Communication in MND
How can we have better conversations?

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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

What do we know about MND communication?

Communication elements in MND
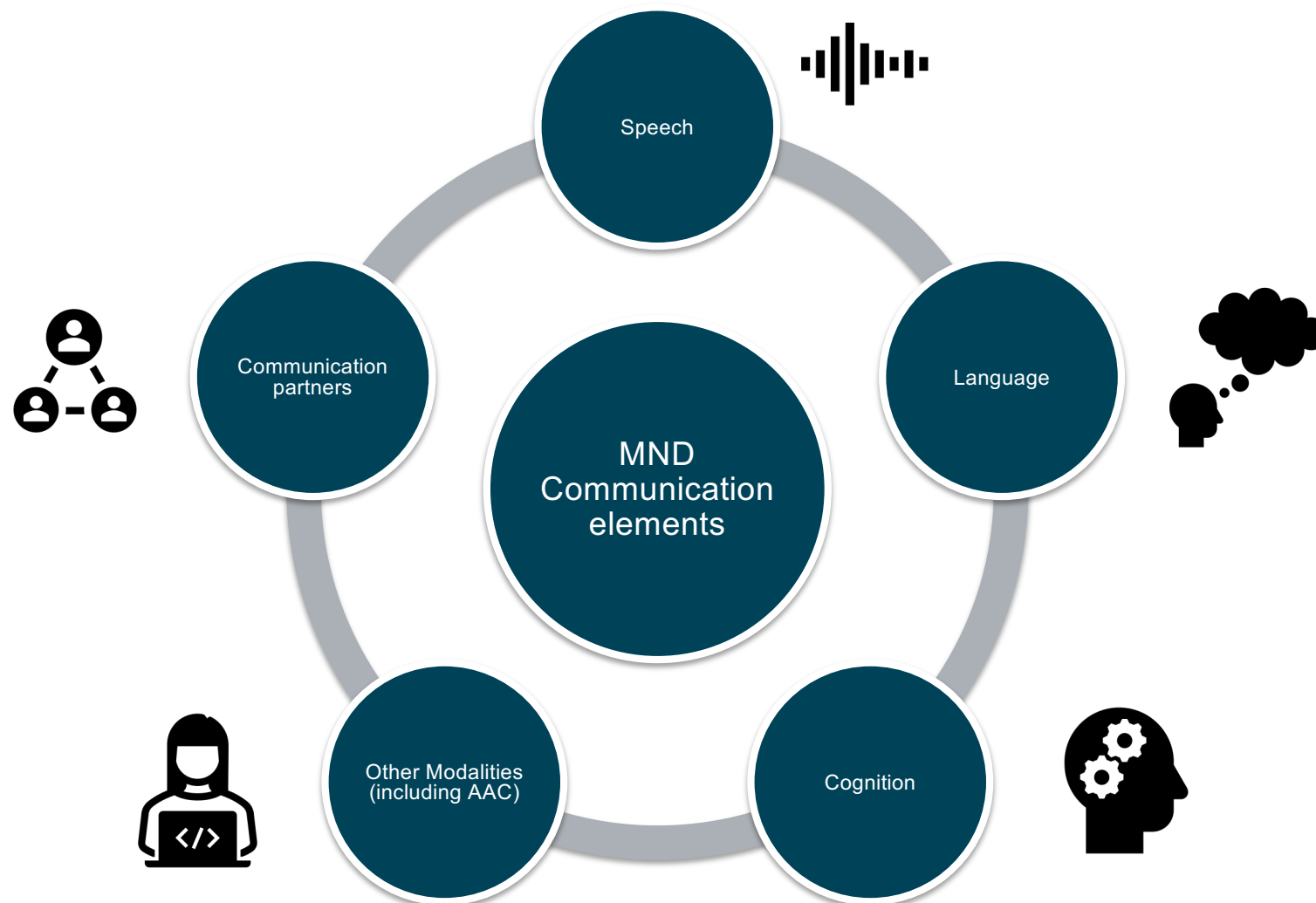
Which element matters the most?

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 it parts: it's not easy to measure in a valid way

MND speech

Motor speech disorder: *dysarthria* (typically 'mixed' upper and lower motor neurones)

Impacts on all levels of speech production – articulation, phonation, respiration and resonance
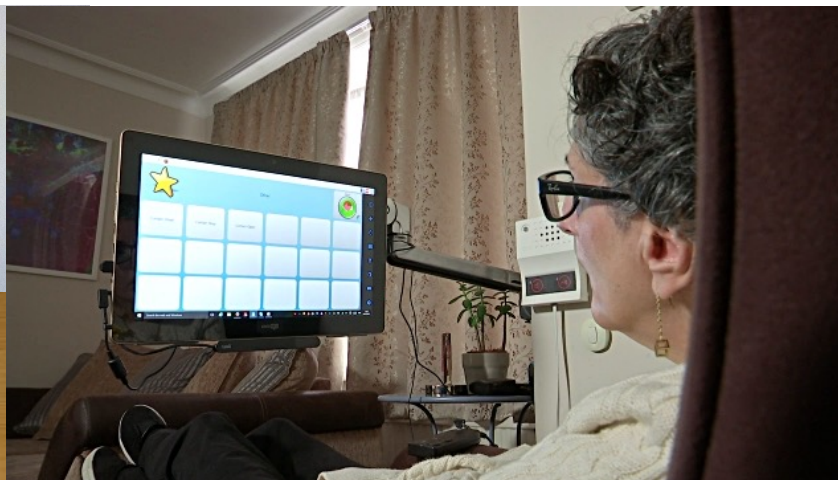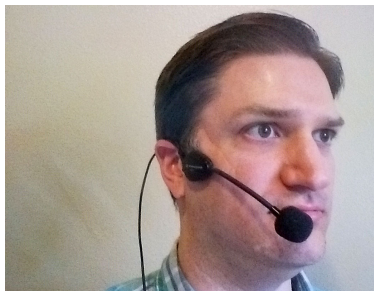
Early signs: mild voice problems – leading to imprecise consonants (slurring), hypernasality and harsh voice quality
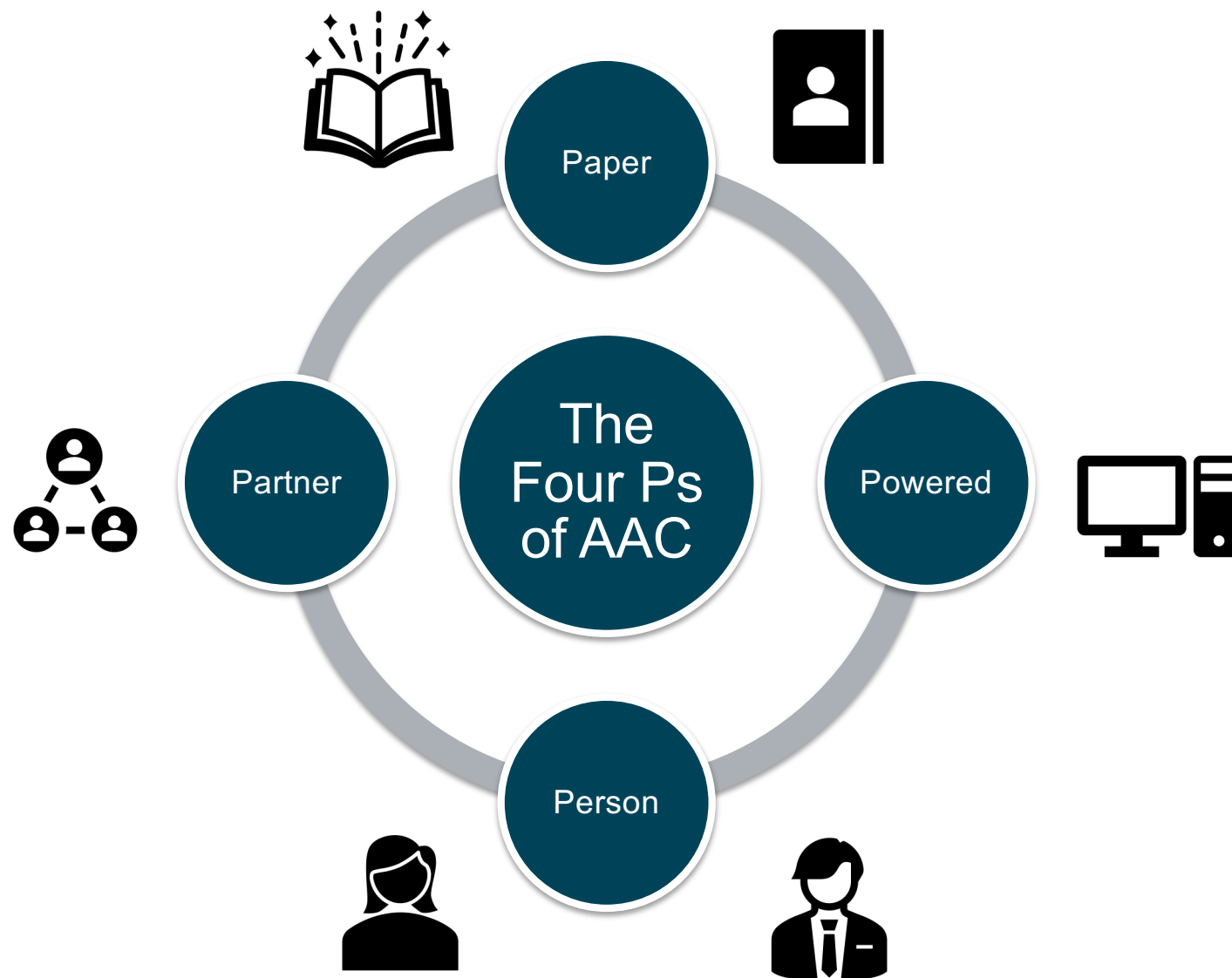
Varying degrees of intelligibility: context, environment, communication partner
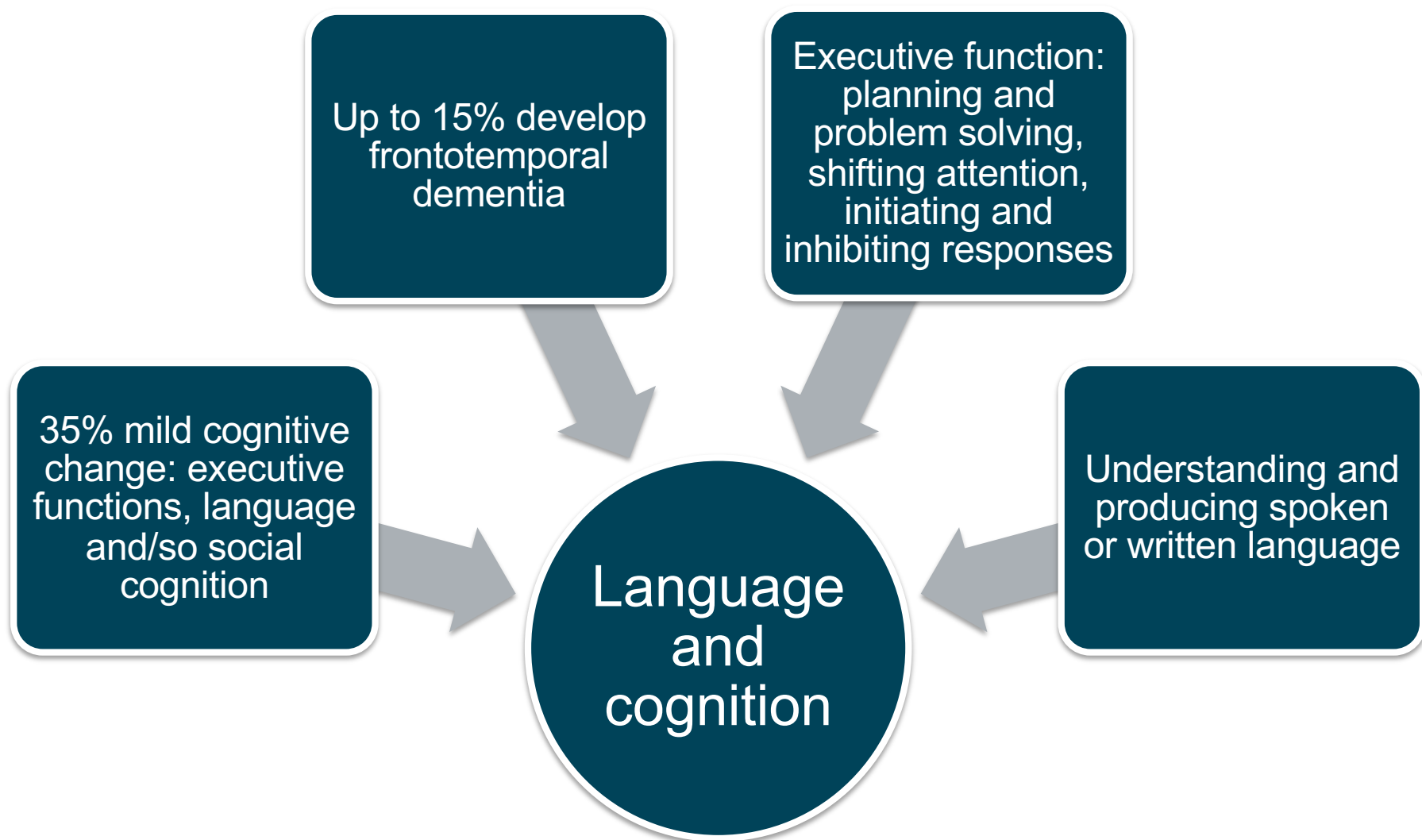
Assistive communication technologies (AAC)

Helen Robinson @HelenATSLT and Andrea Lee @LeeAndieJ

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

All findings clearly corroborated by personal accounts: Robillard, A. (1999). Meaning of a disability - the lived experience of paralysis. Philadelphia, Temple University Press.

How turns can be adapted to deal with deteriorating intelligibility

- Bloch, S. & Saldert, C. (2020) Person reference as a trouble source in dysarthric talk in-interaction. In *Atypical Interaction: Impacts of Communicative Impairments within Everyday Talk. Wilkinson R, Rae, J (eds). Pub: Palgrave Macmillan*

- Bloch, S., Wilkinson, R. (2013) The accomplishment of non-serious talk in severe speech disability: An examination of recipient uptake and delayed other-initiated repair. *Journal of Interactional Research in Communication Disorders* 4 (1) 45-70

- Bloch, S., Beeke, S. (2008). Co-constructed talk in the conversations of people with dysarthria and aphasia. *Clinical Linguistics and Phonetics* 22(12), 974-990

- Bloch, S. (2005). Co-constructing meaning in acquired speech disorders: word and letter repetition in the construction of turns. In Richards, K., Seedhouse, P. (Eds.). *Applying Conversation Analysis* (pp.38-55). Basingstoke: Palgrave Macmillan.

Dysarthria-in-interaction profiling

Blue Profile	Yellow Profile	Orange Profile	Purple Profile
• No observable or reported changes to the interaction of either conversation partner	• Some observable or reported changes in the interaction of either conversation partner	• Significant interaction adaptations made by both conversation partners	• Significant interaction challenges encountered by both conversation partners

Bloch, S. (2013) Conversation and interaction in degenerative diseases. In Yorkston, K. M., Miller, R. M., Strand, E. A. (Eds.). *Management of speech and swallowing in degenerative diseases* (Third ed. pp.195-220). Austin, Texas: Pro-Ed.

Bloch, S., & Tuomainen, J. (2017) Progressive dysarthria and augmentative and alternative communication in conversation: Establishing the reliability of the Dysarthria-in-Interaction Profile. *International Journal of Language and Communication Disorders.* 52(1) 3-9

A connection, feeling included: Jenny Halse, Charlie Harris, Alison Oppetit, Sally Boa, Laura Gilmour, Lesley Scobbie, Hahhan Ellis Gray

Back and forth, collaborative effort, sharing, reciprocity, balance: Elle McWilliam, Seray Ibrahim, Mark Jayes, Emma Shah

Value, respect, equality, Kathleen Graham, Alison Williams, Richard Cave, Linday Perera, Kristina, Michelle Sweeting, Lauren Dowley, Annabel Howell

Active listening and time: Helen Robinson, Bethany Elder, L Brielmaer

Unexpected twist and turns: Alexandra Mallinson

Good conversational space: Jennifer Benson

Resilience: Lean Sakure

Being real with someone: Sophie Borrett

Good enough: Fiona Johnson

Being able to discuss big and small things: Jayne Lindsay

When the magic happens and connection flows freely without barriers: Anna Sutherland

Conversations that aren't always easy - can be 'good' too: Katie Atkinson

What a great and challenging question - I look forward to you telling us… : Charles Antaki

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

Beeke, S, and Bloch S. (forthcoming) *Better Conversations with Communication Disabilities: A Practical Guide for Clinicians.* J&R Press

Bloch, S. and Beeke S. (2022) A Better Conversations approach for people living with dysarthria, in Walshe, M. and Miller, N. (eds) *Clinical Cases in Acquired Dysarthria,* pp. 117-127. Routledge

Bloch, S. (2013) Conversation and interaction in degenerative diseases. In Yorkston, K. M., Miller, R. M., Strand, E. A. (Eds.). *Management of speech and swallowing in degenerative diseases* (Third ed. pp.195-220). Austin, Texas: Pro-Ed.

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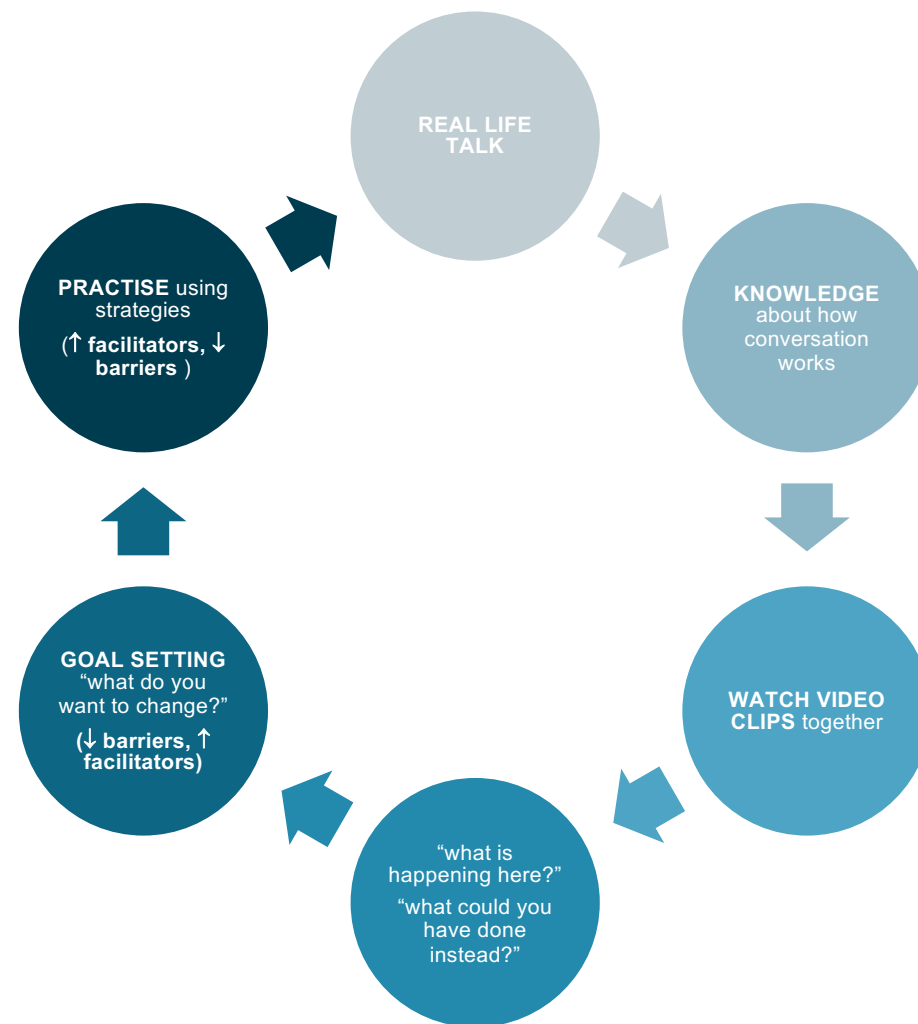
Barriers – behaviours that cause difficulties for conversation participants e.g. asking additional questions when an AAC turn is in progress

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

Bloch, S. (2011). Anticipatory other-completion of augmentative and alternative communication (AAC) talk: A Conversation Analysis study. *Disability and Rehabilitation* 33(3), 261-269

Better Conversations cycle of therapy

Beeke, S, and Bloch S. (forthcoming) *Better Conversations with Communication Disabilities: A Practical Guide for Clinicians.* J&R Press

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