



# WICKING DEMENTIA RESEARCH & EDUCATION CENTRE

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# Engaging families in a palliative approach to care for people with advanced dementia resident in aged care

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## This session...

### Has a focus on:

- What are some of the things we need to think about to improve our communication with family caregivers of people with dementia to better enable a palliative approach for our clients' care?



## Why is dying of dementia a difficult issue to address?

**Death is recognized as one of life's major challenges:**

- *“Death is the end of a world; it unravels a unique geography of feeling, tenderness, creativity, sorrow, doubt and shadow; it all comes apart like knitting unravelling, stitch by stitch...”*

**In addition, carers of people with dementia have an experience of ongoing loss:**

- *“I was mourning him several years before he died, intense sorrow was with me for most of the time...”*

**(Bereaved spouse, Dementia Palliative Care DVD, SA & NT DTSC)**



**The needs of people living and dying of dementia have to be addressed and families/loved ones are key players in this process**

**One strategy that is consistent with a palliative approach is relationship-centred care (Nolan et al 2004)**

**Relationship-centred care involves a collaboration between patients, their families, health professionals and the wider community and values all of these players**



## **Collaborative approaches can...**

**Assist residents, families, and staff, as partners in care, address their needs, fears and concerns through the sensitive sharing of knowledge of the resident, dementia and palliative care**



## **Strategies we can use to begin focusing the care of people with dementia and their families around a palliative approach**

**Recognition of the family as the unit of care – beyond blood and legal ties**

**Active communication of the value of family caring, beyond the ‘visitor’ status**

**Family carers' sharing the practical and physical care may help ease the spiritual and emotional demands of caring, overcome sense of futility, helplessness – consider how this might be achieved**

**Support families to meaningfully participate in care (if they wish to be involved) – e.g. mouth care, positioning, music, gentle touch, supportive presence**



**Strategies we can use to begin focusing the care of people with dementia and their families around a palliative approach  
*cont.....***

**Individual assessment of families' interest, physical and emotional capacity for involvement in care – tailored approach**

**Recognise the different types of family structure, tradition, literacy, and culture**

**Educating families about dementia and palliation in order to ease their fears and improve their knowledge and understanding**

**Facilitate discussions about goals of care, care needs and wishes, to avoid confusion about health status and the consequences of invoking or stopping specific medical interventions**





## Communication with family caregivers of people with dementia

**Communication, primary mechanism to manage uncertainty:**

**Content: What is said**

- Clear, reliable, and informed information, consistent amongst health care team

**Relationship: How it is said**

- Building trusting relationship by demonstrating empathic (feeling with) behaviours – acknowledging family caregivers' emotions; listening; providing emotional support; encouraging questions



## How can we show family members that you want them to be involved?

**Active Listening: turn full attention to the person rather than focusing on your own concerns or what to say in response. Focus not so much on what you say, but demonstrating that you are willing to listen, and prepared to try and understand. Provide feedback showing that you have understood:**

*This is such a hard time. How are you going?*

*It sounds like you are really concerned about his pain?*



## **“NURSE” the Emotions**

**Name – “I see how upset you are”**

**Understand – “You wanted to care for your husband at home. I see how difficult this must be for you”**

**Respect – “I am really impressed by your caring and involvement”**

**Support – “We will help you through this”**

**Explore – “Tell me”**



## Help families to understand what it means for their relative to have dementia

### Why is this important?

- Most people are unaware that dementia is a terminal condition
- Families are often unsure about what will happen to their relative as the dementia progresses
- Families tend to think that their relative will die of a sudden/acute event, rather than a progressive process of decline

### **Some cues for nursing staff:**

- *Can you tell me, what is your understanding of your relative's dementia?*
- *Has anyone talked to you about what dementia means for you relative's future health?*
- *Even though there is no cure for dementia, would you like to know about the type of care we provide to ensure that your relative has the best possible QOL?*



## How might care staff use opportunities in daily practice to raise dementia with families?

Initiating and enabling/continuing a dialogue requires :

- listening, acknowledging and acting

*Fx: “..mum doesn’t seem as well as she used to be...”*

*PCA response: “Can you tell me what changes you have noticed?”*

*PCA response .... “I realise that it must be difficult for you to see your mum like this, some of those changes may be associated with your mum’s condition”*

*“Would you like to speak with the nurse who could provide you with some more information and answer some more of your questions?”*



## How can we reassure families that a palliative approach is appropriate care?

**Families may require repeated, simple explanations to questions that concern them and their reactions to the situation.**

***Why aren't can't you do more?***

- *I realise you were hoping for your relative to improve but having dementia means that they will undergo a continual process of decline. We will do everything possible to make sure that your relative has the best possible QOL/comfort/ dignity*

***Why doesn't he/she want to eat or drink as much?***

- *Many families worry about this. It is a normal part of the progression of dementia. As you relative's dementia progresses it will get more difficult for them to take food and fluids*



## Help family shift their frame of reference to death and dying – the terminal phase

### Concerns about eating and drinking at the end of life:

- *It is also part of the dying process - to lose interest in food, to lose weight, it is to be expected/a part of the condition*
- *We can offer small amounts, but it is natural that he is wanting it less*
- *He will likely continue to decline and become less responsive over time/the next few days/weeks*

### Redirecting hope for cure to understanding, acceptance, comfort, and dignity:

- *I know you were hoping for an improvement (eg in episode of pneumonia). I'm so sorry, but she's just too sick to turn this around*
- *These are normal signs of dying. Let's work together to help her be as comfortable as possible*

# Some strategies to facilitate opening a dialogue with family caregivers...

## Discussion tool:

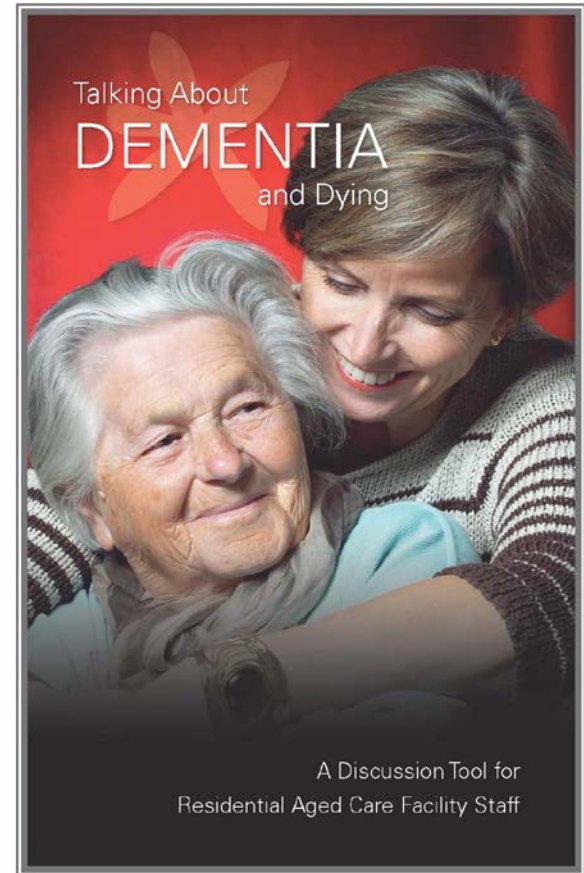
Resource for staff

Importance of process: key steps to holding a conversation about dementia as a terminal condition

Cues to facilitate discussion

Draws on principles of advance care planning

- Collaborative process
- Explores the values, beliefs and goals of care of the person
- Ongoing communication
- Choices discussed





# OUR DEMENTIA DIALOGUE STUDY...

Stirling et al, 2014

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Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

**ScienceDirect**

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## A tool to aid talking about dementia and dying – Development and evaluation

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**KEYWORDS**  
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Communication;  
Aged care;  
Tool development

**Summary**  
Background: Health professionals often avoid talking about death and dying with patients and relatives, and this avoidance is compounded in cases of dementia by lack of knowledge of trajectory and prognosis. Unfortunately, this impacts on care, with many terminally ill dementia clients receiving inadequate palliation and excessive intervention at end-of-life. This study developed and evaluated a tool to facilitate conversations about death and dying in aged care facilities.  
Methods: This study utilised available best-practice evidence, feedback from aged care facility nursing and care staff and specialist input to develop the 'discussion tool', which was subsequently trialled and qualitatively evaluated, via thematic analysis of data from family interviews and staff diaries. The study was part of a larger mixed method study, not yet reported. The tool provided knowledge and also skills-based 'how to' information and specific examples of 'what to say'.

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## Key study findings

**51% of staff (n=270) and 39% of family (n=119) correctly identified that dementia was likely to limit life expectancy**

**Qualitative findings supported this:**

- *It's not as though he's a sick person ... It's the mind involved, it's coming from the mind [FDU14]*
- *I don't think there's anything else wrong with mum. She's never been a sickly person. It's just the way this dementia has hit her ... we think when we go and visit her I think, she's going to live for years ... Because her body's not worn out ... She's still got her own teeth ...[FDU1]*
- *I never see dementia, dying of the dementia. I never see that they're dead from that [PCA FG7]*
- *...How can you say someone's died because of dementia...? What would be the cause? [PCA FG2]*

**65% of staff and 72% of families equated a palliative approach with terminal care**



## **Dementia and Dying Discussion Tool**

**Why it is important to talk with families and friends about dying**

**When to talk with families and friends about dying**

**What to do when talking with families and friends about dying and how to talk about dying**

**AFIRM provides suggestions for more spontaneous conversations about dying**

**A**cknowledge concerns

**F**ind out what family know

**I**mmEDIATE concerns addressed

**R**espond to further questions

**M**eeting suggested\*



## **NINE KEY STEPS IN HOLDING A CONVERSATION ABOUT DYING**

- 1. Prepare** for the meeting
- 2. Introduce** your purpose and all present
- 3. Ask** the family their story
- 4. Flag** the seriousness of approaching topic
- 5. Inform** about dementia and dying
- 6. Allow** space for emotions
- 7. Discuss** care
- 8. Ongoing dialogue** into the future
- 9. Self-care** – debrief



## **Example: Mr Booth**

**Mr Booth has been a resident in the DU for six months and has increasingly been losing physical capacity due to his dementia. As a result he is unable to walk more than a few steps and is eating and drinking less. Over the last month he has noticeably lost weight. His son visits every fortnight and is becoming anxious about his father's worsening condition.**



# ROLE PLAYS...



## **Group interaction Guide**

**Groups of ~4 participants**

**Two to take role of nurse and family member; two to observe  
~10-15 min working through steps from 2-8**

**Swap roles – observers become family member/nurse; previous  
actors become observers**

**Repeat exercise (each ‘family member’ has a distinct question  
sheet)**

**Feedback – feelings, process, content**



# WORKSHOP FEEDBACK





## Feedback post Discussion Tool use

*I didn't know whether or how (family member) would cope talking about death. I felt a huge expectation from my point of view. Death is not an easy subject... [I had a] a copy of the summary of the dialogue [tool]...so I could follow. Last night I sat down and went through it again to familiarise myself again. Previously we've had role play [between DPRNs]. I felt it was a very good conversation. I felt it went really well. [The family member] was engaged, and asked appropriate questions... (DPRN2)*

*...[the dialogue has]...made me feel calmer in the sense that I don't feel great uncertainty, the uncertainty of 'I wonder if this will turn around or I hope that this might happen'. All those things that cause you to be emotionally unsettled are not happening any more... (FC5)*

*... it struck me that it should be just a standard issue for all facilities to have this discussion regularly, and it surprises me in a way that it has to go through a researcher like you to suggest that this is what happens... (FC9)*



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## **Talking about dying and dementia**

**Does not happen routinely**

**Is not 'common sense'**

**Takes time, practice, and skill**

**Offers great potential to enhance remaining  
quality of life of PWD and their families**

# Wicking Dementia Research & Education Centre

**THANK YOU**

<http://www.utas.edu.au/wicking>

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