

Guidelines for a palliative approach to  
residential aged care:

A systematic review of the literature

July 25, 2005

This publication was funded by the Australian Government  
Department of Health and Ageing, under the National Palliative Care Program.

Guidelines for a Palliative Approach in Residential Aged Care: A Systematic Review  
of the Literature

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## **ABBREVIATIONS**

AIHW	Australian Institute of Health and Welfare
CAM	Complementary and alternative medicine
EN	Enrolled Nurse
EO	Expert opinion
GP	General Practitioner
NCISN	National consultative information-sharing network
NHMRC	National Health and Medical Research Council
QE	Qualitative Evidence
QoL	Quality of life
RACF	Residential aged care facility
RCT	Randomised controlled trial
RN	Registered Nurse
SSRI	Selective serotonin re-uptake inhibitors
TENS	Transcutaneous electrical nerve stimulation
WHO	World Health Organization

# EXECUTIVE SUMMARY

Within Australia, there are standards for aged care and standards for palliative care but there is not a set of national guidelines supporting the provision of a palliative approach in residential aged care facilities (RACFs). Palliative practices in these facilities are evolving and there is an expressed need within the aged care literature for the development of guidelines for appropriate care of older persons by non-specialist palliative care teams.

The Australian Palliative Residential Aged Care (APRAC) Project is a federally funded project, which has three components each of which has specific outcomes to be met:

- 1 Development of national guidelines for palliative care in RACFs;
  - 1.1 A systematic review of the evidence for best palliative care practice in residential aged care settings: obtaining, synthesising, and evaluating the evidence. Identification of the gaps that exists in the evidence.
  - 1.2 Formulating the guidelines for palliative care practice in aged care.
  - 1.3 Refinement of the guidelines using the consultative process. Incorporation of ways in which the guidelines may be evaluated.
  - 1.4 Final formatting of the guidelines.
- 2 Development of a national education and training program for RACF aged care workers;
  - 2.1 Review of existing aged care and palliative care education and training programs.
  - 2.2 Development of aged care worker competencies from guidelines. Delphi survey to discover relative importance, feasibility, and applicability of these competencies. Identification of training/education needs.
  - 2.3 National curriculum and program design and refinement after review. Incorporation of ways in which the program may be evaluated.
- 3 Options for communication and implementation of the guidelines and the education and training program.
  - 3.1 Development of options via the consultative process and costing of these. Incorporation of a means to evaluate the dissemination and implementation processes.
  - 3.2 National Health and Medical Research Centre's (NHMRC) approval of the Guidelines.
  - 3.3 Submission of the Final Report.

The purpose of this report is to document the systematic review of the literature that was undertaken by Working Party for the APRAC Project (See Appendix A) to identify evidence-based guidelines that would inform the provision of a palliative approach to Australian residential aged care. Only step 1.1 of Component 1 is contained within this report; steps 1.2 to 1.4 and Component 3 (all steps) are outlined in the Project's Final

Report, which is a separate publication. Component two is covered in a separate document due to the size of the report.

In order to provide a systematic review of the palliative care and gerontological literature the Review Working Party developed 2 protocols, which are outlined in Chapter 1. Based upon these protocols, the review involved several stages:

- A comprehensive search of the literature using 13 domains names as keywords;
- Identification and selection of literature that was both relevant and met the inclusion criteria (see Chapter 1); and
- An analysis of this literature to provide a synthesis and overview of the key findings identified in the literature upon which evidence based guidelines could be developed.

Overall, a total of 929 articles were identified as being relevant to the project and these were then fully evaluated using the appropriate evaluation tool to determine quality and strength. Of this set, 293 articles were found to meet the evidence criteria and upon which evidence-based guidelines were developed.

Chapter 1 provides an overview of the protocol for the systematic review process. A review of the evidence-based literature addressing issues regarding a palliative approach and residential aged care is presented in Chapters 2 through 16 with each chapter focussing on a specific issue such as dignity.

The final chapter of this report discusses the gaps that were identified in the palliative care and gerontological literature and upon which suggestions for future research are made.

# CHAPTER 1      PROTOCOL FOR THE REVIEW

## 1.1 INTRODUCTION

This chapter outlines the processes that were used to organise, collect and evaluate the relevant literature including the search strategies used, the evaluation methods, the collated results of the searches and the limitations to this review process.

## 1.2 AIMS

The aim of this systematic review of the literature was to locate and summarise the evidence for best practice relating to residential aged care practices and psychosocial, cultural, Indigenous, spiritual and physical issues, which are essential factors for providing a palliative approach. Once summarised, the evidence gathered was used to confirm or refute existing practices and make recommendations for practice change for residents in aged care facilities whose care is being managed by a palliative approach.

A secondary aim was to identify gaps in the evidence with a view to suggesting future research directions.

## 1.3 CONTEXT

The National Health and Medical Research Centre's (NHMRC) emphasis in the 21st century is for evidence-based practice; however, there is currently no document to guide RACFs regarding such practice. Standards for Aged Care and Standards for Palliative Care exist, but these do not specifically address the unique and complex issues that arise within RACFs. Australian RACFs have an exhaustive accreditation process in place, which is subsequently tied to the *Aged Care Act (1997)* (CTH). However, palliative practices within RACFs are still in their infancy and there is little direction regarding what is best practice for a palliative approach by non-specialist palliative care teams.

## 1.4 REVIEW METHODOLOGY

The literature review was conducted by the Review Working Party (a group of members of the Project Working Party who were responsible for undertaking the systematic review) to capture the evidence that was currently available on palliative and aged care practices.

All available evidence pertaining to palliative care models, assessment and care practices for older persons requiring a palliative approach was summarised. Relevant evidence included studies that had populations with non-cancer diagnoses, multiple co-morbidities, dementia, and who participants were aged 65 years and older. Studies that helped to identify the entry of an aged care resident into a phase where a palliative approach was warranted were also considered. Documentation related to the physical, psychological, social, cultural, Indigenous, and spiritual care needs for the person who was dying, as well as the care and support of the family were also included.

Evidence based guideline development traditionally involves the search for evidence following the definition of a clinical question. Palliative care and aged care are large

and complex academic fields and areas of clinical practice. Research in these fields crosses many disciplines and draws on a multitude of study designs and approaches.

#### 1.4.1 Search Strategies

Without a specific clinical question to guide the search strategies, the review working party developed an approach built on domain representation. Domains have been used elsewhere in the literature to describe areas of clinical or patient importance in providing care at the end-of-life. (Lynn, 2001; Morrison & Siu, 2000; Singer, Martin, & Kelner, 1999) Domains represented an area for guideline development or an acknowledged area of research.

Based upon the review working party's preliminary content analysis of the literature, the project working party identified 13 domains of literature that were relevant to a palliative approach in residential aged care, which were as follows:

1. a palliative approach, including care models and care practices,
2. assessment & management tools,
3. co-morbidities,
4. cognitive impairment,
5. physical care,
6. psychosocial support,
7. spiritual support,
8. family / carer support,
9. Indigenous support,
10. cultural support,
11. advance care plans,
12. dignity and quality of life, and
13. rural and remote issues.

The specific content covered by each of these 13 domains is provided in the following table.

<b><i>Domain</i></b>	<b><i>Examples of content covered</i></b>
<b>Palliative Approach</b>	Holistic care; World Health Organisation (WHO) definition; volunteers; ancillary workers; staff; interdisciplinary teams; bereavement support; communication; education; training; staff development
<b>Dignity &amp; Quality of Life</b>	Dignity, quality of life, 'Desire to die' statements, privacy; confidentiality
<b>Advance Care</b>	Decision-making; end-of-life decision making; advance directives; advance care planning; legislation; living wills, ethics, surrogacy; power of attorney;

<b>Table 1: Literature domains</b>	
<b>Domain</b>	<b>Examples of content covered</b>
<b>Planning</b>	guardianship
<b>Advanced dementia</b>	Dementia; dementia care, Alzheimer's; confusion; behavioral and psychological symptoms
<b>Physical symptom assessment &amp; management</b>	Pain; symptom control; anorexia and cachexia; hydration; thirst; respiratory; cancer pain; dyspnoea; nausea; pressure ulcers; dysphagia;
<b>Assessment Tools</b>	Quality of life; pain; dignity, Activities of Daily Living (ADL); confusion;
<b>Co-morbidities</b>	Cancer; age-related; Chronic Obstructive Pulmonary Disease (COPD); diagnosis; heart failure; Parkinson's Disease; hematological malignancies
<b>Psychological Support</b>	Depression; anxiety, confusion, delerium; dementia
<b>Family Support</b>	Family; extended family; family relations; genogram; caregivers; bereavement; after death care
<b>Social Support, Intimacy &amp; Sexuality</b>	sexuality and intimacy; social work; psychosocial factors; environment
<b>Rural &amp; Remote</b>	Rural; country; isolated and remote sites
<b>Aboriginal &amp; Torres Strait Islander issues</b>	Indigenous needs; traditional beliefs; Aboriginal and Torres Strait Islanders; cultural safety
<b>Cultural Issues</b>	Cultural; multicultural; English as a Second Language (ESL); Cultural and Linguistic Diversity; ethnicity; beliefs, practices and language
<b>Spiritual Support</b>	Spirituality; religious beliefs; pastoral care; human development; crisis intervention; emotional responses; sociocultural factors; attitudes to death and dying; coping behaviors; grief
<b>Volunteer Support</b>	
<b>End-of-Life (Terminal) Care</b>	Grief and loss, memorial services
<b>Bereavement Support</b>	
<b>Management's Role</b>	

Once the general framework for content was established, a process for identifying, assessing, evaluating and eliminating material in the literature review process was developed.

It became evident that two search strategies were necessary to capture all of the relevant literature for the development of evidence-based practice guidelines. The first search strategy aimed to acquire relevant studies (both qualitative and quantitative) using the 13 domain terms previously outlined (see Table 1). This ‘top down’ approach elicited articles covering a broad range of issues. The second strategy used specific terms that emerged from the articles that were located during the first search strategy. This refinement addressed the specific issues found in caring for older institutionalised persons with life-limiting conditions (e.g. Cachexia in terminal illness), or who were dying as a consequence of the process of ageing.

The literature was searched electronically for English language articles published in peer-review journals from 1990 to Week 3 September 2002 using the first search strategy. Additional electronic searches using the second strategy covered the period 1990 to Week 4 September 2003. (Further searches were required due to stakeholder feedback that recommended additional issues should have been included, such as post-bereavement support for family and friends, continuity of care, complementary therapies, and privacy and confidentiality).

Both search strategies were conducted on databases MEDLINE, CINAHL, EMBASE, Cochrane Library and Current Contents, APAIS, DRUG, PsychINFO, and Dissertation Abstracts International. (See Table 2 for search terms). Relevant secondary references were included in the review.

Searches also included a hard copy search of books and publications at Flinders University libraries (Sturt, Medical and Central) and Repatriation General Hospital libraries (Daw House and Medical) between July 2002 and September 2003. Searches on the World Wide Web for government and non-government publications, standards of care, existing guidelines and reports to government were also conducted between August 2002 and September 2003.

<b>Table 2: Search terms</b>	
<i>Terms</i>	<i>Words or variations of words that were used in searches</i>
<b>Aboriginal</b>	Aboriginal; Indigenous; koori
<b>Advance Care Planning</b>	Advance directive/s; advance care plan/s/ning; decision making; end-of-life care; legislation;
<b>Aged care</b>	Aged care facility/ies; gerontological care; group homes; homes for the aged; residential facility/ies; residential care; residential aged care facility/ies; RACF; halfway houses; health services for the aged; high level care; long term care; long stay homes; nursing homes; hostels
<b>Assessment tools</b>	Symptom assessment; tools; indicators; instruments
<b>Australian</b>	Australia/n; Royal College of Nursing, Australia

**Table 2: Search terms**

<i>Terms</i>	<i>Words or variations of words that were used in searches</i>
<b>Bereavement</b>	bereavement; grie/f/ve/ving; death and dying; hospice; death rit/e/s/ual/s; occupational stress; staff stress; hospital programs; memorial service; life experiences; rit/e/s/ual/s (nonreligious); symboli/c/sm; ritual referral; unresolved grief; complicated grief; at-risk population/s; treatment/s; psychopatholog/y/ies; pathological grie/f/ving; coping behaviour/s
<b>Breast Cancer</b>	
<b>Cancer</b>	Neoplasms; cancer; malignanc/y/ies; oncology
<b>Care Givers</b>	Famil/y/ies; care givers
<b>Cardiac Care</b>	heart
<b>Clinical</b>	Evidence; random/ised/ized controlled trials; guideline/s;
<b>Complementary therapy</b>	Complementary therap/y/ies; alternative therap/y/ies
<b>Cultural</b>	Multicultural; culture/al; diversity; cultural diversity
<b>Dementia</b>	Dementia care; cognitive impairment
<b>Depression</b>	Depress/ed/ion/ing; clinical depression
<b>Education</b>	Train/ing; educat/e/ion/ing; skill/s/ed; staff development; in-service training;
<b>Hospital</b>	Hospitals – special; teaching; urban; rural/remote; acute care setting/s
<b>Nonclinical staff</b>	Maintenance staff; non-clinical staff; cleaner/s/ing; gardener/s/ing; care team/s
<b>Nonprofessional staff</b>	Domestic; non-professional/s; ancillary; uneducated; volunteer/s/ing/ism; nurses' aides; aides; personal care assistants; nurses' assistants; unregistered; care assistants
<b>Neurological</b>	Neurologic/al
<b>New Zealand</b>	New Zealand; NZ
<b>Nursing</b>	Nursing role/s; terminal car/e/ing; end-of-life care; quality of nursing car/e/ing; registered nurse/s; Registrations
<b>Occupational Therapy</b>	Occupational therap/y/ies/ist; OT
<b>Pain</b>	Pain/s; pain management; pain assessment
<b>Palliative care</b>	Hospice Car/e/ing; exp palliative care; end of life; dying; death; terminal care; palliative approach; palliation
<b>Palliative symptomatology</b>	Anorexia; oral care; bowel care; feeding; skin integrity; nutrition; hydration; dysphagia; swallowing; choking;

<b>Table 2: Search terms</b>	
<i>Terms</i>	<i>Words or variations of words that were used in searches</i>
<b>Pastoral</b>	Spiritual; pastoral; religi/on/ous; existential/ism
<b>Prognosis</b>	Prognos/is/tication; treatment/s
<b>Psychological factors</b>	Psychosocial; quality of life; psychological; psychiatric; disorders; personality
<b>Quality</b>	Quality improvement; quality system/s
<b>Renal</b>	Kidney
<b>Respiratory</b>	Dyspnoea; breathlessness; breathing
<b>Rural &amp; Remote</b>	Rural; Remote; nonmetropolitan; nonurban; country
<b>Social Work</b>	Social work/er/ers; counsel/lor/s; counsel/ling
<b>Therapeutic Environment</b>	Person-environment fit; home environment; environment/al; surrounding/s
<b>Volunteer</b>	Volunteer/s/ing/ism; non-clinical staff

Once the general framework for content was established, a process for identifying, assessing, evaluating and eliminating material in the literature review process was developed. Inclusion and exclusion criteria were established for initial decision-making on articles and abstracts.

Following a preliminary analysis of the evidence by the review working party, specific searches on identified gaps were conducted between July 2002 and September 2003. These searches involved specific word searches on the major electronic databases previously outlined, searching of author publication lists, internet searching by author and key word, review of reference lists from related articles, searches of related websites and searches of journal title pages. Inclusion and exclusion criteria were established for initial decision-making on articles and abstracts.

#### 1.4.1(a) Inclusion criteria

Articles of studies (using either qualitative or quantitative methodologies) published between January 1990 and Week 3 September 2003 in English peer-review journals and systematic reviews from Cochrane Collaboration and Joanna Briggs Institute that appear on various electronic databases were included in this review. Studies from countries with comparable health systems and residential care facilities to Australia, with similar social or cultural values were included.

The majority of articles were based in palliative care units and RACFs. Some studies based in the acute hospital, home-based or community-based studies, were deemed transferable to the RACF if there was consensus by the project working

party that such articles were relevant to providing a palliative approach to residential aged care.

Articles that were based on personal, expert opinion and literature reviews (non-systematic) were included if the project team reached consensus regarding the relevance of such articles. Because these articles were generally the result of experiential knowledge, it was considered essential to include such articles in the preamble for each chapter. However, the project team considered that it would be inappropriate to develop guidelines based on personal, expert opinion or literature reviews because these articles were not research based.

The following list was developed to assist the review working party to quickly include articles on the basis that the article:

- Was evidence based;
- Was published in a peer-reviewed journal, book chapters, government and non-government reports, therapeutic guidelines, standards of care and other guidelines;
- Was published between January 1990 and September 2003 (unless seminal paper);
- Was published in an English language;
- Originated in a country with a comparative health system to Australia;
- Originated in a country with social or cultural similarities to Australia; and
- Originated in a country where residential aged care facilities were similar to those in Australia.

#### 1.4.1(b) Exclusion Criteria

Although the academically accepted 5-year norm for the cut off date was considered, the review working party adopted 1990 as the cut-off date for exclusion of studies based on the significant seminal work completed in the early 1990s in palliative care. Hence, studies prior to 1990 have been excluded from this review unless they were considered by the project working party to be significant seminal work. Articles published in languages other than English were excluded as were unpublished studies.

The following list was developed to assist the review working party to quickly exclude articles on the basis that the article:

- Did not meet the inclusion criteria above; and
- Related to settings that were deemed by the working party to be incomparable to Australian residential aged care or long-term care situations.

#### 1.4.2 Evaluation

One of the significant challenges of the evidence review was locating and valuing research from the non-medical fields. No suitable tool was available to assess the scientific merit of quantitative studies according to NHMRC (1999) criterion of quality, strength or relevance nor was there a suitable tool to evaluate qualitative evidence. The Project Team responsible for reviewing the literature therefore, developed evaluation

tools built around the NHMRC criteria and drew upon work done by the Cochrane (2002) and Campbell (2002) Collaborations in evaluating quantitative (See Appendix B) and qualitative studies (See Appendix C). The tools also reflected issues being discussed in the literature relating to the inclusion of research outside the biomedical model. (Porter, 2001) (Green and Tones, 1999) (Freemantle, Wood and Crawford, 1998) (Fossey, Harvey, McDermott and Davidson, 2002) (Benson and Hartz, 2000) (Concato, Shah and Horwitz, 2000) (Rychetnik, Frommer, Hawe and Shiell, 2002). Because the evaluation tools differ, each of this will be discussed separately.

#### 1.4.2(a) Quantitative evidence

The tool that was developed for use with intervention studies used the level of evidence categories outlined by the NHMRC (1999) directly as shown below:

<b>Table 3: Quantitative levels of evidence</b>	
<i>Levels</i>	<i>Criteria</i>
<b>I</b>	Systematic review of all relevant randomised controlled trials (RCTs)
<b>II</b>	At least one properly designed RCT
<b>III-1</b>	Well-designed pseudo-RCT
<b>III-2</b>	Comparative studies with concurrent controls and allocation not randomised, case-control studies or interrupted time series with a control group
<b>III-3</b>	Comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group
<b>IV</b>	Case series, either post-test or pre-test and post-test

To measure the quality, strength and relevance of quantitative studies, additional criteria were developed by the review working party (these criteria were not part of the NHMRC [1999] levels of evidence), as shown in the following table.

<b>Table 4: Quality criteria for quantitative levels of evidence</b>	
<i>Additional</i>	<i>Explanation</i>
Quality	This rating refers to the quality of the methods used in a study to minimise bias. (Score range 1 to 4 with 4 being high quality.)
Strength	This classification refers mainly to the magnitude of the intervention effect. (Score range 1 to 4 with 4 being highest strength.)
Relevance	This rating refers to the relevance of outcome measures and the applicability of the study results to the clinical question and the clinical setting. (Score range 1 to 4 with 4 being highest relevance.)

#### 1.4.2(b) Qualitative evidence

Qualitative studies are usually descriptive with the aim of providing a context for people's experience and behaviours through analysis that is detailed, 'rich' and integrative. Examples of qualitative studies include observational or case study methods that explore comparisons within a group to describe and explain a particular phenomenon (e.g., comparative case studies with multiple communities).

It has been suggested that RCTs are impracticable for studies regarding a palliative approach due to ethical and methodological difficulties, such as early deaths, difficulties in recruitment of participants, and a low compliance rate for completion (McWhinney, Bass, & Donner, 1994). Many research questions about a palliative approach appear to be most feasibly and appropriately addressed using quasi-experimental designs, qualitative studies, surveys, and audits; however, the NHMRC (1999) criteria does not have any provision for their inclusion. Nonetheless, the working party agreed that it was necessary to include and evaluate such evidence because a systematic review based only on data from RCTs can be problematic. For example, specific palliative care issues may not have been studied using these methods or are very difficult, if not impossible to locate, because they are not on the main search engines used for literature reviews.(Cochrane Collaboration, 2002) Additionally, there may be insufficient information from RCTs regarding rare side-effects or long-term benefits of an intervention, because RCTs are generally about short-term results from interventions (Cochrane Collaboration, 2002).

According to the Campbell Collaboration (2002) incorporating relevant qualitative studies in a systematic review is beneficial because it can:

- (a) Contribute to the development of a more robust intervention by helping to define an intervention more precisely;
- (b) Assist in the choice of outcome measures and assist in the development of valid research questions; and
- (c) Help to understand heterogeneous results from studies of effect.

However, the inclusion of evidence from qualitative studies while resolving some of the short-comings of quantitative studies also raises some concerns, such as the potential for biases in the methodology that may invalidate the conclusions.(Cochrane Collaboration, 2002) To overcome this problem, the Project Working Party determined that qualitative evidence would need to be reviewed and examined by the Review Working Party using criteria to measure the quality of these studies. No appropriately validated tool existed that could measure the quality of research studies that were not of an empirical design (qualitative studies). Therefore, the review working party substantially modified the Cochrane (2002) and Campbell(Campbell Collaboration, 2002) guidelines to provide an appropriate evaluation tool (see the following table; for a complete example of the tool, see Appendix C).

<b>Table 5: Qualitative levels of evidence</b>	
<i>Questions</i>	<i>Yes = 1 / No = 0</i>
<p><b>1. Aim of the study:</b></p> <ul style="list-style-type: none"> <li>Was the aim clear?</li> </ul>	
<p><b>2. Paradigm:</b></p> <ul style="list-style-type: none"> <li>Was the paradigm appropriate for the aim?</li> </ul>	
<i>Quality of evidence:</i>	
<p><b>3. Methodology:</b></p> <ul style="list-style-type: none"> <li>Was the methodology appropriate for the paradigm?</li> </ul>	
<p><b>4. Methods:</b></p> <ul style="list-style-type: none"> <li>Were the methods used appropriate for the methodology?</li> </ul>	
<p><b>5. Checking methods:</b></p> <ul style="list-style-type: none"> <li>Did checking methods establish rigour?</li> </ul>	
<p><b>6. Sample:</b></p> <ul style="list-style-type: none"> <li>Did the sampling strategy address the aim?</li> </ul>	
<p><b>7. Data analysis:</b></p> <ul style="list-style-type: none"> <li>Was the data analysis appropriately rigorous?</li> </ul>	
<p><b>8. Findings:</b></p> <ul style="list-style-type: none"> <li>Were the findings clearly stated and relevant to the aim?</li> </ul>	
<p><b>Level of evidence score:</b> (Sum scores. Score range from 0 to 8 with 8 being highest level)</p>	
<b>Additional - (Do not add additional scores to previous totals).</b>	<b>Explanation</b>
<i>Strength of evidence (choose only 1 score):</i>	
<ul style="list-style-type: none"> <li>4. Very high</li> <li>3. High</li> <li>2. Low</li> <li>1. Very low</li> </ul>	
<p><b>Strength score:</b> (Score range 1 to 4 with 4 being highest level of relevance)</p>	
<i>Relevance of evidence (choose only 1 score)::</i>	
<ul style="list-style-type: none"> <li>4. Very applicable</li> <li>3. Applicable</li> <li>2. Somewhat applicable</li> <li>1. Not applicable</li> </ul>	
<p><b>Relevance score:</b> (Score range 1 to 4 with 4 being highest level of relevance): <b>(Do not add relevance score to previous totals.</b></p>	

Because the level of evidence determines the quality for the qualitative studies (designated as qualitative evidence or QE), a single category was created that contained eight questions regarding the aim of the study and the appropriateness of the methodology that was used (See the following table for these questions). Each question in this category required the reviewer to answer ‘yes’ or ‘no’ with yes

scoring 1 and no scoring 0. The score range for the level of evidence was 0 to 8 with 8 being the highest level of evidence, and, therefore, the best quality.

The reviewer then considered the theoretical rigour (strength) of the study (e.g. did the study have soundly constructed arguments and analysis that followed on from each other and were supported with evidence from other sources). Strength had a score range of 1 (very low – no strength) to 4 (very high – very strong).

Finally the relevance of the study was considered. The relevance rating referred to the applicability of the study's results to a palliative approach in Australian residential aged care settings (score range 1 [not applicable – not relevant] to 4 [very applicable – very relevant]).

None of the three scores were added together to ensure that each score was considered separately. To ensure that the specific contextual issues relevant to Australian RACFs took precedence when formulating guidelines, particular emphasis was placed on the relevance score. For example, studies that scored a 1 or 2 for relevance were not included in the guidelines, even if they had a high level of evidence and / or strength.

#### 1.4.2(c) Evaluation Process

Using the search strategies, more than 12,000 references were located and preliminarily assessed for their potential for inclusion in the evidence evaluation phase by the review working party members using the inclusion and exclusion criteria. In total, 929 articles were determined as being potentially suitable for the project and these were formally evaluated.

The review working party was responsible for evaluating the remaining articles relevance to the project. Relevance was scored by judging whether or not the findings from the articles were transferable to the Australian RACFs context. For example, if participants in the study were aged 65 years and older and institutionalised the results would likely be of relevance to the project and were scored as 4 out of 4. If a study reported on people with a cancer diagnosis only who were younger than 65 years the results would be judged of lesser relevance, and were scored 1 or 2 out of 4. The review working party determined that studies with a relevance score of 3 or 4 would be included. Additionally only qualitative studies with a quality rating of 6 or higher (out of 8) and a strength rating of 3 or 4 (out of 4) would be appropriate for development into guidelines.

To ensure the reliability of the review working party's assessments, 20% of the evaluated articles were randomly selected and distributed to two palliative care researchers who were not part of the project for independent rating. A rating discrepancy occurred with two of the 929 articles. In these instances the articles and blank evaluation forms were forwarded to the Lead Chief Investigator and the four Chief Investigators of the project for their evaluation of the evidence. Consensus was achieved amongst the Investigators for the inclusion of these two articles.

Based upon this preliminary evaluation, 446 articles were identified as being relevant to the project and these were then fully evaluated using the appropriate evaluation tool

(either quantitative or qualitative level of evidence checks as previously discussed) to determine quality and strength. Of this set, 206 were found to meet the evidence criteria.

From the subsequent search (see section 1.4.1 Search Strategies as to why further searches were required), a further 483 relevant articles were found. Of these, 87 met the evidence standard as outlined previously; thus creating a total evidence set of 293 articles and studies. This number does not include those articles that were personal, expert opinion or literature reviews, because the process for incorporating these articles was different; guidelines could not be developed upon their findings, as outlined below.

A formal consensus process was used to decide upon the inclusion of evidence designated as Expert Opinion (EO). This process was activated by feedback from stakeholders (particularly from people with specialised expertise [See Appendix D and E for participants), reference group members (See Appendix F) or project working party members regarding work that they considered was seminal to a particular topic. The article was located and distributed to all Investigators with consensus required as to its relevance to the project for inclusion in the preamble section of the Guidelines.

Some issues of relevance to the aged care setting were not found in the palliative care or gerontology literature, which necessitated a wider search for relevant empirical work to formulate the guidelines. Some study findings based on research undertaken in the community or a palliative care setting have been included when these results were deemed to be transferable to the aged care setting.

#### 1.4.3 Limitations

There are several limitations to the literature review, which were inherent in the method of using electronic databases. The searches were limited to articles published in English; however, much of the research in palliative care and aged care has occurred in European countries and is published in other languages, particularly, German, Dutch and Swedish. Additionally, countries publishing in English language journals are predominantly first world countries and this may subsequently limit some exposure to palliative care issues.

Studies not listed on the electronic databases were not captured by either search strategy. Studies may not be listed for a number of reasons including a time delay between being published and appearing on the database, the journal not being picked up by the database or the database not providing an abstract. Results from an Australian study reported approximately 30% of the palliative care literature was missed on the electronic databases. (Abernethy, Currow, & Butler, 2002) Also, different search engines use different key words and different search strategies to identify articles and these differences may have limited the capturing of appropriate articles.

The volume of literature created the most significant difficulty for the review working party. There were major constraints in terms of time and resources to search, locate and evaluate material. Preliminary assessment made on the basis of title and abstract as a result was often cursory. For 80% of the articles, only a single evaluation was undertaken.

The diverse fields from which research and evidence could be derived also created some evaluation difficulties. Determining what was relevant to the project was to some extent arbitrary. Following the working party's preliminary review of the evidence, there was also some relaxation of the inclusion criteria where evidence from the aged care setting could not be found. This process did not affect the evaluation of the study from the point of view of level of evidence or quality of methods.

Hand searching for specific topics also showed that persistent tracking of material could result in the identification of additional relevant studies and evidence. However, given the resource constraints, it was not possible to apply the same approaches to the initial search topics.

#### 1.5 Further research

There were several gaps in the knowledge base regarding a palliative approach to residential aged care, which require further research. These gaps are fully discussed in Chapter 17 of this report.

The following chapters of this report provide a summary of the literature that was fully evaluated and included in the Guidelines document. Quality scores, country of origin and a condensed abstract for each study are provided in a separate document, which also contains the Appendices pertaining to this Report.

## CHAPTER 2: A PALLIATIVE APPROACH

Palliative care has grown from work in cancer care and from a hospice tradition. The last ten to twenty years has seen significant change in how and where care for the dying is provided.

In most western societies, any discussion of death and dying creates discomfort.(O'Gorman, 1998) This distancing response to death and dying is reflected in poor communication about the topic, limited resources directed to this specialty area, and minimal education about how to provide supportive end-of-life care.

RACFs provide care for the frail-aged in the community and for those who require assistance in daily living. In 1998, 6% of Australians lived in nursing homes or hostels. It is projected that by 2031, the number of people requiring this type of accommodation will increase from 520,000 to 1.4 million.(Australian Bureau of Statistics, 2001)

Giles and colleagues (2003) (Level QE) predict that in the period until 2031, there is likely to be a 70% increase in the number of older people with profound disability associated with musculoskeletal, nervous system, circulatory and respiratory conditions and stroke. This will have implications for RACFs who will have an important role to play in providing care for many of these people.

The World Health Organisation (2003) defines palliative care as:

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

Johnston and Abraham (1995) (Level EO) reviewed the literature to determine whether the WHO objectives for palliative care were being met. They found that there were gaps in research and service provision. They noted that the hospice movement has improved standards of care for the terminally ill but that further work needs to be done to implement palliative care in other settings where people are dying.

Hearn and Higginson (1997) (Level EO) have identified outcome measures in palliative care for advanced cancer patients. They found individual measures met some outcome objectives but there was not a single comprehensive tool.

### 2.1 THREE FORMS OF PALLIATIVE CARE

In considering palliative care for residents in RACFs, it is important to distinguish between a palliative approach, specialised palliative care service provision and end-of-life (terminal) care. The distinction among these forms of palliative care is important in care planning and clarifying the goals for treatment for residents.

Identifying when a resident is moving into a terminal phase will assist the aged care team to provide appropriate care and communication. However, this decision is not easily made, because there are few clear indicators to identify when a person should be considered to be in the terminal phase of an illness or ageing process. This is particularly difficult when the resident has a number of co-morbidities (for further discussion see Section 2.2.1, 'Prognostication').

The aged care team needs to acknowledge the important role of the family carers, to respect the choices that the resident and their family make about treatment options, and endeavour to anticipate the needs of those involved(McGrath, 2001) (Level QE).

Careful attention to the following characteristics will assist the aged care team in taking a palliative approach to resident care:

- being available to discuss issues with the individual and family members;
- providing information in a proactive way; and
- having a sense of partnership with people and their families<sup>(Ingleton, 1999)</sup> (Level QE).

McGrath (2001) reported that families especially valued receiving information from the aged care team when death was imminent, so they could prepare for the resident's death (McGrath, 2001) (Level QE). Reynolds and colleagues (2002) (2002) (Level QE) described the needs of residents dying in RACFs following interviews with staff and family after the death of a resident. They found that the most common physical problems were pain, personal cleanliness, dyspnoea, incontinence and fatigue. Respondents felt that there could have been more treatment for emotional symptoms such as depression, anxiety and loneliness.

The following indicators are provided to help the aged care team determine when to discuss end-of-life matters with the resident and family. These indicators are not prescriptive, nor should they be used in place of careful, individualised assessment of each resident.

Symptoms that are considered to indicate a terminal phase of life include (Addington-Hall, MacDonald, & Anderson, 1990) (Level II):

- Requiring frequent intervention
- Being bed-bound
- Loss of appetite
- Profound weakness
- Trouble swallowing
- Dry mouth
- Weight loss
- Becoming semi-conscious, with lapses into unconsciousness
- Experiencing day-to-day deterioration that is not reversible

These indicators are important to note and the aged care team should be alert to helping the resident and their family to prepare for the terminal phase of the resident's life.

Finlay and Jones (1995) (Level EO) drew a distinction between three different aspects of palliative care. They indicated that a palliative approach is relevant to all patients with incurable conditions and should be a core skill of all clinicians. Palliative interventions are a form of intervention to help control symptoms. Specialist palliative care is a more specific function providing specialist care, acting as a resource to general practitioners (GPs) and carrying out education and research functions.

Kristjanson, Toye and Dawson (2003) (Level EO) reiterated this terminology for palliative care. They see the palliative approach, with its focus on quality of life and on identifying the wishes of patients and their families, resonating within aged care settings where transitions from chronic to palliative to terminal may be gradual and progressive.

Although those people over 85 years who are dying have greater needs and often less support than younger patients; they are less likely to be admitted to hospice care

(Cartwright, 1993) (Level III-2). This may mean that there are additional needs or barriers that affect particular groups from accessing appropriate palliative care.

Buchanan and colleagues' (2002) (Level QE) analysis of admission assessments for nursing homes in the United States of America (USA) into hospice care found the most common diseases were, cancer (57%), hypertension (35%), congestive heart failure (21%), emphysema/chronic obstructive pulmonary disease (20%) and depression (18%). Differences in health systems and population health characteristics between the USA and Australia may influence the transferability and applicability of this evidence.

A South Australian study found that 80% of the resident deaths in the surveyed aged care facilities were non-cancer (Grbich, Parker, & Maddocks, 2001) (Level QE). The most common symptoms were constipation, pain, dysphagia, weakness, restlessness, anxiety and anorexia.

Residents in RACFs 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 disease. Older persons who are dying are considered to have different palliative needs to those people diagnosed with cancer.(Blackburn, 1989) These differences may include, that:(Blackburn, 1989) (Level EO)

- 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; and
- some lack family support.

## **2.2 WHEN SHOULD A PALLIATIVE APPROACH BE IMPLEMENTED?**

Covinsky and Colleagues (2003) (Level III-2) investigated the functional trajectories during the last two years of life of patients with progressive frailty, with and without cognitive impairment. The aim was to identify discrete functional indicators that signal the end of life. They found that patients with advanced frailty, with or without cognitive impairment, suffered from a slow progressive functional decline. There was a steady increase in functional dependence rather than sudden changes before death. This mirrors most trajectories of illness requiring palliation as they lead to death.

Work was undertaken to identify the variables to determine a model of survival time for hospitalised patients over 80 years of age (Teno, et al., 2000) (Level III-3). The model included the following variables: patient demographics, disease category, nursing home residence, severity of physiologic imbalance, chart documentation of weight loss, current quality of life, exercise capacity and functional status. The results showed clinical information from a chart review and an interview could predict long-term mortality.

In a review of physicians' survival predictions, Glare and colleagues (2003) (Level I) found that although the clinical predictions of survival were overestimated, the predictions were highly correlated with actual survival. However, the doctor' survival predictions became more accurate closer to the date of death.

Abicht-Swensen and Debner's (1999) (Level IV) work on the Minimum Data Set (MDS) suggests that it is an effective tool in the aged care setting. Of the study's 199 patients, 74% died within 15 days of a documented significant decline in the MDS suggesting it is a good predictor of imminent mortality. The Spitzer Quality of Life

Index was not as useful, however, in reducing prognostic uncertainty. (Addington-Hall, et al., 1990) (Level II)

Unlike people who are dying of cancer, residents in RACFs generally have a gradual decline in functional ability, so there is usually no sharp delineation between curative care and the acceptance that the goal of care is palliation.(Komaromy, Sidell, & Katz, 2000; Teno, Weitzen, Fennell, & Mor, 2001; Travis, et al., 2002; Travis, Loving, McClanahan, & Bernard, 2001b) (Level QE; Level QE; Level QE; Level QE)

For older persons, the dying trajectory is often characterised by a lack of certainty common to chronic conditions, especially in the absence of a significant event to mark the end stage of illness.(Komaromy, et al., 2000) (Level QE)

A South Australian study found that dying residents had the following characteristics: deteriorating mental states and symptoms including weakness, fatigue, pain, anorexia, constipation and dysphagia. The study also found that barriers to care included a lack of knowledge about pain management and a lack of time for care.(Parker & De Bellis, 1999) (Level QE)

Reynolds, Henderson, Schulman and Hanson (2002) (Level QE) described the needs of dying in nursing home following interviews with staff and family after the death of a resident. They found that the most common physical problems were pain, personal cleanliness, dyspnoea, incontinence and fatigue. Respondents felt that there could have been more treatment for emotional symptoms such as depression, anxiety and loneliness.

Farquhar and colleagues (2002) (Level III-3) found that GPs appeared to be reluctant to define patients as ‘palliative’ even though hospital discharge notes had identified the condition as requiring palliative care. A reluctance to define or accept a palliative diagnosis may have implications for clinical care.

Travis and colleagues (2001b) (Level QE) considered the transition between active treatment and palliative care in the last year of life for residents in long-term care and found that most residents die in a palliative care mode. However, the transition to this mode may not always be made early enough to ensure that the resident benefits from the transition.

The aged care team needs to acknowledge the important role of the family carers, to respect the choices that the resident and their family make about treatment options, and endeavour to anticipate the needs of those involved (McGrath, 2001) (Level QE). Careful attention to the following characteristics will assist the aged care team in taking a palliative approach to resident care:

- being available to discuss issues with the individual and family members;
- providing information in a proactive way; and
- having a sense of partnership with people and their families (Ingleton, 1999)(Level QE).

McGrath (2001) (Level QE) reported that families especially valued receiving information from the aged care team when death was imminent, so they could prepare for the resident's death.

The decision to implement a palliative approach should not be based on the individual's clinical stage or diagnosis; rather, it should be offered according to the needs of the individual.(Lo & Woo, 2001) (Level EO)

### **2.3 WHERE SHOULD A PALLIATIVE APPROACH BE PROVIDED?**

The principles of a palliative approach can be applied in any setting and a palliative approach should ideally be provided wherever people who require this approach reside.(Clare & De Bellis, 1997a) Therefore, RACFs may be an appropriate care setting because residents face many of the same issues as others with a life-limiting condition.(Avis, Jackson, Cox, & Miskella, 1999) (Level QE) A palliative approach is appropriate in the resident's familiar surroundings when there is adequately skilled care available.(Hurley, Volicer, & Volicer, 1996)

The implementation of a palliative approach in RACFs can reduce the potential distress to residents and their family caused by a transfer to an acute care setting.(Avis, et al., 1999; Clare & De Bellis, 1997a) (Level QE; Level QE) A study of a palliative approach in South Australian high care facilities found that 47% (N = 71) of the 151 facilities participating indicated that their home had provided and / or were providing a palliative approach to approximately 10% of their residents.(Clare & De Bellis, 1997a) (Level QE) These findings suggest that many Australian RACFs are already providing a palliative approach to their residents rather than transferring these residents to other facilities.

Some facilities have introduced a hospice within the facility.(Baer & Hanson, 2000; Parker-Oliver, Porock, Zweig, Rantz, & Petroski, 2003) (Level QE; Level III-2) Others have formalized care arrangements with community palliative care providers.(Avis, et al., 1999) (Level QE) Others have incorporated palliative principles and approaches within their normal care regimes.(Clare & De Bellis, 1997b; De Bellis & Parker, 1998) (Level QE; Level QE) Yet, there has not been any systematic examination of the relative benefits for residents, staff and families of the different approaches.

Hunt, Fazekas, Luke and Roder (Hunt, Fazekas, Luke, & Roder, 2001) (Level IV) reviewed the place of death of cancer patients in South Australia and found that 9.7% of people with cancer died in nursing homes.

Access to a palliative approach in rural settings may, however, be more difficult. Poor access to a palliative care service was cited by the authors as the probable reason for the finding of a South Australian study that rural terminally ill cancer patients were less likely to receive a palliative approach (59% compared to 71%).(Hunt, et al., 2001) (Level IV) In rural and remote areas it may be unfeasible to support a full time specialised service; however, support from such a service can be accessed over distance by GPs, or other medical and health practitioners via phone or Telehealth consultation.

Dying with dignity involves the right of the dying resident to choose where they wish to be cared for, where they wish to die and whom they wish to care for them (Ackermann & Kemle, 1999) (Level IV)

The question of what defines a good death in a nursing home has been the subject of some studies. Three themes were identified by Hanson and colleagues (2002) (Level QE) – individualized care by consistent care providers, effective care teams that included the family, and comprehensive advance care planning.

Vig, Davenport and Pearlman (2002) (Level QE) also looked at the question of what constituted a good death. They found that participants in the study had a unique set of themes about what would be a good death or a bad death. They concluded that a thorough understanding of the resident's end-of-life preferences would help in the development of patient-centred care plans.

Within the nursing home, Keay and colleagues (1994) (Level EO) proposed a set of indicators that could be used with terminally ill residents. These indicators were communication of advanced directives, attention to pain control and attention to relief of dyspnoea.

Quality of relationships was seen as a key element in the resident's perception of good quality aged care. (Marquis, 2002) (Level QE) Three major themes emerged to define a good death in a nursing home: highly individualized care based on continuity relationships with caregivers, effective teamwork by staff, physicians and family, and comprehensive advance care planning that addresses prognosis, emotional preparation, and appropriate use of medical treatments.

One estimate by Directors of Nursing put the bed requirement for palliative care at 8.4% of total beds. These Directors of nursing saw the main barriers to palliative care provision as lack of resources, insufficient training and confusion in responsibilities for patient management. (De Bellis & Parker, 1998) (Level QE)

Similar barriers were identified by Katz, Komaromy and Sidell (1999) (Level QE) who found homes were limited by the nature of the support and perspectives of attending GPs, and by staff levels and access to training. They also found that the term 'palliative' was not familiar to many staff.

Travis and colleagues (2002) (Level QE) proposed a hierarchy of obstacles to the provision of palliative care in long-term care facilities, which starts with a lack of recognition that a curative or restorative approach is futile. Subsequent obstacles identified by Travis and colleagues were a lack of communication, lack of agreement on a course of care, and the failure to implement a care plan in a timely fashion.

A recent study regarding the quality of care provided to older persons in their homes compared with those in nursing homes in the United Kingdom (UK) found that the quality of clinical care in both settings was inadequate. (Fahey, Montgomery, Barnes, & Protheroe, 2003) (Level III-2) There were concerns about the overuse of unnecessary or harmful drugs such as neuroleptic medication and laxatives, underuse of beneficial drugs such as betablockers, and poor monitoring of chronic disease. Such findings are indicative of concerns regarding the knowledge and management practices in UK nursing homes; however, it is unclear whether similar concerns are applicable to Australian RACFs.

Lack of clarity among the aged care team or lack of openness with residents and families may lead to conflict and confusion about care goals. (Stull, Cosby, Bowman, & McNutt, 1997; Tilse, 1998) (Level IV; Level QE)

A combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach is considered best practice (Hines, et al., 2001) (Level IV). Therefore, open and regular discussions with the resident and family need to be conducted so the aged care team can understand the resident's wishes (Hines, et al., 2001) and to facilitate continuity of care.

Family members report greater satisfaction with the care their relative receives if family members perceive that either they or their relative had control of care decisions, such as where they would die and who would care for them (Teno, Casey, Welch, & Edgman-

Levitan, 2001) (Level QE). Dying with dignity involves the right of the dying resident to choose where they wish to be cared for, where they wish to die and whom they wish to care for them (Barr, Graham, & Ireland, 2002) (Level QE).

Families may become unhappy if they believe that the transfer will result in their family member receiving a sub-standard palliative approach compared with the care possible in an acute care setting (Maccabee, 1994) (Level QE). Prior to such a transfer, there generally is a need to explain to the family that good care with a palliative approach is available in RACFs.

## **2.4 WHO CAN PROVIDE A PALLIATIVE APPROACH?**

One study considered a team beneficial for a palliative approach, when the team discusses treatment plans, including the potential benefits and disadvantages of treatment decisions.(Hanson, et al., 2002) (Level QE)

Members of a palliative team should represent many disciplines to ensure a multidisciplinary approach to care.(Mitchell, Bowman, McEniery, & Eastwood, 1999) (Level EO)

Sheldon (2000) (Level QE) considered the role of the social worker within the palliative care team.

Maddocks and colleagues (1999) (Level QE) investigated the development of a 'link nurse' model within the aged care facility. The link nurse is considered an internal specialist with a liaison role to external palliative support. This approach was seen to provide positive outcomes for the palliative care received by residents.

One member of the team usually assumes the role of coordinator (e.g. the Director of Nursing, or other suitably qualified nurse, or the GP.(Hanratty, et al., 2002) (Level QE) Depending on their roles, different members of the team have varying perceptions regarding a palliative approach, thus necessitating cooperation and good communication amongst members.(Flacker, Won, Kiely, & Ioputaife, 2001) (Level QE) Effective communication and teamwork are considered by nurses and GPs working in RACFs to be essential aspects of a palliative approach for residents.(Hanson, et al., 2002) (Level QE)

Effective multidisciplinary teams are able to articulate common goals and work in a collaborative, non-hierarchical environment.(Larson & LeFasto, 1989) (Level EO) They meet regularly to assess and discuss progress and are able to devise protocols for the provision of a palliative approach.(Hanson, et al., 2002; Vachon, 1997) (Level QS; Level EO)

A palliative approach is best provided by an effective multidisciplinary team(Flacker, et al., 2001; Hanson, et al., 2002) (Level QE) (Hurley, Volicer, Mahoney, & Volicer, 1993) (Level III-2). Effective teams recognise and acknowledge that team members are likely to have different perspectives about a palliative approach, yet team members are able to clarify and address the reasons for these differences. When a multidisciplinary team uses this approach, their job satisfaction improves as does the quality of care that is provided to residents and their families(Flacker, et al., 2001).

A team approach to care planning also facilitates the aged care team in providing residents with highly individualised care, which allows for the discussion of advance care plans that address prognosis, emotional preparation, and appropriate use of medical treatments (including the potential benefits and disadvantages of treatment decisions)(Hanson, et al., 2002) (Level QE).

Ideally, all aged care teams in RACFs should have sufficient training to facilitate sensitive interpersonal communication required for a palliative approach that will improve the satisfaction of residents and their families. (Hurley, et al., 1996)(Level III-2)

The aged care team needs to help the resident's family accept the decision of the resident whenever appropriate, because in most instances the decision to accept a palliative approach should be the resident's (McKinlay, 2001) (Level QE). However, the views of the family are also relevant and need to be understood (Lobchuk & Stymeist, 1999) (Level EO).

## CHAPTER 3: DIGNITY AND QUALITY OF LIFE

### 3.1 DIGNITY

Promoting a person's sense of dignity is central to a palliative approach,(Doyle, Hanks, & MacDonald, 2003) and dignity and quality of life are linked in this approach. Themes that have been identified include having adequate pain and symptom management, avoiding inappropriate prolongation of dying, relieving burdens, achieving a sense of control, and strengthening relationships with loved ones.(Singer, et al., 1999) (Level QE)

Researchers also highlight the difficulty in describing and evaluating the concept of "dying with dignity". One study found three dignity factors of importance to those surveyed: the capacity to communicate, ability to recognise friends and family members, and being continent.(Turner, et al., 1996) (Level IV)

Singer, Martin and Keiner (1999)(Level QE) interviewed patients with life limiting illnesses and residents of a long-term care facility. Five domains of care were identified: receiving adequate pain and symptom management, avoiding inappropriate prolongation of life, achieving a sense of control, relieving burden and strengthening relationships with loved ones.

Dignity has emerged as an important part of quality of life for terminally ill patients and residents. Chochinov and colleagues (2002) (Level III-3) looked at how patients were able to maintain a sense of dignity and recommended that dignity conserving care needs to be identified as the standard for all patients approaching death. Chochinov (2002) (Level EO) argued that the notion of dignity may be influenced by the nature of the illness, culture and ethnicity. Chocinov and colleagues'(2002) review of the evidence suggests that in a practical setting the categories of dignity include illness/ageing-related issues, dignity-conserving strategies and a social dignity inventory.

### 3.2 QUALITY OF LIFE

Quality of life is an important concept with palliative care services. The WHO Quality of Life Group (1993; Level EO) defined quality of life as:

*"Quality of life is defined as an individual's perception of his/ her position in life in the context of the culture and value systems in which he/ she lives, and in relation to his/ her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment."* (World Health Organization Quality of Life Group, 1993, p. 153)

Quality of life measures usually include questions regarding the following domains: physical, social, psychological, and spiritual. Other issues such as sexual function, body image, and financial concerns may be incorporated as well.(Clinch, 1996)

### **3.3 DESIRE FOR DEATH STATEMENTS**

Sometimes the aged care team caring for residents with an advanced disease or in the final stages of the ageing process are confronted by statements indicating that the resident may wish for a hastened death. Such statements may provoke concern and confusion for the aged care team who may be uncertain about how to respond. The aged care team may find themselves grappling to determine if the resident is depressed, suicidal, seeking help to hasten death; or they may believe the expressed wish is an understandable response to the resident's circumstances. (Van Loon, 1999) Occasional thoughts of suicide are not uncommon in palliative settings. (Breitbart, et al., 2000) (Level IV) However, sustained suicidal ideation is less common and all statements of this nature warrant care and attention. (Chochinov, Wilson, Enns, & Mowchun, 1995b) (Level QE)

The reasons for 'desire to die' statements may be associated with issues such as:

- Feelings of hopelessness, depression, and guilt, unrelieved suffering, and a wish for self-punishment (Muskin, 1998) (Level EO);
- A perception of being a burden to others, anxiety, existential distress and family issues (Cherny, Colyle, & Foley, 1994) (Level EO);
- A sense of loss of dignity and a perceived lack of control (Bascom & Tolle, 2002) (Level EO); and,
- A sense of isolation, boredom and loneliness.

Any of these factors may lead to depression or contribute to a resident's wish to hasten death. Appropriate treatment may facilitate a more hopeful outlook for the resident, even at the end of their life. (Breitbart, et al., 2000) (Level IV)

## CHAPTER 4: ADVANCE CARE PLANNING

The purpose of the advance care plan is to elicit the resident's wishes regarding treatment decisions, which will often include decisions related to their impending death; to extend their autonomy, and to guide decision making when the resident may be rendered incompetent of doing so. (Molloy, et al., 2000) (Level II)

Advance care planning is an area that is integral to the establishment and management of palliative care with RACFs and includes practices built on communication with residents and their family about their wishes, beliefs and values about future care.

Current practices of care in palliative care settings include working through the decision-making process for end-of-life care and the completion of advance care plans. This practice requires input from the patient, family, doctor and facility. (Wurzbach, 2002) (Level QE) Residents of a RACF are generally included in this practice, independent of them receiving specialist palliative care intervention for unmanageable symptom control. (Blevins & Deason-Howell, 2002) However, Nair and colleagues' (2000) (Level QE) study of Australian facilities found a very low rate of use of formal advance care plans.

Analysis of data from two studies, the Hospitalised Elderly Longitudinal Project (HELP) and Study to Understand Prognoses and Preference for Outcomes of Risks of Treatment (SUPPORT), revealed that as many as 78% of patients would prefer to have their doctor and family make decisions on resuscitation for them. As few as 22% of subjects would prefer to have their expressed wishes followed if they no longer had testamentary capacity. (Puchalski, et al., 2000) (Level III-2) Two independent predictors preferred for family / doctor are a Do Not Resuscitate order and having a surrogate decision-maker. The evidence showed that the responsibility of making decisions regarding end-of-life care is mixed. Physicians believe it is the responsibility of the patient, while a significant minority of patients believe it should be the physician, and some patients believe it should be up to the family. (Johnston & Pfeifer, 1998) (Level III-3)

Miles (1996) (Level EO) in a review of the empirical studies on the use of advance care plans showed that such plans are a complex and confronting task. The research shows that communications can be limited and unsatisfactory and that the process of record keeping and transfer of information between institutions and providers can be problematic.

There are some indications that a broader, community based approach to advance care planning can improve the prevalence and type of end-of-life planning. (Hammes & Rooney, 1998; Schwartz, et al., 2002) (Level III-3; Level II)

Much qualitative data exists on the importance of end-of-life decision making for those with cancer. (Fried & Gillick, 1994; Wise, et al., 1994) (Level IV; Level QE) Less evidence exists for older persons with a life-limiting condition or chronic illness who are not necessarily identified as being terminally ill. (Lynn, 2000)

Vig, Davenport and Pearlmann (Vig, et al., 2002) (Level QE) focused on the need to seek specific information from older adults on their end-of-life choices and the reasons for these choices. This understanding would assist clinicians and institutions in providing patient centred care plans for the end of life.

#### 4.1 IMPLEMENTING ADVANCE CARE PLANNING

Costello (2002) (Level QE) reminds us that advance care plans are not homogenous. They can include Do Not Resuscitate (DNR) orders, Do Not Hospitalise (DNH) orders, directions regarding artificial nutrition and hydration, Good Palliative Care Orders (Palliative Care Council of South Australia, 1996), and specific directions regarding what treatment, if any, is desired in various situations. It may be in the form of a durable medical agent being appointed for the time when a resident loses testamentary capacity. (Palliative Care Council of South Australia, 1996)

While the concept of advance care planning is well established in the literature, there appears to be many barriers to the plans being formulated, documented and implemented for older persons by RACF staff. (Meisel, Snyder, & Quill, 2000) (Level EO) This is particularly so for residents who are not necessarily identified as having a terminal illness such as dementia. (Evers, Meier, & Morrison, 2002b; Puchalski, et al., 2000) (Level IV; Level III-2)

Advance care plans empower the individual to state his / her wishes, in writing, in accordance with how he or she defines quality of life. (Singer, et al., 1999) (Level QE) By doing so, the burden of responsibility is taken off the shoulders of a surrogate and control is maintained by the writer. Problem-solving therapy is one feasible and acceptable way to achieve this. (Wood, 1997) (Level III-1) The concept of a good / bad death underpins the motivation for people to write an advance care plan as it aims to address issues such as pain control and comfort care. (Hume, 1998)

In Australia, the Good Palliative Care Order (Palliative Care Council of South Australia, 1996) is not a legal document and the status of an advance care plan has yet to be tested in a court of law. However, a person can appoint a medical agent in South Australia under the *Consent to Medical Treatment and Palliative Care Act 1995* (SA), in the Australian Capital Territory under the *Power of Attorney Act 1956* (ACT), and in Victoria, under the *Guardianship and Administration Act 1986* (VIC). The other States and Territories do not currently have legislation to cover advance care plans or medical agents, but a family member can make medical decisions under the *Guardianship and Administration Act 1993* (CTH) if no agent has been appointed. (Palliative Care Council of South Australia, 1996) Surrogates other than next-of-kin or blood relative do not currently have legal status, unless appointed as the medical agent.

In the United States of America, the Patient Self-Determination Act confirms the constitutional right of the person to refuse medical treatment. (Hosay, 2001) (Level IV) However, some nursing homes have refused to follow some resident's wishes for end-of-life care on grounds of conscience. Two issues of debate have centred on artificial feeding and hydration.

The evidence suggests that advance care plans are infrequently used in RACFs (Nair, et al., 2000) (Level QE) and this is dependent on the characteristics of both the resident and the facility. (Castle, 1996) (Level IV) However, if systematically implemented in a facility, patients and family report satisfaction with their involvement with end-of-life decisions. (Molloy, et al., 2000) (Level II).

Advance directives can be a part of the process of advance care planning. The proper use of advance directives in clinical practice is dependent upon the aged care team's knowledge of the legal status of these documents. (Costello, 2002) (Level QE) Advance care planning documents vary considerably. (Costello, 2002) They include a variety of legal documents as well as less formal documents for ascertaining a resident's end-of-life wishes. These types of documents often aim to address issues such as pain control and comfort care. (Hume, 1991)

Most of the evidence on DNR orders originates from the USA and is transferable to the Australian health care system because DNR orders are internationally recognised. Many of the studies are, however, based in acute care settings.(Fins, et al., 1999; Happ, et al., 2002) (Level IV; Level IV) This reflects the acute care setting as one where decisions about life-threatening conditions are frequently made, especially if a resident does not have a DNH order.

Ideally, an advance care plan involves a discussion with the resident, family, and health care team. (Wurzbach, 2002) (Level QE) A facilitated discussion about advance care planning between residents and the aged care team helps define and document the resident's wishes.(Schwartz, et al., 2002) (Level II) When systematically implemented in RACFs, residents and families report satisfaction with their involvement with end-of-life decisions.(Molloy, et al., 2000) (Level II) When a competent person makes an advance directive it is considered, legally, to support that person's common law right to refuse treatment.

Rempusheski and Hurley (2000) (Level EO) argue that it is appropriate for the aged care team to have ongoing discussions about advance care plans with family members to plan end-of-life care that is appropriate for the resident. These discussions require clear communication and assessment strategies regarding the goals and expectations of treatment.(Norton & Talerico, 2000)

#### **4.2 ADVANCE CARE PLANNING FOR RESIDENTS WITH ADVANCED DEMENTIA**

The evidence suggests that family members of people with a dementing illness have unresolved emotional needs, stemming from the illness itself and nursing home placement, that often makes them unprepared to make end-of-life treatment decisions. (Forbes, Bern-Klug, & Gessert, 2000) (Level QE) Yet, they are often required to make a wide range of decisions about the daily lives of residents regarding their quality of life and quality of treatment and health care.(High & Rowles, 1995) (Level QE)

It was found that family members need information on the trajectory of the disease, what might impede a natural death and palliative care options, as well as emotional support so that they can process difficult and painful emotions.(Forbes, et al., 2000) (Level QE)

Hurley and colleagues (1995) (Level QE) developed a four-phase model for the process of recommending treatment decisions for residents with Alzheimers. The model aimed at achieving consensus by considering constructs that included interactive process components of patient, family, and staff adjustment, caring, and knowing. The authors concluded that timing and trust were influential catalysts to family and staff readiness factors for achieving consensus; outcomes were the advice provided by staff and the family conference where treatment options were determined; and consequences included the advance proxy plan and patient care.

#### **4.3 LEGAL CONSIDERATIONS AND DOCUMENTATION**

Research has indicated that it can take a resident between 3 and 18 months to develop a comprehensive advance care plan that addresses all relevant issues as the state of health changes over time. (Molloy, et al., 2000) (Level II)

There is no evidence regarding the best way to document advance care plans in residents' case notes or recommendations for the revision of plans when circumstances change, but experts in the field highly recommend that it be done, especially when residents are transferred between various facilities.(McGough & Ladd, 1999) McGough

and Ladd (1999) (Level EO) recommend that a plan of care, in the form of a small notebook, be transferred with the resident as other medical documentation would be transferred.

Studies have shown that education on advance care plans for staff members, residents and their families has increased the frequency with which directives have been completed and implemented in RACFs, with a corresponding satisfaction with end-of-life care.(Tierney, et al., 2001) (Level II)

#### **4.4 THE RIGHT TO REFUSE FOOD**

Consenting to food or refusing food is an expression of the resident's autonomy. (Wasson, Tate, & Hayes, 2001) A review of relevant literature revealed little empirical work to inform this issue. However, in situations of food refusal in people with advanced dementia, the experts in the field offer three recommendations: (Wasson, et al., 2001) (Level EO)

1. Consider if the cessation of eating is in keeping with an overall deterioration in the resident's health status;
2. Exclude the possibility of a treatable condition like an infection that could affect cognitive ability and appetite; and
3. It may still be appropriate to offer small amount of food and fluids, even if the person is dying - but do not use with undue force and always defer to the resident's cues.

In summary, there is compelling evidence to support the use of advance care planning in a palliative approach. Therefore, RACFs should engage in some form of regular educational programs for the aged care team, residents and families on the issues around end-of-life care, a palliative approach, and advance care planning. This process will facilitate residents' communication of their wishes and enhance their sense of control. The process will also help to acknowledge the role of the family in the aged care facility. An additional recommendation is that a systematic approach to advance care planning be incorporated in RACFs. (Molloy, et al., 2000; Schwartz, et al., 2002) (Level II; Level II).

## CHAPTER 5: ADVANCED DEMENTIA

Advanced dementia is associated with poor prognostic factors such as swallowing disturbance, weight loss, dysphagia, anorexia, and bowel and bladder incontinence, and often results in the person being bedridden. (Ahronheim, Morrison, Morris, Baskin, & Meier, 2000) (Level II) The progression from diagnosis of advanced dementia to death is usually three years, and poorer prognosis is likely if the resident develops an acute illness such as pneumonia or an infectious disease. (Hurley, et al., 1993; van der Steen, Ooms, Mehr, van der Wal, & Ribbe, 2002) (Level III-3; Level III-2) Thus, advanced dementia is a progressive degenerative disease that is life-limiting, and a palliative approach to care should be offered. (Hurley, et al., 1996) (Level III-2)

### 5.1 HOW PREVALENT IS DEMENTIA?

In 2001, Australia's population was approximately 19 million of which 165,000 had dementia. It is estimated that by 2040 the number of Australians with dementia will have risen to 450,000. (Australian Institute for Health & Welfare, 2003) (Level QE) Dementia is currently the second largest cause of disability in Australia (depression is the first) and by 2016 dementia is expected to be the primary cause of major chronic illness. (Giles, et al., 2003) (Level QE)

The proportion of people in RACFs in Australia with advanced dementia is around 50%. People with severe dementia account for approximately 3% in LCFs (low care facilities) and 41% in HCFs (high care facilities) (Gibson, Bol, Woodbury, Beaton, & Janke, 1999) (Level QE). Only 10% of high-care residents have no cognitive impairment.

The issues that arise for family members are similar to those for people with a terminal illness, namely symptom management, advance care directives, end-of-life care and bereavement care, but cognitive decline is insidious and some of the issues are unique and complex.

The number of people living to an age when the prevalence of developing a dementing illness is increasing. Approximately 6% of the Australian population was diagnosed with a moderate to severe dementing illness in 1996 and half of those 134, 800 people live in a RACF. Overall, residents in LCFs diagnosed with dementia were approximately 30% of the population and approximately 60% resided in HCFs. Only 10% of HCF residents have no cognitive impairment. However, this data was dependent on a diagnosis and not functional ability.

The American Academy of Neurology has provided an evidence-based practice parameter dealing with pharmacologic and non-pharmacologic treatments for dementia management (Doody, et al., 2001) (Level I). However, because these parameters were not specific to the palliative population their appropriateness for this population requires further research and guidance.

## 5.2 ADVANCED DEMENTIA AND A PALLIATIVE APPROACH

There is evidence to suggest that a palliative approach benefits not only the individual with the disease, but also the family (Casarett, Takesaka, Karlawish, Hirschman, & Clark, 2002) (Level QE). The features of a palliative approach considered most helpful to the family are continual follow-up evaluation, attention to all symptoms causing distress, emphasising the resident's quality of life, promoting the resident's dignity and a tendency to avoid hospitalisation (Casarett, et al., 2002) (Level QE). Underlying a palliative approach is the assumption that all residents with advanced dementia should be thoroughly assessed with a view to managing all treatable causes of confusion.

Shuster (2000) (Level EO) noted that progressive dementia is an incurable and invariably fatal illness. He recommended palliative treatments as the most appropriate form of care. There is a consistent cluster of symptoms and changes that indicate a patient is entering the final stages of dementia:

- Neurocognitive: Progressive worsening of memory and cognition  
Confusion and profound disorientation  
Behavioral changes (e.g. combativeness, apathy, and coma)  
Progressive worsening of speech leading to incoherence, muteness
- Functional: Loses independent mobility  
Loses capacity for self care
- Nutritional: Loss of appetite  
Difficulty swallowing  
Aspiration becomes increasing risk
- Complications: Bowel and bladder incontinence  
Fever and infections  
Decubitus ulcers

Shuster (2000) also identified a series of issues relating to palliative care of those patients with advanced dementia including agitation and delirium, delusions and hallucinations, pain assessment and management, depression, poor sleeping, fever, prognostic uncertainty and treatment planning and decision-making.

The evidence suggested that the benefits of care in the palliative care setting favours the patient and significantly benefits the caregiver (Casarett, et al., 2002) (Level QE). The features of interest to the caregiver are the continual follow-up evaluation by the primary carers and the emphasis on avoiding hospitalisation.

Blasi, Hurley and Volicer (2002) (Level EO) in their review of end-of-life care in dementia found four barriers to the provision of quality terminal care:

- measurement issues regarding quality of care and quality of life,
- inappropriate interventions stemming from lack of, or disregard, for advance directives, cost considerations, healthcare system factors, and caregiver factors,
- poor symptom management; and
- health policies.

The American health care system imposes a maximum of 6 months survival on the eligibility criteria for admission to hospice care (Keay & Schonwetter, 1998). The funding arrangements by the US Medicare Hospice Benefits are not issues in the Australian context and hence the US literature on funding arrangements for hospice

care and dementia has been rejected in this literature review. However, the American literature cites the development and evaluation of various assessment tools for judging the survival rate in people with end-stage dementia. This data is transferable to the Australian context and may be used to help families understand the trajectory of the disease.

### 5.3 ASSESSMENT

Luchins, Hanrahan and Murphy (1997) (Level III-2) outlined five indicators that are used to predict the 6 month survival rate in end-stage dementia: assessment of activities of daily living; ratings on the Functional Assessment Strategy Tool (FAST); ratings for appetite, nourishment and mobility; medical complications checklist; and care plan concentrating on the use of medications in acute illness. It has been found that a FAST score of stage 7C is significantly related to survival time. While this approach looks conclusive, 41% of the sample in Luchin's study could not be scored on the FAST and the disease progression was not ordinal.

Data drawn from the United Kingdom (UK) Regional Study of Care for the Dying found that the symptoms most commonly identified in the last year of life were: confusion (83%), urinary incontinence (72%), pain (64%), depressed mood (61%), constipation (59%), and poor appetite (57%) (McCarthy, Addington-Hall, & Altmann, 1997) (Level QE). Patients with dementia were compared with cancer patients and it was found that people dying from dementia have symptoms and health care needs comparable to those dying from cancer. The study showed that people with advanced dementia have less contact with the GP and their carers were less satisfied with the assistance received from the GP than the cancer group.

#### 5.3.1 Pain assessment

It has been found that any systematic evaluation of end-of-life care for people with severe cognitive impairment has been hampered by the lack of appropriate evaluation tools (Volicer, Hurley, & Blasi, 2001)(Level QE) .

*The Residential Aged Care Pain Management Guidelines* (Australian Pain Society, 2004) (Level EO) recommend that the Pain Assessment in Advanced Dementia Scale (PAINAD) (Warden, Hurley, & Volicer, 2003) is the standardised tool for use in Australia for residents with advanced dementia. The PAINAD scale is easier to administer and score than the Discomfort Scale for Dementia of the Alzheimer's Type, upon which it was based (Warden, et al., 2003) (Level QE). The PAINAD scale is a five-item observational tool based on behavioural observations, with a scale of 0–2 for each item.

Consequently, several scales and assessment tools were developed and evaluated to be used as outcome measures to assess the effectiveness of treatment in end-of-life care. The Assessment of Discomfort in Dementia (ADD) protocol (Kovach, et al., 2001) (Level QE) and the Discomfort Scales for Dementia of the Alzheimer type (DA-DAT) (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992)(Level III-3) were developed to improve the recognition and treatment of physical pain and affective discomfort in those with cognitive impairment who can no longer articulate their care needs. The ADD was shown to effectively improve symptoms in 83.5% of a sample of people on whom it was trialled and supports the notion that people with severe dementia can be assessed and treated for pain and discomfort (Kovach, et al., 2001) (Level IV).

A study was conducted to investigate the prescription and administration of analgesic medications to treat pain in 339 cognitively impaired nursing home residents (295

women and 44 men; M age = 87) (Horgas & Tsai, 1998) (Level QE). Forty-six percent of the sample had diagnosed cognitive impairment, and 55% had at least one diagnosed painful condition. The results indicated that cognitively impaired nursing home residents were prescribed (per week 32,983 mcg acetaminophen equivalents) and administered (2,871 mg per week) significantly less analgesic medication, both in number and in dosage of pain drugs than their more cognitively intact peers (per week 44,341 mg and administered 5,804 mg acetaminophen equivalents) during the same period. Those residents who were more disoriented and withdrawn residents were prescribed significantly less analgesia by physicians and residents who were more disoriented, withdrawn, and functionally impaired residents were administered significantly less analgesia by nursing staff. The authors' concluded that the findings highlighted the difficulties of assessing pain in cognitively impaired elders and the lack of knowledge among health care providers about effective pain management (Horgas & Tsai, 1998) (Level QE).

The Abbey pain scale is a useful and simple tool for use with residents with dementia who are unable to verbalize (Abbey, et al., 2004)(Level IV).

Chibnall and Tait (2001) (Level III-3) compared four pain scales for use with cognitively impaired and unimpaired older adults and found that the use of a 21 – point box scale was most appropriate for use with in older patients with mild to moderate cognitive impairment. The study also supported the ability of older cognitively impaired patients to rate pain reliably and validly.

One study assessed the ability of residents to complete five frequently used scales (average age was 85 with a mean MMSE score of 12) (Ferrell, Ferrell, & Rivera, 1995) (Level IV). Only one-third of the residents could complete all of the scales, though 83% could complete at least one scale. The authors surmised that most residents with advanced dementia could complete at least one bedside assessment tool, but that significant patience and time was needed to determine the most suitable tool for the resident and to await their responses.

Volicer and Hurley (1999) (Level EO) argue that it is appropriate for nursing staff to have ongoing discussions about advance care directives with family members to plan end-of-life care that is appropriate for that resident, including acute episodes, like hip fracture and pneumonia, that may occur.

In a study to explore the variety of behaviours engaged in by nursing home residents with chronic pain, and to compare the perceptions of family caregivers and nursing home staff found that agreement of both nurse and caregiver's assessment of pain in the resident was poor and the agreement with the resident's assessment of his/her pain was also poor (Weiner, Peterson, & Keefe, 1999b) (Level III-3). The sample included residents who were cognitively intact and impaired. The majority of nurses felt that assessing pain levels in resident's with cognitive impairment was more challenging.

Cohen-Mansfield and Lipson (2002) (Level IV) found that geriatricians were able to evaluate pain effectively in moderately cognitively impaired, but were less successful in evaluating pain in the severely cognitively impaired.

#### **5.4 MANAGEMENT**

There is some discussion in the palliative care and aged care literature regarding the most appropriate management of those diagnosed with severe cognitive impairment in the terminal period. The evidence supports the notion that palliative care is the appropriate care for people with end-stage dementia.(Casarett, et al., 2002; Luchins & Hanrahan, 1993; McCarthy, et al., 1997) (Level QE; Level IV; Level QE) Experts in the

field believe that people with a dementing illness should be managed in-situ, without invasive treatments that are not going to change the ultimate outcome.(Hurley & Volicer, 1999) (Level EO)

Volicer and Hurley (1999) (Level EO) argued that nursing staff who know the resident well can manage resistive behaviour appropriately, whereas staff in the acute care setting neither know the resident nor have the time to manage difficult behaviour.

A systematic review of current best practice on physical restraint in acute and residential care facilities found that there is little agreement on how physical restraint should be used and no evidence of standardisation of practice. (Evans, Wood, Lambert, & Fitzgerald, 2002) (Level II) Based on this systematic reviews findings, the Joanna Briggs Institute (2002) made three recommendations regarding physical restraints:

1. Use only if the potential benefits are greater than the potential harm;
2. The minimal level of restraint be used for the safety of the person or that allows treatment to be completed; and
3. Once initiated, the need for physical restraint is reviewed regularly.

The Joanna Briggs Institute has further recommended restraint-free care through the Restraint Minimisation Program. (Joanna Briggs Institute, 2002b) The program has two components: education to change the culture of the organisation and to provide strategies to remove restraints, and restraint alternatives. The specifics of the restraint alternatives are not well supported at this time as little evaluation has been completed.

There is little clear evidence on best approaches on handling food refusal and dysphagia in older people with dementia. In the UK, around 80% of people diagnosed with Alzheimer's have eating difficulties so the problem is substantial for those involved with patients with dementia. (Alzheimer's Society, 2002)

Wasson, Tate and Hayes (2001) (Level EO) have reviewed a number of practical approaches to dealing with problematic eating in nursing homes. Based on a systematic review of the nursing management of dysphagia in adults with neurological impairment, (Ramritu, Finlayson, Mitchell, & Croft, 2000) (Level I), the Joanna Briggs Institute (2000) (Level EO) has also developed a Best Practice sheet to guide current care practice.

The concept of personhood has also begun to be investigated within palliative care and has been seen to contribute to dignity. In one study, staff were asked how they helped patients cope with the multiple losses involved with terminal illness. Among the concepts identified were "normalising" distressing symptoms such as body odour, encouraging patient activities and personalising their living spaces.(Kabel & Roberts, 2003) (Level QE) This approach parallels Kitwood's concept of personhood as a holistic nursing approach for interacting with residents with dementia.(Kitwood & Bredin, 1992) (Level EO)

## **5.5 ACUTE ILLNESS**

The evidence found that people with advanced dementia who are admitted to hospital with acute illness while under the care of a palliative care team, often have their palliative care abandoned while in hospital.(Ahronheim, et al., 2000) (Level II) The limitations of the study include a small sample size and the way the research team intervened in the treatment plan. However, the study highlights the need to prioritise goals of treatment before a person is sent to hospital when there is less urgency to make life and death decisions.

The use of systemic antibiotic therapy is prevalent in people with end-stage dementia in the last 6 months of life, despite the poor prognosis of severe dementia.(Evers, Purohit, Perl, Khan, & Marin, 2002a) (Level IV) It has been found that people with severe dementia receive similar treatment to those with mild cognitive impairment and in the elderly without cognitive impairment.

Volicer and colleagues (1993) (Level IV) reported that older age and higher severity of DAT (dementia of the Alzheimer type) at the onset of fever, palliative care and admission for long-term care were positively associated with the likelihood of dying within 6 months of a fever occurrence. Hurley, Volicer and Volicer (Hurley, et al., 1996) (Level III-2) found that aggressive medical treatment for fever did not affect the underlying disease process nor prevent the progression of severity in the DAT. They recommended providing palliative care as it prevented patients from undergoing invasive diagnostic workups and does not accelerate the progression of DAT.

People with advanced dementia and hip fracture or pneumonia had a much higher mortality rate at 6 months than patients who were cognitively intact. (Morrison & Siu, 2000) (Level III-2) The mortality rate of those who subsequently acquire pneumonia is dependent on the severity of the cognitive decline, in conjunction with other intermediary factors that actually cause mortality. (van der Steen, Graas, Ooms, Wal, & Ribbe, 2000; van der Steen, et al., 2002) (Level EO; Level III-2) Moderately demented residents, who lost a significant amount of weight and had to be aspirated, had an increased risk of mortality within 3 months of pneumonia. The implications for clinical practice hinge on the presence of these other characteristics that interplay with the underlying pathology. End-of-life treatment decisions need to take these factors into account to ensure the treatment or refusal of treatment is appropriate.

The evidence suggests that the cost of hospital care for fever management of patients with advanced dementia is fiscally and emotionally high.(Hurley, et al., 1993) (Level III-2) The extent of disruption on the resident is not beneficial and it may be appropriate for staff to shift the paradigm from cure to comfort care.

## CHAPTER 6: PHYSICAL SYMPTOM ASSESSMENT AND MANAGEMENT

*To cure sometimes  
To relieve often  
To comfort always*

*Anon*

Failing to relieve physical symptoms and the associated distress is a major cause of loss of quality of life and suffering in the aged care population (Cartwright, 1993) (Level III-2). For this reason, those working in the aged care sector have identified the management of symptoms as a priority area.

There exists a substantial repository of high quality evidence relating to the provision of physical care for palliative patients. The evidence context for this section relates to the care of those residents in aged care settings who are dying. The themes around palliative topics such as dyspnoea or anorexia are related to safety and efficacy in the frail elderly and in particular groups such as the cognitively impaired.

The Australian Therapeutic Guidelines for Palliative Care (Therapeutic Guidelines Writing Group, 2001) outline the clinical assessment and therapeutic management of symptoms frequently experienced by patients receiving palliative care. Issues covered include pain, symptom control, fatigue, the various systems of the body, terminal care and emergencies.

### 6.1 SYMPTOM ASSESSMENT

A comprehensive assessment of the resident's concerns, including early identification of their main symptoms, leads to appropriate treatment plans (Wenger, et al., 1996) (Level IV).

Identification of palliative assessment tools that have been validated against a geriatric population is essential in establishing and acknowledging good palliative care in RACFs. However, the availability of assessment tools that have been validated for use with this population is still limited.

There are several major research projects that have reviewed assessment tools for use in diagnosis, clinical practice and audit in palliative populations generally. The results of this work can be found at websites such as [www.chcr.brown.edu](http://www.chcr.brown.edu) and [www.growthhouse.org](http://www.growthhouse.org).

The Symptom Assessment Scale (SAS)(Kristjanson, et al., 1999) (Level EO) is used to assess symptoms commonly found in individuals in palliative settings, many of whom are older and a large proportion of whom have cancer. Participants are asked to rate each of the following symptoms according to their intensity: insomnia, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. Absent symptoms are assigned a 0, and symptoms that are present are rated from 1 (minimal problem) to 10 (worst possible). Scores are not generally totalled. Sometimes family members and the aged care team sometimes provide proxy responses using the SAS when the person is unable to respond, using their knowledge of ways in which these individuals generally present when experiencing these symptoms.

The assessment and management of pain and other symptoms at the end-of-life is important to patients and families (Blacksher & Christopher, 2002; Steinhauser, et al., 2000) (Level EO; Level IV).

A profile of nursing home residents, who have been identified as dying by staff, reported experiencing symptoms such as weakness, fatigue, pain, anorexia, constipation and dysphagia (Parker & DeBellis, 1999)(Level QE).

Recent work in South Australia found the most common symptoms of palliative residents with non-cancer diagnoses were constipation, pain, dysphagia, weakness, restlessness, anxiety and anorexia (Grbich, et al., 2001) (Level QE).

Addington-Hall, Altmann and McCarthy (1998) (Level III-1) looked at age as a variable in symptom intensity. The authors found that younger patients with cancer are more likely than older patients with cancer to need help in relieving distressing symptoms. Addington-Hall and colleagues (1998) did point out that some older patients did have very distressing symptoms and needed specialist assistance.

For patients who have had a stroke during the last year of their life, the major symptoms were pain, mental confusion, low mood and urinary incontinence (Addington-Hall, Lay, Altmann, & McCarthy, 1995) (Level IV).

Heart disease patients receiving palliative care identified the following problems: pain, loss of independence, difficulty walking, dyspnoea, angina and tiredness (Anderson, et al., 2001) (Level III-3).

A comparative study of patients with chronic respiratory diseases and patients with lung cancer found that those with the chronic condition had physical and psychosocial needs as great as those with lung cancer (Edmonds, Karlsen, Khan, & Addington-Hall, 2001) (Level III-3). In the last six months of life, significant numbers of patients with Chronic Obstructive Pulmonary Disease (COPD) had serious pain and dyspnoea. (Lynn, et al., 2000) (Level IV). Other symptoms identified with COPD include poor quality of life, emotional distress and low physical functioning as well as physical symptoms. (Skilbeck, et al., 1998) (Level QE).

Many symptoms, apart from pain, commonly found in nursing home residents as a result of chronic illness and the effects of ageing, are already successfully addressed by the protocols of nursing care. The symptoms that generally appear in the aged care and palliative care literature are: fatigue, bowel care, skin integrity, dyspnoea, mouth care and issues of poor nutrition and hydration.

The Edmonton Symptom Assessment System is a simple and useful technique for assessing pain on a regular basis by workers (Bruera, Kuehn, Miller, Selmer, & MacMillan, 1991) (Level III-3).

The Functional Pain Scale (FPS) has been validated in geriatric settings and it was found to be a satisfactory tool for use with older patients when compared with other tools including the Visual Analog Scale (VAS), the Present Pain Intensity (PPI), the McGill Short Form Questionnaire (MPQ-SF) and the Numeric Pain Scale (NPS) (Gloth, Scheve, Stober, Chow, & Prosser, 2001) (Level III-2). The FPS was thought to be more sensitive to changes in pain than other instruments (Gloth, et al., 2001).

Chibnall and Tait (2001) (Level III-3) investigated four pain scales in a population of older adults with varying levels of cognitive impairment. The tools compared in the study were a five point verbal rating scale, a seven-point faces scale, a horizontal 21 point box scale and two 21 point box scales. The findings suggest that the 21 point box was most useful for patients with mild to moderate cognitive impairment.

Other scales for use with residents with dementia include the Abbey Pain Scale (Abbey, et al., 2004) (Level IV); the Discomfort Scale - Dementia of the Alzheimer Type (DS-DAT) (Hurley, et al., 1992) (Level III-3); and the Assessment of Discomfort in

Dementia (ADD) Protocol (Kovach, Weissman, Griffie, Matson, & Muchka, 1999) (Level IV).

## **6.2 PAIN MANAGEMENT**

Pain management remains a central feature of good palliative care. The ability to assess the nature and severity of an individual's pain is the first step in managing that pain.

Pain management is an important feature of end-of-life care, which has been undertreated or mistreated (Ashburn & Staats, 1999) (Level EO). Pain management needs a systemic and holistic approach to treatment, which is tailored to the individual's physical, psychological, and spiritual needs (Hassed, 1999) (Level EO). Pain is what the individual says it is and what others think it should be (Dickinson, 1988) (Level EO). Dame Cicely Saunders' notion of 'total pain' (Saunders, 1998) (Level EO) needs a multidimensional assessment for effective multidimensional management (Greenstreet, 2001) (Level QE).

Studies have found that older persons may experience more pain than younger persons, yet are less likely to complain (Bernabi, et al., 1998) (Level IV). Pain management in RACFs does not appear to be well addressed. One US study found that nearly one-sixth of all residents in RACFs are in daily pain and, when reviewed 60 to 180 days later, two-thirds were again reported to have been in daily pain (either moderate or excruciating) (Teno, Bird, & Mor, 1999) (Level IV). A further study found that residents over 85 years of age were more likely to receive no analgesia than younger residents (Bernabi, et al., 1998) (Level IV). A similar finding regarding pain was also found in an Australian study, which reported that 22% of residents who stated that they had pain had no medication administration recorded in their case notes, and 16% did not have analgesics ordered (McClellan & Higginbotham, 2002) (Level QE).

Buchanan and colleagues (Buchanan, et al., 2002) (Level QE) found that over 70% of residents recently admitted to hospice care in the USA experienced pain, with almost half experiencing daily pain.

There is also some evidence that the management of chronic pain in the community in Australia is of concern (Blyth, March, & Cousins, 2003) (Level QE).

The need for multidisciplinary approaches to the management of pain has also been stressed (Molloy, et al., 2000; Virik & Glare, 2000a; Virik & Glare, 2000b) (Level II; Level EO; Level EO).

Changes in practice have resulted due to the research findings on the presence of persistent pain in nursing home residents in the USA. Such changes include improved education of doctors and nurses on pain assessment and prescribing, development of more responsive assessment tools, improved treatment strategies, and better monitoring practices of residents' pain levels (AGS Panel on Persistent Pain in Older Persons, 2002).

One large retrospective, comparative cohort study in the USA (n = 7,929 nursing home residents in USA nursing homes and n = 2,644 hospice patients) found that the analgesic management of daily pain was better for patients receiving hospice care than for those living in nursing homes (Miller, Mor, Wu, Gozalo, & Lapane, 2002) (Level III-3). The study also found that the type of analgesic prescribed differed between nursing home residents and hospice patients, with residents most often being given acetaminophen (without other drugs) (25% of 1,673 prescriptions), whereas hospice patients were more frequently given morphine derivatives (30% of 1,058 prescriptions). The authors of this study concluded that even when the clinical confounders were controlled for, nursing home residents who are dying were twice as

likely as hospice patients to receive adequate daily management of their pain (Miller, et al., 2002) (Level III-3).

Du Pen (1999) (Level II) considered the effect of implementing guidelines for cancer management in a community setting and concluded that the use of algorithmic decision-making in the management of cancer pain was supported. A similar approach to management of pain for residents who are dying may also be required; however, further research is required before such definitive guidelines can be determined.

Formal assessment of pain was found to increase the diagnosis of pain among elderly nursing home residents. (Kamel, Phlavan, Malekgoudarzi, Gogel, & Morley, 2001) (Level III-3). There are particular issues relating to the assessment of pain in cognitively impaired residents; however, there are some tools that can be used with this population. (Kovach, et al., 1999) (Level IV).

The evidence suggests that nurses' knowledge of pain assessment and management is significantly deficient, however, this depends on where the nurse is employed. (Sloman, Ahern, Wright, & Brown, 2001) (Level QE). Horgas and Dunn (2001) (Level QE) found that there was incongruence between nursing assistants' perception of pain and the resident's self-report of pain in the majority of cases in a paired rating study. The results suggest that nursing home residents could be at risk of over or under treatment of pain.

The Numerical Rating Scales (NRS) refers to all the possible combinations of pain rating scales that use numbers, whether they are graphically or verbally presented and whether they contain word anchors or not. However, usually these scales use a continuum from 0 to 10 where 0 signifies no pain and 10 signifies unbearable pain. The advantages of this tool are that it circumvents the difficulties with language as with some assessment tools, is easy to use and has a high degree of sensitivity (Closs, Barr, Briggs, Cash, & Seers, 2004) (Level IV). The disadvantage of this tool is that the higher the cognitive impairment (MMSE score 0-9), the less likely that the resident will be able to complete the NRS (Closs, et al., 2004)(Level IV). Even with repeated explanation to residents with severe cognitive impairment, the rate of successful completion of the NRS was still poor.(Closs, et al., 2004)

The Brief Pain Inventory (BPI) has been used extensively in research due to its reasonable validity and reliability; it has also proven useful in a variety of clinical settings, including with people diagnosed with terminal cancer.(Cleeland, et al., 1994) It takes about 15 minutes to complete and has been translated into Vietnamese, Chinese, Filipino and French.(McCaffery & Pasero, 1999)

Several face-rating scales exist and were originally developed to determine pain levels in children. The most widely used FACES scale is the one devised by Wong-Baker.(Pasero, 1997) The scale has a number of faces drawn along a scale from 0 to 10, with 0 being 'no hurt' (and a smiley face), up to 10 that indicates 'hurts worst' (and a crying distressed face). The scale has been translated into many languages, such as Chinese, German, Greek, Hebrew, Italian, Korean, Japanese, Polish and Russian.(McCaffery & Pasero, 1999) However, for people with moderate to severe dementia completion rates are poor (55% of people with an MMSE of <19, and 41% for those with MMSE <11).(McCaffery & Pasero, 1999) Concern has also been expressed that the FACES scale may be a measure of depression rather than of pain for those with dementia. It is very difficult for older persons who lack abstraction skills to translate reliably a crying face to severe pain instead of to a depressed or sad face.(McCaffery & Pasero, 1999)

Given the difficulties associated with pain assessment for residents who are severely cognitively impaired, it may be more appropriate to use a combination of pain assessment tools (Wynne, Ling, & Remsburg, 2000) (Level QE).

Weiner (2002) argues that there is an urgent agenda for three groups involved in pain management – educators, funding organisations and primary care practitioners. There is also a call for a collaborative approach between doctors and nurses to manage pain (Lockhart-Wood, 2001)(Level QE).

Another study by Weiner and Rudy (Weiner & Rudy, 2002) (Level III-3) suggested that there were attitudinal barriers to pain management in RACFs. Residents believed that their level of pain could not be changed and that they were concerned about addiction and dependence. Nurse assistants felt that there was not enough time available for pain assessment.

Weissman and colleagues, (2001) (Level QE) discussed the special barriers to good pain management in nursing homes in America. The authors cited the following barriers:

1. Heavily regulated industry that hinders doctors from prescribing scheduled analgesics for chronic pain,
2. Lack of support by doctors to prescribe opioids for chronic pain from non-cancer conditions,
3. Infrequent contact between doctor and resident compared with the acute care setting, and
4. Lack of pain assessment skills in some poorly trained nursing staff.

Gloth's (2001) (Level EO) review of the literature suggests that educating clinicians will be important in improving pain outcomes for older adults in pain, particularly as doctor have a low level of knowledge of pain management, as they have had little formal education in this area. (American Geriatrics Society, 2002; Health Care Committee, 1994; Lockhart-Wood, 2001)

There is some evidence that difficulties may be encountered when members of the aged care team lack the necessary skills for adequate reporting and also lack observation skills(Weiner, Peterson, & Keefe, 1999a) (Level QE). Accurate reporting based on good observation skills is particularly important for those residents who do not articulate their pain symptoms verbally and rely on a skilled person to assess their level of pain based upon behavioural cues (Manfredi, et al., 2003) (Level III-3).

The term 'breakthrough pain' (also known as 'intermittent pain') is generally associated with chronic cancer pain and specifically refers to when people with cancer who are already receiving opioids have intermittent episodes of increased pain.(Mercadante, et al., 2002) However, it is important to assess the occurrence of intermittent pain in all individuals, not just those with a diagnosis of cancer. The incidence of breakthrough pain has been found to vary between 40% and 80% among individuals in various settings (Mercadante, et al., 2002) (Level EO). No tool has been developed that specifically assesses the occurrence of breakthrough pain. However, use of a 24-hour assessment algorithm may help to categorise breakthrough pain.

Tricyclic antidepressants in optimal doses appear to be the most efficient treatment for neuropathic pain, but other treatments may be better tolerated by this population (Sindrup & Jensen, 1999) (Level II).

A systematic study examined whether progressive resistance strength training for physical disability in older persons was beneficial (Latham, Anderson, Bennett, &

Stretton, 2002) (Level I). The reviewers concluded that this training increased muscle strength and had a positive effect on some functional limitations in older persons. They also concluded that older persons with pain from osteoarthritis appeared to benefit from this training. Despite the strength of the research regarding progressive resistance training, this approach might not be suitable for residents who require a palliative approach due to co-morbidities, particularly dementia. Therefore, further research is required.

Differences in funding arrangements and prescribing regulations between the UK, USA and Australia means that not all evidence may be directly transferable. However, the management of pain in all three countries appears problematic and may create particular problems for palliative care in aged care settings.

*Therapeutic Guidelines for Analgesics* (Therapeutic Guidelines Writing Group, 2002) are also available as is the *Australian Medicines Handbook Drug Choice Companion: Aged Care* (Australian Medicines Handbook Pty. Ltd., 2003), which provide further information regarding pain management; although both of these are based on expert opinion.

### **6.3 FATIGUE**

Fatigue is defined as a sense of exhaustion, a loss of strength or endurance, or a sense of weariness or tiredness that is not due to exertion and is not relieved by rest. (Liao & Ferrell, 2000) Fatigue is recognised as a multi-factorial symptom, with complex pathology, that may occur alone or in combination with other symptom complexes. (Tyler & Lipman, 2000) People generally do not consider tiredness and fatigue to mean the same thing; hence, it is unlikely that the incidence of fatigue will be over-reported (Richardson & Ream, 1996) (Level QE).

Fatigue is the most frequently cited physical concern reported by individuals approaching death (Tyler & Lipman, 2000; Winningham, et al., 1994) (Level EO; Level EO). However, fatigue should not be accepted as 'normal' or untreatable, especially in residents. Fatigue has been found to have physical, emotional and cognitive components in both individuals with cancer and in healthy individuals (Glaus, Crow, & Hammond, 1996) (Level QE). There is some evidence to indicate that although many residents may experience fatigue the symptoms may be poorly recognised and consequently under-treated (Liao & Ferrell, 2000) (Level IV).

Fatigue is best understood in terms of a sense of wellbeing, level of activity, and level of weakness. It can be part of the anorexia-cachexia syndrome, and can be related to boredom, medical problems, pain, psychological problems, sleep disturbances and medications. (Liao & Ferrell, 2000) However, while no clear leading cause is evident, fatigue has consistently been associated with depression and anxiety (Porock, Kristjanson, Tinnelly, Duke, & Blight, 2000; Winningham, et al., 1994) (Level IV; Level EO). Fatigue may also be associated with pain, a reduction in intermediate activities of daily living, number of medications, and physical function (Liao & Ferrell, 2000) (Level IV).

The Piper Fatigue Scale (1987) was originally developed for patients with cancer and has subsequently been revised (Piper, et al., 1998) (Level IV). This self-report tool is based on the concept that fatigue is a multi-component sensation with behavioural (interference with activities of daily living), affective meaning (how fatigue is perceived), sensory (feelings associated with fatigue) and cognitive (mood, memory and thought processes) aspects. Therefore, the Revised Piper Fatigue Scale (1998) (Level IV) consists of 22 items that measure these four dimensions of fatigue: behavioural / severity (6 items), affective meaning (5 items), sensory (5 items) and cognitive / mood

(6 items). Each item is scored 0 to 10 on Likert Scales. A total score, which was standardised to a 0 to 100 scale with 100 being the most fatigue, was obtained by adding the item scores. The scale has been successfully tested predominantly with people with cancer in the US, China, and Taiwan and its validity and reliability were also found when the Revised Piper Fatigue Scale (1998) was used with 199 older persons (M age = 88 years) living in a RACF (Liao & Ferrell, 2000) (Level IV).

While guidelines on fatigue in patients with advanced cancer have been developed (Coackley, et al., 2002)(Level QE), they may not be relevant in the aged care setting particularly for patients with non-cancer diagnoses. Liao and Ferrell (2000) (Level IV) have investigated fatigue in members of a residential aged facility and found that 98% of residents reported some fatigue symptoms during the study period.

Suggested non-pharmacological methods for relieving fatigue, such as exercise programs and energy conservation, may be effective for people receiving a palliative approach (Porock, et al., 2000) (Level IV). Winningham and colleagues (1994) (Level EO) in a review of the literature regarding fatigue and cancer, found that if people are tired it is often a result of inactivity. Guidelines on fatigue management for people with advanced cancer have been developed (Coackley, et al., 2002) (Level QE) and, although these guidelines have not been tested in the aged care setting, they might offer some useful direction for managing this difficult symptom in the aged care population.

Systematic reviews were conducted to examine the benefits of physical exercise (Montgomery & Dennis, 2002a) (Level I), bright light therapy (Montgomery & Dennis, 2002b) (Level I) and cognitive behavioural interventions (Montgomery & Dennis, 2002c) (Level I) for sleep disturbances in adults aged over 60 years. Physical exercise was found to provide some benefits such as facilitating sleep and improving quality of life; however, the trials had small numbers and reviewers cautioned that exercise was not appropriate for all older persons. No trials on the use of bright light therapy were found; hence, its use is not supported.

Cognitive behavioural therapy was found to have a mild effect on sleep disturbances in older persons, but the effect was not usually long-lasting(<2 months).(Montgomery & Dennis, 2002c) However, the reviewers' expressed concern regarding this therapy's reduced efficacy for those aged 80 years and older. Additionally, because fatigue may have many causes among older persons, such as anxiety and depression, it is not clear that treating one cause in isolation, such as sleep disturbance, results in a reduction of fatigue. However, the reviewers' concluded that, given the potential side-effects of pharmacological interventions such as hypnotics that there was an argument to be made for the use of CBT in preference to pharmacological interventions, particularly for those people who were younger than 80 years of age (Montgomery & Dennis, 2002c). Given that the average Australian resident is aged over 80 years and has a diagnosis of advanced dementia, it is suggested that further research is required prior to the implementation of CBT interventions.

One recent study considered the use of acupressure with 106 people (M age = 58.16 years) who had a diagnosis of end-stage renal disease and found that participants in the acupressure group (n = 35; received acupressure 3 x weekly for 4 weeks plus usual care) had significantly lower levels of fatigue (as measured by the Revised Piper Fatigue Scale [1998]) than the control group (n = 36, received usual care) (Tsay, 2004) (Level III-1). Interestingly, there were no significant differences between the acupressure group and the sham group (n = 35; received sham acupressure [massage with no acupoints] 3 x weekly for 4 weeks plus usual care), with both these groups having decreased fatigue levels post-intervention. These findings appear promising;

however, further studies are required with significantly older participants to determine the appropriateness of this therapy.

#### **6.4 NUTRITION AND HYDRATION**

Nutrition and hydration are associated with more than physiological need. There are many psychosocial, cultural and symbolic meanings that influence the reasons for poor nutritional status (Milne, Potter, & Avenell, 2003) (Level I). For example, the sharing of meals is usually associated with social gathering, communication and life time habits such as when, where and how we eat (Berry & Marcus, 2000) (Level EO). Therefore, if residents are unable to eat or share a meal or drink with others the experience of meal times can be extremely unpleasant and can contribute to refusal to eat. Refusal to eat or drink can also occur when a resident does not like the food or fluid being offered (i.e., therapeutic diets often lack taste (Kamel, Malekgoudarzi, & Pahlavan, 2000) (Level QE), needs assistance or extra time to eat, (Kayser-Jones, et al., 2003) (Level QE) or when the food or fluid is inappropriate to the resident's cultural background (Berry & Marcus, 2000)(Level EO).

There is no agreement regarding the definition for malnutrition or under-nutrition (either term can be used) (Milne, et al., 2003) (Level I). However, it is generally accepted that malnutrition is "... a state of energy, protein or other specific nutrient deficiency that produces a measurable change in body function and is associated with worse outcome from illness as well as being specifically reversed by nutritional support".(Allison, 2000, p. 590) The most common nutritional problems for residents in RACFs are weight loss and associated protein energy malnutrition (Milne, et al., 2003) (Level I). There is some research that suggests that nutritional deficiencies are common in nursing homes and that undernutrition is not recognized and therefore not treated (Abbasi & Rudman, 1994) (Level EO). Morley and Silver (1995) (Level EO) highlighted that weight loss and protein energy undernutrition were common nutritional problems in nursing homes.

The reasons for malnutrition in older persons are multi-faceted and associated with the process of ageing, which affects food intake and body weight and can be intensified by illness or disease (Milne, et al., 2003) (Level I). Depression and adverse medication side effects are the most common treatable causes of malnutrition (Katz, Beaston-Wimmer, Parmelee, & Friedman, 1993) (Level IV). Advanced dementia, apathy, fatigue, and late-life paranoia (e.g., where the resident believes that he / she is being poisoned via food or fluid intake) are other potential factors involved in poor nutritional and hydration status of older persons (Milne, et al., 2003). Finally, the simple act of eating can be problematic for persons with dysphagia or cognitive problems, and can result in aspiration pneumonia.(Morley & Silver, 1995, p. 850)

The person assisting with feeding should be seated at eye-level with the resident and take time to establish and maintain a relationship with the resident to create an atmosphere that is conducive to relaxing the resident. This approach to feeding enhances the resident's nutritional intake and improves his / her social well-being (Ramritu, et al., 2000) (Level I).

The traditional practice associated with a palliative approach is that when interest in food and fluid becomes minimal the individual should not be forced to receive them.(McCann, Hall, & Groth-Juncker, 1994) Indeed, eating and drinking may no longer be relevant to the resident who has already withdrawn and whose attention is now more inward (Byock, 1995) (Level EO).

A study of 32 individuals receiving a palliative approach explored whether the provision of limited food and fluids (only in response to a request from the individual)

would have an adverse effect on quality of life (McCann, et al., 1994) (Level IV). The results indicated that 60% (n = 20) reported that they never experienced any hunger or thirst and that most (n = 27) remained 'comfortable' requiring only sips of water.

Ganzini and colleagues (2003) (Level QE) surveyed nurses about patients who chose to stop eating and drinking. Nurses reported that some patients stopped eating and drinking because they were ready to die. The majority were elderly and could not find a meaning in living.

The difficulties the aged care team experiences are often due to different views on basic human rights and whether interventions to maintain hydration and nutrition are inappropriate active medical interventions instead of a palliative approach (McCann, et al., 1994) (Level IV). Family members may request that everything possible be done for their relative, including treatments that are considered by care providers as invasive or potentially burdensome, contributing to increased suffering and discomfort for the resident. (McCann, et al., 1994) The aged care team needs to be able to initiate discussions with residents and their families about the pros and cons of artificial feeding and hydration (Mitchell, Tetroe, & O'Connor, 2001; Morley & Silver, 1995) (Level IV; Level EO). Additionally, the aged care team needs to be aware that the family may require support when they are faced with making such decisions on their relative's behalf (McCann, et al., 1994) (Level IV).

Many people who are dying often receive intravenous fluids when they are no longer able to maintain a normal fluid balance (Twycross, 1994) (Level EO). Professionals providing a palliative approach generally consider that artificial nutrition and hydration may be detrimental (Byock, 1995; McCann, et al., 1994; Printz, 1992; Twycross, 1994) (Level EO; Level IV; Level EO; Level EO).

Recognising the varied risk factors for poor nutritional status in RACF residents is the key to successful assessment and management strategies (Morley & Silver, 1995) (Level EO). An assessment of potential causes should be made with a view to identifying malnutrition and reversing the causes (Morley & Silver, 1995) (Level EO).

Morley and Silver (1995) developed a mnemonic called "MEALS ON WHEELS" to assist aged care team members in identifying reversible causes of malnutrition in RACF residents.

The aged care team needs to be able to initiate discussions with residents and their families about the pros and cons of artificial feeding and hydration (Morley & Silver, 1995) (Level EO).

A systematic review of protein and energy supplementation in elderly people at risk from malnutrition found a small but consistent weight gain. (Milne, et al., 2003) (Level I). Although, there is some evidence supporting the effectiveness of nutritional supplementation exists for oral protein and energy feeds, it is considered that the strength of this evidence was weak (Avenell & Handoll, 2004) (Level I).

Another systematic review examined the benefits of protein energy supplementation in adults (predominantly aged 70+), which included studies of oral supplementation, modification of food constituents to increase energy density, and studies of enteral feeding (Potter, Langhorne, & Roberts, 1998) (Level I). The reviewers concluded that weight and nutritional indices of adults might be improved by routine nutritional supplementation. However, no reduction in mortality was found for nutritional supplementation. The reviewers also noted that there remain uncertainties as to whether supplements routinely provided can improve outcomes, particularly over longer periods of time. Neither of the systematic reviews considered a palliative approach as a

variable, so the results may not be transferable to the aged care population. Further research is required.

Consenting or refusing food is an expression of the resident's autonomy.(Wasson, et al., 2001) Preservation of the patient's dignity is important in ethical nursing practice and advanced care directives are one way for staff to acknowledge the dignity of the resident and to respect his/her autonomy. In light of the evidence on tube feeding, Gillick (2000) (Level EO) believes that physicians should recommend that artificial nutrition not be recommended as a general rule.

In another study, cancer patients were assessed using the Edmonton Symptom Assessment Scale and the most intense symptoms that were identified were fatigue, appetite and well-being (Jenkins, Schulz, Hanson, & Bruera, 2000a) (Level IV).

Finucane, Christmas and Travis (1999) (Level I) in their review of the clinical evidence on tube feeding in patients with advanced dementia found no data to suggest that tube feeding could prevent aspiration pneumonia, prolong survival, reduce the risk of pressure sores or infections, improve function or provide palliation.

A decision aid has been devised that can be used for the cognitively intact and the cognitively impaired alike (Mitchell, et al., 2001) (IV). The aim of this aid is to help residents and their families decide whether to pursue tube feeding. There are three basic components: (1) information on options and outcomes; (2) steps to decision-making to determine the decision based on the resident's preferences, personal values and clinical situation; and (3) a documented treatment plan designed to put these steps into operation (Mitchell, et al., 2001) (Level IV).

The use of more expensive programs, such as high-intensity or endurance (strength-building), with frail residents is not recommended, either for short (10-week) (Fiatarone, et al., 1994) (Level II) or long (12 months) periods of time, due to a lack of significant beneficial results for participants involved in studies of these programs (Morley & Silver, 1995) (Level EO).

There are also specific issues relating to eating, feeding and nutrition for those with particular diseases or diagnoses. For example, Kumlien and Axelsson (2002) (Level QE) reported that a quarter of stroke patients suffered from dysphagia and 30% had poor food intake and poor appetite. Older persons who have had a hip fracture tend to have a poor nutritional status, as do residents with COPD or Parkinson's Disease (Abbasi & Rudman, 1994; Gore, Brophy, & Greenstone, 2000) (Level EO; Level QE).

## **Hydration**

There are specific issues regarding dehydration and malnutrition in terminally ill patients that have been debated in the palliative care ethics literature extensively.

A systematic review of the evidence for maintaining oral hydration in older people found that there was insufficient evidence to determine the risk factors for dehydration and decreased fluids or the optimum amount of oral fluids. More research is required to determine the optimum, non-invasive method of maintaining adequate hydration in older people. However, regular presentation of fluids to bedridden older people can maintain adequate hydration status. (Hodgkinson, Evans, & Wood, 2001) (Level I)

Ellershaw, Sutcliffe and Saunders (1995) (Level QE) found no statistically significant relationship between the level of hydration of the patient and symptoms such as feeling thirsty and having a dry mouth. They suggested that artificial hydration may therefore be pointless in people with end-stage disease whose bodies are shutting down.

Viola, Wells and Peterson (1997) (Level I) completed a systematic review on the effects of fluid status and fluid therapy on the dying in 1997. They found limitations to many studies. In their view, given the state of the evidence, the clinician should make a treatment decision based on the person's individual circumstances including the patient's and family's wishes.

Dunphy, Finlay, Rathbone, Gilbert and Hicks (1995) (Level EO) reviewed studies relating to rehydration in palliative care. They concluded that decisions should be made on an individual basis, involving both patients and their families wherever possible.

Although there is some evidence that dehydration can increase the risk of ulcers and constipation there is no evidence to date that rehydration makes people more comfortable (Jenkins, Schulz, Hanson, & Bruera, 2000b) (Level IV). Rehydration may also have a negative effect on cognition and anecdotal evidence suggests that improved cognition has been reported after withdrawal of the hydrating process (Andrews, Bell, Smith, Tischler, & Veglia, 1993) (Level EO). Intravenous hydration may have negative psychological effects in that the infusion acts as a barrier between the resident and the family. It is more difficult to embrace a person who is attached to a plastic tube, and doctors and nurses tend to become diverted from the more human aspects of care in order to concentrate on the control of fluid balance and electrolytes when these interventions are used. (Twycross, 1994)

Research into the determinants of the sensation of thirst in terminally ill cancer patients found a number of possible causes including dehydration, hyperosmolality, poor general conditions, stomatitis, oral breathing and opioids. (Morita, Tei, Tsunoda, Inoue, & Chihara, 2001) (Level QE)

A possible indication for rehydration is that the resident feels dry despite good mouth care. Dry mouth is a common problem in many people and is related not only to dehydration but also to other causes such as drugs, oxygen therapy, candidiasis and mouth breathing. (Twycross, 1994) Thus, artificial hydration alone is unlikely to resolve the symptom of dry mouth in most people (Ellershaw, et al., 1995) (Level QE).

Additionally, individual's who are dying may not have any sensation of thirst and should hydration be required it can be successfully alleviated with small sips of liquid and adequate mouth care (McCann, et al., 1994) (Level IV) or finely crushed ice chips (Billings, 1985) (Level EO).

A US study explored whether the regular presentation of fluids to 51 residents would result in an increased consumption of oral hydration (Robinson & Rosher, 2002) (Level IV). The results showed a significant increase in the fluid intake for most of the residents, an increase in the number of bowel movements, a significant decrease in the number of laxatives residents required, a decline in the number of falls, and a decrease in cost during the hydration period (presentation of regular fluids via two beverage carts) (Robinson & Rosher, 2002) (Level IV).

Another study explored whether the fluid intake of 130 incontinent residents could be improved using a behavioural intervention that consisted of verbal prompts and beverage preference compliance (Simmons, Alessi, & Schnelle, 2001) (Level III-1). The authors' reported that the intervention was effective in increasing fluid intake for most of the residents; however, different approaches were required depending on the residents severity of the cognitive impairment. For example, verbal prompting alone increased fluid intake for those with more severe cognitive impairment, but the same result was not found for those with less impairment who only increased their fluid intake when they received their preferred drink.

The decision regarding rehydration should focus on the resident's unique circumstances, including the wishes of the resident and his / her family (Viola, et al., 1997) (Level I). The comfort of the resident is the primary goal, rather than providing optimal hydration (McCann, et al., 1994; Printz, 1992) (Level IV; Level QE). Factors important to family members when considering artificial hydration are issues of symptom distress, ethics, emotional considerations, information exchange and culture (Parkash & Burge, 1997) (Level QE). A timely discussion that includes family members, the aged care team, and where possible the resident is required with the aims being to: (Parkash & Burge, 1997)

- attempt to determine the resident's and his / her family member's wishes and preferences regarding artificial hydration;
- provide information about the pros and cons of artificial hydration, including any limitations in our understanding about this process;
- recognise and explore family members concerns that they might have that have not been spoken.

## **6.5 ANOREXIA**

Anorexia, or a reduced desire to eat, may occur for some residents (Woodruff, 1999) (Level EO). Anorexia can be intermittent and associated with other medical problems, such as infection, constipation or depression. (Abbasi & Rudman, 1994; Morley & Silver, 1995) (Level EO; Level EO)

Yeh and colleagues (2000) (Level II) looked at the effect of a Megestrol acetate oral suspension in stimulating weight gain in nursing home residents. At 12 weeks there was no significant weight gain between the experimental and control groups, however the MA did appear to improve appetite and well-being. There was a weight gain in the experimental group in the 3 months after the intervention.

North American studies indicated that 30–50% of high-care residents had substandard body weight and midarm circumference, and low serum albumin levels. (Abbasi & Rudman, 1994; Yeh, et al., 2000) (Level EO; Level II)

Hill and Hart (2001) (Level EO) have outlined a series of strategies for nutritional support of patients with anorexia and cachexia.

## **6.6 CACHEXIA**

The symptoms of cachexia are a loss of muscle and visceral protein, anorexia, chronic nausea and weakness (Bruera, 1997) (Level EO). Studies indicate that cachexia is likely to be predictive of morbidity (Yeh, et al., 2000) (Level II).

Although cachexia is most commonly associated with cancer, it is also associated with chronic heart failure, renal failure and dementia. Significant cachexia in older persons is related to poorer prognosis (Yeh, et al., 2000) (Level II).

This diagnosis can be made from the resident's clinical history, presence of substantial weight loss, physical examination and laboratory tests. Metabolic abnormalities are the main causes of malnutrition, but decreased caloric intake and malabsorption can contribute to the syndrome. (Yeh, et al., 2000) A nutritionist can help assess the resident's nutritional status and advise regarding dietary options to maximise nutritional intake (Yeh, et al., 2000) (Level II).

The management of anorexia and cachexia should be multidisciplinary and individualised (Morley & Silver, 1995) (Level EO). Residents should be encouraged to

have as many calories orally as possible, or, for the frail resident, single nutrients or liquid meal replacements should be tried before invasive techniques are used (Morley & Silver, 1995) (Level EO), if this is in accordance with the resident's preferences. Management is also aimed at providing psychological support and improving quality of life (Bruera & Pereira, 2003) (Level EO).

Prolonged corticosteroid treatment has been associated with significant side effects, including hyperglycemias, weakness, delirium, osteoporosis and immunosuppression (Bruera & Pereira, 2003) (Level EO).

## **6.7 NAUSEA AND VOMITING**

Nausea is the unpleasant feeling of the need to vomit. Vomiting is the forceful expulsion of gastric contents from the mouth (Allan, 1998) (Level EO). Residents often experience a range of co-morbidities that can cause nausea and vomiting, including renal failure and cardiac failure. (Mannix, 1998)

It is estimated that a major cause of nausea in residents in RACFs is constipation, and secondary causes include reduced fluid intake, low fibre diet, decreased mobility, or medication. Both pharmacological and non-pharmacological approaches have been found to be effective in treating these symptoms. (Mannix, 1998) (Level EO)

Before the prescription of antiemetic drugs, the resident's environment should be assessed to reduce the stimulus to nausea. (Mannix, 1998) Such stimuli could include cooking smells and unpleasant odours. Mannix (1998) includes the following steps for an appropriate antiemetic strategy:

- Determine the probable cause(s) of nausea and/or vomiting;
- Determine a suitable route of administration to ensure that the drug reaches its site of action; and
- Ensure careful titration of the dose, frequent reviews of the resident, and regular provision of the antiemetic.

Treatment of hyperacidity can be accomplished by unabsorbable antacids (magnesium plus aluminium hydroxide preparations), antacid plus alginate preparations, histamine H<sub>2</sub>-receptor antagonist (e.g. ranitidine) or a proton pump inhibitor (e.g. omeprazole). The Therapeutic Guidelines: Palliative Care (2001) provide recommended dosages for these medications.

A recent systematic review of the advanced cancer literature on nausea concluded that there were few well-designed studies which could be used to develop guidelines for the management of nausea (Glare, Periera, Kristjanson, Stockler, & Tattersall, 2004)(Level I).

## **6.8 DYSPHAGIA**

Dysphagia is associated with a number of neurological conditions, end stages of many illnesses as cachexia worsens, and some medications. Assessment and management of this condition is important to reduce the risk of aspiration. Ramritu and colleagues (2000) (Level I) recommend a formalized multidisciplinary management program to deal with issues such as assessment by specialists, feeding techniques, aspiration interventions and nutrition and hydration requirements.

Dysphagia can be managed through various interventions that can reduce the risk of aspiration. During meal times, residents need to be physically well supported in an upright position (Ramritu, et al., 2000) (Level I). Where possible, they should remain in

this position for at least one hour following meals to prevent regurgitation of food from the stomach into the oesophagus (oesophageal reflux).

Residents with dysphagia tire easily; therefore, adequate time needs to be allowed for them to be fed safely while they are fully awake and alert (Kayser-Jones & Pengilly, 1999) (Level QE). After the meal, residents should have their mouths inspected to ensure that food that could be aspirated does not remain in their cheeks (Ramritu, et al., 2000) (Level I).

## **6.9 MOUTH CARE**

Studies have revealed a high incidence of poor oral health in residents of RACFs. (Boyle, 1992; Holmes, 1996) (Level EO; Level QE) Gum recession also creates 'pockets' where food debris and micro-organisms can collect, causing periodontal disease. (Holmes, 1996) (Level QE)

In one RCT, oral side effects were noted in persons receiving treatment for cancer, and other RCTs have been conducted for people with cancer regarding best practice interventions for the prevention of mouth ulcers (oral mucositis). (Clarkson, Worthington, & Eden, 2003) (Level I)

Poor oral health for residents in RACFs is considered to contribute to problems with eating and the low nutrient and vitamin C levels found. (Simons, Kidd, & Beighton, 1999) (Level QE) A UK study of 1041 nursing home residents (249 men and 792 women, with a mean age of 83.9 [SD 7.8 years]) found that 250 residents had problems with eating, 206 with taste, and 261 found it hard to care for their mouths. (Simons, et al., 1999)

When combined with a declined ability to communicate, and functional debility, it was found that residents were more likely to have a very poor oral status and therefore, an increased likelihood of weight loss and dehydration. (Boyle, 1992; Simons, et al., 1999) (Level EO; Level QE) Plaque retention, sore or fissured tongues, and oral ulceration were considered the main problems for residents regarding oral health (Simons, et al., 1999) (Level QE).

The aged care team needs to understand the components of a healthy mouth in order to promote good oral care practices. (Holmes, 1996) (Level QE) A multidisciplinary approach is preferable to ensure that the aged care team are supported in their practice of oral care for residents. (Boyle, 1992) (Level EO) A continuing education program for the aged care team (of all levels) is also recommended to promote good oral care practices (Boyle, 1992) (Level EO).

A thorough oral assessment based on a systematic approach to care is required for sound management of oral care and to facilitate prevention or minimisation of oral complications. (Holmes & Mountain, 1993; Simons, et al., 1999) (Level QE; Level QE) Individualised assessment helps determine specific needs and the level of self-care the resident is capable of, which should then guide any adaptations of standard practices. (Boyle, 1992) (Level EO)

The most appropriate screening tool for use with residents is the Geriatric Oral Health Assessment Index (GOHAI)(Atchison & Dolan, 1990) (Level QE), a self-reported measure designed to assess the oral health problems of older adults, because it is very accurate at identifying people who do not require care. , which was something the D-E-N-T-A-L was unable to do. (Jones, Spiro, Miller, Garcia, & Kressin, 2002) (Level IV)

Clear standards are required that address denture care, 'natural' teeth care, plaque removal, tongue care, requisite materials for mouth care, regular oral screening, pathways for referrals, and types of oral treatments available. (Boyle, 1992) (Level EO)

Despite the number of commercial products available, research has shown that rinsing with water, cleansing with a soft toothbrush and toothpaste, and regular soaking of dentures in a weak non-toxic solution are the most effective oral-cleansing agents. (Dodd, et al., 1996) (Level II)

## **6.10 SKIN INTEGRITY**

Pressure sores are a clinical issue for both nursing homes and palliative care. A recent systematic review of support surfaces for pressure ulcer prevention concluded that higher specification foam mattresses rather than standard foam mattresses could reduce the occurrence of pressure ulcers in people at risk (Cullum, McInnes, Bell-Syer, & Legood, 2004) (Level I). The Reviewers' considered that the benefits of using alternating and constant low pressure devices and different alternating pressure devices (both static and dynamic, i.e., alternating pressure supports, low air-loss mattresses or beds) were unclear due to reviewers' concerns regarding the methodologies used in RCTs. The Reviewers also concluded that there was insufficient evidence to support the merits of overlays (with the exception of Australian medical sheepskins), seat cushions, limb protectors, turning tables, and electrical stimulation (with or without gels) to decrease the incidence of pressure ulcers (Cullum, et al., 2004) (Level I).

Some benefit was found for the use of Australian Medical Sheepskins (natural not synthetic fibre), which are manufactured to conform to Australian standards, for reducing pressure ulcers, particularly for people who were at low to moderate risk (Cullum, et al., 2004) (Level I). Further studies have been conducted and the results appear promising. (Jolley, et al., 2004; Montgomery, Hickey, Gordon, & McGowan, 2001; Pearson, Francis, Hodgkinson, & Curry, 2000) For example, a recent RCT involving 441 people with an average age of 63 years was conducted to determine the effectiveness of the Australian medical sheepskin in preventing pressure ulcers in a hospital population at low to moderate risk (Jolley, et al., 2004) (Level II). After being formally assessed for the risk of developing ulcers the participants were randomly allocated to the sheepskin group (n = 218) or the referent group (n = 223) to receive usual treatment as determined by the ward staff. Participants in the sheepskin group were found to have developed new pressure ulcers at less than half the rate of those in the usual treatment group. Although the setting for this study was acute care, the average age of the participants (M = 62.1 years) suggests that this approach may be appropriate for residents in aged care settings; however, further research in aged care is required.

A systematic review found no evidence to support benefits associated with the use of ultrasound in the treatment of pressure sores (Flemming & Cullum, 2000a) (Level I) nor the use of electromagnetic therapy for the treatment of pressure sores. (Flemming & Cullum, 2000b) (Level I)

## **6.11 BOWEL CARE**

Bowel symptoms can affect a person's sense of wellbeing and have a negative impact on quality of life. Bowel care is therefore a key component of a palliative approach (Cadd, et al., 2000)(Level QE). There is considerable variation in what are considered 'normal' bowel habits among older people. The bowel habits of each resident should be determined, rather than comparing one resident's bowel habits to that of other residents. Faecal incontinence is associated with immobility, constipation, dementia and stroke

for residents in RACFs (Petticrew, Watt, & Sheldon, 1997) (Level I). Bowel changes can increase for residents receiving palliative interventions. The fundamental principles of bowel care in the palliative approach are ongoing assessment, prompt and individually tailored treatments, and minimisation of interventions that can cause loss of dignity.

A daily assessment of bowel function is required and should include the resident's preferences for treatment, history of bowel habits, and management (Cadd, et al., 2000) (Level QE).

Managing constipation requires determining the type of constipation. It may be either primary (or 'simple', i.e. associated with inadequate fibre intake, dehydration, reduced mobility, or withholding faecal evacuation and a reduction in muscle tone), or secondary, which may occur as a result of disease or drug therapy. (Joanna Briggs, 2000) The most significant factor for residents receiving a palliative approach is opioid-induced constipation (Brocklehurst, Dickinson, & Windsor, 1999) (Level II).

Laxatives have been considered as first line treatment for incontinence by RACF staff; however, a recent RCT found that the use of irritant or osmotic laxatives alone was unsuccessful in this regard (Brocklehurst, et al., 1999) (Level II). Instead, the authors found that the use of bulk laxatives (i.e. fybogel or regulan) when combined with suppositories were associated with the lowest rates of faecal incontinence. The authors recommended that suppositories be used after bowel clearing to prevent recurrent constipation (Brocklehurst, et al., 1999) (Level II). Additionally, no evidence was found to support the view that bulk laxatives were contraindicated when used for chronic constipation in older, immobile persons [198] (Level II). A causal relationship between laxative use and diarrhoea in the immobile older person was found, with a recommendation for the additional use of a bulking agent to reduce the incidence of diarrhoea (Brocklehurst, et al., 1999) (Level II).

If a laxative must be prescribed for a resident, then a discussion between the doctor and aged care team members to decide on the most appropriate laxative is encouraged (Brocklehurst, et al., 1999) (Level II). Brocklehurst and colleagues (1999) found that the two most commonly used laxatives in RACFs were lactulose (36%) and senna (29%). Senna was considered to be significantly more effective and less expensive, despite the popularity of lactulose. If laxative is used, compensatory measures for dehydration and electrolyte depletion should also be considered (Brocklehurst, et al., 1999) (Level II).

A study of 100 palliative care patients (average age 67) was conducted to determine assessment procedures for bowel care and patient preferences (Cadd, et al., 2000) (Level QE). The results of the study indicated that patients preferred non-pharmacological approaches for their bowel care such as diet, regular gentle exercise, abdominal massage or administration of a hot pack as first-line interventions whereas nurses preferred to use medication (either oral or rectal) (Cadd, et al., 2000) (Level QE). Despite this patient preference for non-pharmacological bowel care management, the effectiveness of most of these approaches has not been validated (Petticrew, et al., 1997) (Level I) with the exception of one RCT involving exercise.

An RCT was conducted to examine whether an intervention that combined low-intensity exercise and incontinence care would be beneficial and result in cost savings to the RACFs (Schnelle, et al., 2003) (Level II). The RCT involved 190 incontinent residents from four nursing homes who were randomly assigned to the intervention (Functional Incidental Training [FIT]) group or the control group. In all cases, the intervention group performed significantly better than the control group. For example, the number

of residents with constipation or faecal impaction in the control group was significantly higher than for the intervention group for the same periods. This finding indicates that low-intensity exercise combined with incontinence care may be beneficial in reducing the incidence of constipation or faecal impaction for residents, although further research is required with older people who are receiving a palliative approach to their care. The use of the FIT intervention, although cheaper, did not result in significant cost savings compared with usual care methods.

## **6.12 DYSPNOEA**

Breathlessness is a source of distress for many patients requiring palliative care. The causes for breathless are complex and it is a distressing symptom for the patient and their family.

Corner and colleagues (1996) (Level II) considered non-pharmacological interventions for breathlessness in cancer patients. They found patients benefitted from interventions including counselling, breathing retraining, relaxation techniques, and coping and adaptation strategies.

A multisite randomised control trial using these interventions showed that patients receiving the intervention experienced improvements in breathlessness, performance states and physical and emotional states. The intervention consisted of breathing activities, relaxation techniques and psychosocial support. (Bredin, 1999)(Level II) Such interventions may have a limited application within nursing homes where co-morbidities including dementia are common.

Tarzian (2000) (Level QE) looked at elements in caring for terminally ill patients who have “air hunger”. The nurse’s responses identified in the study included being prepared for air hunger, calming patient and their family, medicating patients, improvising care and attending to the family’s needs.

A recent study investigated the effectiveness of oral morphine in relieving breathlessness. The study showed that low dose sustained release oral morphine did relieve dyspnoea in people with predominantly COAD in a community setting. (Abernethy, et al., 2003) (Level II)

## **6.13 COMPLEMENTARY AND ALTERNATIVE THERAPIES**

The National Center for Complementary and Alternative Medicine (NCCAM) (2003) in America defines complementary and alternative therapies as a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. The Centre also distinguishes between complementary and alternative medicines with complementary medicines being use together with conventional medicine and alternative medicines being used in place of conventional medicine.

NCCAM Classifies CAM therapies into five categories:

- Alternative medical systems (eg homeopathic or Ayurveda)
- Mind-body interventions (eg patient-support groups, meditation, creative activities)
- Biologically based therapies (eg dietary supplements, herbal treatments)
- Manipulative and Body-based methods (eg chiropractic, massage)

- Energy therapies including biofield therapies (eg qi gong, Reiki) and bioelectromagnetic-based therapies (eg electromagnetic fields, alternating current fields)

Pan, Morrison and colleagues' (2000) (Level II) review of complementary and alternative treatments in the management of some symptoms near the end-of-life found that there is some evidence to support the use of some therapies. Their conclusions were:

- Acupuncture, TENS, supportive group therapy, self-hypnosis and massage may assist in pain relief in cancer patients.
- Relaxation/imagery may improve oral mucositis pain.
- Acupuncture, acupressure and muscle relaxation with rebreathing training may help relieve dyspnea.

Little research has been undertaken on the prevalence and role of complementary and alternative therapies in residential aged care facilities.

Foster and colleagues (2000) (Level III-3) conducted a random, representative sample of 2055 North Americans and found that 30% of Americans ( $n = 311$ ) aged 65 years and older reported using alternative medicines in the previous year compared with 46% of those who were younger than 65 ( $n = 1738$ ,  $p < .001$ ) and 19% of people aged 65 and older had visited an alternative medicine provider compared with 26% of those younger than 65 ( $p < .05$ ). Chiropractic (11%) and herbal medicine (8%) use were the most common treatments for those aged 65 and over. Also of note was the finding that the more times an older person saw a Western medical doctor ( $> 6$  visits per year), the more likely they were to use alternative medicines (0 visits 7%, 1-2 visits 22%, 3-6 visits 35%, 7 or more visits 44%,  $p < .05$ ).

Spoelhof and Foerst (2002) (Level EO) have commented on issues and concerns in managing alternative therapies in the nursing home. They highlight some of the potential adverse effects of commonly used medicinal herbs and possible side effects of the use magnet therapy.

A RCT conducted in the Netherlands did not support the use of ginkgo as an effective treatment for older people with mild to moderate dementia. This was in contrast to earlier studies. (van Dongen, van Rossum, Kessels, Sielhorst, & Knipschild, 2000) (Level II)

A systematic review into transcutaneous electrical nerve stimulation (TENS) for chronic pain examined 19 RCTs and concluded that the results for the benefits of TENS with chronic pain were inconclusive (Carroll, et al., 2001) (Level I). This was mainly due to the published trials not providing information on the stimulation parameters, nor answering questions regarding the long-term effectiveness of TENS for chronic pain.

### **Aromatherapy**

Aromatherapy has been the subject of some research and investigation. There is some evidence that using essential oils with massage reduced anxiety and improved quality of life scores in hospice patients. (Wilkinson, Aldridge, Salmon, Cain, & Wilson, 1999) (Level III-1)

Aromatherapy has been considered as an appropriate treatment for the reduction of behavioural disturbances in people with severe dementia. Recent studies of the merits of aromatherapy and aromatherapy massage have been conducted, including some

RCTs, which indicate positive effects of aromatherapy with essential oils (Thorgrimsen, Spector, Wiles, & Orrell, 2003) (Level I).

Ballard, O'Brien, Reichelt, and Perry (2002) researched the use of lemon balm (*Melissa officinalis*) (n = 35) versus a placebo oil (sunflower oil) (n = 36) with 71 residents in aged care with severe dementia. Either oil was combined with a base lotion and applied to residents' faces and arms twice a day by aged care staff. Sixty percent (n = 21) of those in the lemon balm group were found to have a 30% reduction in levels of agitation (as measured by the Cohen-Mansfield Agitation Inventory [CMAI] scores), which was significantly higher than the placebo group (14% [n = 5] of the group had a 30% reduction). Quality of life scores (measured with Dementia Care Mapping) also improved significantly for those residents in the lemon balm group compared with the placebo group; percentage of time spent socially withdrawn; and percentage of time engaged in constructive activities. No side effects were observed during the trial. These results suggest that the use of aromatherapy may be beneficial for reducing behavioural disturbances and improving the quality of life for residents with severe dementia (Ballard, et al., 2002) (Level III-1).

An RCT was conducted to determine the merits of using aromatherapy and massage (AM), conversation and aromatherapy (CA), and massage only (M) with 21 people with severe dementia (Smallwood, Brown, Coulter, Irvine, & Copland, 2001) (Level II). Behaviour was recorded using a video camera at four different periods of the day over a two-week period to determine a baseline of the participants' behaviour. The treatment phase commenced with twice daily treatments irrespective of the group to which the participant belonged. AM involved the topical application of lavender oil and massage, lemon balm CA involved the use of lavender oil in a diffuser accompanied by conversation, and the control condition (M) was massage only. The only significant difference was a reduction in agitation for those participants in the AM group during the hours of 3 and 4pm compared with the CA and control group. No other significant differences were found between groups or at the other three times when behaviour was observed. Although the sample is small, it does suggest that the use of aromatherapy with massage may be beneficial for residents with severe dementia, particularly mid-afternoon.

### **Music therapy**

A systematic review of the literature found that the use of recorded music for residents with severe dementia had a positive effect on residents' levels of agitation (Opie, Rosewarne, & O'Connor, 1999) (Level I). For example, Denney (1997) played background music during meal times for one week, followed by a week with no music and found that levels of agitation dropped by 56% after week 1 (Denney, 1997) (Level IV). Disruptive behaviours increased in the following week when no music was played. This finding supported an earlier study that found that music used during meal times for 30 residents (23 women, 6 men, aged 67 to 93 years (M = 81.3 years, SD = 6.9) who were cognitively impaired in weeks 2 and 4 resulted in a reduction in an overall reduction in agitated behaviours (M = 63.4%, SD = 43.2%) compared with a 38.4% increase in agitated behaviours when music was not played during weeks 1 and 3 (week 1, M = 7.52, SD = 7.49, Min score 0, max score 27; week 3, M = 4.79, SD = 5.88, min score 0, max score 23) (Goddaer & Arbraham, 1994) (Level IV).

Another study considered the use of recorded preferred music during bath time to reduce the incidence of aggressive behaviour among 18 residents (14 women, 4 men) aged 55 to 95 years (M = 82 years, SD = 10) with severe levels of cognitive impairment (Clark, Lipe, & Bilbrey, 1998) (Level IV). The preference for resident's music was determined by a family member who was able to provide knowledge about the

resident's music background and preferences. The experimental group played recorded selections of resident-preferred music during a two-week period (10 observations) compared with a control group that had no music played during their bath times. Then, for a further two weeks, the conditions were reversed thus providing 20 observations for each resident (10 with music and 10 without music). The results indicated that playing preferred music ( $M = 65.56$ ,  $SD = 58.02$ ), during bath times led to a reduction in total counts of aggressive behaviours compared with the control condition ( $M = 122$ ). There were also reductions in individual aggressive behaviours such as yelling, abusive language, verbal and physical resistance; however, these behaviours were not statistically significant. Although these results appear significant, the sample size was too small and therefore, the results may not be generalisable to other settings.

Despite concern regarding methodological weakness of the previous study, the evidence does indicate that playing preferred music may be beneficial in reducing the incidence of aggressive behaviours and agitation by residents with severe dementia such as agitation (Opie, et al., 1999) (Level I). Music should be provided using an individualised approach because it is probable that music preferences, including having no music played, will vary considerably amongst residents.

### **CAM therapies in RACFs**

Little research has been undertaken on the prevalence and role of CAM therapies in RACFs; however, some research has been conducted with older persons. Foster and colleagues (2000) found that 30% of North Americans aged 65 years and over reported using alternative medicines and 19% had visited an alternative medicine provider. Chiropractic and herbal use were the most common treatments (Foster, et al., 2000) (Level III-3).

Spoelhof and Foerst (2002) (Level EO) have commented on issues and concerns in managing CAM therapies in RACFs. They highlight some of the potential adverse effects of commonly used medicinal herbs and possible side effects of the use of magnet therapy. There is evidence to suggest that herbal remedies are not necessarily safe. Ernst (1998) (Level EO) reviewed the data on published adverse effects of botanical preparations, and concluded that, given the extent of use, there is an urgent need for serious research into the risks of phytomedicines. An RCT conducted in the Netherlands found that ginkgo was not an effective treatment for older persons with mild to moderate dementia, which contrasted with earlier studies' findings (van Dongen, et al., 2000) (Level II).

An evaluation of the effects of cognitive stimulation therapy groups on cognition and quality of life was explored using an RCT involving 201 older persons with dementia (cognitive stimulation therapy is also known as 'reality orientation') (Spector, et al., 2003) (Level I). The process involved the use of a reality orientation board that showed personal and orienting information. The topics included using money, word games, the present day, and famous faces. The focus of these sessions was to promote information processing rather than to prompt recall of factual knowledge. The authors concluded that:

- Cognitive stimulation therapy groups improve cognitive function and quality of life for people with dementia;
- The results compare favourably with trials of drugs for dementia (i.e. acetylcholinesterase inhibitors);
- Cognitive stimulation therapies can be used in diverse settings; and

- Cognitive stimulation therapies are enjoyable for people with dementia, and the use of this type of cognitive training does not lead to adverse reactions such as frustration, as some studies previously indicated.

The Australian Pain Society (2004) has developed guidelines relating to pain management. These guidelines advocate principles regarding the use of CAM therapies. These principles are reproduced here, with some adaptations, due to their clarity:(Australian Pain Society, 2004)

- For safety reasons, members of the aged care team must always be informed before a CAM therapy is used (for example, St John's wort interacts with numerous prescription medications). This principle also facilitates a comprehensive care plan to be developed based on the needs of each resident;
- To reduce the risk of possible assault claims, clear approval from the resident, whether cognitively or communication impaired, bedridden or fully capable, is essential before a CAM therapy is used on the recommendation of family, friends, staff or doctors;
- Residents who are interested in any CAM therapy should be fully informed about its safety and effectiveness;
- CAM therapists should be carefully selected so that the resident has confidence in their credentials and qualifications; and
- It is advisable to check with private health insurers to determine whether a CAM therapy is covered.

## CHAPTER 7: PSYCHOLOGICAL SUPPORT

Psychological distress is the term applied predominantly to anxiety, phobic and depressive symptoms. (Watts, et al., 2002) A review of the literature on physical frailty in older persons found that frailty referred not only to physical wellbeing but had psychological and social dimensions as well (Schultz & Winstead-Fry, 2001) (Level III-3). The most common psychological problems for residents requiring a palliative approach are depression, confusion and anxiety, with depression being one of the most prevalent psychiatric problems among older persons in general (Watts, et al., 2002) (Level IV). Changes in the resident's emotional and cognitive abilities reflect both psychological and biological effects of the person's medical condition and treatment. Psychological distress, therefore, may be associated with physical distress. For instance, individuals suffering from anxiety may experience increased physical or somatic pain and compromised immune function (Schleifer & Keller, 1991) (Level EO). Therefore, the interactive effects of psychological and physical wellbeing need to be carefully considered.

The palliative approach within a RACF must include psychological support and assessment for the resident and their families. Psychological sensitivity in practice recognises the importance of pre-existing problems or pre-dispositions; care issues within the facility; dignity, sexuality and communication concerns for the resident; specific issues related to dying; and the role of counselors, psychologists and psychiatric staff.

Brodaty and colleagues (2001) (Level QE) reported that up to 90% of residents exhibited at least one behavioral disturbance. Snowdon, Miller and Vaughn (1996) (Level QE) described behaviors demonstrated daily by at least 10-15% of residents which included restlessness, pacing, cursing, verbal aggression and complaining. Matt and colleagues' (1992) report found syndrome prevalence rates in community dwelling elderly people of 3.9% for depression, 1% for agoraphobia, 2.6% for other phobias and 6.9% for anxiety.

Service provision for assessment and treatment is important in providing quality of life for residents. A review of the literature on psychiatric services published in 2000 found that the majority of studies show that psychiatric services have positive outcomes, particularly with regard to depression. (Draper, 2000) (Level II)

Psychiatric aspects take on particular importance when providing end-of-life care. While there is only a limited amount of literature available on the psychological aspects of palliative care, Chochinov argues that psychiatry has an expanding and important role to play in providing care for dying patients. (Chochinov, 2000) (Level EO)

### 7.1 DEPRESSION

Depression is a significant concern both within the geriatric and the palliative literature. Evers and colleagues (2002b) (Level IV) undertook a study on depression among dementia and normal residents of a long term care facility. They found that depression was a major concern for both groups in the last six months of life and that under diagnosis of depression may be an important clinical concern. Brodaty and colleagues (2001) (Level QE) reported an incidence rate for depression of 42% in their study of Sydney nursing home residents.

An early study of volunteer efficacy found that depressed residents improved in mood following the introduction of volunteer counsellors. The age of the volunteer counsellor (either adolescent [M = 15 years] or older [M = 67 years]) had no significance

regarding the counsellor's effectiveness. (Nagel, Cimboric, & Newlin, 1988) (Level III-2)

Depression and anxiety are generally considered to be reactions to loss and to threats associated with end-of-life illnesses. Confusion can also be a complicating factor at this time. The presence of depressive symptoms can make palliation of pain difficult to achieve (Lloyd-Williams, 2002) (Level QE), particularly for residents who have dementia and are dying (Lloyd-Williams & Payne, 2002) (Level IV). Both somatic and psychological symptoms of depression and anxiety can make a diagnosis more difficult (Barraclough, 1997) (Level EO). For example, anxiety might appear as nausea or dyspnoea, and depression may manifest as intractable pain. These symptoms may respond poorly to medical interventions and not appear to be based on medical pathology.(Barraclough, 1997)

Depression is frequently associated with suicidal thinking (Chochinov, Wilson, Enns, & Lander, 1995a) (Level QE) and the aged care team should be aware of the increased risk of completed suicides among older persons, in particular among older men who have recently been bereaved (Byrne & Raphael, 1999) (Level III-3).

## **DEATH STATEMENTS**

Chochinov and colleagues (1995a) (Level IV) have linked depression with the desire for death. They have found that the prevalence of diagnosed depression was 58.8% in patients who had a desire for death and 7.7% among those without such a desire. Depression and hopelessness are strong predictors of a desire for death in palliative patients. (Breitbart, et al., 2000) (Level IV)

Psychological well-being can be supported by and may be improved by good and truthful communication between patients and their carers. (Bishara, Loew, Forest, Fabre, & Rapin, 1997) (Level QE).

In an examination of patient preferences of ordinary nursing and personal care, irrespective of more substantive palliative issues, communicating effectively was seen as important (Bottorff, et al., 1998) (Level QE).

## **ASSESSMENT**

Watts and colleagues (2002) (Level III-3) recognized the importance of assessment tools in screening. They looked at agreement rates between recognition of mental health problems by the primary health care provider and results of screening tests. There are a number of screening tools available, which are discussed in various studies.(Barraclough, 1997; Lees & Lloyd-Williams, 1999; Pomeroy, Clark, & Philp, 2001) (Level EO; Level IV; Level IV)

Depression in palliative settings and geriatric settings may be unrecognized and undertreated. Various measures of depression have been used. Soon and Levine (2002) (Level II) found that screening for depression in long-term care patients increased the frequency of referral and treatment.

Rinaldi and colleagues (2003) (Level III-3) has completed a cross-sectional study on the effectiveness of the 5-item version of the Geriatric Depression Scale in various geriatric settings including the nursing home. The five-item version was found to be as effective as the 15-item scale for screening for depression in cognitively intact individuals. Pomeroy and colleagues (2001) (Level IV) reported similar outcomes with the use of a four item GDS with older adults. A recent study of the GDS-15 found that the tool was suitable for diagnosing depression in the over 85-year-old population(de Craen, Heeren, & Gussekloo, 2003) (Level QE). Additionally, the authors recommended

setting a low cut-off point of 2 out of 3 points to provide GPs with a reliable sensitivity for ensuring that people with clinical depression would not be overlooked. The GDS's suitability for older persons with cognitive impairment has yet to be determined (de Craen, et al., 2003) (Level QE).

The use of a one-question screening tool has even been accepted as a way of identifying those requiring a more detailed clinical assessment for depression (Pomeroy, et al., 2001) (Level IV). The tool found to be most effective was the Mental Health Inventory (1-Item Version; MHI-1) (Berwick, et al., 1991), which asks: "How much of the time over the past month have you felt downhearted and sad?" (Pomeroy, et al., 2001) (Level IV). Possible responses range from 1 to 6, as shown below, with a score of 3 or higher indicating potential depression.

Chochinov and colleagues' (1995a) (Level QE) work also indicated that a simple question such as, "Are you depressed?" can be an effective and easy assessment tool.

If a resident's life expectancy is anticipated to be less than two months, it is suggested that a psychostimulant will relieve their symptoms quicker than an antidepressant (Macleod, 1998; Martin & Jackson II, 2000) (Level IV; Level EO). Psychostimulants may also stimulate appetite and promote a sense of wellbeing. Residents with psychomotor slowing, advanced dementia, dysphoric mood, debilitating weakness or fatigue may also benefit from the 'energising effect' of these drugs (Roth & Breitbart, 1996) (Level EO). Methylphenidate is considered the most appropriate of these for use in a palliative approach (Macleod, 1998) (Level IV).

The Cornell Scale for Depression in Dementia (CSDD) is a 19-item instrument using information gathered from an interview with the person with dementia and a caregiver (e.g. family member or staff member) (Alexopoulos, Abrams, & Young, 1988). The scale's items were developed based on a literature review to determine the experience of depression for people with or without dementia and information based on a questionnaire administered to geriatric psychiatrists and other experts in the field. The scale categorises depression into five content areas (Alexopoulos, et al., 1988):

1. mood-related signs (anxiety, sadness, lack of reactivity to pleasant events, irritability);
2. behavioural disturbances (agitation, retardation, multiple physical complaints, loss of interest);
3. physical signs (appetite loss, weight loss, lack of energy);
4. cyclic functioning (mood swings, difficulty falling asleep, multiple awakenings during sleep, early morning awakenings); and
5. ideational disturbances (suicide, poor self-esteem, pessimism, mood-congruent delusions).

The CSDD was found to be a reliable scale of depressive symptoms among older persons with dementia (Camus, Schmitt, & Ousset, 1993). Additionally, CSDD scores have demonstrated moderate to high correlations with clinical diagnoses of major depression for older persons with or without dementia (Camus, et al., 1993). However, further analysis of the CSDD found evidence of four factors rather than the five proposed by the authors of the CSDD (Harwood, Ownby, Barker, & Duara, 1998) (Level IV).

## 7.2 ANXIETY

Anxiety is an arousal state. People experience anxiety in different ways, but the following three elements are considered to be common symptoms (Wetherell, Gatz, & Pedersen, 2001) (Level III-3):

A conscious feeling of fear and danger without the ability to identify immediate objective threats that could account for these feelings;

A pattern of physiological arousal and bodily distress that may include miscellaneous physical changes and complaints, such as heart palpitations, faintness, feeling of suffocation, breathlessness, diarrhoea, nausea or vomiting; and

A disruption or disorganisation of effective problem-solving and mental control, including difficulty in thinking clearly and coping effectively with environmental demands.

Anxiety symptoms are considered more stable than depression symptoms and it is believed that anxiety may be related to the trait of neuroticism (Wetherell, et al., 2001) (Level III-3). Hence, a resident's psychological history should be documented to determine any previous episodes of anxiety.

There are various validated assessment tools for screening anxiety. This list provides summaries of various findings on the suitability of these tools with either older persons, recipients of a palliative approach, or both:

- The *Hospital Anxiety and Depression Scale* (HADS) was used in a palliative unit for recognition and treatment of depression and anxiety. The researchers concluded that those administering the HADS needed time and skill to deal with the issues it raised. This was due to a finding that an increase in the prescription of antidepressants had occurred and that depression was being over-diagnosed. This, however, may partly be attributed to the influence of the scales used (Holtom & Barraclough, 2000) (Level IV).
- *Visual Analogue Scales* (VAS) is a 10-cm linear scale for use with people receiving a palliative approach. The VAS correlated well with both the depression sub-scale and total score of the HADS and was found to be quick and easy to complete for most people (Lees & Lloyd-Williams, 1999) (Level IV). However, concerns have been raised regarding the VAS, particularly that people with advanced dementia have difficulty completing this scale, so its use with this group is not recommended.
- The *Hopkins Symptoms Checklist* was found to provide many referenced syndrome classifications to the *Diagnostic Statisticians Manual* (3rd ed) (DSM-III) when used with older persons. Anxiety measures were the most accurate determinates of DSM-III classifications for mental health disorders (Matt, et al., 1992) (Level QE).

The effects of gentle massage on two groups of high-care residents were examined (those suffering from chronic pain and those with dementia who were exhibiting anxious or agitated behaviours) (Sansone & Schmitt, 2000) (Level IV). Pain scores declined at the end of each phase, and anxiety scores declined in two of the three phases. Eighty-four percent of the care assistants reported that the residents enjoyed receiving tender touch, and 71% thought this type of massage improved their ability to communicate with the residents. The researchers concluded that the aged care team must be made aware that touch, gentleness, and compassion are integral parts of care.

### 7.3 CONFUSION

Residents experiencing confusion may appear forgetful, and disoriented to time and place, and exhibit changes in mood or behaviour (Barracough, 1997) (Level EO). The two main clinical syndromes associated with confusion are delirium, which is potentially reversible, and dementia, which is usually permanent. It can be difficult to discern between confusion, dementia and delirium; therefore, a comprehensive assessment of a resident undertaken by relevant allied health care practitioners is preferable.

An Australian survey considered the effectiveness of Victorian aged care assessment teams (ACATs) for the management of people with dementia (Howe & Kung, 2003) (Level IV). The authors found that ACATs were effective in differentiating between clients with dementia and those who were disoriented. The following considerations are used by ACATs to successfully differentiate between a person with cognitive impairment and a person with another psychiatric problem (Howe & Kung, 2003):

- The *primary diagnosis* is recorded in broad categories only. The most common primary diagnosis indicating a psychogeriatric problem is dementia.
- Orientation to time and place, mobility and continence is recorded in detail. Each type of orientation is measured by four levels of disability: 'always' and 'often' disoriented are considered to identify a person with a cognitive impairment, whereas 'sometimes' or 'never' disoriented identify those with another psychiatric problem.

ACATs also use comprehensive assessment to screen for cognitive impairments, particularly dementia, and other mental illnesses, such as depression. This assessment includes the Mini Mental State Examination (MMSE) to screen for dementia, accompanied by a detailed history (Howe & Kung, 2003). The team also includes carers, when available, to assist in the process of assessment and to provide history and care preferences for the person being assessed.

### 7.3 DELIRIUM

With such a large proportion of nursing home residents suffering from dementia, the ability to assess treatable changes in cognition is very important. Delirium is common in the elderly, hospitalized and palliative populations. It also shares some symptoms with dementia. Tools that could help detect delirium are therefore important.

#### 7.3.1 ASSESSMENT

Inouye and colleagues (1990) (Level III-2) developed a method to detect delirium quickly. The Confusion Assessment Method was found to be sensitive, specific, reliable and easy to use.

Cacchione (2002) (Level III-2) examined four acute confusion instruments within the long-term care setting. The four instruments were evaluated against the MMSE, the GDS, and the DSM IV. The Visual Analog Scale for Acute Confusion (VAS-AC) was found to be most appropriate for general screening in the aged care setting.

One study explored the course of delirium in 193 older persons in acute care and found that the symptoms of delirium (e.g., inattention, disorientation, and impaired memory) were present up to 12 months following diagnoses for older persons with or without dementia (McCusker, Cole, Dendukuri, Han, & Betzile, 2003) (Level IV). Despite this similarity, the authors' reported that the duration of the first episode of delirium was longer for those with dementia compared with those who had no cognitive impairment

at baseline measurements. Additionally, a longer initial episode of delirium was predictive of a worse prognosis such as long-term functional and cognitive disabilities.

Although, the focus of the study (McCusker, et al., 2003) was an acute care setting, the findings are likely transferable to the aged care context. For example, the authors' reported difficulty in distinguishing delirium from dementia with many participants diagnosed as having both disorders, which is the same issue that aged care team members have in Australian RACFs (Howe & Kung, 2003)(Level IV). Therefore, a thorough assessment of symptoms is required, which includes consideration of the persistence of symptoms (e.g., inattention, disorientation, and impaired memory)(McCusker, et al., 2003) (Level IV). Those residents with delirium are likely to have these three symptoms plus a gradual decline in their ability to undertake the activities of daily living. Those residents with dementia while have the same three symptoms are more likely to have a sudden deterioration in their capacity to complete the activities of daily living (McCusker, et al., 2003) (Level IV).

A systematic review of the effectiveness of prevention interventions for delirium in hospitalised patients found that the most interventions involved psychiatric or medical assessments, support education or reorientation, which had little effect for older persons due to comorbid disorders (Cole, Primeau, & McCusker, 1996) (Level I).

Prescribed drugs and acute infections are perhaps the most common cause of delirium, particularly in older persons (Brown & Boyle, 2002) (Level EO). Many prescribed drugs that can induce delirium are sedating drugs such as benzodiazepines and narcotic analgesics. Precipitating causes also need to be considered. These include the person's age, co-morbid physical illness or dementia, and environmental factors (such as visual or hearing impairment, social deprivation, and being moved to a new environment)(Brown & Boyle, 2002)(Level EO). Good management of delirium requires (Brown & Boyle, 2002; McCusker, et al., 2003) (Level EO; Level IV):

- identifying and treating the underlying causes;
- providing environmental and supportive measures;
- prescribing drugs aimed at managing symptoms; and
- regular clinical review and follow-up.

#### **7.4 DEMENTIA (PSYCHOLOGICAL ASPECTS)**

Behavioural problems associated with care for cognitively impaired in nursing homes are common. Jagger and Lindsay (1997) (Level III-3) found that most of those with behavioural problems were cognitively impaired and that this had implications for staff training and practice. Evers and colleagues (2002b) (Level IV) found that major depression was highly prevalent in both dementia patients and normal controls in the last six months of life. Under diagnosis and under treatment of both cognitively impaired and normal residents therefore could be an important clinical concern.

There are various assessment tools available for determining a resident's level of cognitive impairment. One that is frequently recommended is the Mini Mental State Examination (MMSE).(Folstein, Folstein, & McHugh, 1975) The aged care team needs to be aware of the limitations of the MMSE in residential aged care settings or palliative care settings, because the usual cut-off scores for mental competence (i.e. >21–22) for interpreting the MMSE may not be appropriate.

A recent study considered the question: “Does not knowing where I am mean I don't know what I like?”(Mozley, et al., 1999) (Level IV). The authors found that a high

proportion of older persons in RACFs could answer questions on their quality of life, even when significant cognitive defects were present. Many of their research participants were considered significantly cognitively impaired, with more than half scoring 17 or below on the MMSE, yet the residents were still able to convincingly answer the majority of questions posed.

In instances of psychological distress, referral to a palliative team may be beneficial because of the team's expertise in assessment and care of people with psychological changes during final illnesses. The literature demonstrates the existence of this expertise in the area of depression, anxiety, agitation and loss. (Chochinov, et al., 1995a; Hall-Lord, Larsson, & Steen, 1999; Miller & Walsh, 1991) (Level QE; Level QE; Level EO).

For the family, psychological support will address issues such as an ongoing sense of loss and difficulty in finding a caring role (Rowles & High, 1996; Tilse, 1998) (Level QE; Level QE).

## **CHAPTER 8: FAMILY SUPPORT**

The palliative care model of care sees the family and patient as the 'unit of care' that needs support before, during and after the death of the patient. The hospice environment has been described as 'holistic' and the all-encompassing approach to death and dying is its strength. (Parkes, 2000) The resident and family are seen in a similar way in the aged care setting, but current funding arrangements do not support bereavement care. (Grbich, et al., 2001) (Level QE)

### **8.1 FAMILIES AND A PALLIATIVE APPROACH**

Residents receiving palliative care need emotional and spiritual support to accept the reality of their life-limiting condition, as do the family members. Staff members sometimes become surrogate family members. and also need support. (Sumaya-Smith, 1995) (Level QE) As the changing face of nursing home residents has seen less mentally alert and more terminally ill people being admitted, there has been a dramatic increase in the number and frequency of deaths in RACFs in recent years.

Family members who have had a loved one die in a palliative care setting appear to accept the loss and adapt to their new life situation reasonably well (Eriksson, Somer, & Lauri, 2001) (Level QE). This adjustment is dependent on the relationship with the resident and the age of both the relative and resident. However, it is important to prepare friends and relatives of an impending death so that they can cope with the loss successfully. Parkes (1999) (Level EO) suggests that worrying and grieving are important processes to be worked through before and after a death and should not be ignored out of fear of upsetting a person. He argues that the process of worrying is how people prepare for an upcoming loss and is dependent on receiving clear information.

### **8.2 DOCUMENTING FAMILY RELATIONSHIPS**

When the aged care team has an understanding of the social relationships and functioning of a family they are better able to provide appropriate family care (Davies, Reimer, & Martens, 1994) (Level QE). This can be aided by such tools as a genogram. The genogram usually includes three generations and covers the basic family structure, information on individual family members and family relationships. Discussion while constructing a genogram typically focuses on family illnesses, deaths, stress, and coping mechanisms of the resident and the family (Hockley, 2000)(Level QE).

### **8.3 FAMILY INVOLVEMENT**

Various studies have investigated the views of carers and family members regarding the local services. Carers and family members have identified the need for staff to communicate freely, pass on relevant information, provide emotional support and give them some of their time (Clumpus & Hill, 1999; Rutman & Parke, 1992)(Level QE; Level QE). While carers want their family member's symptoms managed well, they particularly need ongoing psychosocial support from staff members. The three aspects that were identified as being helpful to family members were the caring behaviours of staff, being included in the dying process and the giving of spiritual support (Wilson & Daley, 1999) (Level QE). However, some family members felt excluded from the caring role once the person was admitted to a RACF (Kellett, 2000) (Level QE).

If the resident has been recently admitted, particularly from a palliative care unit, hospital or hospice, the effect of the transfer on the resident and their family needs to

be considered by the aged care team (Atkinson, Tilse, & Schlecht, 2000; Johnson, Morton, & Knox, 1992; Maccabee, 1994) (Level QE; Level QE; Level QE). One study found that family and carers of recently transferred residents perceived that the resident did not adjust to the move and that this resulted in additional trauma for everyone (Maccabee, 1994) (Level QE). Some families perceived the transfer of their relative from a hospice to an RACF as a traumatic experience. In some instances, the level of subsequent care by the aged care team for the resident and their family negated these initial feelings (Maccabee, 1994) (Level QE).

Depression was also found to occur for wives following the placement of their husbands in an RACF (Bartlett, 1994; Rosenthal & Dawson, 1991) (Level QE; Level QE). Such a transition was likely to involve stress, loneliness, identity changes, ambivalence, and a sense of loss and grief (e.g. guilt, anger)(Rosenthal & Dawson, 1991)(Level QE) for residents, family and carers. However, if residents and their family were involved in decision making(Anderson, Hobson, Steiner, & Rodel, 1992) (Level QE), and were supported pre- and post-transfer, they reported higher levels of satisfaction (Atkinson, et al., 2000)(Level QE).

Recognition by the aged care team that family members have contributed significantly to the resident's wellbeing prior to admission may also help build a positive partnership (Clumpus & Hill, 1999) (Level QE). Similarly, giving the family the option of having an ongoing care-giving role can also help them cope with any separation anxiety they might feel and can also provide positive benefits for their family member with dementia (Anderson, et al., 1992) (Level QE). Keeping families informed and responding to any dissatisfaction they express about the care being given may reduce the complexity of the family's grief reaction and guilt over the resident's admission to the RACF (Clumpus & Hill, 1999) (Level QE).

The impact of caregiving on spouses in the palliative care setting has been shown to be high for both psychological and physical health (Haley, La Monde, Han, Narramore, & Schonwetter, 2001) (Level III-2). While the palliative care setting is different to the RACF, people with lung cancer and dementia are frequently admitted to the aged care setting and the issues are similar. It has been subsequently been recommended that health problems and depression be monitored closely by staff.

Open communication has been touted as essential between family members during a terminal illness especially if the autonomy of the patient is to be respected (Hinton, 1998) (Level IV). How a family functions as a unit will indicate how the family is approached during the dying process (Davies, et al., 1994) (Level QE). Families that have had contact with a palliative care service for more than two-years have been found to have a positive perception of the service (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996) (Level III-2). The same study found that older family members functioned better than younger family members did and spouses were more congruent with the patient in their expectations of care than other relatives.

In the context of aged care, 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 (Dempsey & Pruchno, 1993) (Level III-2). Families benefit from emotional support and an opportunity to discuss their concerns about the resident's illness or ageing process (Monahan, 1995) (Level QE). Holding a family conference can facilitate this support and information exchange (Kristjanson, et al., 1996; Monahan, 1995; Rutman & Parke, 1992) (Level III-2; Level QE; Level QE). The conference forum enables families to be involved, as well as enabling them to provide an assessment of their needs should they choose. This involvement and assessment is considered an essential element of a palliative approach (Kellett, 2000)

(Level QE), yet families are often unprepared for this role. Therefore, support to the families, providing training where required and enabling their involvement in care, may be beneficial. This support does not have to be provided by the aged care team only. It is equally appropriate for the aged care team to make referrals to pastoral care workers and social workers (where available) when support for the family is identified and required (Sheldon, 2000) (Level QE).

Health deterioration and death of the resident may also impact upon the physical and emotional health of family members (Haley, et al., 2001) (Level III-2). Family caregivers may also be older and have pre-existing health problems of their own. There is some evidence to indicate that spouses and family members who are non-English speaking may experience more burden than other family members (Waltrowicz, Ames, McKenzie, & Flicker, 1996) (Level QE). The caregiver burden has been found to be heaviest on spouses, followed by daughters, other relatives and then sons (Grau, Teresi, & Chandler, 1993) (Level III-3). Some spouses, especially those of residents with advanced dementia, report feeling like a 'married widow' (Bartlett, 1994) (Level QE) and the term 'quasi-widowhood' is used in the gerontology literature (Rosenthal & Dawson, 1991) (Level QE). Quasi widowhood captures the dilemma for this group of women: still married yet living separately from their husbands and in many ways without the partner they related to previously.

A number of studies report the difficulties families experience when coping with changes in the mental status of their relative (Bonnel, 1996; Fick & Foreman, 2000) (Level QE; Level QE). Management of agitated delirium is a frequent source of conflict between families and nurses (Travis, et al., 2002; Travis, et al., 2001b) (Level QE; Level QE). Family members of confused or unconscious people may have higher expectations of nurses than family members of people who are lucid (Kristjanson, Leis, Koop, Carriere, & Mueller, 1997; Kristjanson, et al., 1996) (Level III-2; Level III-2). The higher the variance between expectations and perceptions, the poorer the family functioning in the bereavement period will be (Kristjanson, et al., 1997) (Level III-2). These findings may be particularly relevant to RACFs, where the incidence of residents with advanced dementia is high. Families who witness a difficult or poorly managed death may experience more grief, guilt and regret in the bereavement period (Kurtz, Kurtz, Given, & Given, 1997) (Level IV). For example, poorly managed pain or shortness of breath is extremely distressing for family members to witness and they may feel guilt later if they believe that the resident suffered a difficult death.

These findings highlight the necessity for the aged care team in RACFs to consider the family's needs so that the capabilities and resources of all members are considered appropriately (Hermann & Looney, 2001) (Level EO). Additional management strategies could involve a member of the multidisciplinary team (e.g. social worker or chaplain/pastoral care worker) identifying family members who have difficulty coping and instigate appropriate social support (Bartlett, 1994; Sheldon, 2000) (Level QE; Level QE). In-house support could also be provided via support group meetings. Family members who attend support group meetings seem to have lower burden levels, possibly because they receive social support and information (Stewart, Craig, MacPherson, & Alexander, 2001) (Level IV).

Some evidence has been found that highlights what issues are important to family members during the dying process and how well they perceive a palliative care service. For example, the evidence suggests that families value not only technically competent physical care, but also regard emotionally sensitive care as especially important (Duncan & Morgan, 1994) (Level QE). There is a dearth of substantiated information on how best to manage the grieving process for the bereaved in either setting or no

evidence for the effectiveness of various mourning rituals. Experts in the bereavement field have developed various theoretical models of bereavement care, which are widely accepted. Volunteers play a significant role in bereavement care in palliative care but no evidence was obtained to support the effectiveness of their involvement.

## **CHAPTER 9: SOCIAL SUPPORT, INTIMACY AND SEXUALITY**

### **9.1 SOCIAL ISOLATION AND SOCIAL SUPPORT**

Although many RACFs provide a caring, comfortable environment, residents may still experience feelings of social isolation during this final phase of their life. Social isolation is considered to occur when a person has a limited network of family and friends (Thompson & Heller, 1990) (Level IV). Social isolation in older persons has been found to lead to poorer psychological wellbeing, such as depression, and diminished functional health (Thompson & Heller, 1990) (Level IV). However, it has been suggested that it is not merely the amount of contact that is predictive of these poor health outcomes; rather, it is the individual's perception, appraisal and interpretation of that contact that are most important (Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000) (Level IV).

More recently, Fratiglioni and colleagues (2000) (Level IV) found that it was not the number of relationships but the quality of those relationships that determined feelings of isolation. The authors also found that an extensive social network, for instance a network that included satisfying social contact, appeared to protect against the development of dementia. A poor or limited social network was found to increase the risk of dementia by 60%. Fratiglioni and colleagues surmised that extensive social networks might delay the onset of dementia by providing emotional and intellectual stimulation and practical support (Fratiglioni, et al., 2000) (Level IV). Further research is required to test this hypothesis. However, the evidence to date suggests that individuals who have limited social networks are at greater risk of poorer outcomes.

To help maintain the resident's links with their social network, it may be beneficial to assess their level of social support (Thompson & Heller, 1990) (Level IV).

Determining a resident's prior social history can be helpful in understanding their social network. A Genogram has been found to be useful in facilitating discussion with residents and/or their families (Hockley, 2000; Lioffi, Hatira, & Mystakidou, 1997) (Level QE; Level EO).

Research supports the occurrence of surrogate family bonds by staff members in RACFs, particularly for those facilities in rural locations (Sumaya-Smith, 1995) (Level QE).

### **9.2 INTIMACY AND SEXUALITY**

Residents need to have appropriate privacy to ensure their intimacy needs are met. Rather than denying the existence of residents' intimacy and sexuality needs, the aged care team is encouraged to acknowledge the legitimacy of such needs (Gibson, et al., 1999; Nay, 1992) (Level QE; Level QE).

There are particular difficulties in managing the issues around the expression of sexuality within nursing homes. Nay (1992) (Level QE), in her work on sexuality and aged women in nursing homes, found that residents often long for closeness, touch and intimacy. The ability to find an expression of intimacy can be limited by guilt, lack of privacy and fear of being "caught".

The few studies of sexuality in long-term care residents that have been conducted suggest that although sexuality is important for older people, several barriers exist

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that affect sexuality being expressed such as poor self-image, poor health status, communication difficulties with care providers, lack of appropriate or adequate information, and limited opportunities due to lack of partners, living arrangements and age-related changes (Aizenberg, Weizman, & Barak, 2002; Bauer, 1999; Walker & Ephross, 1999) (Level QE; Level QE; Level QE).

Sexual behaviour can be context specific. Staff, residents and family may have different views on what is appropriate in a residential setting and these issues may be confounded with issues related to cognitive impairment. (Gibson, et al., 1999) (Level QE) The authors found that residents and spouses were less tolerant than staff of residents masturbating, engaging in sexual relationships, viewing sexual materials, and making sexual approaches to staff.

Rather than denying the existence of residents' intimacy and sexuality needs, the aged care team is encouraged to acknowledge the legitimacy of such needs (Gibson, et al., 1999; Nay, 1992) (Level QE; Level QE). To ensure appropriate support for residents' sexuality and intimacy needs, aged care team members should first assess the resident's sexual and intimacy needs and concerns. Such an assessment should include consideration of the resident's privacy and comfort (Bauer, 1999)(Level QE).

Acknowledging the importance of touch is also important for both the aged care team and residents. (Butts, 2001) (Level IV) Touch has long been viewed as a form of unspoken communication. Butts (2001) actually assessed the effect of comfort touch on perceptions of self-esteem, well-being, and social processes and the resident's life satisfaction. Nurses may enhance the sense of well-being and self-regard felt by elderly residents by incorporating comfort touches such as handshakes, patting of the hand into their interactions with residents.

Massage is another way of providing comfort touch. Nursing attendants believe that resident enjoyed receiving a gentle massage and that this type of interaction improved their ability to communicate with the residents (Sansone & Schmitt, 2000) (Level IV).

The PLISSIT model (Annon, 1976) has been recommended by various experts as an appropriate method for assessing older person's sexuality issues (McInnes, 2003; Wallace, 2001; Weerakoon, 2001). The PLISSIT model has four components (the capitalised letters for each component form the acronym PLISSIT) that are described in the following table. (Annon, 1976)

The PLISSIT model is not a diagnostic tool, but a method of assessment that assists in determining appropriate interventions.(Wallace, 2001) Such interventions may include referral to an appropriate allied health practitioner such as a social worker, should the aged care team member feel that more in-depth information or counselling is required (based on the completion of the first 3 steps). While the tool is helpful in providing an assessment of the resident's sexual needs or issues, it's reliance on self-report requires that the resident is cognitively intact; thus the tool may not be appropriate for many residents. However, Davies and Colleagues (1998) consider that the tool is appropriate for use with the partners of resident's with Alzheimer's Disease (Level EO). Further research is required to determine whether the PLISSIT model is an appropriate mechanism for eliciting the sexual activities of resident's with advanced dementia via a proxy member such as family.

Therefore, a great deal of education and counselling of the aged care team, families and other residents may be required to assist them in accepting the need for residents to express their needs for intimacy and sexuality (Stausmire, 2004; Walker & Ephross, 1999; Weerakoon, 2001) (Level EO; Level QE; Level EO). Members of

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the aged care team invariably project their own sense of personal morality in these situations and thus their spiritual and cultural standards may be challenged (Gibson, et al., 1999) (Level QE).

Although most members of the aged care team are trained in the importance of confidentiality throughout their various careers, issues of sexuality require an additional reminder of confidentiality requirements (Bauer, 1999) (Level QE). It is normal practice for a staff member to share with their co-workers information about the resident's care. Although this information-sharing is valuable in promoting teamwork within a palliative approach, discretion is required when it comes to sharing information with colleagues about a resident's intimacy and sexuality needs (Bauer, 1999) (Level QE).

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## CHAPTER 10: ABORIGINAL AND TORRES STRAIT ISLANDERS ISSUES

Maddocks and Rayner (2003) note that death rates for Aboriginals and Torres Strait Islanders are much higher than those for white Australians and that Aboriginal and Torres Strait Islanders use healthcare services reluctantly and palliative services rarely. With a life expectancy of 20 years less than non-Indigenous Australians, and a high burden of chronic illness, health problems usually associated with people in their seventies or eighties are more prevalent among much younger Indigenous Australians. (Sullivan, et al., 2003) However, across Australia few services are funded specifically to provide a palliative approach to Aboriginal or Torres Strait Islander peoples (Sullivan, et al., 2003) (Level QE).

Meeting the needs of Indigenous Australians requires that non-Indigenous Australian controlled RACFs adopt a respectful attitude and be directed by the unique values, beliefs and experiences of Indigenous Australian residents, their family members and community. (Harrison, 1997; Willis, 1999) (Level EO; Level EO). For example, a recent study on terminal illness in rural Indigenous Australian communities found that participants were aware of the availability of health services, but preferred care to be provided by the family for as long as possible, and for some people dying on their home country had considerable spiritual significance. (Ramanathan & Dunn, 1998) (Level QE) Willis (1999) (Level EO) discusses Indigenous Australians' strong preference for care to be provided by particular relatives and the importance of traditional healers.

A recently completed care needs study has identified Indigenous palliative care needs around several areas: socio-economic contexts, communication, traditional issues, access to palliative care services, planning and delivery of care, settings of care, workforce issues, information, and training and education. (Sullivan, et al., 2003)(Level QE) The study suggests that Aboriginal and Torres Strait Islanders are underrepresented as clients in palliative care services although their mortality burden is actually higher than the non-Aboriginal population.

A recent assessment of Indigenous Australians requiring a palliative approach identified a number of examples of services being able to improve the quality of palliative services while respecting residents' wishes to die in a particular community. (Sullivan, et al., 2003)(Level QE). This report shows that cultural sensitivity goes beyond good communication to acknowledging and respecting the client's right to choose the type and site of care before dying. (Sullivan, et al., 2003)(Level QE)

Ramanathan and Dunn (1998) (Level QE) found that for a group of terminally ill Aboriginal people the chance to talk about their experience was important. Issues such as access and quality of services, carer burden, grief and loss and the community and terminal illness were all raised as Indigenous issues.

Finally, Eckerman and colleagues (1992) (Level EO) warn about transporting simplistic views of traditional values into rural and urban settings.

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## CHAPTER 11: CULTURAL ISSUES

The ability to provide palliative care within an aged care setting must recognize the cultural and physical site of the facility. Palliative care for Indigenous Australians and for Australians from culturally and linguistically diverse backgrounds must be sensitive and respectful to ensure that it is effective and appropriate to the needs of these particular populations.

According to the 2001 census, 22% of Australia's population was born overseas, representing over 200 different ancestries. (Australian Bureau of Statistics, 2001) Recent statistics indicate that 25% of permanent residents in RACFs were born overseas and 13.6% were from countries or regions other than Oceania, the United Kingdom, Ireland and North America. Almost 60% of these residents live in either New South Wales or Victoria. (Australian Institute for Health & Welfare, 2003) (Level QE).

Chan and Woodruff (1999) (Level IV) highlighted the difficulties confronted by patients who are not fluent in English. They concluded that patients not fluent in English received less optimal palliative care than did English speaking patients.

Crawley and colleagues (2002) (Level QE), for the American college of physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel, argue that physicians need to be sensitive to cultural differences and need to develop the skills necessary to work with patients from diverse backgrounds. Challenges that confront physicians and patients regarding good end-of-life care may centre on differences in cultural beliefs and traditional medical practice. The evidence suggests that physicians should assess the cultural background of each patient and enquire about the specific beliefs and practices of each individual.

In a review of the research relating to barriers to optimum end-of-life care for minority patients, Krakauer, Crenner and Fox (2002) found evidence that improvements in end-of-life care are not reaching all populations. They found that disparities in access due to insurance and financial inequities. Other concerns identified included disparities in the provision of analgesics and other care, ethnic differences in preference for end-of-life care, cultural differences in attitudes toward medicine and dying, mistrust and medical racism.

McNamara and colleagues (1997) (Level QE), assessed the perceived competence of 191 Australian palliative care professionals delivering cross-cultural care. The study found that specific education on cross-cultural issues was the key to improving the level of competence in palliative care professionals.

It is considered that the aged care team cannot provide a sensitive palliative approach to minority ethnic groups unless there is a greater understanding about the meaning of death and dying from the cultural perspective of these communities (Die-Trill & Holland, 1993) (Level EO). When the aged care team responds sensitively to the cultural beliefs and practices of residents and families, their satisfaction with care is increased (Kristjanson & Ascroft, 1994) (Level EO).

Whenever possible information about a palliative approach should be provided to culturally and linguistically diverse residents and their families in their own language (Critchley, et al., 1999) (Level II).

Aged care team members can experience stress and frustration caring for ethnic minority patients due to communication difficulties (McNamara, et al., 1997)

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(Level QE). Communication difficulties are reported to compromise the provision of holistic care, including psychosocial support. Furthermore, physical care may be sub-optimal as well (Gerrish, 2000) (Level QE). For example, nurses have been shown to consistently rate the level of pain experienced by individuals differently if they do not share a common language or if the person being cared for is from another culture (Harrison, 1997) (Level EO).

Cultural sensitivity is required by the aged care team to acknowledge that differences exist and to have respect for these differences (Crawley, et al., 2002; Sullivan, et al., 2003) (Level QE; Level QE).

‘Cultural competence’ refers to the aged care team’s knowledge and skills rather than their attitudes. (Crawley, et al., 2002) To be culturally competent, an aged care team needs to have cultural sensitivity, skills in communication, use of interpreters, and an awareness of non-verbal communication. An alternative term to cultural sensitivity and competence is ‘cultural brokerage’ (Hall, Stone, & Fiset, 1998) (Level EO).

To help the aged care team in becoming cultural brokers, education on cultural diversity is recommended (Hall, et al., 1998; Sullivan, et al., 2003)(Level EO; Level QE).

Privacy issues are also relevant; for example, some Chinese residents receiving a palliative approach may experience a cultural conflict with the aged care team (Tong, 1994; Tong & Spicer, 1994) (Level EO). ‘Face’ is a term commonly used within Chinese cultures and refers to respect not just from family and friends but also respect from others, in this case the aged care team (Lo, et al., 2001) (Level IV). To ‘save face’ (maintain respect), any attempt at open discussions between family members and the aged care team will involve very little input or discussion from family members. (Woo, 1999) (Level EO). This behaviour is sometimes referred to as ‘a conspiracy of silence’ and may lead to frustration for the aged care team and family members. (Tong, 1994; Tong & Spicer, 1994) This silence is based on a belief that to discuss dying is the same as wishing that person dead, and such discussion may even lead to their death. (Tong & Spicer, 1994)

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## CHAPTER 12: SPIRITUAL SUPPORT

Grey (1994) in her discussion of the spiritual component of palliative care argues that ignoring spiritual matters would be an omission of care. Dein and Stygall (1997) in an overview paper on whether being religious helped or hindered in coping with a chronic illness, distinguished between religion and spirituality. Their review showed that religion is a common coping mechanism that may have a positive effect. The importance of an effective coping mechanism is that it could reduce the psychological morbidity associated with chronic and terminal illness.

Participants in a hospice-based study perceived spirituality in broad terms not necessarily linked with religion. Six themes associated with spirituality were identified: needs for religion, need for companionship, need for involvement and control, need to finish business, need to experience nature and need for a positive outlook (Hermann, 2001) (Level QE).

Spirituality's role as a coping mechanism was supported by a review of studies dealing with religion and spirituality (Mueller, Plevak, & Rummins, 2001) (Level EO). They found that most studies have shown that religious involvement and spirituality seem to be associated with positive health outcomes. Daaleman (2000) has reiterated many of these themes in his review of studies of religion and spirituality in end-of-life care (Level EO).

Spirituality was found to be an important predictor of the quality of life of individuals receiving a palliative approach (Hermann, 2001; McClain, Rosenfeld, & Breitbart, 2003; Thomson, 2000) (Level QE; Level QE; Level QE). Indeed, impending death is considered a powerful stimulus for reflection on the significance of life and destiny for residents in RACFs; for example, nearly 60% of residents used religion to help them cope (Koenig, Weiner, Peterson, Meador, & Keefe, 1997) (Level IV). Therefore, providing spiritual support is a responsibility of the aged care team that must be fulfilled to enhance a resident's quality of life (Hermann, 2001) (Level QE).

McClain, Rosenfeld and Breitbart (2003) (Level QE) studied the effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. They found that spiritual well-being seemed to afford some protection against end-of-life despair. They have suggested that study of spiritually based interventions may be useful in helping the terminally ill with respect to peace and meaning.

Abbot and colleagues' (2001) (Level II) study on spiritual healing as a therapy for chronic pain found that neither face to face nor distant healing had a measurable effect on chronic pain.

There is also some research that suggests that people are receptive to carefully worded inquiries about their spiritual and religious beliefs (Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999) (Level QE). Wilson and Daley (1999) (Level QE) in their study of family perspectives on dying in long term care found that providing spiritual support was an area identified as important by families. Aspects of spiritual support included staff talking about religion and spiritual matters, visits from clergy, and prayers.

Spiritual care involves sensitive listening, rather than providing answers. It is not necessary for the aged care team to share the same spiritual beliefs as the resident in order to understand the resident's spiritual needs, nor is the aim of spiritual care for members of the aged care team to impose their own views (McGrath, Yates, Clinton,

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& Hart, 1999) (Level QE).

So far there are few tools in this area that have been validated; however one tool that has been validated is the System of Belief Inventory (SBI). (Kash, et al., 1995) The SBI is a self-report inventory that measures two domains: 1) Presence and importance of religious and spiritual beliefs and practices, and 2) the value of support from a religious / spiritual community. (Kash, et al., 1995) The SBI originally contained 54 questions and was developed for use with cancer patients; however, the tool was revised to broaden the applicability to people with non-cancer diagnoses and to shorten the number of questions to 15 (SBI-15R) to reduce participant burden (Holland, et al., 1998) (Level IV). Subsequent studies using the SBI-15R found it was a valid and highly reliable assessment tool (Cronbach's alpha >0.94), which was appropriate for use with people who had non-cancer diagnoses, were older, and from other cultures, such as Australian, German and Israeli (Baider, Holland, Russak, & De-Nour, 2001; Grulke, et al., 2003; Hartog & Gow 2005; Holland, et al., 1998) (Level IV; Level IV; Level IV).

Orchard and Clark's (2001) (Level QE) survey of UK nursing homes investigated spiritual practices in these homes. Many homes had formal processes for religious input and recognised the need for spiritual care for the dying.

Obtaining a comprehensive social / family history at the time of admission may help identify the resident's own past and present resources for their spiritual care (Hermann, 2001) (Level QE). Spiritual assessment is best conducted in a trusting environment by a person with adequate interpersonal skills who can engage the views of the resident and the family through using a conversational style rather than a fact-finding interrogation. (Hermann, 2001)

Whether a resident's spiritual care involves public or private practices, their privacy needs to be respected and an opportunity given to carry out their practices (Hermann, 2001; Wilson & Daley, 1999) (Level QE; Level QE). Spiritual counselling and support are essential to a palliative approach and may help give access to rites and rituals that offer symbolic meaning to residents (Orchard & Clark, 2001) (Level QE).

A regular review of spiritual needs will guide practice, ensuring that spiritual care is flexible and adaptable, (Hermann, 2001; Wilson & Daley, 1999) (Level QE; Level QE) meeting the needs of the resident and family, particularly when needs change (e.g. when death is imminent) (Koenig, et al., 1997) (Level IV). Also evidence indicates that people who profess stronger spiritual beliefs are able to resolve their grief more quickly after a death of a close friend or relative (Walsh, King, Jones, Tookman, & Blizzard, 2002) (Level QE).

In a recent UK study, 73% of residential facilities surveyed (N=1,500) had requested the assistance of someone from the Christian faith to help care for a dying resident (Orchard & Clark, 2001) (Level QE). This suggests that the aged care team may perceive increased spiritual needs at the time of death and readily seek assistance from people who are well trained in the area of spirituality.

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## CHAPTER 13: VOLUNTEER SUPPORT

Palliative care services have historically relied on the involvement and contribution of volunteers, contributions which are considered valuable to the success of these services (Brazil & Thomas, 1995; Fusco-Karmann & Tamburini, 1994)(Level QE; Level IV).

A study by Fusco-Karmann & Tamburini (1994) (Level IV) to evaluate the activity of volunteers in the hospital and at home, as judged by patients, nurses and the volunteers themselves identified that a high quota of patients gave a very positive opinion on the importance of the presence of volunteers in the hospital and at home. Volunteers also helped to improve a patient's mood and to solve practical problems. The main form of intervention of all volunteers is to give psychosocial support to patients. Other activities of the volunteer were support for the family, assistance in social activities, and to give information.

Volunteers provide the backbone to many bereavement programs in the palliative care setting (Osborne, 1999)(Level EO). Two issues are raised in the literature that needs to be addressed, the lack of commitment by some volunteers and not knowing the appropriate boundary between themselves and family members after the bereavement period (Osborne, 1999; Payne, 2001) (Level EO; Level QE).

It is preferable to have a position of coordinator of volunteers to oversee the management of volunteers. A coordinator who has the requisite experience and/or training in volunteer support (Payne, 2001) (Level QE) can provide ongoing supervision and support. A coordinator of volunteers is a person responsible for the recruitment, training, placement and ongoing support of volunteers and for liaising with members of the aged care team to ensure volunteer roles are clearly defined and meeting the needs of residents. The criteria considered important for selecting a suitable candidate for the role of coordinator of volunteers are maturity and highly developed interpersonal and leadership skills (Mount, 1992) (Level EO). For success in this role, it is important for the coordinator to have autonomy and authority and for the position to be salaried (Mount, 1992; Payne, 2001) (Level EO; Level QE).

One study reported that a wider range of volunteers is entering the unpaid palliative workforce; significantly, those who have been actively serving as a volunteer for 4 years or less are more likely to be working full-time or part-time (Roessler, Carter, Campbell, & MacLeod, 1999; Volunteering in Palliative Residential Aged Care (VPRAC) Project Team, 2004) (Level QE; Level EO).

The education and ongoing supervision of volunteers who may provide support to residents and their families can help provide a service that is valued by residents and carers (Franks, Geary, & Smith, 1997; Fusco-Karmann & Tamburini, 1994) (Level QE; Level IV). Following a suitable recruitment, orientation and matching process, volunteers may act as a companion and confidant to the resident and their family (Brazil & Thomas, 1995) (Level QE). Volunteers may also provide bereavement care if they have been trained in this area, and receive ongoing support and supervision (Payne, 2001) (Level QE).

RACFs access to volunteers varies widely, as does the role volunteers play within a facility. However, as appropriately trained volunteers are an integral part of palliative teams providing support and assistance to clients (Fusco-Karmann & Tamburini, 1994) (Level IV), it is suggested that residents in RACFs would similarly benefit (Davidhizar & Bowen, 1995) (Level EO).

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## CHAPTER 14: END-OF-LIFE (TERMINAL) CARE

The quality of end-of-life care can vary from person to person, due to differing beliefs, values, culture, spirituality and basic assumptions. This makes the term 'optimal end-of-life care' difficult to define, and even more difficult to accurately measure (Centre for Policy on Ageing, 1999) (Level QE).

Yedidia and MacGregor (2001) (Level QE) have identified seven themes that characterize the attitudes and perspectives that these patients develop in confronting dying. These themes are: Struggle (living and dying are difficult), dissonance (dying is not living), endurance (triumph of inner strength), coping (finding a new balance), incorporation (belief system accommodates death), quest (seeking meaning in death), and volatile (unresolved and unresigned). Familiarity with such life and dying motifs may provide better care and support for residents.

Determining clinical futility is a step towards providing a successful palliative and end-of-life approach (Travis, et al., 2001b) (Level QE). For residents without an established advance care plan, particularly when discussions regarding end-of-life wishes have been unfruitful or have not occurred, clinical futility can be an issue for the resident, their family and carers, and the aged care team (Travis, et al., 2002) (Level QE). Recognising when the death of a resident without cancer is imminent is more difficult to determine due to co-morbidities (Glare, et al., 2003) (Level I).

Hospice patients who had experienced a fellow patient's death seemed to find it both comforting and distressing. However, those who did witness such a death were significantly less depressed than those who had not (Payne, Hillier, Langley-Evans, & Roberts, 1996) (Level III-3).

The capacity of terminally ill patients to accept their impending death seems to be in part due to how whether their primary caregiver accept death and the way that as terminal prognosis is communicated. Communication appears to influence the patient's acceptance of the death prognosis (Prigerson, 1992) (Level QE).

The most common symptoms during the last year of a person's life with dementia are mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%) (McCarthy, et al., 1997) (Level QE). An audit of the last 48 hours of life has found that the most prevalent symptoms that need to be managed well are dyspnoea, pain and noisy breathing yet 27% of cases of dyspnoea was not treated with opioids (Hall, Schroder, & Weaver, 2002) (Level IV). One distressing symptom noted in the literature in the last days of life is discomfort of the mouth. Comfort care measures may provide relief (McCann, et al., 1994) (Level IV).

Delirium at the end of life is a common occurrence. The care of this type of terminal restlessness requires a different approach to the usual care of residents with delirium (Travis, Conway, Daly, & Larsen, 2001a) (Level EO). Delirium is commonly associated with agitation or restlessness; however, there are difficulties with defining restlessness and delirium (Muller-Busch, Andres, & Jehser, 2003) (Level III-3). Yet, if delirium goes undiagnosed or is poorly managed then the family and health care practitioners will have unpleasant memories of the resident's death (Fick & Foreman, 2000; Inouye, et al., 1999) (Level QE; Level III-2).

The aged care team is in a unique position to assist families in coping with the loss of a relative during the dying process and after death has occurred (Wilson & Daley, 1999) (Level QE). This support may need to be practical as well as emotional

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(Katz, Sidell, & Komaromy, 2001) (Level QE). It is important for the resident and the family to be prepared for the resident's death, and for this a family conference is recommended (Kristjanson, et al., 1996) (Level III-2).

It is a myth that uncontrollable pain frequently develops in the last hours of life when it has previously not been a problem (Ferris, von Gunten, & Emanuel, 2003) (Level EO). If turning the resident to relieve pressure causes them distress, then turning should be avoided, unless the position change ultimately leads to greater levels of comfort (Rousseau, 2000) (Level EO).

Family members need to be advised that these changes in breathing are a normal part of the dying process, and should be reassured that the resident is not necessarily distressed by these changes (Bredin, 1999) (Level II).

Sedation, antibiotic use and the use of opioids in the terminal phase are discussed in the literature. Chiu and colleagues (2001) (Level IV) researched the use of sedation in terminally ill patients in relation to frequency of use of sedation, relationship to intractable suffering and family attitudes to sedation. They found that sedation was used to relieve delirium, dyspnoea, severe pain and insomnia. Thorns and Sykes (2000) (Level IV) found that patients who received increases in opioids in the last week of life did not show shorter survival times than those who did.

Rousseau (2000) (Level EO) reviewed the literature regarding palliative sedation to conclude that this form of care was a compassionate and humane alternative to conscious and continuous suffering.

Novak and colleagues (2001) (Level IV) have tested several instruments to use with actively dying patients to assess and monitor comfort. Ellershaw and colleagues (2001) (Level IV) investigated the use of Integrated Care Pathways (ICPs) as a means of measuring symptom control in the last 24 hours of life.

Incontinence can usually be managed with absorbent pads (Robinson, 2000) (Level QE).

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## CHAPTER 15 BEREAVEMENT SUPPORT

Grief and bereavement services in nursing homes are limited. One study found that 55% of homes sent sympathy cards and 64% attended the funeral if the resident died while in the facility (Murphy, Handrahan, & Luchins, 1997) (Level QE).

Unfortunately, most nursing homes that were surveyed did not offer any follow-up bereavement support either in the form of information, referrals or phone calls.

Volicer (1997)(Level EO) advocates for the inclusion of bereavement care in the aged care setting as modelled in palliative care. Many Australian RACFs have a dementia support group in place, where issues of grief and loss are addressed, but not specifically. People suffering with dementia have often been termed ‘the living dead’ and family members, in particular spouses, find the progressive degeneration difficult to watch and the grieving process can be protracted and painful.

The evidence shows that bereavement follow-up in palliative care services in various countries is less than ideal (Matsushima, Akabayashi, & Nishitaten, 2002; Payne & Relf, 1994)(Level IV; Level QE). Formalized risk assessment procedures were even less so. Yet the risk factors identified were circumstances; factors near or at the time of death; personal factors and social factors. Kissane and colleagues (1997) suggest that bereavement support should start with assessment of family functioning and promoting healthy functioning before the death occurs (Level QE). This is supported by a study that used measures of bereavement symptoms and psychological morbidity to predict symptoms of grief (Kelly, et al., 1999) (Level IV).

The mourning process is not exclusively for those who can cognitively manage the grieving process (Benbow & Quinn, 1990)(Level QE). People with a dementing illness are also affected by grief and loss but do not have the cognitive skills to resolve the issue. Fluctuating lucidity may be confusing for staff and family to understand what the resident knows, understands or comprehends news that is told to him/her. Benbow and Quinn (1990) recommend that staff be honest with residents and be consistent, allow them time to grieve even if they forget the details (Level QE). Protecting them from the truth can create confusion, as the story will not match the reality. They may need bereavement support for an extended length of time before they can accept the reality of the loss.

The criteria for complicated grief have been redefined (Horowitz, et al., 1997) (Level QE). Horowitz and colleagues (1997) argue that some prolonged and turbulent grief reactions include symptoms that differ from the DSM-IV criteria for major depressive disorder. Horowitz and colleagues developed observer-based definitions of 30 symptoms. Complicated grief disorder was characterised by a smaller set of the assessed symptoms. These include bereavement (loss of spouse, other relative, or intimate partner) occurring at least 14 months ago (12 months is avoided because of possible intense reactions around the anniversary reaction). The following common experiences were also identified as characteristic of complicate grief disorder (Horowitz, et al., 1997):

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- Intense intrusive thoughts;
  - Pangs of severe emotion;
  - Distressing yearnings;
  - Feeling excessively alone and empty;
  - Excessively avoiding tasks reminiscent of the deceased;
  - Unusual sleep disturbances; and
  - Maladaptive levels of loss of interest in personal activities.

However, it was suggested that the definition of pathological grief and the distinction between pathological (or complicated grief) and normal grief is not straightforward and that there is a critical lack of evaluation (Stroebe, et al., 2000)(Level EO). Given the lack of agreement regarding the definition of complicated and normal grief, rather than determining the individuals' grief response, it would be more appropriate for the aged care team to be aware that some people require more support than others do when grieving.

The assessment of those who might need more support is a “balancing act”, based on observations, with clinical judgment and input from the relevant sources (e.g., other residents, the aged care team, and family). The following indicators of increased vulnerability to the experience of loss are provided to guide the aged care team in considering those individuals who might require further support:

- If the death was traumatic;
- A lack of reality for the individual (e.g. unable to attend funeral, death occurring overseas/inter-state);
- An individual's belief that the death was preventable;
- Ambivalence by the individual toward the person who died;
- Decreased role diversity;
- Decreased social support;
- Pre-existing factors (e.g. psychiatric disorders);
- Concurrent crises; and
- An overtly prolonged death.

Focused bereavement support reduces risk and improves bereavement outcomes, whereas untargeted services may lack this overall beneficial effect (Parkes, 1999) (Level EO). Similarly, the aged care team require an increased awareness and knowledge about grief and loss issues for residents, their families, and for other staff involved with the resident who died. This improved awareness can enhance early identification of distress and implementation of appropriate support (Payne & Relf, 1994) (Level QE).

Death is the ultimate rite of passage and needs to be marked in a public way (Rawlings & Glynn, 2002) (Level EO). A memorial service is one such public statement about death (DeForge, 1999) (Level EO); (Urbancek, 1994) (Level EO). There is considerable anecdotal evidence that suggests the need for family members to say “goodbye” is crucial, especially if they are not present at the death (Parkes, 1999) (Level EO). This is also true for friends of the deceased, other residents of the RACF, and the aged care team (Komaromy & Hockey, 2001) (Level EO); (Sheldon, 1998) (Level QE).

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A Work Cover NSW Report (Elkington, 2000) (Level EO) indicates that a significant source of stress for members of the aged care team was the issue of unresolved grief. Mourning rituals facilitate psychological recovery and are helpful to aged care team members who do not often attend to the task of mourning because they are busy attending to the next resident's admission (Sheard, 1990) (Level EO). Memorial services are effective for facilities providing a palliative approach. The evidence suggests that these services are a valuable resource for residents, family members, the aged care team and volunteers and that memorial services are appropriate for the grieving process (Foulstone, et al., 1993; Hutchinson, 1995) (Level QE; Level QE).

Despite the appropriateness and benefits of using memorial services, the reality is that their use in RACFs remains limited, particularly when compared with palliative care specific settings such as hospices. For example, one study found that although 55% of RACFs sent sympathy cards, 99% of them did not offer any follow-up bereavement support, either in the form of information, referrals or phone calls (Murphy, et al., 1997) (Level QE); whereas another study found that in palliative care settings 84% provided bereavement follow-up (Payne & Relf, 1994) (Level QE). Although families find bereavement support a positive experience (Foulstone, et al., 1993) (Level QE), it has been suggested that if the focus is on ensuring the best care possible, families are more likely to cope well with the death of their family member (Kissane, et al., 1997) (Level QE).

Davidson (2003) (Level EO) formulated an evidence-based protocol for family bereavement support before and after the death of a resident that includes a number of bereavement support interventions. One study assessed a range of psychosocial variables on family functioning covering the experience of the illness, death and funeral, spousal health, family coping, sources of support, use of ritual, and completion of estate duties (Kissane, et al., 1997) (Level QE). The authors concluded that the nature of family functioning was a key aspect of social support in influencing the outcome of bereavement. In other words, the more social support the family had access to, the better they could cope with the bereavement (Kissane, et al., 1997) (Level QE).

Grief responses are more likely to be difficult for spouses of residents due to recent multiple losses (such as friends or family) (Hegge & Fisher, 2000) (Level QE). Additionally, for those spouses who were not depressed prior to the death of their partner are more likely to be vulnerable to depression post-bereavement (Carnelley, Wortman, & Kessler, 1999) (III-3) particularly if they have poor social networks (van Baarsen, Smit, Snijders, & Knipscheer, 1999) (Level IV). These studies indicate the importance of bereavement follow-up for family members, particularly when the resident has a spouse.

## **PUBLIC ACKNOWLEDGMENT OF DEATH**

Death is the ultimate rite of passage and needs to be marked in a public way. (Rawlings & Glynn, 2002) A memorial service is one such public statement about death. (DeForge, 1999) There is much in the palliative care literature that suggests the need for family members to say "goodbye" is crucial, especially if they are not present at the death. (Parkes, 1999) This is also true for friends of the deceased, co-residents of the RACF, and staff members. (Komaromy & Hockey, 2001; Sheldon, 1998)

There is no evidence to direct best practice for a memorial service but there is some weak evidence regarding the effectiveness of memorial services in a palliative

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care service (Foulstone, et al., 1993)(Level QE). The evidence suggests that it is a valuable resource for residents, family members, staff and volunteers and is appropriate for the grieving process. Staff members, including nurses, housekeepers, custodians, clerks and physicians, do not ordinarily have the opportunities for support and protection during the bereavement period that family members receive and a memorial service is an appropriate way to manage this process.(Sheard, 1990)

Davidson (2003) (Level EO) has formulated an evidence-based protocol for family bereavement support before and after the death of a nursing home resident which include a number of bereavement support interventions.

The evidence suggests that the support needs of relatives, residents and staff members is often centred on needing practical and emotional support (Katz, et al., 2001) (Level QE). Hospice patients who witnessed a fellow patient's death found this awareness of dying to be both comforting and distressing. They were significantly less depressed than those patients who had not experienced a death were (Payne, et al., 1996) (Level III-3).

The literature supports the effectiveness of hospice bereavement services indicating increased emotional, mental and physical stability of those who survive the death (Fauri, Ettner, & Kovacs, 2000) (Level EO). The evidence found that spouses of patients who died in a hospice showed fewer sign of depression and anxiety and greater social involvement at 12-months bereavement than hospital survivors (Ransford & Smith, 1991) (Level QE). However, there are few such services found in aged care facilities in Australia.

Bereavement care in rural and remote areas has additional challenges to overcome such as levels of stress due to role conflict and definition, and poor debriefing opportunities for care providers, poor access to health services, poor quality of services for residents and their families (Dunne, Patterson, Kilmartin, & Sladden, 1994; Ramanathan & Dunn, 1998; Wilkes & Beale, 2001) (Level IV; Level QE; Level QE). The evidence suggests that a bereavement service that encompasses bereavement support and follow-up for any cause of death works well in country areas (Wilker & Lowell, 1996) (Level QE).

Kellehear (2002) argues that the current focus of bereavement care puts the emphasis on personal control and the ability to adapt to loss (Level EO). A new direction in bereavement care stresses the importance of creating a supportive environment in the communities in which bereaved people live and encourages a renewal of meanings through transformation instead of the previous 'letting go' of the attachment. In this light, skilled but unprofessional bereavement workers can adequately manage bereavement care, if coordinated and supervised by a professional bereavement worker. Social workers were found to be effective grief work facilitators (Csikai & Rayner, 2003) (Level QE). However, the role of the social worker in palliative care still needs to be qualified by service receivers (Csikai & Rayner, 2003; Sheldon, 2000) (Level QE; Level QE).

Focused management of bereavement support reduces risk and improves bereavement outcomes, whereas untargeted support may not have such an overall beneficial effect (Parkes, 1999) (Level EO). Similarly, the aged care team will require increased awareness and knowledge about grief and loss issues for residents, their families, and for other staff involved with the resident who died. This increased awareness can enhance early identification of distress and implementation of appropriate support (Payne & Relf, 1994)(Level QE).

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One study assessed a range of psychosocial variables on family functioning covering the experience of the illness, death and funeral, spousal health, family coping, sources of support, use of ritual, and completion of estate duties (Kissane, et al., 1997) (Level QE). The authors concluded that the nature of family functioning was a key aspect of social support in influencing the outcome of bereavement.

The aged care team will likely experience loss following the death of residents with whom they have established meaningful relationships (Albinsson & Strang, 2002; Sumaya-Smith, 1995)(Level QE; Level QE). Therefore, the team should be provided with opportunities to formally acknowledge the loss, and have access to adequate bereavement support (Katz, Sidell, & Komaromy, 2000; Thompson, Rose, Wainwright, Mattar, & Scanlan, 2001) (Level QE; Level QE).

One study reported that members of an aged care team who had experienced many deaths of residents reported being significantly more comfortable when thinking and talking about death to residents who were dying (Vickio & Cavanaugh, 1985) (Level IV). However, these same people still had high levels of death anxiety when measured, which led the authors to conclude that these members of the aged care team were more able to separate their own anxiety from their willingness to discuss death and dying with residents. This would appear to indicate that even members of the aged care team who have experienced many deaths might still require access to support services in order to discuss their own anxieties (Vickio & Cavanaugh, 1985) (Level IV).

Emotional support for the aged care team could include bereavement support services, stress management training, and debriefing sessions (Addington-Hall, et al., 1990) (Level QE). Volicer (1997) (Level EO) argues for the inclusion of bereavement support in the aged care setting, as is the practice in many palliative services (e.g., memorial services, debriefing meetings for the aged care team). Access to a confidant has also been found to be one of the best indicators as to whether a person will require bereavement support (Norris & Murrell, 1990; Vachon, 1995) (Level QE; Level EO). If a person has at least one friend in whom they can confide this enhances their resilience in successfully adjusting to bereavement.

Often, listening to and understanding the multiple losses that a family member may have experienced acknowledges their loss and validates their feelings (Albinsson & Strang, 2002) (Level QE). Providing families with the option to stay with the resident during the night can help reduce their concern that the resident will die alone. Having been present with the resident during the last stages of the illness may also provide them with a sense of comfort as they will have witnessed the care provided, they may have been able to contribute to the care, and knowing that their family member did not die alone (Albinsson & Strang, 2002) (Level QE). Accommodation, such as a portable bed, may be all that is required to meet this need. The following story indicates the need for RACFs to formulate a systematic approach to bereavement so that family expectations are clear.

Many families also mourn the loss of relationship with the person with advanced dementia and may require support in dealing with this 'double death'. People suffering with dementia have often been termed 'the living dead' and family members, in particular spouses, find the progressive degeneration difficult to watch and the grieving process is often protracted and painful (Bartlett, 1994; Waltrowicz, et al., 1996) (Level QE; Level QE). So difficult is the loss of relationship for a spouse whose partner has advanced dementia that many classify themselves as a "married widow"(Bartlett, 1994; Rosenthal & Dawson, 1991) (Level QE; Level QE).

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RACFs that have a dementia support group in place where issues of grief and loss are addressed may help provide families with the support they require. One study found that support groups for bereaved seniors enhanced satisfaction with support given, diminished feelings of loneliness and positively increased their emotional wellbeing (Stewart, et al., 2001) (Level IV). This study was conducted with widows living by themselves in the community, so the findings, while pertinent to this discussion, might not be applicable to males and younger people (e.g. children of residents); hence there is a need for further research. Further research is also required to determine the suitability of support groups in communal settings, such as RACFs, to assist residents to cope with the deaths of other residents.

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## **CHAPTER 16 MANAGEMENT'S ROLE IN IMPLEMENTING A PALLIATIVE APPROACH**

Frameworks such as business cycle planning and quality management systems enable organizations to focus on their responsibilities and can lead to improved performance in the facility (Wagner, van der Wal, Groenewegen, & de Bakker, 2001) (Level QE).

Although education and training are essential elements of a successful implementation of a palliative approach they may not, by themselves, bring about the desired change (Froggatt, Poole, & Hault, 2002; Tuch & Parrish, 2002) (Level QE; Level EO). Other factors have been identified as influencing the success of changing practices such as a commitment of adequate resources, which is considered fundamental to the implementation of changed practices (De Bellis & Parker, 1998; Parker & De Bellis, 1999) (Level QE; Level QE). The organisational culture and leadership in the operational area can also be important in introducing and sustaining change (Kitson, 2001; Locock & Dopson, 2001; Manley, 2000) (Level EO; Level EO; Level EO).

As well, the context for the change and the process of facilitation can affect the change environment (Rycroft-Malone, et al., 2002; Wilson & Daley, 1999) (Level EO; Level QE). Time restrictions and a lack of appropriate members for an aged care team have also been identified as impediments to change.

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## CHAPTER 17 FUTURE RESEARCH

Reviewing the palliative care and aged care literature has shown that there are many potential directions for research and study to improve the quality of care of elderly dying residents and the understanding and application of palliative care in this setting.

There is a need to identify where and how palliative care should be provided for older Australians. Residential aged care facilities are only one provider of palliative care for older Australians. Their specific role within a broader framework of palliative services and providers needs to be examined and clarified.

Within the older age groups, study on disease patterns and trajectories will provide important information on care practices. The relation between chronic, palliative and terminal conditions needs to be examined to ensure that appropriate care is provided in a timely fashion. There are pragmatic difficulties in researching palliative care when there may not be a consensus as to who in the residential aged care population is dying and who of the dying needs a palliative approach or more intensive assessment and support from a specialist palliative care team.

Research on how to improve pain management within residential aged care facilities will be an important component of good palliative care in this setting.

There are specific clinical questions associated with palliative care that could benefit from investigation. These include the management of dysphagia, delirium, dyspnoea, pressure sores and cachexia during the palliative phase in the nursing home.

Further work on the role of artificial nutrition and hydration in this population in the palliative period need to be undertaken. Ethical aspects as well as clinical evidence will need to be investigated.

Similarly, the role of advance directives within palliative care in this setting will be important and need to draw on expertise from many different fields to ensure that the resident's needs and wishes are met within a framework of supporting the individual and the family.

More broadly, the issues relating to advance care planning and mechanisms relating to communication before palliative care is necessary and during the period of this care need to be examined.

The identification, validation and promotion of assessment tools for use with geriatric populations within the aged care setting will improve the quality of care and audit. While some assessment tools have been validated on non-hospice populations, validation of key assessment tools on populations within residential aged care facilities, and specifically, with cognitively impaired people will increase their relevance.

Further work on psychological syndromes within residential care facilities will improve the quality of life for those facing terminal illness. Specifically, the effect of depression on palliative care in this setting needs to be reviewed.

There is a need for further research on the provision of culturally sensitive palliative care that takes into account belief systems, social and community needs, views on medical and physical treatments, and bereavement and family supports.

There is a need for specific guidance on the needs and attitudes of Aboriginal and

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Torres Strait Islanders with regard to the provision of palliative care for older Aboriginal and Torres Strait Islanders.

Research into the most appropriate model of medical care within the aged care facility would ensure that the wishes and needs of the individual resident was maintained while ensuring that there was an adequate standard of medical care across and within the facility itself

Research is needed on the evaluation of organizational and educational interventions to ensure that the desired clinical and care changes do occur for all levels of staff.

More work is needed on the role of relationships in providing quality care. Given the frailty of the aged care population, the high level of cognitive impairment in residential aged care settings and the special human needs of palliative care, understanding the characteristics and role of staff in providing quality care will be important.

Finally there is the need for research into areas associated with evaluation and evidence. Evaluation tools that can be used with confidence to not merely assess but value the contributions from different academic fields are needed. There is a need to develop tools that can assess the value of websites, which are becoming an increasingly important as a resource within aged care and palliative care. There is also a growing need to look at the most effective ways of creating evidence-based practice and of efficiently and effectively disseminating the results of research and their applications to care.

#### Conclusion

A systematic review of the literature was undertaken to identify the evidence supporting best practice for a palliative approach that was relevant to the context of RACFs (i.e. the age group of the studies' populations were 65 years and older). The evidence gathered was used to confirm or refute existing practices and make recommendations for practice change for residents in aged care facilities whose care is being managed by a palliative approach.

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# GLOSSARY

## **acetaminophen**

Acetaminophen is a non-opioid derivative analgesic for mild pain, which is more commonly known in Australia as paracetamol. Because acetaminophen refers to paracetamol, this term does not include other non-opioids such as Aspirin, Salicylates, or Naproxen.

## **advance care plans**

Advance care plans are written documents that explain to aged care workers what a resident has decided about how they want to face their own death. They are called advance care plans, because the resident lets people know his / her wishes in advance. Ideally an advance care plan involves an ongoing discussion with the resident, family, doctor and facility to ensure that the resident's and / or family's wishes are current.

## **advance directives**

Advance directives are formal, legally endorsed documents (usually termed 'living wills') that state instructions for care to be implemented in the event of future decisional incapacity.[362]

## **advanced dementia**

Advanced dementia is a neurologic disease characterised by severe cognitive decline of an irreversible nature that is associated with poor prognostic factors such as swallowing disturbance, weight loss, dysphagia, anorexia, bowel and bladder incontinence, and often being bedridden.(Ahronheim, et al., 2000) This definition would, therefore, include many of the residents in RACFs because of their complete dependence on others for their activities of daily living.

## **aged care team**

The term 'aged care team' includes non-professional workers in RACFs, such as care assistants, and professional workers, such as RNs, GPs and allied health practitioners (social workers, physiotherapists, diversional therapists, podiatrists, chaplains/pastoral care workers, music therapists, etc). Volunteers may also provide aspects of care or play a role in supporting residents and / or their families and as such volunteers or the coordinator of volunteers are considered part of the aged care team.

## **bereavement**

Bereavement is the total reaction to a loss and includes the process of 'recovery' or healing from the loss. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and 'recover' in her / his own way.

## **cachexia**

Cachexia is usually associated with a serious illness, such as cancer. The symptoms include general ill health and malnutrition, marked by weakness and emaciation.

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### **care assistants**

When the term 'care assistant' is used in the guidelines, it refers to the wide range of non-professional workers in RACFs undertaking the direct care of residents. These workers have many titles such as 'assistant in nursing' (AIN), 'personal care assistant' (PCA) or 'aged person carer', depending on the State or Territory in Australia in which they are employed.

### **care plans**

Care plans are dynamic documents that comprise a statement of the resident's care needs determined during assessment, with the addition of resident-centred goals, together with strategies, interventions or actions that are intended to help the resident achieve or maintain those goals. (Commonwealth Department of Health & Ageing, 2002)

### **carers**

Carers are usually family members and sometimes friends. Their work is based on a pre-existing relationship and is unpaid and often unrecognised. The primary carer is the person who has provided the most informal assistance to the resident in relation to self-care, mobility and communication. When the word 'family' is used in the guidelines, it also includes carers.

### **chaplain / pastoral care worker**

A chaplain / pastoral care worker is a person who works within a holistic approach to health to enable individuals and groups to respond to spiritual and emotional needs, and to the experiences of life and death, illness and injury, in the context of a faith or belief system. It is considered best practice for such a person to be incorporated into the management of residents.

### **chronic illness**

A chronic illness has a sudden or slow onset that is characterised by significant exacerbations and a long, drawn-out duration.

### **cognitive behavioural intervention / therapy**

Cognitive behavioural intervention is a psychological therapy (often known as CBT) that is focused on changing particular thoughts or behaviour patterns, or acquiring specific coping strategies. Included in this category is muscle relaxation training, hypnotherapy, systematic desensitisation, biofeedback, and behaviour modification or reinforcement.

### **continuity of care**

Continuity of care refers to the aged care team member's maintenance of knowledge about the resident and his / her family through consistent palliative practices to ensure that optimal staff, resident and family outcomes are achieved.

### **coordinator of volunteers**

A coordinator of volunteers is a person who is responsible for the recruitment, training, placement and ongoing support of volunteers. The coordinator of volunteers also liaises with aged care workers to ensure that volunteer roles are clearly defined and meet the needs of residents. (See also 'volunteers'.)

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## **coping**

Coping is the extent to which a resident is able to deal with the stress of daily life activities and unusual challenges presented by chronic disease, disability, pain, frailty or other issues brought about by the ageing process.

## **coping style**

A coping style is the particular manner in which a person deals with stress, as is evidenced by their behaviour, thoughts and feelings.

## **counselling**

Counselling is a generic term that is used to cover the number of processes of interviewing, testing, guiding, advising, which are designed to help an individual solve problems, plan for the future, etc. There are differing levels of expertise depending on the practitioner's training and experience.

## **depression**

Depression is a pervasive and sustained lowering of a person's mood and demeanour. Clinically, it is a cluster of symptoms which include tearfulness, guilt, irritability, loss of interest in life, loss of energy, poor concentration, poor sleep and either a gain or loss in weight.

## **dysphagia**

Dysphagia is medical term for an inability to swallow food and / or liquids. Dysphagia is associated with a large number of neurological conditions, such as cerebral vascular accidents, Parkinson's disease, dementia, multiple sclerosis and motor neurone disease.(Ramritu, et al., 2000) The risk factors identified include neurological conditions, an altered state of consciousness, decreased cognitive ability, decreased alertness and attention span, increased impulsiveness or agitation, some medications, and advanced age.(Ramritu, et al., 2000) Dysphagia should be managed in accordance with the agreed goals of care as determined in collaboration with the resident, their family and carers.

## **dyspnoea**

Dyspnoea is an awareness of uncomfortable breathing that can seriously affect quality of life and is frequently associated with the end stage of life.(Abernethy, et al., 2003) The experience of dyspnoea comes from multiple physiological, psychological, social and environmental factors that can result in secondary physiological and behavioural responses.(Bredin, 1999) Dyspnoea directly affects all aspects of a resident's activities of daily living, limits mobility, increases anxiety, and can leave residents feeling fearful and socially isolated.(Bredin, 1999) Dyspnoea can also be a sign of a deteriorating condition in residents receiving a palliative approach.

## **emotional adjustment**

Emotional adjustment is the extent that a resident and / or her / his family has adapted to the resident's current circumstances, such as the process of ageing or living in an RACF, and whether they have developed the resilience required to enable them to cope with this

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adjustment. Emotional adjustment includes the resident's and / or his / her family's moods, fears, anxieties, depression, self-esteem, sense of control, satisfaction with care, other attitudes, personality traits, and various types of emotions or distress.

### **empathy**

Empathy is the ability to acknowledge and understand another person's feelings, needs, experiences, and suffering.

### **end-of-life (terminal) care**

End-of-life (terminal) care is a form of palliative care that is appropriate when the resident is in his / her final days or weeks of life. End-of-life care requires that the resident's care decisions are reviewed more frequently and that the goals of care are more sharply focused on the resident's physical, emotional and spiritual comfort needs, and support for the family.

### **family**

Family can be considered as any person who is part of the central core in the support network of an individual, including carers. A definition of family is those individual's who are closest to the resident in knowledge, care, and affection. This definition, therefore, includes the biological family, the family of acquisition (related by marriage / contract), and the family of choice and friends (not related biologically nor by marriage / contract). Based on this definition, family could include carers, friends, neighbours, or the aged care team and extends the boundaries beyond biological and legal relationships. When 'family' is used in the guidelines, it encompasses all the previously mentioned people.

### **genogram**

A Genogram is a visual representation of who a resident considers they are close to and which people are the resident's more distant supports. A Genogram helps the aged care team to determine a resident's prior social history, which can be helpful in understanding the resident's social networks.

### **geriatrician**

A geriatrician is a specialist doctor who deals mainly with the physical aspects of a resident's condition, including function, cognition, and the social context. Geriatricians can assist with symptom control for the resident who is dying, though a palliative specialist may have more specialised knowledge in some circumstances. Involving Geriatricians as part of the care team is most appropriate for those residents who are delirious, or who have a myriad of medical problems.

### **geropsychologist**

A geropsychologist is a psychologist who specialises in the assessment and management of older persons. Geropsychologists provide assessment, consultation and intervention services related to psychological adaptations in later life (e.g., adapting to age-related changes, bereavement), psychopathology (e.g., affective disorders, dementias), behavioral problems (e.g., wandering, aggressive behavior, behavioral aspects of incontinence); problems in daily living (e.g., marital and family problems, coping with acute and chronic stressors); medical and legal decision-making capacity (e.g., legal guardianship); independent living

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arrangements; behavioral competencies (e.g., driving, management of medications, self-care skills, financial management); and socio-cultural and socioeconomic factors influencing the experience and expression of psychological problems. Distinctive interventions include reminiscence and life review therapies, grief therapy, expressive therapies and psycho-educational programs for family caregivers

### **graseby pump**

A Graseby pump is a battery-powered syringe driver designed to administer a pre-determined dose of injectable medication, usually opioids, over a specified period.

### **informed consent**

In Australia, no medical services can be provided without the consent of the person concerned. This consent is considered informed consent when the person agrees to a treatment without duress, voluntarily gives their consent after a reasonable time, and has been provided with adequate information. The only exception to this is when the person's capacity to consent is impaired by a serious mental illness, in which case the relevant State Mental Health Act can be invoked. If a family member has been granted a legal right to make decisions for the resident, then the form stating this must be sighted by a member of the aged care team and its powers and limitations noted on the resident's record. The aged care team can then be directed by this document as to how much information they are able to share regarding the resident. As the legislation may vary regarding the responsibilities of people who are authorised 'in advance' by the resident as 'Enduring Power of Attorney' (financial or medical) or 'Enduring Power of Guardianship', it is incumbent upon each RACF to check legal requirements.

### **medical power of attorney**

Medical power of attorney is the title given to a person who is legally appointed to make decisions relating to the medical care of another. Managers of RACFs are directed to seek independent legal advice regarding medical power of attorney.

### **multidisciplinary team**

Multidisciplinary teams consist of a mix of aged care, health and social welfare disciplines. Team members share common goals, collaborate, and work interdependently in planning, problem-solving, decision-making, implementation and evaluation. Members of a multidisciplinary team could include GPs, surgeons, medical or radiation oncologists, Aboriginal health workers, nurses, care assistants, coordinators of volunteers, dentists, optometrists, psychiatrists, psychologists, social workers, physiotherapists, chaplains / pastoral care workers, volunteers, pharmacists, occupational or speech pathologists, or palliative care specialists.

### **National Consultative Information-Sharing Network (NCISN)**

The National Consultative Information-Sharing Network (NCISN) was a network of people who provided services in the aged care or palliative industry and who indicated that they were willing to be involved in the APRAC Project. NCISN members elected to contribute online their experiences and thoughts regarding a palliative approach for residents in RACFs. To

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participate in the NCISN, individuals completed an online registration at [www.apracproject.org](http://www.apracproject.org).

### **non-pharmacological interventions**

Non-pharmacological interventions are treatments that do not use drugs to alleviate symptoms of the disease. Examples of non-pharmacological interventions include music or art therapy, exercise, transcutaneous electrical nerve stimulation (TENS), massage, aromatherapy and support groups.

### **nurses**

In Australia there are currently two levels of nurses, the Enrolled Nurse (EN –trained through the vocational education and training sector) and the Registered Nurse (RN –university trained). The development of a higher level within the RN group, the nurse practitioner, is also at varying stages of development depending on the State or Territory. Its distinctive traditions, skills, knowledge, values and qualities define nursing practice. The use of the title ‘nurse’ is legally protected in all states and territories. When the term ‘nurse’ is used in this document, it refers to anyone appropriately qualified as a nurse, such as the following groups (this list is not exhaustive):

- Nurse practitioners, nurse managers, nurse educators
- RNs (general, specialist, Div 2), and
- ENs (RN Div1 in VIC).

### **oncologist**

An oncologist is the specialist title of a doctor who treats cancer.

### **opioids**

Opioid is a specific term used to describe drugs (natural and semi-synthetic) that are derived from the juice of the opium poppy.

### **palliative approach**

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

### **palliative care**

The World Health Organization’s (2003)(World Health Organization, 2003) most recent definition of palliative care describes this type of care as a palliative approach.

### **pharmacological interventions**

Pharmacological interventions are treatments that involve the administration of drugs to alleviate symptoms.

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### **problem-solving technique**

Problem-solving technique is a strategy that involves developing a sequence of alternatives leading to an intended goal or solution to a problem.

### **psychiatric disorders**

Psychiatric disorders are mental disorders diagnosed by a psychologist or psychiatrist, according to the Diagnostic Statistician's Manual (DSM).

### **psycho-geriatrician**

A psycho-geriatrician is a specialist doctor who deals mainly with the psychiatric aspects of a resident's condition. This would be particularly important when medication formed part of a psychosocial intervention such as for a resident with clinical depression and the management of disruptive behaviour secondary to dementia.

### **psychosocial needs / support**

Psychosocial needs / support are the culturally sensitive provision of psychological, social, and spiritual care.

### **qualitative studies**

Qualitative studies are usually descriptive and their aim is provide a context for people's experience and behaviours through analysis that is detailed, 'rich' and integrative. Examples of qualitative studies include observational or case study methods that explore comparisons within a group to describe and explain a particular phenomenon (e.g. comparative case studies with multiple communities).

### **quality of life**

Quality of life is defined as an individual's perception of his / her position in life in the context of the culture and value systems in which he / she live, and in relation to her / his goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health and psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment.

### **quantitative studies**

Quantitative studies generally use random assignment to compare the effect of an intervention between otherwise equivalent groups (for example, comparing a randomly assigned group of aged care team members who took part in a palliative approach training program with those who did not). However, quasi-experimental studies, which are also quantitative studies, make comparisons between groups that are not equal or make comparisons within a group over a period of time (such as an interrupted time series involving a pre-test and post-test).

### **randomised controlled trials (RCTs)**

Randomised controlled trials (RCTs) are trials that are conducted using participants selected in such a way that all known selective or biasing factors have been eliminated. The trial involves the comparison of an experimental group with another group of participants, equal in all respects, who do not undergo the treatment being trialled.

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## **Residential aged care facilities (RACFs)**

Residential aged care is for older persons who, for various reasons, can no longer live at home. Residential aged care facilities (RACFs) are owned and operated by organisations which have approval from the government to provide the personal and nursing care that a person requires in accordance with their aged care assessment and the relevant legislations.

## **self-esteem / self-regard**

Self-esteem or self-regard is how people perceive themselves. This self-evaluation is generally thought to influence an individual's thoughts, feelings and behaviours.

## **specialised palliative team**

A specialised palliative team is trained in the provision of a palliative approach. The individuals work as a multidisciplinary team, providing specialist advice, education and support to residents requiring a palliative approach and / or aged care team members providing this care.

## **support groups**

Support groups are groups composed of people with similar problems or illnesses. A formally trained, professional leader may lead these groups; however, depending on the purpose of the group, this may not always be the case.

## **support network**

A support network is a group of people who the resident considers provides for his / her emotional, psychological and practical care needs. A support network usually includes family members and carers (see glossary definitions for 'family' and 'carers' for further explanation).

## **therapeutic diets**

Therapeutic diets are diets ordered by a doctor as part of a resident's treatment to:

- Eliminate or decrease certain substances in the diet (e.g. sodium);
- Increase certain substances in the diet (e.g. potassium); or
- Provide food that the resident is able to eat (e.g. a mechanically altered diet).

Examples include diabetic, low salt, low cholesterol, and renal diets. (Kamel, et al., 2000)

## **volunteers**

Volunteers are people who provide practical and emotional support for residents and their families. They undergo recruitment, orientation and training and may fulfil such roles as making personal visits to the resident, listening, providing companionship and a supportive presence, and general support. (See also 'coordinator of volunteers'.)

## **Xerostomia**

Xerostomia is an abnormal dryness of the mouth resulting from decreased secretion of saliva. Xerostomia can be caused by a number of things, including rheumatoid arthritis, diabetes, kidney failure, infection with HIV (the virus that causes AIDS), drugs used to treat depression, and radiation treatment for mouth or throat cancer.

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# APPENDIX A: WORKING PARTY OF THE AUSTRALIAN PALLIATIVE RESIDENTIAL AGED CARE PROJECT

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## LEAD CHIEF INVESTIGATOR

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Professor Linda Kristjanson	The Cancer Council of Western Australia Chair of Palliative Care Edith Cowan University
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## CHIEF INVESTIGATORS

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Professor David Currow	Chair of Palliative and Supportive Services Flinders University
Associate Professor Paul Glare	Head, Palliative Care Central Sydney Area Health Service
Professor Judith Parker AM	Head, School of Nursing University of Melbourne
Associate Professor Kate White	Head, School of Nursing & Public Health Edith Cowan University

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## ASSOCIATE INVESTIGATORS

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Professor Judith Clare	Professor of Nursing School of Nursing and Midwifery Flinders University of South Australia
Ms Elizabeth Douglas	Director Sir James McCusker Training Foundation
Mr Paul Cook	Chief Executive Officer HN McLean Memorial Retirement Village
Ms Karen Glaetzer	Nursing Coordinator Community Palliative Care Service Southern Adelaide Palliative Services
Ms Pamela Harris	Coordinator of Volunteers Melbourne CityMission Palliative Care
Dr Peter Hudson	Head, Centre for Palliative Care Academic Nursing Unit University of Melbourne
Ms Yasmin Naglazas	Director, Residential Care Churches of Christ Homes and Community Service
Ms Ellen Nightingale	Palliative Care Consultant Western Australia
Ms Debbie Parker	PhD Candidate School of Medicine Flinders University of South Australia

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Dr Jeff Rowland	Director of Aged Care Liverpool Hospital
Ms Wendy Shiels	Dementia Consultant Victoria
Dr Jane Sims	Senior Lecturer in Primary Care Department of General Practice University of Melbourne
Dr Christine Toyne	Postdoctoral Research Fellow in Palliative Care WA Centre for Cancer & Palliative Care Edith Cowan University
Ms Helen Walker	Manager, Palliative Care Education Centre/Volunteer Service Development The Cancer Council of Western Australia

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## RURAL AND REMOTE

### PORTFOLIO

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Associate Professor Ann Larson	Director Combined Universities for Rural Health
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## TAFE PORTFOLIO

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Ms Eugenie Jelly Ms Diana Purcell	Central TAFE, Western Australia.
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## PROJECT MANAGER

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Mrs Jayne Walton	WA Centre for Cancer & Palliative Care Edith Cowan University
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## PROJECT STAFF

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Dr Margaret Behrndt	Project Coordinator (Jul – Oct 2002) WA Centre for Cancer & Palliative Care Edith Cowan University
Mrs Ros Casey	Secretary to the Project Team WA Centre for Cancer & Palliative Care Edith Cowan University
Ms Penny Connellan	Research Officer, Literature Review Southern Adelaide Palliative Services Flinders University
Dr Karen Cooper	Research Associate Competency Development Consultant New South Wales

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## **PROJECT OFFICERS**

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Ms Jennifer Cooper (Aug – Nov 2002)	Southern Adelaide Palliative Services Flinders University
Ms Rhonda Devine (Sep – Dec 2002)	Medical Psychology Research Unit University of Sydney
Ms Kris Dwyer	Combined Universities for Rural Health Western Australia
Associate Professor Rosalie Hudson	Aged Care Consultant Victoria
Dr Elizabeth Lobb (Sep – Dec 2002)	Medical Psychology Research Unit University of Sydney
Ms Jennifer Tieman (Nov 2002 onwards)	Southern Adelaide Palliative Services Flinders University

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## **RESEARCH ASSISTANTS**

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Ms Lara Andrews	WA Centre for Cancer & Palliative Care
Ms Tara Blanchard	Edith Cowan University
Ms Eva Cooper	
Ms Natalie D'Abrew	
Ms Address Malata	
Ms Aurora Popescu	
Ms Karen Rooksby	



## APPENDIX B: AN EVALUATION TOOL FOR QUANTITATIVE STUDIES

### APRAC GUIDELINES: EVIDENCE EVALUATION

#### Quantitative Study

Article No. \_\_\_\_\_

Aim of the study: \_\_\_\_\_

Study design: \_\_\_\_\_

*Level of evidence:* \_\_\_\_\_

- I systematic review of all relevant RCTs
- II at least one properly designed RCT
- III-1 well-designed pseudo-RCTs
- III-2 comparative studies with concurrent controls and allocation not randomised, case-control studies or interrupted time series with a control group
- III-3 comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group
- IV case series, either post-test or pre-test and post-test

*Quality of methods used:* \_\_\_\_\_

- 4 excellent level of scientific merit and rigor
- 3 good level of scientific merit and rigor
- 2 fair level of scientific merit and rigor
- 1 poor level of scientific merit and rigor

*Strength of evidence:* \_\_\_\_\_

- 4 very high
- 3 high
- 2 low
- 1 very low

*Relevance to APRAC project:* \_\_\_\_\_

- 4 very relevant
- 3 relevant
- 2 of some relevance
- 1 of little or no relevance

Evaluator/s:

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## APRAC GUIDELINES: EVIDENCE EVALUATION

### Quantitative Study

#### Inclusion criteria:

- Evidence based
- Published in a peer-review journal, book chapters, government and non-government reports, therapeutic guidelines, standards of care and other guidelines
- Published between January 1990 and September 2004
- Published in English language
- Originating in country with comparative health system to Australia
- Originating in country with social or cultural similarities to Australia
- Originating in a country where the residential care facilities fit with those in Australia

#### Exclusion criteria:

- Articles not meeting the inclusion criteria above
- Articles relating to community based programs rather than residential, aged or long term care situations

#### Scoring:

Each article will be assigned a Level from I –IV as in the first section of the evaluation sheet.

Article will be rated regarding the quality and strength of the evidence as it relates to the particular study cited – quality and strength will each be given a score out of 4.

Article will have a final rating score out of 4 according to its relevance to the Australian Palliative Residential Aged Care project.

#### References:

*Critical Appraisal Skills Program*: 10 questions to help you make sense of Qualitative Research [www.public-health.org.uk/casp/qualitative.html](http://www.public-health.org.uk/casp/qualitative.html)

National Health and Medical Research Council (2000) *How to use the evidence: assessment and application of scientific evidence*, Biotext, Canberra, Australia

The General Practice Section & Program Evaluation Unit (2000) *The relative effectiveness of population health interventions in the general practice setting*: Appendix C: Literature Review Summary Appraisal, Department of General Practice & Public Health, University of Melbourne, Victoria, Australia.

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# APPENDIX C: AN EVALUATION TOOL FOR QUALITATIVE STUDIES

## APRAC GUIDELINES: EVIDENCE EVALUATION

### Qualitative Study

Article No. \_\_\_\_\_

Yes = 1 No = 0

Aim of the study: Is the aim clear? .....

Paradigm: Is the paradigm appropriate for the aim: .....

#### Quality of evidence:

Methodology: Is the methodology appropriate for the paradigm? .....

Methods: Are the methods used appropriate for the methodology? .....

Checking methods: Did checking methods establish rigor? .....

Sample: Did the sampling strategy address the aim? .....

Data Analysis: Was the data analysis appropriately rigorous? .....

Findings: Are the findings clearly stated and relevant to the aim? .....

**Strength of evidence:** \_ .....

4 very high

3 high

2 low

1 very low

**Relevance to APRAC project:** .....

4 very relevant

3 relevant

2 of some relevance

1 of little or no relevance

**Evaluator/s:**

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## APRAC GUIDELINES: EVIDENCE EVALUATION

### Qualitative Study

#### **Inclusion criteria:**

- Published in a peer-review journal, book chapters, government and non-government reports, therapeutic guidelines, standards of care and other guidelines
- Published between January 1990 and September 2004
- Published in English language
- Originating in country with comparative health system to Australia
- Originating in country with social or cultural similarities to Australia
- Originating in a country where the residential care facilities fit with those in Australia

#### **Exclusion criteria:**

- Articles not meeting the inclusion criteria above
- Articles relating to community based programs rather than residential, aged or long-term care situations

#### **Scoring:**

Article will be rated regarding the quality of the evidence as it relates to the particular study cited – it will be given a score out of 8.

Article will have a strength and relevance (to the APRAC project) rating score, each of which will be out of 4.

#### **References:**

Butler, T. (2002) personal communication, July.

Clare, J. (2002) personal communication, August.

*Critical Appraisal Skills Program: 10 questions to help you make sense of Qualitative Research*, [www.public-health.org.uk/casp/qualitative.html](http://www.public-health.org.uk/casp/qualitative.html)

National Health and Medical Research Council (2000) *How to use the evidence: assessment and application of scientific evidence*, Biotext, Canberra, Australia.

*The General Practice Section & Program Evaluation Unit (2000) The relative effectiveness of population health interventions in the general practice setting: Appendix C: Literature Review Summary Appraisal*, Department of General Practice & Public Health, University of Melbourne, Victoria, Australia.

Palliative care guidelines in the Aged care setting: a literature review

## APPENDIX D: SUMMARY OF THE STAKEHOLDER PARTICIPANT GROUPS

Employment category	Aged Care	Palliative Care	Both	Total
Aged Care (group submission)	12	-	-	12
Aged Care Representative	13	-	-	13
Care Assistant	8	-	-	8
Chaplain / Pastoral Care Worker	10	-	-	10
Clinical Nurse Consultant	3	10	5	18
Complementary Therapist	4	-	-	4
Consumer	6	2	-	8
Coordinator of Volunteers	5	9	1	15
Dementia Consultant	3	-	-	3
Director of Nursing / Care Manager	77	-	-	77
Diversional Therapist	4	-	-	4
Domiciliary Care Nurses	-	-	2	2
Educator / Trainer	4	-	2	6
Enrolled Nurses	11	-	-	11
Executive Officer / Senior Administrator	20	1	1	22
General Practitioner	-	-	8	8
Geriatrician	1	-	-	1
Government Department Representative	4	1	5	10
Medical Practitioner	-	7	6	13
Multicultural Specific Service	3	1	-	4
Nurse Educator	-	2	3	5
Nutrition Consultant	-	-	2	2
Peak Body (group submission)	3	-	2	5
Peak Body Representative	8	1	2	11
Policy / Project Officer	1	2	7	10
Registered Nurse	23	2	3	28
Registered Training Organisation	1	-	4	5
Volunteer	4	2	-	6
Wound Care Consultant	-	-	2	2
Not Specified	6	-	-	6
<b>Total:</b>	<b>234</b>	<b>40</b>	<b>55</b>	<b>329</b>

## **APPENDIX E THE AUSTRALIAN GOVERNMENT PROJECT REFERENCE GROUP – TERMS OF REFERENCE AND MEMBERSHIP**

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### **TERMS OF REFERENCE**

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The project reference group will assist the project to achieve its objectives by:

1. Providing comment and input to the overall project plan
2. Providing appropriate guidance and support for the project by ensuring the needs of their sectors are being addressed
3. Providing comment on reports and other deliverables.

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### **MEMBERSHIP**

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Dr Joanne Ramadge (Chair)	Advisor, Ageing and Aged Care Division Australian Government Department of Health and Ageing
Ms Maria Bohan	Executive Director Carers Victoria
Mr Michael Darragh	Representing Australian Nursing Homes and Extended Care Association
Ms Rita Evans	Director, Palliative Care Section Australian Government Department of Health and Ageing
Associate Professor Sally Garratt	Representing Royal College of Nursing Australia –Aged Care Nurses
Emeritus Professor Ian Maddocks	Flinders University of South Australia
Professor Margaret O'Connor	Representing Royal College of Nursing Australia –Palliative Care Nurses
Ms Jill Pretty	Manager, Policy and Consultancy Aged Care Services Australia
Ms Alma Quick	Director, Strategic Support Section Australian Government Department of Health and Ageing
Mr Ian Reed	Representing Palliative Care Intergovernmental Forum

## **Additional contributors**

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Mr Chris Forsey	Assistant Director (2004) Palliative Care Section Australian Government Department of Health and Ageing
Ms Jeanne Mansbridge	Assistant Director (2003) Palliative Care Section Australian Government Department of Health and Ageing
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## **SECRETARIAT**

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Ms Wendy Cook	Project Officer Palliative Care Section Australian Government Department of Health and Ageing
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