Principles of Advance Care Planning

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Mercy Aged Care,
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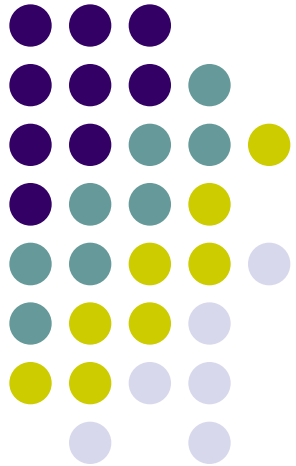
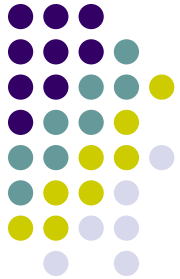


Overview

1. Two Stories
2. Ethical Standards and Legal Rules
3. Facilitated Decision-Making
4. Conversations and Paper
5. Cultural Competence and Cultural Safety
6. It’s a Revolution!
7. Coming to Terms with Sickness, Dying and Death

1. Two Stories



- At 3 am, old Mrs Jones has what is probably a heart attack.
- There is no ACP form, or the night staff don't know where to look.
- Ambulance
- CPR
- ED (Emergency Department)
- ICU (Intensive Care Unit)
- "This is just what Mum was trying to avoid!"
- Mrs Jones never really regains consciousness. She shows some signs of agitation and distress. She dies two days later.

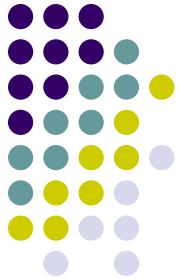
- At 3 am, old Mrs Jones has what is probably a heart attack.
- There is an ACP form – and the night staff know how to access it.
- Mrs Jones has said that she doesn't want CPR. She wants comfort measures which allow natural death (AND).
- The ACP form tells staff whether or not to call the family at night.
- Mrs Jones is cared for at Mercy Aged Care. Just in case medicine is used to keep her comfortable.
- She dies peacefully at 5 am.

2A. Catholic Ethical Standards

= the traditional ethical standard of Western civilisation - and other cultures too:

- We should take reasonable steps to preserve our life
  - ‘ordinary’ or ‘proportionate’ means
- We may refuse anything unreasonable or excessive
  - ‘extraordinary’ or ‘disproportionate’ means

Extraordinary or Disproportionate Means



- Futile and/or
- Overly burdensome
  - physically too painful
  - psychologically too distressing
  - socially too isolating
  - financially too expensive
  - morally repugnant
  - spiritually too distressing
- ‘heroic’ or ‘cruel’ treatment
- may be refused

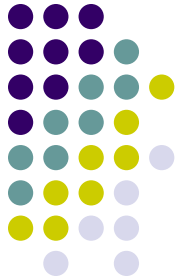
2B. Legal Rules

= Each competent person has an unlimited right to refuse all medical treatment.

- *These two standards:*
  - *traditional morality (Catholic ethical standards), and*
  - *the legal rules*
- *co-exist in health care,*
- *sometimes in an uneasy tension.*

- **If you have ethical concerns about a proposed plan of action, speak to your line manager!**

3. Facilitated Decision-Making



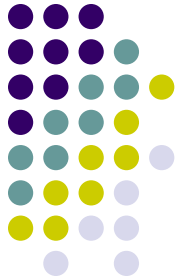
Medical Consultation

- patient reports their symptoms
- health professional provides diagnosis, prognosis, and treatment options
- health professional facilitates the patient's decision-making

Advance Care Planning

- patient reports their state of health, their values and wishes
- health professional provides medical and other information
- health professional facilitates the patient's decision-making

Initiating the Conversation

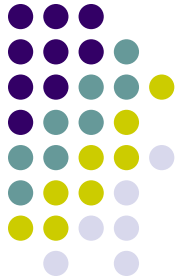


- This is part of our facilitation!
- Most residents are ambivalent about ACP
  - It's about sickness, death and dying!
  - How do you go about making these decisions?
- Even so, research shows that most residents expect us to discuss ACP with them
  - They expect us to raise the issue
  - They expect us to guide them through decision-making
- We must encourage and support them to initiate ACP

Revisiting the Conversation

- This too is part of our facilitation!
- Revisit ACP:
  - at regular intervals (e.g. every 6 or 12 months)
  - if the resident's health situation changes significantly
    - e.g. their health deteriorates; they are admitted into hospital
  - if the resident's social situation changes significantly
    - a significant person in their life dies, or moves away, or doesn't visit much any more
    - a significant goal has been achieved (e.g. they celebrate their 80th birthday, or attend their grand-daughter's wedding)

4. Conversations and Paper

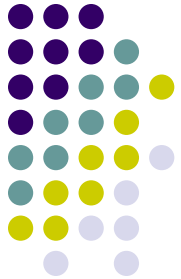


- Both facilitated decision-making and records of the conclusions from this are necessary for ACP.
- There is a reductionistic tendency to reduce ACP to ‘tick-a-box’ or ‘fill-in-a-form.’ (‘paper’)
- The heart of ACP must be facilitated decision-making. (‘conversations’)
- The reductionistic tendency must be resisted!

5A. Cultural Competence

- National Health & Medical Research Council *Cultural Competency in Health* (2006), p. 7:
  - “Cultural competence is a set of congruent behaviours, attitudes, and policies that come together in a system or among professionals and enable effective work in cross-cultural situations.”
  - vitally important in Australian health and aged care
    - recognise diversity
    - positively value diversity

5B. Cultural Safety and Difference Blindness

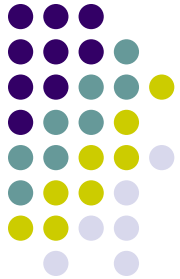


- Cultural safety is “an environment that is safe for people: where there is no assault, challenge or denial of someone’s identity, of who they are and what they need.”
- Difference blindness = ‘we treat everyone the same.’
- Difference blindness does not provide a place of cultural safety. It can be a threat to a person’s very identity.

6. It's a Revolution!

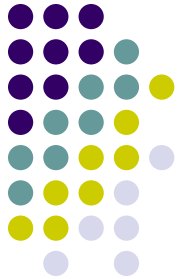
- Advance Care Planning will bring about enormous changes in health and aged care.
- Such revolutionary change is not easy:
  - for carers and health professionals
  - for health care institutions
  - for patients, and their families & friends

6. It's a Revolution! (cont'd)



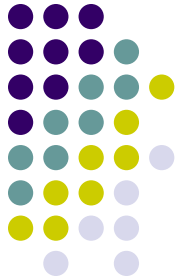
- It's a Copernican Revolution:
  - Copernicus taught us that the sun does not revolve around the earth, but instead that the earth revolves around the sun.
  - ACP teaches us that patients/residents/care recipients should not have to revolve around their carers and health professionals, but instead that we carers and health professionals should revolve around them and around their values and wishes.

7. Coming to Terms with Sickness, Dying and Death



- Henri Nouwen's *Our Greatest Gift: A Meditation on Dying and Caring*
  - Henri's secretary Connie Ellis had a stroke: "She who had always been eager to help others now needed others to help her." (pp 96-97)
  - "I wanted Connie…. to come to see that, in her growing dependency, she is giving more to her grandchildren than during the times when she could drive them around in her car…. The fact is that in her illness she has become their real teacher. She speaks to them about her gratitude for life, her trust in God and her hope in a life beyond death." (pp 103-104)

7. Coming to Terms with Sickness, Dying and Death (cont'd)



- Henri Nouwen's *Our Greatest Gift: A Meditation on Dying and Caring*
  - "She, who lived such a long and very productive life now, in her growing weakness, gives what she couldn't give in her strength: a glimpse that love is stronger than death. Her grandchildren will reap the full fruits of that truth." (p 104)
  - "Not only the death of Jesus, but our death too, is destined to be good for others… to bear fruit in other people's lives." (p 52) "In this way, dying becomes the way to an everlasting fruitfulness." (p 53)

Crossing the Bar

by Alfred Lord Tennyson (1809-1892)

- Sunset and evening star,
  And one clear call for me!
  And may there be no moaning of the bar,
  When I put out to sea,
- But such a tide as moving seems asleep,
  Too full for sound and foam,
  When that which drew from out the boundless deep
  Turns again home.
- Twilight and evening bell,
  And after that the dark!
  And may there be no sadness of farewell,
  When I embark;
- For tho' from out our bourne of Time and Place
  The flood may bear me far,
  I hope to see my Pilot face to face
  When I have crost the bar.