



Communication Changes *with motor neurone disease*

This Booklet Covers:

- Common Communication Methods
- MND's Influence on Communication
- Easy Strategies to try
- Communication Aids to Explore
- Importance of Checking in With Care Team Early
- Advance Care Planning

What are Common Communication Methods?

People usually think of communication as just talking, but it's much more than that. Communication occurs in many different ways. Here are a few examples:

- Talking
- Texting
- Social media (sharing images and videos)
- Letter writing
- Emails
- Non-verbal (facial expression, body language, physical touch)

How can MND Affect Someone's Ability to Communicate?

MND may influence someone's ability to communicate both verbally and non-verbally as seen below:

Verbal Communication

MND affects the nerves that control the mouth, throat and breathing. All of these structures enable speech. If these are affected in MND, speech can then be affected. It can cause slurred speech or voice changes. The voice's volume may also be softer.

Non-Verbal Communication

Muscle weakness from MND can affect a person's ability to use their hands and arms. If someone relies on communication aids that need hand-use, like texting or writing with a pen, their ability to communicate this way might also be impacted. Muscle weakness may also make it harder to show expressions in the face.

Simple Strategies That Might Help With Communication Changes

A speech pathologist and occupational therapist (OT) can offer personalised strategies for managing communication changes.

In the meantime, here are a few communication strategies a person with MND and their caregiver can try:

Modify Social Gatherings

- Consider the seating set-up at events, as the individual with MND may only be able to communicate with those closest to them.
- Catch up in smaller groups
- Rest up before gatherings
- Pick quiet locations rather than noisy restaurants or cafes.

Implement Fatigue Management Strategies

- Plan important conversations for when the person with MND has the most energy during the day.
- Let family and friends know the best times for the person with MND to communicate.

Use Text Messaging and Photo Sharing

- Instead of talking, texting can help preserve the voice (and energy).
- Sharing pictures of events in someone's week - like scenery from a recent walk or pictures from the Friday night footy game - provides detailed updates without needing to talk.



Discuss With Family, Friends and Others

- Family and friends may not be aware of how MND affects communication.
- Taking the time to explain how best to communicate can help to overcome any confusion.
- Sharing this booklet or the accompanying video may also help provide some insight.
- A communication card, like the one provided by MND Victoria (pictured below), is helpful when communicating with others out in the community.



Conserve Words

- Where appropriate, the carer may ask closed questions that require one word answers (yes / no) for simple day-to-day tasks.
- To save energy, someone with MND might prefer to keep their sentences brief and direct. Depending on the wishes of the person with MND, the caregiver might then expand on their behalf.

Allow Extra Time

- Speech may be slower in MND and therefore, allowing someone the time to finish their sentence is really important.
- If in a group setting, the carer might want to create the space for someone with MND to comment or contribute to the conversation, before the group moves onto the next topic.

Low Cost Communication Aids and Equipment Available

It's advisable to consult with a speech pathologist and OT early in an MND diagnosis. They can offer strategies and suggest aids and equipment options. Here are a few low cost options to consider. More advanced options are detailed on the following page.



Alphabet Board

As the name suggests, this is an A4 sheet of paper with the alphabet listed. The person with MND can spell words by pointing to the letters, which is read aloud by their carer. Simple words like "the", "and", "yes", and "no", as well as numbers up to 9, can be included. This can be customised to suit the individual's needs.



Pen and Paper or Boogie Board

This method allows the person living with MND to write out sentences or words. For instance they may write, "Hello, how are you?" or "Small latte please". A boogie board is similar to pen and paper, however, the words are easily erased with a click of a button.



Phrases Board

Similar to the alphabet board, someone with MND can point to different phrases on the board. This is a great one to customise to the person and include common phrases they use, such as their coffee order, "I need a bag", "can I pay with cash?", "I have motor neurone disease".



Text to Speech Apps

This communication option involves the person living with MND typing out a phrase and then hitting 'speak'. The phrase is then read aloud. There are numerous smart phone applications available, some of which are free to download. *An example of this is shown in the Communication Changes Video.*



Thicker Pen / Stylus

A thin pen or stylus can be difficult to hold onto if hand strength is poor. Opting for a thicker pen or stylus can make writing easier. Using foam or a pencil-grip can help to build up a pen or stylus that someone may already have. A felt tip pen may be easier compared to ball point as less pressure is needed to write.



Voice Amplifier

If someone's voice is softer, it may require extra effort to project their voice in a noisy environment. A voice amplifier is a small microphone and speaker. The person speaks as they normally would into the microphone, and the speaker projects their voice at a louder volume, helping to preserve energy.

Other Communication Aids to Explore With the Healthcare Team

Voice Banking

Voice Banking involves creating a digital copy of a person's voice. This can be saved in case they need an artificial voice to communicate in the future. This digital voice will sound more like them compared to the generic options available in communication programs. The process involves recording the person saying around 50 phrases, which the program then uses to generate a digital copy of their voice. It's best to do this as early as possible, as it becomes more challenging if the person with MND experiences changes in their voice as the disease progresses.

Message Banking

Message banking is similar to voice banking, but instead of creating an electronic voice, it involves recording and preserving voice clips in their original format. People often record personal and meaningful messages, such as "I love you honey," or special occasions like a wedding speech for their children or grandchildren.

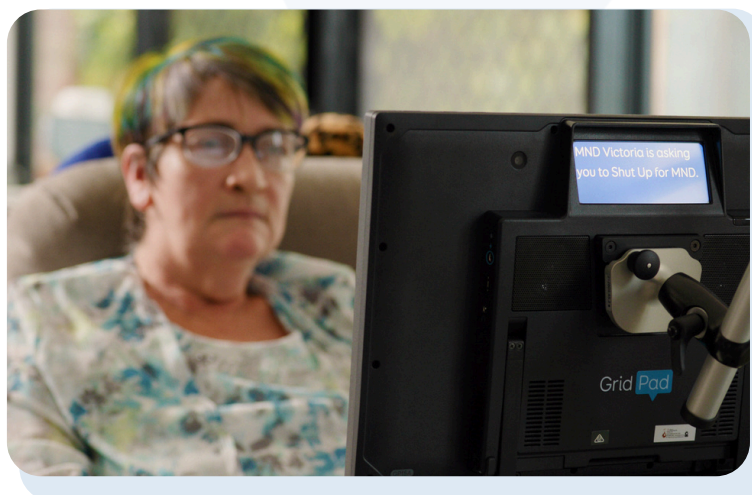


Did you know?

Some build-your-own toy companies have the option to record a message to place inside a plush toy. People living with MND have recorded messages for their younger family members using this option.

Eye Gaze Technology

Eye Gaze Technology is a solution for individuals whose verbal communication and hand function are impacted by MND. The person looks at a computer screen and moves their eyes to select specific letters. The computer detects these subtle eye movements and types out the words, which are then spoken aloud. This is where a banked voice could be used.



Local MND Association's Equipment Options

Some communication equipment can be expensive to buy. Renting certain items may be possible depending on the person living with MND's location. It is advised that anyone interested should reach out to their local MND Association to see what funding is available to them.

The Importance of Checking in With Healthcare Team Early

It is never too early to reach out to a speech pathologist or OT for support. There are so many options which can be tried.

- Strategies recommended by the healthcare team are designed to keep someone doing the things they love for longer.
- They may only want to use these equipment items at home to conserve energy so that they can chat with friends at dinner for a bit longer, and that's okay.
- The health care team team are there to help someone problem solve.
- If someone has heard about a communication strategy which wasn't suggested for them, they should definitely ask the team about it.
- If something hasn't worked, let the health care team know.
- The healthcare team are there to help and there's no such thing as a silly question.

Advance Care Planning

Organising someone's Advance Care Plan early on in the disease progression is important.

- Organising early, while someone is able to verbally communicate their wishes, helps to reduce stress later.
- Keep a hardcopy version of the individual's Advance Care Plan somewhere safe, to easily grab in the case of an emergency.

Want to learn more?

Check out Carers Can!

The "Carers Can" project, 2024 created a suite of videos and booklets like this one. The videos feature health professionals, MND Victoria staff members, carers and people with MND. They provides helpful strategies, lived experiences and other useful tips.

www.mnd.org.au/carers-can



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FIGHT MND.

MND varies greatly between individuals. Always consult your healthcare team for a personalised plan. This resource was developed in 2024 by MND Victoria using information provided by allied health professionals working within the MND health sector.

The information provided is not intended to replace the expert care provided by Healthcare professionals.