

# Ethical care in end stage dementia

## Gippsland Palliative Care Conference

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1

## Objective

By the end of this workshop, participants will be able to

- Identify two main issues in achieving ethical care in end stage dementia

2

## CPR

(Therapeutic Guidelines Palliative Care, 2010, p.25)

- CPR is primarily for people with cardio-respiratory problems.
- The success rate of CPR is poor (< 5%?) even in previously healthy individuals. In serious illness, likely to be universally poor.
- The success rate of CPR in frail older people is minimal (<1%?)
- The best success rate is on *ER!*

3

## CPR (cont'd)

Volicer, L. (2008). End-of-life care for people with dementia in long-term care settings. *Alzheimer's Care Today* (April-June 2008), 84-102.

- Injuries + ICU environment cause more discomfort and suffering
- Death soon after CPR deprives patients & families of a dignified death
- Ethical issue is grounded in *informed consent: what **information** about survival rates, etc, have been provided?*
- ACP (advance care planning) is the key, e.g., in avoiding unnecessary hospitalisation

4

## Resuscitation

(Therapeutic Guidelines Palliative Care, 2010, p.359)

- 'Where possible and appropriate, it should have been agreed and documented **well before the terminal stage** that intrusive measures to support respiratory or cardiac insufficiency will be **clinically futile** and will in no foreseeable circumstances be undertaken'

5

## Duty of care

'Neither the law nor any professional ethical code defines "duty of care" in such a way as to require providers to give **futile or inappropriate** treatment. . .'

6

## Pain and dementia

*True or false?*  
*(Refer handout)*

7

## Pain in advanced dementia

World first study conducted by Melbourne doctors has shown dementia patients feel the same pain as people without the disease, but cannot communicate their distress (Cole, L Farrell, Duff, et al, 2006).

8

## Pain management in dementia

*Pain is frequently undetected, misinterpreted, or inaccurately assessed in older adults with dementia. At particular risk are those patients who are . . . unable to articulate or convey their pain, who are often dismissed as being incapable of perceiving or recalling pain* (ACEBAC, 2008, p.5)

9

## Pain is an *ethical* issue

(Neville et al, 2006)

- Pain is poorly managed in those who are *defenceless* and *voiceless*
- If poorly managed, pain can lead to the over-use of psychotropic medication
- Pre-emptive pain management can result in: improved function, less depression, more sleep, increased quality and control of life

10

## Does analgesia hasten death?

*'There is no evidence that, when drugs are titrated carefully to achieve analgesia or symptom control tailored to the patient's requirements, life is shortened as a result. Quite the contrary, in fact: effective pain relief actually prolongs life by ensuring that patients do not die from the exhaustion of uncontrolled pain'* (Finlay, 2009).

11

## Duty of care

(Therapeutic Guidelines, 2010, pp.29,30)

*'Neither the law nor any professional ethical code defines "duty of care" in such a way as to require providers to give futile or inappropriate treatment, or to compromise pain and symptom relief'*

*'A provider's primary duty is to the patient, and those duties owed to all other parties are secondary'*.

12

## Mrs Papadopolous: chapter 1

(adapted from Hudson, R, 2004, chap 18)

*Mrs Papadopolous, aged 92, was transferred from hospital to nursing home after a four week admission. Her diagnoses included dementia, osteoarthritis, insulin dependent diabetes, and past history of breast cancer. She had decubitus ulcers in the sacral area and both shoulders. She was malnourished, often refusing oral food and fluids. The family had been told to expect her death 'within a matter of days or weeks at most'.*

**Discussion:** What information will be provided from the hospital to the nursing home?

13

## Mrs Papadopolous: chapter 2

*Staff in the nursing home were anxious about Mrs Papadopolous's increasing debility and their fear she was in constant pain, especially when her position was being changed and the wounds attended. They were also unsure of the families' expectations. Unable to articulate her needs, Mrs Papadopolous's sad eyes seemed to implore, 'help me please'. After many weeks, when her death had not occurred as expected, the family were confused, anxious and irritable. An atmosphere of hopelessness pervaded.*

**Discussion:** On a scale of 0-10 how would you rate Mrs Papadopolous's quality of life? Reasons?

14

## Mrs Papadopolous: chapter 3

*In consultation with the family and the local doctor a palliative care physician was called in to address the serious issue of pain management. It was agreed that Mrs Papadopolous's osteoarthritis and painful ulcers warranted the administration of oral slow release morphine, other milder opioids having been tried with no effect. Within days Mrs Papadopolous's appetite improved. She no longer resisted every attempt to change her position.*

**Discussion:** On a scale of 0-10 how would you rate the family's satisfaction with the care? Reasons?

15

## Mrs Papadopolous: chapter 4

- *The family's visits now increased as they provided their own roster to assist Mrs Papadopolous with meals whenever possible, bringing some of her favourite foods from home. Now, the despair felt by the family was replaced by hope. Not hope for a miraculous cure, but hope for improved quality of life, assurance that her pain was relieved and the satisfaction of making their own contribution to her care. The palliative care physician also explained that Mrs Papadopolous's death may not occur as soon as they had expected. 'She may still have some living to do', was her comment.*

**Discussion:** How would you rate Mrs Papadopolous's quality of life now? What made the difference?

16

## Mrs Papadopolous: chapter 5

*When Mrs Papadopolous was unable to consistently swallow oral medication, a low dose continuous subcutaneous infusion of Morphine was commenced. The family were by now fully informed about the use of narcotics, having received relevant literature and having their fears and concerns allayed through open discussion. It was agreed by the family that their mother would 'hate a tube into her stomach'; they preferred to offer her regular small amounts of food and fluid. Greater attention was now given to her skin care, with the advice of a wound consultant. The nurses were no longer anxious about causing her pain.*

**Discussion:** How would you rate the nurses' and other health professionals' satisfaction with the care? Similar examples from your own experience?

17

## Mrs Papadopolous: chapter 6

*Apart from her physical frailty Mrs Papadopolous had spiritual, psycho-emotional and social needs.*

- Name 4-6 factors you would include in her 'holistic' care plan

18

## Mrs Papadopolous: chapter 7

*Aromatherapy, massage, music, visit from the Greek Orthodox priest, sunshine, visits from the family dog, and respectful use of her full name were added to the care plan.*

*Mrs Papadopolous's response could only be gauged from her sparkling eyes.*

*In spite of decreasing oral intake Mrs Papadopolous lived for another four months. She died peacefully and pain free.*

19

**Life & death matters:  
it's the care that counts**

***How people die  
remains in the memory  
of those who live on***

Dame Cicely Saunders

20

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