

Time to decide?

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Scope

- AFCP
- Deterioration
- Balancing pros & cons
- Practical communication

MND

- Uncertainty
 - It's all unprecedented in individual experience
 - Speed?
- Predictability
 - Experience gives a head start
- Cost & burden

MND

- Decline
 - Cognition sometimes, communication usually, stamina ~always
- Nutrition
 - Consider 2 overlapping phases
 - Potentially reversible/preventable nutritional failure
 - Normal reduced intake of frailty, inactivity and dying

Clinically assisted nutrition

- Usually via gastrostomy
- Modest benefits but important for some
- Burden often small but significant for some and can increase with frailty
 - Subjective
 - Objective physical harm



AFCP

- '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.'

AFCP

- Decline may mean losing one's voice
- We may then have to guess or ask others
- AFCP 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

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?



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

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have been continuously unable to blink or otherwise respond for fourteen consecutive days I wish for ventilation to be withdrawn.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 3

- Find ways to hear the lost voice
 - Cognitive or communication failure
 - Exhaustion
- ADRT, ACP, statement of wishes
- 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

Practical points 4

- Preserve future options
 - ‘Least restrictive’
- Don’t rule too many things out too soon

Practical points 5

- 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

Bereavement support

From *Birthday letters*

Then a voice, like a selected weapon
Or a measured injection,
Coolly delivered its four words deep
into my ear:

“Your wife is dead.”

Last Letter, Ted Hughes