

MND Podcast number five:

Communication in MND



### **MND Podcast number 5 Communication**

Hello my name is Robyn Reid. I am the MND Shared Care Worker in the Southern Region of Melbourne. Welcome. This is a series of podcasts on Motor Neurone disease. This podcast may help you to understand the issues around communication both with people with MND and in terms of working with people with life limiting illness. MND affects communication in a number of ways, both due to the weakening, and wasting of muscles of the tongue, lips, facial muscles, pharynx, larynx and respiration. This difficulty with speech is called Dysarthria. Potentially people with MND may also develop frontotemporal dementia which affects the language areas of the brain. Complicating communication is the fact that people with MND may also have emotional lability when there is upper motor neurone involvement. This means they may cry or laugh inappropriately or excessively in response to triggers, which do not necessarily mirror how they feel internally.

MND is a disease with no cure and is progressive, causing less and less ability to communicate. Being able to speak normally and to project the voice to others requires having a suitable amount of air in the lungs. As respiration is affected this air volume is reduced, so having enough breath to have a normal voice volume is affected and the voice becomes softer. Breathlessness and fatigue mean that talking is broken up into shorter sentences, and people must have a rest while talking. The voice can become slurred as muscles deteriorate.

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If people believe the person may be deaf or drunk or intellectually impaired because of the way they sound when speaking, this can mean that others may treat the person in disrespectful ways. Because speaking and answering questions is difficult and tiring, it is important to try to reduce the amount of dialogue that happens. When health professionals are visiting and obtaining information it is important to double up the number of people visiting if information needs are similar, so that nothing has to be repeated over and over again. It is also important that information that needs to be shared with the treating team is written down and sent to all team members, so that there is less need to repeat questions. This does two things – it helps to decrease fatigue and repetition for the person with MND and their family and carers, it also promotes a sense of trust and confidence in the team of health professionals who all know what the treatment needs and issues are, and who communicate and operate well as a team.

When communicating with a person with MND they may have certain short cuts to communication using special gestures, such as blinking for yes or no, or hand gestures to represent sentences such as please, thank you, I love you etc. These unique communication gestures should be noted and available in written form and practiced so that there is no need to constantly explain them to people visiting.

As the disease gets worse dysarthria can turn into anarthria, which is the loss of the ability to speak due to disease. It is critical that there is an early referral to a speech and language therapist who will advise on strategies for communication. They will arrange for assessment and provision of appropriate

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communication aids specifically taking into account the individuals needs for the present and in the future. Family and carers may try to be helpful and buy Ipads and devices that may be expensive. However, they may not be able to be used for a long period of time as peoples continued deterioration means that they may not have the strength to operate them. An experienced speech pathologist will understand the specific communication difficulties and the many and varied options to assist. These are called Augmentation and Alternative Communication devices. Funding and equipment is available from a variety of sources which is another reason to involve a health professional as it can take time to respond and acquire funding, and equipment, and needs may change over time. The person is then able to use different devices and programs with supervision and try them out and find the best solutions, without an initial financial outlay. The occupational therapist can assist with advice on seating, positioning, wrist supports, switches, pointers, mobile arm supports, tables to access communication aids and environmental controls.

Devices can include computers, “lightwriters” and various text to language options and “eye gaze” technology. The lightwriter converts text into sound which is helpful when communicating with others. People who have MND can record their own voices to use in a device such as a lightwriter. However, coming to terms with the losses involved with the disease, often means people are not psychologically or emotionally able to think about the future in time to use this option. Eye gaze technology uses computer programs and eye movements to operate the computer. When intervening in communication

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issues the high technology versus low technology is a consideration in terms of ease of use, availability and expense and the capacity and needs of the person.

Dysarthria can increase emotional reactions, including isolation, when communication is inadequate or avoided. People can be frustrated when others misunderstand what they need or are trying to express. They are unable to communicate their fears and anxieties because it is so hard to speak, making communication exhausting and hard to manage if issues are complex. When people cannot communicate they lose their ability to control many things-how people react to them, their environment, and even such basic needs as getting to the toilet or having something to eat and drink. This is why it is important that the person with MND has appropriate call bells and can call for help easily as they are unable to shout if they are in difficulty.

Because communication is difficult, people around the person may ignore them, stop talking to them, consulting them or including them in conversations and decisions. This may decrease their self-esteem along with the reactions of others to the sound of their speech, which as mentioned earlier, can result in treatment of them that is based on mistaken assumptions. This can mean they are treated less than respectfully. Voice is part of identity and if this is changed it can be a source of distress and loss. Any loss can create a grief response.

There are so many losses for people with MND that they are continually managing loss and their resulting responses and emotions. Not being able to communicate this is a great burden. Anything that reduces self-expression is an

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injury to authenticity, integrity and agency reducing a person's sense of value and purpose.

Communicating with someone with MND takes patience and time. Make sure the environment is going to maximise good communication by screening out noise that may make hearing difficult. Encourage the person to take their time and slow their speech down so that it is easier to understand. Ensure that you allocate enough time for the conversation so that the person does not feel pressured or rushed. As someone with MND can have limited non-verbal cues and body language it may be even more difficult to understand their meaning.

Before speaking make sure you have their attention; address them by name, identify yourself by name and relation and if they are seated, get down to their level and maintain eye contact, if that is culturally appropriate. State your message clearly. Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead pitch your voice lower. If they don't understand wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns and abbreviations. Use language that is common and easy to understand – the use of jargon or hospital related terms is not helpful. Try not to interrupt the person and use words to prompt if appropriate. Ask questions that require a yes or no response to reduce fatigue. Be patient in waiting for a reply. Always strive to listen for the meaning and feelings beneath the words.

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Due to the continual and relentless deterioration in speech it is important to cover end of life issues as early as possible. Ensuring that people's wishes are known and documented is critical if their speech may later disappear, and their ability to write things down is also compromised. Unfortunately people may not be willing or able to come to terms with their diagnosis of MND in order to truly enter into such conversations. Hopefully they will be able to make a will, ensure that they have their affairs in order, and have appropriate Medical Treatment Decision Maker and Financial Power of Attorney attended to while they can communicate more easily. As well they may wish to fill out a Refusal of Medical treatment certificate in discussion with their treating doctor. This document allows the person to opt out of treatments that may prolong their life or have limited benefit in accordance with their wishes.

Given the life limiting nature of the disease communicating about deeply intimate and personal issues with their loved ones is important and if they do not understand the changes that will happen, they may miss important opportunities to say what they want to say, and to express their wishes and needs. There is a tension between where people are in accepting their diagnosis, and their ability to process what is happening. This can conflict with the needs of health professionals to predict their future needs, and discuss the deterioration ahead. This can look like non-compliance or resistance, but is often the individual's capacity for integrating painful emotions and thoughts and the need for normality amongst the reality of having a life limiting illness. Timing of information and the pacing of information needs sensitive understanding of each person as there is no one size fits all approach to

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communication. Quality of life is an important focus and while it is clear the person will die from this disease it is important to harness their short term goals and understand the person and their values.

People often identify as their work or what they achieve. It is difficult then, should they not be able to “do” that they retain a sense of who they are when those activities stop. A person is not their disease. It is important to find out who this person is and who they were before the disease and how that has changed their life. We need to explore their values, the things that give their life meaning and substance. Only by relating to the whole person and not their symptoms will people be trusted to explore the deeply personal and confronting issues faced by people who are going to die from a disease without a cure.

Barbato describes the difficulty of understanding the suffering of the dying and their capacity to communicate this type of often unrecognised pain. The richness of metaphor and image to express the experience and emotion may help when words fail, hence the importance of finding avenues for patients and families and carers to express their distress (Barbato, 2006). The impact of the disease on a family is enormous, often creating complex welfare, legal and financial issues. All these issues are well dealt with by the staff and services of a palliative care agency.

Grief is a process of adjustment to loss and has physical, cognitive, emotional and spiritual dimensions, (Ray,2006). The person with MND is gradually transformed from a state of independence and agency to one of

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complete disability. The person with MND and their family are dealing with multiple losses in a progressive and challenging disease process. Health care professionals who lack the knowledge and familiarity of MND care may find themselves overwhelmed. Emotionally they may feel helpless against the distress that they feel on witnessing the impact of MND. They may experience their own frustration due to the inability of the person with MND not wishing to take, what health professionals view as, the very necessary interventions and equipment. This is often because the person with MND is struggling to come to terms with their illness and its life-limiting outcome, and is not psychologically or emotionally ready to embrace these realities or conversations. Health care professionals inside palliative care and in external agencies need to communicate well and carefully around these issues to avoid negatively affecting people. It is critical that people working in Palliative care have excellent communication skills and expertise in MND to provide the best outcomes. This is important if the person who needs help is not the subject of secondary traumatising via unskilled conversations and interventions.

It is difficult to sort out how the person with MND may be in terms of their mental health. Are they experiencing grief responses in the face of devastating and cumulative losses, or are they clinically depressed? In the face of multiple losses it is not easy to differentiate between sadness and depression. Do they have symptoms of frontotemporal dementia or emotional lability? Perhaps they are responding to particular stressors at this point in time. Are they struggling with fear and anxiety due to breathlessness or do they have



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concerns about how they will die? These are important distinctions and should be assessed thoroughly and continually. The foundation of communication is respect, cultural literacy, trust, skill and unconditional positive regard. There must be a willingness to enter into a genuine relationship with the person with MND to ensure they are treated as a person, not a disease. Health professionals can often feel helplessness when confronted with the complex needs and the awful impact of this disease on people. Practicing reflective practice and receiving support and debriefing, can assist to ensure a positive working relationship that is not held back by discomfort or personal feelings on the part of the health professional.

Early referral to a Palliative Care Service can assist the person with these conversations, provide support and counselling to navigate the financial, legal and health system. They and their family and carers can receive information and exploration of physical, emotional, psychological and spiritual and personal issues. In some palliative care agencies there are music and art therapists who can provide people with an important nonverbal outlet for self-expression and communication. This may help to restore the person with MND's self-esteem, allow meaning-making and processing of what is happening and provide distraction, pleasure and add to quality of life. There are many different people in palliative care services that can provide assistance such as pastoral care workers, counsellors, volunteers, nurses and doctors, allied health workers such as occupational and physiotherapists, psychologists and social workers.

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I look forward to discussing more detail about various aspects of MND management in future sessions which will be available on the SMPPC website. I would like to take this opportunity to give my thanks to staff at Bethlehem Calvary Health care and MND Victoria and VRSS for the support and training received in my role as MND SCW in the Southern Region. Please feel free to contact me should you wish to have an education session on MND for your agency or to receive a secondary consultation. You can contact me on: 0428264446 or email me at: [Robyn.reid@smrpcc.org.au](mailto:Robyn.reid@smrpcc.org.au)

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