Welcome to the webinar:
Living with motor neurone disease (MND): supporting speech, communication and swallowing

Tuesday, 5th June 2018

#RCSLTw webinar
#MotorNeuroneDisease
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• Send in chat messages at any time by using the Chat button

• Send in questions by using the Q&A button

• This event is being recorded. See here for recordings: www.rcslt.org/news/webinars/rcslt_webinars

• Kaleigh Maietta is on hand to help!
Aims and objectives

After attending the webinar, delegates will be familiar with:

• How speech, communication and swallowing are affected by motor neurone disease

• How speech and language therapy can support people living with motor neurone disease

• The Motor Neurone Disease Association and the support it offers professionals and people living with motor neurone disease

• The support the RCSLT offers its members, including its relevant networks
Steven Bloch
Senior Lecturer
University College London
Living with motor neurone disease (MND): supporting speech, communication and swallowing

Steven Bloch PhD, MRCSLT

RCSLT MND Webinar  Tuesday 5th June 2018
Learning outcomes

By the end of this presentation you will be familiar with:

- the impact of MND on *speech, communication* and *swallowing*
- how speech and language therapy can support people living with MND
- sources of more specialist advice and information
How can MND affect a person’s speech?

Motor speech disorder: dysarthria

Early signs: mild voice problems – leading to more generalised slurred speech

Impacts on all levels of speech production – articulation, phonation, respiration and nasality

Varying degrees of intelligibility: context, environment, communication partner
What can SLT do to support speech?

- Understand the person’s perspective towards their speech (don’t deny their experience of change)
- Minimise barriers to intelligibility (e.g. others paying attention)
- Get to know the person, their significant others and their environment
- Recognise and maximise existing abilities (e.g. getting attention)
- Small changes to behaviour (e.g. maintain a slow and steady rate, reducing length of breath groups)
How can MND affect communication?

- Reduced confidence & opportunities for communication & participation = social isolation
- Focus on the here and now
- Altered roles, relationships and impact on intimacy
- Effects of cognitive changes on thinking and behaviour

The above apply to family, friends and professionals as well as people living with MND
What can SLTs do to support communication?
What can SLT do to support communication?

**Past**
- Legacy work e.g. life histories, recorded stories
  - recordmenow.org

**Present**
- Current strengths, needs and relationships
- Participation
  - Involving significant others

**Future**
- AAC planning: emotional, technical and ongoing
- Voice/message banking
- Living wills, decision making etc.

- Provide space and time for talking
- Deal with today’s problems today but also prepare for potential problems a month ahead
- Avoid viewing AAC as the only solution to communication problems
- Address issues at the client’s pace, not your own
Assistive communication technologies (AAC)
CALL Scotland: Wheel of AAC Apps for Communication
### Summary of interventions for speech and communication in MND

#### Normal speech
- Confirm normalcy
- Establish person’s perspective towards speech and communication – what’s important to them?
- Consider planning for the future – voice/message banking, advance care planning, legacy work
- Build a strong relationship
- Provide clear and honest information re: speech and dysarthria – base on client’s own desire for information

#### Emerging unintelligibility
- Maximise the environment for speaking/listening – treat this as part of therapy – not just an add on
- Establish context of message if possible
- Develop strategies for coping with groups/noisy environments
- Introduce concept of AAC as a potential for the future – link to existing use of technology (e.g. social media)

#### Behaviour modification
- Increase precision of articulation by slowing down
- Breath control for shorter phrases
- Conserve energy
- Develop breakdown resolution strategies (repair) with communication partners
- Functional problem solving – involve family/friends as part of the solution – not just an add on

#### AAC
- Introduce early
- Introduce portable writing systems (pen/paper, Boogie Boards)
- Address social competence as well as operational competence (see Light, 1989)
- Work with AAC hubs for specialist equipment – particularly re: access methods
- Review AAC needs and use regularly (at least monthly)

#### Severely reduced physical access to AAC
- Develop reliable yes/no systems
- Focus attention on skills of communication partners – particularly less familiar/new partners in care environments
- Focus on quality of communication – not amount of communication
- Allow as much time as needed for communication

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Inspired by Yorkston et al (2013) Management of Speech and Swallowing Disorders in Degenerative Diseases
How can MND affect eating, drinking and swallowing?

- Aspiration and chest infections
- Weight loss (in association with muscle loss/atrophy)
- Nutrition and hydration (confusion, constipation and UTIs)
- Saliva management
- Mealtimes and sociability
- Psychological impact - fear of choking
What can SLT do to support eating, drinking and swallowing?

- Oral-hygiene care and promotion
- Saliva management
- Postural changes and diet modification in partnership with OT, physio and dietician
- Non-oral feeding: PEG management & comfort issues
What additional specialist advice is available?

- AAC specialised assessment hubs (see Communication Matters website for contact details)
- RCSLT specialist advisors
- MND Association & Regional Care Advisors
- Web resources e.g. MND Association best practice guidelines for AAC, ACE Centre for free AAC downloads
Six key points re: MND and SLT

MND is a complex condition that demands a strong multi-disciplinary team approach (NICE, 2016)

SLTs are specialists in communication and swallowing and are integral to the team and long term care

AAC is important but technology can’t replace human face-to-face communication and interaction

Anticipatory work for all areas can be successful: digital legacies, voice banking, advance care planning etc.

Communication and eating are highly social activities – intervention should involve families and friends

Working with people with MND can be very rewarding but also emotionally demanding – consider your own mental wellbeing as a therapist
With extra thanks to:

Richard Cave, SLT, Compass, Putney

Dr Olly Clabburn, Edge Hill University, Lancashire

Julia Johnson, SLT, Clinical Lead, Kings College Hospital, London

Helen Paterson, SLT, Compass, Putney

Dr Christina Smith, SLT, Senior Lecturer UCL
Jennifer Bedford
Head of Partnerships
Motor Neurone Disease Association
Motor neurone disease (MND) is a fatal, rapidly progressive disease that affects the brain and spinal cord. It is a severe and incurable condition. MND attacks the nerves that control movement so muscles no longer work. It does not usually affect the senses such as sight, sound, feeling etc.

Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice. MND can leave people locked in a falling body, unable to move, talk, swallow and eventually breathe.

Around 35% experience mild cognitive change causing difficulties with planning, decision-making and language. A further 15% of people show signs of a form of dementia resulting in more pronounced behavioural change.

MND affects people from all communities.

A person’s lifetime risk of developing MND is around 1 in 300. That’s one person in an average size cinema screen.

It affects up to 5,000 adults in the UK at any one time.

Six people are diagnosed every day. Up to 5,000 people are fighting MND at various stages of the disease. Six people die each and every day.

MND - there is no cure.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Should you need any information or support please contact our MND Connect helpline.

mndconnect
0808 802 6262
mndconnect@mndad association.org

MND Association
PO Box 246 Northampton NN1 2PR
Telephone: 01604 250505
Email: enquiries@mndad association.org
www.mndassociation.org

Registered Charity no. 254354
How the MND Association can support you

- Remote support
- Local support
- Equipment loan
- Communication specific support
- Grants
- Education
- Campaigns
- Remote support
- Local support
- Equipment loan
- Communication specific support
- Grants
- Education
- Campaigns
Remote Support

Website
www.mndassociation.org
Information resources
Research
Online courses

MND Connect
0808 802 6262
mndconnect@mndassociation.org
Monday to Friday between 9am to 5pm and 7pm to 10:30pm
Local Support

Regional Care Development Adviser (RCDA)
• work with local health and social care staff to improve services
• educate and raise awareness about MND

Association Visitor (AV)
• confidential emotional support
• practical advice and accurate information
Equipment Loan

Loan service with a limited range of equipment provided where it is not readily available from a statutory source.

MND Connect
0808 802 6262
mndconnect@mndassociation.org
Communication support

- Communication aids service
- Communication aids coordinator – Matthew Hollis
- Equipment loan
- Voice Banking Volunteer pilot
  
  https://www.mndassociation.org/getting-support/communication-aids-service/voice-banking-volunteer-support-application-form/

- Grants

  communicationaids@mndassociation.org
Grants

- Support grant
- Quality of Life grant
- Carer’s grant
- Young person’s grant

MND Connect
0808 802 6262
mndconnect@mndassociation.org
Education

• Master classes
• Special Interest Groups
Campaigns

DON’T LET ME DIE
WITHOUT A VOICE:
Any Questions?