Organising Advance Care Planning for Priests and Religious

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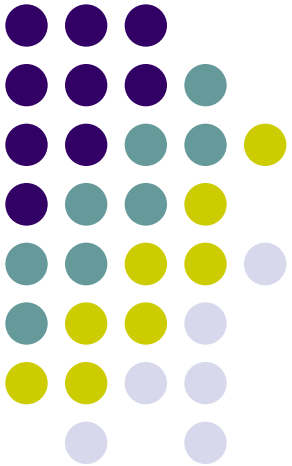
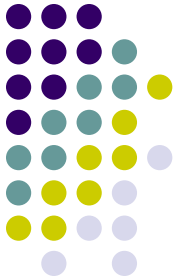


Outline

1. Why should we do ACP?
2. Catholic Ethics
3. Advance Care Planning
4. Practical Steps
5. Finding Hope in Sickness, Dying and Death



1. Why should we do ACP?

Two Stories

- At 3 am, old Sr Mary at the RACF 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 Sr Mary was trying to avoid!"
- Sr Mary never really regains consciousness. She shows some signs of agitation and distress. She dies two days later.

- At 3 am, old Sr Mary at the RACF has what is probably a heart attack.
- There is an ACP form – and the night staff know how to access it.
- Sr Mary 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 anyone at night.
- Sr Mary is cared for at the RACF where she lived. Just-in-case medicine keeps her comfortable.
- She dies peacefully at 5 am.

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.

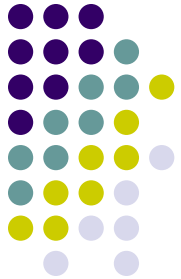
2. Catholic Ethics

Catholic Ethics

= 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

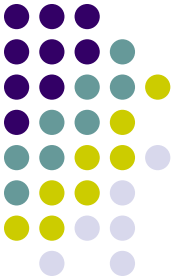
Advance Care Planning

- 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 Catholic standards
  - 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

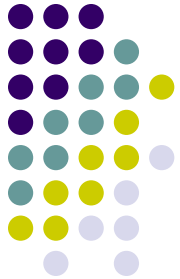
Advance Care Planning



- Legally binding Advance Directives are often 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. Advance Care Planning

Facilitated Decision-Making



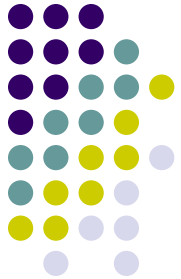
Medical Consultation

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

Advance Care Planning

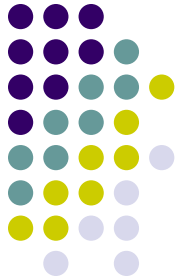
- patient reports their state of health, their values and wishes
- ACP facilitator may provide medical and other information
- ACP facilitator facilitates the patient's decision-making

Initiating the Conversation



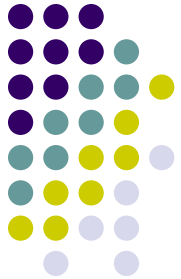
- This is part of our facilitation!
- Most people are ambivalent about ACP
  - It's about sickness, death and dying!
  - How do you go about making these decisions?
- Even so, research shows that most people expect their carers to discuss ACP with them
  - They expect us to raise the issue
  - They expect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

Revisiting the Conversation



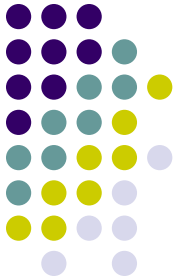
- This too is part of our facilitation!
- Revisit ACP:
  - at regular intervals (e.g. every 6 or 12 months)
  - if a person's health situation changes significantly
    - e.g. their health deteriorates; they are admitted into hospital
  - if a person's social situation changes significantly
    - a significant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



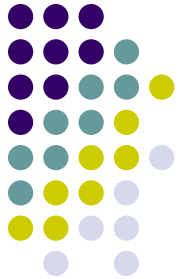
- Form to appoint a Substitute Decision-Maker =
  VIC **Enduring Power of Attorney (Medical Treatment)**
  - For this form, see **http://www.publicadvocate.vic.gov.au/file/file/Publications/Booklets%20and%20guides/Enduring%20Power%20of%20Attorney%20Medical%20Treatment%20form%20with%20instructions%202014.pdf**
- **Statutory Substitute Decision-Maker**
  - For VIC list, see **http://www.publicadvocate.vic.gov.au/medical-consent/175/**
- Form to refuse treatment =
  VIC **Refusal of Treatment Certificate**
  - For this form, see **http://www.health.vic.gov.au/__data/assets/pdf_file/0004/275251/mta88_sched01.pdf**
  - lapses after current bout of illness → a new form must be completed next time

Catholic Resources

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

4. Practical Steps

Who Should Organise ACP?



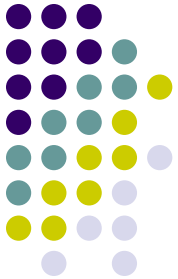
- Is it you? Is it someone else?
  - knowledge about ACP
  - interest
  - time
  - pastoral skills
  - patience
- Should your leadership appoint a ‘Vicar for ACP’?

Triage

1. Those in reasonable health
   - appoint Substitute Decision Maker (SDM)
   - advise SDM of their values and wishes

2. Those with a serious chronic disease
   - appoint Substitute Decision Maker (SDM)
   - advise SDM of their values and wishes
   - advice about disease trajectory
   - bucket list?

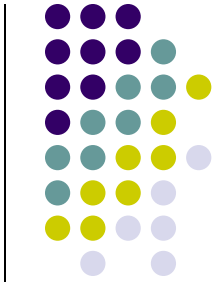
Triage (cont'd)



3. No to the trigger questions: 'Would I be surprised if this person died in the next 12 months?'
   - appoint Substitute Decision Maker (SDM)
   - advise SDM of their values and wishes
   - advice about disease trajectory
   - bucket list?
   - recording treatment preferences, e.g. Advance Directive

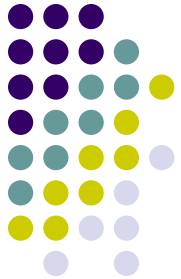
4. Death is imminent (e.g. 48-72 hours)
   - hopefully, all the plans are in place
   - as the situation changes, new decisions may still have to be made

ACP Process



- What do they understand about their condition (diagnosis, prognosis)
- “We hope for the best and we prepare for the worst”
- hopes and fears
- bucket list
- values and wishes (“Are you someone who believes that every last thing must be done to preserve life, or do you believe that treatment may be refused if it is futile or too burdensome?”)
- Choosing and appointing a substitute decision maker
- Recording treatment wishes (e.g. doctor’s notes, hospital and aged care records, Advance Directive): Should these guide or bind their substitute decision maker?
- Make plans for review (e.g. 6 or 12 months, or if their health, personal or social situation changes)

Choosing a Substitute Decision Maker

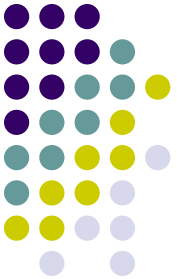


- someone who is reasonably accessible
- someone I trust
- someone I can talk to
- someone who is at least a bit assertive
- someone who is not so close to me that they might be overwhelmed by their own emotions when my end draws near
- Is this my religious superior? another religious? a friend?

ACP Skills

- Visit **http://depts.washington.edu/oncotalk/** for videos and other resources

“Tell me more”



- Try to avoid closed-ended questions (which elicit answers like ‘yes’ or ‘no’)
- Instead, make open-ended requests like “Tell me more” or “Help me to understand”

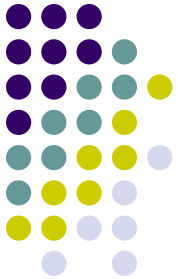
Ask-Tell-Ask

- ASK what the other person already understands about their condition
- ASK e.g. “May we talk about what the future could hold?”
- TELL no more than 3 points at a time, using simple and non-technical language
- ASK what questions they have
- ASK them to summarise what they have heard

Respond to emotions

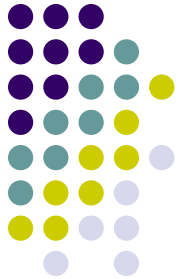
- Bad news elicits emotions
- NAME the emotion
- ACKNOWLEDGE the challenges of the situation
- Offer SUPPORT
- If emotion is not honoured, it will detract from good decision-making in Advance Care Planning

Elicit hopes and fears



- “If your time is limited, what is most important to you?”
- Discuss goals and what is achievable
- “When you think about the future, what worries you?”
- DON’T say “I’m sorry.” Say “I wish…” e.g. “I wish we had more options or better treatment”

Making a recommendation



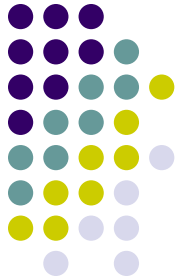
- “Do you want a recommendation?”
- Start with what can be achieved
- After you have made your recommendation, ask what they are thinking
- If necessary, explain why other courses of action cannot achieve what is wanted
- “At the point when death is very close, have you given any thought to the type of care you would want?”

Other Matters

- Have I made a will? Do I have special things that I want to leave to specific people? (Make a list!)
- Any last messages for anyone?
- As death nears, do you want:
  - people to be told you are sick and asked to pray for you?
  - people with you? Who?
  - to have people talk to you and hold your hand, even if you don't seem to respond?
- Funeral wishes
  - eg readings, hymns, readers, pall bearers, etc
- Burial wishes
- What else is important for you?

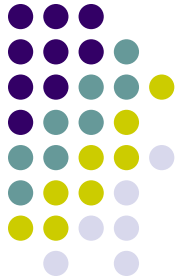
5. Finding Hope in Sickness, Dying and Death

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)

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.