



Patients with disabilities and complex communication needs

The GP consultation

BACKGROUND People with complex communication needs vary in terms of their underlying disability and the methods and strategies they use to communicate.

OBJECTIVE This article describes the varied communication profiles that a general practitioner is likely to encounter in patients with disabilities, and the various types of augmentative and alternative forms of communication that might be used in such consultations.

DISCUSSION This article provides strategies to facilitate doctor-patient communication involving patients with complex communication needs, some of which are illustrated in a case study of a young woman with an intellectual disability.

Many developmental disabilities such as Down syndrome, autism, and cerebral palsy – and acquired disabilities such as traumatic brain injury, stroke, and Parkinson disease – are associated with communication impairments. People who fall at the more severe end of the communication impairment severity spectrum are said to have complex communication needs. A recent demographic study by Perry¹ indicated that one in 500 Victorians has a complex communication need. All general practitioners therefore, are likely to have patients whose communication problems cause difficulties in obtaining histories, understanding management recommendations, and patient-doctor rapport.²⁻⁴ This article aims to:

- provide an overview of the common types of communication profiles seen in people with complex communication needs associated with either acquired or developmental disabilities
- describe communication systems that are used by this group
- provide strategies to enhance communication in a consultation with these patients, and
- provide a case study of a GP consultation with a patient with complex communication needs.

Common profiles

People with complex communication needs have any one or a combination of the following:

- speech that is difficult to understand
- problems in understanding what is said to them, and/or



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Table 1. AAC systems

Types	Examples
Unaided	
Informal	Vocalisations (may be unrelated to speech or word approximations) Facial expressions Body language Idiosyncratic movements (eg. rocking vigorously when excited) Gestures
Formal	Manual signs (eg. key word signing)
Aided	
Nontechnology	Communication boards and books Community access cards Gesture dictionaries
Technology	Single message switches (eg. Big Mack®) Multilevel dedicated electronic systems Integrated computer software to facilitate word processing and communication

Augmentative and alternative communication

People with complex communication needs rely on augmentative and alternative communication (AAC). This includes systems that augment speech such as the use of facial expression, pointing to photos, or pointing to the first letter of words to help people understand their speech. On the other hand, they may use alternatives to speech such as the use of a spelling or graphic symbol board (eg. line drawings) to communicate most messages.

The different types of AAC systems are summarised in *Table 1*. Informal systems such as body language and facial expression can be very useful in interpreting what an individual is feeling. However, people with physical impairments may not be able to control this aspect of their communication. The result is that they are often misunderstood when attempting to communicate with someone who does not know them well, eg. a person with spastic cerebral palsy may be thought to be smiling when this is not the case, while people with Parkinson disease display little facial expression or communicative body language. Hence, care is needed when interpreting communication produced using such informal systems. Similarly, gestures and idiosyncratic movements may appear random but are meaningful to people who know the person well.

Many people with intellectual disability use key word signs taken from the Makaton vocabulary.⁵ The key words in the following sentence are shown in bold: **I am going to the shops.** People learn to sign because other people use sign language around them. Key word signs are always accompanied by speech from the communication partner. The Makaton vocabulary comprises list of concepts organised according to nine stages – the choice of signs to teach an individual is based on what is relevant and important to that person. It has been used widely in Australia for the past 20 years, especially with people with intellectual disability.^{6,7} As a result, many people with intellectual disability will know and use a varying number of signs.

An AAC system may incorporate the use of an aid that is designed according to the individual’s needs and abilities. Examples of both nontechnology and high technology systems are provided in *Table 1*. These systems incorporate graphic symbols that are used to formulate a message. People with intellectual disability are most likely to use photos, coloured pictures or line drawings, while adults who have had a stroke may use a combination of written words, an alphabet board and conversational phrases or sentences (eg. ‘How’s the

- problems in expressing themselves because of limited vocabulary and sentence formulation skills. Speech intelligibility is most commonly caused by cognitive impairment (as occurs in intellectual disability) and disorders that affect motor control such as dysarthrias that result from myasthenia gravis, stroke or cerebral palsy, or articulatory dyspraxia that result from strokes or traumatic brain injury.

Both the ability to understand and to produce language can be impaired by intellectual disability or brain trauma (most commonly strokes or traumatic brain injury). People often have better receptive skills, ie. their understanding of language is better than their production of it. This profile is common in people with intellectual disability, although receptive skills may be similarly limited. For people with acquired disabilities such as stroke, any of the following profiles can occur:

- better understanding than language production
- better production than understanding of language, or
- problems with both.

It is important to remember that problems with speech or language do not necessarily mean that the person has an intellectual impairment. For example, people who have suffered a stroke are often frustrated when others think their intellect has been impaired because of their problems with communication.

family?'). Technology speech generating devices range from simple systems such as the Big Mack®, used to produce a single message (eg. 'Can you help me?') to those that are more complex and include multi-level and dynamic displays enabling the individual to access a large vocabulary, sentences and phrases and the alphabet. Unfortunately, such systems are costly (from \$150–17 000).

Facilitating communication in a consultation

Obtaining information about a person's communication abilities and the systems used to communicate with familiar and unfamiliar people before a consultation will provide some understanding of how to communicate with the patient. A GP's ability to obtain a comprehensive history will often depend on whether an accompanying person has provided continued support (eg. a family member or direct support worker who has known the person for a long period) or is relatively unfamiliar with the individual. Unfortunately, for people with developmental disabilities who live in supported accommodation, frequent staff changes or people working different shifts, will often mean that someone who can provide only limited information accompanies the patient. These problems can be overcome to a large extent through a case conference, attended by a family member, paid support worker, and other relevant professionals; in particular a speech pathologist who has been involved in developing the patient's AAC system. If the patient has not recently received services from a speech pathologist, then relevant services should be accessed. In Victoria, for example, GPs can seek input from a speech pathologist through the Communication Resource Centre, which supports locally based speech pathologists throughout Victoria (see *Resources*).

The following strategies facilitate communicating with patients who have complex communication needs, regardless of the type of AAC system used:

- Consider ensuring a double appointment has been booked – this will allow for the longer time needed for communication
- Whenever possible, direct conversation to the patient – even if comprehension is limited, the patient will be more responsive
- If the patient uses an aided AAC system, make sure he/she can access it during the consultation
- Develop a tolerance for silences. Many patients require extra time to process your questions and/or

formulate a response

- Do not talk while the patient is formulating a message – this is very distracting
- If the patient is using a nontechnology aid (eg. communication book, alphabet board) it will help if you repeat back the message to make sure you've understood it correctly. When using this strategy, give the patient time to confirm you got it right
- Find out if the patient has his/her own way of indicating 'yes' and 'no' – (eg. looking up for 'yes' and a slight shake of the head for 'no'). If so, try asking a series of yes/no questions (keep them short and simple) and allow the patient time to respond. Remember, however, that responding to these types of questions requires good understanding of language
- If you are having difficulty conversing with the patient, ask for his/her permission to direct your questions and conversation to the support person. Remember to look back to the patient intermittently so that he/she still feels engaged in the conversation
- Use gestures and pictures to help the patient understand you. Examples include waving as you greet the patient, pointing to body parts, or showing simple pictures to clarify procedures.

Case history – Kathy

Kathy, 32 years of age, has an intellectual disability and lives in a community residential unit. She visits her GP, Dr Fiona Sanson, each year for a check up. Dr Sanson has recorded in her files that Kathy has communication problems – she makes some sounds, but nothing that seems meaningful and has limited understanding. The notes also indicate that Kathy uses some signs and her support worker who attended Kathy's last consultation reported that she used a communication book, which she had not brought along to previous appointments. At the last consultation, Dr Sanson asked that Kathy bring the communication book with her to all consultations. The medical files indicate that, in general, Kathy had enjoyed relatively good health with no major periods of illness recorded during the time she had been seeing Dr Sanson. Because of Kathy's general health and good nature, Dr Sanson had never considered suggesting a double appointment time for Kathy. The day of Kathy's consultation, Dr Sanson was running 20 minutes late with her appointments. On going to the waiting room to collect another

patient, she saw Kathy who seemed a little agitated (repeatedly getting up and sitting down). Dr Sanson got Kathy's attention, waved and said 'hello', and then told her that she would be about 20 minutes, while pointing to the clock on the wall. She suggested to Kathy and her support worker that they might go for a short walk.

When it was Kathy's turn to enter the surgery, Dr Sanson waved and said: 'Hello Kathy' and introduced herself to the support worker, James, who she had not met previously. She pointed to the chair as she asked Kathy to sit down. Dr Sanson asked Kathy how she was feeling, but Kathy was nonresponsive. Dr Sanson noted that Kathy was clutching her communication book, so she pointed to it and asked if she could have a look. The book contained some information about Kathy's communication including that she uses a few signs which were pictured (Figure 1) and pictures in the book which were organised according to categories (Figure 2, 3). Dr Sanson noticed the sign for 'good' (thumbs up gesture) and used it as she asked: 'Are you feeling good?' Kathy smiled and signed 'good' back. Dr Sanson asked Kathy if it was okay for her to ask James about how she had been feeling (she pointed to James). Kathy smiled again. James reported that Kathy had lost her appetite, and some behavioural problems such as the agitation seen in the waiting room, were occurring. He also reported that Kathy had been refusing to clean her teeth over the past month, which had not happened previously. Dr Sanson weighed Kathy and noted that she had lost 2 kg since her last visit. Dr Sanson asked Kathy about the food she likes to eat, as detailed in the following extract from the consultation.

Dr Sanson: (refers to Kathy's communication book and signs 'eat' as she says), 'Kathy, what do you like to eat?' She opens the communication book at the food section

Kathy: becomes animated and points to chicken and chips

James: 'That's her favourite dinner, she'd have it every night if she could, at least up until recently'

Dr Sanson: points to chips and signs 'good', as she says, 'You like chicken?'

Kathy: signs 'good'

Dr Sanson: 'Kathy, is your mouth sore?' (as she points to her own mouth) or your teeth (as she taps on her own teeth)

Kathy: puts her hand over her mouth

Dr Sanson: sits next to Kathy and says, 'Can I look inside your mouth?' She holds a mirror in front of them both. 'Open your mouth like this Kathy' (demonstrating by opening her mouth wide)

Kathy: opens her mouth.

Dr Sanson noted that Kathy's gums were very red and felt a visit to a dentist was needed. She was unable to continue further because of the time (she was aware of being late with her other appointments). She asked James to organise a visit to a dentist and then to contact the surgery for a further appointment.

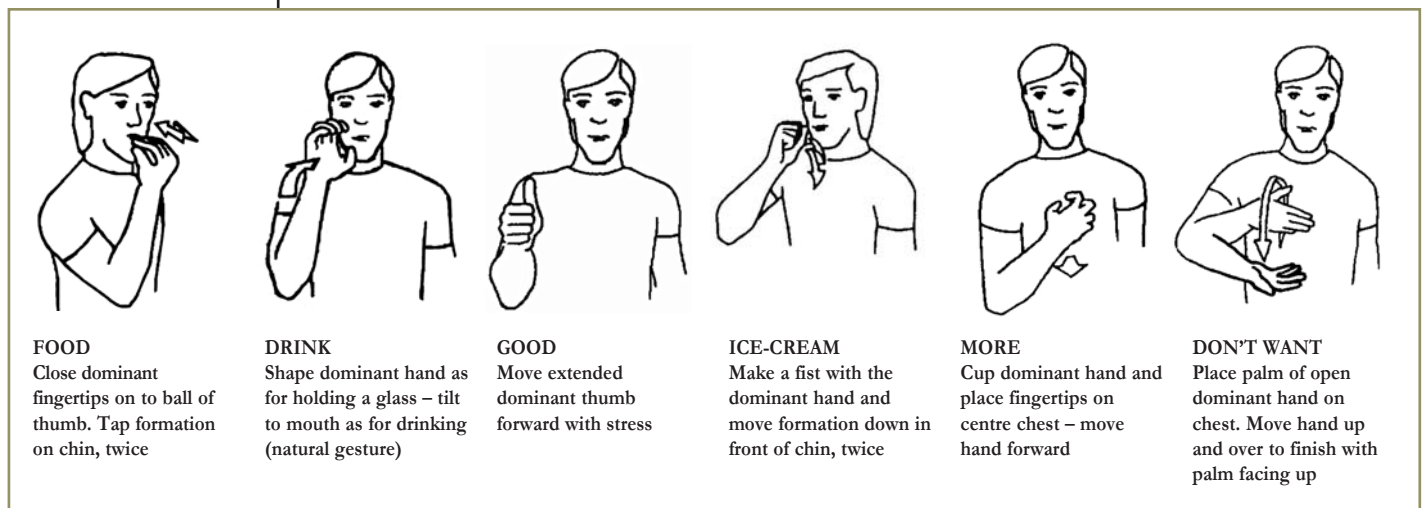


Figure 1. Kathy's sign dictionary

Conclusion

People with complex communication needs are varied in terms of their abilities and the strategies that will most assist them in the communication process. As a result, trial and error is always necessary when learning about how to best communicate with people with speech and language difficulties. A common mistake is equating communication with the ability to speak – people with complex communication needs are reliant on their informal systems of communication as well as more formal systems to which they may have access. These will be useless however, unless the person attempting to communicate with them is willing to acknowledge, learn and make use of those alternative modes and strategies for communication. Of course, such a process requires a substantial time commitment – which is difficult in a busy practice – and slow communication can be difficult to tolerate. The strategies offered in this article provide simple but effective means of alleviating the frustrations of communication for both a patient with speech and language difficulties and his/her GP.

Summary of important points

- Both the ability to understand and to produce language can be impaired by intellectual disability or brain trauma.
- Problems with speech or language do not necessarily mean that the person has an intellectual impairment.
- A case conference, attended by a family member, paid support worker, and other relevant professionals can assist with communication.

Resources

Makaton vocabulary: www.newcastle.edu.au/centre/sed/makaton/
 Speech Pathology Australia: www.speechpathologyaustralia.org.au/

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Figure 2. Kathy's communication book



Figure 3. Using the communication book

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