's physical access to school, access to the school curriculum and transition to high school are an important focus for the 7–12 age group.



Self-care

- Children who are able to wash, feed and toilet themselves as independently as possible, feel more confident and in control of choices in their lives
- Children with any type of cerebral palsy can work towards self-care goals when a task-specific training approach is used, along with appropriate equipment.



Pain

- Reducing pain is a good thing on its own, but it can also reduce sleep problems, time away from school, anxiety and low mood.



Behaviour and mental health

- Providing support for any behavioural, emotional or mental health challenges that your child faces can provide them with the opportunity to feel better. Children who feel good within and about themselves are more able to participate in life, have fulfilling relationships, and manage the challenges and frustrations that come with life.



Family

Parent and family health and wellbeing is important. Parents can participate in specific programs to support emotional wellbeing and help promote children's positive behaviour. This in turn can improve parents' confidence, wellbeing, and relationships with each other.



Friends

An individually tailored program can be developed to teach your child to better understand social situations. This can help them gain skills that will help their relationships with family and friends.



Fitness

- Physical activity is essential for your child's health
- Children who use wheelchairs can also participate in physical activity safely
- Specific training, rather than a generalised approach, is important to improve outcomes for physical activity.



Future

- A successful transition from primary school to high school is important for all children, particularly those with disabilities.
- Teachers, education support personnel, career advisers, student support groups, and specialist transition planners in your local community can all provide advice and assistance.



Best practice therapy approaches

Motor-training-based interventions that are goal-directed, task-specific, motivating and enjoyable are the gold standard approach. They can help your child's brain and nervous system change and adapt. They can also improve how your child's body functions; in ways that matter.

These approaches are also called child-active approaches. 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. Task-specific practice is also useful for the development of other skills such as thinking and language.

Traditional approaches are different to child-active approaches in that they rely on specific techniques where the child is often a passive recipient. But evidence shows us that these traditional approaches don't help children learn new skills as well as child-active approaches do.



Child-active therapy approaches should:

- Be goal-based
- Involve practice of the actual task your child wants to learn
- Involve large amounts of repetition
- Take place in real-life environments, as much as possible.

Practice can be organised over a short intensive period or it can be spread over a number of weeks or months. The type of practice will vary according to the goals and preferences identified by you and your child.

Three approaches to aid skill development for children with cerebral palsy are:

- Goal-directed therapy (GDT)
- Cognitive Orientation to Occupational Performance (CO-OP)
- Home programs.

These approaches are used by physiotherapists, occupational therapists and speech pathologists to support progress towards lots of different goals that can be individually tailored to your child.

Goal-directed therapy (GDT)

GDT involves you, your child, and your family setting goals together to support participation in everyday life. Your child then practises specific activities to reach these goals.

The goals might need to be broken down into parts or modified to make them achievable. The specific tasks should be practised in real life as much as possible. For example, practising climbing stairs that are in your child's home or community is more beneficial than practising climbing stairs in a therapy room. As your child's skill levels improve, the task can be made harder to maintain a level of challenge. The task/s and the environment should be varied to help your child consolidate their skills.

GDT should be offered to all children who have motor goals. The goal and expected performance need to be at just the right level of challenge: not too easy and not too hard. GDT can be carried out in individual or group sessions, as well as in intensive camps. But, regardless of how GDT is conducted, all children should have individually identified goals and activities that are fun and motivating for them to work towards.

Depending on the specific goals chosen, weekly physiotherapy and/or occupational therapy is recommended. For goals involving arms and hands, between 14 and 25 hours is needed to achieve a goal using GDT.

How quickly a child can learn a new task or movement skill using GDT depends on many different factors. These include age, type of cerebral palsy, understanding of the task or skill, level of motivation and opportunities to practice the task or skill. Children who are able to set their own meaningful goals are more likely to be motivated to practice and achieve gains.

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

Cognitive orientation to occupational performance (CO-OP)

CO-OP is a goal-oriented intervention that helps your child develop new ways to think about and perform skills they want to learn or improve. The aim is for your child to improve their motor and/or self-care skills, as well as improve their ability to plan and problem solve 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 problem-solving strategy called GOAL, PLAN, DO, CHECK, which is used to help their motor learning. CO-OP is suitable for children aged five or older, who can set their own goals, and who have the thinking and verbal skills to identify possible ways to achieve goals. Therapists need specialised training to use this approach.

You can talk to your therapist/s to find out if this approach is appropriate for your child.

Home programs

In addition to any therapy that your child receives either in person or via telepractice, it is important that they also have access to a customised home program for you to carry out with them at home. This program should be written down, and preferably have photographs to make sure it is clear. This will support your child to continue to practice skills at home and progress towards their goals. The program should be adjusted regularly as your child's skills develop and include fun, motivating and task-specific practise opportunities.



How therapy works

Your child will continue to learn, grow and develop new skills throughout their life.

A typical process includes:

- **Assessment** of your child's current skills and **goal setting** of your child's wants and needs.
- **Therapy sessions** to practice the skills needed to meet the goals, with support for practice to occur at home. The frequency of your therapy sessions can be worked out on an individual basis with support from your therapist.
- **Review** of goals and **re-assessment** of your child's wants and needs, and start the process again.

How much and how often?

Therapy that focuses on practice of specific, functional goals needs 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.

For children with cerebral palsy, the school years are an important time for ongoing development, consolidation and refinement of skills, and sourcing adaptive supports where needed. Customised intervention programs based on their goals should be available for every child.

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.

FUN



Children participate more in life if they enjoy what they are doing. In turn, more participation helps their physical and emotional development.

Leisure activities and hobbies are great ways to encourage your child to have fun. Some leisure activities may help your child progress towards their therapy goals too. It is important to encourage your child to choose their own leisure activities, based on what they enjoy doing. This will help them to stay engaged and involved in activities.

Participating in sports and active hobbies are great ways to get fit, have fun, make friends, and learn new skills. Playing team sport encourages cooperation and sharing, resilience, goal setting and relationship building.

Disability Sports Australia is the national body that represents people with a disability. Sports can be adapted to allow children with a disability to participate to the best of their ability.

Reducing environmental barriers, which can include negative or non-supportive attitudes, can help your child participate more in life.





What will help?

Your child is most likely to participate if:

- They can set or contribute to their own goals
- Their goals emphasise involvement and joining in, rather than 'getting a task right' (task achievement)
- Your child chooses their own leisure activities based on what they enjoy, rather than just for therapy outcomes
- You and your child plan activities that capture their motivation. For example, there are some great 'Exergames' available. These are games played with a therapy or educational purpose
- Your child practices the leisure activity in real-life environments
- You and your child work together with a therapist to identify attitudes and environmental barriers that limit participation
- You, your child and a therapist focus together on problem solving and reducing those barriers.



Outcomes

Making tasks and activities fun makes it more likely that your child will want to take part and give it their best. This will increase their enjoyment and participation in life, and improve the chances of them reaching their goals.



Walking and gross motor skills

Many children with cerebral palsy will walk without any assistance. However, children with more severe cerebral palsy will reach their maximum gross motor skill potential at a younger age. For these children, accessing assistive technology as early as possible is essential.



What will help?

Goal directed training and home programs, as described earlier, can support your child to achieve their gross motor goals. In addition, gait training, treadmill training, hydrotherapy, ankle foot orthoses, taping, and assistive technology can all assist development of walking and gross motor skills. We will explore each one of these therapy interventions in more detail.

Gait training

Gait training is specific practice of walking, in a range of different contexts. The aim is to improve either the quality of your child's walking pattern or their endurance (how far and for how long they can walk).

Gait training has been shown to improve walking speed, but is less effective in improving other gross motor skills. Gait training should be implemented using a GDT approach.

Robotic-assisted gait training is where a child uses a robotic-like suit (called an exoskeleton) linked to a computer to receive specific guidance on their walking movements. This approach can improve the ability to walk through repetitive training. It can also support standing and gait.

Treadmill training

Treadmill training offers a way for a person with cerebral palsy to practice walking, potentially improve their walking pattern, and other aspect of their health. Treadmill training can improve speed of walking, walking endurance and gross motor function. If a regular treadmill can't be used, you can add a harness that partially supports your child's weight.

Treadmill training is most effective when your child is actively walking. This means they are the one putting in the walking effort. Robotic devices that passively move your child's legs, make it less effective.

Children using a treadmill should always have overground walking training at the same time, so gains in walking skills can be transferred to real-life situations. Therefore, treadmill training is an intervention often used together with gait training and goal directed training.

Hydrotherapy

Hydrotherapy is an activity or exercise that is performed in warm water. Specialist hydrotherapy pools are heated to 32–34 degrees Celsius, as warm water can help increase a person's circulation, reduce their muscle spasms and relieve pain. For some children, hydrotherapy can be a useful addition to their GDT program. For others, it can provide a freedom of movement not easily achieved elsewhere.

Ankle foot orthoses

Ankle foot orthoses (AFOs) are plastic splints commonly used to improve the position of the foot for standing and walking. If your child uses an AFO, there should also be an appropriate GDT program. This is something that can be discussed and decided upon in collaboration with your therapist.

AFOs can make small improvements to walking and gross motor abilities. It is not yet clear from the research evidence whether regularly wearing an AFO can prevent the development of a contracture (where the muscles are shorter and tighter than usual).

If you are thinking about whether or not to use an AFO consider the cost, the chance of pain and skin irritation, the look of them, as well as the potential for short-term and long-term improvement.

Taping

Taping aims to stabilise joints and assist postures. It should only be used when combined with task-specific motor training. Talk to your child's therapist to see if it is appropriate.

Assistive technology for walking and mobility

Some children need specialised equipment to help with walking. Options include walking frames, crutches, walking sticks and smart walkers. Children often use different equipment for different activities, such as crutches inside and a wheelchair for longer distances.

Some children need equipment for a short period as their independent walking develops. Other children will continue to use their equipment for life. Specialised walking equipment is not just for children who can walk by themselves. Children who don't walk independently can also benefit from using a supportive walker for fun, fitness and socialisation.

Stem cell therapy

Stem cell therapy may reduce symptoms of CP by directly targeting the underlying brain injury. Some research has shown small but significant changes in motor function for children with cerebral palsy. While there are no approved stem cell treatments for children with cerebral palsy available in Australia, clinical research trials are currently underway. Ask your therapist about staying informed about stem cell therapy research updates for your child.



Outcomes

Gait training can improve your child's walking speed. Treadmill training can improve your child's walking speed, walking endurance and gross motor function. AFOs can make small improvements to your child's walking and gross motor abilities. Assistive equipment can improve your child's mobility. Talk to your child's therapist and decide together what intervention is appropriate for your child.



Hand function and fine motor skills

Many children with cerebral palsy have difficulty using their hands. At this age, goals relating to hand function are often related to independence at home and participation at school. An assessment of your child's needs at home and school can help guide the specific interventions that may be needed.

What will help?

As previously discussed, Goal Directed Training (GDT) is a recommended intervention for developing hand skills. Children with unilateral cerebral palsy need 30 to 40 hours of goal directed practice in order to achieve meaningful outcomes.

Children with other types of cerebral palsy require 14 to 25 hours of goal-directed interventions to achieve changes in their individualised hand function goals.

In addition to GDT, CO-OP, and home programs, the following interventions can improve hand function and fine motor skills:

Constraint-induced movement therapy

Constraint-Induced Movement Therapy (CIMT) is useful for children with unilateral cerebral palsy (one side of the body affected). The approach involves restraining the unaffected hand with a mitt, a sling or a cast. At the same time, the child practices carefully chosen activities using their more affected hand, at high intensity. The aim of the intervention is to improve the control and coordination of the more affected hand.

Bimanual therapy

Bimanual therapy is another approach for children with unilateral cerebral palsy. It involves the use of specific instructions and prompts to teach your child to use two hands together. High intensity bimanual therapy with a home program is recommended.

Hand/arm orthoses/splints

Orthoses or splints for the hand and arm are used to help position the hand, arm and fingers. There are two different types of splints: functional hand splints which are worn during activities; and night-time splints which are worn at night to provide a stretch to the muscles over an extended period of time. Splints should be used in combination with other therapy interventions such as goal-directed training.

It is not clear from the research evidence whether wearing hand splints can prevent a contracture (where the muscles are shorter and tighter than usual) from developing. Many children find hand splints uncomfortable to wear, so it is important to consider the potential advantages against the needs and preferences of your child.

You can ask your therapist if a splint may be suitable for your child to help them to achieve their goals.



Taping

Taping is a technique that aims to prevent muscle contraction, stabilise joints and change postures in the hand and thumb.

If your child has tightness or weakness in their hand, taping might be useful. Children can find taping uncomfortable. It might not be suitable if your child has a skin allergy. Talk to your child's therapist. If used, it should be combined with task-specific motor training.

Assistive technology for hand function

For children with cerebral palsy who find it difficult to use their hands, there are alternative ways to use toys, computers and other equipment. These include specialised keyboards, switches, joysticks, or eye-gaze technology. To help position the assistive technology in the right place, mounting arms and systems are available. The goal of these assistive technologies is to help children access equipment and their environment as independently as possible.

Using assistive technology to support mobility, learning, play and communication can help improve your child's participation at school across a range of activities and curriculum areas.

Adaptive seating system

An adaptive seating system is an important assistive device for children with cerebral palsy who need assistance to sit. This type of system encourages sitting skills while the child is participating in other activities. They also allow caregivers to support children more easily and effectively, and allow the child to concentrate on their academic work at school.



Outcomes

If your child has unilateral cerebral palsy, GDT, CIMT and bimanual therapy all provide similar outcomes. Bimanual therapy and CIMT both need 30–40 hours to be effective.

If your child has both hands affected, GDT and bimanual therapy can help them achieve their goals, help their self-care skills, and help the quality of arm and hand movement.

If your child requires assistance to use their hands, technology and computers can help to support their access to the school curriculum, communication, learning and play.

For some children, splints are helpful if used together with task-specific motor training.



Hips and musculoskeletal development

Some children with cerebral palsy may develop hip displacement. This is where the hip bone doesn't sit properly in the hip socket. Many children with cerebral palsy also have tightening and/or contractures of their muscles. Hip displacement and contracture can cause pain and loss of function.



What will help?

Different interventions will work at different times for different people. Frequent monitoring and early use of evidence-based treatments is essential to prevent more severe problems from developing. An active monitoring approach (hip surveillance), is an intervention that is appropriate across your child's whole life. Hip surveillance, through CP check-up appointments and hip x-rays, is recommended to help monitor your child's hip development.

Regular check-ups

Your child needs a check-up of their musculoskeletal system each year. Programs such as CPUP in Sweden and CPA's *CP Check-Up*™ are best practice. CPA's *CP Check-Up*™ program is based on the Swedish program, but it goes beyond the musculoskeletal system to also include areas such as cognition and learning, eating, drinking, communication and family wellbeing.

Serial casting

Serial casting involves putting a plaster and/or synthetic cast on your child's arm or leg for a short time, then replacing it with another. This is repeated several times, and helps to gradually stretch tight muscles and increase your child's range of movement.

If your child has serial casting, it can be used alongside botulinum toxin injections to minimise discomfort and maximise functional outcomes.

To help your child make the most of their gains following serial casting, active strength training combined with goal-directed training is recommended.

How frequently?

Your child should have a *CP Check-Up*™ appointment each year.

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



Outcomes

Active surveillance is important to monitor pain and help prevent severe contractures, hip dislocation, and scoliosis.

Serial casting can increase the range of movement of a muscle and can improve a child's function for a short time after the casts are applied. Serial casting 4 weeks after botulinum toxin improves the length of the muscle more than serial casting alone. Talking with your therapist will help you work out whether this is the right intervention for your child and when is the best time to consider it



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 are movements that they do not have control over. 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. They can contribute to the development of muscle contractures and bone problems. For many children they may also 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. Less is known about treating chorea and athetosis.

A multidisciplinary team will assess your child and select the most appropriate treatment approach for their needs. This team may include a rehabilitation physician, orthopaedic surgeon, neurologist, neurosurgeon, physiotherapist and occupational therapist.

Botulinum toxin

Botulinum toxin is given by injection into a muscle or muscles, *temporarily* reducing spasticity. The goal is that during the period when the botulinum toxin is effective, your child will experience more relaxed muscles, improvements in function, and reduction in pain. The effects last for about 4 months, so it is common for young children to have a series of botulinum toxin injections.

Selective dorsal rhizotomy

Selective dorsal rhizotomy is a surgical procedure where sensory nerves in the spinal cord are cut, *permanently* reducing lower limb spasticity and improving walking.

Some children with spastic diplegic cerebral palsy might benefit from this procedure. However, rehabilitation after selective dorsal rhizotomy is long and intensive. It is important to discuss with your child's therapists and medical team if this intervention is suitable.

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. A surgical procedure is needed to insert the pump and catheter.

The benefit of baclofen delivered in this way is that it can be given often and in small doses.

Intrathecal baclofen might help children who have spasticity or dystonia that affects most of their body. It can make a difference for comfort and ease of personal care.

Oral medications

Oral medications are those that are ingested. They require swallowing. There are many different types of oral medications used to achieve different outcomes.

Diazepam is a medication shown to be effective for the short-term treatment of spasticity. Oral baclofen reduces spasticity and dystonia. Other medications such as benzodiazepines, clonidine and gabapentin are used to manage the movements associated with dyskinesia.

It is always important to discuss the potential benefits and possible side effects of all oral medications with your child's doctor.

Deep brain stimulation

Deep brain stimulation is an established treatment for people with movement disorders. Electrodes are placed in areas of the brain and controlled via a pacemaker. These electrodes help regulate the messages that go to the muscles and help to control and manage movements. Deep brain stimulation is a surgical procedure that needs referral to a specialist team. It is useful for children with severe dystonia.



Outcomes

Muscle tone management can reduce spasticity and dystonia in children with cerebral palsy. Different options are available depending on type and severity of cerebral palsy, functional abilities and goals of the child.

Botulinum toxin combined with other interventions can improve function and reduce spasticity. This can help your child reach their goals.



Swallowing, eating and drinking

Children with cerebral palsy often experience difficulty swallowing – this is also called dysphagia. Swallowing problems are often under-recognised. Swallowing difficulties can:

- Cause food, drink or saliva to enter the airways which can lead to chest infections
- Contribute to poor growth, low body fat stores and poor nutritional status.

Many children experience other swallowing and nutrition related issues such as reflux and/or constipation. These conditions can result in discomfort, pain, feeding or behavioural issues.

A speech pathologist, dietitian and/or your child's doctor can advise you on safe, effective ways to help your child with nutrition, hydration, safe mealtimes and management of swallowing risks.



What will help?

Dysphagia management includes interventions designed to:

- Improve your child's drinking and chewing skills
- Help your child swallow safely
- Enable your child to enjoy their mealtimes with friends and family.

Mealtime interventions work best when they happen at the times and in the places that your child would normally eat and drink. A speech pathologist can help you and your child set and measure goals related to eating and drinking.

If your child is not gaining weight, is losing weight, has frequent chest infections, or experiences severe reflux, talk to your child's doctor. Specialist care might be needed.

Nutritional interventions

A multidisciplinary team, which includes your GP and a dietitian, can provide important dietary advice to you and your child.

Your child should have a blood test each year to check their vitamins, minerals, proteins and trace elements, especially if they have difficulty eating or swallowing.

Monitoring a child's growth over time is important. Reliable serial measurements of weight, height, skinfold thickness and body composition are recommended. The body mass index, or BMI, is a well-known measurement of weight and growth. But it is not considered reliable in children with cerebral palsy. Alternative measures do exist.

A thorough nutritional assessment is needed for children with cerebral palsy who have poor growth, low or high body fat stores, poor chewing skills, reflux or a gastrostomy button.

Non-surgical interventions

Modifying the texture of food and drinks

can reduce the risk of choking and inhaling food. A mealtime assessment conducted by a speech pathologist can explore appropriate foods, fluids, and assistance techniques to help your child swallow safely during their meals.

Positioning of the body and head during mealtimes is important for safe swallowing. A speech pathologist and occupational therapist or physiotherapist can work together with you and your child to achieve this. In some cases, an adaptive seating system can improve feeding skills and promote safe swallowing for children with cerebral palsy. Specialised cups and spoons can also help your child learn the skills needed to feed themselves.

Oral motor and sensorimotor exercises

can lead to small improvements in oral function and chewing skills in some children. About 60–90 hours of practice is needed over weeks and months, and it is best to do these exercises in task specific contexts, such as when your child is eating food.

Electrical stimulation combined with oral sensorimotor treatment (five sessions of 30 minutes per week for 4 weeks) can lead to improvement in feeding skills and a reduction in drooling. Research supporting this intervention is still new and you should discuss it with your doctor or speech pathologist.

Some **medications** can reduce the frequency and severity of drooling. Discuss options with your doctor, and be aware that the medications have side effects.

Early and regular routine **dental care** results in improved dental health.

If your child experiences constipation, **massage** has been shown to help.

Surgical interventions

If feeding problems are severe and long-lasting, surgery might be needed.

Gastrostomy is the surgical placement of a feeding tube through the wall of the abdomen. This can help your child maintain a healthy rate of growth. It has some risks – if you are considering it for your child, talk to doctors and others about it. Options include percutaneous endoscopic gastrostomy (a PEG tube) and jejunostomy.

If your child has severe reflux, **fundoplication** is a surgical procedure used to prevent acid from the stomach flowing backwards up the oesophagus (tube that connects the mouth and the stomach). It also has some risks – if you are considering it for your child, talk to doctors and others about it. Options include a Nissen fundoplication, laparoscopic fundoplication and gastric plication.



Outcomes

- Timely interventions to support feeding skills and safe swallowing will promote weight gain and prevent chest infections. They can also improve sleep and mealtime enjoyment, and reduce parental stress.
- Adaptive seating systems may improve your child's ability to develop independent feeding skills and participate in mealtimes.
- Gastrostomy can improve growth and nutrition for a child, and can improve quality of life for parents.
- Fundoplication can lead to reduced gastro-oesophageal reflux for some, but not all, children.



Communication

Learning to communicate with others is a vital part of any child's development.

What will help?

Speech pathologists provide detailed assessments that help you and your child identify communication goals such as developing speech skills, using alternative or augmentative methods of communication, or using a combination both.

Communication interventions work best in real-life situations where your child needs to communicate. For example, interacting with family at home or teachers and friends at schools. Communication partners are an important part of any intervention approach and benefit from specific training about how to use different communication techniques.

Expressive language therapy

Expressive language therapy focuses on language skills such as sentence structure, grammar and vocabulary. The aim is to help children use language to share accurate, effective messages with each other.

Language can be expressed verbally, in written forms, and through Alternative and Augmentative Communication (AAC) strategies. An approach that combines multiple methods of communication is referred to as multimodal communication. Children with cerebral palsy who have speech difficulties and delayed language development are typically encouraged to use multimodal communication to support their expressive communication.

Expressive language therapy works best when it is done in familiar daily situations, for example during bath time and mealtime routines, when sharing a book with your child, playing a game, or on an outing in the community.



Receptive language therapy

Receptive language therapy aims to improve your child's ability to understand what others say. It can include verbal, written, and augmentative and alternative communication strategies. Up to 96 hours of practice is needed over 6 months to gain a substantial improvement in receptive language skills. Those hours can include time spent with a speech pathologist as well as practising home program tasks at home and school.

Alternative and Augmentative Communication (AAC)

AAC is an intervention approach that promotes speech and language development. AAC strategies include communication books and boards with words and picture symbols, manual signing approaches such as Key Word Sign, and technology-based strategies like computers and speech-generating devices. AAC can be used by a child pointing using their hands, eyes or head movement, as well as using a mouse or a switch. Often children with CP will use more than one method of AAC alongside their speech skills.

Multimodal communication

Multimodal communication involves using several communication modes – speech, signs and gestures, pictures, symbols and speech-generating devices. Different communication modes may be used in different situations. For example, a child may like to use their key word signs and gestures at home with their family and use their speech-generating device at school and in the community. Having a range of communication modes, or options, gives your child control over their communication and promotes independence.

Aided language stimulation

Aided language stimulation is an intervention approach that involves modelling the use of AAC. The goal is to show a child how a communication system can be used and encourage its use across environments. For example, the communication partner may point to a picture symbol on the child's AAC system at the same time speaking the corresponding word. The child is encouraged to use their system in the same way and is provided with multiple opportunities to do so. Aided language stimulation can be used with any type of AAC system.

Motor speech or articulation therapy

To work on motor speech or articulation goals requires regular therapy with a speech pathologist. Research suggests 2-3 sessions a week for 6 weeks, along with daily practice via a home program is effective. Examples of specific motor speech approaches include Rapid Syllable Transition Treatment (ReST), the Nuffield Dyspraxia Program, intensive voice treatment (LSVT LOUD) and Dynamic Temporal Tactile Cuing (DTTC). You can talk to your speech pathologist about whether these programs may support the needs of your child.

Communication partner training

You, other carers, family members and/or teachers are vital partners in supporting your child's communication. As such, learning how to use specific strategies to support and promote your child's communication is of benefit. It is very important that communication partner training is offered at the same time as other communication interventions. This is to ensure consistent use of communication strategies across different environments. It is also to support use of communication approaches across real life settings such as at home, at school and in the community, not just in the clinic room.

Literacy and pre-literacy interventions

Literacy and pre-literacy interventions promote improvement in pre-reading, early reading and writing skills, as well as academic and classroom participation in children with cerebral palsy.

Stuttering therapy

Stuttering can be present in a small number of children with CP. Stuttering therapy aims to lengthen the stutter-free speech, but it does not alter the speech pattern. It usually needs an hour a week for 25 weeks, followed by 30 minutes a week for a year. If your child stutters and has an intellectual disability or another impairment, more therapy might be needed.



Outcomes

Supporting children to communicate reduces frustration and supports meaningful relationships.

Expressive language therapy helps your child to share messages with others. Receptive language therapy can improve your child's ability to understand what others say.

Motor speech therapy or articulation therapy can improve the intelligibility of your child's speech, and help them to be more easily understood.

Communication partner training is an essential component of any communication approach and helps people around your child to support their communication.

Augmentative and Alternative Communication (AAC) allows your child to communicate more widely, and take part in conversation and activities more meaningfully. AAC can also improve your child's ability to understand others, and to follow instructions and routines. It does not inhibit the development of speech.

Multimodal communication means using multiple ways of communicating. This can help your child learn to communicate and understand words, instructions and events in lots of different settings and situations.



Learning and school

It is important to think about how best to support your child at school and how to gain support from others. Things to think about include:

Moving around the school

Moving around school includes in the classroom, from one space to another, in the playground, accessing safe pick up and drop off points, and organising school transport if needed.

Participating in the school curriculum

Optimising participation in the school curriculum involves working with school staff and therapists to help your child make the most of learning opportunities.

This may include:

- Accessing the curriculum
- Participating in academic tasks (e.g. reading, writing, maths)
- Joining in physical activities safely
- Contributing to social activities such as play, group work and peer support
- Negotiating reasonable and necessary adjustments to classroom work and assessment tasks.

Transitioning to high school

Children nearing the end of primary school need to prepare for moving to another, often larger, school environment. At high school, your child will have increased responsibilities in terms of their learning, independence, and developing friendships and peer relationships. Planning for support needs to start early.





What will help?

General strategies

There are many ways to help maximise your child's learning potential. Examples include:

- Talking to your child's teachers and school leaders so they are aware of your child's individual needs
- Removing background noise while your child is trying to concentrate
- Breaking complex questions or sentences down so there is only one thought or one step per request
- Providing visual and verbal prompts when necessary
- Seating your child near the front of the classroom.

Physical adaptations and modifications

An occupational therapist and/or a physiotherapist can work with you and your child to carry out a physical access assessment. They can visit your child's school. They can make recommendations about modifications that the school could make to ensure the environment is accessible.

Assistive technology for learning

Some assistive technology-based programs can improve some children's academic performance. For example, children who use communication devices might benefit from tailored literacy interventions.

There are numerous high-quality software and online programs that can help with reading and numeracy skills. These can be accessed using a switch, an adaptive keyboard or a trackball mouse.

Adapted curriculum and tailored learning supports

If you think your child might have learning difficulties, a cognitive or neuropsychological assessment will help to identify their strengths and weaknesses. They can provide an understanding of their skills and an overall idea of intellectual abilities.

From this, interventions and strategies based on your child's strengths and particular needs can be identified. These strategies can often also be transferred to the classroom.

Interactive reading and literacy

Literacy is an important life skill. Reading with your child does more than help your child with their reading. It helps develop their attention, memory, thinking and language skills, and it supports your relationship with your child.

If you want support with helping your child to read, speech pathologists can help. They can help you choose books and reading materials appropriate for your child, and support you to use evidence-based strategies when reading with your child.

If your child has an identified literacy delay, a number of early literacy programs are available. Talk to your child's therapist or teacher about this.

Play skills therapy

Play skills therapy can support your child to develop their play skills, and can help you to support your child.

Examples include providing toys and experiences that match your child's ability level, creating engaging play spaces and environments, using prompts, and facilitating play by using imitation, expanding play sequences and providing equipment. As your child gets older, toys and equipment that require problem solving skills, procedural steps, or imaginative play, can all assist with development of learning.

Medication

At times, medication can help children with diagnosed conditions such as attention deficit hyperactivity disorder (ADHD). Any medications need to be carefully discussed and managed by your child's treating doctor.

Yoga

Yoga can improve some children's attention and reduce their impulsivity. This intervention can help children manage their energy and activity levels and regulate their responses and behaviour.



Outcomes

Adaptations to the environment can help make learning more suitable for your child's individual needs. These can physical adaptations, use of assistive technology, and curriculum adjustments. Interventions such as play skills therapy, interactive reading and literacy programs can help foster important learning skills. Speak to your therapist about organising an assessment in collaboration with your child's school.



Self-care

Children are likely to be more autonomous and confident if they can wash, feed and toilet themselves as independently as possible. Self-care interventions may also focus on sleep quality and managing the changes a child will experience as they enter puberty.

What will help?

GDT and CO-OP

These interventions, described earlier, can help children learn to become more independent in caring for themselves. Examples of goals include learning to put toothpaste on a toothbrush, wiping themselves after going to the toilet, or washing hands independently.



Assistive technology

Assistive technology includes equipment that can help your child be more independent with their daily care tasks. Examples may include mealtime utensils of different shapes and sizes, a chair to sit on while showering, an adjustable change table, or a wet bed alarm.

Some children need help to move between equipment. A hoist and sling, lifts and home modifications can make transfers easier for your child and family.

Your occupational therapist and physiotherapist can support conversations around what equipment and modifications may benefit your child.

Sleep hygiene

Many children with cerebral palsy have difficulties sleeping. These may include falling asleep, waking up during the night, being sleepy, or being overly energetic during the day due to over-tiredness. Breathing problems, pain, and difficulty positioning comfortably can influence sleep quality.

Establishing a good sleep routine is important. There is much you can do with support from a therapist. Selecting the right sleep intervention should be part of a multidisciplinary approach by both therapy and medical teams.

You might be offered a referral to a specialised sleep clinic or service, melatonin to reduce the time taken to fall asleep, analgesics to help manage pain, or breathing equipment for obstructive sleep apnoea. Other options include a height-adjusted bed, body position supports, a pressure-relieving mattress, a mattress protector, a bed pole, a stick and a grasp bar.

Your occupational therapist can help to guide you on the best sleep intervention for your child.

Puberty

Puberty is when the body develops from childhood into adulthood. Puberty for girls usually begins between 10 and 11 years old. Puberty for boys is usually around 11 or 13. But it can begin earlier or later for boys or girls – everyone is different. Because this is a time of change, it can sometimes be helpful for children to have someone to talk to, especially if they are feeling a bit up and down at times.

Your daughter may also need extra help learning to manage her menstrual periods. GDT and CO-OP can both help.



Outcomes

Supporting your child to care for themselves to the extent that it is possible, will support personal independence and reduce frustration.



Pain

Children with cerebral palsy are more likely to experience pain than other children without a physical disability.

What will help?

Pain is best managed using a team approach. Pain is influenced by a combination of biological (body), psychological (mind), interpersonal (social) and environmental factors. Therefore, a multidimensional perspective will help to ensure all important factors are considered. Pain is a very individual experience and so management strategies need to be individually selected and monitored in an ongoing way.

If your child has pain related to increased muscle tone, you can talk to your doctor or a rehabilitation specialist about oral medications and/or botulinum toxin treatment. In some cases, surgical management of underlying causes of pain is the solution.

It is important to ensure that specialised equipment and assistive devices (such as ankle foot orthoses, wheelchair, and specialised seating systems) are properly fitted so they don't cause pain.

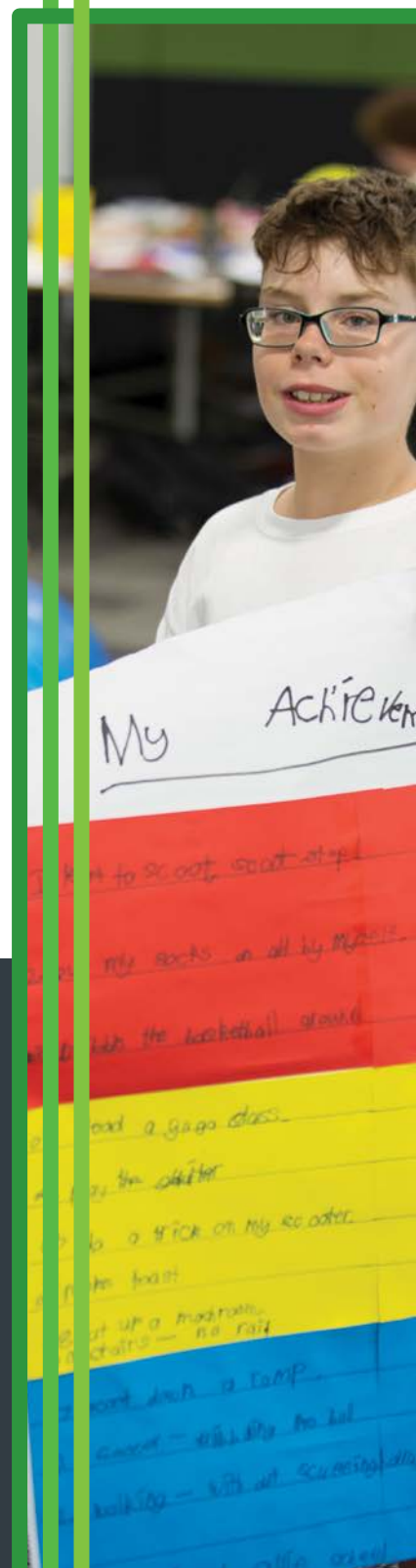
Non-pharmacological strategies such as massage, hydrotherapy, heat packs, cold packs and distraction can help. You and your child should talk to your therapist to develop a toolkit of techniques to manage pain.



Outcomes

Interventions for muscle tone management and adjustment of specialised equipment and devices can help treatment or minimise the source of pain. Non-pharmacological strategies can provide short-term pain relief or provide helpful coping strategies.

Timely and holistic management of pain can also lead to better sleep, improvements in mood and anxiety, and less school absenteeism.





Behaviour and mental health

Some children with cerebral palsy experience behavioural and mental health challenges related to their disability. These challenges can be heightened in times of change, such as starting a new school or going through puberty.

What will help?

Psychological support

For some children, referral to a psychologist may help them. Psychologists can help with positive behaviour support and behavioural interventions. Approaches such as cognitive behavioural therapy, acceptance commitment therapy, and mindfulness-based therapies have been shown to be effective in managing stress, anxiety and depression.

Parenting programs

Positive parenting is an approach that involves carers changing their interaction style with their child. This approach promotes positive adaptive behaviours and is another evidence-based intervention offered by trained therapists.

Stepping Stones Triple P is a parenting program for parents of children with disability aged 2-12. The Stepping Stones program provides families with the necessary skills and strategies to address parenting concerns.

Assistive technology for behaviour

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



Outcomes

Providing support for any behavioural, emotional or mental health challenges your child faces can provide them with the opportunity to participate in life as much as possible.

Stepping Stones Triple P can reduce children's problem behaviour and emotional problems, and can improve parents' confidence, wellbeing and relationship with each other. Mindful parenting promotes secure attachments and emotional wellbeing in children, parents and carers.

FAMILY



Caring for children with cerebral palsy comes with extra responsibilities. Many parents of children with cerebral palsy experience higher levels of stress, anxiety and depression than parents of children who do not have a long-term health condition. This is especially so for those whose children have a communication or intellectual disability, or who experience pain.

Many parents benefit from:

- Emotional and social support to aid family adjustment and provide an optimal caring environment for the child
- Access to detailed information about appropriate schooling and learning supports
- Support during times of change such as starting major school transitions, starting to use assistive technology or having medical interventions
- The opportunity to discuss their concerns, fears, emotions and the impact of the diagnosis on the whole family
- The opportunity to connect with other parents in similar circumstances through mutual support groups or online forums
- Information about how to access services and supports for their child.

Some parents will benefit from referral to a psychologist to deal with anxiety or depression.





What will help?

Respite provides families with a short break from the extra responsibilities associated with caring for a person with cerebral palsy.

Parenting programs such as Stepping Stones Triple P and Mindfulness for Positive Parenting can increase parents' confidence, wellbeing, and relationship with each other.

Acceptance and commitment therapy (ACT) incorporates mindfulness, acceptance and engagement.

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 yours as a parent.

Combined therapies can be useful – for example, Stepping Stones Triple P Parenting program is more effective when combined with ACT.

Another option is solution-focused brief therapy, which is flexible, future-focused, goal-directed and focuses on realistic solutions.

Assistive technology can reduce the load on families to some extent. Speak to your occupational therapist about ways that assistive technology can reduce burden for your family.

You can talk to any of your child's therapists, a psychologist or social worker to determine whether you or your family may benefit from family wellbeing interventions such as those outlined above.



Outcomes

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

FRIENDS



Children want and need friends. Positive friendships give a sense of belonging, build self-esteem and help to develop social skills.

Some children with cerebral palsy, particularly those with learning difficulties, find it harder than others to make and sustain friendships.

A program can be developed to teach your child to better understand social situations. It can help them gain skills that will support positive relationships with family and friends.

Such programs involve an assessment of the child, including observation across a range of settings. This will be followed by therapy appointments to develop and practice strategies, parent/carer training, and coaching to support the child.



Social stories

These are individualised, visually displayed stories that are developed to help a child prepare for challenging and varied social situations. They can be tailored to the specific needs of your child and the situations they are in. Social stories support a positive behaviour approach to managing social interactions.

Group-based therapies

Some therapies can be delivered in a group setting. Examples include bimanual therapy and constraint-induced movement therapy. Some group interventions use a themed approach, such as pretending to be pirates.

Group-based interventions encourage the child not only to develop the skills targeted by the program, but also social skills, self-regulation and communication. Important skills like attention, turn-taking, problem solving, negotiation and resilience are supported. Working with others is also fun and can add a layer of motivation to participating in therapy.

Community and extra-curricular activities

Activities such as art classes, dance and sport give your child the chance to interact with other children, watch how they do things and learn different ways of approaching situations. Seeing modelled behaviour supports social skill development.

Assistive technology for social skills and friendships

If your child has behavioural and/or learning difficulties, educational software that addresses safety skills and social skills is available.



Outcomes

Social stories can improve behavioural outcomes and social communication. Group interventions can provide a sense of belonging, feelings of inclusion, and opportunities for children to learn about themselves and their abilities. They also provide opportunities for your child to observe other children who may have similar levels of abilities and who experience similar challenges with everyday tasks.

Group involvement can help children develop social skills such as taking turns and sharing. They can also lead to a greater sense of independence, and more confident communications with their peers and friends.



FITNESS



Physical activity is an important part of maintaining a healthy lifestyle for all children, especially for children with cerebral palsy. People with cerebral palsy who have difficulty moving are likely to be more sedentary than others. It is important to make opportunities to move every day in order to reduce sedentary behaviours.

Participating in sports and active hobbies is a great way to get fit, have fun, make friends, and learn new skills. Playing team sports encourages cooperation and sharing, resilience, goal setting and building relationships. Learning to lose is also an important skill that's often uncovered through playing sport.

Your child can join in with sport at a level that is right for them. Some children are looking for a casual fun activity, others want to join a local sport team, while others still want to work towards an elite sport level. Sporting activities can also take place at sports camps, school holiday programs or at school. There are so many different sports to try.

In Australia, Disability Sports Australia is the national body that represents people with a disability who participate in sports. They provide information about different sports that are available and ways to become involved.

Sports can be adapted to allow children with a disability to participate to the best of their ability. Equipment and modifications can be put in place to help your child achieve their sporting goals. These may include:

- Modifications to equipment to support teenagers of all mobility levels to participate (e.g. wheelchair sports, RaceRunners).
- Changing the format of the sport to help minimize the likelihood of fatigue or pain (e.g. reducing the duration of a session, adding more break times).
- Modifications to the physical environment to remove potential barriers to accessibility (e.g. ramps, parking, accessible venues).



To learn more about what Disability Sports Australia can offer, visit their website at www.sports.org.au.

There are also other therapies and supports that can help children to build their skills and get the most out of their physical activity.



What will help?

Fitness training

Fitness training is structured physical activity which uses more energy and is more intense than daily living. It aims to improve or maintain physical fitness levels. Fitness activities include walking, swimming, hydrotherapy, cycling, dance, gymnastics, martial arts, and team sports such as soccer and basketball.

Strength training

Strength training is often recommended by exercise physiologists, occupational therapists and physiotherapists as a way to increase muscle strength and improve a person's ability to complete everyday activities such as dressing, using cutlery, throwing and catching balls, and pushing one's own wheelchair. Your child will benefit most from three sessions per week for 40–50 minutes each.

If you and your child are interested in strength training, partnering with an appropriate professional to discuss your goals and identify the appropriate muscle groups to exercise, is recommended. The gains made during strength training are likely to be lost once the program ends, so together with your therapist you will need to consider strategies to help your child maintain gains in strength after the program has finished.

Activity training

Activity training is the practice of specific skills such as jumping, throwing or catching in a one-on-one setting or in a small group.

Behaviour change strategies

Behaviour change strategies consider the child, the context and motivation. Talking to your child about the reason for their activity makes it more likely they will participate.

Assistive technology for physical activity

Some children will need specialised devices or adaptations to support participation in physical activity. Options include adapted tricycles, bikes and RaceRunners. Learning to use these devices should be part of a GDT program.



Outcomes

Physical activity, such as exercise and strength training, can contribute to improvements in fitness, walking, mobility, participation and quality of life.

You need to specifically train in physical activity you if want to improve the outcome of physical activity.

Strength training can improve muscle strength and activity. Fitness training can improve fitness.

It is possible that participation in physical activity will improve gross motor skills.



Planning for high school

A successful transition from primary school to high school is important for all children, particularly those with cerebral palsy. The key to developing a good transition is to know as much as possible about what high school options are available and to plan towards these as early as possible.

During this time, it is important that children with cerebral palsy and their parents learn to advocate for themselves and for the supports they need.

Advice and assistance can be provided by teachers, education support personnel, careers advisers, student support groups, and specialist transition planners in your local community.

What will help?

- Identify people or friends that you know that will be attending the same school
- Attend transition to high school sessions provided by your service provider or local school
- Arrange orientation visits to the new high school to become familiar with the new environment
- Practice getting to school with public transport or your transport provider
- Access support from your therapy service provider to assist you to set things up for you at your new school
- Plan in advance – so that you have all the assistive technology and equipment you need ready to start high school.

If your child will be transitioning to high school in the next few years, you and your child may like to read the *CPA Student Success Guide for Year 7 & 8*. This is the first in a series of guides designed to support students to achieve their best outcomes during secondary school. Informed by CPA's evidence-based thinking and long-time learnings, the guides have also been aligned to both the Australian Curriculum and the known educational, social and emotional goals of students. The guide is available to download from the Cerebral Palsy Alliance website at www.cerebralpalsy.org.au.



Outcomes

Children and families who develop a transition plan, with help from others if required, feel ready and more confident to start high school.

Classification systems

Describing walking and gross motor skills

The Gross Motor Function Classification System (GMFCS) is a scale used to broadly classify the severity of mobility issues in children with cerebral palsy. GMFCS levels are helpful to indicate focus of walking and gross motor skill training. A child at:

- **GMFCS Level I** walks at home, school, outdoors and in the community
- **GMFCS Level II** walks in most settings, though they may have difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects
- **GMFCS Level III** walks using a hand-held mobility device in most indoor settings
- **GMFCS Level IV** uses methods of mobility that require physical assistance or powered mobility in most settings
- **GMFCS Level V** is transported in a manual wheelchair in all settings.

Describing hand function and motor skills

The Manual Ability Classification Scale (MACS) level is helpful to indicate focus and develop goals relating to hand function training. A child at

- **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; 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** is not able to handle objects and not able to complete simple actions with hands.

Describing swallowing, eating and drinking skills

The Eating and Drinking Classification Scale (EDACS) describes how people with cerebral palsy usually eat and drink. A child at:

- **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.

Describing communication skills

There are two scales used to describe the speech and communication of children with cerebral palsy.

Communication Function Classification System

The Communication Function Classification System (CFCS) describes the everyday communication of people with cerebral palsy. It takes into consideration all modes of communication, not just verbal speech. A child at:

- **CFCS I** is an effective sender and receiver with unfamiliar and familiar partners
- **CFCS II** is an effective but slower sender and/or receiver with unfamiliar and/or familiar partners
- **CFCS III** is an effective sender and receiver with familiar partners
- **CFCS IV** is an inconsistent sender and/or receiver with familiar partners
- **CFCS V** seldom is an effective sender and receiver, even with familiar partners.

Viking Speech Scale

The Viking Speech Scale classifies speech production in children with cerebral palsy. A child at:

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



What does that word mean?

Ankle foot orthoses: plastic splints used to improve the position of the foot for standing and walking, also known as AFO

Athetosis: slow 'stormy' movements

Bilateral: affecting both sides

Bimanual: using both hands

Chorea: irregular dance-like movements

Contracture: the muscle is shorter and tighter than usual

Cognitive: concerned with thinking and intellectual abilities

Dyskinesia: involuntary movements

Dysphagia: difficulty swallowing

Dystonia: repetitive twisting movements

Intervention: a treatment or therapy

Intrathecal: the space around the spinal cord

Literacy: concerned with reading

Motor: concerned with muscles

Motor skill: the ability to use a muscle as intended

Multidisciplinary: involving a number of different professionals and therapists working together

Respite: a break from caring

Therapist: a trained professional who works with you and your child

Spasticity: tightening of the muscles

Unilateral: affecting one side only.

References

All sections

Novak, I., Morgan, C., Fahey, M., Finch-Edmondson, M., Galea, C., Hines, A., Langdon, K., Namara, M., Paton, M., Popat, H., Shore, B., Khamis, A., Stanton, E., Finemore, O., Tricks, A., Te Velde, A., Dark, L., Morton, N., & Badawi, N. (2020). State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. *Current Neurology and Neuroscience Reports*, 20(3), 1-21. <https://doi.org/10.1007/s11910-020-1022-z>

Rosenbaum, P., & Gorter, J. (2012). The "F-words" in childhood disability: I swear this is how we should think. *Child: Care, Health & Development*, 38(4), 457-463. <https://doi.org/10.1111/j.1365-2214.2011.01338.x>

Function



Learning and school

Perilli V., Stasolla F., & Laporta D. (2019). Enhancing academic performance of children with cerebral palsy through technological aids: A mini review. *Archives in Neurology & Neuroscience*. 2(3), 105. DOI: 10.33552/ANN.2019.02.000537

Spittle, A., Orton, J., Anderson, P. J., Boyd, R., & Doyle, L. W. (2015). Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database of Systematic Reviews*, (11).



Walking and gross motor function

Dodd, K., Imms, C., & Taylor, N. (2010). *Physiotherapy and occupational therapy for people with cerebral palsy: A problem-based approach to assessment and management*. London: MacKeith Press.

Ekstrom Ahl, L., Johansson, E., Granat, T., & Brogren Carlberg, E. (2005). Functional therapy for children with cerebral palsy: An ecological approach. *Developmental Medicine and Child Neurology*, 47(9), 613-619.

Ketelaar, M., Vermeer, A., Hart, H., Beek, E., & Helders, P. (2001). Effects of a functional therapy program on motor abilities of children with cerebral palsy. *Physical Therapy*, 81(9), 1534-1545. <https://doi.org/10.1093/ptj/81.9.1534>

Law, M., & Darrah, J. (2014). Emerging therapy approaches: An emphasis on function. *Journal of Child Neurology*, 29(8), 1101-1107. <https://doi.org/10.1177/0883073814533151>

Law, M., Darrah, J., Pollock, N., Wilson, B., Russell, D., Walter, S., Rosenbaum, P., & Galuppi, B. (2011). Focus on function: A cluster, randomised controlled trial comparing child versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine and Child Neurology*, 9, 1-9. <https://doi.org/10.1111/j.1469-8749.2011.03962.x>

Lowling, K., Bexelius, A., Brogren Carlberg, E. (2009). Activity focused and goal directed therapy for children with cerebral palsy – Do goals make a difference? *Disability & Rehabilitation*, 31(22), 1808-1816. <https://doi.org/10.1080/09638280902822278>

Lowling, K., Bexelius, A., & Brogren Carlberg, E. (2010). Goal-directed functional therapy: A longitudinal study on gross motor function in children with cerebral palsy. *Disability & Rehabilitation*, 32(11), 908-916. <https://doi.org/10.3109/09638280903353422>

Novak, I., Walker, K., Hunt, R. W., Wallace, E. M., Fahey, M., & Badawi, N. (2016). Concise review: Stem cell interventions for people with cerebral palsy: Systematic review with meta-analysis. *Stem Cells Translational Medicine*, 5(8), 1014-1025. <https://doi.org/10.5966/sctm.2015-0372>

Paton, M., Finch-Edmondson, M., Fahey, M., London, J., Badawi, N., & Novak, I. (2021). Fifteen years of human research using stem cells for cerebral palsy: A review of the research landscape. *Journal of Paediatrics and Child Health*, 57(2), 295-296. <https://doi.org/10.1111/jpc.15329>

Sorsdahl, A., Moe-Nilssen, R., Kaale, H., Rieber, J., & Strand, L. (2010). Change in basic motor abilities, quality of movement and everyday activities following intensive, goal directed, activity focused physiotherapy in a group setting for children with cerebral palsy. *BMC Paediatrics*, 10(26). <https://doi.org/10.1186/1471-2431-10-26>



Hand function and fine motor skills

Rodrigues de Sousa Junior, R., de Lima, P., da Silva, J.N., & Vaz, D.V. (2017). Effects of kinesiology taping in children with cerebral palsy: a systematic review. *Fisioterapia Em Movimento*, 30(suppl 1), 373–382. <https://doi.org/10.1590/1980-5918.030.s01.ar06>

Jackman, M., Lannin, N., Galea, C., Sakzewski, L., Miller, L., & Novak, I. (2020). What is the threshold dose of upper limb training for children with cerebral palsy to improve function? A systematic review. *Australian Occupational Therapy Journal*, 67(3), 269–280. <https://doi.org/10.1111/1440-1630.12666>

Law, M., & Darrah, J. (2014). Emerging therapy approaches: An emphasis on function. *Journal of Child Neurology*, 29(8), 1101–1107. <https://doi.org/10.1177/0883073814533151>

Law, M., Darrah, J., Pollock, N., Wilson, B., Russell, D., Walter, S., Rosenbaum, P., & Galuppi, B. (2011). Focus on function: A cluster, randomised controlled trial comparing child versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine and Child Neurology*, 9, 1–9. <https://doi.org/10.1111/j.1469-8749.2011.03962.x>

Nithianantharajah, J., & Hannan, A. J. (2006). Enriched environments, experience-dependent plasticity and disorders of the nervous system. *Nature Reviews Neuroscience*, 7(9), 697–709. <https://doi.org/10.1038/nrn1970>

Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.A., & Goldsmith, S. (2013). State of the evidence: Systematic review of interventions for children with cerebral palsy. *Developmental Medicine and Child Neurology*, 55(10), 885–910. <https://doi.org/10.1111/dmcn.12246>

Novak, I., Cusick, A., & Lannin, N. (2009). Occupational therapy home programs for cerebral palsy: Double-blind, randomized, controlled trial. *Pediatrics*, 124(4), e606–14. <https://doi.org/10.1542/peds.2009-0288>

Nordstrand, L., Eliasson, A.C., & Holmefur, M. (2016). Longitudinal development of hand function in children with unilateral spastic cerebral palsy aged 18 months to 12 years. *Developmental Medicine & Child Neurology*, 58, 1042–1048. doi:10.1111/dmcn.13106



Swallowing, eating and drinking

Arvedson, J. C. (2013). Feeding children with cerebral palsy and swallowing difficulties. *European Journal of Clinical Nutrition*, 67(S2), S9–S12. <https://doi.org/10.1038/ejcn.2013.224>

Blair, E., Langdon, K., McIntyre, S., Lawrence, D., & Watson, L. (2019). Survival and mortality in cerebral palsy: observations to the sixth decade from a data linkage study of a total population register and National Death Index. *BMC Neurology*, 19(1), 111. <https://doi.org/10.1186/s12883-019-1343-1>

Diéguez-Pérez, M., de Nova-García, M.J., Mourelle-Martínez, M.R. & Bartolomé-Villar, B. (2016). Oral health in children with physical (Cerebral Palsy) and intellectual (Down Syndrome) disabilities: Systematic review. *Journal of Clinical and Experimental Dentistry*, 8(3), e337–43. <https://doi.org/10.4317/jced.52922>

Ferluga, E. D., Archer, K. R., Sathe, N. A., Krishnaswami, S., Klint, A., Lindegren, M. Lou, & McPheeters, M. L. (2013). Interventions for feeding and nutrition in cerebral palsy. *Comparative Effectiveness Reviews*, (94), 43. <https://doi.org/10.13-EHC015-EF>

Orhan, C., Kaya Kara, O., Kaya, S., Akbayrak, T., Kerem Gunel, M., & Baltaci, G. (2018). The effects of connective tissue manipulation and Kinesio Taping on chronic constipation in children with cerebral palsy: a randomized controlled trial. *Disability & Rehabilitation*, 40(1), 10–20. <https://doi.org/10.1080/09638288.2016.1236412>

Sridharan, K., & Sivaramakrishnan, G. (2018). Pharmacological interventions for treating sialorrhea associated with neurological disorders: A mixed treatment network meta-analysis of randomized controlled trials. *Journal of Clinical Neuroscience*, 51, 12–17. <https://doi.org/10.1016/j.jocn.2018.02.011>

Umay, E., Gurcay, E., Ozturk, E., & Unlu Akyuz, E. (2020). Is sensory-level electrical stimulation effective in cerebral palsy children with dysphagia? A randomized controlled clinical trial. *Acta Neurologica Belgica*, 120(5), 1097–1105. <https://doi.org/10.1007/s13760-018-01071-6>



Communication

- Norberg, A., Miniscalco, C., Lohmander, A., & Himmelmann, K. (2012). Speech problems affect more than one in two children with cerebral palsy: Swedish population-based study. *Acta Paediatrica*, 102, 161–166. <https://doi.org/10.1111/apa.12076>
- Clarke, M., Price, K., & Griffiths, T. (2016). Augmentative and alternative communication for children with cerebral palsy. *Paediatrics and child health*, 22(9), 367–371. <https://doi.org/10.1016/j.paed.2016.04.012>
- Millar, D.C., Light, J.C., & Schlosser, R.W. (2006). The impact of augmentative and alternative communication intervention on the speech production of individuals with developmental disabilities: A research review. *Journal of Speech, Language, and Hearing Research*, 49(2), 248–264. [https://doi.org/10.1044/1092-4388\(2006/021\)](https://doi.org/10.1044/1092-4388(2006/021))
- Granlund, M., Björck-Akersson, E., Wilder, J., & Ylven, R. (2009). AAC interventions for children in a family environment: Implementing evidence in practice. *Augmentative and Alternative Communication*, 24(3), 207–219. <https://doi.org/10.1080/08990220802387935>
- Pennington, L., Goldbart, J., & Marshall, J. (2004). Interaction training for conversational partners of children with cerebral palsy: a systematic review. *International Journal of Language & Communication Disorders*, 39(2), 151–170. <https://doi.org/10.1080/13682820310001625598>
- Proctor-Williams, K. (2009). Dosage and Distribution in Morphosyntax Intervention: Current Evidence and Future Needs. *Topics in Language Disorders*, 29(4), 294–311. <https://doi.org/10.1097/TL0.0b013e3181c29dc0>
- Murray, E., McCabe, P., & Ballard, K.J. (2015). A randomized control trial of treatments for childhood apraxia of speech. *Journal of Speech, Language and Hearing Research* 58(3), 669–686. https://doi.org/10.1044/2015_JSLHR-S-13-0179
- Pennington, L. (2016). Speech, language, communication, and cerebral palsy. *Developmental Medicine and Child Neurology*, 58(6), 534–535. <https://doi.org/10.1111/dmcn.12975>
- Williams, E. (2014). Measuring the effectiveness of interventions for children with cerebral palsy. *Developmental Medicine and Child Neurology*, 56(5), 417–418. <https://doi.org/10.1111/dmcn.12388>
- Mandak, K., Light, J., & Boyle, S. (2018). The effects of instruction on single-word reading for individuals who use aided AAC: A systematic review. *Augmentative and Alternative Communication*, 34, 206–218. <https://doi.org/10.1080/07434618.2018.1470668>



Self-care

- Appleton, R.E., Jones, A.P., Gamble, C., et al. (2012). The use of melatonin in children with neurodevelopmental disorders and impaired sleep: A randomised, double-blind, placebo-controlled parallel study (MENDS). *NIHR Health Technology Assessment*, 16 (40), 1–239. <https://doi.org/10.3310/hta16400>
- Dodd, K., Imms, C., & Taylor, N. (2010). *Physiotherapy and occupational therapy for people with cerebral palsy: A problem-based approach to assessment and management*. London: MacKeith Press.
- Humphreys, G., King, T., Jex, J., Rogers, M., Blake, S., Thompson-Coon, J., & Morris, C. (2019). Sleep positioning systems for children and adults with a neurodisability: A systematic review. *British Journal of Occupational Therapy*, 82(1), 5–14. <https://doi.org/10.1177/0308022618778254>



Muscle tone and spasticity

- Australasian Academy of Cerebral Palsy and Developmental Medicine (2014). *Australian Hip Surveillance Guidelines*. Available at: <https://www.ausacpdm.org.au/resources/australian-hip-surveillance-guidelines/>
- Buizer, A., Martens, B., van Ravenhorst, C., Schoonmade, L., Becher, J., & Vermeulen, R. (2019). Effect of continuous intrathecal baclofen therapy in children: a systematic review. *Developmental Medicine & Child Neurology*, 61(2), 128–134. <https://doi.org/10.1111/dmcn.14005>
- Fehlings, D., Brown, L., Harvey, A., Himmelmann, K., Lin, J., Macintosh, A., Mink, J., Monbaliu, E., Rice, J., Silver, J., Switzer, L., & Walters, I. (2018). Pharmacological and neurosurgical interventions for managing dystonia in cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*, 60(4), 356–366. <https://doi.org/10.1111/dmcn.13652>
- Fehlings, D., Brown, L., Harvey, A., et al. (2016, June 04, 2018). Care Pathways: Dystonia in Cerebral Palsy. Retrieved from <https://www.aacpdm.org/publications/care-pathways/dystonia>
- Häggglund, G., Alriksson-Schmidt, A., Lauge-Pedersen, H., Rodby-Bousquet, E., Wagner, P., & Westbom, L. (2014). Prevention of dislocation of the hip in children with cerebral palsy. *The Bone & Joint Journal*, 96-B (11), 1546–52. <https://doi.org/10.1302/0301-620X.96B11.34385>
- Häggglund, G., Andersson, S., Duppe, H., Lauge-Pedersen, H., Nordmark, E., & Westbom, L. (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. <https://doi.org/10.1097/01202412-200507000-00007>
- Pron, G. (2017). Lumbosacral dorsal rhizotomy for spastic cerebral palsy: A health technology assessment. *Ontario Health Technology Assessment Series*, 17(10), 1–186.
- Wynter, M., Gibson, N., Willoughby, K.L., Love, S., Kentish, M., Thomason, P., Kerr Graham, H., & National Hip Surveillance Working Group. (2015). Australian hip surveillance guidelines for children with cerebral palsy: five-year review. *Developmental Medicine & Child Neurology*, 57, 808–820. <https://doi.org/10.1111/dmcn.12754>



Pain

Mckinnon, C., Meehan, E., Harvey, A., Antolovich, G., & Morgan, P. (2019). Prevalence and characteristics of pain in children and young adults with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*, 61(3), 305–314. <https://doi.org/10.1111/dmcn.14111>

Ostojic, K., Paget, S., & Morrow, A. (2019). Management of pain in children and adolescents with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*, 61(3), 315–321. <https://doi.org/10.1111/dmcn.14088>

Penner, M., Xie, W., Binopal, N., Switzer, L., Fehlings, D., & Penner, M. (2013). Characteristics of pain in children and youth with cerebral palsy. *Pediatrics*, 132(2), e407–e413. <https://doi.org/10.1542/peds.2013-0224>



Behaviour and mental health

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. <https://doi.org/10.1017/jrc.2014.6>

Nicolson, A., Moir, L., & Millstead, J. (2012). Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review. *Disability and Rehabilitation: Assistive Technology*, 7(5), 345–349. DOI: 10.3109/17483107.2012.667194

Rentinck, I., Ketelaar, M., Jongmans, M., Lindeman, J., & Gorter, J.W. (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

Whitney, D., Warschausky, S., & Peterson, M. (2019). Mental health disorders and physical risk factors in children with cerebral palsy: a cross-sectional study. *Developmental Medicine & Child Neurology*, 61(5), 579–585. <https://doi.org/10.1111/dmcn.14083>

Whittingham, K., Sanders, M., McKinlay, L., & Boyd, R. (2014). Interventions to reduce behavioral problems in children with cerebral palsy: an RCT.(Report). *Pediatrics*, 133(5), e1249–57. <https://doi.org/10.1542/peds.2013-3620>



Family

Brown, F., Whittingham, K., Boyd, R., McKinlay, L., & Sofronoff, K. (2015). Does Stepping Stones Triple P plus Acceptance and Commitment Therapy improve parent, couple, and family adjustment following paediatric acquired brain injury? A randomised controlled trial. *Behaviour Research and Therapy*, 73, 58–66. <https://doi.org/10.1016/j.brat.2015.07.001>

Whittingham, K., Sanders, M., McKinlay, L., & Boyd, R. (2016). Parenting intervention combined with acceptance and commitment therapy: A trial with families of children with Cerebral Palsy. *Journal of Pediatric Psychology*, 41(5), 531–542. <https://doi.org/10.1093/jpepsy/jsv118>



Friends

Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation*, 30(24), 1867–1884. <https://doi.org/10.1080/09638280701673542>

Kang, L., Palisano, R., King, G., Chiarello, L.A., Orlin, M.N., & Polansky, M. (2012). Social participation of youths with cerebral palsy differed based on their self-perceived competence as a friend: Participation and competence of youths with cerebral palsy. *Child: Care, Health & Development*, 38(1), 117–127. <https://doi.org/10.1111/j.1365-2214.2011.01222.x>



Fitness

O'Brien, T., Noyes, J., Spencer, L., Kubis, H., Hastings, R., & Whitaker, R. (2016). Systematic review of physical activity and exercise interventions to improve health, fitness and well-being of children and young people who use wheelchairs. *BMJ Open Sport & Exercise Medicine*, 2(1), e000109–e000109. <https://doi.org/10.1136/bmjsem-2016-000109>

Verschuren, O., Darrah, J., Novak, I., Ketelaar, M., & Wiat, L. (2014). Health-enhancing physical activity in children with cerebral palsy: More of the same is not enough. *Physical Therapy*, 94(2), 297–305. <https://doi.org/10.2522/ptj.20130214>

Park, E., & Kim, W. (2014). Meta-analysis of the effect of strengthening interventions in individuals with cerebral palsy. *Research in Developmental Disabilities*, 35(2), 239–249. <https://doi.org/10.1016/j.ridd.2013.10.021>

Reedman, S., Boyd, R. N., & Sakzewski, L. (2017). The efficacy of interventions to increase physical activity participation of children with cerebral palsy: a systematic review and meta-analysis. *Developmental medicine and child neurology*, 59(10), 1011–1018. <https://doi.org/10.1111/dmcn.13413>

Notes

**For more information,
please get in touch:**



Call us on **1300 888 378**



Email us at
ask@cerebralpalsy.org.au



Visit **cerebralpalsy.org.au**



Cerebral Palsy
ALLIANCE