

Fact Sheet

Cerebral Palsy

What is cerebral palsy?

Cerebral palsy (CP) is lifelong physical disability that begins in early childhood. It is due to an injury to or abnormality in the developing brain in pregnancy or early childhood. It effects movement, posture, muscle control and co-ordination of movement. Some people may also have additional secondary conditions (described in common characteristics).

CP is a condition that can change and worsen over time, however it is not a degenerative condition. For some people with CP the impact of the condition, over the life course, may become more complex. CP is the most common childhood onset physical disability.

There are currently around 34,000 people living with CP in Australia and this is growing rapidly.

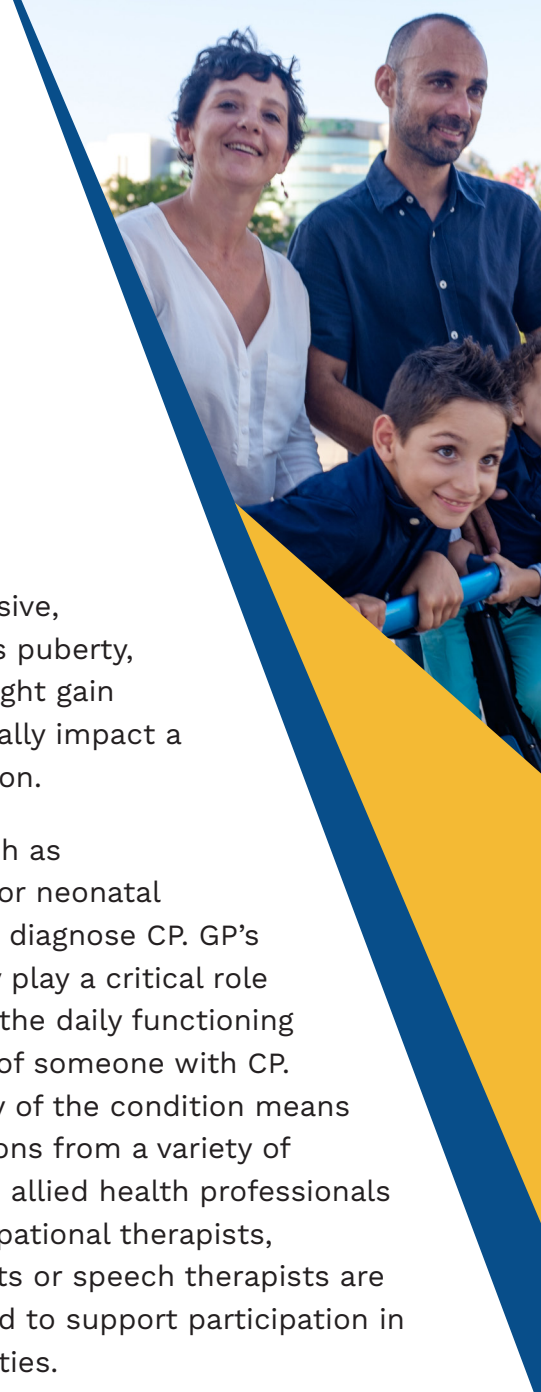
One in 500 Australian babies are diagnosed with the condition. Often the cause is unknown.

CP can affect gross and fine motor skills, as well as speech. This impacts everyday activities and someone's ability to participate in usual life situations and activities. Although the brain injury in CP

is non-progressive, factors such as puberty, ageing and weight gain may detrimentally impact a person's function.

Specialists such as paediatricians or neonatal specialists can diagnose CP. GP's also frequently play a critical role in maintaining the daily functioning and wellbeing of someone with CP. The complexity of the condition means that interventions from a variety of specialists and allied health professionals including occupational therapists, physiotherapists or speech therapists are usually required to support participation in everyday activities.

CP can be classified according to the type of movement disorder, the severity of the physical impairment and the parts of the body affected (distribution). These classifications are discussed below.



Different types of cerebral palsy

The different types of CP include **spasticity, dyskinesia, athetosis (or dystonia), ataxia and mixed**.

Spasticity

Spasticity is the term used when muscles are stiff and tight. People with spasticity have slow jerky movements which are difficult to control and often have substantial underlying weakness. It is the most common type of CP affecting 70 - 80% of people.

Spasticity can increase and be more noticeable when a person moves faster or when undertaking an action such as talking or displaying emotions such as anger, sadness or excitement. Spasticity can affect the arms and legs and in more severe cases the whole body. Drooling can occur, and speech can be slurred.

Dyskinesia

Dyskinesia is the term used for movement disorders that are involuntary with variable muscle tone. The movements differ quite markedly from person to person. At least 6% of people with CP have dyskinesia. There are three different types of dyskinesia; dystonia, athetosis and chorea. The three subtypes differ in terms of muscle tension and movement.

- **Dystonia** is a movement disorder in which sustained or repetitive muscle contractions result in twisting and repetitive movements or abnormal fixed postures.

- **Athetosis** is a movement disorder characterised by slow, involuntary, convoluted, writhing movements of the fingers, hands, toes and feet and in some cases arms, legs, neck and tongue.
- **Chorea** is a movement disorder characterised by brief, random, irregular movements that are not repetitive or rhythmic but appear to flow from one muscle to the next in a “dance-like” fashion.

These movement disorders can also affect speech and swallowing. Individuals with these movement disorders can present as constantly moving or restless. This is because they are constantly trying to hold their body upright or re-adjust their posture.

Ataxia

Ataxia is the least common of all the types of CP. It is the term used for a movement disorder characterised by unsteadiness and tremor. People with ataxia are more prone to falls. Ataxia can affect the legs, arms, hands, speech, and eye movements. Swallowing and unsteady face muscles can cause a person to drool.

Mixed

Mixed pattern is a combination of the types of CP. The most common being the combination of spasticity and dystonia.

Measures for describing cerebral palsy

There are several classification tools used to determine how severe the condition is and how it affects individuals including eating, drinking, speech and hand skills. The **Gross Motor Function Classification System (GMFCS)** is the most commonly used.

This system has a 1-5 rating scale, with 1 being the least severe and 5 being the most. The GMFCS classifies the level of a person's function in terms of their ability to perform gross motor actions, including sitting, standing, walking and running. The most commonly used scales are for children aged 2-12 years old and another for adolescents 12-18 years old (useful in adulthood). The descriptors are as follows.

Level 1

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

Level 2

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces.

Children may walk with physical assistance, a handheld mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

Level 3

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use

wheeled mobility when traveling long distances and may self-propel for shorter distances.

Level 4

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community, children are transported in a manual wheelchair or use powered mobility.

Level 5

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain anti-gravity head and trunk postures and control leg and arm movements.

Parts of the body affected

The terms used are as follows:

Quadriplegia where both upper and lower limbs are affected. Often the trunk and head are affected.

Diplegia where the lower limbs are affected. The upper limbs may be only slightly affected.

Hemiplegia where only one side of the body is affected.

How is cerebral palsy diagnosed?

A physical assessment of an infant's movements should be conducted as soon as possible when concerns are raised. The **General Movements Assessment**, which can be conducted up to 5 months of age, can help to make an early diagnosis of CP. This is a strong predictor of CP, particularly when changes to the brain are seen on an MRI brain scan. However, this assessment cannot predict the severity of CP. This is important so that children at high risk receive early intervention.

For children of all gestations CP is a clinical diagnosis supported by evidence from physical assessments, MRI brain scans and sometimes other investigations. Very premature babies are usually monitored carefully and may have an early MRI scan to detect CP, which sometimes shows an injury to the brain.

Common characteristics and impacts of CP

Although everyone with CP is different, there are some commonalities including;

- Many people with CP have a second or third disability or associated impairments such as **intellectual disability (50%), epilepsy (25%), hearing or vision impairment (10%), speech impairment (25%), behaviour disorder (25%), incontinence (25%), sleep disorder (20%) and saliva control problems (20%)**.
- Some people with CP have a mental health condition. Anxiety and depression are common. Reasons for this are not usually the underlying physical disorder but the associated

psychological and social factors that may impact the individual.

- Anecdotal evidence suggests that some people with CP are hyperemotional.
- Many people with CP experience **chronic pain (75%)**, particularly in adulthood.
- Most people experience a significant decline in physical functioning in adulthood because as other activities, such as studying, working and socialising are prioritised, often there is less time for exercise, stretching and therapy which are needed to maintain strength and function.
- Often people with CP have underlying muscle weakness which can have a more significant impact than the CP itself.

Often the complexities of these additional impairments have a greater impact than the CP itself and will require a higher level of supports to enable someone to engage in everyday life. Some examples include someone who does not have good hand function and speech impairment will likely need assistive technology such as an eye gaze device to help them communicate.

People with cerebral palsy often require the use of a range of assistive technology (AT) to minimise the impact of their disability on their functioning and participation. The AT required can vary from 'off the shelf' technology to specialised and customised technology. During childhood and adolescence, due to physical growth, assistive technology items usually need replacing much more regularly than during adulthood.

Myths and misunderstandings

CP is not a genetic condition

One percent of cases are genetic (more than one person in the family has CP) and between 10%-30% has a genetic component, particularly where multiple siblings have CP.

Everyone with CP uses a wheelchair or walking aid.

Most people with CP can walk with minimal support. In fact, in some individuals the disorder is too mild that it may go unnoticed by others.

Everyone with CP has an intellectual disability.

Intellectual disability affects 50% of people with CP. Generally, the less physically impaired someone is, the less likely they are to have an intellectual disability. However, this is not always the case. Some people who have mild CP also have intellectual disability and some people who have a severe physical impairment have no intellectual disability.

Everyone with CP has a limited life expectancy.

CP is not usually a life limiting condition. In rare cases, where a person has profound CP, associated factors such as severe scoliosis or respiratory problems, may cause premature death.

People with CP are not sexually active.

Most adults with CP can and do have regular sex. In some cases, physical limitations, societal attitudes and other social barriers may present challenges to sexual activity and to attracting partners.

Myths and misunderstandings

People with CP cannot have babies

People with CP have the same reproductive systems as everyone else. Women with CP are expected to have typical pregnancies.

Everyone who is non-verbal and has CP also has an intellectual disability and cannot understand me.

Never presume the capacity of a person with CP. An inability to communicate verbally does not always indicate the presence of an intellectual disability. Non-verbal people with CP are most likely able to understand you.

You can test for CP before birth.

CP is diagnosed in early childhood. It is a clinical diagnosis often supported by physical assessments and MRI brain scans. There are no prenatal tests for CP and it may take some time to be diagnosed, particularly if the baby has a typical birth and complications are only recognised after birth.

A person with CP is drunk.

One should always be careful before judging by appearances. A person with CP can often appear intoxicated if they have uncoordinated, shaky, walking patterns. They are not intoxicated.

People with CP belong together and away from their community.

Everyone has the right to full citizenship and inclusion. Historically, people with CP were often segregated into 'special' schools, sheltered workplaces and group homes. This is not always appropriate. People with CP are more likely to succeed in inclusive and supportive environments. This could be in mainstream schools or workplaces, and in everyday homes.

Common barriers to social and economic participation

People with CP have the same aspirations as their fellow citizens: to be in a loving relationship, to have friends, to participate in community life and work, and to feel included as full citizens.

However, like many people with disability, people with CP encounter multiple barriers to social, economic and civic participation.

These barriers include discriminatory attitudes, perceptions and misconceptions, and environmental and social obstructions.

People with CP are entitled to the same opportunities as everyone else.

Barriers to participation include:

- Limited understanding of CP, resulting in stigma and exclusion.
- Difficulties in connecting to mainstream services.
- Inadequate policies and supports relating to the inclusion of people with CP in schools and workplaces.
- Limited support to assist people with their life transitions, such as moving between adolescence and adulthood.
- Limited community resources and venues that support people with CP to be included in the community such as sporting facilities, public spaces, educational settings and medical practitioners (particularly GP's that do not understand CP).
- Limited resources and investment from employers to support people with CP throughout their working life, including changes to the work environment, policies to support people to attend medical appointments and disability specific health and well-being programs.
- Inadequate access to independent living options.
- Limited or no physical access to buildings, facilities and transport.
- Lack of adequate, timely and appropriate disability funding and support particularly for communication devices, equipment and assistive technology.

Common language and terminology

In all instances, use language which focuses on people's strengths and their abilities instead of their cerebral palsy.

Don't say...

Instead say...

Here's why.

Spastic	Person with CP
Retarded	Person with CP
Wheelchair bound	Wheelchair user
Vegetable	Profoundly disabled

Medically, spastic means tight and stiff muscles. It is ok to use in a technical medical context; however, it is offensive and derogatory when used to define, insult, tease or belittle someone.

If discussing intellectual function use "intellectual disability". The term retarded is outdated, offensive and harmful. It is not socially acceptable irrespective of context.

This term is offensive and outdated. The term wheelchair bound implies that people are permanently stuck in their wheelchairs. Wheelchair user is more appropriate because a wheelchair is used for mobility.

This derogatory word implies that people who require full support are less than human. This is also outdated, offensive and harmful. This term is disempowering.

Suffers from CP	The person 'has' CP, or is a person 'with' CP	This phrase implies that the person is suffering and does not have a good life. This is often incorrect as many people with CP have great lives.
Special needs	Has cerebral palsy	The term 'special' is now seen as derogatory implying that the person is less than, or that people with CP are only amazing because of their CP and nothing else.
Inspirational		The term inspirational can be offensive when used in simple everyday circumstances like getting out of bed or going out with friends. In this case you are best to say nothing and treat the person with CP the same as other people.

What is the role of the family in providing support?

Everyone's family plays a different role in their life, however the family of an individual with CP will play a vital role in their physical, social and emotional health for an extended period. A family's ability to provide these supports will vary based on their own physical health, mental health, economic status, parenting capacity and resilience, or if a parent has a disability themselves.

Family members of a child with CP are usually more involved in providing direct support with personal care, daily living, management of assistive technology and specialised equipment, assistance with play or social interaction, implementing therapy, teaching and supporting communication, study and work, as well as attending medical and allied health appointments. This may be beyond the age or to a greater extent than which you would typically expect a parent or family member to be involved. In cases where the needs of the person with CP increase over time or due to life circumstances, families will require formal supports to help reduce the associated workload.

The level of support differs for each person with CP depending on the severity of their condition.

For some people family support may reduce over time whilst for others it can increase and become more complex as the child with CP grows into adulthood.

Some complexities include a person becoming bigger and heavier, more pronounced physical support needs, less available appropriate long term supports, and aging parents.

Family members are often expected to play a role in advocating for their family member with CP, which is not always possible. Often family members themselves feel disempowered, exhausted and lacking in confidence to challenging systemic barriers and mainstream services where supports are inadequate. Supports for family members are critical to maintain their own health and wellbeing and sustain their caring role.

Family members supporting adults with CP will be presented with the challenges that life transitions bring such as accessing adult support and services, building and maintaining relationships, sexual health, moving out of home, education and coping with social changes. Family members are often more involved in supporting the individual with CP in these life areas.

Supporting and considering holistic family needs, as well as other informal supports, are crucial when working with an individual with CP. This will ensure that the individual and those important to them can function at their best.

Assistive Technology

People with cerebral palsy often require the use of a range of assistive technology (AT) to minimise the impact of their disability on their functioning and participation. The AT required can vary from ‘off the shelf technology to specialised and customised technology.

Generally, people with more complex cerebral palsy and associated conditions require increased amounts of AT to participate, however, due to the complex and varying presentation of cerebral palsy, there is no set rule that links the severity of the condition with the level of specialisation or customisation of the AT required. For example, a participant with ‘mild’ cerebral palsy may require the use of a highly customised foot orthotic to walk, or an electronic communication device to communicate.

Consideration needs to be given to the use of AT across a participant’s life situations. At times this will mean individuals require alternate or additional forms of AT for different situations. For example, a participant who uses an electronic communication device may not be able to use it in all environments, such as at the pool or bath where it is not safe, or outside in bright sunshine where it is not effective, or when the battery cannot be charged. In these situations, a nonelectronic communication system is also required.

For the prescription of safe and effective AT, a skilled therapist, or team of therapists require funded time to:

- Fully assess the participant, often including their home, school or work environments;
- Research, trial and discuss features and options with the participant and multiple equipment suppliers. For children, this will include identifying equipment which can be adjusted as the child grows. Funding sufficient (often considerable) time to consult and coordinate during these activities increases the likelihood of the best selection and value for money of an AT solution.
- Adjust and ‘grow’ the AT item as the participant grows or their needs change.

How can I tailor a meeting to suit CP?

Every person with CP is unique. Each one has different needs, wants, likes and dislikes, with their individual personality, strengths and support requirements.

Before the meeting

- Before meeting with the individual and families/support workers ask if there are any accessibility requirements to consider. This means checking if the meeting place is wheelchair accessible (has a ramp or elevator and spacious disabled toilet with railing).
- Consider time of day and duration of meeting. It can take many hours for a person with CP to get up, dressed and ready to leave their home. Travel is also often more complex, because public transport is often inaccessible and time consuming.
- People with CP can become fatigued and overwhelmed with complex information and may need to have breaks. Consider the length of the meeting and ask what time of the day suits them best (morning/afternoon meeting). Early morning meetings may not suite everyone.
- Ask the person if they require additional supports to understand information being presented (e.g., seeing it written down, pictographs, or sign language). Check if the person has a hearing or vision impairment that may impact on how they need to receive information.
- Check to determine whether the participant will be bringing an advocate or support person with them.
- Provide as much information as possible about the purpose of the meeting ahead

of time as they may need to discuss and prepare their responses with their support person/family member. People using a speech generating device to communicate may need to prepare their messages and store them in their device before the meeting.

- Provide any written material in Plain English or Easy Read if required well before the meeting.

Communication during the meeting

It's important to remember that each person is different in their communication and the support they might need. Approximately twenty five percent (25%) of people with CP have challenges verbally communicating. This could be due to muscle weakness in the mouth or throat or coordinating movements for speech. They may have sensory issues that affect their vision or hearing, which may also affect their language and speech. They may have an intellectual disability, have difficulty in planning how to say complex sentences and may use easy, simple or plain English. They may use speech that is difficult to understand.

- When speaking, use appropriate volume and speed. Speak to the person directly, observe how those known to the person communicate with them, listen to the person and clarify understanding.
- Check if the person has a personal communication system such as a communication book, board or speech generating device that they use to communicate. If they do, ensure you give them enough time to respond, ask questions and interact during the meeting. Modern technology including iPhones and iPads may also be used to assist communication.

- **Don't assume that people who have communication difficulties have intellectual disabilities.** They may not use speech to communicate but may still be able to understand everything you say. When communicating with someone with CP where speech may be affected, speak normally and use age appropriate language.
- Be patient. If the person does have an intellectual disability, provide pauses after every few words you say to break up sentences and give the person enough time to hear and process what you are saying. Avoid using jargon.
- If the person has speech that is difficult to understand you may need them to repeat what they are saying. Speaking can be very effortful for people with CP so repeat what you have understood so the person can concentrate on saying the part you did not understand. If the person has repeated themselves 3 times and you still don't understand them don't get them to repeat themselves again. Ask if there is another way they can communicate it such as using a gesture, using a communication board/ device or pointing to an alphabet display.
- Otherwise, speak as you usually would. **Be aware that it may take a while for someone to verbalise what they want to say.** Do not correct them or jump ahead or make assumptions about what they are trying to say. Some people may use informal methods to communicate including facial expression, gestures, body language and behaviour to express themselves.
- Understand that some people may need more meetings to discuss everything.

Helpful links for further information

Cerebral Palsy Support Network cpsn.org.au