

## ESSAY REVIEW

Laura Middleton, Jane Chatterjee, Sarah Russell and Murna Downs. (2017). *End of Life Care for people with Dementia: A Person-Centred Approach*. London: Jessica Kingsley Publishers. ISBN 978-1-84905-047-0

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Accepted for publication: 7 March 2017

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## Introduction

There are currently 850,000 people living with dementia in the UK and this number is expected to rise over the coming years. Dementia is predominantly a disease of the elderly, who are more likely to suffer co-morbidities and have a need to access health and social care for a variety of reasons including those associated with their dementia. This means that the majority of those who work in health and social care will have frequent contact with people with dementia.

There is a lack of robust evidence on which to base end of life care in those dying with dementia. This is, in part, due to methodological and ethical difficulties in undertaking research with this vulnerable patient population. However, the authors explain that this lack of evidence does not mean that we do not know what constitutes best practice. Throughout the book, case examples from clinical practice and international innovative service development are drawn on in order to describe the many and varied ways in which professionals working in this difficult but rewarding area of practice are able to strive to continually improve the quality of life until death for those affected by dementia.

## What the book is about

This book offers an account of some of the challenges inherent in providing effective and compassionate end of life care to people dying with dementia. Each chapter uses current theory and evidence to develop ideas, including real-life case studies to illustrate key points. This book demonstrates some of the challenges faced and the skills, knowledge and commitment required by family members, professionals and support workers in health and social care to provide high-quality person-centered

care for people with dementia at the end of life. Prompted by the *National Dementia Strategy* (DH 2009b) recommendation for ‘an informed and effective workforce’, education, training and support are widely acknowledged as fundamental to ensuring that the health and social care workforce are able to meet the needs of people with dementia including those at the end of life.

The introduction explores the impact of education and support on the quality of care and provides suggestions for empowering the health and social care workforce to be innovative in end of life care for people with dementia. They suggest that an information pack could obtain the following information:

- An information leaflet for identification of the ‘actively’ dying phase
- Forms for documentation of discussions with the person and family as end of life approaches
- Guidelines: management of physical symptoms, emotional and spiritual support
- Referral forms: fast track to continuing healthcare funding, out-of-hours general practitioner (GP) cover
- Guidance: implementation of advance care planning, Lasting Power of Attorney and other person-centred care plans and end of life care tools as appropriate
- Pre- and post-bereavement support for family and carers
- Individualised plan of care

- Record of discussions and decisions regarding resuscitation (Do Not Attempt Cardiopulmonary Resuscitation, DNACPR).

Chapter 1 “Transitions” explores the impact of transitions in dementia and varied definitions associated with this topic and considers some of the unique challenges posed when a person moves from living with dementia to dying with dementia.

Chapter 2 “Physical wellbeing and dignity” discusses some of the challenges in maintaining dignity and physical comfort in those dying with dementia. This chapter includes consideration of other conditions that may cause distress such as arthritis and life-limiting illnesses such as cancer. The Mental Capacity Act (2005) states that all practicable steps should be taken to support people with cognitive impairment to express their feelings. People with dementia who can communicate verbally could benefit from supportive communication techniques such as using gestures and visual aids, asking short questions, allowing a response time, addressing sensory impairments, minimising distractions and seeking confirmation about any assumptions made. As dementia progresses and a person’s verbal communication skills diminish, a greater reliance is placed on observations of their behaviour to detect their distress. While a large proportion of people with dementia are able to communicate the presence of pain, observing their behaviour remains an important part of the pain assessment. They may, for example, report that they have no pain, but if their behaviour indicates they are distressed, it may prompt further questions about pain using alternative words as well as consideration of other causes of distress. Their levels of cognition can fluctuate so that while they may be able to report on their pain at one time, at other times they may not be able to. The very presence of pain can be so overwhelming at times that it hinders a person’s ability to respond to pain assessment questions.

Chapter 3 “Emotional wellbeing and dignity” focuses on emotional and spiritual wellbeing. Through the use of case studies, examples of interventions aimed at improving psychological wellbeing are discussed. Creative ways in which carers can connect with people *via* the senses are explored. The learning outcomes for this chapter enable the reader to be able to identify the universal needs of people at the end of life. They also learn how to identify barriers to enhance dignity and emotional wellbeing for people with dementia. When identifying the dying phase, the carer should consider how a person’s needs change as they enter the last days of life.

In Chapter 4 on the impact of caring for people dying with dementia is considered. Common causes of stress are discussed and possible solutions offered. The ethical and legal context of decision-making (including advance care planning) are explored.

Chapter 5 on “Supporting the health and social care with people with dementia” includes any member of staff working in this sector, ranging from general practitioners (GPs) and hospital consultants to health and social care support workers. It also includes education for commissioners and education providers who aim to

ensure the availability and accessibility to training and education at a range of levels to meet service needs. End of life education is necessary for the workforce to be competent and up to date in knowledge and practice as well as in more specific groups such as people with dementia. Palliative care and hospice advocacy groups such as the National Council for Palliative Care (NCPC) and Hospice UK advocate a partnership approach in which palliative care services learn from dementia services and *vice versa* (NCPC 2009). As education alone is not enough to change practice, leaders within services are recognised as being critical to setting an appropriate learning culture and context for the delivery of high-quality care, effective team working and support to care staff. This chapter explores the impact of education and support on the quality of care and provides suggestions for empowering the health and social care workforce to be innovative in end of life care for people with dementia.

Throughout the book, case examples from clinical practice and international innovative service development are drawn on in order to describe the many and varied ways in which professionals working in this difficult but rewarding area of practice are able to strive to continually improve the quality of life until death for those affected by dementia.

When addressing the subject of complementary therapy the authors avoid the mistake of generating divisive arguments about orthodox and non-orthodox therapies, the focus here is on person-centered care. They explain that: “Complementary therapy such as gentle hand massage and aromatherapy oils can provide relaxation.” The section on providing “Comfort Measures at the End of Life” emphasizes the importance of keeping the environment peaceful and surrounding the person with familiar objects, if they enjoy this. Family members are encouraged to sit with residents and communicate through non-verbal methods of touch, tone of voice and facial expressions.

The Mental Capacity Act (2005) states that all practicable steps should be taken to support people with cognitive impairment to express their feelings. People with dementia who can communicate verbally could benefit from supportive communication techniques such as using gestures and visual aids, asking short questions, allowing a response time, addressing sensory impairments, minimising distractions and seeking confirmation about any assumptions made. As dementia progresses and a person’s verbal communication skills diminish, a greater reliance is placed on observations of their behaviour to detect their distress. In discussing Physical wellbeing and Dignity” the key concepts focus on discomfort/distress, total pain, behavior. The authors explain that symptom assessment needs to be holistic and involve the family and family carers. Information should be gathered using multiple methods and a range of sources to provide a comprehensive picture of the person’s experience. Pain assessment for people with dementia who can report their pain should involve a mixture of supportive communication techniques, self-report assessment tools in a visual format and behavioural observation tools. For people with advanced dementia and severe communication difficulties, behavioural

observation tools are used to identify when they are distressed. A systematic approach is then needed to determine the cause of their distress, which may be physical, psychosocial or spiritual.

## Taboo

Our culture is often seen as one that denies death and celebrates the supremacy of medicine and its increasing ability to seemingly fend off death with ever more elaborate interventions. Although, of course, this is a cause for celebration, it is also a cause for concern. Healthcare professionals may be reluctant to discuss end of life issues with people at the point of receiving a diagnosis of dementia, for at this stage hope may still be high and nobody relishes the prospect of destroying hope. In addition, people and their families receiving this diagnosis are likely to be shocked and require sensitive, timely and appropriate information. It may be clumsy, or insensitive, to begin to ask them whether they have considered where they would like to die. The value of approaching care through the eyes and experiences of people with dementia and those who are important to them has been demonstrated in this book.

## The argument

In the last weeks and months of life, meaningful communication may become more restricted and some people appear to withdraw entirely from the interpersonal realm. This impacts on the quality of care in two key ways. First, it makes the assessment of the presence of any physical needs or discomforts challenging, such as thirst or pain. Second, there may be an impact on the caregiver. Humans exist in relation to one another and communication is defined as a process involving more than one being. Thus it is essential that we identify creative ways to connect with people dying with dementia, maintain their physical and psychological comfort and support their carers and families.

The National Survey of Bereaved People (VOICES), commissioned by the Department of Health, asked bereaved relatives about the quality of care received by their loved ones in the three months prior to death. The findings relating to dementia are unsettling. Almost 30% of relatives stated that their loved one was treated with respect none or only some of the time. Interestingly, more relatives identified low levels of respect and dignity when their loved one had a diagnosis of dementia than when another illness was identified as the cause of death. This strongly suggests an inequality in the level of respect and dignity afforded to people with dementia at the end of life. Research in the United States looking at family satisfaction with end of life care of relatives with dementia in nursing homes demonstrated that overall satisfaction was specifically associated with communication of what is happening, including

the dying process and the perceived level of comfort of their loved one.

## Vocabulary

Hospice care provides a person-centered approach to care that includes the patient and those who matter to them from diagnosis through to bereavement. Palliative care is applicable from the point of diagnosis through to bereavement. In these situations everyone involved is focused on quality of life and holistic care. End of life care identifies the care of patients who are likely to be in the last year of life in order to plan and support care. Terminal care (or actively dying) refers to the maintenance of comfort and provision of support for the patient and family in the final hours, days or possibly weeks of life. All of these terms represent a place, approach, intervention and philosophy of care. Terminal care (or actively dying) focuses on maintenance of comfort and provision of support for the patient and family in the final hours, days or possibly weeks of life. All of these terms represent a place, approach, intervention and philosophy of care.

## Intended audience

Prompted by the *National Dementia Strategy* (DH 2009b) recommendation for 'an informed and effective workforce', education, training and support are widely acknowledged as fundamental to ensuring that the health and social care workforce is able to meet the needs of people with dementia including those at the end of life. The 'workforce' includes any member of staff working in health and social care with people with dementia, ranging from general practitioners (GPs) and hospital consultants to health and social care support workers. It also includes education for commissioners and education providers who aim to ensure the availability and accessibility to training and education at a range of levels to meet service needs. End of life education is necessary for the workforce to be competent and up to date in knowledge and practice (National Palliative and End of Life Care Partnership 2015) as well as in more specific groups such as people with dementia.

Palliative care and hospice advocacy groups such as the National Council for Palliative Care (NCPC) and Hospice UK advocate a partnership approach (Hospice UK 2015), in which palliative care services learn from dementia services, and *vice versa*. As education alone is not enough to change practice, leaders within services are recognised as being critical to setting an appropriate learning culture and context for the delivery of high-quality care, effective team working and support to care staff.

## Conclusion

A significant strength of this book is the clarity of writing, the avoidance of scientific jargon and the provision of succinct summaries for major themes in the form of “Key Points” and “Key concepts” as well as “Learning Outcomes”. The text is provided in a well structured format, which makes it readily usable for busy care providers as a portable inexpensive paperback. This is part of a series of Dementia Good Practice Guides provided by the well-respected Centre of Excellence in the University of Bradford, UK.

The concluding chapter describes “Supporting Families through Advanced Dementia and End of Life” lists the principal topics and summarizes the authors’ ideas in a careful summary of key points. For example: “Health and social care professionals need to work in partnership with the carer, supporting them to stay connected to their relative and to make informed decisions on their behalf within a legal and ethical context.” They also emphasize that: “Health and social care professionals need to provide carers with knowledge and support and develop a trusting relationship at an early stage. This will help carers build on their strengths, develop skills and adjust to the changing demands of caregiving. This, in turn, should help them achieve greater psychological and physical resilience when faced with the end of life period of their loved one and in bereavement”

It is refreshing to find a book on dementia care which is well supported by current bibliographical references from the nursing, medical and general research literature. I can strongly recommend this book to all those practitioners, support workers and carers involved in the care of people with dementia and where there are concerns about caring at the end of life. The book is also reassuring for family carers with descriptions of connecting with the dying person and supporting the health and social care workforce in their very demanding work.

## Conflicts of Interest

I declare no conflicts of interest.