

Multiple Sclerosis and Communication Changes

Multiple sclerosis (MS) is one of the most common neurological conditions affecting young and middle-aged people worldwide.

In MS, the immune system attacks the protective covering of nerves (myelin sheath) in the brain and spinal cord. The myelin sheath is often compared to the insulation on an electrical wire. When this covering is damaged, the signals transmitted by the nerve are slowed or blocked. The body can repair only some of the damage and, therefore, the disease leaves lesions or scars that can form in any part of the brain or spinal cord. This is why MS symptoms can be variable from person to person and over the disease course.

There are different types of MS. Most people have the relapsing-remitting disease course. Other people experience a steady course with no remissions.

MS can cause motor, sensory, and/or cognitive symptoms such as:

- Weakness
- Walking difficulties
- Swallowing difficulties
- Numbness
- Pain
- Fatigue
- Visual problems

People with MS can also experience communication changes.

Communication changes in MS

MS can affect communication in many ways, and it can affect everyone differently. Communication changes in MS can include:

Language and/or cognitive changes

- Word finding difficulty
- Substituting a word for another word e.g., saying 'fork' for 'spoon'
- Difficulty structuring clear explanations, stories, opinions, and arguments
- Leaving out important details when giving information
- Difficulty understanding long and complex messages
- Misinterpreting what others say
- Difficulty following conversations, especially in complex situations such as noisy places, group conversations, on the telephone, or while doing something else

- Using less complex language
- Literacy difficulties (reading, writing, spelling)
- Difficulty remembering conversations and/or people's names
- Increased time to process information and form a response
- Losing one's train of thought
- Difficulty with inhibition during speech e.g., making inappropriate comments
- Difficulty maintaining the topic of a conversation

Speech, voice, and fluency changes

- Slurred speech
- Slow speech
- Reduced volume
- Difficulty controlling pitch and volume
- Harsh, breathy, hoarse, and/or strained voice
- Stuttering

Other factors can interfere with communication in MS

Personal or environmental factors can trigger communication changes or make them worse. These include:

- Stress
- Anxiety
- Fatigue
- Poor sleep
- Heat
- Illness
- Relapses

Managing these factors is important. Understanding what can cause symptoms to worsen can help to avoid a flare-up.

The impact of communication changes.

When communication changes happen, they can affect the person with MS in many ways. These include:

- **Mental wellbeing:**
 - Avoidance
 - Embarrassment
 - Frustration
 - Low self-esteem
- **Relationships:**
 - Tense relationships
 - Loss of friendships
 - Social isolation

- **Work:**
 - Difficulty completing work tasks
 - Fear of appearing incompetent
 - Changing career pathways
 - Difficulty communicating with colleagues

- **Tertiary studies:**
 - Difficulty completing study tasks
 - Reduced participation
 - Difficulty communicating with students and/or teachers

What strategies can help communication

- **Strategies for word finding difficulty:**
 - *Circumlocution:* Describe the word
 - *Synonym:* Think of and use a word that means the same or something similar
 - *Association:* Think of something related to help prompt the word
 - *Gesture:* Use your hands to act out the word or point to an item
 - *Visualise:* Try to picture the word in your head
 - *Rephrase:* Rephrase the sentence to reduce/avoid word finding difficulty
 - *Delay:* Be patient with yourself and ask others to give you time to think of a word
- **Focus:** Concentrate on communication and avoid multi-tasking
- **Minimise distractions:** Reduce distractions when having conversations
- **Request for repetition:** Ask someone to repeat what they said if you did not understand
- **Take notes:** Take written notes to help remember what was said
- **Rehearsal:** Repeat verbal information in your head to help remember what was said
- **Plan:** Prepare a list of ideas and/or questions before talking
- **Use written over spoken language:** Use written instead of spoken communication if easier
- **Speak clearly:** Over-articulate your sounds and speak slowly
- **Use supportive aids:** Use assistive technology and memory aids e.g., calendars, alarms, to do lists to help with memory
- **Supportive communication partners:** Tell others what helps and what does not help
- **Have a positive outlook:** Take one day at a time, be kind to yourself, and you are not defined by your MS
- **Manage personal factors:** Relax, breathe, stay calm, and manage fatigue

How speech pathologists can help:

A speech pathologist can help people with MS in many ways to support communication. These include:

- Assessment and diagnosis
- Education
- Counselling
- Teaching people with MS compensatory strategies and tips
- Teaching communication partners strategies to support the person's communication
- Therapy exercises
- Recommendation of aids or technology like tablets
- Referral to and collaboration with other allied health professionals e.g., psychologist, neuropsychologist, and occupational therapist to support communication needs
- Advocacy for services e.g., National Disability Insurance Scheme (NDIS)

More information about MS, communication, cognition, swallowing, and support can be found here:

<https://www.eurims.org/images/stories/documents/SlG/Communication/Family%20booklet%20RIMS2013.pdf>