

COMMUNICATION DIFFICULTY HELP SHEET



This Help Sheet explains some of the changes in communication that occur as a result of Machado Joseph Disease and shares ideas on ways to communicate well with someone with MJD.

BACKGROUND

People with Machado Joseph Disease (MJD) experience significant speech loss throughout the progression of the disease. Dysarthria, or slow, slurred speech, is often an early sign of MJD, and may progress over time to complete speech loss (Anarthria). The speech loss progresses in parallel with the ataxic gait pattern so that the person experiences increasing disturbances in balance, mobility and speech while their intellectual capacity is not affected.

DYSARTHRIA (slurred speech)

Dysarthria is a group of motor speech disorders resulting from disturbed muscular control of the speech mechanism. Damage to the peripheral or central nervous system causes weakness, incoordination, or paralysis of speech musculature.

ANARTHRIA (total loss of speech)

Anarthria, the most severe form of dysarthria, is the complete loss of ability to vocalise words. This is caused by injury to the part of the brain or the nerves responsible for controlling the larynx or 'voice box' and also affecting the lips, tongue, jaw and palate. Anarthria is present in the more severe stages of MJD. Receptive language and comprehension remain unaffected: the person will understand what is being said but will be unable to respond verbally. By this stage of the disease the person's ability to use gesture or aids to communicate will also be diminished.

EARLY SIGNS OF SPEECH IMPAIRMENT

Early signs of speech impairment include:

- Weak cough
- Decreased sustained voice
- Decreased volume when tired
- Decreased breath support for speech
- Dribbling when tired, and

- Slurred speech when tired.

These early signs of speech impairment may not impair speech intelligibility and the person can still communicate effectively in the mild and moderate stages of the disease progression. Communication challenges increase as speech, gesture and ability to use communication aids deteriorates.

CULTURAL CONSIDERATIONS

Indigenous people communicate using a range of non-verbal communication including facial expression, gesture and body language. The intricacies of this integrated communication style may be unnoticed or misinterpreted by non-Indigenous care-workers.

Cultural safety and cultural awareness

The MJDF is committed to cultural safety as a core principle of our work. Cultural safety means people experience care and support in an environment that is spiritually, socially & emotionally safe, that respects their cultural identity. It requires careworkers to reflect & consider the impact their own culture has upon their work practice and their interaction with people from different cultures.

Cultural awareness training is an important step in developing culturally safe work practice.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)

People with anarthria often rely on augmentative and alternative communication (AAC) techniques including:

- Alphabet boards
- Photo boards
- Technologies such as Mobile phone texting, Skype, emails and the Apple iPad.

Apple iPad and associated AAC applications (eg. Proloquo2Go) The Apple iPad was chosen as the AAC

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device to use for MJD Foundation clients because it is affordable, it has high social acceptance as 'non-disabled' technology, it links with the internet and it is light and portable. It is a powerful tool in promoting social and emotional wellbeing.

COMMUNICATION ASSESSMENT & CARE PLANNING

Formal assessment of a person's speech and communication abilities is conducted by a qualified Speech Pathologist. Following the assessment, the speech pathologist may devise a treatment plan of speech exercises designed to assist the person with MJD to improve and maintain their speech.

Daily speech exercises may be incorporated into the daily care plan with instructions to support staff. Family and support staff can provide valuable input by noting what works well for the person they are supporting.

SUPPORT STRATEGIES

As MJD is a progressive disease, it is very important that the management of the communication disorder begins early. Education about the speech disorders in MJD and everyday strategies to keep the person's speech as clear as possible, for as long as possible, should be implemented with guidance from a speech pathologist. Culturally acceptable speech strategies that are embedded in daily activities should focus on:

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

Carers and support staff may be asked to assist the person with speech exercises to improve and maintain their speech. An individualised speech treatment plan will be developed by a speech pathologist and they will monitor the progress periodically. Feedback from family and support staff is crucial to the monitoring process.

If assisting a person with their speech exercises, remember that the exercises require an increase in effort and can be tiring. It is best to undertake the exercises when the person is not already tired. Carers and support staff can provide valuable assistance by ensuring the person has appropriate time, place and support to practise the speech exercises according to the treatment plan. Adding a 'fun' element to practising the exercises usually works well and enhances motivation and commitment.

COMMUNICATION TIPS

- Have a good understanding of the communication difficulties associated with Machado Joseph Disease (MJD).
- Get to know the person with MJD well, build a relationship of trust and respect. Get to know their likes, dislikes and sense of humour.
- Get to know how each person is affected by MJD and the skills they have in living with the symptoms of the disease.
- Notice their strengths and work with the person on communication skills that are meaningful to them.
- Remember that MJD does NOT affect people's cognitive skills.
- Have a good understanding of other factors which interfere with communication eg. English as their second language, visual or hearing impairments, breathing problems, fatigue, distress, mood. (Note: Indigenous Australians with MJD rarely have English as their first language). Slow your speech down, and try not to use technical terms.
- Respect age-appropriate norms. Communicate with each person according to their age, interests and abilities.
- Speak directly to the person with MJD, not the person who is with them, being mindful of cultural norms

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- regarding eye contact, direct questions/answers, body language.
- Make sure the 'right people' are involved in communication and decision-making.
- If at all possible work with a first language speaker who can act as a translator and cultural advisor. This may be a family member, health worker or MJDF worker.
- 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. Think about how you will do this and what might help build a conversation, for examples photos, current news, You Tube etc.
- In a conversation with a person in a wheelchair, sit down and communicate at their level. Avoid standing over them or talking over their head. 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?)*

If you do not understand what the person with MJD is saying:

- Be honest, let the person know you do not understand what they are saying
- **Ask closed questions to clarify:** "Do you mean X?" then wait, so the person can indicate 'Yes' or 'No'
- Repeat the part of the message that you understood
- If appropriate, ask them to repeat what you didn't understand
- Is there someone else who can be involved? Eg. A family member or language speaker? (being mindful of kinship rules)

- If appropriate, ask the person to write or spell it, or show it visually eg. With iPad, photo board or other communication aid
- Use your knowledge of the person and the context to develop a checklist of possible communication points.
- 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, that you are unable to understand at the moment, but you will come back and try again, and/or you will bring someone who can. Be specific about when you will come back. **Make sure you follow up as promised.**



REMEMBER:

- Be patient, pay attention and allow the time that is needed.
- Focus 1:1 if possible. Group conversation may be more difficult unless another person present can provide helpful interpreting advice.
- Try not to suddenly and frequently change topic, and don't all talk together.
- Use closed (yes/no) questions.
- Provide information & instructions thoughtfully. Be brief, clear and consistent. Break down into step-by-step.

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- Utilise the communication aids people use and understand.
- Enlist the help of family, language speakers or interpreters. Make sure they are the 'right people' to help, being mindful of kinship rules.

Reflection and Empathy

Reflect on the challenges the person with MJD is living with.

1. How would *you* feel living with these challenges?
2. How would your day to day interactions be affected?
3. How can you support people with empathy?
4. What will you be mindful of when you communicate with people with MJD?

Who can I talk to if I have questions or concerns?

MJD Foundation staff

Leah Clarke (Darwin)	0499 334 856
Jill Turner (Groote Eylandt)	0499 330 207
Mark Kilpatrick (Alice Spings)	0499 330 238
Wyam Morris (Cairns)	0499 771 143

Your Health clinic doctors, nurses and health workers.