

Decision making and equipment in MND: supporting patients/carers

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Overview

- Why are we talking about this?
- How do human beings decide to do things?
- Equipment decision making in MND
 - Patients' and carers' perspective
 - Clinicians' perspective
- What's our role and responsibility?
- Some ideas
- Summary

Why are we talking about this?

Lots of different equipment options for patients with MND due to the impact of the disease on multiple aspects of functioning

Patients, carers and clinicians are not always on the same page.

How do we best support patients and carers in their decision making and use of equipment.

- Impact on patient-clinician-carer relationship
- Clinicians can feel anxious and concerned about risk/negative outcome.
- Hours++ spent supporting a patient (trying to persuade?)
- Managing health crises
- Understanding principles of collaborative decision making
- Understanding principles of health behaviour change
- Understanding the contribution of our own values, fears and priorities.

How do we decide to do things?

- Economic theories tend to focus on cost/benefit analysis of a decision
- BUT logic often plays less of a role than we think (Chaiken, 1980).
- Psychosocial models have a broader framework (e.g. Collaborative Decision Making Model, Elwyn et al 2014) often due to complex contexts in which they apply. Factors include:
 - Personal experience so far
 - The personal meaning of an action (not just the logical outcome)
 - Cognitive biases
 - How information (including numbers) is present to us e.g. 'low' risk.
 - Social support
 - Sense of belief in ourselves (self-efficacy)
 - And in healthcare: **the relationship with and trust in the clinician.**

Transtheoretical Model of health behaviour change (Prochaska and DiClemente, 1983)

- 6 stages to change
 - Precontemplation - 'NO' 'it's not a problem for me yet'
 - Contemplation – 'maybe', 'this is a problem but I'm thinking about pros/cons'
 - Preparation – 'getting set' / 'what do I need to do'
 - Action – 'do'
 - Maintenance – 'keep going'
 - Termination – 'give up'

Example – to use a wheelchair? Patient

Factor	Example
Personal experience	Friend in wheelchair – everyone stopped talking to her My bowels are impossible to manage right now – how on earth can I use a wheelchair?
Personal meaning of an action	I can still walk – I don't need that yet. I'll have to stop wearing the types of clothes I like Being tall is part of my identity. If I'm 'shorter' than others, I won't be me. This is a sign I'm giving up/giving in to the disease. It would mean I can't go into certain rooms in my house. I couldn't get in the garden on my own.
Cognitive biases and beliefs	Mind reading, predicting the future, catastrophising Stigma – real and perceived.
How information is presented including risk info	When information focuses on risk (prevent falls) versus benefit (improving access/managing fatigue) Language of risk 'low' vs 'high' – interpretations. Methods of communication
Social Support and impact on others	I'll have to have someone with me all the time. Tiring for them to push me. No one around to help me.
Belief in self (self efficacy)	I don't think I could learn how to use the controls. I'm terrible with technology.
Relationship with clinician	But the last thing you suggested wasn't helpful. I feel safe that you have experience of this.

Common reasons for declining equipment or interventions (patient and carer)

Unclear or uncertain outcome – will this help me much? I'm dying anyway?

Ongoing change in functionality – how long will this help me for?

Other health concerns – not a priority / not a problem yet.

Burden of more hospital visits – it creates more problems.

Concern for impact on others – it creates more problems

Loss of sense of self / holding on to self

Holding onto normal

Holding onto independence

Fear of stigma

Fear and discomfort

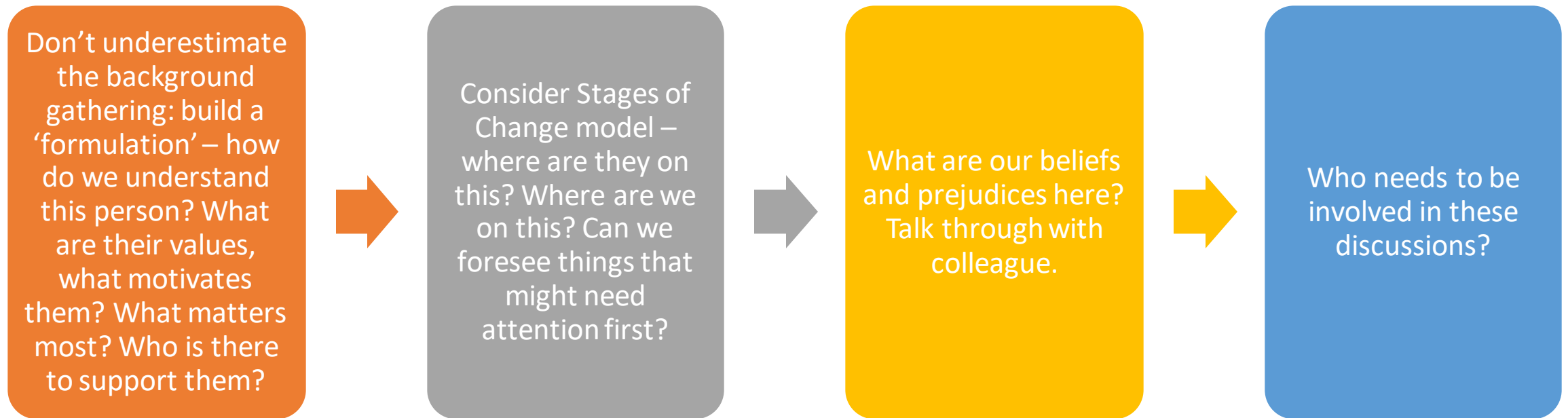
Example – to use a wheelchair? Clinician.

Factor	Example
Personal & professional experience	People get on better with this kind of wheelchair. Recall past patients and conversations. Knowledge of waiting times.
Personal meaning of an action	If I get you to use a wheelchair, then I'm doing my job ok. If you don't use a wheelchair, you'll have more falls and people will think badly of me. What's my responsibility here? What's my role? It doesn't matter if you decline it – it's your choice. I'm leaving in 1 month so I don't really need to resolve this.
Cognitive biases and beliefs	Mind reading – 'you're not going to like this' predicting the future, catastrophising Wheelchairs are commonplace – you don't need to worry about it.
How information is presented including risk info	How well can our patient explain their perspective? Methods of communication
Social Support and impact on others	Is this my responsibility? Are there people around to help me support you with this? Do I think your carer is supportive? What are people's expectations of me?
Belief in self (self efficacy)	I'm not very confident when patients say no. I'll leave it to my colleague – they know more.
Relationship with patient	The last time I suggested something she didn't like it. He has already said he doesn't want to discuss it further.

What is our role and our responsibility?

- NICE Shared Decision Making Guideline (NG197:2021)
 - Core principle within healthcare is to enable shared decision making – shared between HCP and patient/family.
 - Choices need to be based on evidence AND a person's preferences, beliefs and **values**.
 - Need to ensure patients understand personalised risks, benefits and possible consequences of different options through discussion and information sharing.
 - NB! Interpretation of risk, benefits and consequences are fundamentally embedded in personal values and priorities.
 - Need to use different methods of sharing this – numbers, pictures, videos, testimonies.
 - 3-talk model: 1. Choice talk. 2. Options talk. 3. Decision talk.

Preparation



Approach – 3 talk model

1. Choice talk.

'You have a choice to make' versus 'we need to think about wheelchair'.

What is the problem that the equipment is being proposed for?

“Ok – we can see things are getting tricky in terms of stability when you haven't got things to hold onto / walking for distances is becoming really tiring and yet you want to go out and about. You've got a choice to make about how we approach this.”

Our team has some expertise in the evidence and options, you are the expert on you. We need to put our heads together

2. Options talk.

Lay out the options. Provide evidence and information without emotional overlay or leading options. Remembering an option is doing nothing or delay. Be clear when there are medical recommendations.

3. Decision talk


Use of socratic questions and motivational interviewing. What/where/who/how? Elicit pros/cons.

- **Open up** the patient/carers thinking
 - What are your thoughts about this?
 - What do you think your wife's/others view will be?
 - If you imagine using this, how do you imagine it will feel?
 - Have you known anyone else to use this before? What's your experience of this?
 - What do you think it will help with? What are the pros of starting to use this?
 - What problems can you foresee?
 - What's the worst thing about this for you?
- Be prepared for emotion. When talking about what matters, it will really show up. 'I can see that really matters to you' or 'I can see you are feeling emotional as we talk about this. I'm wondering what is really important to you here'.
 - Watch out for emotional avoidance – patient and clinician!
 - Therapist investment versus patient/carer investment.




4. Reflect/check

Have I shared the information/evidence I have about this piece of equipment?



Am I confident this patient understands the information I've shared? (Have I shared it in various ways, can they explain back what I've shared, have I shared it at different time points; Are there any questions I have about mental capacity?)



Do we understand what matters to this person and what their barriers to using a piece of equipment are?

Next steps



Tailor an intervention to the barrier if appropriate:

Anxiety - can patients experiment / use a graded hierarchy?

Shame & stigma - can patients engage in self-re-evaluation? Do they need space to process loss? E.g. referral to psychology

Paradoxical interventions – step back, accept and respect choice we consider to be unwise (without judgement).



Plan to revisit



Notice your own response and emotional reaction



Take to supervision or consultation with a colleague

Feedback from carer

- Offer options
- Encourage an experimental approach – take everything offered and try it out before deciding.
- Autonomy really matters in MND – choices are often one thing a person has control of.
- Accept people's decisions but also remember decision making is fluid.
- Revisit things!

Summary

- Decision making about equipment is personal and complex
 - Psychosocial theories of decision making can help us understand this and reduce the divide between us and them.
 - Offering equipment solutions needs attention to the broader context of who this person is, what matters to them etc.
 - Never underestimate the contribution of therapeutic relationship (with appropriate boundaries). When patients/carers feel heard, understood, valued – they will feel safer to share their vulnerabilities, further strengthening our relationship with them and enabling our support to be more effective.
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- Thank you