Death and dying in dementia care: a good end?

Rosalie Hudson explores a range of issues that shape care practices to support a person dying with dementia, including ethical decision making, language, pain management and the place of hope, and offers some guidance in response

Many health professionals are unaware that dementia results in death. Failing to acknowledge it as a life-threatening condition results in sub-optimal support for the dying person and their family. Families may also have limited awareness of dementia's outcome, reducing their preparedness for death. When general practitioners (GPs) show a limited understanding of dementia as a terminal illness, their care of people in the advanced stages is compromised. Medical undergraduates may receive a one-hour lecture on dementia, hardly equipping them for exposure to the disease in hospitals, residential aged care homes or the community.

Dementia is the second highest cause of death, next to heart disease, and for women it is the most common cause of death (Dementia Australia 2018). What does this significant knowledge deficit mean for the person dying with dementia and their families? What kind of care and support will they receive? This article raises some of the urgent issues needing to be addressed and offers some guidance in response.

Diagnosis

One way of introducing appropriate care and support for a person dying with dementia is for professional carers to note what constitutes their diagnosis of dementia. When and by whom was this diagnosis made? Has the diagnosis been confirmed and by what means? What type of dementia is it? What information has been given to the family? Do staff understand the significance of the different types of dementia and the associated prognoses?

In a recent interview, the co-chair of the US Alzheimer's Association Diagnostic Evaluation Clinical Practice Guideline workgroup noted, "...there is data to show that upwards of half the people who end up in nursing homes that are in later stages of dementia actually have never been given a formal diagnosis. That's not right," (Medscape website 2018). Unless these discussions are initiated by health professionals, many people with dementia and families miss the opportunity to recognise the dying trajectory and to plan for a dignified death.

On the other hand, knowing the facts about each person's specific dementia diagnosis and type can influence a more comprehensive process, particularly in residential aged care homes where many people with advanced dementia are cared for. Families can be educated, with written material provided in their own language if relevant. Regular education sessions may be offered to staff and families. This is not to suggest the focus should be on death from the time of the person's admission. However, if opportunities for timely discussion are missed, families may remain uninformed about options for end-of-life care. Without such information comments such as the following may be heard:

- "You don't die of dementia."
- "She's no longer a person."
- "She'd be better off dead."
- "His life's not worth living."
- "For me, she died many years ago, when she lost her mind."
- "Shoot me if I ever get like that!"

What is conveyed by these statements? For example, how would the last statement affect the care of a frail older person with dementia? If I think this person would be better off dead, would I be prompted to provide the very best care possible, or would I begrudge the effort?

Does the plea, "Shoot me if I ever get like that!" really mean I would prefer to be murdered than cared for? Similarly, if I think such a person should be shot, there is no allowance for compassion or holistic end-of-life care.

When an elderly female partner of a person with advanced dementia says: "He's no longer a person", what does this convey? How may she be encouraged to consider him, not as inhuman, but still a person despite his deficits? What remains? How does she know he cannot hear her, or know she's there? What prompts may she be given to reassure her that her presence may still have meaning, particularly at the end of his life?

I know of a gentleman who had been caring for his wife at home for many years, as her Alzheimer's disease slowly progressed to the stage where there was no alternative to aged care home admission. The nurse checking the admission details asked the gentleman about visiting his wife, suggesting that he must now be exhausted after his years of care. "It's time for you to have a break now", she said, hoping to be reassuring. "Your wife won't know whether you've visited or not, she no longer knows who you are, so why don't you come less often?" His response was to remind the nurse very gently, "She may not know who *I* am, but I know who *she* is."

Language for death and dying

The commonly used term 'pass away' is often shortened to 'pass' or 'passed' or 'passing'. "I'm ringing to tell you your father has just passed," said the night nurse to the nursing home resident's son. "Passed *what*?" he replied, not understanding the ambiguous message. Or, using another euphemism, a nurse with no knowledge of the family circumstances said to the patient's wife: "I'm so sorry to be ringing you at this hour, but your husband has *gone*". "Gone *where this time?"* was the frustrated response from the person who had lived with her husband's "wanderings" for more than 10 years. While society in general appears reluctant to speak of 'death' or 'dying' or 'died', the use of various euphemisms by professional staff can easily lead to misunderstanding. Such outcomes are compounded when there has been no attempt to prepare families for the person's death. As death for a person with dementia seldom occurs suddenly, opportunities should be given for careful planning, including frank discussion of death and dying.

Palliative care

Palliative care, when understood in its entirety, has hopeful connotations for those dying with dementia. When palliative care was first introduced, it only applied to people with cancer; it now encompasses people living with any incurable illness, including dementia (van Riet Paap *et al* 2015). Furthermore, it is not generally understood that people dying with dementia have symptoms similar to those dying with cancer (Cole *et al* 2006). The result of this misunderstanding is that many people die without hope, their basic needs unmet. Similarly, families are not always informed about the terminal nature of dementia and the benefits which can ensue from palliative care (Hudson & O'Connor 2007). For example, such discussion may include the issue of inappropriate admission to hospital and the use of other overly aggressive or futile treatment.

Palliative care is often regarded as care in the final days or hours of life ("We'd better call in the palliative care team. She looks as though she won't last the weekend!"). With thoughtful, comprehensive planning a palliative approach to end-stage dementia care can be offered well before the dying phase. Such an approach, which may include pain relief, how or when to offer food and fluids and other issues of palliation, does not necessarily involve a specialist palliative care team – it is the *approach* that counts.

This approach asks: what are the goals of this person in this situation? It is an approach that prepares families for the uncertainties of prognosis and empowers them with knowledge of what is available. What preferences are outlined in this person's Advance Care Plan? Rather than wait until death is imminent, it is good practice to involve the family in a meeting to discuss the goals of care, in enough time for effective planning. If this is well documented, commonly heard disputes can be avoided, such as: "I think mum should go to hospital." "Well, I don't! I know she'd much rather stay here!"

Palliative care does not mean ceasing all treatment, as some believe, or the excessive use of opioids. Families need education about the inclusive nature of palliative care which focuses on the holistic needs of the person, including psychological and spiritual care as well as physical.

Pain management

Prominent in the research literature is the lack of adequate pain management for people with end-stage dementia. It is frequently undetected or inaccurately assessed, particularly in those who cannot verbally report their pain or point to its intensity on a visual analogue scale. While people with dementia have similar painful comorbidities as an older person without dementia, their pain is not readily acknowledged because they have no words to describe it. Does this mean they have less pain? Failure to adequately address pain management in end-stage dementia care is an urgent ethical issue. While it is difficult to assess the level of pain in a person without speech or with seriously impaired cognition, it is unethical to ignore it. One way of addressing this issue is to use readily available assessment tools designed especially for those with poor cognition or no speech (The Australian Pain Society 2018).

Family involvement

Verbal reports I've received indicate that some families of people with dementia are not receiving enough relevant information. One person had the courage to articulate her anger when she realised what she had *not* been told, relating to the imminent death of her father. Sadly, this lack of knowing the facts and lack of involvement in decisions resulted in a less than optimum dying process for her father. Who is responsible for these discussions? If nobody is responsible then, more than likely, there will be no discussion. Consequently, more and more families are left with no opportunity to ask questions, let alone receive answers. A key point in any context where a person with dementia is being cared for is to raise the question: 'Who will speak with the family, and when?'


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Quality of life

"She's got no quality of life" is a judgment frequently made not only by family members but also by some staff in hospitals or aged care homes. Families may be told there is little or no hope for improvement in quality of life. "She can't do anything for herself" may belie the truth that this person, albeit with end-stage dementia, may still be able to turn the pages of a magazine, or lift a glass of brightly coloured drink to her lips, or respond to music using headphones. With comprehensive information from family members and imaginative care planning, many against whom this judgment is made may exhibit surprising signs of remaining 'quality' in their lives.

Person or non-person

Sabat (in Sabat & Harre 1992, p444) questions whether a person with dementia can be described as someone who has suffered 'loss of self' or personhood. He maintains, "...there is a self, a personal singularity, that remains intact despite the debilitating effects of the disorder...". In other words, the social and publicly presented person can be 'lost' but only *indirectly* because of the condition. Sabat believes one of the main problems is with those who do not have dementia, who generally regard the person with dementia as 'helpless' or 'confused'. He says that we place the person with dementia in jeopardy when we 'label' them according to our criteria. For example, why do we describe a person with dementia as 'wandering aimlessly'? If the same person chose to sit and flip through a magazine would she have been described as being engaged in 'irrational or aimless reading'? Sabat maintains that the self of personal identity "remains intact even in the face of quite severe deterioration in other cognitive and motor functions" (1992, p459). This distinguished dementia researcher counsels his readers not to make assumptions about quality of life or loss of personhood or general incapacity based on our own criteria. We should not, therefore, assume the person with dementia has 'lost their mind'.

Palliative care resources

Palliative Care Needs Round Checklist (Palliative Care Australia 2017) is a simple, easy-to-use checklist for palliative care needs rounds that can help improve the quality of life and death for nursing home residents. The evidence-based checklist was based on data, descriptions and interviews which captured what occurred during monthly palliative care needs rounds. Available at: http://bit.ly/roundchecklist

The Palliative Care Evaluation Tool Kit (Centre for Health Service Development, University of Wollongong 2004) is a compendium of tools to aid in the evaluation of palliative care projects. Available at: http://bit.ly/evaluationtoolkit

End of Life Directions for Aged Care (ELDAC), a government-funded initiative that aims to connect people working in aged care to palliative care and advance care planning information, resources and services, has developed five online toolkits providing the latest clinical evidence, learning opportunities and tools to support palliative care and advance care planning. Available at: www.eldac.com.au

palliAGED provides links to palliative care evidence and resources for aged care professionals which may inform discussions and practice around decision-making, communication and assessment for people with dementia approaching the end of their life. Available at: www.palliaged.com.au/tabid/4248/Default.aspx

CareSearch Palliative Care Knowledge Network: provides information about palliative care for patients, carers and families as well as for health professionals. Topics for health care staff include common care issues at the end-of-life and communication skills for end-of-life discussions. Available at: www.caresearch.com.au

Advance care planning in aged care: a guide to support implementation in community and residential settings (Advanced Care Planning Australia April 2018): free to download at: http://bit.ly/acpaguide

Palliative Care NSW has online resources to educate and equip professionals, volunteers and the community about palliative care. Available at: www.palliativecarensw.org.au/new/get-equipped/resources/

Many readers will be familiar with the writing of Tom Kitwood, with his specific emphasis on the *personhood* of the human being with dementia. In one of his earlier articles he states: "The presence of dementia on a large scale in contemporary society, and the dire process which it often entails, raises very deep questions about what it means to be a person" (Kitwood & Bredin 1992, p270). According to this account, the personhood associated with dementia is deeply paradoxical. On one view, he or she is and will remain a person while many factors indicate their personhood is diminishing. According to Kitwood and Bredin the answer lies in relationships, for, they say, "...interdependence is a necessary condition of being human" (p284).

Christine Bryden, speaking from first-hand experience as a person living with dementia, raises questions about death and dying from the depth of her own existential crisis. On the question of dying with dignity she asks: "Will I have any personal resources left within me to deal with it?" (2016 p273). In this text and several others, Bryden emphasises the need for people with dementia to have their personhood sustained by relationships with others. "Like you", she says, "we are human beings with emotional and spiritual needs. We are more than mouths to be fed, bodies to wash and clothe... Help us find meaning and affirm our humanity as death approaches" (p190).

Who is this person?

To emphasise person-centred care it may be helpful for aged care homes to provide a short, well-written profile of each resident with dementia, accessible to all staff members. Examples abound to demonstrate how knowing the person's background can help staff to understand that person's behaviour. Staff at one aged care home had no idea a resident whose obsession with managing/organising was related to her academic doctorate in public policy; she had been a distinguished people manager. Another resident panicked when he heard the meal bell – staff had not realised he'd been a fire fighter and he assumed this was his call to action. Another resident was labelled as cantankerous and loud-mouthed until it was explained she had been a prominent civil rights activist, often using her loud voice at protest rallies. Such narratives are important in helping to craft a person-centred care plan which acknowledges the uniqueness of each person's life. Here's another example:

A former professor of music, Frank's favourite instrument was the flute. He now lay in his care home bed with no speech, little independent movement and his hands always tightly clenched, fingers separated by carers with great difficulty. His wife had an idea! She brought him his beloved flute and placed it on his chest. Slowly, but very purposefully, Frank uncurled his fingers and caressed the flute. Would this action have been an appropriate inclusion in his daily care plan?: *'Spend a few minutes several times per day encouraging Frank to hold his flute'*. Unfortunately, this expectation was beyond the capacity of the care home's routine. Fortunately, his wife had access to a musician who would visit regularly and play the flute for Frank, encouraging him to hold it afterwards. Frank remained connected to his flute until close to the time of his death.

These examples indicate the scope of imaginative, personalised care that can be offered to a person dying of dementia. However, the move from ideas to everyday care requires sensitive leadership from those who have a comprehensive knowledge of advanced dementia and the difference such knowledge can make for the dying process.

Leadership in dementia care

Poor leadership in dementia care results in increased stigma, lack of attention to detail and lack of sensitivity to the unspoken and therefore unmet needs of people with dementia in any care setting. Lack of appropriate leadership also results in poor decisions at the end of life, and little understanding of a palliative approach for end-stage dementia. When the management team pay little regard to education, careful recruitment and identifying and correcting shortcomings in care, the result can be devastating for the person dying with dementia and their family.

On the other hand, when continuous education is the focus, such knowledge can translate into comprehensive, person-centred care. Most relatives have had little education in the complex nature of dementia. When, for example, the aged care home takes proactive steps to address this anomaly, there is increased potential for excellence in end-of-life care, both for residents and their families.

When staff are valued, incentive is accentuated: "Marj, I noticed how kind you were when speaking to George this morning. Even though he may not understand I'm sure he appreciates that you care about him." Alternatively, when poor care is identified: "Marj, I heard you refer to George in rather derogatory terms. You may assume he does not understand, but to respect his basic human rights, you should always speak kindly to him and about him."

Lingering memories

Dame Cicely Saunders, founder of the modern hospice movement, knew better than most of her medical colleagues the qualitative difference humane bedside care could produce. She had, personally, kept vigil at hundreds of bedsides, leading her to observe: "How people die remains in the memory of those who live on" (cited in *BMJ* 2013).

In whatever role we undertake we have the capacity to focus on important ethical issues, doing all in our power to influence a dignified death and dying for those in our care. While people dying with dementia suffer significant memory loss, carers whose memory is intact can influence the memories of those who live on. ■

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