



Communication Devices - Vital for Care in Patients with MND Speech Pathology & Occupational Therapy

Natalie Mohr (speech pathologist) and Fiona Barry (occupational therapist) present on why communication devices are vital for people with MND.

Almost all people living with Motor Neurone Disease (MND) experience changes in their speech and voice. At some point 85-90% of people living with MND are unable to speak well enough to communicate their basic everyday needs. [1] People living with MND may also slowly lose the ability to use their arms and hands and therefore cannot type or write to communicate. The speech pathologist and occupational therapist work together to advise and provide communication devices, also known as augmentative and alternative communication (AAC) devices, that are tailored to each individual.

It is vital that doctors, nurses and other therapists can communicate with people living with MND in order to care for them: *'If MND patients don't have a way of communicating we can't do anything! We can't! It's very difficult to help them without the speech pathologist and occupational therapist coming in and sorting out a system. Our jobs would be so much harder, impossible!'* (MND Coordinator)

The following are a collection of quotes from colleagues regarding the impact of AAC on their provision of care.

Medical care via high-tech eye-gaze device

'He was essentially unable to communicate other than with eye gaze and once the eye gaze was set-up he had quite effective face-to-face communication and even via email. It was the only way we could negotiate advance care planning, symptom management, everything!'

Medical care via low-tech writing board

'He needed a low-tech device because he didn't want any of the keyboard devices so he communicated with an e-writer so he could tell us what his symptom was, and define it very clearly, which no one else could have done, because only he understood it. So it helped us with his care because we could understand his problem better'

Nursing care via low-tech eye-gaze device

'This lady used a MegaBee so she had to use eye gaze to track letters to spell out words very slowly. We used it when she was here on the hospital ward and without it I think she would have been even more tormented. It helped us, the family, her, the whole care team be involved in discussions to talk about everything with her'

Social Work care via high-tech iPad app

'I remember a lady, she was quite elderly, but she really took to the iPad app. And she was just a great communicator before MND and it just allowed her to express herself, keep her personality, and stay engaged, and tell jokes, it was just a whole outlet and she loved it and it was great to just sit down and enjoy talking to her'.

These examples demonstrate the need for MND patients to have access to communication devices. Speech pathologists and occupational therapists work together to ensure people living with MND have access to appropriate communication devices so they can communicate and therefore access better health care. It's also important to remember that for the person living with MND being able to communicate reduces feelings of isolation, fear, low self-esteem, frustration and lack of control.

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References

1. Beukelman D, Fager S, Nordness A. [Communication support for people with ALS. *Neurolog Res Int.* 2011; 2011: 714693.](#) doi:10.1155/2011/714693