Palliative Care in a Dementia Unit:

The Presbyterian Support Southland experience

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Overview

- What the literature is saying
- Palliative Care challenges
- Our experiences
- Case example

What is the literature saying?

- Palliative Care in dementia is a hot topic!
- Dementia needs to be formally recognised as a terminal illness
- Prognostication is often difficult
- People with ‘moderate’ to ‘severe’ dementia should be receiving palliative care
- Under-treated (or untreated) pain is common in people with dementia
- Assessment and symptom management is challenging
- Person centred care is important
- Advance Care Planning is extremely important

Advance Care Planning

- Whilst still able to make own independent decisions – maximum opportunity to direct, or influence, own care
- EPOA
- If no longer competent to make own healthcare decisions, discussions with EPOA/family
- Assessing competence can be tricky

Treatment decisions

- What are we trying to achieve for this person?
- Burden vs. benefit
- Hospitalisation is distressing, detracting from QOL and survival
- Investigations may not be in best interests
- No evidence that feeding tubes improve survival or comfort in dementia

Palliative Care challenges

- Acceptance of dementia as a terminal illness
- Prognostication
- Embarrassment, reluctance to ask for help
- Communication barriers
- Assessment
- Diagnosis of other problems / comorbidities
- Family support/grief

IONA: our dementia unit

- PSS has a total of 280 beds
- Iona is a 40-bed secure dementia unit
- Residential area & hospital area

Why focus on palliative care?

Recognition of:

- Lack of forward planning, crisis prevention
- Burden of hospital transfers
- Need to increase capacity and capability internally
- Need for staff to understand pall care and how it ‘fits’ alongside some active treatments

Implementing palliative care

- ACP
- Palliative Care Resource Folder
- Palliative Care Workbook for staff
- LCP
- Working alongside staff with assessments, monitoring and care planning
- Policy related to palliative care in dementia
- Encouraging medical planning (GPs)

Case example

- Annie
- 80s, widowed, supportive daughter
- Lived in other Residential dementia unit
- Dementia/anxiety/?depression
- Ca left kidney => conservative management
- I assessed her for GP
- Hospice referral => declined

- Urgent transfer to Iona Unit one week later
- Pain +++++
  - Pacing
  - Guarding / posture
  - Facial expressions
  - Moaning
- Refusing oral meds, food and fluid 3 days
- Anxiety +++++ (?pain, ?BPSD)

Pain

- Had been on oral morphine 10mg (none for 3 days)
- Morphine 5mg SC x2 => pain relieved
- PRN morphine 5-10mg SC PRN charted
- Fentanyl patch 25 mcg/h
- Appeared comfortable ?pain free for 24h
- Pain escalated
- Syringe driver 60mg/24h (fentanyl patch d/c)
- Pain free for remainder of her life (3 weeks)

↓Oral intake

- Staff and daughter assumed due to end of life
- H/o thrush – had been on Nilstat
- Spat out pus on day 2
- Temporary sedation => inspected and cleaned mouth
- Herpes Simplex => treated
- Eating and drinking until last week of life
- Interacting, sense of humour

Anxiety

- Long-term, worsened several months ago
- O/A: FEAR:
  - New environment
  - Strange people
  - Pain & mouth discomfort
  - Declining physical condition (?awareness)
- Once pain and herpes resolved anxiety => baseline and less

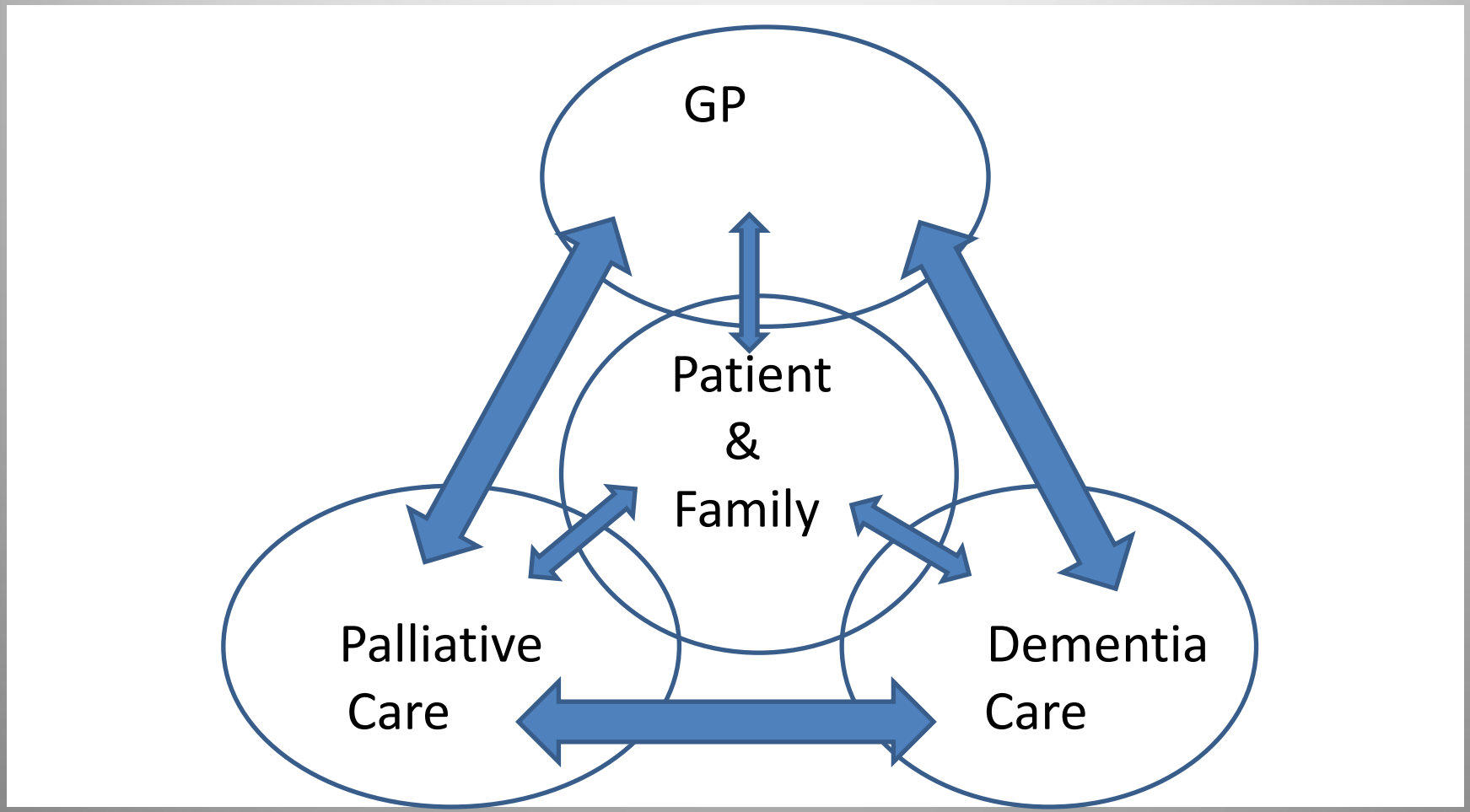
Communication

- 2 weeks prior – basic conversation
- On admission – nonsensical rambling, body language saying “keep away”
- Once pain resolved – interacting more, basic responses, sense of humour evident
- Building relationships with staff – needs and wishes better understood

End of life

- Last 6 days – in bed, sips fluid til last 3 days
- Pain free
- Some anxiety/fear but less than on admission
- Quality time with daughter
- Midazolam 15mg/24h added to syringe driver
- Last 3 days – extreme fear intermittently => midazolam increased to 30mg => settled, barely rousable

Collaboration



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CARESEARCH

- CARESEARCH palliative care knowledge network pages available at:

http://www.caresearch.com.au/caresearch/tabid/2785/Default.aspx

Pages include:

- Palliative Care Challenges
- Prognosis and Advance Care Planning
- Symptom management

Literature list – ACP and dementia

- Clarke, G. et al (2013). How are Treatment Decisions Made about Artificial Nutrition for Individuals at Risk of Lacking Capacity? A Systematic Literature Review. PLoS ONE 8(4): e61475. doi:10.1371/journal.pone.0061475.
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ACP and dementia cont.

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THANK YOU

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