

Date of Briefing – August 2004

## Terminal care in care homes

The topic of this briefing is the provision of care to terminally ill older people aged 65 and over within care homes settings.

### Key Messages

- More than half a million older people aged 65 or over live in care homes (nursing and personal care) and substantial numbers end their lives in these care settings. The provision of appropriate terminal care is recognised to make the process of dying more comfortable and meaningful for a person and their family
- There is a lack of detailed standards governing the provision of terminal care to older people in care homes, especially for conditions other than cancer
- The National Council for Hospice and Specialist Palliative Care Services (NCH&SPCS) is the principal source of documents containing practice recommendations
- Care homes can only provide appropriate terminal care if barriers to the provision of care are addressed
- Adequate and appropriate terminal care requires the following: care home staff trained in palliative care; regular access to supporting specialist palliative care staff; resources to support the provision of such care; clear and comprehensive plans of care reaching beyond the management of symptoms alone; training in how to communicate effectively with residents and their families about death and dying.
- Research into factors determining transfer from homes to hospital at end of life, or the appropriateness of such transfers, is lacking
- Residents of care homes tend to be very conscious of the probability that they will end their life within the home and are very appreciative of efforts to manage death with discretion within these settings. Specialist terminal care and support, including bereavement support, is highly valued by the terminally ill and their families

### Introduction

This section introduces and defines the scope of the briefing and the topic.

A SCIE briefing provides up-to-date information on a particular topic. It is a concise document summarising the knowledge base in a particular area and is intended to act as a 'launch pad' or signpost to more in-depth material. The briefing is divided into the different types of knowledge relevant to health and social care research and practice, as defined by the Social Care Institute for Excellence (SCIE).

(<http://www.scie.org.uk/publications/knowledge.asp>)

The topic of this briefing is the provision of care to terminally-ill older people aged 65 and over within care homes (personal care and nursing). The terminal care described here encompasses the principles of palliative care. Terminal care is defined as "the management of patients with active and progressive disease for which curative treatment is not possible or not appropriate and from which death can reasonably be expected" within a timeframe of days or months <sup>(1)</sup>. The palliative care approach requires ". . . the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of best quality of life for patients and their families" <sup>(2)</sup>. Palliative care is considered to be applicable to all diseases, not just cancer. The majority of care homes are personal or residential, and the majority of these are private <sup>(3)</sup>. Most terminal care within care homes is provided by generalist care staff; specialist palliative care staff only become involved in certain circumstances <sup>(4)</sup>.

## Why this issue is important

This section summarises research findings relating to the impact or consequences of inadequate, inappropriate or limited terminal care in care homes.

This issue is important because more than half a million older people aged 65 or over live in care homes, and substantial numbers end their lives in these settings <sup>(5,6,7)</sup>. It is also the case that increasing numbers of older people are dying in these homes rather than in hospices or hospital <sup>(7,8)</sup>, and it is projected that the number of older people dying in care homes is likely to continue growing <sup>(9)</sup>. Care homes are therefore an increasingly important place of dying for older people, and the quality of terminal care provision within these settings is therefore very important <sup>(10)</sup>. Nursing homes have also been shown to be appropriate settings for the provision of such care <sup>(11)</sup>. The provision of appropriate terminal care is recognised to make the process of dying more comfortable and meaningful for a person and their family, but appropriate care relies on sufficient generalist and specialist staff being available, and these staff being adequately trained and having the time to care for residents fully <sup>(12,13,14)</sup>. Older people are also known to have problems accessing good quality health care, including palliative care services <sup>(9)</sup>.

What do the different sources of knowledge show?

## Organisational Knowledge

This section lists and briefly summarises documents that describe the standards that govern the conduct of statutory services, organisations and individuals working in the field of terminal care in care homes.

Department of Health (2002). Care Homes for Older People. National Minimum Standards. Care Homes Regulations

[http://www.csci.gov.uk/information\\_for\\_service\\_providers/national\\_minimum\\_standards/default.htm](http://www.csci.gov.uk/information_for_service_providers/national_minimum_standards/default.htm)

This document sets out standards for the provision of services in care homes. This includes the provision of palliative care services for the terminally ill. Standard 11 relates specifically to Death and Dying.

Department of Health. National Service Framework for Older People

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/fs/en>

The NSF for older people sets national standards and service models of care across health and social services for all older people, including those in care homes. The NSF “Standard 2 – Person-Centred Care” applies to End of Life care in all settings.

It has been pointed out however that existing standards relating to care homes can be vague with reference to details of terminal care, especially in the assessment and management of pain <sup>(15)</sup>.

Making Decisions. Helping people who have difficulty deciding for themselves. Planning Ahead for the Future (2003). Lord Chancellor’s Department.

<http://www.dca.gov.uk/family/mi/mibooklets/guide5.pdf>

Chapter 5 of this document covers planning for health care decisions. This includes a description of the scope and legal authority of Advance Statements, also known as Advance Directives or Living Wills.

## Policy Community Knowledge

This section summarises documents describing proposed structural models for the delivery of policy and improved practice. These documents are published by public policy research bodies, lobby groups, think tanks and related organisations.

NICE (2004). Supportive and palliative care for people with cancer.

<http://www.nice.org.uk/page.aspx?o=110005>

This NICE guidance describes key recommendations for the co-ordination of palliative and supportive care services for adults with cancer, but the section on general palliative care is relevant for all settings.

NCH&SPCS (2003). National guidelines for the use of complementary therapies in supportive and palliative care.

<http://www.hospice-spc-council.org.uk/public/complementaryguidelines.pdf>

This document offers evidence-based guidance on patient safety and the provision of complementary therapy services for cancer, including clinical governance, regulation and training of therapists, audit and evaluation. These guidelines are intended to complement the NICE guidance.

National Council on Ageing (2002). End of Life Issues. Policy Position Paper.

<http://www.ageconcern.org.uk/AgeConcern/media/EndoflifepppSept2002.pdf>

This document makes recommendations regarding equality, adequacy and appropriateness of palliative care services for older people, including their rights to express views on their place of dying.

Firth S. (2001). Wider Horizons: Care of the dying in a multicultural society. NCH&SPCS.

The principle behind the document is to examine ways of improving services from the perspectives of black and ethnic minorities. Recommendations are made on good practice in the provision of care, training, and the future research agenda.

Mount J. et al. (2001). Palliative care services for different ethnic groups. NCH&SPCS.

This report identified the need for hospices and palliative care services to provide culturally sensitive services in respect of language, religion, spiritual and dietary needs, and for particular attention to be given to providing appropriate and accessible information to those communities.

These last two documents highlight how the provision of appropriate terminal care must take into account the needs of different ethnic groups. Information about these publications appears under the Publication heading "Commissioning and Provision".

<http://www.hospice-spc-council.org.uk/publications/publicationslist.htm>

PRODIGY Guidance (2004). Palliative Care – Respiratory Secretions at the End of Life.

<http://www.prodigy.nhs.uk/guidance.asp?qt=Palliative%20care%20-%20secretions>

The aim of this guidance is to alleviate the distress to the patient caused by accumulated respiratory secretions at the end of life, and to alleviate the distress to the family and carers caused by noisy respiratory secretions at the end of life.

Department of Health and Ageing (2004). Guidelines for a Palliative Approach in Residential Aged Care. Australian Government.

<http://www.palliativecare.gov.au/pubs/workforce/pallguide.htm>

These are evidence-based guidelines on the provision of palliative care in care homes (personal). This resource has been recommended to the SCARE group by a subject expert.

Centre for Policy on Ageing (1996). A Better Home Life. A Code of Good Practice for Residential and Nursing Home Care.

<http://www.cpa.org.uk/bhl/bhl.html>

This document includes a section on Dying and Death, which briefly covers policy and procedures, expressed wishes of the resident, dying in the home, hospices and hospitals, other residents, and the role of care staff.

South Manchester University Hospitals NHS Trust (2001). Care of the Dying.

<http://libraries.nelh.nhs.uk/Pathways/viewResource.asp?searchText=palliative+care&searchZone=%2FPathways%2FsearchResponse.asp&uri=http%3A//libraries.nelh.nhs.uk/common/resources/%3Fid%3D37700>

This is a local integrated care pathway developed by a trust-based team for the provision of terminal care to older patients. The pathway is designed for acute care within hospital, but contains elements which may inform the provision of terminal care within care homes.

Ellershaw J. Wilkinson S. (2003). Care of the Dying. A Pathway to Excellence

<http://www.oup.co.uk/isbn/0-19-850933-2>

This multi-professional care pathway was developed by the Royal Liverpool University Hospitals Trust and the Marie Curie Centre, Liverpool. It shows how the hospice model of care can be successfully translated into both care home and hospital settings.

## Practitioner Knowledge

This section describes studies carried out by health and social care practitioners, documents relating their experiences regarding the topic, and resources produced by local practitioner bodies to support their work.

Department of Health. Good practice examples and case studies of “Standard 2 – person-centred care” from the NSF for Older People

[http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/OlderPeoplePromotionProject/OlderPeoplePromotionProjectArticle/fs/en?CONTENT\\_ID=4002285&chk=f8JgQm](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/OlderPeoplePromotionProject/OlderPeoplePromotionProjectArticle/fs/en?CONTENT_ID=4002285&chk=f8JgQm)

These are examples of practice aimed at ensuring that older people receive appropriate and timely packages of care which meet their needs as individuals, regardless of the boundaries of health and social services.

Macmillan Cancer Relief (2004). Foundations in Palliative Care: A programme of facilitated learning for care-home staff.

<http://www.macmillan.org.uk/news/pressreleases.asp?nid=1275>

This is a teaching resource designed for staff at all levels and covers four modules: the principles of palliative care; communication; pain and symptom

management; and bereavement care. It is only available in hardcopy from Macmillan Cancer Relief.

Sander R. & Russell P. (2001). Care for dying people in nursing homes. *Nursing Older People* 13 (2).

[http://www.healthinfo4u.org/rcn\\_pdf/NOP/NOP%2021-26%20APRIL%202001.pdf?issn=1365-2524&vol=9&page=228](http://www.healthinfo4u.org/rcn_pdf/NOP/NOP%2021-26%20APRIL%202001.pdf?issn=1365-2524&vol=9&page=228)

This resource is produced by nurses for staff working within care homes (nursing). The document contains practice recommendations to improve communication and promote an understanding of the concept of palliative care and symptom management. It also advances methods for providing emotional support for the dying person and their family.

A set of actions and procedures outlining the responsibilities of the nurse working in this field have been produced by a nurse who practises within care homes<sup>(16)</sup>: nurses need to be aware of how to contact and access specialist palliative services; they need to be well-informed about their patient's condition, wishes and care plan; be aware of formal procedures for communicating with family members at all stages in the terminal care process; and be able to refer family members to bereavement services.

A terminal care plan strategy was recently developed in a locality in the UK to improve terminal care within care homes. This strategy recognised the organisational requirements for the provision of effective terminal care within nursing homes. This involved the provision of minimum standards of accommodation and care; access to specialist palliative care services; identifying the training needs of care home staff in this field, and providing educational support to them<sup>(17)</sup>. This strategy successfully reduced the numbers of older people being transferred to acute care.

## Research Knowledge

This section summarises the best available research literature. The focus is on studies undertaken in the United Kingdom, so that their findings are as relevant as possible to the intended audience of the briefing.

### **Who receives and who provides terminal care?**

Care homes (personal care and nursing) have been shown to be appropriate settings for the provision of terminal care, but concerns have been raised over the quality of care that may be provided by the homes' own care staff<sup>(4,11,18)</sup>. Most terminal care within both types of care home is provided by generalist staff; specialist palliative care staff only become involved in certain circumstances<sup>(4)</sup>. All care home staff therefore rely on the support of external specialists to provide appropriate terminal care, and research has highlighted the potential value of developing ongoing links between specialist palliative care teams and staff within care homes, with the intention of promoting good quality and comprehensive terminal care by care homes and their staff,

beyond administering only to the clinical needs of the dying <sup>(4,19,20)</sup>. However, the research has found that specialist palliative care services do not have any systematic involvement in terminal care for all older people in care homes. Their involvement tends to be restricted almost entirely to older people with cancer, although research has indicated that the majority of older people with terminal illness in care homes die from circulation problems, respiratory disease and end-stage organ failure <sup>(9,21)</sup>. It is also pointed out in the research that existing palliative care standards and resources have been developed principally for cancer, but the dying trajectory, and therefore the palliative care plan that applies for cancer may not be appropriate for other terminal conditions <sup>(7,8)</sup>. Palliative care provided by specialist staff has also been found to be largely reactive and limited to addressing immediate clinical needs, rather than providing comprehensive palliative care for all older people with terminal illness <sup>(3,4,7,11,21,22)</sup>. For example, social, spiritual and psychological care for both the resident and their family tends to be relatively poorly provided for <sup>(20,23)</sup>.

### **Roles in terminal care**

Referral to specialist palliative care services has been shown to be initiated by a range of individuals and groups, including care home managers, GPs, patients, care staff and family members <sup>(21)</sup>. There does not appear to be a single, recognised pathway for referral. A survey of care home managers reported that about half expressed a desire to make use of specialist palliative care services, but less than ten percent actually did so <sup>(21,24)</sup>. General palliative care for terminally-ill people is provided by staff within the homes, such as health care assistants and nurses. Specialist palliative care within care homes is usually provided by external staff, such as district nurses or clinical nurse specialists, for example, Macmillan nurses <sup>(4)</sup>. A survey of district nurses reported that more than one third of these professionals hold qualifications or have had training in palliative care, yet most care home managers do not seek to utilise this expertise <sup>(3)</sup>.

### **What factors have been identified as affecting the provision of adequate and appropriate care?**

The following barriers have been identified as preventing the provision of effective terminal care: a lack of communication between decision-makers, including medical staff, care staff, the resident and their family; the failure to recognise that no curative or restorative treatment is longer possible, so that terminal care can then be provided; a lack of agreement on a plan of care; and a failure to implement the plan in a timely fashion <sup>(25,26)</sup>. The absence of standards regarding the timing of the provision of specialist palliative care to terminally-ill patients has also been raised as an issue in other studies <sup>(27)</sup>. Other factors identified as barriers to the provision of appropriate terminal care include limited resources in care homes, especially in personal care facilities <sup>(21,28,29,30)</sup>, and the absence of hospice protocols for the management of symptoms and the dying process in both types of care homes <sup>(31)</sup>.

The education and training of staff in palliative care within care homes has been identified as one of the potentially most important means of improving the quality of terminal care for the dying <sup>(4,24,32,33,34)</sup>, but the research literature

has also indicated that such educational programmes are largely informal and random in their delivery, and the high turnover of staff within care homes can dramatically reduce the impact of such training on actual practice <sup>(3,4,11,21,34)</sup>. The simple provision of education and training to staff has also been found to be inadequate in terms of promoting long-term, organisational change within these care settings: a commitment to providing comprehensive, well-resourced terminal and palliative care plans is also needed <sup>(35)</sup>. The research has also highlighted the differences between the services offered by the two types of care homes. This includes the more frequent provision of specialist care to care homes (nursing) than care homes (personal care) <sup>(21)</sup>, and more palliative care training for qualified nursing home staff than to unqualified care staff <sup>(11,15)</sup>. This in turn may affect the quality of terminal care potentially provided within the two settings.

The research has also shown that care home staff can be reluctant to discuss end-of-life issues with patients and their families, so training should include instruction on how to communicate with patients and family members about their wishes regarding their end-of-life care, and their concerns and wishes relating to dying <sup>(32,33,36,37)</sup>. It has also been pointed out that, as a result of the close relationship they enjoy with residents, unqualified care staff have a vital role to play in end-of-life care, and can also have essential knowledge which may be extremely valuable in assessing patients' clinical and emotional needs <sup>(8,31,37)</sup>. However, the findings of the research on whether health assistants are confident about sharing their observations on symptoms with qualified nursing staff have been mixed <sup>(32,37)</sup>. The principal training needs of unqualified care staff have been identified as an awareness of the principles of palliative care, especially pain control, and how to communicate in a sensitive fashion with older people and their families about death and dying <sup>(37,38)</sup>. UK and US studies of care homes (nursing) also found that a failure to attend to the basic care needs of terminally-ill residents, such as bathing, oral hygiene, repositioning in bed, and privacy, had an adverse effect on the sense of comfort, well-being and dignity of residents at the end of their life <sup>(12,39)</sup>.

The literature has also raised the issue of how the dying communicate their wishes or problems <sup>(14,40)</sup>. Substantial minorities of older people in care homes can experience some form of cognitive impairment, including dementia <sup>(41)</sup>. This in turn can have a serious impact on an individual's capacity to communicate their wishes or concerns about their own end-of-life care, as well as any symptoms they may be experiencing, such as pain <sup>(3,14,15,41,41,42)</sup>, although practices and tools do exist which have some value for identifying pain in cognitively-impaired older people <sup>(43)</sup>. It has been found that more than two thirds of care homes (nursing) have no written policy on pain management for residents and do not employ a standardised tool for assessing pain <sup>(15)</sup>. The result can be that older people affected by such impairment may experience serious inequalities in the delivery of adequate and appropriate terminal care <sup>(14)</sup>.

### **What factors have been identified as affecting transfer to hospital?**

Hospital transfers are known to be inevitable in some cases, and necessary due to medical needs and complications, but studies from the UK have found

that such hospitalisations for dying patients may be both unnecessary and inappropriate<sup>(29)</sup>. A small amount of research has been conducted into hospitalisation for terminally-ill residents of care homes (nursing) in the United States<sup>(22)</sup>. In regions where nursing homes sought residents' wishes about transfer to hospital and end-of-life care, there were lower levels of hospitalisation, with residents preferring to die within the home<sup>(22,44)</sup>. Research from the United States has also indicated that where hospice service care was made available in care homes (nursing), levels of hospitalisation for dying patients was much lower than the average<sup>(22)</sup>. No research has been conducted in the UK on outcomes from the use of living wills or advanced directives relating to terminal care.

## User & Carer Knowledge

This section summarises the issues raised by service users and carers in relation to this topic, both as described by the literature and as defined through local consultation.

What does the research say about service users' views on end-of-life care?

There is little research into the views of the terminally ill with reference to their expectations and wishes regarding end-of-life care. This is in part a result of difficulties of collecting data from a group with high rates of rapid attrition and withdrawal<sup>(45)</sup>. However, a small scale qualitative research study in the UK has found that older people expressed a preference for dying in their place of residence rather than being transferred to hospital<sup>(14)</sup>. The deterioration in health of terminally-ill residents, and their greater reliance on carers, also led to a loss of personal choice and freedom, which residents have reported finding difficult to accept<sup>(39)</sup>. Research has also shown that there is no common attitude towards death and dying among older people<sup>(8,14,39)</sup>.

Small surveys of care home residents in the UK have found that they were very conscious of the probability that they would end their life within the home<sup>(14,39)</sup>. They were therefore very appreciative of efforts to manage death with discretion within these settings. Residents also expressed a desire to have a formal recognition of the death of a fellow resident, and considered bereavement support for both fellow residents and family members to be a valuable service<sup>(29,39,46)</sup>. They were especially critical of attempts to hide or fail to mention deaths<sup>(39)</sup>. Research has also found that residents and their families considered their relationship with care home staff to be very important, especially the presence of somebody familiar and comforting during the last stages of care<sup>(14)</sup>. Consultation with a local focus group also highlighted the concerns of family members, who considered their role on decision making to be too limited.

## Useful Links

This section lists sources of information relevant to services users and professionals who work within this field.

#### National Council for Hospice and Specialist Palliative Care Services

<http://www.hospice-spc-council.org.uk/>

The NCH&SPCS (Council) is the umbrella and representative body for hospice and palliative care in England, Wales and Northern Ireland. This body makes available an extensive range of publications touching on issues relevant to the delivery of care to the terminally ill, including ethical considerations, guidelines for managing end-of-life care, measures of quality for palliative care, and planning, managing and commissioning palliative care services (some of these documents are listed elsewhere in this briefing).

#### Age Concern

<http://www.ageconcern.org.uk/>

Age Concern is a registered charity that works for and supports older people.

#### Palliative-medicine

<http://www.mailbase.org.uk/lists/palliative-medicine/>

This is a discussion list which covers all aspects of palliative medicine and palliative care. Its aim is to facilitate communication between practitioners involved in research or educational initiatives and also to allow the exchange of information or advice relating to clinical matters.

#### Help the Hospices

<http://www.helpthehospices.org.uk/>

This organisation supports hospices in their work and is a source of palliative care education. This support includes training, education, information, grant-aid, advice and national fundraising events and activities.

#### Hospice Information

<http://www.hospiceinformation.info>

Hospice information is a joint venture between St. Christopher's Hospice and Help the Hospices. The organisation provides palliative care education and training, and an information service for health professionals and members of the public on UK and international hospice and palliative care.

#### Comments

Please address all comments, suggestions or ideas for improvement to [scharrlib@sheffield.ac.uk](mailto:scharrlib@sheffield.ac.uk)

#### Acknowledgements

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## Reference List

1. **National Council on Ageing** (2002). End of Life Issues. Policy Position Paper [online] National Council on Ageing. Available from: <http://www.ageconcern.org.uk/AgeConcern/media/EndoflifepppSept2002.pdf> [Accessed 8 September 2004]

This document makes recommendations regarding equality, adequacy and appropriateness of palliative care services for older people.

2. **NICE** (2004). Supportive and palliative care for people with cancer [online] NICE. Available from: <http://www.nice.org.uk/page.aspx?o=110005> [Accessed 8 September 2004 ]

This guidance describes key recommendations for the co-ordination of palliative and supportive care services for adults with cancer.

3. **Goodman C., Woolley R., Knight D.** (2003). District nurse involvement in providing palliative care to older people in residential care homes. *International Journal of Palliative Nursing*, 9 (12), 521-527.

This UK study details the nature of the specialist palliative care provided by community nurses to care homes (personal care).

4. **Froggatt K.A., Houlst L.** (2002). Developing palliative care practice in nursing and residential care homes: the role of the clinical nurse specialist. *Journal of Clinical Nursing*, 11 (6), 802-808.

This UK study surveys the nature of the palliative care provided by specialist nurses to care homes.

5. **Katz J. S., Peace S. M.** (2003). End of life in care homes: a palliative care approach. Oxford, Oxford University Press. 2003.

This book considers the possibilities for improving the care of older people dying in care homes, and the aspects of palliative care that are transferable to dying people in settings.

6. **Davies S., Seymour J.** (2002). Historical and policy contexts. In: Hockley J., Clark D. (eds) *Palliative care for older people in care homes*. Milton Keynes, Open University Press. pp.4-33.

This book chapter describes and defines the nature of care within UK care homes.

7. **Sidell M., Katz J.S., Komaromy C.** (1997). Death and dying in residential and nursing homes for older people: examining the case for

palliative care. Report for the Department of Health. Milton Keynes, Open University.

This is a report evaluating the value of providing palliative care in care homes (nursing).

8. **Froggatt K.A.** (2001). Palliative care in nursing homes: where next? *Palliative Medicine*, 15 (1), 42-48.

This paper reviews current approaches to the provision of palliative care in care homes (nursing).

9. **Seymour J., Clark D.** (2001). Palliative care and geriatric medicine: shared concerns, shared challenges. *Palliative Medicine*, 15 (4), 269-270.

This is a brief review current and future issues affecting older people in care homes.

10. **Peace S M.** (2003). The development of residential and nursing home care in the United Kingdom. In: Katz J.S., Peace S M. (eds) *End of Life in Care Homes: A Palliative Care Approach*. Oxford, Oxford University Press. pp.15-42.

This chapter describes the policy context of care homes in the UK.

11. **Avis M., Greening Jackson J., Cox K., Miskella C.** (1999). Evaluation of a project providing community palliative care support to nursing homes. *Health and Social Care in the Community*, 7 (1), 32-38.

This study assesses a project to extend 'hospice standards' of palliative care to residents of a group of care homes (nursing) in the UK and identifies barriers to the provision of such care.

12. **Kayser-Jones J.** (2003). Factors that influence end-of-life care in nursing homes: the physical environment, adequate staffing and lack of supervision. *Gerontologist*, 43 (Special Issue II), 76-84.

This US study identifies barriers to the provision of terminal care within care homes (nursing).

13. **Hockley J., Clark D.** (2002). *Palliative care for older people in care homes*. Milton Keynes, Open University Press.

This book contains a collection of papers on the nature of palliative care in care homes.

14. **Lloyd L.** (2000). Dying in old age: promoting well-being at the end of life. *Mortality*, 5 (2), 171-188.

This article discusses the nature of terminal care interventions for older people in the UK.

15. **Allcock N., McGarry J., Elkan R.** (2002). Management of pain in older people in the nursing home: a preliminary study. *Health and Social Care in the Community*, 10 (6), 464-471.

This is a survey of the prevalence of chronic non-malignant pain among residents of a group of care homes (nursing) in the UK, and current practices to assess and manage that pain.

16. **Lethem W.** (1999). Nursing home nurses deliver palliative care. *Nursing Times*, 95 (44), 54-55.

This is a brief article describing practice recommendations for nurses providing terminal care within care homes (nursing).

17. **Last S.** (2000). Intermediate care. Bed spread. *Health Service Journal*, 110 (5717), 22-23.

This is a brief report on a project to develop a terminal care plan strategy by a UK local authority.

18. **Katz J.S., Peace S.M.** (2003). Introduction. In: Katz J.S., Peace S M. (eds) *End of Life in Care Homes: A Palliative Care Approach*. Oxford, Oxford University Press. pp.1-14.

This is a summary of the principal issues regarding the application of palliative care in care homes.

19. **Katz J.S., Peace S M.** (2003). *End of Life in Care Homes: A Palliative Care Approach*. Oxford, Oxford University Press.

This book considers the possibilities for improving the care of older people dying in care homes, and the aspects of palliative care that are transferable to dying people in settings.

20. **Forbes S.** (2001). This is Heaven's waiting room: end of life in one nursing home. *Journal of Gerontological Nursing*, 27 (11), 37-45.

This is a US survey of the opinions of residents and their families on the end of life care provided within a group of care homes (nursing).

21. **Froggatt K.A., Poole K., Hoult L.** (2002). The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work. *Palliative Medicine*, 16 (6), 481-487.

This UK study details the nature of the palliative care provided by specialist nurses to care homes.

22. **Mezey M., Dubler M.M., Mitty E., Brody A.A.** (2002). What impact do setting and transitions have on the quality of life and end of life and the quality of the dying process. *Gerontologist*, 42 (Special Issue III), 54-67.

This US study offers a survey of residents' wishes regarding hospitalization and their end of life care.

23. **Katz J.S., Sidell M., Komaromy C.** (2000). Death in homes: bereavement needs of residents, relatives and staff. *International Journal of Palliative Nursing*, 6 (6), 274-279.

This article reports the findings of a UK study investigating the case for applying the principles and practices of palliative care to caring for older people dying in residential and nursing homes.

24. **Komaromy C., Sidell M., Katz J.T.** (2000). The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing*, 6 (4), 192-200.

This is a large UK multi-method study on the management of death and dying in care homes, focusing on the factors that affect the provision of terminal care.

25. **Field D., Froggatt K.** (2003). Issues for palliative care in nursing and residential homes. In: Katz J.S., Peace S M. (eds) *End of Life in Care Homes: A Palliative Care Approach*. Oxford, Oxford University Press. pp.175-194.

This article discusses the principal issues surrounding the provision of end of life care in care homes.

26. **Travis S.S., Bernard M., Dixon S., McAuley W.J., Loving G., McClanahan L.** (2002). Obstacles to palliation and end-of-life care in the long-term care facility. *Gerontologist*, 42 (3), 342-349.

This US study identifies barriers to the provision of palliative and terminal care by care home staff.

27. **Parker D., McLeod A.** (2002). Assessment of need in care homes. In: Hockley J., Parker D. (eds) *Palliative Care for Older People in Care Homes*. Milton Keynes, Open University Press. pp.34-51.

This is a review of literature assessing the needs of older people in care homes.

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