

Building your communication system

Use this guide to:

- build your communication system with support from a speech pathologist (SP) and occupational therapist (OT)
- think about what you want and need from your system
- find the right tools and technology for you, for now and later
- understand how your SP and OT works with you and your carer to set up, use and adjust your system.

It includes simple strategies, tips, and support options for you and your family.

About this guide

This guide is designed to be used **when speech gets harder**. 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 to learn more



The right communication system for you

Communicate in your own way

Your communication system is designed for you, based on who you are, what you want, and what you need. A good system helps you stay connected with the people and activities that matter most. With the right system in place, you can communicate with comfort, clarity, and in your own way.

Stay connected now, and in the future







Your communication system will likely include a mix of tools you can use now, and others you might need as speech gets harder. This helps you plan and prepare for any changes.

Support from your team as needs change

The idea is to build a complete communication system over time, with support from a speech pathologist (SP) and occupational therapist (OT).

Building your system: typical steps

Working with your communication team, building your system will likely include the following steps:

- | | | |
|----------------------------|---|---|
| Assess your needs |  | define your goals. |
| Trial and error |  | try a few systems and access options (switch, touch, eye-gaze) to see what works for you. |
| Choose your system |  | decide on a main system, plus backup. |
| Set up the system |  | add your voice, messages, and mount your device if needed. |
| Learn how to use it |  | your team will train you and your carers. |
| Regular review |  | check and update system if your needs change. |

Your communication team: who does what?

Building a communication system will work best with a team around you. Primary members of your team are a speech pathologist and occupational therapist.

Your speech pathologist



Leads communication assessment



Helps you select suitable communication tools and technology



Sets up your vocabulary and messages



Trains you and your family and carers on how to use tools



Works with you to address swallowing, saliva, breathing and thinking to improve communication

Your communication team might also include carers, support workers, physiotherapists, psychologists and other health professionals.

Your occupational therapist



Advises on how body positioning may affect communication



Looks at how your movement might impact your ability to access a communication system



Checks if your environment is ready for the device



Installs mounts and access switches

AAC

You may hear the term AAC. It stands for augmentative and alternative communication. It means any tool, method or technology that helps you communicate. This includes simple things like yes/no signals and communication boards, as well as high-tech devices that speak for you. See *Communication tools and technology* for more.

Building your system, your way

What matters most to you?

A good communication system will help you stay involved in daily life, not just in medical care. Your speech pathologist will ask questions to work out what matters most to you.

Here are some things you might want to think about:

- who you want to talk to
- where you spend your time
- what you need to say
- how you want to deal with urgent needs (like calling for help)
- exploring options for social chat, games and other fun activities.

Your team looks at the whole picture – not just speech



Speech and language

How clear your speech is, how much energy you use, and what phrases or words you use most.



Thinking and memory

Changes to thinking and memory can make some tools easier or harder to use.



Vision and hearing

These can affect screen size and brightness, and whether eye-gaze control is suitable for you.



Movement

How your body moves now and might move later (finger, head, eyes, foot, breath) affects how you use communication supports and devices.



Breathing and saliva

These can affect how well you use a system. Your team may also give ideas to manage these.



Position and comfort

Your OT will check how you sit to make sure you can reach switches or see the screen, even when tired. They may also mount your device so it's easier to use when sitting, moving, or in bed.



Environment and carers

Where will you use the tools, who will help, and what space and power is available?

A system that supports your needs

Your communications team will help you make sure your system supports your needs now, in the future, and in an emergency.



Now

Quick and easy options (yes/no signals, boards, partner-assisted scanning), or technology that you can use straight away.



Next

Planning the next step early, e.g. changing from touch to eye-gaze.



Back-ups

Back-ups include paper or low-tech options in case a device fails or you are too tired to use it. A back-up may also help in an emergency.



Your team will consider things like speed, size, voice, and access method when selecting supports and devices for your system.

You can try doing daily tasks with different devices before you choose.

How to find out more

To explore your options, scan the QR code on the front of this guide to check out the full **Speech and communication in MND** series, including:

- *Voice and message banking*
- *Communication tools and technology (AAC)*
- *PAS (partner-assisted scanning) and communication boards*
- *'I have MND' wallet card*
- *My care needs form*

Setting up your system

Adding voice and messages



If you have chosen a speech generating device (SGD), your speech pathologist can add your banked voice to the device.



If you don't have a banked voice, you can choose a digital voice and add personalised phrases – for care needs, social life, and emergencies.



You and your family or carers need to practice using your communication system.

Ask your team to review your system regularly to make sure it meets your needs.

Making it easy to use



Your OT and SP may mount the device to your wheelchair or a stand to make it easier to use.



Your team can help connect it with your phone, email, social media, TV, or nurse call button if possible.



Ask your team to train family and carers to charge, set up, and fix small problems.

Ready to build your system?

Contact a speech pathologist or your MND Association

Staying connected without speech

As your MND journey progresses, your communication team will help you stay connected. Some of the ways they do this include:

- assist you and your carer to express your needs and feelings, as well as communicate pain, comfort needs, and care choices
- work with you and your carer to simplify systems, so they are easy to use even if you have very low energy.

See *Staying connected without speech* to find out more.