Carer guide:
Staying connected without speech

Even without speech, communication can still feel familiar, warm, and meaningful. It is possible to understand each other in everyday care and in emotional moments.

This guide will help you to:

- stay connected in a way that feels manageable for both you and the person with MND
- set up small signals, simple tools, and shared routines to stay connected
- get help from the care team and other supports for carers
- understand the importance of correcting posture and positioning
- use daily checklists so the person with MND you are caring for stays as comfortable as possible and has ways to communicate

About this guide

This guide is designed to be used for **staying connected without speech**. It is part of the *speech and communication in MND* series of guides and practical tools. This series was developed with MND Queensland, people living with MND, and their carers to help prepare for and adjust to speech changes, get support, and stay connected.

Scan for more

This project and MND Australia received funding from the Australian Government Department of Health, Disability and Ageing.

Staying connected as needs change

There are many ways to keep communicating as needs change. See these other guides and tools to find out more:

- *Building your communication system*
- *Communication tools and technology (AAC)*
- *‘I have MND’ wallet card*
- *My care needs form*
- *Partner assisted scanning and communication boards*

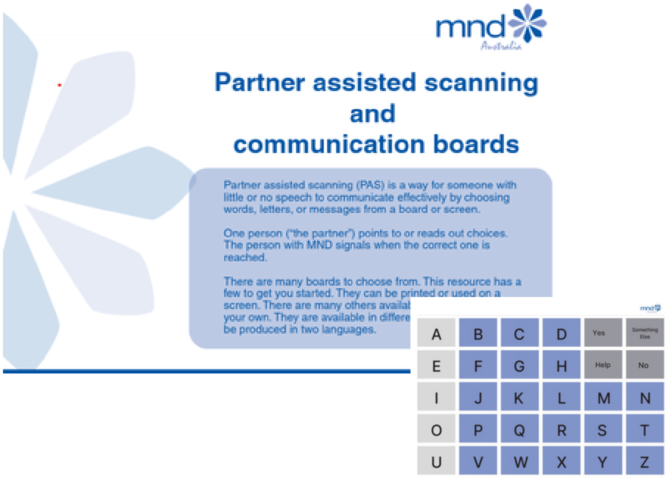
Ask your speech pathologist for support to navigate changing communication needs.

Keeping communication and connection: Six steps

1. Agree on a Yes/No signal

Pick a clear way to show yes and no and practice it together. Here are some examples:

- Eyes look up / down.
- Blink once / twice.
- Thumbs up / down.
- Written card for pointing or partner assisted scanning.
- Use a switch or communication device.



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Partner assisted scanning and communication boards

Partner assisted scanning (PAS) is a way for someone with little or no speech to communicate effectively by choosing words, letters, or messages from a board or screen.

One person ("the partner") points to or reads out choices. The person with MND signals when the correct one is reached.

There are many boards to choose from. This resource has a few to get you started. They can be printed or used on a screen. There are many others availab your own. They are available in differe be produced in two languages.

A	B	C	D	Yes	Something Else
E	F	G	H	Help	No
I	J	K	L	M	N
O	P	Q	R	S	T
U	V	W	X	Y	Z

Things you can do

- Write down what you have decided to use and place it near the bed or chair so everyone uses the same system.
- Confirm answers**:** repeat back what you think the person said (“You want to sit up?”).
- Practice your yes/no signals with the Partner assisted scanning (PAS) and communication boards

2. Position for comfort and access

Check	Why it matters
Head, neck, and torso aligned	Not being too bent, twisted or slumped helps breathing, opens airway, supports any non-speech signals (eye gaze, facial expressions).
Support under arms, shoulders, back & hips	Reduces fatigue and helps breathing.
Feet supported (on footrest or floor)	Helps whole body support, reduces strain elsewhere.
Lighting good, no harsh glare on screen or board	Easier to see; avoids eye strain.
Adjust seating so device is in clear view	If someone uses an eye-gaze device or board, they need to see it without strain.
Mouth care regularly (moist lips, manage saliva)	Keeps mouth clean & comfortable; important even if speaking isn’t possible.
Frequent small breaks / repositioning	Sitting in one position for long causes discomfort.

3. Keep communication tools available

Task	Why it matters
Use partner-assisted strategies	When speech & movement are limited, partners help interpret intended messages. Partner strategies (e.g. pause, wait, allow signal, read small facial cues or eye movements) can be essential.
Always have low-tech backups close by 	Devices can fail and batteries go flat. Using high-tech devices can be harder when tired. Make sure there are backups close by like yes/no cards, communication boards or picture charts.
Keep all communication tools powered, clean & charged	Including switches, eye-gaze devices, tablets. This means they will be ready when you need them.
Position tools and devices so they are easy to see or reach	If tools are hard to reach, or using them causes strain or pain, people may give up or be unable to use them.
Pre-program messages for frequent basic needs	Making common messages large and easy to access (e.g. pain, thirsty, reposition, rest, help) reduces effort and time needed to get essential messages across.
Protect vision	Ensure glasses or visual aids are clean, aligned, available, because eye-based communication relies on vision.
Keep environment quiet & free from distractions	Helps focus, especially when signals are subtle.

4. Ask simple questions

Ask one thing at a time.

Wait for a response — don’t rush to fill silence.

Offer choices (“Do you want to sit up — yes or no?”).

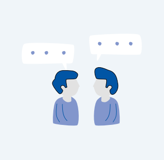
5. Save important messages

Plan for the things that you don’t want to leave unsaid.

Comfort needs:
“Pain”, “Suction”, “Turn me”, “Too hot/cold”.

Emotional:
“I love you”, “I’m scared”.

Environmental:
“Quiet please”, “Play music”.



Spiritual and personal:
Prayer requests, goodbyes, family messages, common phrases and favourite topics.

When speaking gets harder, having key messages ready can make everyday life feel easier and more connected.

Pre-saved messages give the person living with MND a reliable voice. This helps them to share their care needs, express humour and feelings, and offer comfort.

Preparing these phrases ahead of time helps with practical communication and the small interactions that keep relationships warm and familiar.

A Speech Pathologist can help to capture these messages

6. Stay calm and connected

WAIT Give extra time for answers.

If it is safe, take breaks when communication becomes stressful. Return when calmer.

Use touch (if welcomed) to reassure: hold hands, gentle pat on arm.

After difficult moments, debrief with a nurse, speech pathologist, or other support person. It's normal for communication to feel harder on some days than others.

Talking with someone using eye-gaze
Tips from a person living with MND*

Someone using eye-gaze can think, hear, and understand – only their speech is affected. Here are some things you can do, and things to avoid, to have a good conversation with a person using eye-gaze. Remember patience and respect make it work.

Do	Don't
Do sit or stand in clear view	Don't stand behind the device
Do treat it like any other conversation	Don't ask multiple questions at once, or interrupt while they are replying
Do look at the person	Don't read the screen, unless asked to
Be patient – responses take time	Don't talk to others while waiting
Do let them finish	Don't guess their words

Respect independence and have a great conversation

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*Thanks to Stacey Ebben, who lives with MND and uses eye-gaze

Daily checklist

Use and adapt this checklist to suit your needs.

Tip: first get the person into a comfortable position, then adjust the position of the communication devices to suit them.

- ☐ How comfortable is the person now? Think about pain, pressure, breathing.
- ☐ Is seating or bed position the same as yesterday? Adjust if they're slumped, shifted, or uncomfortable.
- ☐ Yes/no signal system still clear and agreed. (Blink, look, lip movement, squeeze hand, etc.)
- ☐ Do all carers today know the signals and how to confirm messages?
- ☐ Has anything changed (vision, motor control)? Might need new positioning or tool setup.
- ☐
- ☐
- ☐
- ☐ Backup board or card in reach.
- ☐ Devices charged, visible and positioned.
- ☐ Glasses/hearing aids on, lights good.
- ☐ Key comfort/emotion phrases saved and easy to find.
- ☐
- ☐
- ☐
- ☐

Carer wellbeing

Caring for someone who can no longer speak can be rewarding, but can also be very hard.

- When a person depends on you to help them communicate, the mental load increases. It's normal to feel tired, stressed, or overwhelmed at times.
- Remember, your wellbeing matters too. Extra pressure can increase your risk of burnout.
- Take short breaks, share tasks when possible, and look after your own mental health. This can help you stay steady, patient, and safe while caring for someone.

The care team

The speech pathologist and occupational therapist can help choose the best communication device/method for the stage.

Positioning and access needs often change. The care team can help you adjust.

They can assess posture, seating and supports, and modify equipment so the person can use what remains of their movement (e.g. eye motion, head motion, cheek, etc.).

They can train carers in partner-assisted methods and how to read subtle cues.

Support for you

MND Associations: Support groups, carer education, equipment help.

Carer Gateway: 1800 422 737 – counselling, respite, coaching.

Palliative care service: For comfort and emotional support.

Lifeline: 13 11 14 – 24/7 crisis support.