



Therapy and other supports for teenagers

A guide for parents
of 13 to 17 year olds
with cerebral palsy

What works and how much is needed

People with cerebral palsy (CP) 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. It occurs due to injury to the developing brain. It is a life-long physical disability; however, it can change over time.

Who is Cerebral Palsy Alliance?

Cerebral Palsy Alliance (CPA) is a leading provider of evidence-based therapy, life skills, sport and leisure programs for teenagers living with CP and other similar conditions. Our research foundation supports the world's best and brightest researchers to find ways to prevent and cure CP and to improve current treatments.

What's in this guide?

This guide helps you to understand therapy and support approaches that are available to your teenager. These approaches are underpinned by neuroscience, supported by research evidence, and can be adapted to meet the needs of your child and your family.

In this guide, we refer to six concepts that are important to consider when planning services and supports for your teenager. These six words were gathered by researchers from an organisation called CanChild in Canada. They can be used to start a conversation with your teenager's service providers so they understand what is important for you and your family (Read more at canchild.ca/en/research-in-practice/f-words-in-childhood-disability). These words are:

- **Fun:** leisure and recreation activities that your teenager enjoys
- **Friends:** helping your teenager develop friendships, relationships and social skills
- **Family:** ways to involve your family, and think about the needs of all your family members
- **Fitness:** staying physically active and healthy through exercise and participation in other recreational and fitness activities
- **Function:** the activities and tasks that your teenager needs to do on a daily basis
- **Future:** thinking about your own and your teenager's goals and plans for the future, especially for what happens when high school finishes.

The aim of this guide is to support you to feel more confident about helping your teenager build their independence and manage their own disability, choices and goals.

A separate guide is also available for teenagers.

This guide provides general information only. This information 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, your child and your circumstances.

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Highlights



Fun

- Teenagers are highly motivated to participate in activities and life experiences if they enjoy what they're doing and are having fun.
- Involvement in a range of social, leisure and recreation experiences helps with cognitive, physical, social and emotional development.
- Embedding 'therapy' within fun activities that are motivating and meaningful can also enhance outcomes.



Friends

- Your teenager may wish to explore new friendships, relationships and activities. Families can work together to navigate the social and recreation opportunities available to young people, including ways to safely connect and interact with others face to face and online.
- You and your teenager can participate in social skills training programs, such as PEERS® (Program for the Education and Enrichment of Relational Skills). This program helps teenagers and young adults learn ways to manage social situations, friendships and relationships.



Family

- A lot happens as children enter adolescence and move through their teenage years. Experiences may be joyful and fulfilling, as well as challenging or confronting.
- As well as supporting teenagers at this time of their life, it's important for you to look after yourself and your emotional wellbeing.
- Services and supports such as respite care, paid disability support workers and parent/carer support groups can help families manage care responsibilities. They also offer teenagers time and opportunity to explore new experiences, develop new skills, and build independence.



Fitness

- Physical activity is essential for your teen's health.
- Specific training tasks, rather than a general approach, are important to improve physical outcomes.
- 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 teenagers with a disability to participate to the best of their ability.



Function

- Teenagers with CP have worked hard to develop their skills and abilities. There are many evidence-based interventions that assist your teen to maintain their function, improve and refine the way they do things. A goal for many teenagers is to optimise their independence across skill areas.
- Motor interventions that are goal-directed, task-specific, motivating and enjoyable are still the gold standard in this age group.



Movement, mobility and motor function

- The best interventions to help your teenager with movement and mobility, are ones that focus on goals that are important and meaningful to them. They should be specific, real life tasks that are active, fun and enjoyable.
- Treadmill training, gait training, strength training, AFOs, hydrotherapy and assistive technology can all be used alongside a Goal-Directed Training approach.
- Research evidence tells us that a minimum of 14 hours of intervention is needed to help your teen achieve each one of their goals.



Pain

- Pain is an individual experience: only your teenager really knows what their pain feels like. Encouraging open communication and proactive management can reduce negative impact on daily activities and participation.
- Managing pain involves a multidisciplinary team of people sharing information.
- Preventing pain is an important part of successful management.



Looking after bones and muscles

- Your teenager should continue to have hip, spine and muscle check-ups every 12 months or as outlined in the Australian Hip Surveillance Guidelines. This is an effective way to stay on top of changes in the body and to prevent severe problems from occurring.
- There are many different treatments available to help with keeping bones, joints and muscles healthy. There is also a range of surgical, non-surgical, and pharmacological options to manage musculoskeletal changes and muscle tone.
- A team of people will be involved in recommending the best treatment approach for your teenager to meet their individual needs and goals.



Hand and fine motor skills

- A range of assistive technology options can support improvement of hand function and fine motor skill. An occupational therapist and/or physiotherapist can work with you and your teenager to make decisions about suitable options.
- Constraint Induced Movement Therapy and Bimanual Therapy are equally effective in improving upper limb function for teenagers with CP affecting one side of their body; 30-40 hours of intervention is needed.



Communication

- Many people with CP will communicate using methods other than speech or in addition to speech. These methods are known as Augmentative and Alternative Communication (AAC).
- Speech Pathologists can help your teenager work towards their communication goals. Goals may focus on speech, language, literacy skills, social skills and/or communicative participation.



Eating, drinking and swallowing

- Eating, drinking and swallowing are complex skills that require many muscles to work together.
- A multidisciplinary team including speech pathologists, dietitians and medical professionals, can contribute to positive eating, drinking, swallowing and nutritional experiences and outcomes for your teenager.



Self-care and independence

- Managing your teenager's personal care/self-care is about finding a balance between what they can do safely and efficiently for themselves, and the assistance they need from others.
- Goal directed training and CO-OP approaches can help. A range of assistive technology and equipment is also available.



Behaviour and mental health

- Teenagers with CP are at increased risk of behavioural and mental health issues including depression, anxiety and behaviour/conduct problems.
- Positive behaviour support and behavioural interventions such as cognitive behavioural therapy, acceptance commitment therapy, solution focussed brief therapy and other mindfulness-based approaches may help teenagers with CP.



Learning

- Early planning for transitions into and out of high school are essential. Supporting individualised learning needs is an important focus for the 13-17 year old age group.



Future

- Further education, part-time or full-time work, community participation and life skills programs are all options your teen may wish to consider when they have finished school.
- The process of transitioning from child health services to adult health services starts when your teenager is 12-13 years old and continues throughout their adolescence. Specialised transition services can make this process smoother.
- Planning for where your teenager might live as an adult and the supports they may need will likely begin during the teenage years. Exploring different options and what these mean for your family is a process that takes time.

Best practice approaches for teenagers with CP

Task specific training

Motor-training-based interventions that are goal-directed, task-specific, motivating and enjoyable are the gold standard approach for teenagers with CP.

This means that your teen is working towards real skills, in real life tasks, in real life settings, with *lots* of practice and feedback.

Two approaches supported by research and widely used are:

- Goal directed therapy (GDT) or training
- Cognitive Orientation to Occupational Performance (CO-OP).

Goal directed therapy (GDT) or training

GDT involves you, your teen and your family setting goals together to support participation in everyday life. Your teen then practises specific activities or tasks to reach these goals. You may have used this approach with your child during their therapy as a younger child. The principles of the approach are the same, but you may see your teenager becoming more involved with the selection and prioritisation of their goals. The nature of their activities may also become highly focused on participation.

A GDT approach works best when:

- ✓ Your teenager is able to choose specific goals, activities or skills that are important to them. The goals need to be challenging so they can work towards them over time. The goals could be about physical skills, self-care, communication, leisure, sport or school-based activities.
- ✓ The goal is just the right challenge level – not too easy and not too hard. At the beginning, the goal can be broken down into smaller tasks. As your teen's skills progress, the tasks can be made more difficult.
- ✓ Between 14 and 25 hours of training and practice is spent on each goal. The evidence particularly supports this intensity when the goal involves the arms and/or hands.

How quickly your teen learns a task or skill depends on many factors. These include:

- Age
- Type of CP
- Understanding of the task and what it requires
- Level of motivation
- Opportunity to practice the task
- Amount and quality of practice.

In the teenage years, GDT can continue to be used effectively for both motor and non-motor-based goals. Self-care, communication, cognitive, school-based and work readiness skill development may all be important areas of focus.

Cognitive Orientation to Occupational Performance (CO-OP)

CO-OP is another approach that your teenager can use to complete everyday tasks that are important to them. The aim of this program is to help your teen develop new ways to think about and perform skills by planning and talking about the steps involved. CO-OP is a 'thinking program' that helps with problem solving within every day routines and activities.

There are four key parts:

- 1 Goal**
Your teen will identify a goal that is important to them
- 2 Plan**
They will develop a plan for how they will achieve the goal
- 3 Do**
They will execute the plan
- 4 Check**
They will check to see whether the plan worked.

As a teenager, your child will have their own likes and dislikes, passions and interests. They will want to become involved in decision-making more and more, ultimately taking control of decisions that affect them.

For therapy and services to work well, it is important that they are built around your teenagers' goals and priorities. You can speak with your child's therapists to find out how GDT or CO-OP approaches would work for them.



Delivery of therapy

As with the earlier years, in-person therapy is the most common mode of allied health intervention delivery for teenagers. This can be delivered at home, in a centre, or out in the community. As your teenager gets older, they may wish to participate in more group-based programs with peers. They may also wish to try activities that are more focused on community access and participation.

The growth and improvement of online platforms means many of the interventions and services discussed in this guide can now also be effectively delivered via telepractice. You can speak with your therapist or health professional to discuss the best way to access the supports your teenager's needs. This may be in-person, via telepractice or a combination of the two.

FUN



Therapy that is embedded within fun, motivating and meaningful activities of interest to your teenager will be more effective.

Without a doubt the most important 'F' word is fun. Fun comes in many forms. For a teenager it often centres around friends, family, leisure activities, and hobbies that are enjoyable and mean something important to them.

Hobbies are activities that we do for pleasure in our spare time. These can include reading, listening to or playing music, camping, arts and craft, and gaming. Going to music festivals, attending concerts and parties, hanging out with friends and enjoying sports are all ways that your teen can be involved and participate in activities they enjoy.

Leisure and recreational activities

Participation in everyday activities has an important impact on a young person's development. Teenagers with CP can be more restricted in their participation, for a range of reasons. As a result, they participate less often and may be less physically active compared to their typically developing peers.

For many teenagers, increased participation is a goal. When this is the case, interventions should be focused on supporting teenagers to overcome any personal, social, and environmental barriers they experience.

What will help?

Preliminary research shows that participation increases when:

- Your teenager sets their own goals
- A clinician helps you and your teen identify personal, social and environmental factors that can either be a barrier to or improve participation
- Intervention focuses on problem solving and finding solutions to overcome the identified barriers, combined with practice of the specific activity within real-life situations.

It's important that your teenager is encouraged to choose their own leisure activities based on what they enjoy, rather than just on skills that they need to develop from a 'therapy' perspective.

ParticiPate CP

ParticiPate CP is an evidence-based intervention that supports young people with CP to reach their goals. Over eight weekly sessions of one hour, a therapist works with your teen and family to set goals, identify barriers and facilitators to participation, form strategies and explore preferences using motivational interviewing.

Pathways and Resources for Engagement and Participation (PREP)

PREP is another evidence-based intervention that promotes participation through changing factors in the environment. Your teen and the people supporting them work together to problem solve within the activities they want to participate in.

Individualised coaching

Interventions aimed at changing personal, social, and environmental barriers using a coaching approach have also been shown to be effective.

Gaming and virtual reality (VR)

Gaming and VR systems can be used to engage and motivate teenagers to participate in their therapy programs, particularly to improve upper limb function and postural control. Any technology or system should be used alongside an appropriate evidence-based therapy approach such as Goal Directed Training.





Friends play a big role in your teen's life. They can offer support, encourage involvement in activities, and help your teen appreciate the things they can do.

Friendships and social skills

Many young teenagers with CP have a strong group of friends formed through school and participation in hobbies. Research shows that having friends has a positive impact on long-term psychological well-being. Friends can cushion the impact of stressful events, promote healthy self-esteem, and help reduce anxiety and depressive symptoms.

Some teenagers with CP do find it difficult to make and keep friends. Many may worry that if they have difficulty moving around, talking with others or need help with self-care tasks, this will limit what they can do with their friends. A diagnosis of Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD) in addition to CP may also contribute to social challenges. If your teen worries about these things or would like to have more friends, there are programs that can help.



What will help?

Social skills training programs

Social skills training programs can help your teenager develop skills that are important for friendships and relationships.

One of these programs, called PEERS® (Program for the Education and Enrichment of Relational Skills), offers group sessions for teenagers and separate group sessions for parents. The interactive sessions are held weekly and participants practice new skills with each other during the session. The same skills are then practised at home or in another familiar environment. Parents can meet other like-minded parents and learn new strategies to support their teenager's social skill development at home and in the community.

Communicating about friendships

Encouraging your teen to share their friendship goals with you and their therapy team is important. Therapists can help prioritise a focus on friendships and participation within therapy sessions, especially if your teen would like to:

- Become involved in new activities or hobbies that are social in nature
- Safely connect and communicate with other young people online or through social media
- Start a part-time job or do some volunteer work that involves meeting new and different people.

Support to attend social activities

Your teen may benefit from support to attend social activities that are of interest to them. Support may be as simple as having a buddy accompany them when trying something new. Or it could be paid or unpaid practical support such as making sure someone is available to assist with mobility or personal care. Your teen can have an active role in choosing the skills and interests that their support personnel may share.

Access to transport

Reliable access to transport to attend activities, discussions or events will make it much easier for them to become involved. If funding is required to secure reliable access to transport, further information about relevant schemes can be sought from service providers or funding agencies.

FAMILY



Family is one of the most important parts of our lives, if not *the* most important. Being a parent of a teenager is an intensely fulfilling experience, but it's hard work too.

Parenting a teenager is a joy, but it can also be challenging and stressful. Your teen is navigating new experiences and changes in themselves and their world. Finding the right supports at this time can be difficult. This may be particularly the case if your teenager has a number of needs that require support (e.g., pain, epilepsy, intellectual disability, behavioural challenges).

The demands and challenges of caring for a teenager with CP can take a toll on the wellbeing of parents/carers. Parents may be more likely to experience stress if they are dealing with other issues such as financial, relationship, or work-related challenges at the same time. Therefore, support for parents is essential.

What will help?

Short breaks and respite

Support services that provide teens and families with a short break from each other are available. These breaks can be planned ahead of time or arranged during an emergency/crisis. They can be overnight, for several days or for several weeks.

Respite care is provided by trained disability support professionals in a supportive and caring environment. This can be a great time for you as a parent to have a break, pursue one of your interests, spend time with other children or family members, and look after your own wellbeing. It is also a good opportunity for your teen to learn independent living skills, experience new activities and make new friends.

Paid support workers

Disability support workers are trained, paid professionals able to provide your teenager with companionship, care and support with daily activities. They can provide support within your home or out in the community.

Assistive technology

If your teen needs assistance with personal care, equipment and aids can be used around the home to help with dressing, showering and transfers. Perhaps these supports were not needed when your child was younger and smaller. But as your teen grows the right equipment can help you to provide care and support in a safe way with less physical demand on your body. Using adaptive or customised equipment can help your teen to maximise what they can do for themselves and increase their independence during every day activities. Occupational therapists and physiotherapists can support the trial and prescription of aids and equipment.

Parent and carer support

Parents can find support for themselves and their role as a parent in many different ways. You may wish to join Facebook groups, local community networks, online forums or access specific parent support programs. These networks offer information, connections with other parents and families, and ways to get involved with events in the community. Ask your service provider about any parent and family support services that they offer or can recommend.

FITNESS



Exercise is important for everyone – and there are so many ways to do it.

Physical activity is an important part of maintaining a healthy lifestyle. At least 60 minutes a day of moderate to vigorous physical activity is recommended as the ideal amount.

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.

Your teenager can join in with sport at a level that is right for them. Some teenagers are looking for 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.



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 teenagers with a disability to participate to the best of their ability. Adaptations 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, you can view their website: www.sports.org.au

FITNESS

What will help?

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

Strength training

Strength training improves strength in targeted muscle groups. It also helps support involvement in physical activity. An exercise physiologist or physiotherapist can provide information about strength training. Three 40–50 minute sessions per week is a great start.

Activity training

Activity training refers to the practice of specific skills (e.g., jumping, throwing, catching, balancing). There has not been an optimal protocol developed for activity training. However, it is known that a targeted approach to physical activity intervention is more effective than a generalised one.

Resistance training and weight bearing exercises

Resistance and weight bearing exercises include weight training, body weight exercises, Pilates, yoga, circuit training and adaptive exercise programs.

Resistance training and weight bearing exercises improve fitness and they can also help with bone health, muscle strength, endurance, and function.

To start with, your teenager will aim to repeat an exercise ten times. As they get stronger the exercises can be made harder by adding more resistance or weight and by slowly increasing the number of repetitions.

Whole body vibration (WBV)

WBV involves standing, sitting or lying down on a machine with a vibrating platform. Whole body vibration may help reduce tightness in muscles (spasticity) and improve muscle strength and coordination. Further research is needed to better understand the benefits of WBV for teenagers and young adults with CP.

Fitness training

Fitness training involves repeated exercises that target specific muscle groups and require lots of energy. These types of interventions can improve fitness. An exercise physiologist can design an individualised fitness program that matches your teenager's goals, abilities and preferred activities.

Behavioural strategies

We all need help to stick to our fitness goals sometimes! A behavioural change approach encourages teenagers to understand more about themselves and their reasons for exercising (or not). A helpful plan that fits in with their life and choices can be developed. This helps teenagers stick to their exercise commitments and steadily progress towards their fitness and activity goals. Individualised coaching can be a great approach if this is something your child needs.

Assistive technology

Some teenagers with CP benefit from modifications or supports to help them participate in sports, activities and hobbies. Assistive technology can include things like adapted bikes, RaceRunners, modified equipment and other devices. Your teen can learn to use individualised equipment as part of a tailored goal-directed training program.



Key messages

- Activity and exercise are an essential part of good health for everyone
- Teenagers with CP can participate in physical activity that is fun, enjoyable and adapted to meets their individual needs
- Working together as a team to understand and address barriers is the best way to encourage and promote participation
- In order to see gains in a specific area (e.g., muscle strength), targeted work on that specific area is needed.

FUNCTION



We all have different abilities. Your teen will find ways of doing things that work for them and their life.





Movement, mobility and motor function

Most adolescents with CP have reached 90% of their gross motor skill and capacity. However, motor function and quality of movement can continue to change as teenagers get older.

During adolescence it's important to maintain gross motor function. There are interventions that focus on specific elements of this (e.g., walking speed, endurance and stability). But it's also important to support safe mobility participation. For example, rather than walking long distances across their school, some teenagers may choose to use a manual wheelchair. This allows them to move more quickly in the school setting, keep up with their peers and prevent fatigue. But in other settings where there are less time and safety constraints, walking independently or with the use of aids, may be preferable.

What will help?

In addition to GDT and CO-OP approaches (described earlier), the following specific interventions have been shown to support teenagers to achieve their mobility and gross motor goals.

Gait training

Gait training is specific practice of walking in a range of different contexts. The aim of the approach is to support your teen to improve either the quality of their walking pattern or their endurance (how far and for how long they can walk). Gait training has also been shown to improve walking speed, but is less effective in improving other gross motor skills. Gait training should be implemented as part of a Goal Directed Training approach.

Treadmill training

Treadmill training has been shown to improve speed of walking, walking endurance and gross motor function in young children with CP. As such it could be considered an appropriate intervention for your teen.

Treadmill training can be done with or without the support of a harness. When a harness is used this is also known as *partial body weight supported treadmill training*.

Treadmill training is most effective when your teenager is actively doing the walking practice. If robotic devices are used to move your teenager's legs for them, this form of treadmill training is unlikely to lead to similar gains.

Walking training on regular surfaces should always be done in parallel with treadmill training. This helps any gains in walking skills to be transferred into real world situations.

Strength training

Strength training improves strength in targeted muscle groups and is important for maintaining function. When used alongside a GDT approach, improvements in functional goals such as walking, transfers, and daily tasks can be achieved.

Hydrotherapy

Hydrotherapy is an activity or exercise that is performed in a pool. It can help a person achieve the goals set for their therapy. For some teenagers, hydrotherapy may be a useful addition to their goal directed training program. For others it may provide a freedom of movement not easily achieved in a land-based program.

Hydrotherapy programs can be individualised to meet specific needs and goals.

Ankle foot orthoses (AFOs)

AFOs are splints commonly used by teenagers with CP to improve the position of the foot for standing and walking.

AFOs have been shown to make small additional improvement to walking and gross motor abilities. However, it is not clear from research evidence whether wearing AFOs can prevent excessive tightness in muscles from developing (a contracture).

If you and your teen are thinking about whether or not to use an AFO consider the cost, the chance of pain and skin irritation, and the look and feel of them. You can then weigh up the potential for short term and long term improvements.

Taping

Taping involves using rigid or flexible tape to hold joints and muscles in a good position. It works best when used with task-specific motor training.

More research is needed to better understand the benefits of taping for teenagers with CP. Some people tolerate taping better than AFOs and prefer the look and feel. This intervention should be discussed with your teen's therapist to see if it is appropriate.

Assistive technology

Assistive technology to assist with walking and mobility includes the use of walking frames, crutches, walking sticks and Smart walkers.

Teenagers may use different equipment for different activities. Your teen will likely have their own thoughts about what equipment works best in different situations. This will be dependent on their activities and goals.

All young teenagers with CP, including those who do not walk independently, will benefit from using a supportive walker for fun, fitness and socialisation.

Learning to use equipment effectively should be embedded within a Goal-Directed Training program. Physiotherapists and occupational therapists can assist with trialling and selecting appropriate equipment and designing a program.



Key messages

- Motor-training based interventions that are goal directed, task specific, motivating and enjoyable are recommended as the gold standard for teenagers with CP.
- The best interventions to help your teenager with movement and mobility are those designed to address meaningful and motivating goals. They should be focused on specific, real world tasks, and be active, fun and enjoyable.
- Programs could include treadmill training, gait training, strength training, AFOs, hydrotherapy and assistive technology, alongside a Goal-Directed Training approach.



Pain

Chronic pain can be common in teenagers with CP. Encourage your teen to let someone know if something doesn't feel right in their body. Prevent, monitor and manage pain.

It is common for teenagers with CP to experience pain. This can include joint or muscle pain, or pain associated with posture and positioning. They may also experience typical causes of pain such as headaches, growing pains and menstrual pain.

Depending on type of CP and level of motor ability, the source of pain can be different. For example, teens at GMFCS Level I–II are more likely to have pain in their lower limbs caused by tight muscles. This can become worse during movement. Young people at GMFCS Levels IV–V frequently experience hip pain, muscle spasms, and stomach pain related to constipation. Individuals with spastic quadriplegia or dyskinesia, are more likely to experience chronic pain. The likelihood of experiencing chronic pain increases with age.

If your teen is in a lot of pain it may affect their sleep, school work, leisure, participation and their mental health. So it is important for teenagers to communicate about their pain if they can and to seek help from you, their doctor and the wider team of people who support them.

What will help?

- Pain is influenced by combination of biological (body), psychological (mind), interpersonal (social) and environmental factors. Therefore, pain is best managed using a team approach.
- Pain is a very individual experience. Talking with a health care professional (e.g. GP, paediatrician, rehabilitation specialists, physiotherapist, occupational therapist, and/or psychologist) is recommended so your teen gets a treatment plan that meets their specific needs.
- If your teenager's pain is related to tightness or increased tone in their muscles then medication, Botulinum Toxin Treatment or surgery may be appropriate. Discussion with your child's medical team will help inform the best course of action.
- If your teen experiences pain in their hips then regular monitoring through active hip surveillance can help keep your child comfortable and moving well. It will also assist with planning for future management strategies.
- If your teen uses equipment or devices such as a wheelchair, seating system, ankle foot orthosis or hand splint, ensure that these are fitted well so they don't cause pain.
- Other strategies like massage, hydrotherapy, heat packs, cold packs and distraction can help. These strategies should be discussed with your child's medical team to find a combination of individualised supports that work well.



Key messages

- Pain is an individual experience – only your teenager really knows what their pain feels like
- Encouraging open communication, prevention and proactive management of pain can reduce its impact on daily activities and participation
- There are different pain management strategies that can help depending on the type of pain, what's causing it, the location, and how bad it is
- Managing pain involves a multidisciplinary team of people sharing information.



Looking after bones and muscles

We all get just one body. Helping your teenager look after their body will allow them to continue to do what is important to them.

Teenagers and young people with CP can be at risk of developing problems with their bones, muscles and joints as they get older. These problems may affect the:

- **Hips:** *hip subluxation/dislocation* is where the ball of the hip doesn't sit in the socket of the joint properly. This can cause pain, limit movement and restrict participation. Individuals at GMFCS Level IV and V can be affected more.
- **Spine:** *scoliosis* is a condition of the spine in which it develops a sideways curvature. This can be mild, moderate or severe. The incidence of scoliosis increases with age and GMFCS level, and can develop or worsen between the ages of 10–20 years.
- **Muscles:** *contractures* are shortening of the muscles or tendons due to tightness. People with CP who have spasticity in their muscles are most at risk. A high proportion of teenagers with CP experience contracture.



What will help?

Hips and spine

Active surveillance

Active surveillance can help prevent pain, scoliosis, severe contractures and hip dislocation. Teenagers with CP should receive regular surveillance of their musculoskeletal development (hip x-ray) and timely intervention.

Active surveillance and monitoring through programs such as CPUP in Sweden and CPA's CP Check-Up™ continue to be considered best practice throughout your child's teenage years. An annual or biennial check-up is recommended. Your doctor can follow the The Australian Hip Guidelines to promote good hip health for your child.

Scoliosis surveillance for teenagers functioning at GMFCS Levels IV and V is also recommended.

Scoliosis surgery

Scoliosis surgery is effective in correcting scoliosis in teenagers who are not able to walk. The possible need for surgery can be discussed with your teen's therapy, rehabilitation and surgical team.

Muscles and muscle tone

Some medical and surgical interventions are available to help manage and dyskinesia in teenagers with CP. A multidisciplinary team including a rehabilitation physician, orthopaedic surgeon, neurologist, neurosurgeon, physiotherapist and occupational therapist may be involved. Recommended interventions include:

Botulinum toxin (BoNT)

BoNT is treatment administered by injection into specific muscles, resulting in a *temporary* reduction of spasticity. There is good evidence for the effectiveness of BoNT on upper limb and lower limb spasticity in children and young people with CP.

Botulinum toxin in combination with other interventions (e.g., serial casting, occupational therapy, physiotherapy, electrical stimulation, orthoses) can lead to improvements in range of motion, hand function, gross motor function, and goal attainment.

Serial casting

Serial casting involves plaster and/or synthetic casting materials applied to the arm and/or leg to immobilise it in a desired position. The cast provides a prolonged stretch to the muscles over time. Casts are usually left on for three days, and re-applied every 3-4 days.

Serial casting can increase the range of movement of a muscle. It may also lead to improvements in how a person walks for a short time after the casts are applied. Casting only has a short-term effect and may need to be repeated several times, particularly during growth spurts.

It may be recommended that serial casting follows another intervention, such as Botulinum Toxin therapy. Research shows that serial casting offered four weeks after Botox, improves the length of the muscle more than serial casting alone.

Serial casting is usually prescribed as part of a therapy program that addresses a variety of goals and will often be used alongside a targeted activity approach such as goal directed training.

Selective Dorsal Rhizotomy (SDR)

SDR is a surgical procedure where sensory nerves in the spinal cord are cut. This *permanently* reduces lower limb spasticity and can lead to improvements in walking.

SDR is most often performed in school-aged children, with most children selected for SDR in Australia being aged between 4-8 years. However, some older children with spastic diplegic CP may benefit from this procedure.

Rehabilitation after selective dorsal rhizotomy is long and intensive. Therefore, it is important to discuss with your teen's therapists and medical team if this intervention is suitable for them.

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.

Oral baclofen is the most frequently prescribed medication to help manage muscle tone. It is considered the first line oral medication.

Diazepam is another medication shown to be effective for the short-term treatment of spasticity.

Other medications such as *benzodiazepines*, *clonidine* and *gabapentin* may be 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 teen's doctor.

Intrathecal baclofen

Baclofen, used to help relax muscles with spasticity or dystonia, can be given intrathecally as well as orally. *Intrathecally* 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 may be suitable for teenagers who have spasticity or dystonia that affects most of their body. It can make a difference for comfort and ease of personal care.



Key messages

- Your teenager should continue to have a check-up of their hips, spine and muscles every 12 months, or as outlined in the Australian Hip Surveillance Guidelines. This is an effective way of proactively monitoring and managing changes in the body and helps to prevent severe problems from occurring.
- There are many different treatments available to keep bones, joints and muscles healthy. Surgical, non-surgical, and pharmacological options are currently supported by research evidence.
- A multidisciplinary team of people are involved in supporting decisions about what treatment approaches may be best for your teenager.



Hand and fine motor skills

We use our hands every day for many tasks. Improving your teenager’s use of one or both of their hands supports their participation and independence.

Many teenagers with CP have difficulties using their hands. Some have difficulties using one hand (*unilateral CP*) while others will have difficulties using both hands (*bilateral CP*). There are a number of interventions that can optimise hand function and skill development and enhance participation.

What will help?

Research has shown that children with unilateral CP need 30 to 40 hours of goal-directed, task specific practice to see changes in the use of their hands. Individuals with other types of CP benefit from 14 to 25 hours of goal-directed interventions to achieve changes in their individualised hand function goals.

In addition to GDT and CO-OP approaches (described earlier), the following interventions can improve hand function and fine motor skills:

Constraint Induced Movement Therapy (CIMT)

If one of your teenager’s hands is more affected than the other then CIMT will be of benefit.

In this approach a mitt, sling or cast is placed on the less affected hand. Your teen then uses their more affected hand to work on activities.

This approach encourages targeted practice to build control and coordination of the more affected hand.

Between 30 and 40 hours is needed to see significant improvements.

Bimanual hand therapy

Bimanual therapy is a different motor learning-based approach that uses cognitive strategies to optimise learning, motivation, and skill development of the hands.

By following specific verbal instructions and prompts, your teen will practise using two hands together to carry out everyday activities.

As with CIMT, between 30 and 40 hours of bimanual therapy has been shown to lead to improvement in hand function.

Both CIMT and bimanual therapy have been shown to work well for teenagers with CP.

Both require about the same number of hours in order to see good results. This means that your child can decide, in collaboration with you and their therapists, which approach may be most appropriate. They may prefer one approach over the other.

Hand/arm orthoses/splints

Orthoses or splints for the hand and arm are used to help position the hand, arm and fingers. Functional hand splints (worn during activities) and night-time splints (worn at night) provide a stretch to the muscles over an extended period of time. Splints should be can be used in combination with other therapy interventions such as goal-directed training.

Taping

Taping aims to position and stabilise joints, and change postures in the hand and thumb.

Taping may be a useful intervention for teenagers with CP if they have tightness or weakness in their hand. Taping should be combined with task-specific motor training.

As with hand splints, some teens may find taping uncomfortable and this can affect their willingness to wear the tape. If your teen has a skin allergy, taping may not be a suitable intervention.

Taping is a new intervention that is increasing in popularity for young teenagers with CP. This approach does require more research, so should be discussed with your teenager’s therapist to determine if it is appropriate.

Assistive technology for hands

Teenagers who have significant difficulty using their hands should have access to assistive technology to support their activities and participation. Options may include switches to access equipment, a joystick in place of a mouse, specialised keyboards, or eye-gaze technology. Mounting systems are available to help position the equipment.

Research suggests that the use of exergames (games where the primary focus is education and/or rehabilitation), robotics and technology to enhance computer access, assist with improvements in hand function and visual-motor coordination.

Specialised seating systems are also important in the daily life of some teenagers with higher support needs. Good positioning helps them use their hands to their maximal capacity.

Handwriting programs

For teenagers who wish to improve the ease and legibility of their handwriting there are programs available with a specific focus on this skill.

A task specific approach that engages cognitive and problem-solving skills is most effective in improving handwriting.

A minimum of 20 sessions has been shown to result in significant improvement.



Key messages

- Task specific, motor training-based interventions are recommended as the gold standard for teenagers with CP. Between 14-25 hours of practice (including therapy) is needed to see improvement in a specified goal.
- Constraint Induced Movement Therapy and Bimanual Therapy are both equally effective in improving upper limb function for teenagers with unilateral CP. About 30-40 hours of intervention is needed.
- A range of assistive technology options can support individual goals related to hand function and fine motor skill.



Communication

Communication is a vital part of life. We all communicate in different ways to share information, build relationships and participate in life.

Sharing a clear message, being understood and connecting with others are all essential components of communication. We communicate for different reasons, with different people, and in different situations. We all use different communication methods including speech, gestures, facial expressions, technology, and other visual forms of communication.

Some teenagers with CP have difficulty producing clear speech. This means they may be hard to understand or unable to speak at all. Communication difficulties are more likely when a person's motor difficulty is more severe, both sides of the body are affected, if the person has a dyskinetic type of CP or if they have an intellectual disability and/or epilepsy.

To optimise communication success many people with CP will communicate using methods other than speech or in addition to speech. These include symbol boards or books, speech generating devices, and non-verbal communication methods like signs and gestures.

Having alternative and augmentative methods of communication that are effective and efficient, can help reduce frustration and difficult behaviours that impact learning, development, participation and quality of life.



What will help?

Speech Pathologists can help your teenager work towards their unique communication goals. Strategies may focus on speech, language, and/or social skills and will aim to support communicative participation. Here are some specific approaches that may assist:

Expressive language therapy

Expressive language therapy helps your teenager use clear and effective communication by focusing on skills such as sentence structure, grammar, and vocabulary. Expressive language goals can be worked on using any single or combined method of communication (e.g., speech, signs and gestures, symbol or sentence boards, communication books and speech-generating devices).

Practising specific expressive language strategies within natural communication situations enhances use of these skills outside of a clinic setting. As communication is a social and interactive activity, group-based leisure or skill-development activities can be excellent settings in which to practice communication skills.

Receptive language therapy

Receptive language therapy aims to improve your teenager's ability to understand what others say and also what they read. Understanding the meanings of words, concepts, instructions, fiction, and non-fiction texts may be the focus.

Improvements in receptive communication can take some time to achieve. Some research suggests that up to 96 hours of intervention/practice is required over a 6-month period in order to obtain a 50% improvement in language skills. This may include direct therapy with a clinician as well as time spent practising home program tasks at home and school.

As with expressive language therapy, it is important that practice occurs in familiar, natural communication situations, as well as in dedicated practice times. This will help with the transfer of skills from one setting to another and with maintaining improvements.

Motor speech or articulation therapy

Teenagers with CP may have unclear speech due to:

- Difficulty using the correct sounds in a word (speech sound disorder),
- Planning the correct movements needed to make those sounds (apraxia of speech), and/or
- Controlling and coordinating the muscles that produce speech movements (dysarthria).

Motor speech interventions address difficulties with planning and production of movements for speech. They are based on principles of motor learning and require regular therapy sessions with a speech pathologist to be most beneficial. **Two to three sessions per week for six weeks**, followed by exercises to do at home, has been shown to lead to good results. The focus of such therapy can be on sounds, control of speech movements, pitch, loudness, rhythm and/or fluency.

The following programs have been shown to improve speech outcomes for some children with CP: Rapid Syllable Transition Treatment (ReST), Nuffield Dyspraxia Program, LSVT Loud Intensive voice treatment, and Dynamic Temporal Tactile Cuing (DTTC).

Your speech pathologist can assist with selecting the most appropriate approach for your teenager's needs.

Augmentative and Alternative Communication (AAC)

AAC can help your teenager to communicate when speech alone is not effective. AAC can include body language, signs and gestures, pictures, symbols, and speech-generating devices. Most teenagers with CP will have a preferred method of communication, but may communicate in many different ways, depending on the situation. This is known as *multimodal communication*. Having a range of communication options offers your teenager control over their communication and helps them to be more independent.

AAC intervention may focus on increasing vocabulary, locating and combining symbols, learning how to create more complex sentences, independently operating the AAC system, and exploring how to effectively use AAC in social situations with different communication partners.

Aided language stimulation (ALS)

ALS is an intervention approach whereby other people use a teenager's AAC system to *model* language and communication. The message on the AAC system is paired with a spoken message, so that an individual receives the information via at least two channels (visual and auditory). It's a good way to learn how to use an AAC system and to improve expressive and receptive language skills.

The value of using aided language stimulation when learning a new communication system is that people around your teenager get to know their preferred communication method. However, it is important to appreciate that some teenagers may have been using AAC since they were very young. They may feel confident in their chosen communication method, and may prefer others not to touch their communication system without permission.

Communication partner training

Communication partner training involves people around your teenager learning about their communication methods and the specific strategies they use to communicate. It is important to have communication partner training included as part of any speech pathology program. This way, familiar communication partners will develop the skills needed to effectively support your teenager's active communication.

Literacy programs

Literacy interventions can improve the reading and writing skills of teenagers with CP at a range of different reading levels: emerging, novice, or fluent.

Strategies to support reading and writing may focus on:

- **Phonemic awareness:** learning how to recognise and organise individual sounds
- **Phonological awareness:** learning how to recognise and organise the spoken parts of words and sentences
- **Orthographical awareness:** learning how sounds are represented using the written alphabet (letters); Recognising and organising groups of written letters in patterns e.g. 'igh', 'ing'
- **Decoding:** using knowledge of letter-sound relationships to read and pronounce written words
- **Encoding:** using knowledge of letter-sound relationships to spell and write words
- **Text comprehension:** understanding and drawing meaning from pieces of writing
- **Text construction:** combining words, sentences and paragraphs into a meaningful piece of writing.

As your teenager gets older, literacy skills become more and more important to support learning, life skills and independence. Decisions about health, work, leisure activities and finances all involve literacy skills.

Stuttering therapy

Stuttering therapy is a behavioural intervention available to teenagers who stutter. The aim of the intervention is to reduce stuttered speech whilst increasing fluent speech.

Stuttering therapy for younger children aims to systematically lengthen the stutter-free speech through graded activities. For older children and adults, therapy aims to change the speech pattern.

A substantial time commitment is required for stuttering interventions. Two evidence-based programs, the Lidcombe Program (for young children) and the Camperdown program (for adolescents and young adults), require an hour a week for 25 weeks, followed by 30 minutes a week for another year.

If your child stutters and has an intellectual disability or another impairment, more therapy might be needed.



Key messages

- Many people with CP will communicate using methods other than speech or in addition to speech. These are known as Augmentative and Alternative Communication.
- Speech Pathologists can help your teenager work towards their unique communication goals. Strategies may focus on speech, language, and/or social skills and will aim to support communicative participation.
- As your teenager gets older literacy skills become more and more important to support learning, life skills and independence. Decisions about health, work, leisure activities and finances all involve literacy skills.



Eating, drinking and swallowing

There is nothing better than sitting down for a good meal with friends and family! Safe, enjoyable and nutritious meals are important for everyone.

Eating and drinking are complex skills that require coordination and control of many muscles working together. Teenagers with CP may experience difficulties with biting, chewing, and swallowing. This is known as dysphagia. Dysphagia can affect how someone eats, drinks, takes medication, manages their saliva, and participates in social mealtimes with friends and family.

Difficulty swallowing may cause particles of food, drink or saliva to enter the airways (known as aspiration). If it continues to happen over time this can lead to frequent chest infections and serious respiratory complications. A small proportion of people unable to eat or drink safely may require non-oral feeding.

Swallowing difficulties can lead to poor growth, low body fat stores, and poor nutritional status. It is also not uncommon for teenagers with CP, particularly those with reduced mobility, to experience reflux and/or constipation. These conditions can lead to discomfort, pain, eating or behavioural issues.

A speech pathologist or dietitian can provide guidance on safe and effective ways to your teenager meet their nutritional needs, stay hydrated, and reduce the risk of preventable health conditions, such as chest infections.



What will help?

Regular and ongoing surveillance and timely intervention for eating and drinking difficulty is recommended for teenagers with swallowing problems to ensure good health and growth.

If a teenager presents with medical concerns associated with mealtimes, such as not gaining weight, weight loss, frequent chest infections or stoma care, a referral to a GP and, or to a specialised hospital-based feeding clinic is necessary.

Mealtime interventions can be organised into different categories:

Non-surgical interventions

Non-surgical interventions include:

- **Modifying texture** of food and drinks to reduce the risk of coughing, choking and aspiration
- **Optimising positioning and posture** to promote safe swallowing. Different swallowing techniques such as using a ‘tucked chin’ may also be used
- **Specialised equipment** such as cups and spoons to promote independence and safer eating/drinking
- **Oral motor and sensorimotor exercises** to improve oral function and chewing skills.

Emerging research suggests that electrical stimulation combined with oral sensorimotor exercises (5 x 30min sessions per week, for four weeks) may improve eating and drinking skills and drooling. However, to date, research has also only focused on children 2–6 years of age. The safety and ongoing effects of this intervention requires further research.

A Speech Pathologist can conduct a mealtime assessment, advise on the most appropriate intervention, and write up specific recommendations that work for your teenager in a Mealtime Management Plan.

Surgical interventions

Surgical interventions may be needed if swallowing difficulties are very severe.

- For some people with CP who require a safer and more efficient way of taking in nutrients, food can be put directly into the stomach using a **gastrostomy**. For individuals with severe dysphagia or nutritional issues this intervention can prevent food and drink going into the lungs, improve nutrition and growth and increase quality of mealtimes. Specific options include percutaneous endoscopic gastrostomy (a PEG tube) and jejunostomy.
- There is also a surgical option to help manage severe reflux. This is called a **Nissen fundoplication**. In this surgery, a ring of tightened muscle is created at the top of the stomach to prevent acid from the stomach flowing up the oesophagus (tube that connects the stomach to the mouth). Specific options include a Nissen fundoplication, laparoscopic fundoplication and gastric plication.

Outcomes of surgery can be different for different individuals, and there are some risks associated with each surgical procedure. Surgical options require discussion and decision-making with a team of people that includes you, your teenager, medical professionals, and members of your therapy team.

Nutritional interventions

Nutritional interventions are focused on helping your teenager to grow well, get the right nutrients and minerals, and take in enough food and drink to meet their energy needs. Regular monitoring of growth is important in the teenage years. Specific investigations are recommended as follows:

- A **nutritional assessment** is often required for young teenagers with CP who have poor growth, low body fat stores, poor oral movements, gastrointestinal complications such as reflux, or a gastrostomy button. Monitoring your teen's growth over time is important. Reliable measurements of weight, height, skinfold thickness and body composition are recommended.
- Your teenager should have a **blood test** each year to check their vitamins, minerals, proteins and trace elements. This is especially important if they have difficulty eating or swallowing or have been receiving enteral feeds (via a gastrostomy or jejunostomy) over a long period of time.
- Research suggests that teenagers with CP can have **low bone density** as a result of low Vitamin D and calcium intake. Insufficient weight bearing activity (e.g. standing, walking) and delayed puberty, can also contribute to this. A multi-disciplinary team including your GP and a dietician can provide important dietary advice to you and your teenager to optimise their growth, nutrition and development.

Drooling interventions

Drooling interventions help people with CP who have difficulty swallowing their saliva. When saliva falls out of the mouth, this is called *sialorrhea* or drooling.

If your teenager has difficulties with drooling, there are simple things they can do, like carrying a cloth or wearing an absorbent wrist band to wipe their mouth.

Aesthetics and hygiene are important to teenagers. Wearing a scarf or neck bandana can prevent saliva from falling onto clothes, and can be easily washed. There are many different colours and fabrics available which can be fashionably styled with outfits.

Some teenagers with CP take medication to reduce the amount of drooling. Botulinum toxin injected into selected salivary glands and surgical options can also be used to control more severe or chronic drooling. These strategies should always be discussed with your doctor as there can be side effects or time limited effects.

Dental interventions

For some teenagers it is challenging to complete regular and effective oral care. Teenagers with CP have been found to have higher rates of dental caries and poor oral hygiene than typically developing teenagers. Poor oral hygiene can increase the risk of bacteria from the mouth being aspirated into the lungs. Dental problems such as tooth decay, teeth grinding and reflux can cause pain if left untreated. Frequent and regular routine dental care results in improved dental health.

Special care dentistry is a subspecialty of dentistry that caters to people with a disability who have special needs. A range of services can be provided depending on requirements. Special needs dental services are usually available within the public or private hospital system and may require a referral from an appropriate health professional to access.



Key messages

- Eating, drinking and swallowing are complex skills that require coordination and control of many muscles working together.
- Teenagers with CP may experience dysphagia. Dysphagia can affect how someone eats, drinks, takes medication, manages their saliva and participates in social mealtimes with friends and family.
- Non-surgical and surgical interventions exist to help manage swallowing difficulties, saliva problems and dental issues.
- A multidisciplinary team including speech pathologists, dietitians, and medical professionals contribute to positive eating, drinking and swallowing outcomes.





Self-care and independence

Adolescence is an exciting time as teenagers are trying new experiences, learning to do many things for themselves and exploring different ways to become more independent.

For teenagers with CP the desire to be independent is no different to their typically developing peers. But many teenagers with CP will need some extra help with daily self-care activities like toileting, bathing, moving between positions, dressing, mealtimes and positioning for sleeping. The ability to carry out self-care activities is influenced by gross and fine motor function, swallowing function, vision and cognition.

A goal for teens is often to achieve a balance between self-independence and receiving the right amount of help from others. Where full independence has not already been reached, the teenage years are an important time to identify compensatory strategies that maximise participation in self-care.



What will help?

The self-care goals your teenager has at this time in their life may be focused on performing a task themselves or involving a parent or carer to assist with the task. As children get older new and different challenges may arise. As such, goals and strategies may be revisited, revised and refined at different times.

Goal directed training and CO-OP

These interventions, as noted throughout this guide, can help teenagers learn to complete self-care activities to the best of their ability by using techniques and strategies that are tailored to individual needs. Ideally, as your teen learns to do more and more of a task themselves, caregiver support can reduce.

Assistive technology

Assistive technology includes equipment and devices for bathing, showering, toileting, dressing, supporting sleeping, moving between positions and accessing spaces around the home and in the community. This can help your teenager to be as independent as possible whilst still doing tasks in a safe and efficient way.

Assistive technology can support:

- **Personal care/self-care:** examples include bidets, commodes, toilet frames, rails, shower chairs, changing equipment and moisture alarms
- **Sleep:** examples include height adjustable beds, body position supports, a pressure relieving mattress, night CPAP mask, bed pole and grasp bar, and sleep systems. More research is needed to understand whether sleep systems improve sleep quality
- **Transfers:** examples include a hoist and sling, transfer board or bench, a lift, and home/vehicle modifications.

Specific equipment can be trialled and prescribed based upon your teenager's individual needs. Talk to your occupational therapist and/or physiotherapist about appropriate options.

Puberty

Teenagers with CP will most likely begin puberty at around the same time as other peers and experience the same physical, emotional and hormonal changes. However, they may need additional support to understand how these changes affect them and how to manage them.

For example, teenagers with CP may need assistance with learning self-care skills such as independent toileting, hygiene and menstrual management. GDT and CO-OP are two recommended therapy options for learning these skills.

Sexuality and sexual health

Adolescence is a normal time for young people to become more curious about sex, sexuality, and sexual identity. It is also an important time to help your teenager build their awareness of practices and services to support sexual health.

As a parent, you will know when and how you would like your child to learn about these topics. It is important to help your teen feel comfortable to seek information or assistance in exploring and understanding their sexuality and sexual health needs, when they are ready.

Having a disability can sometimes change the way a person experiences and expresses their sexuality. For example, individuals who have sustained a traumatic brain injury may be less sexually inhibited, leading to inappropriate behaviour around others. Guidance from a doctor or other knowledgeable health professional may help if you or your teen are worried or concerned about anything or need more information to help inform good choices and decisions.

Adolescence may be the time when teenagers first experience a need to know about and use contraception. Teenagers have the right to make their own informed choices about the method of contraception to use, why it is being used, and the range of appropriate contraception options available.

To find out more you and your teenager can talk to a health care professional, pharmacist, family planning centre or reproductive health nurse.

 **Key messages**

- Managing your teenager’s personal care/self-care is about finding a balance between what they can do safely and efficiently for themselves, and the assistance they need from others.
- Goal directed training and CO-OP approaches can help. A range of assistive technology and equipment is also available to support your teenager’s individual needs and goals.
- Exploring sexuality is a natural part of adolescence and is supported through access to good quality information and sexual health services.



Behaviour and mental health

Everyone needs to learn healthy ways to deal with tough times and difficult situations. Teenagers with CP are no different.

Teenagers with CP are at increased risk of experiencing behavioural and mental health issues including depression, anxiety and behavioural/conduct problems.

These issues may be related to their disability, but can also be about adjusting to and coping with everyday challenges. Common experiences that can be hard for teenagers with a disability include making friends, keeping up with school work and bullying. Sometimes these things can become overwhelming.



What will help?

Any support provided to a young person with CP should be tailored to their individual needs. You and your teen can consult with a doctor of health professional regarding assessment and management of mental health concerns. Referral to a trained mental health professional including a psychologist or psychiatrist may also be helpful to provide support for mental health and emotional concerns.

Understanding behaviour

Behaviours of concern can arise for different reasons. A person may feel frustrated but have an inability to communicate in clear and appropriate ways. They may experience pain or discomfort but can't tell anyone. They may feel uncomfortable or uncertain when things in their routine or environment change without warning.

Understanding the reasons why a behaviour occurs can help prevent that behaviour from occurring again. Helpful information can be collected by observing patterns of behaviour and keeping a diary. Observations should include the A-B-C's of behaviour:

- **Antecedents:** what happened directly before the behaviour took place
- **Behaviour:** what the behaviour involved, how long it lasted, and how intense it was
- **Consequences:** what happened directly after the behaviour, including how it was managed and the resolution reached.

Managing behaviour

Behaviour support plans

Behaviour support plans help everyone around an individual to understand why a behaviour occurs and how to manage that behaviour in a way that is positive, respectful and safe.

A behaviour support plan based on a detailed assessment of the cause and function of behaviour is considered best practice. Behaviour support plans are a legal requirement in Australia where any type of restrictive practice (including pharmaceutical) is used. All behaviour plans should include detail about individualised management strategies.

Plans should be reviewed and updated frequently, with collaborative input from a range of people including the individual where possible, parents and family, carers and support workers and behaviour support professionals.

Behaviour therapy

Positive behaviour support and behavioural interventions may help teenagers with CP who are experiencing emotional or behavioural difficulties or mental health challenges such as anxiety or depression.

- **Positive behaviour support** is an individualised approach used by parents and carers to encourage an individual to behave appropriately. The approach aims to make challenging behaviour unnecessary by teaching alternative and more appropriate ways to reach a goal. It also focuses on removing things that trigger behaviour or provide unwanted encouragement or reward for the behaviour.
- **Cognitive Behavioural Therapy (CBT)** can help children and adolescents with CP manage chronic pain and identify unhelpful thoughts and behaviours that are contributing to anxiety and/or depression. The approach encourages healthier ways of thinking, and skills and habits to deal with mental health challenges. It is a form of 'talking therapy' that relies on an ability to communicate, either verbally or using augmentative and alternative communication methods.
- **Acceptance Commitment Therapy (ACT)** is one particular type of cognitive behavioural therapy that incorporates mindfulness and non-judgmental attention to thoughts, feelings and experiences. The aim is to increase psychological flexibility: the ability to respond and adapt to life events.
- **Solution focused brief therapy**, where children, adolescents and adults take an active role in identifying their own strengths and resources. Solution focused brief therapy can assist individuals and their family to address mental and emotional health and wellbeing, behaviours of concern or relationship difficulties. It can be used with children and adults who have the capacity to reflect on their own situation, take an active role in identifying their own strengths and resources, and work towards how they want things to be different.

Parenting programs

Positive parenting approaches involve family and carers changing their interaction style to promote positive relationships with an individual demonstrating challenging behaviour.

Teen Triple P is a parenting program delivered online or face to face that focuses on helping parents develop skills to support and encourage positive behaviour in their teen. It is designed to support families with teenagers aged 10–16 years. Information on positive parenting strategies, managing emotion, respectful relationships, getting along with others, and approaching problem solving in effective ways is covered.

Educational software programs

Educational software addressing safety skills and social skills is commercially available for children and young people with behavioural difficulties and/or learning difficulties. One such program, Coping with Chaos, is a story-based program about emotions and behaviour, designed for children and adults with autism, behavioural difficulties and/or learning difficulties.



Key messages

- Teenagers with CP are at increased risk of experiencing behavioural and mental health issues including depression, anxiety and behavioural/conduct problems.
- Support provided to a young person with CP should be tailored to their individual needs.
- Positive behaviour support and behavioural interventions such as cognitive behavioural therapy, acceptance commitment therapy, solution focussed brief therapy, and other mindfulness-based approaches, may help teenagers with CP.
- Parents can also support their teenagers through positive parenting approaches that focus on changing their interaction style to promote positive relationships.





Learning

Every young person with CP deserves an equal opportunity to learn and thrive within their educational settings. Learning needs of teenagers with CP will vary widely.



Starting high school

Making the leap from primary to secondary school is both exciting and challenging.

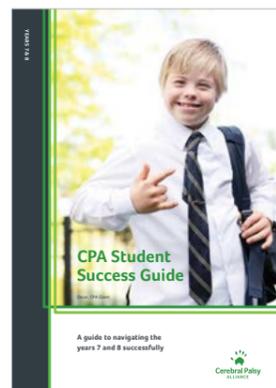
Adjustments will need to be made as your child transitions from primary to secondary school. They may be moving from a setting where their needs are well known to an environment where there may be lots of teachers, lots of students, multiple class locations, and different learning expectations.

It's natural to feel a certain level of anxiety when making a big change. Planning, preparation, good communication, and a team approach can help facilitate a smooth change to a new school.

What will help?

- **A Physical Access Assessment** can be completed by an Occupational Therapist and/or Physiotherapist. Your child's therapy team can go to their new school and provide information about the safest and most efficient ways for your teen to move around the school. They can identify any equipment needs and support the school to make any necessary accessibility modification to keep all students safe, including your teenager.
- Having **good access to the school curriculum** will also help your teen to learn more effectively. This includes finding the best way for them to complete academic tasks such as handwriting and maths, as well as sporting activities and communication tasks. Your child's Occupational Therapist, Speech Pathologist and/or Physiotherapist, together with their classroom and learning support teachers, can help find ways to support participation in learning activities and optimise learning.

Additional information about transitioning to school can be found in the *Cerebral Palsy Alliance Student Success Guide, Years 7–8*. It is available to download and read on the Cerebral Palsy Alliance website: cerebralpalsy.org.au/cpa-youth/cpa-student-success-guides.



The right learning supports

Everyone has different learning interests, strengths and learning needs. It is important to find ways to harness strengths and interests while supporting unique learning goals.

Often teenagers with CP can be quite surprised to find out that learning difficulties can be very common. Some teenagers with CP can find it difficult to control certain thinking skills that are important for learning. These can include:

- Attention: focusing on a task
- Memory: holding information in the mind for either a short time (working memory) or a longer time (short-term/long-term memory)
- Organising information
- Planning the steps that are needed to complete a task
- Thinking of solutions to problems
- Managing emotions and behaviour.

There are general and also specific strategies that can help your teenager with their learning success.

What will help?

General strategies

Teenagers will learn best when they get enough sleep, and any pain or other conditions like epilepsy, are well managed. Strategies to help your teen hear, understand and use information effectively will help. These can be things like:

- Limiting background noise
- Sitting near the front of the classroom
- Having information broken down into simpler chunks
- Asking teachers to use visual supports or verbal prompts to support comprehension.

Other strategies such as more time to complete work, using a scribe during written assessment tasks, or speaking rather than writing information, may be considered reasonable and necessary adjustments that can be reflected within an individualised education plan (IEP).

Specific strategies

- A cognitive assessment is recommended if your teenager has any learning or behaviour challenges. This assessment will help your child, family, teachers, and support team to better understand their specific learning needs and goals and how to address them.
- For some people with CP, who also have difficulties with attention (e.g., Attention Deficit Disorder), medication may help. Medications need to be managed by a doctor and will always be discussed with you and your teenager.
- Assistive technology programs and interventions can help with learning in specific areas such as literacy (reading and writing), communication, social skills and thinking skills (cognition).
- Your child's teachers are experts in the curriculum. Collaborating with allied health professionals will help ensure your child has access to the curriculum in the ways that they need.

As your child moves through their teenage years needs and supports will likely change. More information about the middle years of high school and what can be expected can be found in the *Cerebral Palsy Alliance Student Success Guide, Years, 9–10*. It is available to download from our website: cerebralpalsy.org.au/cpa-youth/cpa-student-success-guides.



Leaving high school

For young teenagers with CP, planning for the transition into adulthood starts earlier than for young teenagers without disabilities. What can you be thinking about now?

The final years of secondary school can be a big challenge for students and their parents. This can be even more so for those students with CP. In addition to managing school work, exams, and activities outside of school, your teenager may be thinking about other important life goals also. These may include friendships and relationships, skills and independence, and after school options.

What will help?

To assist with planning for life after school, it is important to consider:

- Further education pathways e.g., vocational education, university
- Life skills development
- Employment.

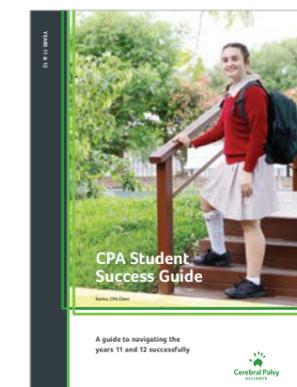
If further education is something your teenager would like to pursue discussions with teachers, education support staff, careers advisors and family may be helpful. Information about what options are available, entry requirements, HSC preparations, and disability services and supports, can assist with planning.

To help with identifying goals and considering post school options, a number of programs and services exist for teenagers. These include life skills training, mentoring, and coaching which can be offered one-on-one, in classes, as workshops or at camps.

Some people with CP choose to focus on practical skills that will help them secure future employment. Others focus on skills needed for daily activities. Others still want to work on their social skills, friendships and relationships.

The focus of these programs is all about your teenager and their needs. This means working with your child and their support network to establish individualised, meaningful goals and strategies.

You can find more information about the final years of high school and planning for life after school, in the *Cerebral Palsy Alliance Student Success Guide, Years 11–12*. It is available to download from our website: cerebralpalsy.org.au/cpa-youth/cpa-student-success-guides.





It's important to acknowledge and think about the future and the opportunities ahead. What are the possibilities? What can you start planning now?

During your child's final years of school, there may be discussion about options and opportunities beyond school. There are many decisions to be made and this can be an overwhelming time for many students, especially for those with disabilities.

While there are popular ideas about what 'should' come next, this is an important time for your teenager and your family to reflect and consider all of the options available.

Some young people will love the idea of pursuing further study or employment. But that doesn't mean it's for everyone, and that's OK. What is important is that your teen feels they are doing something they are interested in, they are challenged, and have opportunity to participate in meaningful activities.

What are some options?



Further study

If your teen wishes to complete further study there are a number of different education options available after school. Some options involve completing a formal qualification, whilst others don't.

Tertiary education

In Australia, tertiary education refers to formal education provided after secondary school by both government and private providers. It is generally divided into two sectors: vocational education and training (e.g. TAFE, private colleges) and higher education (e.g., universities).

- **Vocational education and training (VET):** VET qualifications help prepare students with skills for work. These qualifications usually have a very practical focus. As well as focusing on specific skills for a chosen occupation, a VET course will often include general work-based topics such as workplace health and safety.
- **Higher education:** higher education providers offer qualifications ranging from undergraduate awards (e.g., bachelor degrees, associate degrees and advanced diplomas) to postgraduate awards (graduate certificates and diplomas, masters and doctoral degrees). There is a wide variety of courses and flexible learning options available.

Community education

Community colleges or community education providers offer both accredited qualifications and non-accredited interest-based courses. If your teenager is not seeking a qualification but wants to learn a new skill or explore a new topic, then community education may be appropriate. Short courses in areas like art, business, languages, lifestyle, sports and fitness, are available.

Most education providers nowadays offer face to face options, online options, or a mixture of both. Your child can choose to study in a way that matches how they like to learn and the supports that they need.

It is recommended to start thinking about learning and education plans early. Exploring and discussing options with your teen, their teachers, learning support staff and career advisors is a good way to make well informed decisions. These professionals can also help your child get ready for further study by linking them with any specific assessments and/or disability support services that may be needed.

Part-time or full-time work

If your teen doesn't want to go into further study straight after school, they may wish to explore opportunities for part-time or full-time work or an apprenticeship.

These opportunities can be in open or supported work settings, depending on individual abilities, needs and preferences.

It is a good idea for your teen to try and gain volunteering, training and work experiences throughout their school years. This will help them to confidently approach employment opportunities later.

Many organisations will offer employment focused programs that support transition into the workplace. As an example, Cerebral Palsy Alliance offers the CPA School Leavers Employment Support (SLES) program. In this program participants can learn a range of employment specific skills, including:

- Writing a resume and cover letter
- Searching and applying for a job
- Communicating at work
- Money handling and budgeting
- Travel training and catching public transport
- Understanding what your employer needs from you
- Starting a new job
- Health and safety.

This program also includes individualised functional assessments dependent on your child's needs, as well as coaching support, either individually or in groups.



Community participation

Some teenagers and young people with CP may not wish to pursue further education or employment immediately after school. For those people there is also the option of joining a community participation or life skills program.

The focus of these programs is going out and participating in the community, making friends and connections, and pursuing individual interests. For example, a program could include:

- Music
- Visual arts
- Technology
- Home and living skills
- Personal development
- Yoga
- Cooking
- Sports.

You and your teenager may also wish to explore workshops or programs offered in the community that build life skills and capacity for independence. Living independently and accessing the community independently means different things for different people. A program can be designed to meet the learning needs and interests of your child.

Life skills training, mentoring and coaching

A number of programs and services exist for teenagers with CP such as life skills training, mentoring and coaching. These specialized services can be delivered as a one to one session, workshop, group class or camp.

The focus of these programs is to provide individualized training that builds the skills and independence of adolescents and young people. The training/coaching is client centred and goal directed. Goals are often practical and may focus on securing employment, developing skills to carry out activity of daily living, developing social skills and maintaining friendships.

Youth-focused programs may help teenagers with CP increase their self-efficacy and self-determination, provide opportunity to spend time with peers and increase independence.

Moving out of home – is it an option?

One day your child may want to live by themselves, with friends, or in supported accommodation. What might this look like? What planning can start now?

As with study and employment options, there is no one-size-fits-all when it comes to living arrangements for people with CP. Very few teenagers move out of home as soon as they turn 18. This is the same of teenagers with CP. But planning for what, where, and how your child may want to live and what supports they might need, does start at this time.

Does your teenager want to stay living with family? If they plan further study, do they wish live on campus at university or college? Do they have friends that they want to move in with? Or is their ultimate goal to live independently in their own place, or in shared and supported living arrangements?

While plans do not need to fully developed and finalised right now, being aware of what is available, possible and realistic for your teen, is a great start.



Managing health care

A transition to adult health care services offers teenagers with CP an opportunity to gain independence and take more control of their health care needs and services.

Once your child turns 18, they will transition to adult health care and hospital services in your local community. Your child's doctor (or general practitioner) and community-based therapists may remain the same. But specialised medical services such as general pediatricians, rehabilitation specialists and neurologists will change over to adult-based services.

It is best to start a transition plan early, around 12–14 years of age, as there are different stages of the transition.

Early stage

This stage includes the time from your child's diagnosis, to the age of about 12 years. Services will be received from your GP, pediatrician and child specialist services or hospitals.

Preparation stage

Between the ages of 12-16, you and your child will talk to health providers about drawing up a transition plan. You might start to visit adolescent services. If your teenager has the ability and willingness to do so, they may begin to attend some of their doctors' appointments by themselves. They can start learning about how to independently communicate with their doctor and manage their own health care.

Active stage

Between the ages of 16-19, your child may be attending more appointments independently, if this is what you and your teenager decide. This will help your child build skills in self-managing their health care. Your teen will always have help if they need it. But they will be offered more opportunity to start making decisions about their health. They may have joint visits with both child and adult service representatives present. This helps to ensure that information is shared effectively.

To support and prepare your family, many children's hospitals will refer you to a Transition Service to help with this big change.

More general information about transitioning to adult health care services can be found on the Raising Children website raisingchildren.net.au/teens/mental-health-physical-health/chronic-conditions/teens-with-chronic-conditions-adult-care. This is a parenting website, so the information is written for parents. But teenagers can also benefit from knowing about the processes that are involved in moving towards adult health care.

Classification systems

The Gross Motor Function Classification System (GMFCS) tool is helpful to indicate the gross motor level of an individual with CP including sitting, walking and use of mobility devices. Teenagers who are functioning at:

- **GMFCS Level I** will walk independently at home, school, outdoors and in the community. Teenagers are able to walk up and down stairs without the use of a railing
- **GMFCS Level II** will walk in most settings and may use a hand-held mobility device for safety in some settings. Teenagers walk up and down stairs holding a railing or with physical assistance
- **GMFCS Level III** are capable of walking using a hand-held mobility device and require assistance when climbing stairs. Teenagers may use a manual or powered mobility device at school, outdoors or in the community
- **GMFCS Level IV** will use wheeled mobility devices in most settings by operating a powered device or being transported in a manual mobility device. Teenagers may walk short distances indoors with physical assistance
- **GMFCS Level V** use wheelchairs specifically modified for their needs in all environments.

The Manual Ability Classification System (MACS) is a scale which helps to describe how individuals with CP handle objects in everyday tasks. It is often used to develop goals and focus relating to hand function training.

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

The Eating and Drinking Ability Classification System (EDACS) is a five-level scale used to describe how teenagers with CP usually eat and drink. A teenager at:

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

The Communication Function Classification System (CFCS) is a five-level scale used to describe the everyday communication of teenagers with CP. This includes both verbal and non-verbal communication.

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

The Viking Speech Scale (VSS) is a four-level scale used to classify speech production using different methods of communication.

- **Viking Level I:** speech is not affected by motor disorder
- **Viking Level II:** speech is imprecise, but is usually understandable to unfamiliar listeners
- **Viking Level III:** speech is unclear and not usually understandable to unfamiliar listeners out of context
- **Viking Level IV:** 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 teenager

Spasticity: tightening of the muscles

Unilateral: affecting one side only.

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