

# Mental health and wellbeing



Use this guide to:

- understand the emotional impact of changes to speech
- learn ways to cope with the changes
- identify when changes start to affect your mental health
- explore practical ways to work with the people close to you to support wellbeing and mental health
- learn tips to help stay respectful, calm, and person-centred
- support a person living with MND.

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

## About this guide

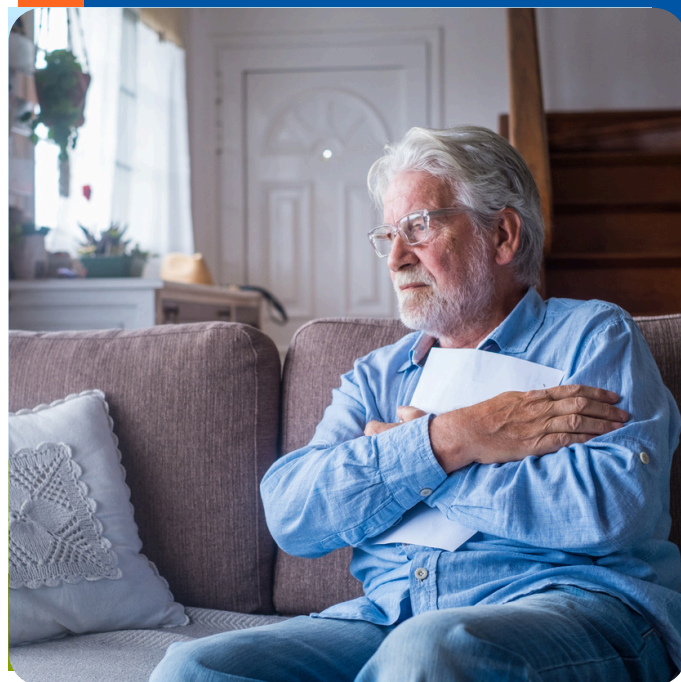
This guide is part of the *speech and communication in MND* series of guides and practical tools. This series was developed with MND Queensland, people living with MND, and their carers to help prepare for and adjust to speech changes, get support, and stay connected.

[Scan to learn more](#)



# How speech changes affect emotions

Changes in speech affect many parts of life. The changes can bring up a range of emotions – for you, and people close to you. You may feel frustrated, sad, angry, worried, or alone. This is normal.



## Changes in speech can affect:



### Identity and dignity

Not being able to speak can change how you see yourself. You may feel uncertain about your role in your family and the community. This can impact feelings of self-worth. Having other ways to communicate will help you to maintain connection.



### Social connection

It can be harder to take part in groups, social outings, or medical appointments. Misunderstandings can cause tension in families or friendships.



### Mental health

You and those around you can feel frustrated. You may feel a sense of loss for the way things used to be. Carers may feel stressed, guilty, or alone. Fear of not being heard or not having needs met can cause distress. Communication may take longer and be tiring for everyone.



### Non-verbal expression (smiling or showing feelings)

Showing feelings with your face or body may be affected. For example, you might feel happy, but your face may look blank or still.

**Talking about these impacts, and planning for support, can help protect both mental health and relationships.**

# Practical steps to supporting mental health and wellbeing – together

Working together to support communication helps to maintain mental health and wellbeing as speech gets harder. Follow these practical steps to reduce stress and support communication and keep relationships strong.

## Step one: Make communication reliable

When speech gets harder, having clear and consistent ways to express messages is essential.

### Supporting each other



Agree on a yes/no system and keep it consistent.



Keep devices charged and boards in reach.



Plan for breakdowns: Have backup options ready and practise using them.

### Person living with MND



Plan talks for your best energy times.



Use backup tools (pen and paper, boards, devices) when you are tired.



Tell others how you want them to help (e.g., repeat what they heard, don't interrupt, yes/no questions).



Take breaks if communication feels overwhelming.

### Carers, family and others



Stay patient and give extra time. Silence is okay.



Don't speak for the person unless asked.



Notice signs of fatigue and suggest a rest.



Repeat back what you heard to confirm it is correct.



Acknowledge feelings: "I know this is hard — let's pause."

## Step two: Support self-expression

When speech gets harder, there are still ways to express yourself and stay connected.



Add feelings words or emojis to devices/boards (sad, worried, happy, angry).



Use partner-assisted scanning for emotional check-ins (“Are you feeling worried? yes/no”).



Encourage openness – share feelings, memories, thoughts, spiritual beliefs.



## Step three: Keep things simple

As communication becomes slower and more tiring, slowing down and keeping things simple can reduce stress and emotional strain.

- Ask one question at a time.
- Reduce background noise.
- Allow extra time for responses.
- Be okay with silence.
- Take regular breaks.
- Switch to low-tech options when you are tired.
- Focus on small wins – a successful message, or a shared memory.



**Take the time to enjoy quiet moments of calm together. These moments can remind you that meaning and closeness are still possible, even as speech gets harder. This can bring hope.**

In some cases, a person living with MND may also have cognitive (thinking) changes. These changes can make communication harder. Speak with your doctor if you feel like your thinking has changed.

## Step four:

### Support dignity



**Supporting dignity as speech gets harder is important.**

Small actions can help communication feel safer, more respectful, and less emotionally draining for everyone. These include:

- involving the person living with MND in all decisions, even if it takes longer
- respecting signals, especially “stop,” “wait,” or “quiet”
- using saved messages about care, comfort, and personal preferences so wishes are always clear. See *Voice and message banking* for more

## Step five: Support for carers and family

**Changes to speech also impacts carers and others close to the person living with MND. Carers need their own support to stay steady and connected in their role. Understanding this early helps carers stay calmer, feel more supported, and prevent burnout.**



### Prepare emotionally

Supporting communication can also take a lot of emotional and physical energy. Accept that you will feel frustrated, stressed, sad or unsure. All these feelings are normal.



### Seek support early

Support includes family education sessions, counselling, support groups, and carer coaching (e.g. Carer Gateway), and support for children and young people.



### Take breaks

Take regular breaks and share tasks. Respite services give carers a break, reduce stress and can prevent burnout.



### Debrief

Talk with friends, family, your team or support workers after challenging moments.

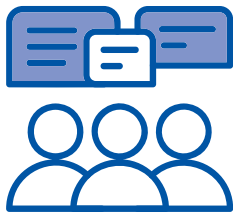
## Step six: Connect with your peers for support

Talking with others who understand MND can reduce feelings of isolation.



MND Associations in each state and territory run support groups, both in-person and online. These are open to people with MND and carers.

**Call the MND Info Line 1800 777 175 to find out more.**



There are also online communities such as forums, webinars, and social media groups.



## Step seven: Seek professional help if needed

Seek help if you notice you are feeling:

- ongoing sadness, fear, or agitation
- withdrawal from people close to you and social activities
- feelings of hopelessness or distress.

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Support can include psychologists, social workers, palliative care teams.



Reaching out early for emotional support and practical guidance protects wellbeing, and helps you cope with changes.



Meaningful moments, comfort, and closeness can still be shared, even without speech. Clear routines, trusted partners, and the right mix of tools, you help you to stay part of daily life. Carers can also feel more confident and supported in their role.

# Key contacts

<b>MND Australia</b>	National information and support <a href="http://mndaustralia.org.au">mndaustralia.org.au</a>
<b>MND Associations</b>	Local support and advice MND Info Line 1800 777 175
<b>Carer Gateway</b>	National support for carers 1800 422 737
<b>Lifeline</b>	Crisis support, 24/7 13 11 14
<b>GP and allied health team</b>	Local counselling and support
<b>Beyond Blue</b>	24/7 mental health support 1300 22 46 36 (or chat online)
<b>MensLine Australia</b>	Free 24/7 support for men 1300 78 99 78 or chat online.
<b>Friendline</b>	For people feeling lonely or isolated <a href="http://friendline.org.au">friendline.org.au</a>

## Staying connected as your needs change

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

- *Voice and message banking*
- *Building your communication system*
- *Communication tools and technology (AAC)*
- *'I have MND' wallet card*
- *My care needs form*