

RCSLT and MND Association Webinar: Living with motor neurone disease (MND): supporting speech, communication and swallowing

Question and Answer

I'd be interested in a discussion around the SLT role in:

- saliva management
- respiratory function

Saliva : Please refer to the MND Association info for health and social care professionals on managing saliva problems : <https://www.mndassociation.org/wp-content/uploads/information-sheet-p3-managing-saliva-problems.pdf>

Respiratory function: This requires a co-ordinated team approach. Please refer to the MND Association info for health and social care professionals on managing Evaluation and management of respiratory symptoms in motor neurone disease: <https://www.mndassociation.org/wp-content/uploads/information-sheet-p6-evaluation-and-management-of-respiratory-symptoms-in-mnd.pdf>

Information around those who gain a MND diagnosis who have autism and learning difficulties

The MND Association has an easy-read resource: <https://www.mndassociation.org/wp-content/uploads/2015/02/easy-to-read-guide-to-mnd.pdf>

How to support people with voice banking in the community

The MND Association has a webpage of resources:
<https://www.mndassociation.org/forprofessionals/aac-for-mnd/voice-banking/>

And factsheets: <https://www.mndassociation.org/wp-content/uploads/voice-banking-information-sheet-for-professionals.pdf>

The RCSLT has a factsheet on MND:
https://www.rcslt.org/speech_and_language_therapy/docs/factsheets/mnd

What grants are available for my patients with MND? And how would they go about applying for one?

The MND Association has information on grants and how to access support here:
<https://www.mndassociation.org/getting-support/financial-support-information-for-people-with-mnd/>

Do you have any advice on how to manage MND patients in an acute setting?

The MND Association has an acute setting factsheet, found here:
<https://www.mndassociation.org/wp-content/uploads/px017-mnd-in-acute-urgent-and-emergency-care.pdf>

What are the recommendations around discussing AAC and the options for clients with MND? When are SLTS doing this and do they feel they have access to the right information about these options?

Expert consensus and some published evidence points to early AAC intervention being better than late. However, when AAC is introduced as a topic and how it is done depends very much on the individual circumstances of the case. For an overview of the process of AAC work please see: [MND Association AAC pathway](#)

There is also some discussion of the clinical decision process for AAC in MND at: <https://www.mndassociation.org/forprofessionals/aac-for-mnd/>

For community therapists what would you consider to be the key elements of a dynamic assessment for adults with new diagnosis's of MND?

Key elements are outlined at: <https://www.mndassociation.org/forprofessionals/aac-for-mnd/how-do-i-assess-for-aac/>

What is the time scale for losing speech for someone with MND and are there any treatments or therapy to prolong the process?

The timescales can vary depending on initial presentation of symptoms. For recent evidence see: [Int J Lang Commun Disord. 2018 Mar;53\(2\):385-392. Speech deterioration in amyotrophic lateral sclerosis \(ALS\) after manifestation of bulbar symptoms.](#) (<https://www.ncbi.nlm.nih.gov/pubmed/29159848>)

[Makkonen T](#) et al. This paper investigates how long natural speech will remain functional and to identify the changes in the speech of people with ALS. Altogether 30 consecutive participants were studied and divided into two groups based on the initial type of ALS, bulbar or spinal. Their speech disorder was evaluated on severity, articulation rate and intelligibility during the 2-year follow-up. The ability to speak deteriorated to poor and necessitated augmentative and alternative communication (AAC) methods with 60% of the participants. **Their speech remained adequate on average for 18 months from the first bulbar symptom.** Severity, articulation rate and intelligibility declined with nearly all participants during the study. To begin with speech deteriorated more in the bulbar group than in the spinal group and the difference remained during the whole follow-up with some exceptions.

There are no evidenced treatments or therapy that can prolong speech itself.

Is early PEG insertion generally deemed best practice? How should we be supporting patients to make an informed decision?

Key findings from the ProGas study: <https://www.mndassociation.org/wp-content/uploads/progas-study-key-findings-and-recommendations.pdf>

What is the latest evidence base in how to support people with spastic-flaccid dysarthria?

The evidence base for treatment in this area is very poor. **Dalbello and Florence 2013** - Despite the high incidence of muscle weakness in individuals with amyotrophic lateral sclerosis (ALS) or motor neuron disease (MND), the effects of exercise in this population are not well understood.

[Int J Speech Lang Pathol. 2017 Expiratory muscle strength training improves swallowing and respiratory outcomes in people with dysphagia: a systematic review.](#) [Brooks M¹](#), [McLaughlin E^{2,3}](#), [Shields N^{1,2}](#). (<https://www.ncbi.nlm.nih.gov/pubmed/29090601>)

Abstract

PURPOSE:

To investigate the effects of expiratory muscle strength training on communication and swallowing outcomes in adults with acquired motor based communication and/or swallowing difficulties of any aetiology.

METHOD:

A systematic review was conducted. Six databases (CINAHL, MEDLINE, EMBASE, SPEECHBYTE, AMED and PUBMED) were searched from inception until end of May 2016. Randomised and non-randomised controlled studies and pre-test/post-test studies published in English that investigated the effects of expiratory muscle strength training were included. Study quality was assessed using the PEDro scale. Data were analysed descriptively and effect sizes and associated 95% confidence intervals were calculated.

RESULT:

Seven articles reporting data from five studies were included. Preliminary data suggests expiratory muscle strength training improved airway safety during swallowing in people with dysphagia and increased the strength of the expiratory muscles in all patient groups. There was little evidence to suggest changes in communication outcomes after expiratory muscle strength training.

There are no studies that are robust enough to recommend one treatment over another at this level.

What is the latest research evidence related to providing early oro-motor and facial exercises in MND with view to maintenance ?

See above evidence

Are there any areas of MND research, currently, that are specifically related to efficacy of SLT input?

What are the recent updates for SLTs and what research papers should we be reading to update ourselves? Is there anything specific to MND and risk feeding? Are there any new developments to support people with MND in the community?

Recommended reading:

Tomik, B. and R. J. Guilloff (2010). "Dysarthria in amyotrophic lateral sclerosis: A review". *Amyotrophic Lateral Sclerosis* **11**(1-2): 4-15.

Linse et al (2018) [Communication Matters—Pitfalls and Promise of Hightech Communication Devices in Palliative Care of Severely Physically Disabled Patients With Amyotrophic Lateral Sclerosis](https://www.frontiersin.org/articles/10.3389/fneur.2018.00603/full?utm_source=F-NTF&utm_medium=EMLX&utm_campaign=PRD_FEOPS_20170000_ARTICLE) (https://www.frontiersin.org/articles/10.3389/fneur.2018.00603/full?utm_source=F-NTF&utm_medium=EMLX&utm_campaign=PRD_FEOPS_20170000_ARTICLE)

What is the latest research about role of exercise with people with MND?

See above evidence from Brooks et al 2017

Is EMST a recommended treatment in MND?

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4879103/>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5048392/>

See also RCSLT guidance and resources on:

- [AAC](#)
- [Acquired motor speech disorders](#)
- [Progressive neurological disorders](#)