

# Carer guide:

## Communicating at end of life

What to expect and how to prepare

When a person is near the end of life, clear and kind communication helps everyone feel calmer and more in control. Your care team will guide you, but here are some examples of what usually happens, and how you can prepare.

### What to expect

**Less energy:** People often get tired quickly and communicate less.

**Body changes:** Weakness, lack of breath, dry mouth or extra saliva can make talking or using a device hard.

**Changes in thinking:** Some people may feel confused, worried, or distracted.

**Final days:** People may sleep a lot more, eat and drink less, and stop speaking.

### What you can do

Try asking short questions.

Keep conversations calm and about one topic at a time.

Use yes/no signals, eye movements, or pointing to communicate.

Simple moments of presence and touch can keep connection strong, even when communication becomes harder.

## The care team can help

**Speech pathologist:** Makes communication systems simple and easy to use, sets up comfort-care messages, and trains carers.

**Occupational therapist:** Adjusts seating, bed supports, and switch placement.

**Nurses, doctors & palliative care team:** Manage pain and other symptoms, teach carers what to expect, and provide emotional support.

# How carers and family can prepare

## To do

### Discuss care wishes early



### Agree on a clear Yes signal



### Keep tools simple



### Prepare messages



### Prepare the space



### Support emotions



## Details

- Decide what care is wanted (or not wanted), where the person wants to be, and who should be there.
- Write down choices and share with family, GP, nurses, and the MND care team.
- Review often as things change.
- Choose a signal you all understand (eye look, blink, thumb up, card, or switch).
- Practise so everyone reads the signal the same way.
- Write the agreed signal down and place it near the bed.
- Keep backup tools nearby: yes/no card, alphabet board, or list of pre-written needs e.g. “mouth care” “turn me”.
- If you use a device, make a simple page with buttons for key needs e.g. pain, breathing help, position change.
- Pre-save phrases like pain scores (0–10), “give medication,” “I’m comfortable,” “I want quiet.”
- Add personal messages such as names, goodbyes, or faith-based words.
- Position so breathing and communication are easiest.
- Keep mouthcare supplies and suction (if prescribed) close.
- Have a list of who to call 24/7 (palliative care nurse, GP after-hours number) nearby.
- Use short, honest phrases like “This is hard, we’re here.”
- Keep the room quiet or play favourite music if preferred.

### 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 to learn more

