Ethical aspects of care in neurology – how do we discuss and manage difficult situations?

Idris Baker Consultant in Palliative Medicine Tŷ Olwen, Swansea Bay University Health Board WCN Dubai 29 October 2019

idris.baker@wales.nhs.uk





Disclosures

• None

Learning objectives

- To discuss some ethical principles and communication difficulties in difficult situations in neurology
- To discuss how to use these principles
- To discuss how to overcome the communication difficulties
- To increase confidence in managing these difficult situations

What situations?

- Diagnostic uncertainty
- Decisions about whether to intervene
- Decisions about whether to stop
- Conflict & collusion

What makes these situations difficult?

- What about these conversations can make them difficult?
 - For us?
 - For other people?

• How can we use this knowledge to make them less difficult?

Don't make it harder

 'We are guilty sometimes that we have first raised up a cloud of dust and then complain that we cannot see.'

- George Berkeley, 1710

Ethical principles

- One way of framing them:
 - Beneficence
 - Nonmaleficence
 - Respect for autonomy
 - Justice
- Use treatments that may work well enough, without disproportionate harm, are acceptable to the person receiving them and not unfair to others

Discussing with whom?

- With patients?
- With families?
- With colleagues?

About what?

- Think of all the things we've looked at today
- We find these hard

 Try doing it with no prior knowledge and through a cloud of MND-related impairments

Know your stuff

- Or find someone who does

 Communication is partly about what you say but that bit is only as good as the content

- Decide to listen
- Facilitate expression

• Listen

Listening properly

• How long have I got



 How long have I got to wait for the nursing home?

- Pick your questions
- Think communication is hard? – Harder for pwMND than for you
- So conserve time & energy
- Be perceptive about the unfolding answers

- Find ways to hear the lost voice
 - Failure of cognition, communication or stamina
- Substituted judgment
 - Get to know the person while you can, so that when it's too late you can fit their shoes a little more closely
- And listen for a change of mind

- Foster unconditional hope
- The hope that transcends particular objects of hope and can be preserved and augmented in the face of the worst of circumstances
- Bolstered by truthful disclosure
- Finds new objects

Summary

• Ethics can seem difficult but principles help if you use them well

Understand why communication can be difficult

 Use sound principles in how you approach it

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