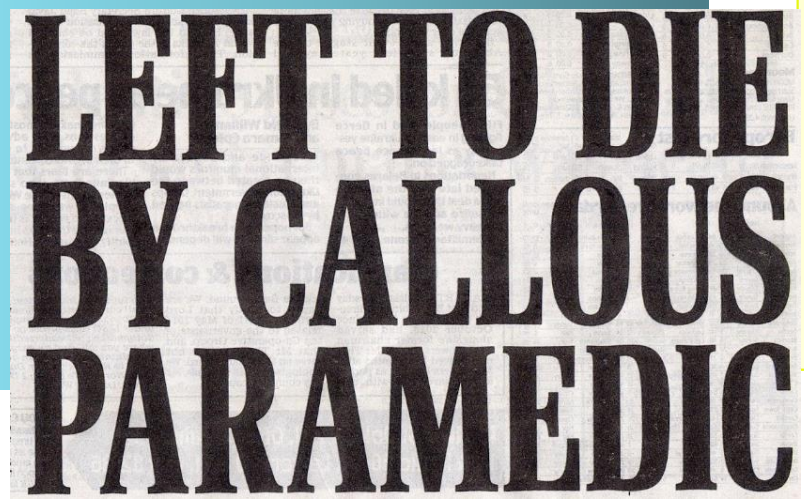
The public understanding of dying:
why we need to 'midwife' the deathbed

The public understanding of dying


MY RIGHT TO DIE IN DIGNITY


Cancer mum denied chance to say goodbye 'because doctors did not try to keep her alive'


NHS HIT BY NEW HOSPITAL DEATHS COVER-UP


LEFT TO DIE BY CALLOUS PARAMEDIC


Our mum was drugged up and denied any food


BBC

The public understanding of dying

- Misinformation
- Media distortion
- Soap opera/cinema trivialisation
- Lack of direct experience, or mistrust of own experience

- This is the space in which we are trying to deliver a service.
- This is a Public Health issue

How we die 1

Changing energy levels; increasing sleep

Periods of being unrousable

Periods of being awake

Possible restlessness

Onset of unconsciousness

'Periodic Breathing' reflex

Respiratory noises

Slowing of respiration; pauses

Last breath usually 'nothing special'

How we die 2

- Gradual process of normal dying is interfered with by discomfort/physical symptoms
- ACP needs to consider plans for possible symptoms depending on specific patient and their condition:
  - Bowel cancer: nausea; colic; constipation; diarrhoea; liver pain
  - Brain tumour: fits; headache; nausea; mobility challenges; agitation
  - Kidney failure: nausea; itch; changes in drug metabolism; delirium; fits; myoclonic jerks; CA
- Relief of symptoms will allow patient to settle: level of unconsciousness without symptoms may surprise the family so warn them what to expect.

‘Midwifing’ Dying

- Preparation: what to expect, options for place of care, who will provide care, what backup will be available
- Monitoring: familiarity with symptoms; planning for anticipatable emergencies; ‘step up’ as well as ‘step back’ plans
- Interventions: less ‘treatment’ and more ‘care.’
- Deathbed accompaniment: narrating the process, explaining to patient and family, reassurance, pro-active symptom management, reactive symptom management
- Normalising normal dying
- Beginning the stories to be told in bereavement
- Every death an opportunity to educate

Helpful phrases

- Tell me what you think is going on.
- Tell me what you expect to happen in the future.
- 'What if…' (avoids crushing denial)
- Treatment of X will restore you to how y… …w were you then?
- You're at a crossroads.
- There are important deci…
- What matters most …
- How much det… …ou? Is there someone you'd like to talk to with me? …k to?
- Would yo… …things are likely to happen? It's probably gentler than you're …
- 'Sick enough t…
- 'If s/he could tell u… …hat would s/he say now?'

When in doubt….

Summarise

Ask an open question

Covid Complications

- Absence from deathbed: information vacuum will impact of grief and bereavement
- Decisions about non-escalation reported in media as 'rationing.'
- Decisions to remain in usual place of care reported in media as 'left to die.'
- Danger that 'ACP' will be mistaken for rationing or therapeutic nihilism
- Hard to campaign by saying 'It's not….'
- We need a clear, multi-stakeholder campaign that says ACP is about respecting people's right to know about their health and make plans for their future care based on respect for their preferences, values and wishes.