

Speech & Communication

“I first saw the task as one of preserving my personality, of showing the world that my mind has not gone down the tubes with my voice. If I cannot say as much as I use to say, I have to say it better. So the choice of words becomes crucial.”

We all need to communicate, both in order to get things done and to share our thoughts and feelings with others. Communication is not just about speech and writing. We express things to others by gestures, facial expressions, laughter and tears. MND can affect your ability to do all these things and one of the main challenges of living with MND is to overcome these problems.

The topics covered in this section are:

- How MND affects speech
- Who can help?
- Ways to maintain speech intelligibility
- Alternative ways of communicating

How MND affects speech

How we produce speech

Air from the lungs passes up the windpipe and through the vocal cords, which vibrate and produce sounds.

Shaping these sounds with the muscles of the tongue, lips, teeth and palate produces speech.

What happens in MND?

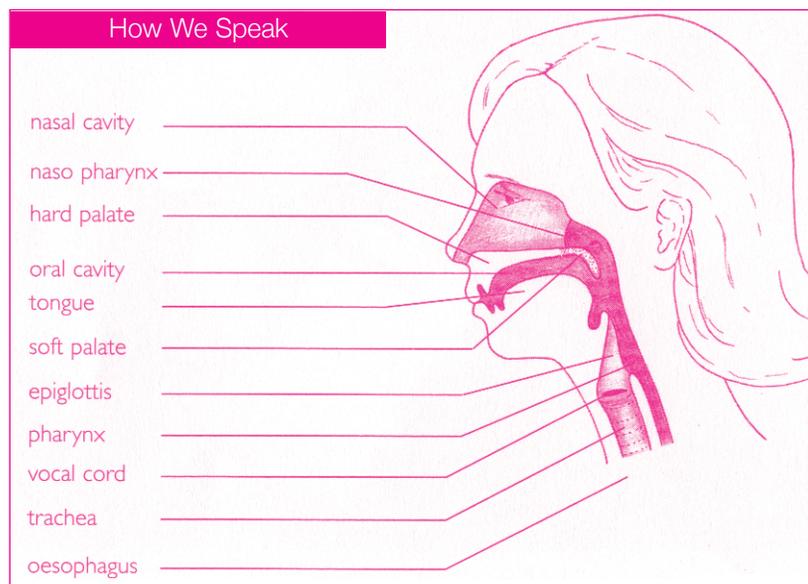
Too much tone (spasticity) or too little tone (flaccidity) in the mouth, throat and respiratory muscles can lead to:

- Difficulty articulating certain consonant sounds (e.g. p b t d etc)
- Limited movement of the soft palate causing “nasal” quality speech
- Impaired movement of the vocal cords resulting in hoarseness (weak and breathy or strained and strangled)
- Shortness of breath when speaking

Each of these changes can impact on how well a person’s speech is understood in conversation (i.e. their speech intelligibility).

Who can help?

A Speech & Language Therapist can give strategies to make speech as clear as possible for communicating with others. The Speech & Language Therapist also works with family and carers on ways to communicate more efficiently at home and in some cases recommends pieces of equipment either to augment speech or to be used as an alternative to speech.



Ways to maintain speech intelligibility

What you can do

- Speak more slowly
- Pause frequently to take a breath and clear your mouth of saliva
- Over emphasise words and break them into distinct syllables
- Save energy by using short sentences
- Get your meaning over early in a sentence by starting with a keyword
- Provide a context to the listener when switching topic in conversation (e.g. shopping)
- Arrange meetings/social visits for a time of the day when you are least tired/when speech is at its best
- Avoid background noise (e.g. turn off radio/television)
- Make sure your listener is actively listening and watching for non verbal clues
- Face your conversation partner
- Signal to get attention (e.g. with hand) when you want to contribute to a group conversation
- Use gestures to emphasise or replace speech

You may not realise how your voice sounds to others. Often people close to you will be able to understand even when strangers can't. Strangers may assume that you are drunk or deaf and this can be hurtful and embarrassing.

"I must admit that the strange tone of my voice causes most people to stop momentarily for a brief stare. I'm getting used to that, and I give them a grin or a wave. All is well, sometimes I feel like wearing a label, MND."

Useful aids

- Keep a pen and pad handy or a wipe clean "magic slate"
- Your Speech & Language Therapist may recommend a voice amplifier if your speech is clear but your voice is low in volume
- A palatal lift prosthesis is occasionally recommended when there is significant weakness of the soft palate without other aspects of speech being affected
- A range of communication aids are available from the IMNDA on recommendation by your Speech & Language Therapist

It is important to remember that you will need to deal with different situations and environments. What works in a quiet sitting room with friends may not work in a noisy shop. It's worth practising different tactics so that you can cope in less commonly met situations.

Share your frustration and challenges with your family and friends. Involve them in finding ways to help.

Tips for families and carers

- Impaired speech does not mean impaired understanding, so don't talk down to someone with MND
- Don't change the speed or sound of your speech unless the person with MND has a hearing loss
- Be patient of slow speech - it may be taking a lot of effort
- If a person has speech difficulties, do not finish his/her sentences or guess what they are saying while they are still talking unless this has been requested
- Encourage the speaker to pause between phrases and rest often
- Encourage over-articulation of speech to make up for slower and weaker movements as this will help make speech clearer
- Face one another and watch the person's face and lips

- Sit in a quiet room, turn the television off and avoid distractions
- Keep a pencil and paper/communication board handy
- Think about using eye pointing or gesture if speech is becoming tiring
- Use 'closed' questions that only need a "yes/no" answer. For example "Would you like a cup of tea?" rather than "Would you like tea or coffee?"
- Do not pretend to have understood what a person with speech difficulties has said when you are unsure. Instead, ask for repetition or request confirmation on what you think you have heard

Alternative ways of communicating

More ways to help communication if speech problems are increasing

- Work out some hand signals for frequently used phrases with your immediate family and other carers
- Establish a 'Yes' or 'No' signal. This could be a particular sound or a slight head or limb movement or blinks/eyebrow rising
- Compile a list of your regular questions/requests so that when communicating your partner goes through the list until you indicate 'yes'/'no' by agreed signal

Using the alphabet

- A partner can help you to spell out words by reciting the letters until you signal that the target letter is reached. The alphabet can be handled in sections such as A-K, L-Z, to speed up this process
- If you have some hand movement, try using an alphabet board (which can be home-made) to supplement your speech. A partner scans his/her finger along the board until you signal the correct letter or word
- An alphabet chart with colour coding of different letters can be provided by your Speech & Language Therapist. Colour coding allows scanning of letters which can speed up communication
- You will no doubt work out your own modifications of these ideas like one lady who communicates in morse code with her eyebrows
- When you know that you are going to be seeing your doctor or other professional you may find it helpful to prepare a written list of the main things that you want to say or ask

Equipment

You may need a combination of communication systems including both high and low-tech options. What you use is likely to change as your MND progresses.

Types of equipment include:

- Portable electronic communication aids, powered by rechargeable batteries. These have a small keyboard, display screen and synthesised speech. You type a sentence and press a button for the machine to speak it. You can select from a range of voices but the electronically produced voice takes a bit of getting used to. They can be adapted to be operated by a single switch for people with limited hand movement and can be pre-programmed with frequently used words and phrases and have text prediction to speed communication up
- Portable electronic devices can also come as hand held devices (e.g. palm pilot)
- Computers have extra functions such as voice activation and can be used to access the Internet and communicate by email
- Eye-pointing frames use a sheet of clear plastic with groups of colour-coded letters
- Your Speech & Language Therapist will advise you on the most suitable ones for you and demonstrate how to use them

- Other equipment may be needed to help you use communication aids, such as arm supports, clamps to hold equipment steady or an adjustable table

Funding equipment

- Aids can be bought privately but they are very expensive and your needs are likely to change as MND progresses
- The IMNDA has a range of communication aids to loan. These are supplied following an assessment by a Speech & Language Therapist
- The Employment Services Officer at your local FAS Office can work with you and your employer so that you can continue working. Fas offer the disabled worker and their employer a range of schemes and grants to cover workplace adaptation, and employee retention. For more information contact Fas at their head office at 01 607 0500. Alternatively visit their [website www.fas.ie](http://www.fas.ie), click on [Job Seeker Section](#), then click on [Equality and Inclusion](#) and finally click on [Disability](#)
- Also check your health care insurance provider (VHI or HIBERNIAN AVIVA HEALTH or QUINN) as to what equipment costs they can cover for you

Other forms of communication systems

Telephones

Difficulty or inability to use the phone can make you feel isolated. Equipment that can help you continue to use the phone includes:

- A cordless phone to carry around the house. This can reduce the risk of accidents when trying to answer the phone
- A hands free phone for those with upper limb difficulties. These can be pre-programmed so you can use a single button to dial your regular numbers including emergency services
- An answer phone will enable you to screen calls and choose to answer only those from family and friends or use your recorded message to explain your difficulties to the caller
- A fax machine may help but can only communicate with another fax
- A text phone. You type and a call centre operator will read out what you have said to the caller

Alarms

These can be used to call for assistance in an emergency. They can be used around the house or further a field:

- Inexpensive portable door chimes, available from electrical stores
- Intercoms and baby alarms which plug into 13 amp sockets and connect through your mains electric wiring
- Telephone alarm services to summon help. These give you a hands free main telephone unit and a remote switch to wear round your neck or keep in a pocket. They work through a call centre or can be pre-programmed to dial your chosen numbers. These are available through the IMNDA on referral from your Occupational Therapist or Public Health Nurse

Environmental controls

These systems are designed to help you stay independent at home. They provide a control panel that you can operate with a switch that is suitable for you. You can use this to:

- Operate lights, television and radio
- Open the door or curtains
- Answer the phone or call for help
- Change the position of your chair or bed

These systems are provided by the IMNDA once you have been assessed and the items recommended by a Technology Advisor. Assessment can be organised through the IMNDA, your Occupational Therapist or your Speech & Language Therapist.