# Communication and cerebral palsy

### The challenges

Communicating with others is central in all our lives. Through communication we share our thoughts and ideas, our questions and concerns, our hopes and our dreams.

Some people with cerebral palsy may face particular challenges with communication related to:

- Motor difficulties. Some people with cerebral palsy have impairment of the muscle function and coordination of the oropharynx (mouth and throat) makes production of speech sounds difficult.
- Motor planning. Some people with cerebral palsy have difficulty planning and executing the complex sequence of movements of multiple muscle groups needed for speech production.
- **Cognitive factors.** Some people with cerebral palsy have an intellectual disability, which may range from very mild to profound. People with cognitive impairment may find both the formulation of what they want to say and understanding language difficult.
- Sensory factors. Some people with cerebral palsy also have impairments of vision or hearing. This makes the understanding and use of language, both verbal and non-verbal, more difficult. Some people with cerebral palsy have sensory sensitivity, particularly oral sensitivity.

## Ways of communicating

Many people with cerebral palsy who experience difficulties with communication are very resourceful in how they get their message across, and use a variety of methods to do so.

Formal methods of communication are those that rely on language, with a vocabulary, grammar and syntax. The language used may be spoken, written and/or signed. Methods include:

- Speech;
- Communication device such as a board, book or electronic device using either pictures, symbols and/or letters; and
- Signing; Auslan or key word signing.

People who do not have a formal method of communication express their preferences, likes and dislikes, pleasure and joy, fear and confusion or pain and distress through informal methods of communication which may include a change in:

- Facial expression;
- Body language; and/or
- Behaviour.

#### How to support and assist communication

When people have trouble expressing themselves they may find it helpful to:

- Spell their message using an electronic communication aid (e.g. LightWriter, iPad), low tech alphabet board or text message facility on their phone.
- Use a speech output app or device employing text-to-speech or image-to-speech based on letters, symbols, pictures or photographs.
- Use an iPad with a communication app.
- Use formal sign language such as key word signing or Auslan.

Many people with cerebral palsy experience communication difficulties but can use a variety of methods to get their message across.



These resources are designed to support General Practitioners in the care of their patients with cerebral palsy. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. The project was funded by an Avant Quality Improvement Grant 2017.









When meeting someone for the first time who does not use speech, ask about the ways they prefer to communicate. You can ask them to demonstrate their methods of communication so you can ensure you have optimal direct communication and engagement with your patient.

Many people with communication difficulties who in the past may have used purpose built communication devices, are now using communication apps on their iPad or other tablet device. These apps are cheaper than specialised equipment, socially desirable and acceptable, and multifunctional as they can also can enable people to access music, movies, games and much more.

# Remember just because someone has difficulty expressing themselves, it doesn't mean that she/he:

- Has nothing to say. Give people the time they need to construct their message, be patient.
- Has a cognitive impairment. If unsure, it is best to assume that someone has average intelligence and then adjust as you get to know him or her better, as you do for any patient.
- Has a hearing impairment.

When people have trouble understanding others, they may find it helpful if others communicate:

- Slowly giving them adequate time to process.
- Clearly using clear simple language with no jargon.
- In chunks.
- With visual cues such as gestures, signs, pictures.
- With support from a familiar trusted person.



- Use an appropriate volume according to the person's hearing ability. Most people do not have a hearing impairment. Therefore it is not appropriate to raise the volume of your voice when speaking to them.
- **Speak directly to your patient.** Whenever possible communicate directly to your patient, rather than to the person who has come with them.
- Ask how your patient prefers to communicate.
- **Observe:** look at how those who know the person well communicate with him or her.
- Listen to the person themselves. They may express themselves verbally, through a communication device, through their facial expression and body language and/or their behaviour.
- Speak as you would to anyone else of that age and gender using a tone of voice appropriate for the person's age; for example avoid using the tone in which you speak to a child when speaking to an adult. Simplify your language if you think they are not understanding clear speech, short sentences, one idea at a time. Avoid using medical jargon.
- Check that you have been understood.

Make your practice both suitable and comfortable for individuals with communication difficulties, even if you don't currently have any patients with these problems. Strategies might include:

- Ensure your premises and facilities are physically accessible to people using a wheelchair.
- Providing resources to office and booking staff on communication.
- Opportunities for raising awareness, and practice for staff to be comfortable in supporting people with communication difficulties.
- Procedures for automatic double appointments.
- Having booking facilities where someone can email their request for an appointment and for their support person to attend.

#### Resources

**Speech pathology:** Specialist knowledge is required to inform and assist people who use Augmented and Assisted Communication (AAC).

**Communication tips:** <u>www.cddh.monashhealth.org/</u> <u>wp-content/uploads/2016/11/2016-working-with-people-</u> <u>with-intellectual-disabilities.pdf</u>



The increasing presence of common technology is making communication easier. Many people with communication difficulties are now using communication apps on their iPad or other tablet devices.