



Queensland University of Technology
Brisbane Australia

This may be the author's version of a work that was submitted/accepted for publication in the following source:

[Abbey, Jennifer](#), Froggatt, Katherine, [Parker, Deborah](#), & [Abbey, Brian](#) (2006)

Palliative Care in Long-term Care: A System in Change.

International journal of older people nursing, 1(1), pp. 56-63.

This file was downloaded from: <https://eprints.qut.edu.au/225267/>

© Consult author(s) regarding copyright matters

This work is covered by copyright. Unless the document is being made available under a Creative Commons Licence, you must assume that re-use is limited to personal use and that permission from the copyright owner must be obtained for all other uses. If the document is available under a Creative Commons License (or other specified license) then refer to the Licence for details of permitted re-use. It is a condition of access that users recognise and abide by the legal requirements associated with these rights. If you believe that this work infringes copyright please provide details by email to qut.copyright@qut.edu.au

Notice: *Please note that this document may not be the Version of Record (i.e. published version) of the work. Author manuscript versions (as Submitted for peer review or as Accepted for publication after peer review) can be identified by an absence of publisher branding and/or typeset appearance. If there is any doubt, please refer to the published source.*

<https://doi.org/10.1111/j.1748-3743.2006.00010.x>



COVER SHEET

Abbey, Jennifer and Froggatt, KA and Parker, Deborah and Abbey, Brian (2006)
Palliative care in long term care: a system in change. *International Journal of Older People Nursing* 1(1):pp. 56-63.

Copyright 2006 Blackwell

Accessed from: [https://eprints.qut.edu.au/secure/00003616/02/PD3_-_Palliative_Care_\(Revised\).doc](https://eprints.qut.edu.au/secure/00003616/02/PD3_-_Palliative_Care_(Revised).doc)

PALLIATIVE CARE IN LONG TERM CARE: A SYSTEM IN CHANGE

Jennifer Abbey, RN, PhD, FRCNA
Professor of Nursing (Aged Care)
Centre for Health Research – School of Nursing
Queensland University of Technology
Victoria Park Rd
Kelvin Grove
Brisbane
QLD 4069
Australia
Ph: 617 3350 8600
Fax: 617 3350 8984
Email: j.abbey@qut.edu.au

KA Froggatt PhD, Bsc (Hons), RGN
Senior Lecturer
Palliative and End-of-Life Care Research Group
School of Nursing and Midwifery
University of Sheffield
Bartolomé House
Winter Street
Sheffield S3 7ND

Tele: 0114 222 8300
Fax: 0114 222 9712
E-mail: k.froggatt@sheffield.ac.uk

Deborah Parker BA, MSoc
Project Manager
Centre for Health Research – School of Nursing
Queensland University of Technology
Victoria Park Rd
Kelvin Grove
Brisbane
QLD 4069
Australia
Ph: 617 3864 3840
Fax: 617 3864 5941
Email: d.parker@qut.edu.au

Brian Abbey BA, MEd
Research Fellow
Centre for Health Research – School of Nursing
Queensland University of Technology
Victoria Park Rd
Kelvin Grove

Brisbane
QLD 4069
Australia
Ph: 617 3350 8600
Fax: 617 3350 8984
Email: b.abbey@qut.edu.au

PALLIATIVE CARE IN LONG TERM CARE: A SYSTEM IN CHANGE

ABSTRACT

The provision of palliative care for older people within the next decade will need to be substantially different to that provided today. In long term care settings the achievement of quality palliative care will require attention to all levels of the health and social care system, in both its formal and informal manifestations. We suggest that long-term care facilities will become the hospices of the future, caring for older people with chronic conditions with a long trajectory to death, the most common being dementia. We see this progression as inevitable and appropriate if the right support is provided. We discuss the impact that transferability and sustainability has had on the present provision of palliative care for older people and how that may affect the future. Four forces which are important factors in public policy; leadership, a culture that supports learning throughout the care process, an emphasis on effective team development and the use of information technologies for quality activities are used as a framework for our vision of social planning. We then go on to discuss the impact of costs, workforce, service planning and public awareness as three vital areas where progress needs to be carefully tackled. We suggest some likely poor outcomes if this planning does not occur, but indicate that if planning and implementation is effective then services can provide the kind of care the baby boomer generation seeks.

PALLIATIVE CARE IN LONG TERM CARE: A SYSTEM IN CHANGE

INTRODUCTION

The editors' invitation to present a paper that is '...visionary, challenging and futuristic ..., to take the reader beyond what is currently known about [palliative care in long term care¹] ... challenging existing thinking in the area' is both very exciting and not a little daunting. This is especially so in a field that has experienced rapid change in its short life. In order to consider a future vision for palliative care for people in long term care settings we need to study issues internal and external to the field in question, in both the present and the recent past. The interplay of competing forces must be acknowledged with respect to changes in demography, economics public policy formulation, medical sciences, industry structures, workforce provision and societal values. We will also move between macro and micro levels of concern, considering the broad global context which shapes the care that individuals experience in this setting.

In this paper we therefore present a contextualised account of current trends in the gerontological world and the nature of dying and death for older people. The development of palliative care in long term care is briefly described. Underlying issues of transferability and sustainability are discussed as major impact factors in shaping the culture of care we have today. We use Ferlie and Shortell's (2001) model

¹ It is important to note that different terminologies are adopted in different countries. Whilst the UK uses the generic term care home to encompass care provided in long term care settings for older people, in Australia care is provided in Residential Aged Care Facilities (RACFs). Where country specific reference is made the appropriate term will be used, otherwise the generic term long term care will be used.

to propose a framework in which we might move forward to address the consequences of aged care's past theories and practices and develop a sustainable model of long term care for older people that integrates end of life care into its practice.

THE CONTEXT FOR CHANGE

The context within which long term care for older people is provided is changing in a number of ways. For example, it is increasingly difficult to recruit and retain staff in long-term care, due to a continuing nursing shortage and the apparent unattractiveness of careers in caring for older people. Demographically, therefore, the balance is shifting between the number of people who need care services and the number willing and able to provide them (Productivity Commission 2005). The industry structure itself is in a process of change. In both Australia and the UK the numbers of small independent facilities and not-for-profit and charitable providers are decreasing, replaced by the amalgamation of ever larger corporate-style organisations in the for-profit sector. A parallel development, certainly prominent in Australia, is the offering of 'extra services', a term generally used to denote more luxurious accommodation, special facilities and a range of peripheral services, to those able to afford them. This formalises for the first time a deliberately structured quality gap between the well-to-do and the less well-off; but, equally, may give new weight to consumer preferences in the resolution of difficult policy and practice issues

Against this backdrop, current international and national policy that focuses on older people and ageing emphasises a positive, active image of the ageing experience, eradication of bias against older age groups, facilitation of the involvement of older people in a wider range of social activities, and fosters an understanding of self-care

(United Nations 2002). Prevention and management of illnesses, including the facilitation of early diagnosis is the focus of aged care work. Consequently, end of life issues receive relatively little attention from politicians, policy-makers and professionals. It is as if a prolonged healthy ageing phase obscures recognition that, however successful such an approach might be, disability and decline leads inexorably to death. This gap in our thinking and preparedness for action is already coming under sharp notice in the USA, the UK and Australia as a result of a number of well publicised legal battles over the painful, protracted and poorly managed deaths being endured by people who might be said to be already beyond life. The new 'older' generation is going to be better educated and will require more information and choices from health services as they tackle the losses and infirmities of chronic illness. It is safe to predict that this cohort will also be more demanding in respect of an accessible process for a managed death.

Having said that, older people are not a homogeneous group when it comes to their experience of dying, and consequently the care and service provision they require will vary greatly. Lynn and Adamson (2003) propose that the group of people who have a serious progressive, eventually fatal illness, many of whom are resident in long term care settings, may follow one of three illness trajectories.

1. People with cancer who tend to become disabled only when the disease is in its last weeks.
2. Those with long term limitations with intermittent serious episodes such as organ system failure. This group can live for a long period of time from diagnosis with few symptoms but eventually they will have an exacerbation of symptoms and many will die from an unpredictable complication.

3. Those with a protracted decline prior to death are typical of those who are frail and/or have dementia. Death may be many years from diagnosis and the ability for self care may be lost years prior to death.

While the health care needs associated with each of these trajectories are different the needs of the dying person are universal, such as the desire for comfort, dignity and control over bodily functions where possible.

For those following the cancer trajectory there will be a need to adapt to rapid changes in care that may be required in the final weeks or months of life and coordination between multiple service providers will be required. For those with organ failure quality of life will be related to the prevention of exacerbations of symptoms or early and effective treatment. Care will fluctuate between settings. In the final trajectory, where frailty and dementia prevail, the provision of supported long term care services either in the home or institution will be required. Carers need assistance and strategies for endurance; and they must be able to find meaning in caring for someone who may not have spoken or recognised them for months or years. In all cases advance directives, symptom control and providing family support during the person's illness and after the person's death are important. However, it is the group of people with serious, progressive, eventually fatal chronic illness that we are most concerned with in this paper, a group that has received very little attention from policy makers

EMERGENCE OF PALLIATIVE CARE IN LONG TERM CARE

Palliative care is now delivered in a broader range of settings and to a broader patient population than was the case when the first modern hospices, intended largely to meet

the needs of people with cancer, appeared in the 1960s. Currently available through in-patient palliative care units, hospitals, people's own homes, day care and long term care settings for older people, palliative care is now prescribed for people with other conditions (Addington-Hall and Higginson 2001), initially neurological conditions, AIDS, and more recently heart failure, renal disease and dementia (Abbey 1998).

Awareness of the palliative needs of older people dying in long term care settings has grown in both the UK and Australia since the early 1990s, mirroring what was happening in North America. Early descriptive studies (Hunt and Bond 1990; Maddocks 1996; Sidell et al. 1997) identified the importance of these care settings as places where dying occurred. Later studies began to promote interventions based on educational approaches (Sidell et al. 1997; Froggatt 2000) or to evaluate interventions such as link nurses, education, the use of palliative care nurse specialists and interface between specialist palliative care services and long term care settings (Parker et al. 2005a). Others (Froggatt and Hoult 2002; Ling 2005) identified remaining gaps in care, showing, for example, the limited extent to which palliative care clinical nurse specialists are engaged in long term care settings. New roles began to be developed for nurses at the end of the 1990s to support the development of palliative care in long term care settings, both in Australia (Maddocks et al. 1999) and the UK (Hirst 2004). As indicated in the earlier paper (Froggatt et al. 2006), these studies have remained largely descriptive and exploratory and further work is required to rigorously evaluate their impact and effectiveness on the care older people receive in this care setting.

Since 2000, the impetus to undertake research and develop practice in this area has increased. In Australia, a recent government initiative with the potential to foster such

change is the development of evidence based guidelines for a palliative approach in the long-term care setting (Australian Government Department of Health and Aging 2004). These guidelines are meant to assist RACFs to develop and apply suitable policies and procedures.

Under the Australian guidelines trained resource nurses will assist with implementation in each facility. The inclusion in the best practice model of a case conference where doctors, family and care staff attend to discuss management of end-of-life issues appears to be effective (Parker et al. 2005b). The fact that Australian doctors can now be reimbursed for this role through Medicare rebates will help to make this model of care sustainable.

In the UK, a three year government End of Life Programme (Department of Health 2003) is being funded to meet the needs of people dying in any setting, including care homes. Three specific tools are being promoted to support this initiative; an integrated care pathway for the last days of life (Ellershaw and Wilkinson 2003); a framework for identifying people who may require palliative care support (Thomas 2003); and a form of advance care planning (Storey et al. 2003). Whilst developed originally for hospital and community settings, these tools are being adapted for use in care homes. As indicated by (Partington 2006), there are challenges associated with the introduction of these tools to this care setting, which need to be addressed.

ISSUES OF DEVELOPMENT

Issues of transferability and sustainability have had a major impact on shaping care for older people towards the end of life in long term care settings. These concern what is being introduced and how it is being implemented.

Transferability

The form of palliative care developed decades ago to meet the needs of cancer patients, such as the use of education and palliative care nurse specialists, may need adaptation to suit patients with other terminal conditions (Froggatt 2001). The traditional palliative care teachings may omit some aspects of the care required for older people with chronic conditions. For example, the behavioural problems of a person with dementia may indicate the need for palliation as much as other physical symptoms (Hughes et al. 2005).

Promoting change in any care setting requires careful attention to the established practices within the existing context, especially the obstacles to change and the available means for pursuing it; and the form in which the new objectives need to be presented. Palliative care may challenge many of the practices embodied in the received wisdom in long term care settings. Difficulties in the implementation of palliative care in RACFs (Australian Government Department of Health and Aging 2004) are an illustration of the need to appropriately tailor initiatives to their context.

The traditional way of caring in RACFs – that is doing everything to keep people alive - makes nurses feel they are giving ‘good care’, treating the resident as a ‘person’ like any other, in possession of a life of their own, more or less unchanged until death occurs. These traditional ‘caring’ interventions may give rise to

inappropriate practices, such as getting people out of bed, even when they are very weak, or continuing with assisted feeding when food is being refused. Modifying such views and gaining acceptance of the value and appropriateness of palliative care where the focus is on relief of suffering and comfort rather than cure, will take a major educational initiative and cultural change.

Sustainability

A further factor concerns the sustainability of current change initiatives. Many of the projects and initiatives just described and noted elsewhere are short term initiatives, with no long term funding, which raises questions about their capacity to gain and keep adherents and develop through application and experimentation in diverse contexts over time (Froggatt 2002).

Sustainability may also be affected through the adoption of shallow change strategies. For example, a focus on the individual's thought or behaviour, that neglects the structure and dynamics of the organisational context, will rarely lead to sustained change and improvements over time. Such perspectives see the staff as deficient in terms of knowledge and skills and rest on the easy assumption that the provision of new knowledge will be enough to ensure that changes occur. As has already been established, education may be necessary, but it is not necessarily sufficient (Froggatt 2001).

There must be instead a 'root cause analysis' perspective, with subsequent interventions carefully aimed at the generative forces which have made the institution what it is. It is these that produce and reproduce each day the assumptions, mores and

imperatives that ‘realistically’ shape the range of imaginable futures and ‘naturally’ allocate priorities to the way energies and other resources are expended. This, the organisation’s hidden curriculum, will more often than not overwhelm by wearing down any hopes and aspirations aroused by training sessions provided in ‘time out’. A close examination of the wider organisational culture in which the staff are working is required to identify points of purchase for the forces of change (Hockley 2002; Hockley et al. 2005).

The current interest in palliative care provision in long term care may not be sustained at a governmental and policy level, as new issues arise and take precedence. Need is not enough to produce action, as numerous precedents demonstrate.

A VIEW OF THE FUTURE

We suggest that a systemic approach to change is more likely to lead to the evolution of a coherent and integrated multi-faceted action program with extensive stakeholder involvement under local ownership with protection and direction provided by higher levels of leadership. A common program is required, embracing the relevant disciplines and authorities, establishing shared milestones, with media able to disseminate news and views, and periodic events or occasions designed to renew and refresh the spirit of change until the goal is achieved. These are the qualities most likely to ensure the durability and effectiveness of a broadly-based campaign to redress the present deficits in the availability and quality of palliative care in long-term residential care facilities.

Four main forces or change levers must be harnessed to ensure coordinated action between policy makers and practitioners in order to pursue sustained overall improvement in health services (Ferlie and Shortell 2001). The four levers, are all clearly important in social planning and action: leadership, a culture that supports learning throughout the care process, an emphasis on effective team development and the use of information technologies for quality activities and external accountability.

The same integrated, comprehensive approach to change outlined above must be applied or supported at four levels: the environment in which the organisations operate, the organisation itself, the team and the level of the individual. For present purposes we limit our exposition of this perspective to a few illustrative examples.

Leadership

As outlined at the start of this paper we consider that the principles published to guide care for older people fall short of adequately recognising the need for end-of-life care a deficiency reflected in government policy and reproduced daily in bedside practice. Strong leadership is required at an international and national level to demonstrate that such reticence is not at all in the interests of older people and is incompatible with the introduction of appropriate and sought-after forms of end-of-life care in long term care settings. There has been some recent recognition of the importance of this in Europe (Davies and Higginson 2004; Froggatt 2004; Seymour et al. 2005) and Australia (Australian Government Department of Health and Aging 2004). However, further development is required to ensure this work is not marginalised and forgotten.

One clear marker of whether this issue is being taken seriously at a national level will be seen in the way in which the funding and resourcing of this care occurs. How policy makers tackle the funding of care will make the difference between a society that shows it has risen to the challenge of an ageing population and one that has not. Clear leadership that has recognised the need for end-of-life care in the long term care context and addressed fundamental issues of resourcing will then be in a position to support managers further down the system. Leaders of corporate and not-for profit organisations who manage groups of institutions, and leaders of individual care providers need to be confident and supported about the relevance and importance of the provision of palliative care at the end-of-life.

A culture that supports learning throughout the care process

Learning at all levels about end of life issues and care requires attention to these matters within public and policy domains as well as within long term care organisations. For individuals to have their needs met there must be a more open awareness of the inevitability of death within society generally. There is a place within the future programmes and structures for public education to increase awareness about dying and death (Kellehear 1999). Western society has become inured to dying and death as an observed phenomena rather than an experienced one. Some individuals, because of life events, do face up to their own mortality, but for the vast majority this is not addressed ahead of time. It is important that people have knowledge about the different kinds of palliative care available and the need for advance directives to guide this care when the person is no longer able to do so.

For too long within health care organisations the culture of ‘denial of death’ (Hudson and Richmond 1994) has also hampered learning. Leading ethicists and palliative care physicians in Australia have noted the change in public opinion about end-of-life issues, especially those related to futility, but also the difficulties that arise in day-to-day practice.

Despite polls reporting a widespread public pragmatism about death and dying (“I would never want to be a vegetable”, “When my time comes I do not want to be kept alive artificially”), when clinicians do try to discuss treatment abatement with patients and families, they often meet disbelief, even hostility. Clearly, polls reflect public attitudes as distinct from personal situations. In personal health care encounters, the idea that cure is improbable or impossible, or that continued life support is inappropriate or unkind, is unacceptable to many families. The wider problem here is that acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in our culture. (Ashby et al. 2005).

Palliative care requires long term care staff to readjust their focus and acquire skills and knowledge beyond their usual brief, in order to address specific end of life issues. Palliative care specialists too are required to consider their own educational needs as they are called upon to use their expertise for people in unfamiliar care settings and for individuals with non-cancer conditions.

As well as increasing the quantity and improving the realism of the available education about end of life issues, we must also ensure that the other structural,

processural and behavioural features that distinguish ‘learning cultures’, ‘learning environments’ and ‘learning organisations’ become standard practice in the conduct of long term care facilities and especially in the preparation and ongoing development of staff.

Emphasis on effective team development

The emergence of Nurse Practitioners, telemedicine and larger long-term care facilities will change the format of the present inter-disciplinary teams. A greater recognition of the importance of consumer involvement in the delivery of health and social care will need to be addressed. We must also acknowledge that such teams will increasingly be made up of people from different cultures, with different moral values and attitudes towards ageing and death. The workforce issues discussed previously will become more prominent in the next decade and, in both Australia and the UK, immigration will probably have to be increased to provide a workforce willing to undertake such jobs as working in long-term settings. This means teams will be made up of people with different language abilities, different attitudes and cultural understandings, constituting a new challenge, to ensure that the standard of care remains high and culturally appropriate in these circumstances. Measures introduced to raise present standards of care will need to anticipate and prepare for these population changes. Taking note of such issues as leadership and appropriate education become even more vital in these circumstances.

Both Australia and the UK, and many other places beside these, face workforce difficulties in the aged care sector. There are clear problems of recruitment and retention, linked to low pay and the low regard with which work with older people

and in the sector is regarded (Davies and Seymour 2002). The high turnover and increasing casualisation of staff in this setting impacts upon the ability to effect change in care practices and develop new approaches to care (Froggatt 2004). Attention to ways of working that value individual staff members may go some way to improving the work environment, although for reasons given above when discussing the role of individual education, it will not be sufficient in itself. The organisation and associated culture of the workplace is another powerful variable that if addressed can improve job satisfaction, reduce absenteeism, cut turnover and increase the power of transformational learning (Perlow and Weeks 2002). By these means, the quality of care provided to residents can be raised directly and indirectly.

Use of information technologies for quality activities and external accountability

Despite an explosion of the use of information technology in many aspects of our daily lives, the infiltration of information technology into health care in long term care settings has been minimal. The opportunity for staff at all levels to have access to information technology for gaining clinical knowledge, communicating with members of the health care team, overcoming professional isolation, improving record keeping and providing quality assurance opportunities should not be underestimated.

Widening access to technology and spreading competence in its use is an aspect of aged care management that has often been overlooked when planning for future models of care.

However, important as these developments are, their promotion and use must not hide the inter-personal work that is at the heart of good care. Technology should be seen as only a tool, not a master of what we do, despite its insidious capacity for inserting

itself between the provider and recipient of any service in ways that limit, apparently objectively, what is possible within the relationship. Unless this insight is widely shared and kept in mind, there is a risk that developing initiatives with sophisticated technological dimensions may be to the detriment of more fundamental input in caring work.

A WAY FORWARD

In order to address our vision for a way forward, we raise two of the many public policy issues which need to be tackled by the kind of systemic response we describe above.

Who will pay and how much?

In both the UK and Australia the move toward a much stronger ‘user pays’ focus in health care is emerging (Bruen 2005). If this agenda continues it will need to ensure that the money raised will provide the kind of end-of-life experience and managed death the baby boomers are seeking rather than the lack of quality found in some long term care settings in the United States (Kayser-Jones 2002). If the expectation is that the financial responsibility for funding old age will fall on taxpayers of working age with some co-payment from users then even the present standards may not be maintained, let alone improved, as the working age population decreases and the aged population increases. Careful attention will need to be given to the construction and operation of effective yet flexible regulatory bodies charged with ensuring reasonable standards are maintained, especially for those without the means of purchasing quality long-term care from their own resources.

If policy makers can set up schemes such as medical levies incorporated into the tax system, or workable and equitable insurance schemes, combined with an element of user pays, then we could have a sustainable and quality level of care to offer older people at the end of their lives. Without this we are likely to see an increase in the aged impoverishing themselves, an increase in older suicides (Catell 2000) and the 'granny dumping' phenomenon (Wilson 1992) that occurs elsewhere.

Public education and awareness

Given the known attributes of the baby boomer generation who are going to create increased demands upon the wider system, and will have high expectations with regard to their own care, there is a question of the way in which they take responsibility for their own futures. The number of people with advance directives is still very low. Using a public health perspective is a form of health promotion (Kellehear 1999). From this flows a need to build a well-funded and well designed public education component into future programmes and structures in order to increase public understanding of dying and death, including the vital need for advance directives. There have been no concerted efforts by governments in either country to support a wide ranging television/media campaign to raise public awareness of this issue. This needs to be on the agenda of every political party as a major public health issue.

CONCLUSIONS

Due partly to medical science and public health measures, the demographic profile is changing rapidly; and the last years of life are extending beyond anything even our

grandparents could have imagined, let alone their antecedents. Other changes, described earlier, combine to ensure that the context will not be as it has been.

But even as our active, healthy, later years continue to stretch out before us, another change - a change in public opinion as to what constitutes a life worth living and how much life is enough – is also occurring, inexorably. The recorded trend in public opinion on this matter over many years is sufficient to allow us to say that the public has made up its mind that new perspectives on this central human issue will be found and new avenues opened. Palliative care professionals in particular cannot leave themselves or their discipline unprepared for this epochal change.

The consequential question is: how then, in what circumstances, with what care and what priorities observed, do we want our lives to end? However precisely this issue unfolds, there is a daunting challenge ahead of society to equitably and humanely meet the changed needs of large numbers of frail, dependent older people in the last years of their lives. This challenge will be faced first and most commonly by the health services in long term care settings; and a new theory and practice of palliative care, adapted to that setting, will be a central part of the response.

We ask that leadership, starting at the level of the UN, through the WHO, faces these issues and encourages policy and resource decisions in member states that will make such care possible. We see the best possibility of providing this care is to change the culture, management structures, clinical orientations and practices, equipment and knowledge in long term care facilities.

It has been said that

the way we care for the dying and those who are in great difficulty as they come to death really is a sign or a symbol of the sort of society we wish to be, or wish to be known to be. (South Australian Parliament 1992).

Our vision is that our societies will rise to the challenge.

REFERENCES

- Abbey J. (1998). Breaking the silence: palliation for people with dementia. *Palliative Care Explorations and Challenges*. J. Parker and S. Aranda. Sydney, MacLennan and Petty: 172-183.
- Addington-Hall J. and I. Higginson, Eds. (2001). *Palliative Care for Non-Cancer Patients*. Oxford, Oxford University Press.
- Ashby M., A. Kellehear and B. Stoffell (2005) "Resolving conflict in end-of-life care." *eMJA*:
http://www.mja.com.au/public/issues/183_05_050905/ash10454_fm.html, 16th November 2005.
- Australian Government Department of Health and Aging (2004). Guidelines for a Palliative Approach in Residential Aged Care. Canberra, Rural Health and Palliative Care Branch, Australian Government Department of Health and Aging.
- Bruen W. (2005). Aged care in Australia: past, present and future. *Australasian Journal of Ageing* **24**(3): 130-133.
- Catell H. (2000). Suicide in the Elderly. *Advances in Psychiatric Treatment* **6**: 102-108.
- Davies E. and I. Higginson (2004). Better Palliative Care for Older People. Copenhagen, World Health Organisation.
- Davies S. and J. Seymour (2002). Historical and policy contexts. *Palliative Care for Older People in Care Homes*. J. Hockley and D. Clark. Buckingham, Open University Press: 4-33.

- Department of Health (2003). Building on the Best. Choice, Responsiveness and Equity in the NHS. London, HMSO.
- Ellershaw J. and S. Wilkinson (2003). *Care of the Dying. Pathway to Excellence*. Oxford, Oxford University Press.
- Ferlie E. and S. Shortell (2001). Improving the quality of health care in the United Kingdom and the United States: A framework for change. *The Millbank Quarterly* **79**(2): 281-315.
- Froggatt K. (2000). Evaluating a palliative care education project in nursing homes. *International Journal of Palliative Nursing* **6**(3): 140-146.
- Froggatt K. (2001). Palliative care and nursing homes: where next? *Palliative Medicine* **15**: 42-48.
- Froggatt K. (2002). Changing care practices through staff development: beyond education and training to practice development. *Palliative Care for Older People in Care Homes*. J. Hockley and D. Clarke. Buckingham, Open University Press: 151-164.
- Froggatt K. (2004). Palliative Care in Care Homes for Older People. London, The National Council for Palliative Care.
- Froggatt K. and L. Houlst (2002). Developing palliative care practice in nursing and residential care homes: the role of the clinical nurse specialist. *Journal of Clinical Nursing* **11**: 802-808.
- Froggatt K., D. Wilson, C. Justice, M. MacAdam, K. Leibovici, J. Kinch, R. Thomas and J. Choi (2006). End-of-life care for older people in long-term care settings: A literature review. *International Journal of Older People Nursing*.
- Hirst P. (2004). Establishing specialist palliative care provision for care homes. *Cancer Nursing Practice* **3**(2): 29-32.

- Hockley J. (2002). Organisational structures for enhancing standards of palliative care. *Palliative Care for Older People in Care Homes*. J. Hockley and D. Clark. Buckingham, Open University Press: 165-180.
- Hockley J., B. Dewar and J. Watson (2005). Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. *Journal of Research in Nursing* **10**(2): 135-152.
- Hudson R. and J. Richmond (1994). *Unique and Ordinary, Reflections on Living and Dying in a Nursing Home*. Melbourne, Ausmed.
- Hughes J., L. Robinson and L. Volicer (2005). Specialist palliative care in dementia. *British Medical Journal* **330**: 57-58.
- Hunt R. and M. Bond (1990). Terminal care in nursing homes: A survey of South Australian directors of nursing. *Geriatrics Autumn*: 7-8.
- Kayser-Jones J. (2002). The Experience of Dying: An Ethnographic Nursing Home Study. *The Gerontologist* **42**(III): 11-19.
- Kellehear A. (1999). *Health Promoting Palliative Care*. Oxford, Oxford University Press.
- Ling J. (2005). Palliative care in Irish nursing homes: the work of community clinical nurse specialists. *International Journal of Palliative Nursing* **11**(7): 314-321.
- Lynn J. and D. Adamson (2003). *Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age*. Santa Monica CA, RAND.
- Maddocks I. (1996). Palliative care in the nursing home. *Progress in Palliative Care* **4**(3): 77-78.
- Maddocks I., D. Parker, A. McLeod and P. Jenkin (1999). *Palliative Care Practitioners in Aged Care Facilities. Report to the Department of Human Sciences*. Adelaide, Flinders University.

Parker D., J. Abbey, C. Douglas, H. Edwards, C. Courtney and P. Yates (2005b).

Palliative care for people with end stage dementia. 8th National Palliative Care Australia Conference, Sydney.

Parker D., C. Grbich, M. Brown, I. Maddocks, E. Willis and P. Roe (2005a). A

palliative approach or specialist palliative care? What happens in aged care facilities for residents with a non-cancer diagnosis? *Journal of Palliative Care* **80-87**.

Partington L. (2006). The challenges of adopting care pathways for the dying for use in care homes. *International Journal of Older People Nursing*.

Perlow L. and J. Weeks (2002). Who's helping whom? Layers of culture and workplace behaviour. *Journal of Organizational Behavior* **23**: 345-361.

Productivity Commission (2005). Economic Implications of an Ageing Australia. *Research Report*. Canberra.

Seymour J., R. Witherspoon, M. Gott, H. Ross, S. Payne and T. Owen (2005). End of life care: promoting comfort, choice and well being for older people at the end of their lives. Bristol, The Policy Press with Help the Aged.

Sidell M., J. Katz and C. Komaromy (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.

South Australian Parliament (1992). Second Interim Report of the Select Committee of the House of Assembly on the Law and Practice Relating to Death and Dying. Adelaide.

Storey L., C. Pemberton, A. Howard and L. O'Donnell (2003). Place of death: Hobson's choice or patient choice? *Cancer Nursing Practice* **2(4)**: 33-38.

Thomas K. (2003). *Caring for the Dying at Home*. Abingdon, Radcliffe Medical Press.

United Nations (2002). The Second World Assembly on Ageing. Report Madrid. New York, United Nations.

Wilson J. (1992). Granny dumping: a case of caregiver stress or a problem relative? *Home Health Nurse* **10**(3): 69-70.