Advance Care Planning

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Calvary Health Care Bethlehem,
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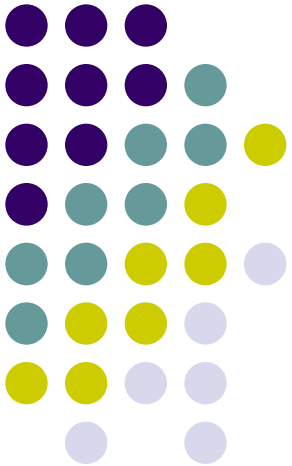


Outline

1. Why should we do Advance Care Planning?
2. Ethics
3. Process

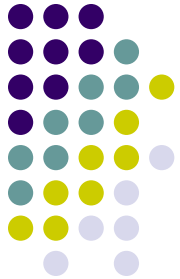
1. Why should we do Advance Care Planning?

Two Stories

- At 3 am, old Mrs Jones at the RACF had what is probably a heart attack.
- There was no ACP form, or the night staff didn'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 regained consciousness. She showed some signs of agitation and distress. She died two days later.

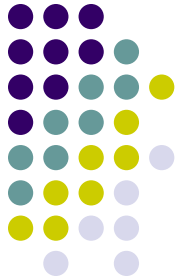
- At 3 am, old Mrs Jones at the RACF had what is probably a heart attack.
- There was an ACP form – and the night staff knew how to access it.
- Mrs Jones had said that she didn't want CPR. She wanted comfort measures which allow natural death (AND).
- The ACP form told staff whether or not to call anyone at night.
- Mrs Jones was cared for at the RACF where she lived. Just-in-case medicine kept her comfortable.
- She died peacefully at 5 am.

Two More Stories – Part 1



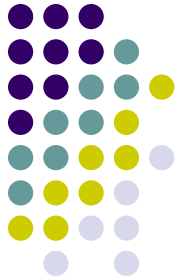
- Kath is a 50-year-old woman who has just being diagnosed with early-onset dementia. Kath lives with her husband of 30 years; none of their 5 adult children live in the family home anymore. Kath and her husband talk to the specialist regarding Kath's new diagnosis. Given that the progression of Kath's condition is unknown, the specialist introduces Advance Care Planning to Kath. Kath, her husband and their children think and talk about her values and wishes. Kath feels empowered to be able to make decisions while she is still cognitively able to do so. At her next specialist meeting, Kath gives her husband an Enduring Power of Attorney (for both financial matters and medical treatment). She also completes the CHA Advance Care Plan.

Two More Stories – Part 2



- Mark is a fit young man in his mid-20s. He learnt about Advance Care Planning at university, but hadn't really thought much more about it. Then, a footballer on a local team was seriously concussed with an on ground head injury. The footballer ended up in intensive care and, sadly, failed to recover. His parents had to hastily make difficult decisions, and were obviously traumatised because they didn’t really know what their son wanted. The media publicity prompted Mark to think about his own situation. A quick search of the internet gave Mark a document to give his uncle an Enduring Power of Attorney (Medical Treatment). Mark was close to his uncle, and he told his parents that if something happened, he thought they would be too upset to make difficult decisions. His parents accepted this, but asked Mark to talk to Uncle Jim, so that Jim would know what Mark wanted if something ever did happen.

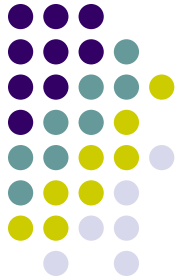
The Blessings and Burdens of Modern Medicine



- From C20, modern medicine has greatly increased average life expectancy
  - BUT
    - many more are old, frail and chronically ill
    - towards the end of life, medical treatment probably won't cure, but may make a final illness and death very unpleasant ('dysthanasia')
    - towards the end, many are unconscious or incompetent → at that time, they cannot say no to further treatment

Random Clinical Trial

- Karen M Detering et al, “The impact of advance care planning on end of life care in elderly patients: randomised controlled trial,” *British Medical Journal* 340 (2010):1345-1353:
  - ACP significantly increased patient satisfaction with their hospital stay.
  - ACP significantly increased the percentage of patients whose EOL wishes were both known and followed.
  - ACP significantly increased family satisfaction with the process of their loved one’s dying and death.
  - If their loved one died without ACP, 15-30% of family members experienced significant stress, serious depression or severe anxiety. ACP greatly reduced all these negative reactions.



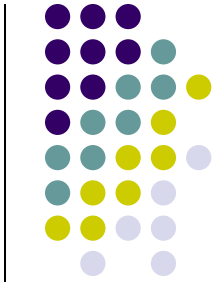
2. Ethics

Traditional Morality

= 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

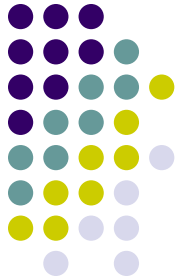
Legal Standard



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

- *These two standards*
  - *traditional morality*
  - *the legal standard*
- *co-exist in health care,*
- *sometimes in an uneasy tension.*

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

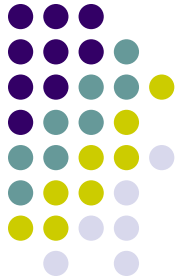
Advance Care Planning

- Our best first step is to appoint a Substitute Decision Maker (SDM), who speaks for us if we cannot speak for ourselves.
- Decisions by an SDM should be :
  - faithful to our values and wishes
  - substituted judgement = not **deciding** for us, but **speaking** for us

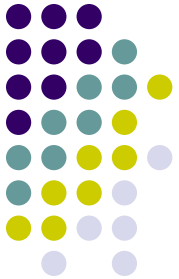
Advance Care Planning

- We must guide our SDM:
  - ongoing communication between person, SDM, significant others, and health professionals
  - telling them our wishes verbally
  - recording our wishes in doctor's notes, hospital and aged care records

Advance Care Planning

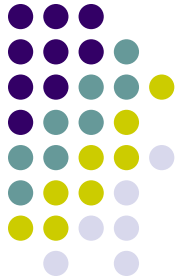


- Legally binding Advance Directives are sometimes problematic because they can bind us to a course of action which is inappropriate in unforeseen circumstances.
- Advance Directives may become more appropriate for those who are aged and frail, or those with serious or life-threatening disease.



3. Process

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

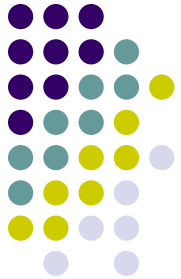
Advance Care Planning

- patient reports their state of health, their values and wishes
- ACP facilitator may provide medical and other information
- ACP facilitator facilitates the patient's decision-making

NB

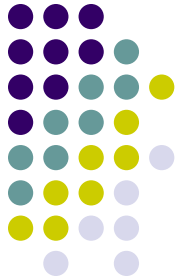
- Chaplains (Pastoral Practitioners or Spiritual Care Practitioners) have useful skills for Advance Care Planning.
- What structures should be set up so that chaplains are able to part of the multidisciplinary team involved in Advance Care Planning?

Initiating the Conversation



- This is part of our facilitation!
- Most people are ambivalent about ACP:
  - It's about sickness, dying and death!
  - How do you go about making these decisions?
- Even so, research shows that most people expect their carers 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

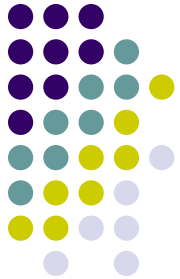


- This too is part of our facilitation!
- Revisit ACP:
  - at regular intervals (e.g. every 6 or 12 months)
  - if a person's health situation changes significantly
    - e.g. their health deteriorates; they are admitted into hospital
  - if a person's social situation changes significantly
    - a significant 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 a significant celebration)

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’)

Victorian Paperwork

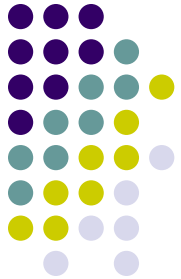


- Enduring Power of Attorney (Medical Treatment)
  - For this form, see http://www.publicadvocate.vic.gov.au/file/file/Powerofattorney/Power%20of%20attorney%20forms%202010/Enduring_power_of_attorney_medical_treatment_with_instructions2010.pdf
- Refusal of Treatment Certificate
  - only for current conditions
  - For this form, see http://www.health.vic.gov.au/__data/assets/pdf_file/0004/275251/mta88_sched01.pdf
- Person Responsible
  - See http://www.publicadvocate.vic.gov.au/medical-consent/467/

Catholic Resources

- Advance Care Plan
- A Guide for People Considering Their Future Health Care
- A Guide for Health Care Professionals Implementing a Future Health Care Plan
- Code of Ethical Standards for Catholic Health and Aged Care Services in Australia
  - Download them all for free from the **Catholic Health Australia** website: **http://www.cha.org.au/publications.html**

Catholic Health Australia Advance Care Planning website



- **www.myfuturecare.org.au**
  - Guidance:
    - for Patients and Residents
    - for Healthcare Professionals
  - Videos
  - Resources
  - FAQs
  - Getting Help