



# The ethics surrounding advance care planning

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# Scope

- A perspective from palliative medicine practice
- Observations on ethics, motor neurone disease, ACP & expertise
- Constraints on choice & control
- Reasons for trying to promote ACP
- Some practical strategies

# Observation on ethics

## What's ethics for in MND?

- Predictable need to decide
  - Place of care & death, clinically assisted nutrition & hydration, ventilation...
- Predictable loss of ability to make, express & act on choices

# Observations on MND

“The relatively rapid and unrelenting course meant that it was sometimes difficult for us and health care professionals to keep up with the advancement of his condition. [The progression] is in some ways predictable and needs can be anticipated.”

# Observations on MND

- Uncertainty
  - It's all unprecedented in individual experience
  - Speed
- Predictability
  - Experience gives a head start
- Decline
  - Cognition sometimes;
  - communication usually;
  - stamina always



# Observations on ACP

- Advance not advanced
- 'A process of discussion between an individual and their care providers ... to make clear a person's wishes ... usually ... in the context of an anticipated deterioration in the individual's condition ... with attendant loss of capacity to make decisions &/or ability to communicate wishes to others.'

# Observations on ACP

- Voluntary by definition
- Decline may mean losing one's voice
- We may then have to guess or ask others
- Some people sit there silently saying 'Noooooooo.....'
- ACP gives a person the opportunity to take out an insurance policy against complete voicelessness

# Observations on Expertise

- Who has greater expertise – us or patients?
- Wrong question
- Patients have expertise in goals
- We have expertise in means and in attainability



# Constraints

- Promoting choice & control is important
- But it is constrained
  - Having MND
  - Nature & speed of progression, largely
  - External circumstances \*
  - Everyone else's risk aversion \*
  - The treatment won't work - DNACPR

# So why promote ACP?

- Basic question of ethics
- Respect for autonomy is commonly (mis)understood as a duty to do what a patient wants
- This is very limited
- More about
  - Duty not to do what someone doesn't want
  - Duty to foster choice

# So why promote ACP?

- Practical relevance to decisions
  - Riluzole?
  - NIV? TV?
  - Clinically assisted nutrition and hydration?
  
  - Admission?
  - Withdrawal? (Does starting have to make it harder to stop?)

# So why promote ACP?

“There is, from the outset, an almost overwhelming sense of loss which gradually becomes more physically manifest as the disease progresses... [He] acutely felt the impending loss of control over most of the basics of life, which I think was as distressing for him as the terminal diagnosis.”

# Practical points 1

## **Decide to listen**

- Facilitate expression
- Listen

# Listening properly

- How long have I got



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

# Listening properly

“4 months after DX I started finding things at home difficult, turning taps on and off, ... 4 months after applying I received the long awaited lever taps. 4 months too late I think? downstairs shower room, was told had to wait 18 months?.....I don't think I need to explain my problem there !!! now I apply for aids before I need them. but if I don't know what aids I will need how can I apply.”

# Practical points 2

## **Understand risk**

- Competent patients are allowed to take risks and to make unwise decisions
- We may overestimate size of risks (likelihood, seriousness, and immediacy)
- Patients lacking capacity need us to decide but their voice can still influence how we gauge risk

\*



# Practical points 3

**Recognise the limits** on how much choice and control is available

- Not much

# ADRT

“I have motor neurone disease. I communicate by blinking and am ventilator-dependent. When I have been continuously unable to blink or otherwise respond for fourteen consecutive days I wish for ventilation to be withdrawn. I recognise that this withdrawal will shorten my life.”

Or...

**I do not want to be a  
vegetable.**

# Practical points 4

## **Find ways to hear the lost voice**

- Cognitive or communication failure
- Exhaustion
- ADRT, ACP, ...
- 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

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# Practical points 5

## **Preserve future options**

– ‘Least restrictive’

- Don't rule too many things out too soon

# Practical points 6

## **Challenge what is wrong**

- Arbitrary distinctions
- Unreasonable delays

# Practical points 7

## Withdrawal

- *eg* Noninvasive ventilation may need to be stopped if/when it is
  - Not working
  - Not tolerated
  - Not wanted
- Ethics pretty clear
  - Harm > benefit or autonomous refusal
- But thoughts & feelings need care



# Practical points 8

## **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



# End of life

“It’s something I don’t deliberately ignore, it just isn't an issue for me right now. I am aware its not too far away, but can you imagine how screwed up my head would be worrying about money, stairlifts, access whilst shopping, songs at my funeral, kids future ? ? ?

Stop the world, I want to get off.”

