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

GP

Patient & Family

Palliative Care

Dementia Care
Literature list


NHS National End of Life Care Programme (2010). Improving End of Life care for People with Dementia: an online resource guide.


Van der Steen, J. et al (2013). White paper defining palliative care in older people with dementia: A Delphi study and recommendations from the European Association of Palliative Care. Palliative Medicine, 0(0) 1-13. Full text available at: http://pmj.sagepub.com/content/early/2013/07/05/0269216313493685

Watson, J. (2013a). What is dementia? Implications for caring at the end of life. End of Life Journal with St Christopher’s 3 (1).

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  Pages include:
  o Palliative Care Challenges
  o Prognosis and Advance Care Planning
  o Symptom management
Literature list – ACP and dementia


• Davies, J. & George, R. (2013). Advance decisions to refuse treatment in cases of dementia. End of Life Journal with St Christopher’s 3 (2).


• Palliative Care NSW and Alzheimer’s Australia (2011). The Dementia Journey: Information and Workbook for Planning Ahead.

ACP and dementia cont.


THANK YOU

Please feel free to contact me for further information:

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