



Communication Difficulty

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1. Background – Communication Difficulty and MJD

Individuals with Machado Joseph Disease (MJD) experience significant speech loss (dysarthria) throughout the progression of the disease. This greatly reduces their ability to communicate verbally and subsequently further reduces the autonomy and quality of life of people who are already seriously physically disabled. Dysarthria, or slow, slurred speech, is often an early clinical sign of MJD, and may ultimately progress to complete loss of speech (anarthria). The speech disturbance progresses in parallel with the ataxic gait pattern and is significantly associated with disease progression, duration, and number of expanded CAG repeats (Jardimet al., 2001; Keilinget al., 2008; Rüb et al., 2003). Jardimet al. (2001) found in a study of 62 MJD patients that 85.5% had dysarthria (from mild dysarthria to anarthria).

1.1 Dysarthria

'Dysarthria is a group of motor speech disorders resulting from disturbed muscular control of the speech mechanism due to the damage of the peripheral or central nervous system causing weakness, incoordination, or paralysis of speech musculature' (Roth, 2011). There are seven recognised types of dysarthria (flaccid, spastic, unilateral upper motor neuron, ataxic, hypokinetic, hyperkinetic and mixed) each with different levels of neurologic impairment/dysfunction (Roth, 2011). The onset, progression and prognosis for dysarthria is dependent on: type, severity, etiology, and level(s) of nervous system involvement (Roth, 2011).

Dysarthria associated with spinocerebellar ataxias (SCAs) is comparable to ataxic dysarthria (sometimes with features of spastic dysarthria). Ataxic dysarthria is caused by damage to the cerebellum or to the neural pathways connecting the cerebellum to the central nervous system, resulting in the general breakdown of motor organisation and control as well as reduced muscle tone (Duffy, 2005; Schalling et al., 2007). Dysarthria that occurs with cerebellar damage is distinctive to other types of dysarthria (Duffy, 2005).

The most common aspects of speech that are affected are:

- articulation (imprecise consonants, distorted vowels and intermittent articulatory breakdowns);
- prosody (excess and equal stress on syllables 'scanning of speech', monotony, prolonged speech intervals and slow speech rate); and
- phonation (harsh voice quality and slow speech rate) (Kent et al., 2000; Schalling et al., 2007; University of Mississippi for Women, online).

Ataxic dysarthria is mainly characterised by: scanning pattern of speech (each syllable in a word receiving equal stress), words and syllables are usually produced at an extremely slow rate with long pauses between them, and the person may present with an abnormal voice quality.

A study of 21 SCA patients, including 6 with MJD, with mild to moderate dysarthria, found that 51% of the differences in perceptual data compared to control group was attributed to articulatory timing (dyscoordination in timing, equalised stress and speech rhythm) and 15% to voice quality (harshness, strained-strangled and glottal fry) (Schalling et al., 2007). Acoustic analysis found that the speech rate was significantly slower (166.6 words/minute) for SCA patients compared to the control group (211.1 words/minute)¹. As per previous studies, Schalling et al. (2007) also found alternating and sequential motion rates (AMR/SMR) to be significantly slower for SCA patients².

¹p<0.001; standard deviation of 41.5. Control group 211.1 words/minute (SD 26.2).

²p<0.001

1.2 Anarthria

Anarthria, the most severe form of dysarthria, is the complete loss of the ability to vocalize words as a result of an injury to the part of the brain or the nerves responsible for controlling the larynx or "voice box". Language and cognition of the anarthric patient may be intact, such as in the case of an MJD patient, but their disordered neuromuscular system prevents speech (Roth, 2011). Anarthria is present in the more severe stages of the MJD.

1.3 East Arnhem Land

A University of Queensland study of 11 MJD Foundation clients, found varying levels of severity of dysarthria, (slight to severe) consistent with previous studies. The most common perceptual findings included reduced breath support for speech, loudness, rate of speech, precision of speech sounds and phrase length, and a breathy vocal quality. These findings were supported by motor speech impairment predominantly in respiratory-phonatory function and tongue function. Impaired vocal fold adduction, breath control for speech, and reduced range and speed of tongue movements during speech were evident. Respiratory-phonatory function relates to the person's capacity to breathe and produce a normal voice.

Early signs of motor speech impairment were evident in some people with MJD but did not consistently impair speech intelligibility. These included:

- weak cough
- decreased sustained phonation
- decreased volume when tired
- decreased breath support for speech, and
- dribbling when tired.

(Theodoros and Ward, 2011)

1.4 Augmentative and Alternative Communication (AAC)

MJD clients who experience anarthria and family carers, medical professionals and carers are often reliant on alternative non-verbal (augmentative and alternative) communication techniques including alphabet boards; picture mats; electronic communication devices; and unaided techniques such as sign language, pointing with finger/s or chin, head, other body parts, and blinking of the eyes.

See Section 4.1 for more information on AAC techniques.

The MJD Foundation and University of Queensland research project initially trialled the *Techscan* communication device; however, as a result of recent developments in technology, the *Apple iPad* and associated AAC applications (e.g. *Proloquo2Go*) are being now trialled. The findings of this project will be published in 2012-13.

2. Recommended Guidelines for addressing Communication Difficulty in MJD Patients

2.1 Assessment – conducted by a qualified Speech Pathologist

1. **Conversational speech sample** – Engage person with MJD in a short conversation about a familiar topic of interest e.g. family. Listen to specific aspects of speech:
 - a) breath support - does the person run out of air when talking?
 - b) voice - is the voice hoarse or croaky?
 - c) clarity of the speech – is the speech slurred?
 - d) loudness – is the voice soft , normal or loud?
 - e) rate of speech – is the speech slow, normal, or fast?
2. **Picture Description** - Have the person with MJD talk about familiar pictures (photos) of local people and everyday activities within his/her environment. Use this task to listen to specific aspects of speech as above.
3. **Informal Motor Speech Assessment**
 - a) Respiratory- phonatory function – breathing and voice
 - b) Velopharyngeal function – Does the speech sound nasal?
 - c) Lip and tongue function – range and speed of movement of the lips and tongue during speech and nonspeech tasks.
4. **Suitability/preferences for communication system**
 - a) Discuss willingness to use picture symbols. Some Indigenous clients may be reluctant to use picture symbols. Therefore, consider having a client/family member draw the pictures themselves, or use text (word/phrase) based only with minimal 'picture-ness' associated.
 - b) Assess management of system e.g. minimum size of symbols/text that can be seen, minimum number of locations (messages) that can be reliably accessed (i.e. more if they can point, less if they can fist point, less if someone reads the options aloud- i.e. partner assisted auditory scanning).
 - c) Consider literacy skills (e.g. for alphabet board use, and/or initial sound cues).
 - d) Consider language skills for communicating conversational breakdown (are they able to understand what strategies they can use, are they able to express when a breakdown has occurred and how to repair it?).

2.2 Treatment

As MJD is a progressive disease, it is very important that the management of the communication disorder begins early. Early intervention in the form of education about the speech disorder in MJD (early signs, what happens to speech) and simple strategies to keep the person's speech as clear as possible, for as long as possible, should be implemented. Culturally acceptable speech strategies that are embedded in everyday activities should focus on:

- Increasing the person's awareness of his/her speech
- Improving breath support for speech
- Increasing vocal fold adduction
- Increasing loudness
- Increasing speech effort.

3. Therapeutic Treatment Options

There is a range of speech exercises that may assist a person with MJD to improve and maintain their speech. Selection of these exercises for any person must be based on an assessment of their speech and the various motor speech subsystems of the speech mechanism. The assessment, and the selection of the speech exercises should be done by a speech pathologist. Where possible, the initial speech treatment should be performed by a speech pathologist, or alternatively, a healthcare worker, under the supervision of a speech pathologist.

This is important because these exercises involve an increase in effort in order to strengthen the voice. ***Yelling or screaming must be avoided, as this will harm the voice.*** These exercises are to be used to target a good healthy loud voice.

These exercises require an increase in effort on the part of the person with MJD. Some fatigue may occur but this effort is necessary to activate the muscles involved in breathing and speech. With practice, this fatigue will lessen. These exercises should be completed when the person is not already fatigued.

3.1 Breathing Exercises

Do NOT RAISE your shoulders when breathing in.

1. Have the person sit comfortably in a chair with his/her back against the back of the chair. Take a DEEP breath in through the nose and mouth, and then ***slowly*** let the air out through the mouth. These breaths should be large breaths so the lungs are filling with air. Place your hand on your stomach just below the ribs and feel how the hand moves out as the lungs are filled with air.

Do this exercise 4-5 times taking a break between each breath. Do this exercise at least 2-3 times throughout the day.

2. Take a deep breath and ***count*** for as far as possible on one breath. This can be done in English or the client's first language. Stop counting as soon as you start to run out of air. Take another breath and start again. If you can count up to 5 on one breath easily, try to count up to 8 on the next breath, and so on. Counting up to 20 on one breath is the goal.

Do this exercise 4-5 times taking a break between each breath. Do this exercise at least 2-3 times throughout the day.

3. Take a deep breath and say as many ***days of the week*** as possible on the one breath. Stop as soon as you start to run out of air. Take another breath and start again. If you can say 3 days of the week on one breath easily, try to say at least one more day on the next breath, and so on. Saying all of the days of the week on one breath is the goal.

Do this exercise 4-5 times taking a break between each breath. Do this exercise at least 2-3 times throughout the day.

3.2 Voice Exercises

Deep Breath - Mouth open WIDE - Use LOUD Voice. Do not YELL or SCREAM

1. Take a deep breath, open your mouth **WIDE**, and say AH in a **LOUD** voice for as long as you can on the one breath. Stop saying AH as soon as you start to run out of breath. If you can say AH in a LOUD clear voice for 3 seconds on one breath easily, try to say AH for 5 seconds on the next breath, and so on. A stopwatch or the second hand on a watch can be used to time your AH.

Important: You must do this exercise with your mouth OPEN WIDE, and in a LOUD voice. A LOUD voice should make your voice clearer. You must **NOT** scream or yell.

Do this exercise at least 10 times, once every day

2. Take a deep breath, open your mouth **WIDE**, and use a **LOUD** voice to sing AH *up* the scale to a high pitch. Hold that high voice for a couple of seconds.

Do this exercise at least 10 times, once every day

3. Take a deep breath, open your mouth WIDE, and use a LOUD voice to sing AH *down* to a low pitch. Hold that low voice for a couple of seconds.

Do this exercise at least 10 times, once everyday

4. Practise singing your favourite songs in a **LOUD** voice
5. Practise talking in a **LOUD** voice:
 - a. Greet people in a LOUD voice
 - b. Answer people in a LOUD voice
 - c. Every time you speak, make sure that you use a LOUD voice.

4. Other Treatment Options

4.1 Augmentative and Alternative Communication

Due to the nature of MJD and the associated progressive loss of speech, at some point the majority of clients may benefit from the use of augmentative and alternative communication (AAC). It is recommended that the client understands why AAC strategies are important and why they are needed. AAC techniques include unaided and aided techniques. Not one AAC technique will meet all of a client's communication needs and they will often rely upon a combination of techniques, depending on the situation or the communication partner (Mirenda, 2005).

Unaided techniques include:

- Sign language
- Pointing with finger/s or chin, head, other body parts, and
- Blinking of the eyes.

Low tech aided techniques include:

- Communication books
- Boards (alphabet or symbols)
- Picture mats
- Wallets
- Photographs
- Date books, and
- Note pads.

High tech aided techniques are electronic devices which operate and produce output in the form of a screen display, printed page, or synthetic or digitised voice output. High tech devices include:

- iPad and associated applications such as *Proloquo2Go*
- Tech/Scan, and
- Computer access software.

(Mirenda, 2005)

It is important that clients understand the range of AAC techniques available and that the practitioner and carers know and use their preferences. For example, a client may prefer to use activity specific boards (e.g. 'mealtime' page) rather than the core vocabulary board and the alphabet board. Or, prefer single board rather than communication books. Other symptoms of MJD (spasticity, non functional fingers/limbs, involuntary movements, fine motor deterioration, and delayed reaction times) are likely to impact on a person's preference and in some cases, where motor access is limited, additional adaptive items, such as a stylus or key guard, will be required.

If using a visual aid (low or high tech) it is important that symbols/ messages are kept in the same location on the page. This will enable the client to become more proficient at using the technique and eventually making it easier to use.

Regardless of the type of communication technique, it is important to establish and focus on the development of a 'core vocabulary' such as 'yes', 'no', 'want', 'not', 'you/yours', 'I/my/me', 'stop', 'like', 'more', 'go' etc. The establishment of a core vocabulary allows for greater control in a variety of situations and it requires less effort (physically) than using an alphabet board. Make sure the client has input into what messages are important/frequently used, and how these can be communicated (e.g. on picture board, using sign, verbally).

Clients may have their own way of communicating messages that are not easily understood by an unfamiliar communication partner. They may use approximations of speech or sign, or use behaviours or gestures to communicate (e.g. rubs chin when hungry). This information can be captured in a Personal Communication Dictionary which describes the behaviour/speech/sign and what it might mean, what you should do, and can even give tips on making the message more 'intelligible' (e.g. Jake rubs his chin to sign 'eat', when he does this you should respond- 'you're telling me you're hungry', model the correct sign for eat, and offer food).

4.1.1 Conversational repair strategies

The use of picture symbols can support both the teaching and use of conversational repair strategies/messages. It is important to explicitly teach repair strategies- i.e. if someone doesn't understand what you have said, you can:

- a) say it again
- b) say it louder
- c) slow down
- d) say it a different way
- e) say the key word
- f) use visuals e.g. point, act it out, gesture, take them to it, draw it

Ensure that in severe cases the focus is on establishing (and making sure everyone knows) a reliable way(s) for the client to communicate accept/confirm or reject/deny.

4.1.2 East Arnhem Land

The MJD Foundation has prioritised enabling greater communication between MJD patients and their carers/ medical professionals to increase autonomy and improve social and emotional wellbeing. The MJD Foundation has drafted an effective communication tip sheet (see **Appendix A**) and is trialling AAC on the *Apple iPad* and the associated application *Proloquo2Go*³.

The iPad was chosen as the AAC device to use because:

- Its cost - the iPad costs significantly less than a *Techscan* device.
- Its social acceptedness – the iPad is seen as standard 'non-disabled' technology. It is "cool", or "trendy", whereas many other AAC devices are seen as something for the disabled.
- The iPad can integrate with the Internet.
- The iPad has a wide range of applications that may be used for communication.
- The iPad is very light and portable.
- It is a powerful tool in promoting social and emotional wellbeing.

Issues that impact on communication for Aboriginal MJD clients include low levels of English literacy, high rates of chronic suppurative otitis media (middle ear infection) and low awareness of cross-cultural communication among service providers.

In Aboriginal communities, high rates of otitis media occur in school-aged children and therefore affect speech and language development (Coates et al., 2002). Long-term conductive hearing loss also contributes to the development of auditory processing problems (Hogan & Moore cited in Howard, 2006). Auditory processing problems make it difficult for people to listen in noisy environments, and to understand and remember spoken information (Howard, 2006).

³<http://www.assistiveware.com/product/proloquo2go>

Appendix A – Communication tips

- Have a good understanding of the communication difficulties and communication skills of the person with MJD.
- Remember that a person with MJD is physically disabled, but intellectually intact. MJD does NOT affect their cognitive skills.
- Have a good understanding of other factors which interfere with communication eg. English as their second language, visual or motor impairments, breathing problems, fatigue, distress.
- Treat the person as an adult. Speak directly to the person with MJD, not the person who is with them.
- Use a normal tone of voice and body language.
- Don't focus conversation only on MJD 'problems'. Engage the person in a range of topics just as you would in a conversation with other people.
- When the person with MJD is communicating, pay attention and observe them as they talk or use a communication aid.
- In a conversation with a person in a wheelchair, sit down and communicate at eye level. Be 'present' with the person and listen actively.
- Help the person with MJD to be relaxed and don't hurry them, allow the time it takes. *(If this is a challenge in a busy environment/time of day, how will you prioritise needs so the person is supported to communicate their message?)*
- Find out whether the person with MJD wants you to finish sentences for them...will this help or hinder their communication?
- If you are not understanding what the person with MJD is saying:
 - Let the person know you do not understand what they are saying
 - Repeat the part of the message that you understood
 - Ask them to repeat what you didn't understand
 - Ask them to write or spell it, or show it visually e.g. with iPad, photo board or other communication aid
 - Ask closed questions to clarify: "Do you mean... or...?" so the person can indicate 'Yes' or 'No'
 - Use a checklist with possible topics to identify what the person is talking about
 - Use your observation skills to check the person's immediate needs and comforts and attend to care needs, checking with the person if this is what they are trying to communicate. If you still do not understand, make sure the person is

comfortable in regard to basic needs (warmth, food, fluids, toilet etc). Tell them that what they are trying to tell you is important but that you are unable to understand at the moment, but you will come back later and try again. Explain why you cannot stay and follow through now, and be specific about when you will come back. Make sure you follow up as promised.

- Conversation among several people is more difficult. Try not to suddenly and frequently change topic, and don't all talk together. Try to help the person with MJD to take their turn to talk/communicate. Encourage inclusive communication.
- Use closed questions more when the person is tired or unwell.
- Use closed questions when you need a clear response from the client on an important issue.
- Facial expression in people living with MJD is limited by the condition. Hence when communicating with these clients facial expression will be quite subtle.
- If the person with MJD has difficulty understanding and/or remembering complex information:
 - provide information & instructions in a way they will understand
 - instructions should be clear, consistent and step-by-step
 - accompany verbal instructions with visual demonstrations
 - utilise the communication aids they use and understand.
- Remember to work in ways that are Person-Centred and aim to empower the person with MJD.
- Remember the principles of Person-Centred Active Support so that you always notice opportunities to 'do things with the person' not 'do things to the person'.
- Work with the person's strengths.
- Reflect on the challenges the person with MJD is living with. How might they feel about the symptoms of MJD and the effect on their life and autonomy? How can you support them with empathy?

A PDF version is available on the [MJD Foundation website](http://www.mjd.org.au)⁴.

⁴http://www.mjd.org.au/cms/file_library/Other/Other_531.pdf
MJD Protocol – Communication Difficulty

Appendix B – Contributors to the Development of this Protocol

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Appendix C – Definitions

Augmentative and Alternative Communication (AAC): improving the communication skills of individuals with little or no functional speech or handwriting ability (Mirenda, 2005).

Anarthria: the most severe form of dysarthria, is the complete loss of the ability to vocalize words as a result of an injury to the part of the brain or the nerves responsible for controlling the larynx or "voice box".

Chronic suppurative otitis media: Persistent discharge from the middle ear through a tympanic membrane perforation for more than 6 weeks (Coates et al., 2002).

Dysarthria: is a group of motor speech disorders resulting from disturbed muscular control of the speech mechanism due to the damage of the peripheral or central nervous system causing weakness, incoordination, or paralysis of speech musculature (Roth, 2011).

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ⁱ *Nothing contained in this protocol constitutes medical or other advice and is only intended for use by qualified healthcare providers. Healthcare providers considering this protocol must use their own clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this protocol or other guidelines to any particular patient or treatment scenario.*

The recommendations set out in this protocol are a guide only and may not be appropriate for use in all situations or with all patients. The decision whether to adopt or not adopt any of the recommendations set out in this protocol must be made by each healthcare provider on a case-by-case basis.

This protocol does not guarantee any specific outcome, result or benefit, nor does it establish a standard of medical or therapeutic care. It is not inclusive of all appropriate or possible approaches or treatments, or exclusive of others.

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