



Principles for inclusion of a palliative approach to aged care in undergraduate nursing curricula

September 2005



THE NATIONAL
PALLIATIVE CARE
PROGRAM

Prepared by Queensland University of Technology

ISBN: 0 642 82964 0

© Commonwealth of Australia [2005]

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from the Commonwealth available from the Australian Government Department of Communications, Information Technology and the Arts. Requests and inquiries concerning reproduction and rights should be addressed to the Commonwealth Copyright Administration, Intellectual Property Branch, Australian Government Department of Communications, Information Technology and the Arts, GPO Box 2154, Canberra ACT 2601 or posted at <http://www.dcita.gov.au/cca>.

Principles for Inclusion of a Palliative Approach to Aged Care in Undergraduate Nursing Curricula

Contents

Acknowledgements	2
1. Introduction	3
2. The Need for a Palliative Approach in the Care of Older People	4
3. Undergraduate Nursing Education in Aged and Palliative Care	6
4. Purpose and Outline of the Paper	8
5. Core Values	9
6. Desired Learning Outcomes	12
7. Principles for Learning and Teaching a Palliative Approach to Aged Care	21
8. Benchmarks for Inclusion of a Palliative Approach to Aged Care	22
References	23
Glossary	25
Appendix 1 - Project Participants	26
Appendix 2 – Australian Nursing and Midwifery Council Competency Standards for Registered Nurses	27
Appendix 3 – Guidelines for a Palliative Approach in Residential Aged Care – Summary of Guidelines	28

Acknowledgements

Funded by the Australian Government Department of Health and Ageing through the National Palliative Care Program, this paper builds on work undertaken to develop guidelines for a palliative approach to residential aged care, as well as two further Australian Government projects: the Palliative Care Curriculum for Undergraduates Project (PCC4U) and the Aged Care Nursing Curriculum Project. These latter projects sought to define core values, principles and strategies for improving the quality of undergraduate education in palliative care and aged care nursing respectively.

The work presented in this paper represents a synthesis of the original work developed by those involved in these three major initiatives:

- *A Project to Develop a Palliative Approach in Residential Aged Care*
- *Palliative Care Curriculum for Undergraduates Project*
- *Aged Care Nursing Curriculum Project*

The Project Team wishes to acknowledge the contributors to the above projects. The work from these projects has been used extensively in the development of the principles presented in this paper.

1.0 Introduction

The demographic profile of the Australian population has changed significantly as a result of increasing life expectancies and declining birth rates^{1,2}. The trend toward a progressively ageing population has placed increasing demands on health services to meet the needs of older people, many of whom may experience complex co-morbidities and chronic and life-limiting health problems.

The demand for improved health care services for the aged has highlighted the need for health professionals, and in particular nurses, to be adequately prepared for the unique challenges associated with the care of the older person. Given the particular health needs of the aged population, nurses require the capacity to incorporate a palliative approach when caring for older persons with life-limiting conditions.

The recent publication of *'Guidelines for a Palliative Approach to Residential Aged Care'* and the subsequent report on possible approaches to developing national training and education funded by the Australian Government Department of Health and Ageing, has provided evidence based guidance in the palliative approach for residents in aged care facilities. The purpose of the current project is to identify principles for promoting the incorporation of a palliative approach to aged care in undergraduate nursing curricula. As such, the primary focus of this project is to improve professional awareness and understanding of the principles and core values underpinning palliative care, specifically in the context of aged care nursing. The overall aim of this project is to improve access to quality palliative care for all persons who may benefit from such care.

Funded by the Australian Government Department of Health and Ageing through the National Palliative Care Program, this paper builds on work undertaken to develop guidelines for a palliative approach to residential aged care, as well as two further Australian Government projects: the *Palliative Care Curriculum for Undergraduates Project (PCC4U)* and the *Aged Care Nursing Curriculum Project*. These latter projects sought to define core values, principles and strategies for improving the quality of undergraduate education in palliative care and aged care nursing respectively. Drawing on these developments, this paper includes four components to guide and support inclusion of a palliative approach to care of older people in undergraduate nursing curricula. These components include:

- Core values
- Desirable learning outcomes
- Principles for learning and teaching
- Benchmarks for inclusion in curricula.

This paper was developed through a consultative process involving academics, clinical experts, and representatives from professional and consumer associations.

The Principles identified in this paper are derived from the *Guidelines for a Palliative Approach in Residential Aged Care* and the subsequent draft report on national education and training options related to residential aged care. The undergraduate nursing curricula prepares nurses to work in any health care setting, so these Principles are relevant for nurses working with older people in any health care setting, not only for those nurses working with older people in residential aged care.

2.0 The Need for a Palliative Approach in the Care of Older People

2.1 The needs of older persons with life-limiting conditions or who are dying as a consequence of the ageing process

The demographic profile of the Australian population has changed significantly over the past century, with predictions of significant growth in the number of aged persons in the future (up to 4.2 million or 18% of the total population in 20 years time).^{3,4} Currently in Australia 12% of the total population is aged 65 years and over and it is predicted that this will increase to around 25% by the year 2041.⁴ The progressive increase in life expectancies and declining birth rates have resulted in an increasingly ageing population^{3,4} and it is predicted that the numbers of the very old (over 80 years), will triple over the next 50 years.^{1,4}

As the population continues to age, the incidence of people diagnosed with serious chronic and life-limiting conditions such as heart disease, respiratory disease and cancers increases. Additionally, older people often have co-morbidities accompanied by significant functional impairment and prolonged periods of symptoms.⁵ Many older persons thus have health and support needs that may benefit from palliative support that enables them to achieve the best possible quality of life through effective symptom management and maintenance of functional ability.²

However, the care issues for this population are especially complex. Care of older persons with chronic or complex illnesses may also require a palliative approach when they are dying due to the ageing process, that is not only as a consequence of an incurable disease². Older persons with chronic and complex illnesses are considered to have different palliative needs to those people diagnosed with other diseases such as cancer². These differences may include that:

- They have multiple clinical diagnoses that require a variety of treatments
- They require end-of-life (terminal) care for a shorter length of time (an average time of two days of intense care prior to death)

- Confusion, dementia, and/or communication difficulties may be present
- They require a palliative approach for long periods to promote quality of life and reduce suffering through adequate assessment and management of symptoms².

Therefore, there is a special need for older persons with a life-limiting illness or who are dying as a consequence of the ageing process to receive a palliative approach.

2.2 A palliative approach in aged care

Palliative care has been defined by the World Health Organization⁶ (WHO) as:

...an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The WHO⁶ further states that palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

This definition emphasises that the need for palliative care does not depend on a specific medical diagnosis, but on the person's needs. Palliative care is delivered, where possible, where the person wants to be, and can be provided in the person's own home, a specialist in-patient hospice unit, a hospital, or a residential care facility.⁷

While not all older persons with a life-limiting condition will require the support of specialist palliative care services, there is a growing body of evidence that supports the inclusion of a palliative approach to the care of older people^{2,8}. A *palliative approach* in aged care aims to improve the quality of life for people with life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.² A palliative approach is not confined to the end stages of an illness. Instead, it provides a focus on active comfort care and a positive approach to reducing a person's symptoms and distress, allowing residents and their families to understand that they are being actively supported through this process. Involvement of a specialised palliative service may augment a palliative approach with focused, intermittent specific input sought by consultation and referral as required². This distinction emphasises that all persons with life-limiting conditions require careful attention and appropriate responses to the concerns, fears and needs associated with dying. Effective palliative care practices will help to provide older persons with the option to die in familiar and comfortable surroundings among people who are, and have been a part of their normal daily life².

A *palliative approach* to care has become increasingly recognised as being a set of core skills required of every clinician who may, in addition, seek expert palliative specialist help to ensure the best possible quality of life for the person when this is required.⁹ As such, nurses involved in the care of the older person in any health care setting require core knowledge and skills in the palliative approach, in order to meet the essential health needs of this population.

2.3 The national palliative care strategy

The National Palliative Care Strategy (NPCS)¹⁰ has three primary goals:

1. To improve community and professional awareness and understanding of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families of care;
2. To support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia;
3. To promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings.

The NPCS represents the commitment of the Australian Government, and the State and Territory governments, in conjunction with other key stakeholders, to the development and implementation of palliative care policies, strategies and services that are consistent across Australia, and to the delivery of quality palliative care that is accessible to all people who are dying.

2.4 A project to develop a palliative approach in residential aged care.

The development of the *Guidelines for a Palliative Approach in Residential Aged Care* was funded through the National Palliative Care Program (NCP) and supports the goals of the NPCS. Edith Cowan University led the development of these evidence based guidelines, which aim to support and guide the delivery of a palliative approach in the 3,000 plus residential aged care facilities across Australia. The development of a framework for education and training of health workers in palliative aged care comprised four components:

1. Development of a list of aged and/or palliative care education and training providers in Australia.
2. Determining competencies for a palliative approach in RACFs for each level of workers in the aged care team. These were developed through a two stage Delphi process with a range of stakeholders.
3. Gap analysis to identify the discrepancy between competencies that already exist in education and training programs and those required for the implementation of the Guidelines.
4. Development of a report on options for national training and education based on the Guidelines to enable the aged care team to develop competencies in providing a palliative approach in residential aged care which includes:
 - Competencies (developed using the Delphi process at stage two), with competency elements and performance criteria; and
 - Stages of education and training.

The report provided the basis for further work around developing training and education strategies to support implementation of the Guidelines. The Department of Health and Ageing has recognised that there is a range of staff working in the residential aged sector with varying educational requirements. The purpose of this paper is to provide principles for promoting the incorporation of a palliative approach in aged care in undergraduate nursing curricula. As such, the primary purpose of this paper is to improve professional awareness and understanding of the principles and core values underpinning palliative care, specifically in the context of aged care nursing. The overall aim of the project is to improve the quality of life for all older persons as they near the end of their life. Other projects will support the implementation of the Guidelines and address training for other health care workers.

3.0 Undergraduate Nursing Education in Aged and Palliative Care

3.1 Nursing education in aged care

Reviews of undergraduate nursing curricula in Australia suggest that the current educational preparation of student nurses in aged care is not always adequate. A review by Pearson et al.¹¹ on Australian aged care nursing identified that undergraduate nursing education concentrated on primary health care and acute hospital services, rather than aged care topics. Similarly, a recent review by the Nurses' Board of Victoria (NBV) of aged care content in undergraduate nursing curricula in Victoria found an absence of identifiable educational strategies to ensure student nurses were prepared and competent in the care of older people¹². Difficulties obtaining quality clinical placements in aged care with positive learning environments have been highlighted in both the NBV review¹² as well as Fitzgerald et al.'s¹³ systematic review of nursing curricula clinical education in Australia. Lack of recognition of the need for aged care preparation and the poor image of aged care nursing may also influence the degree of aged care content within undergraduate nursing curricula. The NBV report further noted that aged care subjects or clinical placements were often scheduled in the first year of the Bachelor of Nursing degree, giving students the impression that aged care was simple and of lesser importance¹².

Historically, there has not been a high level of demand or interest from nurses to practice or specialise in gerontological nursing. Aged care nursing generally has a poor image among student nurses, qualified nurses and within the broader community^{11,14}. Contributing factors include ageism¹⁵, the perceived lack of status and/or excitement associated with non-acute nursing¹⁶⁻¹⁸ and relatively poorer rates of pay and working conditions within the aged care sector^{11,19}.

It was against this background that the Australian Government recognised the need to promote nurses caring for older people¹⁴. The provision of quality health care services for older people is a goal relevant to every member of the Australian population and all health care professionals. Addressing undergraduate nursing education in aged care is one strategy to achieve this goal.

In September 2002, representatives from academia, the Nurses Registration Boards, Council of Deans in Nursing and national aged care sector stakeholders met to determine the extent of aged care content in nursing undergraduate curricula in Australian universities and how best to support the Government's initiatives. The following issues were raised:

- How well aged care nursing content was integrated into undergraduate nursing curricula around Australia was questioned;
- Teaching of aged care nursing within Australian universities was highly individualistic;
- Aged care nursing content in undergraduate nursing curricula tended to be biased toward acute nursing care practices; and
- The capacity of universities to teach aged care was questioned²⁰.

In response to these issues, in February 2003 a project to develop principles for a core component of aged care in undergraduate nursing curricula was commissioned. The project involved consultation with experts in aged care from academia and representatives from professional nursing organisations, aged care industry organisations and consumer organisations. The principles developed for the aged care curriculum project provide a framework for considering how a palliative approach in aged care may be incorporated into undergraduate nursing curricula⁴.

3.2 Nursing education in palliative care

Limited emphasis has been placed on establishing core palliative care curricula, with only a few surveys of palliative care nursing curricula reported in the literature²¹⁻²⁵. In 1994, the European Oncology Nursing Society identified core elements of a curriculum for pre-registration courses in all European Union member states. The curriculum has five themes, the overarching one being the principles of palliative care. The four others are symptom control, facing death, ethical and legal issues and communication. An ideal of twelve hours teaching time was recommended although no specific guidance was given as to when in the course this should occur, or over what period of time²⁴.

More recently in the United Kingdom, Lloyd-Williams and Field²¹ surveyed nursing schools offering both diploma and degree courses. However as only 40% responded, results may not reflect all courses. All programs offered topics in palliative care with twelve teaching hours on average for degree courses and eight hours for diploma courses. Teaching was largely didactic with limited opportunity for clinical placement. There was also difficulty in identifying appropriately qualified teachers but the need to provide teaching from the interdisciplinary team was considered important. Respondents identified the importance of including palliative care within the curriculum but highlighted the issue of fitting this into crowded curricula. Similar to surveys of other curricula, the authors found that 76% of degree and 83% of diploma courses did not formally assess the palliative care content. The authors concluded that current palliative care content in undergraduate nursing courses would not equip students with the knowledge and skills they require.

In Australia, a 1994 survey by Burney-Banfield²⁴ provides the most comprehensive understanding of palliative care teaching in undergraduate nursing programs. The survey was sent to all 45 Australian tertiary institutions listed in the Directory of Higher Education Census 1991/2 offering undergraduate nursing programs. A response was received from 28 program coordinators (62.2%). A wide range of time was spent on death education (5-192 hours) across the programs. Topics where most hours were devoted were on emotional, behavioural and cognitive reactions of the nurse, personal coping strategies and types of loss. In 19 of the 28 programs clinical experience was the primary teaching strategy although a combination of didactic, experiential and clinical experience were used in most programs. The survey did not explore the timing of the education or curricula format.

More recently, two surveys were conducted as part of the scoping and consultative phase of the Australian Government's *Palliative Care Curriculum for Undergraduates* (PCC4U) Project²⁶. The *Palliative Care Curriculum* Scoping Survey involved a survey of course coordinators for all undergraduate health courses in Australia. Of the 18 nursing course coordinators who responded to the survey, 13 indicated that palliative care was included only to a minor degree in their course, with total hours dedicated to palliative care ranging from 6-80 hours. Despite the limited extent to which palliative care appears to be included in today's nursing curricula, over 60% felt their curriculum reflected a palliative approach, at least to a moderate degree, with fourteen of the respondents indicating that palliative care was integrated throughout the curriculum rather than taught as a discrete unit. Respondents identified barriers to inclusion of palliative care including lack of time, few placement opportunities and limited clinical exposure, and lack of staff knowledge about palliative care.

A second survey of 710 health professionals working in palliative care or in training positions in health facilities was distributed by the PCC4U team in early 2004 to identify health professionals' perceptions of the attributes required for graduates to provide palliative care²⁶. Of the 125 nurse respondents, only around 42% agreed that palliative skills were well developed in their discipline. Nurse respondents identified topics of communication, pain and symptom assessment and management, and psychological care as being important for inclusion in undergraduate training in palliative care. Similar to the barriers identified by nurse academics, clinicians identified barriers to inclusion of palliative care in undergraduate curricula as being an already crowded curriculum and lack of understanding of palliative care.

4.0 Purpose and Outline of the Paper

There is limited data to determine the extent to which a palliative approach in aged care is reflected in current undergraduate curricula. The increasing recognition of the unique needs of older persons who are dying, especially those who do not have a diagnosis of cancer, suggests that the development of clearly defined principles to provide guidance for curriculum design and selection of teaching and learning strategies will assist with promoting the uptake of best practice in this field.

This paper outlines:

- The core values underpinning teaching and learning of a palliative approach to aged care in undergraduate nursing curricula;
- Desirable learning outcomes associated with a palliative approach to aged care in undergraduate nursing curricula;
- Principles for teaching and learning a palliative approach to aged care in undergraduate nursing curricula;
- Benchmarks for inclusion of a palliative approach of aged care content in undergraduate nursing curricula;
- Resources/materials to support the inclusion of a palliative approach to aged care in undergraduate nursing curricula.

The paper is intended to provide a resource for regulatory and professional bodies with respect to standards required for nurse education programs, as well as for educators in university and clinical settings to provide a framework for including a palliative approach to aged care in undergraduate nursing education.

Consistent with the objectives of the National Palliative Care Strategy, the overall objective of documenting and disseminating principles for inclusion of a palliative approach to aged care in undergraduate nursing education is to:

- Improve professional awareness and understanding of, and commitment to palliative care practices; and
- Support continuous improvement in the quality and effectiveness of palliative care service delivery.

5.0 Core Values

5.1 Core values underpinning a palliative approach in aged care nursing

Palliative Care Australia⁷ has developed national palliative care service standards based on the core values and principles of:

- The **dignity** of the patient, their caregiver/s and family
- **Empowerment** of the patient, their caregiver/s and family
- **Compassion towards** the patient, their caregiver/s and family
- **Equity** in access to palliative care services and allocation of resources
- **Respect** for the patient, their caregiver/s and family
- **Advocacy** on behalf of the expressed wishes of patients, families and communities
- **Excellence** in the provision of care and support
- **Accountability** to patients, caregiver/s, families and the community.

Two principal core values underpinning the care of older persons were developed as part of the Aged Care Nursing Curricula project⁴. These values were developed so that they could be identified and examined by students during their undergraduate nursing course, and included respect for personhood at all times, and the right to quality care in all settings.

When caring for the older person with a life-limiting illness or who is dying as a consequence of the ageing process, the core values defined for aged care nursing will be applied with particular attention to the following principles:

Core value in aged care nursing: to respect personhood at all times.

- The older person is entitled to be cared for with the same dignity and respect as all members of humanity.
- The older person has the same rights as other adults, including the right to take risks if desired.
- The older person is entitled to have choice and control in their environment, manner of living and health care.
- The individuality, diverse backgrounds and natural networks of older people are recognised and respected.

In the context of a palliative approach in aged care, these values are expressed by:

- Quality of life concerns of the older person are considered and incorporated in decision-making.
- The unique spirituality of the older person is supported.
- The older person's decisions regarding treatment options are to be respected.

Core Value in Aged Care Nursing: To have the right to quality care in all settings.

- Quality care incorporates the commitment to evidence based practice.
- Quality care reflects the respect for personhood identified above.
- Quality care incorporates culturally appropriate holistic care.
- Quality care incorporates care that is therapeutic and safe.
- Quality care incorporates individualised care, provided by skilled, specialised interdisciplinary teams of aged care health professionals.

In the context of a palliative approach in aged care, these values are expressed by:

- Quality care incorporates the whole person approach, including the older person's past life experiences and their current situation.
- Quality care incorporates care of the older person, their family and significant others.
- Quality care incorporates the principles of quality of life and good symptom control.
- Quality care incorporates open and sensitive communication.
- Quality care incorporates a positive and open attitude towards death and dying.
- Quality care incorporating a palliative approach is accessible and available to all older people regardless of the setting.

5.2 Core values underpinning the learning and teaching of a palliative approach to aged care

Core values underpinning the learning and teaching of aged care in undergraduate nursing curricula were developed as part of the Aged Care Nursing Curricula Project⁵. These values and their application in the specific context of a palliative approach in aged care include:

5.2.1 Aged care content should be a significant compulsory component of the undergraduate nursing curriculum and be integrated throughout the undergraduate nursing curriculum. Aged care content should be clearly identifiable and incremental across each year of study.

Application: A palliative approach in aged care should be integrated throughout the entire curriculum.

5.2.2 The learning and teaching of aged care should reflect the core values 'to respect personhood at all times' and 'to have the right to quality care in all settings'.

Application: The curricula should reflect attention to quality of life concerns of the older person, access to quality care, the whole person approach, care for their family and significant others, attention to spiritual needs, open and sensitive communication, a positive and open attitude towards death and dying, and decisions around treatment options.

5.2.3 The provision of positive role models and messages related to ageing in university and health service providers are essential to the learning and teaching of aged care in undergraduate nursing curricula.

Application: Role models and messages should reflect a positive and open attitude to ageing and dying as a normal part of the life cycle. The curricula should reflect the role of a palliative approach to care of older persons with a life-limiting condition or who are dying as a consequence of the ageing process.

- 5.2.4 Good partnerships between universities and health service providers are a necessary attribute of learning and teaching aged care and linkages with interdisciplinary teams are highly valued.

Application: Partnerships between universities, palliative care and aged care services should be fostered.

- 5.2.5 Aged care content should be taught from an evidence based approach.

Application: The curriculum content should reflect a palliative approach in aged care that relies on the best available evidence within the context of clinical expertise and patient values.

- 5.2.6 A focus on student learning outcomes is necessary.

Application: Learning and teaching strategies should encompass the beliefs, values and emotions of nurses as well as the clinical skills and knowledge required.

- 5.2.7 Aged care content should be of equal status with other areas of clinical specialty.

Application: A palliative approach to care of older persons needs to be a core skill of every clinician, no matter what their practice setting, and therefore should be an integral component of undergraduate curricula.

6.0 Desired Learning Outcomes

Currently, nurses in Australia are regulated and accountable to the community for providing high quality care through safe and effective work practice²⁷. The Australian Nursing and Midwifery Council (ANMC) has developed National Competency Standards that provide a framework for professional nursing practice. These competency standards encompass the various roles and functions that nurses fulfil, and identify the attributes that a competent nurse is expected to demonstrate²⁷.

Education courses leading to registration, or enrolment, are accredited by nurse regulatory authorities. Importantly, the regulatory authorities and education programs require graduates to demonstrate the ANMC competency standards. The competency standards assist by providing a framework for course development and ensuring that registered nurses are fit to provide safe, competent care in a variety of settings²⁷.

As part of the Australian Government's Aged Care Nursing Curriculum Project⁴, a set of desired learning outcomes for aged care content in undergraduate nursing curricula was developed to integrate with the ANMC competency standards framework. These learning outcomes defined specific knowledge, skills and attitudes related to the nursing care of older persons that should be evident in graduates from an undergraduate nursing course.

To facilitate a *palliative approach in aged care nursing*, a set of desired learning outcomes for undergraduate curricula need to be articulated. The desired learning outcomes associated with a palliative approach in aged nursing have thus been developed to ensure integration with the following existing curriculum and practice frameworks:

1. *ANMC Competency Domains*: ANMC defines four core domains of nursing practice: Professional and Ethical Practice; Critical Thinking; Management of Care; and Enabling. These four domains are used as an organising framework for categorising learning outcomes associated with a palliative approach in aged

care. These ANMC Domains and related competency standards are included as Appendix 2.

2. *Guidelines for a Palliative Approach in Residential Aged Care*²: The key elements of practice defined in these Guidelines have been examined to define the context in which each of the four domains may be applied when providing a palliative approach to aged care nursing. The 83 Guidelines identified in the Guidelines for a Palliative Approach in Residential Aged Care are included as Appendix 3.
3. *Desired Learning Outcomes for Aged Care Nursing*⁴ and *Graduate Capabilities in Palliative Care*²⁶: The desired learning outcomes for aged care nursing and the graduate capabilities for palliative care that relate to the four domains of practice outlined in the ANMC competencies are described. These learning outcomes and graduate capabilities were developed as part of previous Australian Government initiatives.
4. *Draft Report on Options for National Education and Training for a Palliative Approach in Residential Aged Care*: This draft report identifies competencies based on best practice principles. The competencies have been examined and incorporated into the specific learning outcomes associated with a palliative approach in aged care for each domain.

To provide guidance for those involved in the education of undergraduate nursing students and to facilitate their integration into existing curricula, this document identifies the specific *desired learning outcomes for a palliative approach to aged care*, mapped against these existing frameworks and guidelines for nursing education and practice in Australia (see below). As shown, the ANMC Competencies have been used to provide the over arching framework for the articulation of learning outcomes for a palliative approach to aged care.

DOMAIN

Identifies a core domain of nursing, as defined by the ANMC

Context

This section includes a description of the context in which the core domain of practice may be applied when providing a palliative approach to aged care.

COLUMN A	COLUMN B	COLUMN C
Learning Outcomes for Aged Care Nursing Graduate Capabilities in Palliative Care	Specific Learning Outcomes Associated with a Palliative Approach in Aged Care	Associated Competency Standard
<p>This section includes a listing of the following outcomes that relate to this domain and context of practice:</p> <ul style="list-style-type: none">• Learning Outcomes in Aged Care Nursing (drawn from the Aged Care Nursing Curriculum Project) <i>AND</i>• Graduate Capabilities in Palliative Care drawn from the PCC4U Project and Standards for Providing Quality Palliative Care for all Australians (Palliative Care Australia 4th Edition).	<p>This section includes a description of the specific learning outcomes associated with a palliative approach to aged care that would be reflected in the curriculum component addressing the learning outcomes for aged care nursing and graduate capabilities in palliative care associated with this domain of practice (listed in Column A).</p> <p>This section includes information drawn from:</p> <ul style="list-style-type: none">• Standards for Providing Quality Palliative Care for All Australians (drawn from Palliative Care Australia's 4th Edition Standards) <i>AND</i>• Guidelines for a Palliative Approach in Residential Aged Care <i>AND</i>• Draft Report on National Education and Training Options.	<p>This section includes a listing of the ANMC Competency Standards that relate to the specified domain of practice.</p> <p>These competency standards provide the overarching framework for the articulation of specific <i>learning outcomes for a palliative approach to aged care</i> (described in column B).</p>

DOMAIN: Professional and Ethical practice

Context

In the context of providing a palliative approach in aged care, practice within the professional and ethical domain should reflect an emphasis on maintaining the older person's dignity at the end of their life and in the period leading up to the end-of-life. Such practice incorporates the older person's quality of life concerns in decision-making, respectful attention and understanding of diverse cultural needs taking into account beliefs regarding illness, healing, comfort, care practices, location of care, and death and dying, and respect for the unique spiritual needs of the older person.²

Care that enhances the dignity of the older person is part of a palliative approach and is a general therapeutic goal for all people who are dying. Factors that contribute to retaining dignity are: having adequate pain and symptom management, appropriate incontinence management, relieving burdens, achieving a sense of control, strengthening relationships with family and significant others, having the capacity to communicate, being able to recognise friends and family members, and avoiding inappropriate prolongation of dying.² Awareness of legal and ethical guidelines for decision making, including the role of a comprehensive advance care plan that addresses all relevant issues as the older person's state of health changes over time is integral to nursing practice.

DOMAIN: Professional and Ethical practice

Learning Outcomes for Aged Care Nursing/Graduate Capabilities in Palliative Care	Specific Learning Outcomes Associated with a Palliative Approach in Aged Care	Associated ANMC Competency Standard
<p><i>Learning Outcomes for Aged Care Nursing:</i></p> <p>Demonstrate knowledge and respect of the rights of the older person to enable the older person to maintain control over their environment, manner of living and health care.</p> <p>Plan and deliver nursing care that incorporates respect and understanding of the older person's individual beliefs, background and choices.</p> <p><i>Graduate Capabilities in Palliative Care:</i></p> <p>Respect and understanding of the diverse human and clinical responses of the individual/s throughout an illness trajectory.</p>	<p>Apply legal and ethical decision making principles in planning and delivering care of the older person with a life-limiting illness or who is dying as a result of the ageing process.</p> <p>Acknowledge the need to assess and communicate potential benefits and adverse effects of health care interventions whilst respecting the older person's wishes for treatment.</p> <p>Understand the function and application of advance care planning in decision making and care planning.</p> <p>Provide culturally appropriate care that demonstrates respect and understanding for older person's beliefs and preferences regarding health and illness, care provision, location of care and death, dying and grieving.</p> <p>Provide care that promotes and maintains the dignity of the older person with a life-limiting illness or who is dying as a result of the ageing process.</p> <p>Understand and respond appropriately to the spiritual needs of the older person with a life-limiting illness or who is dying as a result of the ageing process and his/her family.</p> <p>Accept responsibility and accountability for facilitating care that incorporates quality of life concerns in decision-making, a focus on effective symptom management, promoting personal control and relief of burden.</p>	<p>Unit 1 Functions in accordance with legislation and common law affecting nursing practice.</p> <p>Unit 2 Conducts nursing practice in a way that can be ethically justified.</p> <p>Unit 3 Protects the rights of individuals and groups in relation to health care.</p> <p>Unit 4 Accepts accountability and responsibility for own actions within nursing practice.</p>

DOMAIN: Critical Thinking and Analysis

Context

In the context of providing a palliative approach in aged care, this domain of practice should emphasise evidence based approaches to palliative care, and regular education programs for the aged care team, older persons and their families on issues about end-of-life care. It should also emphasise appropriate support for members of the team to deal with the experiences of loss and grief associated with death of older persons with whom they have established meaningful relationships.

DOMAIN: Critical Thinking and Analysis

Learning Outcomes for Aged Care Nursing/Graduate Capabilities in Palliative Care	Specific Learning Outcomes Associated with a Palliative Approach in Aged Care	Associated Competency Standard
<p><i>Learning Outcomes for Aged Care Nursing:</i></p> <p>Plan and deliver evidence based nursing care relevant to older people in a variety of settings.</p> <p>Identify the complexity of gerontological nursing and be aware of its importance as a clinical speciality.</p> <p><i>Graduate Capabilities in Palliative Care:</i></p> <p>Understanding principles for assessment and management of clinical and support needs</p> <p>The capacity for reflection and self evaluation of one's professional and personal experiences and their impact on the self and others.</p>	<p>Demonstrate knowledge of the principles, aims and philosophy of a palliative approach in aged care.</p> <p>Provide care that reflects an understanding of the unique needs of the older person with a life-limiting illness or who is dying as a result of the ageing process, including the needs of their family and significant others.</p> <p>Acknowledge that dying is a normal part of the life cycle.</p> <p>Nursing care provided is based on current evidence and best practice principles.</p> <p>Understand the impact of own personal attitudes and values on the provision of a palliative approach.</p> <p>Use the Guidelines for a Palliative Approach in Residential Aged Care and other relevant sources of evidence to plan and deliver care of the older person with a life-limiting illness or who is dying as a result of the ageing process.</p> <p>Actively participate in debriefing sessions with colleagues and critically reflect on own practice.</p> <p>Acknowledge personal and team members' need for professional development and support to deal with personal loss and stressors associated with care of older persons who are dying.</p> <p>Contribute constructively to the conduct of research into the provision of a palliative approach to care of the older person with a life-limiting illness or who is dying as a result of the ageing process.</p>	<p>Unit 5 Acts to enhance the professional development of self and others.</p> <p>Unit 6 Values research in contributing to developments in nursing and improved standards of care.</p>

DOMAIN: Management of Care

Context

In the context of providing a palliative approach to aged care, this domain of practice should reflect emphasis on appropriate treatment plans being developed from a comprehensive assessment of the older person's needs using appropriate tools and processes, including early identification of symptoms and needs such as pain, depression, cachexia, bowel function, oral health, cognitive function, intimacy and sexuality needs, incorporating continual follow-up evaluation. A comprehensive plan of care, including ready access to appropriate medication treatment along with non-pharmacological interventions is recommended.² The importance of interdisciplinary assessment for specific problems such as dysphagia may be beneficial in promoting early recognition, appropriate management and prevention of complications.²

Careful consideration should be given to the role of aggressive treatment and its capacity for improving quality of life in situations such as infection and eating difficulties, with a combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach being considered best practice.²

Assessment of an older person's needs may be compromised by communication difficulties, however many older persons can answer questions regarding their quality of life even when significant symptoms of dementia are present, and as such particular attention to ascertaining an older person's preferences for quality of life concerns should still be sought and incorporated in decision-making.² Specific assessment tools may at times be required.

A palliative approach benefits the family as well as the older person, and as such the needs and concerns of family members and significant others should be addressed.

DOMAIN: Management of Care

Learning Outcomes for Aged Care Nursing/Graduate Capabilities in Palliative Care	Specific Learning Outcomes Associated with a Palliative Approach in Aged Care	Associated Competency Standard
<p><i>Learning Outcomes for Aged Care Nursing:</i> Plan and deliver nursing care which incorporates physical, psychological, social, cultural and spiritual aspects/knowledge pertaining to the older person.</p> <p><i>Graduate Capabilities in Palliative Care:</i> Apply principles for assessment and management of clinical and support needs.</p>	<p>Plan and deliver palliative care "...in good faith and with reasonable care and skill³³."</p> <p>Undertake multidimensional and continuous assessment of common physical symptoms for the older person with a life-limiting illness or who is dying as a result of the ageing process, using multiple approaches to gathering information.</p> <p>Practice in a way that meets the special needs of people with dementia or other communication difficulties.</p> <p>Apply evidence based principles in the management of common symptoms (spiritual, emotional and physical) experienced by older persons for the older person with a life-limiting illness or who is dying as a result of the ageing process.</p> <p>Assess and provide support for the emotional, social and spiritual needs of the older person with a life-limiting illness or who is dying as a result of the ageing process and their family.</p> <p>Assess and provide support for the relationships, intimacy and sexuality needs of the older person for the older person with a life-limiting illness or who is dying as a result of the ageing process.</p> <p>Provide support for the older person and his/her family and significant others in the loss, grief and bereavement process.</p> <p>Plan and deliver care that is responsive to changing needs and goals of care of the older person with a life-limiting illness or who is dying as a result of the ageing process.</p> <p>Determine the effectiveness of nursing interventions on clinical outcomes through regular and ongoing assessment of the older person.</p>	<p>Unit 7 Carries out a comprehensive and accurate nursing assessment of individuals and groups in a variety of settings.</p> <p>Unit 8 Formulates a plan of care in collaboration with individuals and groups.</p> <p>Unit 9 Implements planned nursing care to achieve identified outcomes within scope of competency.</p> <p>Unit 10 Evaluates progress toward expected outcomes and reviews and revises plans in accordance with evaluation data.</p>

DOMAIN: Enabling

Context

In the context of providing a palliative approach in aged care, this domain of practice should reflect emphasis on the care of persons in their environment of choice where possible, providing information about a palliative approach and the end phase of life to older persons their families and significant others according to their needs and wishes, the use of comfort measures to enhance a sense of control, wellbeing and self regard, effective communication with families and assessment of their needs and coping, and identifying and drawing on sources of social and emotional support for the older person and their family and significant others prior to and following the older person's death.

An interdisciplinary team, which may include trained volunteers, that promotes goal setting in collaboration with the family is critical to the success of a palliative approach.² Incorporating the use of specialised health practitioners who have expertise in assessment and care of older persons with clinical problems such as uncontrolled symptoms, depression, agitation, loss and/or anxiety should be considered where such needs are identified.

DOMAIN: Enabling

Learning Outcomes for Aged Care Nursing/Graduate Capabilities in Palliative Care	Specific Learning Outcomes Associated with a Palliative Approach in Aged Care	Associated Competency Standard
<p><i>Learning Outcomes for Aged Care Nursing:</i></p> <p>Communicate and network with interdisciplinary teams of health professionals skilled in aged care when planning, delivering and assessing care of the older person.</p> <p>Act as an advocate for the positive aspects of ageing.</p> <p>Apply knowledge of safe and therapeutic care when planning and providing nursing care of the older person.</p> <p>Identify and respect the natural networks of the older person and involve them in that person's care.</p> <p><i>Graduate Capabilities in Palliative Care:</i></p> <p>Effective communication in the context of an individual's responses to loss and grief, existential challenges, uncertainty and changing goals of care.</p>	<p>Communicate with members of the interdisciplinary care team including the older person, their family and significant others where required to plan and deliver a palliative approach to care and obtain expert advice where required.</p> <p>Analyse societal, cultural and local community influences on how a palliative approach is implemented for older persons.</p> <p>Provide information to older persons, their family and significant others about the palliative approach and respond appropriately to questions about death and dying.</p> <p>Establish and maintain an environment that encourages the older person who is dying to express his/her values, needs, feelings and preferences in relation to optimal end-of-life care.</p> <p>Assess and respect the wishes, choice and skills of the family and significant others, regarding their participation in care.</p>	<p>Unit 11 Contributes to the maintenance of an environment which promotes safety, security and personal integrity of individuals and groups.</p> <p>Unit 12 Communicates effectively with individuals and groups.</p> <p>Unit 13 Manages effectively the nursing care of individuals and groups.</p> <p>Unit 14 Collaborates with other members of the health care team.</p>

7.0 Principles for Learning and Teaching a Palliative Approach in Aged Care in Undergraduate Nursing Curricula

- 7.1 Expertise in a palliative approach is essential to facilitate the integration and teaching of a palliative approach in aged care content in undergraduate nursing curricula.
- 7.2 The involvement of recognised industry, academic and clinical experts and consumers in a palliative approach in aged care is important in the teaching of a palliative approach to aged care in undergraduate nursing curricula.
- 7.3 Evidence of evaluation of palliative and aged care content in consultation with industry, professional bodies and consumers and students should be conducted regularly, eg. annually or at the time of each review of the undergraduate nursing curriculum.
- 7.4 A palliative approach should be reflected in aged care content, integrated throughout the undergraduate nursing curricula and should form a core component of aged care content.
- 7.5 Students need opportunities to integrate the principles of a palliative approach in ageing in a variety of clinical practice settings.
- 7.6 Evidence of assessment of both theoretical and where possible clinical components of a palliative approach in aged care content should be present and identifiable in the Bachelor of Nursing course.
- 7.7 Emphasis should be placed on the exploration of values, attitudes, assumptions and beliefs and promoting students to develop positive feelings about the care of older persons who are dying, their families and significant others.¹⁸
- 7.8 The following areas have been identified as essential components for the inclusion of a palliative approach in aged care content in undergraduate nursing curricula:

Principles of a palliative approach in aged care:

Aims, philosophy, standards, evidence based guidelines, principles and care locations; personal attitudes to dying; dignity promoting and maintaining interventions; Guidelines for a Palliative Approach in Residential Aged Care.

Legal/Ethical decision making in palliative aged care:

Legal and ethical issues associated with withdrawing/withholding treatment; advance care planning and medical power of attorney.

Communication in palliative aged care:

Assessing needs and goals about end-of-life care; providing information about the palliative approach; responding to questions about death and dying.

Principles for managing common symptoms for older persons with a life-limiting illness or who are dying as a result of the ageing process:

Multidimensional approaches to assessment; evidence based principles for managing pain, nutrition and hydration problems; oral care; bowel care; fatigue; breathlessness; skin integrity; responding to signs of imminent death.

Support for the emotional, social, cultural and spiritual needs of older persons who are dying and their family:

Principles of supportive care.

Coping with dying and bereavement:

Awareness and effective management of the personal stresses experienced by people who work with the dying.

8.0 Benchmarks for Inclusion of a Palliative Approach to Aged Care in Undergraduate Nursing Curricula

The benchmarks have been developed from the Principles for Learning and Teaching A Palliative Approach to Aged Care in Undergraduate Nursing Curricula. They are intended for use by those involved in developing, implementing and evaluating curricula, and provide a framework for accrediting bodies including the Australian Nursing and Midwifery Council and the state and territory registration authorities.

Benchmark 1

A palliative approach forms a core component of the aged care content and is integrated throughout the undergraduate nursing curriculum.

Source of data:

Undergraduate curriculum documents, course materials, assessments, clinical placement records and schedules.

Benchmark 2

Academic staff and clinical practitioners with expertise in a palliative and aged care are involved in guiding and teaching a palliative approach to aged care content in undergraduate nursing curricula.

Source of data:

Undergraduate curriculum documents, course materials, School of Nursing teaching schedules, clinical placement records, student evaluations, subject or unit databases, credentials and curriculum vitae for academics and clinical practitioners.

Benchmark 3

Evidence is present of the inclusion of the following topics in the aged care undergraduate nursing curricula:

Principles of a palliative approach in aged care; Legal/Ethical decision making in palliative aged care; Communication in palliative aged care; Principles for managing common symptoms for the older person with

a life-limiting illness or who is dying as a result of the ageing process; Support for the emotional, social and spiritual needs of older persons who are dying and their family; Coping with dying and bereavement.

Source of data:

Undergraduate curriculum documents, course materials, assessments.

Benchmark 4

Palliative content within aged care content of undergraduate nursing curricula is based on the best available evidence.

Source of data:

Undergraduate curriculum documents, course materials, assessments.

Benchmark 5

Where possible, clinical experience related to a palliative approach to aged care is provided within curricula.

Source of data:

Undergraduate curriculum documents, course materials, clinical placement records and schedules, clinical experience objectives and/or performance criteria, clinical placement evaluations and graduate course reviews.

Benchmark 6

Representatives from aged and palliative care professional, consumer and regulatory authorities and students are included in the consultative processes used to review and evaluate undergraduate nursing curricula and to provide feedback to the teaching staff and students of the School of Nursing on an annual basis.

Source of data:

Minutes / records of School of Nursing curricula evaluation meetings, industry stakeholder's committee meeting minutes (for example, representatives from organizations such as: Palliative Care Australia; Aged Care and Community Services Association, Australian Nursing Homes & Extended Care Association, Geriaction, Alzheimer's Australia, Carers Australia).

References

1. Australian Bureau of Statistics (1998). *Population Projections 1997 – 2051*, ABS catalogue No. 3222.0 ABS, Canberra, ACT.
2. Australian Government Department of Health and Ageing (2004). *Guidelines for a Palliative Approach in Residential Aged Care*. Australian Government Department of Health and Ageing, Canberra, ACT.
3. Australian Institute of Health and Welfare (AIHW) (2002). *Older Australia at a Glance*. AIHW Cat no. AGE 25. Canberra: AIHW & DOHA.
4. Queensland University of Technology (2004). *Aged Care Core Component in Undergraduate Nursing Curricula. Principles Paper (Australian Government Initiative)*. Brisbane: Queensland University of Technology.
5. Flinders University (2003). *Palliative Care in Aged care Facilities for Residents with Non-Cancer Diagnoses*. Adelaide: Flinders University, Department of Palliative and Supportive Services.
6. World Health Organization (2002). *National Cancer Control Programmes: Policy and Managerial Guidelines (2nd Ed)*. Geneva: World Health Organization.
7. Palliative Care Australia (2005). *Standards for Providing Quality Palliative Care for All Australians*, Canberra, Palliative Care Australia.
8. Davies, E. and Higginson, I. (eds) (2004). *Better Palliative Care for Older People*. Denmark: World Health Organization.
9. Finlay, I.G. and Jones, R.V.H. (1995). Definitions in palliative care. *British Medical Journal*, 311:754.
10. Australian Government Department of Health and Ageing (2000). *National Palliative Care Strategy. A National Framework for Palliative Care Service Development*. Canberra: Australian Government Department of Health and Ageing.
11. Pearson, A. Nay, R. Koch, S. Ward, C. Andrews, C. Tucker A. (2001). *Australian Aged Care Nursing: A Critical Review of Education, Training, Recruitment and Retention in Residential and Community Settings*. National Review of Nursing Education, Web Document, http://www.dest.gov.au/highered/nursing/pubs/aust_aged_care/1.htm, Accessed 2nd June, 2003.
12. Nay, R. Bennett, M. Garreffa, J. Price, H. Creber, J. Dunning, T. et al. (2002). *Review of Aged Care Nursing Component of the Undergraduate Nursing Program: Final Report*. Melbourne: Nurses Board of Victoria.
13. FitzGerald, M. Pincombe, J. McCutcheon, H. Evans, D. Wiechula, R. Jordan, Z. (2001). *An Integrative Systematic Review of Nursing Curricula Undergraduate Clinical Education and Transition Support for New Graduates*. University of Adelaide and the Joanna Briggs Institute for Evidence Based Nursing and Midwifery, Web Document, http://www.joannabriggs.edu.au/pubs/systematic_reviews.php, Accessed 30th May, 2003.
14. Commonwealth Department of Health and Ageing (2002). *Department of Health and Ageing's Budget Initiative Meeting: Background Paper - 'Ageing'*. Canberra: Commonwealth of Australia.
15. Gething, L. (1999). Ageism and health care: The challenge for the future. *Australasian Journal on Ageing*, 18(1):2-3.
16. Burke, K. (1998). Can gerontological nursing survive? *The Canadian Nurse*, 94(4):47-48.
17. Fagerberg, I. Winblad, B. Ekman, S. (2000). Influencing aspects in nursing education on Swedish nursing students' choices of first work area as graduated nurses. *Journal of Nursing Education*, 39(5):211-218.
18. Pearson, A. Nay, R. Koch, S. Rosewarne, R. (2002). *Recruitment and Retention of Nursing in Residential Aged Care - Final Report*. Canberra: Commonwealth Department of Health and Ageing.
19. Courtney, V. (2000). Employment in private care homes. *Elderly Care*, 12(3):28.
20. Commonwealth Department of Health and Ageing (2002). *Report on Budget Initiatives Meeting "More Aged Care Nurses" Undergraduate Scholarships*. Canberra: Commonwealth of Australia.
21. Lloyd-Williams, M. and Field, D. (2002). Are undergraduate nurses taught palliative care during their training? *Nurse Education Today*, 22(7): 589-592.
22. Dupont, E.M. and Francoeur, R.T. (1988). Current state of thanatology education in American health professions and an integrated model. *Loss, Grief and Care*, 2(1-2): 33-39.

23. Dickson, G.E. Sumer, E.D. Frederick, L.M. (1992). Death education in selected health professions. *DeathStudies*, 16(3): 281-289.
24. Burney-Banfield, S. (1994). Preparing students for their patients' deaths. *Australian Journal of Advanced Nursing*, 11(4): 24-28.
25. Downe-Wamboldt, B. and Tamlyn, D. (1997). An international survey of death education trends in Faculties of Nursing and Medicine. *Death Studies*, 21(2): 177-188.
26. Yates, P. Currow, D. Nash, R. Hegarty, M., Grbich, C. Devery, K. Canning, D. Grantham, H.I. (2005). *Palliative Care Curriculum Scoping Survey*. Unpublished Report.
27. Australian Nursing Council (2002). *ANC National Nursing Competency Standards*. Australian Nursing Council, Web Document, <http://www.anci.org.au/competencystandards.htm>, Accessed 20th September, 2004.
28. Australian Government Department of Health and Ageing (2004). *National Education and Training Framework for a Palliative Approach in Residential Aged Care* (Draft) Prepared by Edith Cowan University.
29. Palliative Care Australia. *Training Strategy to Support the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care Project*. Web Document http://www.pallcare.org.au/documents/APRAC_fact_sheet.pdf, Accessed 13th January, 2005.

Glossary

Advance Care Plan

Advance care plans are written documents that explain to health care workers what an older person has decided about how they want to face their own death².

Aged Care

In the context of this project, aged care refers to care of older persons in any setting including residential aged care facilities, acute care facilities and community settings.

Caregiver

The caregiver is generally in the close kin network of the patient and is usually self-identified, e.g, spouse, partner, adult child, parent or friend⁷.

End-of-Life Care

End-of-life care is a form of palliative care that is appropriate when the older person is in the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on the resident's physical, emotional and spiritual comfort needs and support for the family².

Evidenced Based Practice

Evidence Based Practice is defined as “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients.”³²

Family

Those who are closest to the patient in knowledge, care and affection. The family may include biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends⁷.

Life-Limiting Illness

An illness where it is expected that death will be a direct consequence of the specified illness. This definition is inclusive of illnesses of both a malignant and non-malignant nature⁷.

Older Person

This project defines the older person as being anyone over the age of 65 years.

Palliative Approach

A palliative approach aims to improve the quality of life for individuals with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain and physical, psychological, social and spiritual problems. A palliative approach is not delayed until the end stages of an illness. Instead it provides a focus on active comfort care and a positive approach to reducing a person's symptoms and distress, which facilitates individuals and their families understanding that they are being actively supported through the process. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying².

Palliative Care

Traditionally palliative care has focused on the needs of people with cancer and their families. It is a multidisciplinary care that recognises that people and their families are the unit of care, and respects the right of each person to make informed choices about the type of care they receive².

Spirituality

Spirituality refers to the spiritual and religious practices, values, beliefs, attitudes and experiences of the older person. Assessment of spiritual needs is an ongoing responsibility for the health care professional in their care of older persons.²

The Ageing Process

“Ageing is a process that produces changes and deteriorations with diminished reserves in most physiological systems and an increasing vulnerability to most diseases and to death.”¹⁴

Appendix 1

Project Participants

This principles paper was commissioned by the Australian Government Department of Health and Ageing.

Project team

Principal Consultant: Professor Patsy Yates, A/Director, Centre for Palliative Care Research and Education.

Principal Consultant: Professor Helen Edwards, Head, School of Nursing, Queensland University of Technology.

Principal Consultant: Professor Mary Courtney, Director of Research, School of Nursing, Queensland University of Technology.

Principal Consultant: Ms Robyn Nash, Director of Undergraduate Programs, School of Nursing, Queensland University of Technology.

Project Coordinator: Ms Dee May, School of Nursing, Queensland University of Technology.

Project Consultative Group

Academic Representatives

Professor Jennifer Abbey, Professor in Aged Care, School of Nursing, Queensland University of Technology and Prince Charles Hospital & Health Service District

Professor Lynn Chenoweth, Professor of Aged and Extended Care Nursing, University of Technology, Sydney

Associate Professor Patricia Davidson, Associate Professor of Nursing, School of Nursing, Family and Community Health, University of Western Sydney

Ms Kathleen Finlayson, Project Coordinator, Aged Care Nursing Curriculum Project, School of Nursing, Queensland University of Technology

Dr Susan Koch, Associate Professor Gerontic Nursing, Gerontic Nursing Clinical School, La Trobe University and the Australian Centre for Evidenced Based Aged Care

Ms Meg Hegarty, Lecturer, Palliative and Supportive Services, International Institute of Palliative and Supportive Studies, Flinders University

Ms Debbie Parker, Project Coordinator, Multidisciplinary Undergraduate Palliative Care (PCC4U) Project, School of Nursing, Queensland University of Technology

Dr Marie Heartfield, Senior Lecturer, School of Nursing and Midwifery, University of South Australia

Clinical Representatives

Ms Veronica Casey, Director of Nursing/Executive Officer, Eventide

Ms Anne Lastovicka, Registered Nurse, Eventide

Ms Margaret Male, Queensland President, Geriaction

Dr Karen Cooper, Project Coordinator, Training Strategy to Support the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care, Palliative Care Australia

Industry Representatives

Ms Mary Reynolds, Director of Nursing, The Grace Garden Aged Care Facility, Representing the Aged Care Association of Victoria.

Consumer Representatives

Ms Jill Pretty, Manager, Policy and Consultancy, Aged & Community Services Association, NSW & ACT

Mrs Helen Walker, Project Officer, Alzheimer's Australia

Professional Nursing Organization Representatives

Ms Margaret Proctor, International Section Manager, Australian Nursing and Midwifery Council

Dr Cindy Leigh, Council of Deans of Nursing

Appendix 2

Australian Nursing and Midwifery Council Competency Standards for Registered Nurses

DOMAIN: Professional and ethical practice.

- Unit 1 Functions in accordance with legislation and common law affecting nursing practice.
- Unit 2 Conducts nursing practice in a way that can be ethically justified.
- Unit 3 Protects the rights of individuals and groups in relation to health care.
- Unit 4 Accepts accountability and responsibility for own actions within nursing practice.

DOMAIN: Critical thinking and analysis.

- Unit 5 Acts to enhance the professional development of self and others.
- Unit 6 Values research in contributing to developments in nursing and improved standards of care.

DOMAIN: Management of care.

- Unit 7 Carries out a comprehensive and accurate nursing assessment of individuals and groups in a variety of settings.
- Unit 8 Formulates a plan of care in collaboration with individuals and groups.
- Unit 9 Implements planned nursing care to achieve identified outcomes within scope of competency.
- Unit 10 Evaluates progress toward expected outcomes and reviews and revises plans in accordance with evaluation data.

DOMAIN: Enabling.

- Unit 11 Contributes to the maintenance of an environment which promotes safety, security and personal integrity of individuals and groups.
- Unit 12 Communicates effectively with individuals and groups.
- Unit 13 Manages effectively the nursing care of individuals and groups.
- Unit 14 Collaborates with other members of the health care team.

Appendix 3

The Australian Palliative Residential Aged Care Project

Guidelines for a Palliative Approach in Residential Aged Care

A palliative approach

1. Methods used to identify survival time have limitations in accuracy and precision, and are therefore not recommended. Rather, a combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach is considered best practice.
2. Implementing a palliative approach in Residential Aged Care Facilities (RACFs) can reduce the potential distress to residents and their families caused by a transfer to an acute care setting.
3. A palliative approach can be provided in the resident's familiar surroundings if adequately skilled care is available.
4. Providing information about a palliative approach may help residents and their families to consider a palliative approach as active care rather than withdrawal of treatment.
5. An interdisciplinary team that promotes goal setting in collaboration with the family is critical to the success of a palliative approach. This approach decreases discomfort for residents, saves valuable resources and improves satisfaction levels for the family when they recall the care provided.

Dignity and quality of life

6. Care that enhances the dignity of the resident is part of a palliative approach and is a general therapeutic goal for all people who are dying. Factors that contribute to retaining dignity are: having adequate pain and symptom management, appropriate incontinence management, relieving burdens, achieving a sense of control, strengthening relationships with loved ones, having the capacity to communicate, being able to recognise friends and family members, and avoiding inappropriate prolongation of dying.

7. Appropriate care that maintains a resident's dignity may lead to a more hopeful outlook for the resident at the end of their life, which reduces the desire for a hastened death.

Advance care planning

8. Advance care planning that is systematically implemented in an RACF and that involves communication between the resident, their family and the doctor increases the satisfaction of the resident and their family with end-of-life care. Advance care planning helps define the resident's wishes, which can then be clearly documented.
9. Regular education programs for the aged care team, residents and their families on issues about end-of-life care and the completion of advance care plans increases the frequency of these plans being completed and implemented in RACFs, and increases satisfaction with end-of-life care.
10. Ongoing assessment is required to develop a comprehensive advance care plan that addresses all relevant issues as the resident's state of health changes over time.

Advanced dementia

11. A palliative approach benefits the family as well as the resident, particularly when it incorporates continual follow-up evaluation, attention to distressing symptoms and avoidance of hospitalisation, and emphasises and promotes the resident's quality of life and dignity.
12. Remaining in familiar surroundings is beneficial for residents with advanced dementia as this helps maintain their palliative care plans and promotes feelings of orientation and security.

13. Residents with advanced dementia can be assessed and treated for pain and discomfort with the use of dementia-specific assessment tools.
14. The use of aggressive medical treatment of infections is not recommended for residents with advanced dementia. Instead, a palliative approach is recommended for the resident's comfort, which might include short-term antibiotic therapy to ease symptoms and improve quality of life.
15. A policy of restraint-free care using a restraint minimisation program is considered best practice. Through education designed to change a facility's culture, such a program minimises the use of restraints and provides strategies for the removal of restraints.
22. Potential factors associated with fatigue include depression, anxiety, pain, a reduction in intermediate activities of daily living, number of medications, and physical function. These factors, therefore, need to be carefully assessed.
23. Suggested non-pharmacological methods for relieving fatigue, such as exercise programs and energy conservation, may be effective for people receiving a palliative approach.
24. As there are many causes for weight loss in residents, an assessment of the cause is required with a view to identifying inadequate nutrition and reversing the causes.
25. It is considered best practice for residents requiring a palliative approach to receive oral foods and fluids, even in minimal amounts, rather than enteral (nasogastric or PEG) feeding.

Physical symptoms – assessment and management

16. Residents and their families perceive good care with a palliative approach to include adequate relief of pain and effective symptom management.
17. Appropriate treatment plans are developed from a comprehensive assessment of the resident's needs, including early identification of their main symptoms.
18. The resident's own determination of the intensity of pain is considered to be the best assessment.
26. Weight loss, low albumin levels and postural changes (orthostatism) are associated with therapeutic diets, so these diets should be avoided whenever possible for RACF residents.
27. In order to formulate recommendations regarding fluid therapy, each resident's circumstances, including the wishes of the resident and their family, require assessment.
28. Frequent small sips of fluids can reduce the sensation of thirst and oral discomfort associated with dehydration.

Summary of guidelines

19. Pain management is enhanced by a comprehensive assessment of the resident's pain and evidence based analgesic decision-making.
20. The use of assessment tools for pain is more accurate than just asking the resident "Do you have pain?" For the resident who is unable to verbalise their pain, accurate reporting based on good observation skills using behavioural cues, by a skilled person, is particularly important for determining pain.
21. Fatigue is the most frequently cited physical concern reported by people approaching death, and warrants attentive assessment.
29. A diagnosis of cachexia can be made from the resident's clinical history, presence of substantial weight loss, laboratory tests and physical examination.
30. Residents should be encouraged to have as many calories orally as possible. For the frail resident, a trial of single nutrients or liquid meal replacements is warranted before more invasive techniques are used.
31. A formal interdisciplinary assessment program may be beneficial in promoting early recognition, appropriate management and prevention of complications associated with dysphagia.
32. To provide effective dysphagia management for residents at risk of swallowing problems, a interdisciplinary team approach is required, including input from a speech pathologist.

33. The aged care team should ensure that the texture, consistency and type of food and fluid are as prescribed.
34. The aged care team should ensure that feeding techniques are undertaken in accordance with the specific methods recommended by the speech pathologist or physician, and they should also be aware of the safe feeding techniques generally recommended for individuals with neurogenic dysphagia.
35. Oral complications can be reduced by good hygiene, regular assessment, cleansing of dentures and use of oral fluids.
36. Asking an older person "How would you describe the health of your teeth and gums? Would you say it is excellent, very good, good, fair or poor?" is an accurate way to identify individuals with any denture-related needs, as well as those who do not need dental care. It is recommended that this question be included in oral health assessments as a reliable basis for determining when to refer for further evaluation and dental treatment.
37. The most effective oral cleansing routine is rinsing with water and cleansing with a soft toothbrush and toothpaste. Dentures require regular soaking in a weak non-toxic solution.
38. An interdisciplinary approach to oral health is preferable, with collaboration between the aged care team, dental services, occupational therapists and dieticians to ensure that members of the aged care team are supported in their practice of oral care for residents.
39. The use of air-fluidised and low-air-loss mattresses is effective in the reduction of ulcers.
40. A daily assessment of bowel function is required. Management decisions may take account of the resident's preferences for treatment and their history of bowel habits.
41. A discussion between the doctor and nursing staff to decide on the most appropriate laxative for use with a resident should be encouraged.
42. The combined use of bulk laxatives and suppositories is associated with the lowest rates of faecal incontinence. The use of the suppository after bowel clearing prevents recurrent constipation.
43. If a laxative is used, compensatory measures for dehydration and electrolyte depletion are recommended.
44. A complete history and physical examination will generally provide enough information to determine a diagnosis of dyspnoea. The history should cover factors that are likely to have influenced the severity of the symptom, including pre-existing illnesses (such as chronic obstructive pulmonary disease), exacerbating factors (such as anaemia or profound anxiety) and additional factors (such as pulmonary embolism, infection or left ventricular failure).
45. Non-pharmacological interventions based on psychosocial support, controlled breathing and learned coping strategies can help people cope with dyspnoea, which will further reduce physical and emotional distress.
46. People with dyspnoea can benefit from the use of a sustained-release low-dose oral morphine administered orally or parenterally.
47. A comprehensive plan of care, including ready access to appropriate medication treatment along with non-pharmacological interventions to reduce psychological distress, may prevent residents with gradually increasing dyspnoea being transferred to hospital unnecessarily.
48. In general, complementary and alternative therapies for symptom management in palliative care are beneficial for those who refuse or cannot tolerate pain medications in enhancing their sense of control and cultural sensitivity.
49. The combination of traditional analgesic treatments with acupuncture, TENS, relaxation and imagery, and hypnosis are helpful in symptom management.
50. To treat the underlying causes of dyspnoea (for people with moderate to severe breathing difficulties) and to improve functional capabilities (e.g. walking), the use of acupuncture, acupressure, muscle relaxation with rebreathing

training, and rebreathing training combined with coping strategies are considered to have a beneficial effect.

51. An aromatherapy intervention to treat agitation and neuropsychiatric symptoms in people with dementia can have positive effects.
52. A massage with essential oils is beneficial for reducing anxiety and improving quality of life when used with people receiving a palliative approach.
53. The use of ginkgo for older persons with mild to moderate dementia is not recommended as it was found to be an ineffective treatment.

Psychological support

54. Using a Geriatric Depression Scale (GDS) to screen for depression can increase the frequency of treatment or referral of residents in RACFs by their doctors.
55. Although suicide attempts or requests may seem understandable, they are often an indication of clinical depression and require an active response.
56. Gentle massage can reduce anxiety levels or agitated behaviours for residents with chronic pain and/or dementia.
57. Using the standardised confusion assessment tool is recommended for residents with delirium as it enables non-psychiatric clinicians to quickly detect delirium in older persons.
58. Many residents can answer questions on their quality of life even when significant symptoms of dementia are present. Therefore a resident's preferences for quality of life concerns should still be sought and incorporated into decision-making.
59. Incorporating the use of a specialised palliative team who have some expertise in assessment and care of those with depression, agitation, loss and/or anxiety is considered beneficial.

Family support

60. The family may play a particularly important role in assisting with managing symptom distress, communicating with the resident, and assisting with their physical care needs.

61. Deteriorating health and the death of the resident may impact on the physical and emotional health of family members. Therefore the family members' stress requires monitoring by the aged care team.
62. Families appreciate good communication with the aged care team, affirmation from the team that the family's input is valued, and permission to withdraw at times from the caregiving situation.
63. Families benefit from emotional support and an opportunity to discuss their concerns about the resident's illness or ageing process. This support can be provided during a family conference.

Social support, intimacy and sexuality

64. A lack of social support may lead to deteriorating psychological wellbeing, depression and diminished functional health. Therefore, a thorough assessment of the resident's social network is required, including the resident's perceptions, appraisal and interpretation of what contact is most important to them.
65. The use of comfort touch (e.g. massage, hand holding) by a member of the aged care team can enhance the resident's sense of wellbeing and self-regard.
66. Rather than denying the existence of residents' intimacy and sexuality needs, the aged care team needs to acknowledge the importance of this area of resident care.

Aboriginal and Torres Strait Islander issues

67. Respectful attention to the individual needs of Indigenous residents, taking into account beliefs regarding illness, healing, comfort, care practices, location of care, and death and dying is needed in a palliative approach to residential aged care.
68. Aboriginal health workers, liaison officers, other Indigenous Australian health care practitioners and community organisations have important knowledge about local cultural values and individual situations. When developing protocols and when working with individual Indigenous Australian residents it is beneficial to involve them.

69. Communication with Indigenous Australian residents in their own language enhances understanding and attention to their needs. Regular reviews of these residents' needs are required, as their needs may change.

Cultural issues

70. Understanding care preferences of cultural groups is important in a palliative approach, and efforts to accommodate these promote individualised care for the resident.
71. Where possible, information about a palliative approach should be provided to the resident in their own language as this enhances cultural sensitivity for culturally and linguistically diverse residents and their families.

Spiritual support

72. A palliative approach supports residents and families to express their unique spirituality. Respecting their privacy and providing an opportunity for them to continue their spiritual practices enhances a resident's spiritual care and quality of life, as does spiritual counselling.
73. Understanding the resident's current or desired practices, attitudes, experiences and beliefs by obtaining a comprehensive history helps meet the spiritual needs of the resident, as does a regular review.
74. The aged care team is encouraged to respond in an open, non-judgemental manner to residents' questions relating to spiritual matters. Involving a chaplain or pastoral care worker with experience and knowledge about these issues is considered best practice.

Volunteer support

75. Trained volunteers can be integrated into interdisciplinary teams to help provide a palliative approach for residents.
76. Volunteers who are part of an interdisciplinary team providing a palliative approach require ongoing support and education from a trained coordinator of volunteers.

77. Suitably screened and matched volunteers may act as a companion and confidant to the resident and their family. All those involved consider that this support is valuable.

End-of-life (terminal) care

78. Family caregivers need to be advised that the changes their family member may experience in the end-of-life phase (e.g. noisy breathing) are a normal part of the dying process. Families should be reassured that their relative is not necessarily distressed by these changes.
79. Well-planned family conferences, conducted in private and attended by the GP and other members of the aged care team, provide an opportunity for building trust and discussing end-of-life issues of concern.

Support

80. Members of the aged care team can experience loss following the death of residents with whom they have established meaningful relationships. Therefore the team should be provided with opportunities to formally acknowledge the loss and have access to adequate bereavement support. Even members who have experienced many deaths might still require access to these support services.
81. A memorial service is a valuable resource which facilitates the grieving process for residents, family members, the aged care team and volunteers.
82. The more social support a family has access to, the better their ability to cope with the bereavement of their family member will be. However, it is the quality of the support rather than the quantity that enhances this resilience.

Management's role in implementing a palliative approach

83. Formal management systems will support the introduction and maintenance of a palliative approach through the allocation of appropriate resources.

