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 'Noooooo….'
- 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 – IN & PPD
  - Everyone else's risk aversion – JE & feeding at risk
  - 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?

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

- DM

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
- JO'B

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
  - JJ

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.”