

# Communication and Swallowing Issues in Patients with Motor Neurone Disease: The Role of Speech and Language Therapy

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## **Abstract**

Motor Neurone Disease (or MND) is a degenerative disease which directly targets the motor neurones in the spinal cord which in turn causes a global reduction in muscle movement. Patients diagnosed with the disease often die within 3-5 years with a gradual decline in overall health and mobility. During this period, a patient's ability to swallow and speak will likely also deteriorate which has an impact on both physiological and mental/emotional quality of life. Speech & Language therapists attend to both of these areas but their role has arguably not been well defined by professional bodies until recently. The following paper is an attempt to highlight methods of assessment and treatment that can be utilised by clinicians for patients with MND.

**Keywords:** Motor Neurone Disease, Language, MND, Speech & Language Therapy, Communication, Speech

## **Introduction**

Motor Neurone Disease (hereinafter MND) is a degenerative disease that directly affects both upper and lower motor neurones in the brain and/or spinal cord, which in turn reduces muscle movement. Those afflicted with the condition on average die within 3-5 years, and in the majority of cases this

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is through respiratory failure (Schiffer et al. 1987). Since the muscle wastage caused by the disease occurs at a global level, it has wide implications for the patient; the care provided spreads across many medical disciplines.

One of these disciplines is Speech and Language therapy (hereinafter SLT). The two key areas of focus for SLT are communication and swallowing function; both are vital, but arguably for different reasons. Being unable to swallow has consequences for the medical health of the patient as there is greater risk of malnutrition and weight loss (Körner et al. 2013), as well as the additional risk of pneumonia caused by aspiration<sup>1</sup> (Langmore et al. 1998). Communication impairment interferes less with the physical health of the patient, but can have negative effects on their mental and emotional health. Therefore the role of SLT is unique in its responsibility in maintaining communication between the patient and their loved ones, as well as to the staff managing the health of the patient. The failure of a patient to be able to communicate their wishes has been reported to be linked with depression, a sense of powerlessness and emotional disengagement (Hecht et al, 2002). Additionally, many relevant sources such as the Royal College of Speech & Language Therapists (hereinafter RCSLT) do not provide specific documents that focus on the role of SLT for this population.

This piece aims to catalogue the relevant issues for this field in a holistic context, presenting the evidence and rationale for therapies at the disposal of SLTs to maximise the patient's quality of life both physically and emotionally.

Following on from a diagnosis of MND the organisation of care should be established using interprofessional teams, with the patient and their family at the nucleus. This approach aligns with the fourth objective of the NHS Constitution (2015), which aims to have care tailored and coordinated around the patient and their family. These interprofessionals will usually be led by a neurologist and may also involve the general practitioner, a nurse specialist, occupational therapist (OT), physiotherapist (PT), SLT and/or dietician. In the later stages of the disease the involvement

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<sup>1</sup> Aspiration is the term given for when food/fluid matter enters the airway. If substantial enough this can lead to a chest infection (aspiration pneumonia).

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of gastroenterology and respiratory physicians may be required; also the involvement of other organisations such as the MNDA (Motor Neurone Disease Association), hospices, social workers or advocates should be linked to the patient (Wood-Allum & Shaw, 2010). The interprofessional method is highly recommended by the National Institute for Clinical Excellence (hereinafter NICE) (NICE, 2016) guidelines and is further endorsed by qualitative studies that have explored the opinions of healthcare professionals (Hogden et al. 2012) and of patients themselves (Oishi & Murtagh, 2014). Although there does seem to be a lack of systematic research exploring the effectiveness of interprofessional working in MND, the evidence currently available would imply that this method is effective.

### **Swallowing Assessment**

The progression of muscular degeneration and reduced muscle control means that patients with MND are at risk of dysphagia. Dysphagia is the term that denotes an impairment of the swallow mechanism. SLTs are one of the primary professionals managing a patient's swallow mechanism, but other professionals that can also advise include: dieticians, OTs and PTs (MNDA, 2017). The cooperation of these professions means that the patient's weight, risk of aspiration and positioning are evaluated so that the patient's comfort is ensured. The patient's swallow mechanism is an important factor for many other treatments to be carried out, for example, the administration of drugs or the management of nutrition. These depend on the SLT to assess and manage any dysphagic symptoms that may occur. Whilst the NICE (2016) guidelines state the importance of the swallowing assessment, there is seemingly a lack of SLT specific guidance in relation to MND dysphagia assessment; this may be due to the rarity of the condition and therefore a lack of participants to carry out research upon. Thus, SLTs may use different assessment techniques depending on the setting in which the patient resides at the time of assessment. If the patient is receiving care in their own home then a bedside swallowing assessment, monitoring the sound of the swallow using a stethoscope and measuring the blood-oxygen levels, may be carried out to establish if the patient is experiencing difficulties in their swallow such as aspiration, which will have a detrimental effect on their respiration, which is the leading cause of death in patients with MND (Rowland & Shneider, 2001). Despite evidence suggesting that these methods of assessment are determined to be less accurate (Ramsey et al. 2003), they are easily accessible and timely. If the

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patient is in a specialist facility then the options of more in-depth and thorough assessments such as videofluoroscopy<sup>2</sup> become available. Such assessments have found to be accurate but are also uncomfortable for the patient (ibid, 2003). It can be argued that the comfort of the patient in a degenerative condition is paramount unless the clinical risk of aspiration outweighs the patient's comfort. In such instances discussions with the patient and their family would be ideal and would reflect the NHS constitution (2015) in providing dignity, respect and compassion. Overall it would appear that the assessment of swallowing for patients with MND solely relies on the judgement of the SLT and their own experience as there are no specific guidelines or research to suggest that certain methods are more suitable for patients with MND.

### Communication Assessment

Dysarthria, a disorder of motor speech that causes a slurring of speech to occur, can become a symptom of the disease in the first instance; Duffy (2013) claims that 25% of patients with MND develop dysarthric symptoms. Whether or not the patient has dysarthria post diagnosis is arguably irrelevant as dysarthria develops in over 80% of patients with MND at some point in the disease (Tomik & Guiloff, 2000). Therefore early assessment and subsequent management should be put in place to help the patient and their family ease through the transition of the disease. To this end, the SLT plays a vital role in maintaining the patient's ability to communicate, which in turn has wide implications that range from the patient giving consent, to ultimately, their quality of life (Hecht et al. 2002), which the NHS constitution states as vital (NHS, 2015). Therefore all parties involved need the SLT to allow the patient to have a meaningful method of communication to express their thoughts and desires.

The SLT should initially carry out assessments to establish whether the patient at the early stage of the disease has dysarthria and if so, its severity. In order to establish a baseline the SLT could use a standardised dysarthria assessment such as the Frenchay Dysarthria Assessment (Enderby, 1983), which would allow a comprehensive assessment of the patient's potential dysfluency; furthermore it would allow the SLT to track the deterioration of the patient and therefore begin to develop

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<sup>2</sup> An examination of a patient's swallowing function using an X-ray machine.

contingencies for their communicative deterioration. Duffy (2013) has reported that in a sample of dysarthric MND patients in the Mayo clinic, nearly 99% had mixed dysarthria. Mixed dysarthria impairs the larynx, resulting in a quiet, breathy voice as well as weakening the oral musculature leading to imprecise consonants (ibid, 2013). If the SLT decides that speech is still a functional option for the patient then adjustments would need to be made to accommodate the patient's dysarthria. The SLT may employ strategies including: reduced speech rate, over-articulation and the use of breath control (Tomik & Guiloff, 2010). In order to help facilitate the patient's speech the patient's family may need to be trained to develop helpful conversational practices that will enable the patient to be heard, for example, a reduction in background noise via home adaptations. Such decisions can be challenging for the patient's family to undertake and therefore discussions alongside occupational therapy should be held to make suitable adaptations for carrying out activities for daily living (Scott & McPhee, 2014).

There is little evidence in the literature regarding therapy in MND patients with dysarthria, and the evidence itself consists of limited case series designs (Murphy, 2004; Yorkston et al. 1996). Scott & McPhee (2014) state that dysarthria management should be used with caution as the inevitable deterioration of a patient's speech may lead to the patient feeling powerless, despite efforts to manage the dysarthria symptom. Studies have also claimed that overexertion of oral mechanisms through therapies can be detrimental in the long term (Beukelman et al. 2011). Neither the RCSLT nor the NICE guidelines provide any information for SLTs regarding managing dysarthria in the context of patients with MND. In comparison with other degenerative diseases such as Parkinson's disease, the evidence for dysarthria in MND is lacking. This is particularly worrying as the patient literature also suggests that patients with MND wish to retain their own speech for as long as possible (Murphy, 2004). Therefore, more research needs to find dysarthria management strategies in MND otherwise patients' own perception of their quality of life may be harmed.

### **Swallowing Intervention**

As the disease progresses the risk of aspiration in a patient increases, therefore the SLT, as well as other health professionals, have a duty of care to ensure that the risk of swallowing difficulties is managed. One method of managing swallowing is texture modifications of food. Texture

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modifications involve blending food so that it becomes a thicker consistency to allow for a patient to swallow it more easily; this has been shown to slightly improve swallowing safety in patients with risk of dysphagia (Steele et al. 2015). Texture modifications allow the patient to continue orally feeding and arguably retain some normality in their quality of life (Leigh et al, 2003). However texture modification intervention will need the input of the dietician as weight loss and malnutrition may become a risk for those with MND (ibid, 2003).

Initially the SLT may opt to teach the patient safer swallowing techniques such as the chin tuck or the supraglottic swallow (Desport et al. 1999; Heffernan et al. 2004) to reduce the risk of aspiration during the swallow. This method allows the patient to feel that they are managing their own condition (NHS England, 2015). The difficulty may be that further in the disease process the ability for the patient to voluntarily carry out these techniques will be limited. Therefore, the SLT may adopt this technique in the early stages of the disease but they may not be appropriate in the later stages so the SLT should carefully monitor the swallowing of the patient.

Other professionals are also able to contribute to the management of a patient's swallow mechanism in MND. OTs and PTs are able to suggest optimal positioning and modified cutlery to enable a more comfortable and safer entry for food/fluid into the mouth (Wood-Allun & Shaw, 2010) and therefore collaboration would allow the symptoms of the muscular degeneration to be less impactful on eating and drinking. In the later stages of the disease, patients with MND can begin to have difficulties with saliva control, which in turn can lead to aspiration. In such cases the SLT may need to begin to consult with nurses to carry out suctioning or specialist nurses to administer drugs to manage the saliva production and its thickness. Finally, when the disease process reaches a severity whereby the patient becomes unable to physically swallow, then the SLT will need to raise the possibility of inserting a PEG<sup>3</sup> tube in the patient. Such a decision would first and foremost require the consent of the patient and their families. Moreover, a meeting would need to be held to discuss the implication of the PEG for other healthcare professionals; for example the SLT would need to balance the risk of aspiration via oral feeding as opposed to enteral as there is still debate as

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<sup>3</sup> An instrument used to insert foods and fluids directly into a patient's stomach through the abdominal wall.

to whether PEG feeding prevents aspiration (Heffernan et al. 2004; Blumenstein et al. 2014). Nevertheless, a referral to a gastroenterologist to assess the viability of a PEG insertion would be required. Considerations at this stage of the disease must balance the desires and quality of life of the patient and family, alongside the clinical risk of aspiration.

### **Communication Intervention**

When the patient reaches a stage in which the SLT decides it is no longer viable for them to use their own speech to communicate, then the SLT must consider alternative methods in which the patient is able to communicate. The SLT may incorporate Alternative Augmentative Communication devices (hereinafter AAC), but prior to their implementation the SLT should consult both the patient and their family to establish the desires and motivations behind the use of an AAC device and implement it based on the will of these parties (MNDA, 2016; Scott & McPhee, 2014). A series of assessments will be carried out to examine the eligibility of the patient and whether the stage of their disease allows them to physically access either low-tech or hi-tech devices. Low-tech AAC devices include: voice amplifiers, pen and paper, alphabet boards which need little training and can be easily adapted for the specific needs of the individual. In MND the control of the eyes is usually spared from the disease (Duffy, 2013) therefore a patient can use hi-tech AAC eye-gaze systems to communicate with others if they are unable to use their limbs for low-tech devices. However, the downfall of using such a device is that the effective use of them requires prolonged training as well as the installation and continued management of the electronic device.

If the patient is deemed to have sufficient need to use hi-tech AAC, then the equipment is loaned from a specialist AAC hub complying with the NICE (2016) guidelines that state that patients should be given a suitable device without delay. Once the AAC device is able to be used at a functional level by the patient, the SLT should specifically train family members, since they will be the prime facilitators of the patient and their communication (Ball et al. 2005). The SLT's role in training the family members is vital as studies have found that successful implementation and use of AAC comes down to the training that the SLT provides to the patient, their family and other professionals (Ball et al. 2010; Murphy, 2004).

The SLT must ensure that the interprofessional team is aware of the AAC system and how it is used so that they can effectively communicate and carry out their interventions with the consent of the patient. Furthermore, the SLT may consult with PTs and OTs to ensure that the AAC equipment is in a position that is accessible and comfortable for the user (Scott & McPhee, 2014). The patient literature overwhelmingly suggests that the successful implementation of AAC has positive impacts to patients with MND; studies report feelings of purpose, happiness and mental and emotional wellbeing (Beukelman et al. 2011; Murphy, 2004; MNDA, 2016). Although, Murphy (2004) also found that some patients felt that AAC correlated to admitting defeat and wished to use their own voice for as long as possible. Clearly, the wishes of the patient are crucial as their own perceived quality of life could be changed if an AAC device is applied without the patient's full acknowledgement and consent; these actions are supported by the NHS constitution (2015). Ultimately it is the right of the patient to decide the care pathway they use from the options they have available to them, and as healthcare professionals we must respect the patient's dignities and choices.

### **End of Life**

As MND is terminal, the outcome of the disease will be death; ergo the care aim of these professionals is palliative (Maclomness, 2005). At this stage the SLT should regularly review the communication of the patient (NICE, 2016) to ensure that it is functional. Functionality of communication is vital at this stage as discussions with health professionals regarding end of life preparations (advanced care planning or lasting power of attorney) will likely take place (ibid, 2016). The SLT may be required to help facilitate the communication of the patient to enable the messages of the patient to be unambiguous. These should be documented in a health plan for all professionals to be aware of so that they can act in accordance with the patient's requests. If the patient wishes to die in a new location then accommodations must be made to ensure this is carried out; the SLT may have to retrain those around the patient in their preferred method of communication. The interprofessional team may refer the patient to specialist palliative services, if there are additional concerns regarding family members surrounding the patient, then referrals may be made to mental health teams and social services to aid in the affairs of the patient once they



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have died (NHS England, 2015; MNDA, 2013). Clearly, at the final stages of the patient's life, the ability to communicate with loved ones is of the utmost importance and all staff involved with the patient must be receptive to the wishes of the individual.

### Conclusion

The role of the SLT in MND is twofold, firstly the assessment and management of the swallow has implications on the medical health of the patient, the second is to assess and provide a suitable method of communication in which the patient can express themselves. This piece aimed to document the unique responsibilities of SLT within this population and has subsequently highlighted multiple areas in which further research is needed to improve our practices in terms of both swallowing and the recognition and facilitation of communication.

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