Palliative and end of life care for people living with dementia in care homes: part 1


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Abstract

The terms palliative and end of life care are often used interchangeably and healthcare practitioners may perceive that palliative care is only appropriate during the terminal stages of an illness. This article, the first of two parts, provides healthcare practitioners with an overview of the concept of palliative care. It explains how this can be differentiated from end of life care and how it should be commenced in a timely manner, so that people who are living with dementia can contribute to the planning of their future care and their death. The policies and tools used in the provision of palliative and end of life care are discussed, including advance care planning and The Gold Standards Framework. The article is framed in a care home context; there is little research about how to optimise palliative care for people living with dementia in care homes. The second part of this article will discuss end of life care and the best practices for providing end of life care, including nutrition and hydration, oral hygiene, pain management and spiritual care.

Keywords
advance care planning, care homes, communication, dementia, end of life care, holistic care, older adult care, palliative care, person-centred care

Aims and intended learning outcomes

The aim of this article, the first of two parts, is to provide care home practitioners with an overview of the policies and tools involved in the delivery of palliative and end of life care for people with dementia living in care homes. After reading this article and completing the time out activities you should be able to:

- Differentiate between palliative care and end of life care.
- Discuss the provision of dementia care in care homes and the trajectory of dementia.
- Explain how to commence or continue palliative and end of life care for people living with dementia in a care home.
- Outline the policies that can be used in planning palliative and end of life care.
- Discuss the importance of advance care planning for people with dementia and explain what is involved.

Introduction

The ethos of palliative care places the person at the centre of their care. Dame Cicely Saunders said ‘you matter because you are you, and you matter until the last moment of your life, and we will help you not only to die peacefully, but to live until you die’ (Saunders 1976). The World Health Organization (WHO) (2012) defined palliative care as: ‘An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

It is estimated that every year more than 20 million people worldwide will require palliative care at the end of their lives. 69% of these people are over 60
years old, indicating that the majority of palliative care is delivered to older people, particularly those living with cardiovascular diseases, cancer, chronic obstructive pulmonary disease (COPD) and dementia (WHO and Worldwide Palliative Care Alliance (WPCA) 2014). The terms palliative care and end of life care are often used interchangeably in clinical practice (Russell 2015). However, it is important to note that palliative care differs from end of life care. Palliative care relates to the entire patient journey of people who are living with an incurable illness, and should begin when the illness is no longer curable. It is appropriate for all people who are living with an incurable illness and reflects the concept of person-centred care (Mitchell 2015). End of life care is a continuation of palliative care, and should commence when an illness has advanced sufficiently that death is near. ‘End of life care’ is used to describe care for people who are thought to be approaching death within 12 months (The Gold Standards Framework Centre CIC 2011). The primary aim throughout end of life care is to enable the person to feel comfortable, and to attend to their needs and wishes as the end of their life approaches (Kelly and Innes 2010).

Palliative and end of life care policies
This article has been developed on the basis of the following central policy documents: the End of Life Care Strategy Promoting High Quality Care for All Adults at the End of Life (Department of Health (DH) 2008) for England and Wales; Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland for Scotland (The Scottish Government 2008); and Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland for Northern Ireland (Department of Health, Social Services and Public Safety (DHSSPS) 2010. These policy documents are reflected in the National Institute for Health and Care Excellence (NICE) (2011) End of Life Care for Adults Quality standard. These policy documents share the following conclusions:

- Some people die as they would have wished, but many do not. Many people do not die in the place they would choose to; many do not receive quality care at the end of their lives and there are reports that people have not been treated with dignity and respect.
- End of life care has had a relatively low profile in the NHS and in society, leading to variability in access to end of life care and the quality of end of life care throughout the UK and in different communities.
- People are uncomfortable talking about dying and death. This means that friends or family are often not aware of a person’s end of life preferences, when people come to the end of their lives.

Everyone deserves ‘a good death’ and this is more likely to be achieved by discussing it early on (DH 2008, The Scottish Government 2008, DHSSPS 2010, Wales Palliative Care Implementation Board 2010). Every individual will have a different idea about what would constitute ‘a good death’ for them. This may involve (DH 2008):

- Being treated as an individual, with dignity and respect.
- Being without pain and other symptoms.
- Being in familiar surroundings.
- Being in the company of close family and/or friends.

Dementia in care homes
There are over 17,500 care homes in the UK, which provide long-term care to around 500,000 people (Laing and Buisson 2013). Approximately 80% of these people have dementia (Alzheimer’s Society 2013). However, this is an estimate since dementia can be difficult to identify and many people are not formally diagnosed (Mitchell et al 2013a, Mitchell et al 2013b). The majority of research and development of palliative and end of life care takes place in hospital settings rather than care homes. The British Geriatrics Society (2011) asserted that the health needs of older people in care homes are often not
adequately met by the NHS, and that the independent sector is required to deliver this care, sometimes without direct assistance or guidance from specialist hospital-based teams.

The development of evidence-based practice was a central recommendation of the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis 2013). This is central to improving clinical outcomes for residents in care homes (Mitchell and Strain 2015). In response to the requirement for evidence-based practice and acknowledged deficits associated with palliative care for people with dementia, this article aims to provide care home nurses with an overview of optimal clinical practices which should be adopted to improve the palliative care provided to residents living with dementia in care homes.

Illness and palliative care
Historically, hospices and palliative care programmes have focused on the needs of people living with cancer. It is now recognised that the majority of people who require palliative care are diagnosed with non-malignant conditions (WHO and WPCA 2014). However, palliative care is still mostly associated with treatment of advanced cancer in a hospice or hospital setting (National Council for Palliative Care 2009). Three types of illnesses have emerged as the main illnesses which necessitate palliative care: cancer, organ failure and dementia (Lunney et al 2003). Typically these illnesses follow one of three trajectories:

- A consistent steep decline, often as a result of cancer.
- A general decline over time, but with peaks and troughs in levels of functioning. This is often as a result of organ failure, for example, heart failure or COPD.
- A gradual decline over a longer period of time. This is often as a result of advancing age and dementia.

The challenges of delivering palliative care in dementia are often a result of the gradual decline over time, meaning that the ‘terminal’ or ‘dying phase’ can be difficult to define. This is in contrast to cancer, where the terminal phase often causes a dramatic and marked reduction in the person’s abilities and independence.

TIME OUT 1
Refer to the Alzheimer’s Society website (www.alzheimers.org.uk/typesofdementia). How would you differentiate between the four main types of dementia: Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal lobe dementia? Make brief notes on each.

Disparities in palliative care provision
Palliative care is appropriate for all people living with a progressive chronic illness (WHO 2011, European Association for Palliative Care 2013). In consideration of international human rights, provision of palliative care should be non-discriminatory and available to all people across the three disease trajectories. The palliative care needs of many older people are not being met, according to Graham et al (2010), while Brennan (2007) describe current practices as ‘abysmal’. The disparity between palliative care available for people living with dementia compared to that for people with other illnesses has been recognised at an international level by the Office of the United Nations High Commissioner for Human Rights which identified that many a number older people were not supported to access palliative care (Office of the High Commissioner for Human Rights 2012, Morris 2012). These disparities cause concern, given the large number of people experiencing progressive chronic illnesses such as dementia in care homes. The disparity in provision of palliative care for people living with dementia is most likely to result from a lack of knowledge about the progression of dementia; often people living with dementia will decline over a number of years, so the focus will not be on providing palliative care.

Palliative care for dementia
The DH (2010) asserted that by 2014, every person living with dementia in England
should agree with the following statement: ‘I am confident my end of life wishes will be respected. I can expect a good death.’ It is estimated that 20% of people living with dementia will die in a care home. In addition, a further 15% of people living with dementia in care homes will die in a hospital setting (DH 2010).

Evidence indicates that the quality of care provided to dying residents with dementia in care homes is often inadequate (Brazil et al 2012). A high turnover of care home staff, alongside the perception that dementia is not a terminal neurodegenerative condition has been proposed to explain why palliative care is often inadequate in care homes (Thuné-Boyle et al 2010). Examples of these inadequacies include (Brazil et al 2012):

- Inadequate pain management.
- Not commencing or maintaining advance care plans.
- Inappropriate or unnecessary hospitalisation at the end of life.
- Limited bereavement support for care partners.
- Educational gaps in palliative care outside of a cancer setting.
- Consideration rarely given to dying until the last few months of life.

The provision of palliative care should be part of the diagnostic process for all progressive non-curable illnesses, whereby people are given their diagnosis, if they choose to have it, alongside information related to palliative care. However, this is not always routine practice in dementia care (Mitchell et al 2013a).

TIME OUT 2
Refer to The Gold Standards Framework (tinyurl.com/nlbqsp2) (The Gold Standards Framework Centre CIC 2011). List the ‘specific indicators’ of death for people living with dementia. These will help you identify when a person living with dementia is in the last 12 months of their life. Print this resource and distribute it among your clinical team, since it provides specific indicators of death for other conditions including COPD, heart failure and renal disease that are common co-morbidities for people living with dementia.

The Gold Standards Framework
There are several tools available to assist care home nurses in the delivery of palliative care for people living with dementia. The most widely used tool to assist in the delivery of palliative care in this setting is The Gold Standards Framework (2006). This framework may be adapted to correspond with local needs and resources (Hansford and Meehan, 2007). The Gold Standards Framework provides seven key tasks (7Cs) that are important in the delivery of palliative care and demonstrate the importance of an integrated approach (Table 1).

The Gold Standards Framework (2011) advocates the use of a coding system, or prognostic indicators, to enable healthcare staff to identify where residents are in

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**TABLE 1. Seven key tasks (7Cs) of The Gold Standards Framework**

<table>
<thead>
<tr>
<th>Task</th>
<th>Description</th>
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<tr>
<td>Communication</td>
<td>Care home nurses to communicate openly with residents, their family, other members of the care home team and the multidisciplinary team, such as the GP or specialist palliative care services.</td>
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<tr>
<td>Co-ordination</td>
<td>A named co-ordinator leads the person’s palliative care. In the care home setting this should be the resident’s named nurse.</td>
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<td>Control of symptoms</td>
<td>An important aspect of palliative and end of life care is symptom management, to lessen any pain and distress that may be experienced by the resident. Consideration should be given to the person’s psychological, social and spiritual needs. Care should be holistic and person-centred.</td>
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<tr>
<td>Continuity</td>
<td>The care home nurse, or care home nurse co-ordinator, should inform the GP and secondary care teams in advance so that they can provide collaborative care at an early stage.</td>
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<tr>
<td>Continued learning</td>
<td>There is limited knowledge around provision of palliative care for people living with dementia. Everyone should take responsibility for ensuring that education on palliative care is at an acceptable level.</td>
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<tr>
<td>Carer support</td>
<td>This involves emotional and practical care of the resident’s care partners, family and next-of-kin. It is important to ensure that care continues after death, for example, bereavement support for the resident’s family.</td>
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<tr>
<td>Care in the dying phase</td>
<td>This gives consideration to the death of the resident. Previously The Gold Standards Framework advocated the use of a protocol for the last 48-72 hours of life, such as the Liverpool Care Pathway, which has now been discontinued. Care home practitioners now have a responsibility to provide an individual approach to the care of residents in the dying phase. This may include stopping non-essential interventions, considering comfort measures and providing psychological and spiritual support.</td>
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(Adapted from The Gold Standards Framework 2006)
relation to their death. An example of the coding would be:
A: It is expected that the person should live more than 1 year.
B: It may be the last year of the person’s life.
C: It is possibly the last months or weeks of the person’s life.
D: It is probably the last few days or hours of the person’s life.

This assessment can only be used as a guide given the uncertainty around death and dying. It should be accompanied by the colour coding of care files so that nursing and care staff can easily identify residents who are moving towards the end of their life, and enable more effective communication between members of the team. The recommended colours are: A: blue, B: green, C: yellow and D: red.

TIME OUT 3
In a small group, or with another colleague, discuss the potential benefits and challenges of implementing a colour coding system for resident’s clinical notes as recommended by The Gold Standards Framework.

When considering frameworks to assist practitioners in the delivery of palliative care, the Liverpool Care Pathway should no longer be used in practice (DH 2013).

The Liverpool Care Pathway was designed to be used to guide nurses in the delivery of quality end of life care for people expected to die within a number of days or hours. It received widespread criticism by the media and patient advocacy groups as a tool that involved ‘tick-boxes’ rather than active compassionate care (DH 2013).

TIME OUT 4
Consider case study 1. Discuss with a colleague the questions that you would ask Susan and her family to formulate an advance care plan. You should consider psychological, social and spiritual aspects of care, in addition to physical needs.

Advance care planning
Advance care planning is an important component of palliative care for people living with dementia. It is defined as ‘a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline’ (NHS End of Life Care Programme 2008). These discussions can also include family and friends, with the consent of the resident. It is important that advance care planning is commenced in a timely manner, given the clinical manifestations of dementia, including progressive cognitive decline (Dempsey 2013). The advance care plan identifies the resident’s wishes regarding their care and their preferences relating to their death (Dening et al 2011).

In clinical practice, compiling an advance care plan involves a series of discussions between the resident, their care partners or family and the care home nursing team. It should detail the residents preferences and be reviewed regularly and as the resident’s condition changes (Exley et al 2009). However, an advance care plan does not override the decision of an individual who is competent to make decisions and should only be used when the resident loses mental capacity. It is advisable for the resident to name and to commence the legal process of appointing a lasting power of attorney during the completion of an advance care plan. A

CASE STUDY 1. Susan
Susan is a 75-year-old woman living with dementia. She is married to John and they have two daughters, Jane and Lucy. Susan also has a grandson called Caleb. Susan began experiencing symptoms of dementia approximately 3 years ago, including short-term memory loss, difficulty in finding the right words, short periods of disorientation and confusion. These symptoms progressed over the next year or so, before Jane and Lucy encouraged Susan to visit the GP. The GP took Susan’s medical history and carried out some investigations before diagnosing her with Alzheimer’s disease, the most common type of dementia. Over the next six months, Susan’s dementia progressed to the extent that she had severe memory dysfunction, was frequently disorientated to time and place, experienced significant periods of distress and was no longer able to adequately provide self-care. John also became unwell during this time, so Jane and Lucy made the decision to place Susan in a care home so that she could be supported with 24-hour nursing care.
The named nurse (or senior carer in residential nursing homes) will be in charge of the resident's care and as such it will be their responsibility to commence advance care planning.

- The advance care plan should be completed alongside involvement with the next-of-kin or close members of the resident's family (if the resident consents to this).
- The resident's advance care plan should be commenced within 1 month of the resident’s admission to the care home.
- Where the person makes an advance care plan it is documented. If the person does not wish to discuss their future care needs this should also be clearly documented.
- With the consent of the resident, the advance care plan will be shared with all members of the clinical team who look after the resident.
- The person's GP should be involved in the completion of the advance care plan and should sign the document.
- Where appropriate the person may be included in local palliative care registers held within the care home, the care home organisation, the GP surgery or the local care trust.
- The advance care plan is not a static document and as such should be reviewed and evaluated regularly with the opportunity to add to these.
- The advance care plan should go with the resident if they are transferred to another care home unit, to hospital or return home.

References


Wales Palliative Care Implementation Board (2010) Quality Requirements for End of Life Care. Wales Palliative Care Implementation Board, Cardiff.

