



DISABILITY EMPLOYMENT AND ADVOCACY SERVICES

communicating with people with cerebral palsy

a fact sheet for managers and support staff
of disability employment and advocacy services

Introduction

Cerebral palsy (CP) is a developmental disability that results in disorders of movement or other nerve functions. It is caused by injury to the brain before or during birth, or in the early years of life. CP occurs in about two births per thousand. A person with CP can find voluntary and purposeful movement very difficult, and he or she might also be unable to prevent unintended movement, or maintain the posture they want. These physical problems are often referred to as motor problems. Some people may have only minor motor skill effects; other people may require assistance with all their daily activities.

The impact of CP is different for every person with CP. It will vary depending on:

- ▶ which area of the brain has been injured
- ▶ how extensive the damage to the brain is
- ▶ whether the person has learned skills that give him or her more control over movement. Because specific areas of the brain control different motor functions, the way in which an individual's movement will be affected by CP will depend on the extent of the brain damage and which areas are affected.

There is no 'cure' for CP but there are many interventions and technologies that assist people with CP to maximise their functioning and quality of life.

Different types of cerebral palsy

The main types of CP are classified according to muscle function in the affected person.

Spastic cerebral palsy

People with this type of CP will have some weak and some stiff muscles. The stiffness (or 'spasticity') results in overactive muscles that cannot work in cooperation with the other muscles in the joint, resulting in jerky or awkward movements. This is the most common type of CP.

Ataxic cerebral palsy

In this form of CP, the area of the brain that plays a key role in the control of movement, posture and balance has been damaged. A person with ataxic CP will have difficulty with movements that are quick, or require a lot of control. Uncontrollable trembling will often be apparent.

Athetoid cerebral palsy

This type of CP results from damage to the part of the brain that assists the coordination of voluntary movement. People with athetoid CP have poor control over their muscles and joints, resulting in frequent involuntary movements. At the same time, the affected person may be unable to carry out a desired activity because they cannot coordinate the required movements.

Note: Some people have a mix of the different types of CP, such as a combination of spastic and athetoid CP.

Other disabilities and conditions associated with cerebral palsy

A person with CP may have additional disabilities and conditions.

- ▶ **Vision or hearing impairment**
Sometimes CP can affect the person's ability to control their eye movements, hold gaze and have effective visual scan. Hearing can also be affected at many different levels.
- ▶ **Seizure disorder (epilepsy)**
A large proportion of people with CP have epileptic seizures. Sometimes the physical signs of the seizure can be 'masked' by the jerky or awkward movements resulting from CP.
- ▶ **Intellectual or learning disability**
There is a broad range of intellectual ability in people with CP. Sometimes individuals will have difficulty learning specific tasks, such as reading, or arithmetic because of damage to a particular part of their brain.
- ▶ **Spatial perception difficulties**
Brain damage accompanying CP can sometimes lead to an inability to perceive space and equate it correctly with distance, or to think spatially.
- ▶ **Speech difficulties**
Much of our ability to speak is controlled by the muscles of our tongue, mouth and throat. Speech can be affected if these muscles are affected by CP.
- ▶ **Pain**
A lot of people with CP will experience pain and discomfort, sometimes on a constant basis.
- ▶ **Feeding and digestive problems**
People with CP often have reflux and related digestive problems, as well as problems swallowing food and liquid. For some people, aspiration (inhalation of food or liquid into the lungs) is a great risk.
- ▶ **Drooling**
A lot of people with CP suffer from unintentional loss of saliva from the mouth. This condition usually results from abnormalities in swallowing, problems in moving saliva back to the throat, and difficulty in closing the mouth.
- ▶ **Breathing problems**
The muscles that control lung function can be disabled by CP, causing breathing difficulties.

Issues for disability employment and advocacy services staff working with people with cerebral palsy

It is important to remember that no two people with CP (even the same type of CP) will have the same issues or needs.

To work effectively with a person with CP, you need to know how their condition affects them, and then develop and use strategies that are appropriate to the specific individual and context.

Each state has an association to assist people with CP (for example, Scope in Victoria or the Cerebral Palsy Association in Western Australia). They provide expert advice and professional services to people affected by CP. You can get individual assessments and recommendations for equipment and assistive technology for the person with CP from these and other organisations.

Obtain the equipment and technical assistance you need to make the environment better suited to the person with CP. For example, your service can access funding from your state's association for workplace aids and equipment for supported employees.

From the team leader's notebook

When I first started to work here, I couldn't understand a word Darren said. It just seemed to come out as one big booming sort of noise and I had no idea what to say to him. I didn't think he'd understand anyway.

I had a chat with Mary about him, though – she works with Petra who also has cerebral palsy. She just tells Petra when she can't understand what she's saying and Petra points things out, sometimes even writes it down for her. I've started the same thing with Darren. I was surprised that he can read and write really well: I didn't think he could do that. I am also finding that as I get to know him better, I am able to understand him a lot better.



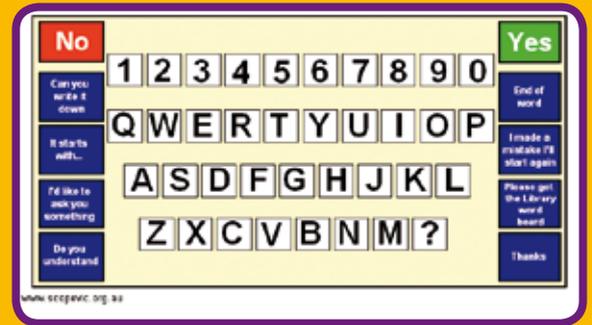
Nicki's story

Nicki, who is now 24, was a premature infant. She was first diagnosed with cerebral palsy at the age of seven months. Nicki has spastic quadriplegia, so she has severe muscle stiffness in all four limbs. Many of the muscles in her neck, face and mouth are also affected. Nicki has problems swallowing food. She cannot unclench her hands, walk or talk. She cannot move her eyes so it is extremely difficult for her to see a lot of things that happen around her.

Nicki has had treatments and therapies, many on a daily or more frequent basis, to stop her muscles contracting further, enable her develop oral function for feeding, and assist her communicate. Through all of this, it has been clear that Nicki is alert and intellectually able.

Nicki was first introduced to a computer when she was four. From her first attempts to respond 'yes' or 'no' to programs displaying choices, Nicki has learned to use her computer through a head operated touch pad. This enables her to work with various communication aids, including models with voice outputs, and automatic scanning systems that enable whole 'messages' to be spoken. She can give information about things, answer and ask questions, and verbally contribute to conversations. She can also go to work for a few hours each week. 'I love my job and my friends at work. We have a fun time together' says Nicki.

Nicki's job is assisting to maintain databases. She is very good at this, as she has an eye for detail, and is very thorough. Nicki has an aide, Joyce, who assists her with personal care in the workplace, which includes toileting, feeding, and ensuring she is repositioned regularly in her wheelchair. Nicki says, 'Joyce is great. We really get along well'.



Communication strategies

1 Work out how best to communicate with the person with cerebral palsy.

The key to achieving effective communication with a person with CP is to consciously accept the responsibility for it. This means looking for every strategy that will support good communication. Work with your colleagues, and try to get some advice from one of the agencies that specialise in services to people with cerebral palsy.

2 Really listen to the person when they speak.

While many people with CP have problems with speech, you can usually learn to understand their verbal communication if you try.

- ▶ It may be helpful to go to a quiet place and so that you are completely focused on listening.
- ▶ Show the person you are listening to that you want to understand. Lean forward, ask questions of clarification if you need to. Be an active listener.

- ▶ Give them time to say what they want to say (a lot of people with CP have very slow speech). Don't interrupt, don't finish sentences for them or cut them off with statements like 'OK. Don't worry. I know what you mean' and don't speak for them.

3 Tune in.

Remember that the speech rhythms and voice pitch of someone who has vocal impairment are often very different from those of someone who does not. Once you become familiar with these differences, comprehending the person's speech will be much easier.

4 Be technology knowledgeable.

It is important that you have a good understanding of the technological aids a person with CP might use. You need to be familiar with and able to respond to electronic or non-spoken forms of communication used by people with CP. Your state's CP association will help you with this information.

5 Communicating electronically.

If you are 'talking' with a person through an electronic communication form, learn how they use language and how to respond in the same way – it will be easier for both of you. Abbreviations and using numbers instead of words for to/too/two and 'for/four/fore', 'ate', etc, are strategies that are probably familiar to you if you text on a mobile phone. Sometimes reading the message aloud makes it easier to follow.

6 Let's talk.

People who cannot speak or have speech that is hard to understand still want and need to communicate and we want and need to communicate with them.

There are two dimensions to what we call 'language'.

Expressive language is the ability to communicate perceptions, ideas, feelings, experiences, wants, needs, or intentions to others, by spoken or written language.

Receptive language is the ability to receive and understand language that may be communicated verbally or visually. It's the capability to translate the sounds that we hear into their intended meanings.

Some people with CP may have difficulty speaking or have speech that is hard to understand. That is, they will have difficulty with expressive language. Find out how the person says, 'yes', and how they say 'no'. It sounds simple but once we know the answer to this, communication can really start to happen.

Some people may not speak at all, but they may have good understanding of what is said to them. Work with the person to establish ways in which they can show you whether or not they are receiving what you say and understanding it.

We can all 'talk' to each other in some way – whether or not it is with words. With some people, we just have to work a little harder to discover the communication path.



www.scopevic.org.au provides some excellent resources and practical hints on how to establish communication with people with complex needs. The storyboard pictured below is an example of such a resource.



National and state CP associations

CP Australia

www.cpaustralia.com.au

New South Wales

www.thespasticcentre.com.au

Victoria

www.scopevic.org.au
www.yooralla.com.au

South Australia

www.cara.asn.au
www.novita.org
www.leveda.org.au
www.scosa.com.au

Queensland

www.cplqld.org.au
www.cootharinga.org.au

Tasmania

www.cerebralpalsytas.org.au

West Australia

www.tccp.com.au