



Welcome to the webinar:

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

Tuesday, 5th June 2018

#RCSLTwebinar

#MotorNeuroneDisease



Chair of webinar:



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Motor Neurone Disease
Association

Housekeeping

- 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

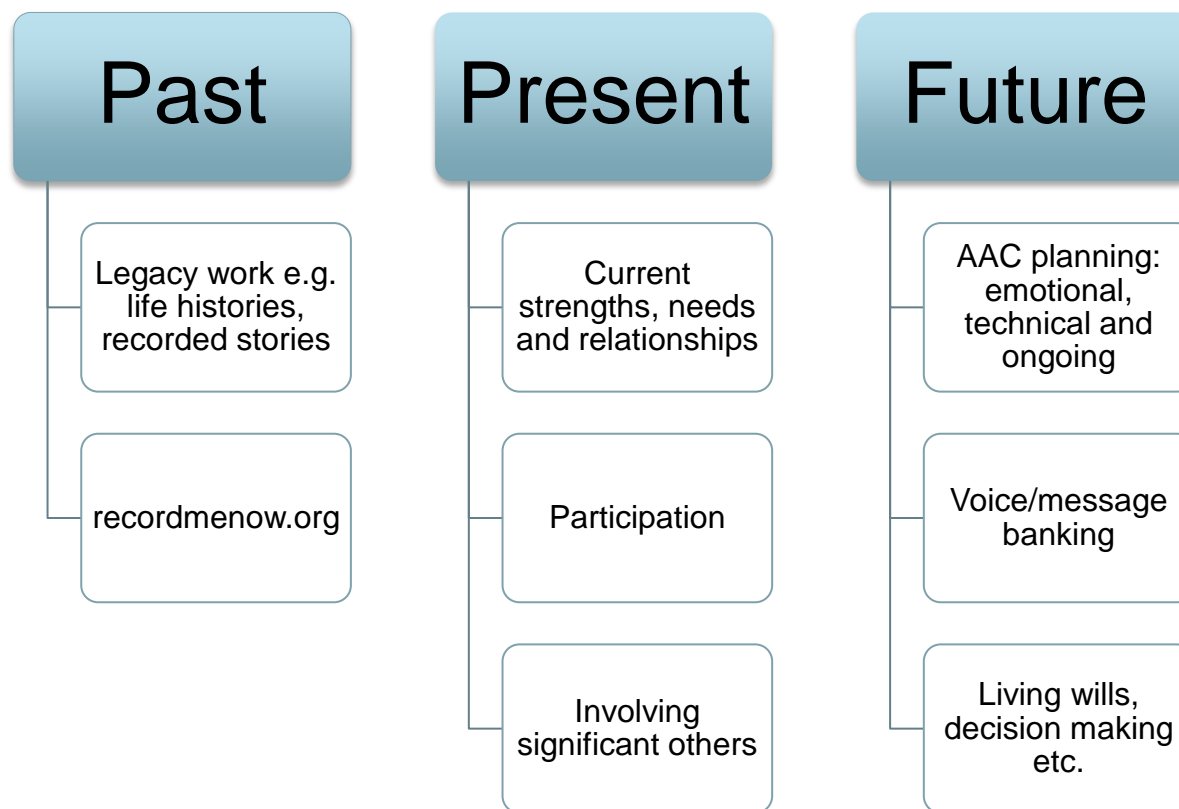
Effects of cognitive changes on thinking and behaviour

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?

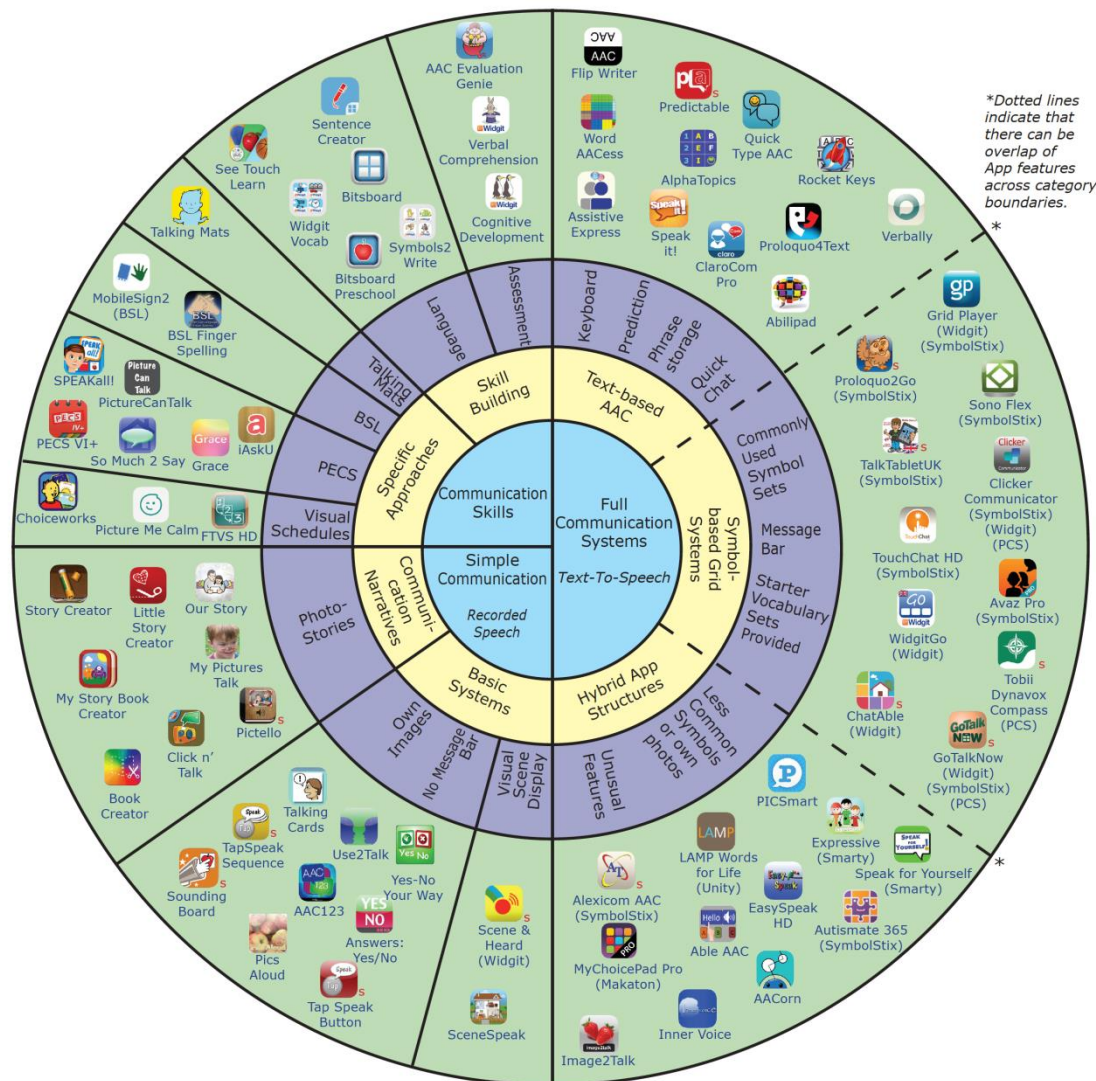


- Provide space and time for talking
- Deal with today's problems today but also prepare for potential problems a month ahead
- Avoid viewing AAC as the only solution to communication problems
- Address issues at the client's pace, not your own

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

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 kills a third of people within a year **and** **more than** **half within** **two years of** **diagnosis.**

MND is a
fatal, rapidly
progressing
disease that
**affects the
brain and
spinal cord.**



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.**



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.**



MND can leave
people locked
in a failing body,
**unable to move,
talk, swallow and
eventually breathe.**



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@mndassociation.org



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

Registered Charity no. 294354

How the MND Association can support you



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





Any Questions?