Communication in MND
How can we have better conversations?

Professor Steven Bloch, Psychology and Language Sciences
University College London
Overview

What do we already know about communication in MND?

What makes a conversation ‘good’?

Developing a Better Conversations approach to communication in MND
Four key terms

**Speech:** the physical production of sound for meaning

**Language:** words, symbols and signs used to express and understand ourselves (spoken written, signed, graphic etc.)

**Communication:** the use of language and behaviours to express and understand ourselves (by any means available)

**Conversation:** organised two-way use of turns and sequences of turns to accomplish social actions (institutional as well as non-institutional)
What happens in a conversation?

- Start the conversation: greetings
- Take turns
- Ask and answer questions
- Tell news, troubles/problems, stories
- Give and elicit views and opinions and advice, agree and disagree
- Argue, complain, flirt, gossip, tease, collude
- Explain things, show understanding
- Repair troubles in understanding or hearing
- Close the conversation: not always easy!

All are organized and all are available for systematic examination
‘Talk is a revelation’ and what it reveals is that a game you have been playing nearly every day has a set of rules you didn’t even know about.

Ian Leslie, author of *Curious* and *Born Liars*

*talk*

*the science of conversation*

ELIZABETH STOKOE
What do we know about MND communication?
Communication elements in MND

- Speech
- Language
- Cognition
- Other Modalities (including AAC)
- Communication partners
Which element matters the most?

Speech, language, cognition, other modalities, communication partners, all matter
What are the challenges for communication change in MND?

- It can impact on: identity, health care decision making, autonomy, social participation, control and relationship intimacy and cohesion.
- It can deteriorate over a relatively short period of time and between different people in different ways – considerable variability.
- It’s a highly complex, interactive, dynamic, interpersonal and behavioral activity – it defies ‘simple’ solutions.
- Technology fixes (AAC) do ‘work’ but can present additional problems: one part of the story, but they are not a proxy for communication.
- Communication is more than the sum of its parts: it’s not easy to measure in a valid way.
Motor speech disorder: dysarthria (typically 'mixed' upper and lower motor neurones)

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

Early signs: mild voice problems – leading to imprecise consonants (slurring), hypernasality and harsh voice quality

Varying degrees of intelligibility: context, environment, communication partner
Language and cognition

Up to 15% develop frontotemporal dementia

Executive function: planning and problem solving, shifting attention, initiating and inhibiting responses

35% mild cognitive change: executive functions, language and/or social cognition

Understanding and producing spoken or written language
Assistive communication technologies (AAC)
The Four Ps of AAC

Paper

Partner

Person

Powered

Helen Robinson @HelenATSLT and Andrea Lee @LeeAndieJ
AAC should always be people focused
What about conversation MND?

- Troubles and repair: how things go wrong and how people fix them
- Timing matters for many social actions (e.g. humour, teasing, new topics)
- How people adapt their turns over time using different forms of AAC
- The critical role of the communication partner

How turns can be adapted to deal with deteriorating intelligibility


Dysarthria-in-interaction profiling

Blue Profile
• No observable or reported changes to the interaction of either conversation partner

Yellow Profile
• Some observable or reported changes in the interaction of either conversation partner

Orange Profile
• Significant interaction adaptations made by both conversation partners

Purple Profile
• Significant interaction challenges encountered by both conversation partners


What makes a conversation ‘good’?
<table>
<thead>
<tr>
<th>Connection, feeling included:</th>
<th>Jenny Halse, Charlie Harris, Alison Oppetit, Sally Boa, Laura Gilmour, Lesley Scobbie, Hahhan Ellis Gray</th>
</tr>
</thead>
<tbody>
<tr>
<td>Back and forth, collaborative effort, sharing, reciprocity, balance:</td>
<td>Elle McWilliam, Seray Ibrahim, Mark Jayes, Emma Shah</td>
</tr>
<tr>
<td>Value, respect, equality:</td>
<td>Kathleen Graham, Alison Williams, Richard Cave, Lindsay Perera, Kristina, Michelle Sweeting, Lauren Dowley, Annabel Howell</td>
</tr>
<tr>
<td>Active listening and time:</td>
<td>Helen Robinson, Bethany Elder, L Brielmaer</td>
</tr>
<tr>
<td>Unexpected twist and turns:</td>
<td>Alexandra Mallinson</td>
</tr>
<tr>
<td>Good conversational space:</td>
<td>Jennifer Benson</td>
</tr>
<tr>
<td>Resilience:</td>
<td>Lean Sakure</td>
</tr>
<tr>
<td>Being real with someone:</td>
<td>Sophie Borrett</td>
</tr>
<tr>
<td>Good enough:</td>
<td>Fiona Johnson</td>
</tr>
<tr>
<td>Being able to discuss big and small things:</td>
<td>Jayne Lindsay</td>
</tr>
<tr>
<td>When the magic happens and connection flows freely without barriers:</td>
<td>Anna Sutherland</td>
</tr>
<tr>
<td>Conversations that aren't always easy - can be 'good' too:</td>
<td>Katie Atkinson</td>
</tr>
<tr>
<td>What a great and challenging question - I look forward to you telling us...</td>
<td>Charles Antaki</td>
</tr>
</tbody>
</table>
Authenticity

Attention, listening and showing understanding

Turn taking, reciprocity and timing

Intimacy and collusion
1. Authenticity
Developing a ‘Better Conversations’ approach to MND communication
Why go beyond speech and AAC and in MND?

Working on speech and/or prescribing AAC in isolation rarely addresses a communication problem as fully as it should – particularly as part of a wider neuro-disability.

Working on speech and AAC alone means there’s no room for building on existing skills of the plwMND and communication partners – they are the experts in their own communication and interaction.

Significant speech problems and AAC use must be contextualized in terms of opportunities for interaction and participation.
What characterises a conversation approach to MND?

- Everyday conversation more representative than a formal assessment
- Both communication partners matter
- Recognises and uses existing skills in conversation – the conversation fingerprint
- Accepts and works with change over time - conversations with speech and AAC
- Goal setting using meaningful facilitators and barriers for each dyad: choice
- The importance of practice – behaviour change theory principles


Barriers and facilitators to conversation

**Facilitators** – behaviours that enable conversations to flow, e.g. writing a word when you can’t say it, giving someone more time to speak

**Barriers** – behaviours that cause difficulties for conversation participants e.g. asking additional questions when an AAC turn is in progress

What might be a barrier for one couple may be a facilitator for another e.g. completing someone’s turn before they have finished speaking

**Better Conversations cycle of therapy**

1. **REAL LIFE TALK**
2. **KNOWLEDGE** about how conversation works
3. **WATCH VIDEO CLIPS** together
4. **GOAL SETTING**
   - "what do you want to change?"
   - (↓ barriers, ↑ facilitators)
5. **PRACTISE using strategies**
   - (↑ facilitators, ↓ barriers)

Almost finally (just one more slide to go): what makes us as professionals effective in our conversations with people living with MND?

- Building and maintaining a relationship - being who you are (both an expert in X and a human being who is already an excellent communicator, but not always)

- Accepting that we are an expert in X, but that people living with MND, and their significant others, are experts in their own lives

- Agreeing what’s going to work best when communicating and that this will change over time. Sometimes communication is challenging – the trick is not giving up and learning what works best over time

- Accepting that AAC solutions cannot replicate existing skilled modalities – most AAC mediated interactions take longer, and that’s ok. Using technologies will always be different from our experiences of real time, co-present, conversation.

- Allowing time and space to listen, understand, and talk - this can be the most challenging, but also the most rewarding – it takes practice and self-awareness: be curious – see Mannix (2021) Listen
“Remember to look up at the stars and not down at your feet. Try to make sense of what you see and wonder about what makes the universe exist. Be curious. And however difficult life may seem, there is always something you can do and succeed at. It matters that you don’t just give up.”

Stephen Hawking