Talking About DEMENTIA And Dying

A Discussion Tool For Residential Aged Care Facility Staff

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Overview: Talking about dying with relatives and friends of people with dementia

This discussion tool deals with the issue of dying from dementia in a residential aged care facility. It is a resource to help people working in facilities to openly communicate with people with dementia and their families and friends about death and dying. Talking about dying is often difficult and this tool provides guidance for those who would like to improve their skills.

In the following guide you will find:

- Part 1: **Why** it is important to talk with families and friends about dying
- Part 2: **When** to talk with families and friends about dying
- Part 3: **What** to do when talking with families and friends about dying and **How** to talk about dying
- Part 4: **AFIRM** provides suggestions for more spontaneous conversations about dying
- Part 5: Some additional tools that might be useful prompts in your facility

Part 1: Why talking about death and dying with the families of people with dementia is important

Dementia is a terminal illness.

Many people are unaware that dementia is a terminal illness and this is partly because there has been little information on this topic until recently. One reason for this is that the person with dementia can decline so gradually that people do not link their eventual death with dementia. As people decline with dementia they are likely to have episodes of acute illness caused by infections, from which they only partially recover, so each illness causes further decline in function. Recent studies though are confirming that dementia causes death[1-2]. With this information we can provide more appropriate care for people with dementia, even when it is difficult to recognise that end of life is near.

A palliative approach to care.

A palliative approach gives the most appropriate type of care for people with dementia at any stage of the illness. It should definitely be the focus of care by the time a person reaches advanced stages of dementia. In the advanced stages of dementia, the person will likely be unable to recognise people and objects, have difficulty communicating, be increasingly chair or bed-bound, need assistance to dress, wash or feed themselves and may experience pain, sleep disturbances, incontinence, confusion, and depression[3]. At this point, death may be weeks or even several years away, but the resident will still benefit from a palliative approach.

A palliative approach to care means a focus on:

- The overall quality of life
- Reducing suffering by early recognition and treatment of pain and other distressing symptoms
- Affirming life and treating dying as a normal process
- Caring for spiritual, psychological and cultural needs as well as physical needs
- Offering a support system to help the family cope during their relative's illness and in their own bereavement
- Using a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
  (List adapted from Gold Standard Palliative Care Community Project 2010)

Preventing inappropriate care at the end of life

Unfortunately care for people with dementia often does not follow a palliative approach, even at the end of life. For example, aged care facility residents with advanced dementia are frequently hospitalised, despite the increased risk of delirium and distress and lack of evidence of any treatment benefit. Other burdensome interventions (such as multiple medications) may be used and symptoms such as pain, dyspnoea, and agitation poorly controlled[5-6]. This type of end of life care comes about partly because of a lack of understanding that dementia is a terminal illness. As a result, families can become distressed as they see their relative deteriorate and feel unsure about the best care. This makes it difficult for them to make decisions about whether treatment options may be overly aggressive or unnecessary. Overall, families feel less burdened by care decisions and people with dementia have less burdensome interventions when families understand the course of advanced dementia[6]. This is a good reason to make sure that all those caring for the person with dementia - including families - understand that dementia is a terminal illness and that the best care will focus on a palliative approach.

Part 2: When to talk about dying for the person with dementia

When should we talk about a palliative approach with carers and family?

There is no clear indication for when talking about a palliative approach with carers and families is most appropriate. But because a palliative approach to care means a focus on comfort and quality of life there can be advantages for the person with dementia even if they are not close to death. For example, there may be an aspect of care that the resident finds distressing, such as swallowing large tablets. Residents and relatives can weigh up the advantages and disadvantages of the medication with overall comfort and quality of life as the main outcome. This discussion tool works on the assumption that good communication and information sharing between staff and families will help families to make appropriate care decisions that prioritise the interests, comfort and dignity of their relatives, and help families deal with grief and loss.

How long will the person with dementia live?

We know that dementia is a terminal illness, but we still do not know enough about dementia to be able to tell people with dementia, or their families, what their life expectancy is. While many family members will ask 'how long have they got' we need to make it clear that the life-span of someone with dementia is very varied. At best we can offer some statistical averages, and once people with dementia deteriorate to an advanced stage we can be sure they are in the final years of life. People with advanced stages of dementia are closer to dying than people with early stage dementia, and people with a rapid course of deterioration will not live for as long as people with a slower course of dementia.

Below are some statistics that might help you understand that dementia is a life-limiting illness:

The average survival time for dementia is 4.5 years[7] but many people live for 8 years and some for 20 years after diagnosis:

- Half of the people with advanced dementia will die within 1.3 years[2]
- One quarter of those with advanced dementia will die within 6 months[2]
- Most people with advanced dementia do not die from devastating acute events, such as heart attack[2]

Three important influences on dementia life-span are the type of dementia, the stage of dementia, and whether the course of deterioration is rapid or slow[2,7]. These, along with other illnesses, all impact on how long the person with dementia will live and make it impossible for you to predict a life-span when planning care or talking to patients or families.

Part 3: What to do and how to talk about dying

This section explains **WHAT** you can do to talk with people with dementia and their families about the terminal nature of dementia. It also provides some helpful phrases that suggest **HOW** you can talk about the dementia trajectory and the need for a palliative approach to care while being both frank and compassionate.

Nine Key Steps to holding a conversation about dying

We suggest the following key steps to holding a meeting about dying with families and friends of the person with dementia. There may be other times though where the full process cannot occur, or you may already be comfortable with your own process. Looking over the steps can, however, help you to make sure that you are meeting the key emotional and information needs of families and friends as well as your own support needs. The following pages provide details with suggested wording to match each step.

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

Some communication tips

Talking about dying is a sensitive matter and requires good communication skills. We suggest you keep in mind the three A's of communicating sensitive information as you talk about dying[8-9]:

a. Allow space for silence

b. Acknowledge your own emotions and help the family to give a name to emotions if they appear shocked, angry or relieved using reflective language

c. Answer any questions

What to do – the discussion process	*How to talk about dying – suggested wording*
1. Prepare ▶ Organise to have enough time for discussion ▶ Ensure a suitable meeting space with privacy and no interruptions ▶ Make sure the discussion is being held with the right person/people (i.e. consider the cognitive capacity of the person with dementia, check who is the responsible or contact person). Check with the family who they think should be present ▶ Consider who needs to be present from the facility ▶ Ask the family to write down any questions they have to bring to meeting ▶ Know your own feelings about dementia and dying	**1. Prepare** ▶ As part of our normal care planning, [I/We/the RACF] would like to invite you and any family members you would like to include to meet with me/us to discuss [your relative's] condition and care ▶ From the facility we expect [list people expected] to attend ▶ If you have any questions you would like to ask about this, can you write them down and bring them along, as it will be an ideal opportunity to talk about them
2. Introduce ▶ Introduce yourself and everyone present if necessary and outline purpose of meeting and ask what family would like to achieve ▶ Ask the family what questions they have, write them down and assure them they will be dealt with before end of meeting	**2. Introduce** ▶ Thanks for coming in today. From my point of view, for the next 30/60 minutes we want to talk about how [your relative] is doing and what we think might happen in the next 12 months, so that we can plan together to give the best care ▶ Did you have any things that you wanted to talk about at this meeting? I'll write them down and make sure that we answer them before the meeting is over
3. Ask ▶ Ask the family to tell you about their relative: their illness, past life, personality	**3. Ask** ▶ Tell me about your (dad, mum, sister, brother, friend, etc.). What has been happening to them, what sort of person are they, what was their life like up to now?

4. Flag ▶ Provide a 'red flag' warning if family story indicates they are unaware of dementia diagnosis or trajectory	**4. Flag** ▶ We know that [your relative] has dementia and this has serious consequences
5. Inform ▶ Outline the diagnosis of dementia and the implications for cognitive and functional decline ▶ State the facts simply and use plain language ▶ It helps to explain that dementia is a disease of the brain, for example ▶ Discuss the prognosis frankly. Outline the trajectory of dementia and what is known about average life span after diagnosis. ▶ Be honest about the amount of uncertainty	**5. Inform** ▶ Dementia results from a progressive shrinking of the brain ▶ People with dementia live for different lengths of time, but we know that it is a terminal illness with life-spans of 5-10 years ▶ People with dementia differ in how quickly they are affected by the disease, but we know their abilities will decline. As dementia progresses many body functions are affected and people lose the ability to walk, talk and swallow normally. This means they are more at risk of problems such as pneumonia, or other infections, malnutrition and weight loss ▶ We have noticed that lately your relative has not been eating or drinking as much and is losing weight/We have noticed lately that your relative doesn't like to get out of bed as much and seems to sleep a lot more. This/these are signs that dementia is advancing
6. Allow ▶ Allow space for emotions and acknowledge strong emotions. Families and the person with dementia may not have heard such information before. Help the family to give a name to their emotions if they appear shocked, angry or relieved, using reflective language	**6. Allow** ▶ To break the silence or acknowledge strong emotions you can say something like – I wish the news was different/or I wish the situation was different ▶ I can see that you are upset...

7. Discuss	7. Discuss
▶ This step may occur at a second meeting, depending on how family members respond to the discussion about dementia ▶ Discuss care needs and the focus of care by linking to the family's story of their relative ▶ Discuss goals of care with family and ask family about their care wishes or any expressed by the resident/person with dementia – understand what the family hope for and attempt to reach a consensus ▶ These hopes and wishes can be turned into documented goals for care. Goals of care must be shared throughout the facility ▶ Encourage the family to visualise what different care and treatment courses would be like – present benefits and risks evenly. Be specific if appropriate about antibiotics, admission to hospital, etc. Focus on care goals – keeping relative comfortable, happy, engaged – and draw distinction between life saving and palliative care ▶ Discuss specifics of end of life care and limits of treatment if appropriate at this meeting or schedule further meeting to discuss. Goals of care must be shared throughout the RACF. Encourage the family to visualise what different care and treatment courses would be like – present the benefits and risks evenly. Be specific, if appropriate, about feeding tubes, or admission to hospital, for example	▶ Given what we know about dementia and your relative's condition, we need to think about providing care that keeps them comfortable as they become more frail ▶ Given what we know about what your relative is up against, it would help me if I could hear from you what you are hoping for, what you are worried about and what you would like to see happen ▶ What do you think your relative would want for their care as they approach the end of their life? ▶ Let's write down some of those things so that we can make sure they are an important focus for the care we provide at the facility. While dementia can't be cured, here at the facility we can do everything possible to make sure that your relative has the best quality of life, and that their comfort and dignity are maintained as the dementia progresses ▶ If your relative continues to lose weight/to be sleepy or inactive/gets another chest infection...

8. Ongoing Dialogue ▶ Answer any questions. Check how information has been understood ▶ Discuss next meeting to discuss further or answer any questions	**8. Ongoing Dialogue** ▶ I think we should organise to meet again if you have any more questions, and that we should meet every 3 months anyway to discuss your relative's condition ▶ If you think of any more questions between now and our next meeting please call me or ask for me at the office
9. Self-care ▶ Acknowledge your own emotions to yourself and a colleague – preferably as soon as possible, within minutes	**9. Self-care** ▶ That was upsetting; when I spoke to Mrs M about her husband's dementia she was very upset. I found her grief really difficult to handle/really distressing

Adapted from Derksen et al. (2006) and Feudtner (2007).

Part 4: AFIRM with Spontaneous Conversations

Ideally, all family members would have the opportunity to attend a family meeting to discuss issues of death and dying. However, we know that not all facilities offer family meetings, and that even if they are offered not all family members will come. Therefore it is likely that all staff will find themselves being asked questions about prognosis, decline and best care options by family and friends. These questions might come in the corridor, on the phone or by the bedside and are often directed to care assistants who have the most contact with family.

Many staff feel uncomfortable with spontaneous questions and do not want to give answers which might upset the family member, or talk about things they are unsure of. For example, a concerned daughter might comment 'Mum doesn't seem to want any lunch today', and receive an evasive response like 'Oh well, she might eat something at tea time'. Such responses can leave relatives concerned about the quality of care and do not allay fears. If in reality, the resident is increasingly eating less due to advancing dementia, then the daughter's question is an ideal opportunity to begin a dialogue about the course of dementia, and death and dying. Relatives and carers with better knowledge are likely to be less anxious. In this case, you may prefer to provide a brief answer; the AFIRM process below is helpful in these situations. It is important as with all conversations about residents conditions to make sure you know who you are talking to – is it a relative, a friend, or an acquaintance? Clearly an immediate family member would receive more information, and an acquaintance would be best directed to ask family members. It is also important that you make sure you know if the resident has a diagnosis of dementia.

What do you need to consider?

Many staff are afraid to answer questions directly in case they 'say the wrong thing'. Here are some suggested processes and examples of what to say that will allow you to deal with spontaneous conversations without 'saying the wrong thing'. We call this the **AFIRM** response:

- **A**cknowledge concerns
- **F**ind out what the relative knows about the resident's condition
- **I**mmediate concern addressed – Provide an appropriate and factual response to the question
- **R**espond to subsequent questions – continue to provide factual responses that are within the scope of your work role
- **M**eeting arranged. Suggest that you can arrange a meeting for them to discuss their relative's condition with the Registered Nurse or other relevant person, such as the GP

Example 1: Mr Booth

Mr Booth has been a resident in the 'secure dementia unit' 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.

You are the care assistant looking after Mr Booth when his son Paul comes to visit. Paul stops you in the corridor to ask you whether his father is eating enough as he seems to be losing weight. You know that Paul is Mr Booth's son and a regular visitor, but you aren't sure that he knows about Mr Booth's diagnosis.

Your response:

Acknowledge concerns – *Your father is certainly eating less now.*

Find out what he knows about his father's prognosis – *What have you been told to expect about your father's condition?'*

Immediate concern addressed – *We know that your father has dementia, and that difficulty with eating is a major factor in the progression of dementia. We have several strategies to help your father eat, but we know that it is more comfortable for him to eat only when he feels like it.*

Respond to further questions – *Yes, your father is walking less too, but that is also part of the progression of dementia.*

Meeting suggested – *Given that your father's condition is changing, it would be a good time for you to discuss his future care needs with nursing staff, so that we can plan the best care for your father. It would also be a good time for us to answer any questions you have about your father's condition. Would you like me to organise a meeting?*

Example 2: Mrs Wilson

Mrs Wilson has lived in the residential aged care facility for two years and has moderate stage dementia. She has had three falls in the last month while walking around the facility and her husband is becoming very concerned. You are the RN on duty and he stops you in the corridor after hearing about the latest fall. Mr Wilson says his wife needs further tests to ascertain why she was falling, thinking that perhaps it is due to her Parkinson's disease and that something could be done about it.

Your response:

Acknowledge concerns – *Your wife is certainly falling fairly often now.*

Find out what he knows about his wife's prognosis – *What have you been told to expect about your wife's condition?*

Immediate concern addressed – *We know that your wife has dementia a well as Parkinson's disease, and that falling is often a major factor in the progression of dementia. We have several strategies to help protect your wife, but we don't want to stop her from being able to walk around while she is able.*

Respond to further questions – *Yes your wife is walking less too, but that is also part of the progression of dementia.*

Meeting suggested – *Given that your wife's condition is changing, it would be a good time for you to more fully discuss her future care needs with nursing staff, so that we can plan the best care for her. It would also be a good time for us to answer any questions you have about your wife's condition. Would you like me to organise a meeting?*

Part 5: Additional tools

Accessing additional resources

You may want to look up further information about some of the topics covered in this discussion tool. Some valuable websites and tools we have found include:

Palliative Care

Palliative Care Australia – For up to date information on palliative care and care standards www.palliativecare.org.au

ACH Group – For a useful resource kit on planning palliative dementia care www.ach.org.au/site/page.cfm?u=469

Communication

Clinical Practice Guidelines – For clinical practice guidelines for communicating about death and dying with patients and families www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html

Advanced Care Planning

The Royal Australian College of General Practitioners – For useful state-based links www.racgp.org.au/guidelines/advance care plans

Dementia

Alzheimer's Australia – For helpful information on dementia and advice for families www.alzheimers.org.au

Department of Health and Ageing – For helpful information on quality dementia care http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide-2009-toc.htm~ageing-dementia-resource-guide-2009-9.htm

Helpful prompts to embed changes into normal practice

On the following page you will find a Discussion Checklist that has been designed to be used as part of your facility's normal record keeping. The Discussion Checklist will help you to keep a record of what has been discussed with families and friends for the person with dementia. A new Discussion Checklist can be completed either on a regular review basis, or on an as needs basis, depending on the facility procedures.

On page 18, you will find a diagram that shows the key steps in 'communicating bad news'. While this was developed specifically to prompt staff in acute care systems, it provides a quick reminder about the process of talking about dying. (Thank you to Chris Feudtner for granting us permission to use the guide.) Depending on how relatives respond to the discussion of dying, care planning may occur at the same meeting or at a later meeting.

Discussion checklist - dementia and a palliative care approach

Resident's Name .....

Meeting Date .....

Attended Meeting .....

- Meeting arranged with relevant family members ☐
- Family aware of dementia diagnosis and prognosis ☐
- Deterioration of relative discussed ☐
- Difference between palliative care and life preserving care discussed ☐
- Advance care plan developed/Statement of Wishes ☐

Discussed:

- Nutrition and hydration ☐
- Infections ☐
- Place of care ☐
  - End of Life/Advance Directive and care plan completed ☐
  - Facility staff aware of care plan and directives ☐

Staff Member's Name .....

Signed .....

A diagram to prompt discussions about death

BAD NEWS

PREPARE

- MAKE A PLAN
- GET THE SETTING AND PEOPLE RIGHT

Visualize how you will do this

DELIVER

- BRIEFLY RECAP THE SITUATION
- PROVIDE A WARNING SHOT
- STATE THE BAD NEWS SIMPLY
- ALLOW SILENCE
- ACKNOWLEDGE EMOTION
- ANSWER QUESTIONS

This is important

Be forthright and straightforward

I wish ....

FOLLOW-UP

- FORMULATE A NEXT-STEP PLAN
- LEAVE BUT DO NOT ABANDON
- *FOR YOU*: DEBRIEF WITH SOMEONE

Simply state what will happen next

Chris Feudtner, 2007

How can I tell if the person is getting closer to the end of life?

There are some indications that a person with dementia may be getting closer to the end of life. These indicators may be useful to think about before starting a discussion with relatives about the course of dementia and the complications often associated with its progression

- If in last six months the person with advanced dementia has had:
  - A febrile illness, they have a 44% chance of dying within 6 months
  - Pneumonia, they have a 46% chance of dying in the next 6 months
  - Difficulty eating/drinking, they have a 39% chance of dying in the next 6 months
- If the person with advanced dementia is experiencing an increase in the following distressing symptoms:
  - Dyspnoea
  - Agitation
  - Pain
  - Pressure ulcers
  - Aspiration[2]
- If the answer is NO to the following question – Would you be surprised if this person were to die in next 6-12 months?

Specific indicators for approaching end of life for people with dementia

- Unable to walk without assistance
- Urinary and faecal incontinence
- No consistently meaningful verbal communication
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform ADLs
- Plus any one of:
  - 10% weight loss in last 6 months without other causes
  - Pyelonephritis or UTI
  - Severe pressure sores
  - Recurrent fevers
  - Reduced oral intake/weight loss
  - Aspiration pneumonia

(Adapted from the Palliative Care Information Guide[3])

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Notes

Notes