Guidelines for a Palliative Approach in Residential Aged Care

May 2004

THE NATIONAL PALLIATIVE CARE PROGRAM

Prepared by Edith Cowan University

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Palliative care – quality of life for people with a life-limiting illness, their families and carers

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Guidelines for a Palliative Approach in Residential Aged Care

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LIST OF 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	Quasi-experimental study
QOL	Quality of life
QS	Qualitative study
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

IMPORTANT NOTICE

This document is a guide to providing an appropriate palliative approach, and should be followed subject to the aged care team's judgement in each case.

These guidelines are designed to provide information to assist decision-making and are based on the evidence available at time of publication. They are not meant to be prescriptive.

This is the first edition of the Guidelines to a Palliative Approach in Residential Aged Care. A second edition will be published in due course. Your feedback on this first edition would be appreciated. A form for your use is at the back of this document.

National Health and Medical Research Council endorsement of these guidelines is also being sought.

Foreword

Palliative care as a specialty continues to evolve in Australia and this has resulted in community expectations that people with a life-limiting illness or condition can die in an atmosphere of care and support.

As health professionals continually strive to improve the delivery of palliative care, there is a widespread recognition that the benefits of palliative care are not limited to the final days and weeks before dying. In response to this, there has been a shift in the provision of palliative care as health providers move towards providing a palliative approach. A palliative approach can help reduce the suffering of many people and encompasses a positive and open attitude towards death and dying.

Increasingly, residents of aged care facilities are older and frailer, with complex co-morbid conditions. Staff are constantly faced with the challenge of meeting the complex care needs of this diverse group of people.

A palliative approach has much to offer to residents, their families and staff in our aged care facilities.

These evidence-based guidelines, developed by the Australian Palliative Residential Aged Care (APRAC) project team, aim to provide support and guidance for the delivery of a palliative approach in the 3,000 residential aged care facilities across Australia. Until the guidelines' production, evidence-based guidelines for the implementation of the palliative approach in the residential aged care facility did not exist. The guidelines incorporate the best scientific evidence available regarding all facets of a palliative approach, including early identification and treatment of physical, cultural, psychological, social and spiritual needs.

Importantly, these guidelines are consistent with Goal Two of the National Palliative Care Strategy—to support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia. The guidelines also represent an important contribution to Palliative Care Australia's mission to improve palliative care options available to ALL Australians through advocacy and setting high standards for practice, policy, research, and service and community development.

Developing the guidelines involved a broad consultation process that included both palliative and aged care sectors. I would like to commend all of those involved in this project, including those members of the community who displayed a commitment to the development of these guidelines.

These guidelines are not prescriptive; rather their intent is to provide guidance and support to all those caring for people with a life-limiting illness or condition in residential aged care facilities. I trust that they will offer a great deal to health care workers, families, carers and residents. I encourage you to become familiar with them, to make them readily accessible, and to refer to them when delivering a palliative approach.

Professor David Currow
President, Palliative Care Australia
May 2004

Introduction

Using these guidelines

These evidence based guidelines are intended to help practitioners in applying a palliative approach in a residential aged care facility (RACF). They cover all major aspects of providing a palliative approach for an RACF resident, from attending to physical symptoms (e.g fatigue, dehydration) and spiritual needs to dealing with the reactions of family members.

Each chapter deals with a major issue, discussing the issue in detail then stating some guidelines that encapsulate the 'message' of that chapter (though Chapter 5, which devotes a section to each physical symptom, has guidelines at the end of each section). For quick reference there is a Summary of Guidelines at the front of the document, though the guidelines are much better read in conjunction with the detail given in the chapters.

The guidelines are not meant to be rigid, prescriptive pathways on 'what must be done' in an RACF. Rather, they aim to prompt creative solutions that will be appropriate to the particular RACF in which a palliative approach is being applied. They may also be used to identify strengths and weaknesses of the approach being taken, and provide a mechanism for change and evaluation over time.

The guidelines have been developed after a major search and study of the relevant literature (see Appendix C), so that practitioners can see at a glance whether there is research-based support for the practices and beliefs common in a palliative approach. Within the text of this document, each study referred to is given a number (referring to 'Reference list' at the end of the document) and also a 'level' indicating the type of study undertaken, as follows:

Level I	A systematic review of all relevant randomised controlled trials (RCT).
Level II	At least one properly designed RCT.
Level III-1	Well-designed pseudo-RCTs.
Level III-2	Comparative studies with concurrent controls and allocation not randomised, case-control studies, or interrupted time series with a control group.
Level III-3	Comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group.
Level IV	Case series, either post-test or pre-test and post-test.
Level QE	'Quasi-experimental' studies that had a relevance score of either 3 or 4 and a quality and strength rating greater than 9 (out of a possible 12) (See 'Glossary' for definition).

Level QS	'Qualitative studies' that had a relevance score of either 3 or 4 and a quality and strength rating greater than 9 (out of a possible 12) (See 'Glossary' for definition).
Level EO	'Expert opinion' studies in which evidence that was not quantitative or qualitative but contained an opinion from an expert or experts in that field, as agreed by the project team. (Because expert opinion is generally the result of experiential knowledge, it was considered essential to the guidelines' development and accordingly, has been included in the preamble for each chapter. However, as the expert opinion was not research based, it was not used as the basis for any guidelines.)

Other resources will also be developed to assist in using these guidelines; however, in the interim a Resource List has been included in these guidelines (Appendix F).

How the guidelines were developed

The Australian Palliative Residential Aged Care (APRAC) project team developed these guidelines for the residential aged care setting. The team was comprised of investigators who had expertise in aged care, palliative care and education, and individuals with special expertise in guideline development, dementia, cultural issues and volunteers (see Appendix A). The guidelines are also the result of collaboration between the project team, the aged and palliative care sectors and the Australian Government Department of Health and Ageing.

The principles for guideline development, as outlined by the National Health and Medical Research Council (NHMRC),[9] were used in preparing these guidelines. One of the key principles is involvement of stakeholders, including representatives of all relevant disciplines and consumers. Therefore, use of the National Consultative and Information-Sharing Network (NCISN: see 'Glossary') was actively incorporated into the process of guideline development and refinement. Evidence for best practice in a palliative approach in RACFs was assessed and gaps in the evidence specifically identified. Guidelines were drafted and refined using the NCISN with the aim of producing the final guidelines. (Details of the guideline development process are described in Appendix C, and evaluation tools used to rate the evidence are shown in Appendix D.)

The guidelines were refined thanks to the input and guidance of a Reference Group (see Appendix B) and using a process of national consultation with key stakeholders. Key stakeholders were recruited, and project staff coordinated the consultative process in each State and Territory, involving a broad cross-section of participants from aged care, palliative care, education, volunteering, and consumer advocacy. A special emphasis was placed on involving those with knowledge of rural/remote area issues, dementia care, and culturally specific care.

Project staff members convened initial meetings of key stakeholders in each State and Territory to ensure that consultation was nationwide. In addition, several rural and remote stakeholders group were convened to review the guidelines. A useability and feasibility assessment of the guidelines from the perspective of aged care providers further refined the guidelines, with detailed input from staff members in various RACFs (e.g. rural, remote, regional, metropolitan, low care and high care).

What is palliative care?

The World Health Organization[1] defines palliative care as:

> *An approach that improves the quality of life of individuals 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.*

WHO further states that palliative care:[1]

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

This recent definition and description of palliative care asserts that, contrary to earlier definitions, individuals with diseases other than cancer that have a terminal phase and are progressive in nature would benefit from the philosophical underpinning of the palliative approach.[2] These include chronic obstructive pulmonary disease (COPD), Alzheimer's disease, and acute massive cerebrovascular accident, to name a few.[3]

What is a palliative approach?

A palliative approach aims to improve the quality of life for people with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs.[4] Each of these facets is considered essentially separately in this document, but it is important to realise that cultural issues are integral to all aspects of care provision and so should underlie the implementation of any part of these guidelines.

Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying. Promoting a more open approach to discussions of death and dying between the aged care team, residents and their families makes it much easier to identify the wishes of all regarding end-of-life care.

A palliative approach is not confined to the end stages of an illness. Instead, it provides a focus on active comfort care and a positive approach to reducing a person's symptoms and distress, allowing residents and their families to understand that they are being actively supported through this process.[4]

The need for a palliative approach

In Australia, over the last two decades, research has indicated that the proportion of people dying in RACFs has steadily increased.[5] This has led to the recognition that a palliative approach enhances the care already provided to both residents and the families.[6, 7]

Due to the type of residents they support, RACFs face unique and significant difficulties in using a palliative approach. Not only do the majority of residents have dementia; they generally have co-morbidities (other diseases) that involve dealing with physical, psychological, emotional and social issues. The residents are generally highly dependent and require many medications, further complicating the provision of a palliative approach.[3]

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.[8] These differences may include, that:[8]

- 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.

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

The need for evidence-based guidelines for aged care facilities

Although separate Australian standards for aged care and standards for palliative care exist, these do not fully address the unique and complex issues associated with providing a palliative approach within an RACF. The aged care literature calls for the development of guidelines for appropriate care of older persons by non-specialist palliative teams, but to date no guidelines for implementing a palliative approach in aged care facilities have been created. As well, there are no specifications for how members of an aged care team in an RACF should be trained to provide a palliative approach to these residents. Finally, there is no systematic approach to palliative education for this workforce.

The APRAC Project was established in response to recognition that there was a critical need for a palliative approach in residential aged care.

Summary of Guidelines

The following table provides a summary of the guidelines with their corresponding level/s of evidence as presented in this document. To understand the context of the guidelines, readers are strongly urged to review the appropriate chapter.

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
A PALLIATIVE APPROACH			
When should a palliative approach be implemented?			
1. Methods used to identify survival time have limitations in accuracy and precision, and are therefore not recommended. Rather, a combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach is considered best practice.	I IV	23 21	1.2
Where can a palliative approach be provided?			
2. Implementing a palliative approach in RACFs can reduce the potential distress to residents and their families caused by a transfer to an acute care setting.	QE	34	1.3
3. A palliative approach can be provided in the resident's familiar surroundings if adequately skilled care is available.	III-2	31	1.3
4. Providing information about a palliative approach may help residents and their families to consider a palliative approach as active care rather than withdrawal of treatment.	QE	34	1.3
Who can provide a palliative approach?			
5. A multidisciplinary team that promotes goal setting in collaboration with the family is critical to the success of a palliative approach. This approach decreases discomfort for residents, saves valuable resources and improves satisfaction levels for the family when they recall the care provided.	III-2 QE QS	45 43 37	1.4

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
DIGNITY AND QUALITY OF LIFE			
6. Care that enhances the dignity of the resident is part of a palliative approach and is a general therapeutic goal for all people who are dying. Factors that contribute to retaining dignity are: having adequate pain and symptom management, appropriate incontinence management, relieving burdens, achieving a sense of control, strengthening relationships with loved ones, having the capacity to communicate, being able to recognise friends and family members, and avoiding inappropriate prolongation of dying.	III-3 IV QE	47 45 46	2
7. Appropriate care that maintains a resident's dignity may lead to a more hopeful outlook for the resident at the end of their life, which reduces the desire for a hastened death.	IV QE	52 53	2
ADVANCE CARE PLANNING			
8. Advance care planning that is systematically implemented in an RACF and that involves communication between the resident, their family and the doctor increases the satisfaction of the resident and their family with end-of-life care. Advance care planning helps define the resident's wishes, which can then be clearly documented.	II II	58 62	3
9. Regular education programs for the aged care team, residents and their families on issues about end-of-life care and the completion of advance care plans increases the frequency of these plans being completed and implemented in RACFs, and increases satisfaction with end-of-life care.	II	58	3
10. Ongoing assessment is required to develop a comprehensive advance care plan that addresses all relevant issues as the resident's state of health changes over time.	II	58	3
ADVANCED DEMENTIA			
11. A palliative approach benefits the family as well as the resident, particularly when it incorporates continual follow-up evaluation, attention to distressing symptoms and avoidance of hospitalisation, and emphasises and promotes the resident's quality of life and dignity.	IV	75	4
12. Remaining in familiar surroundings is beneficial for residents with advanced dementia as this helps maintain their palliative care plans and promotes feelings of orientation and security.	III-2	71	4
13. Residents with advanced dementia can be assessed and treated for pain and discomfort with the use of dementia-specific assessment tools.	III-3	81	4

14.	The use of aggressive medical treatment of infections is not recommended for residents with advanced dementia. Instead, a palliative approach is recommended for the resident's comfort, which might include short-term antibiotic therapy to ease symptoms and improve quality of life.	III-2 III-2	72 31	4
15.	A policy of restraint-free care using a restraint minimisation program is considered best practice. Through education designed to change a facility's culture, such a program minimises the use of restraints and provides strategies for the removal of restraints.	II II	93 94	4

PHYSICAL SYMPTOMS—ASSESSMENT AND MANAGEMENT

Symptom assessment

16.	Residents and their families perceive good care with a palliative approach to include adequate relief of pain and effective symptom management.	QE	98	5.1
17.	Appropriate treatment plans are developed from a comprehensive assessment of the resident's needs, including early identification of their main symptoms.	QE	99	5.1
18.	The resident's own determination of the intensity of pain is considered to be the best assessment.	III-3	100	5.2

Pain management

19.	Pain management is enhanced by a comprehensive assessment of the resident's pain and evidence-based analgesic decision-making.	II	128	5.2
20.	The use of assessment tools for pain is more accurate than just asking the resident "Do you have pain?" For the resident who is unable to verbalise their pain, accurate reporting based on good observation skills using behavioural cues, by a skilled person, is particularly important for determining pain.	III-3	122	5.2

Fatigue

21.	Fatigue is the most frequently cited physical concern reported by people approaching death, and warrants attentive assessment.	QE	141	5.3
22.	Potential factors associated with fatigue include depression, anxiety, pain, a reduction in intermediate activities of daily living, number of medications, and physical function. These factors, therefore, need to be carefully assessed.	QE	140	5.3
23.	Suggested non-pharmacological methods for relieving fatigue, such as exercise programs and energy conservation, may be effective for people receiving a palliative approach.	IV	144	5.3

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
Nutrition and Hydration			
Nutrition			
24. As there are many causes for weight loss in residents, an assessment of the cause is required with a view to identifying inadequate nutrition and reversing the causes.	III-2	154	5.4
25. It is considered best practice for residents requiring a palliative approach to receive oral foods and fluids, even in minimal amounts, rather than enteral (nasogastric or PEG) feeding.	I	152	5.4
26. Weight loss, low albumin levels and postural changes (orthostatism) are associated with therapeutic diets, so these diets should be avoided whenever possible for RACF residents.	III-2	154	5.4
Hydration			
27. In order to formulate recommendations regarding fluid therapy, each resident's circumstances, including the wishes of the resident and their family, require assessment.	I	169	5.4
28. Frequent small sips of fluids can reduce the sensation of thirst and oral discomfort associated with dehydration.	IV	172	5.4
Cachexia			
29. A diagnosis of cachexia can be made from the resident's clinical history, presence of substantial weight loss, laboratory tests and physical examination.	II	176	5.5
30. Residents should be encouraged to have as many calories orally as possible. For the frail resident, a trial of single nutrients or liquid meal replacements is warranted before more invasive techniques are used.	III-2	154	5.6
Dysphagia			
31. A formal multidisciplinary assessment program may be beneficial in promoting early recognition, appropriate management and prevention of complications associated with dysphagia.	III & IV	180	5.8
32. To provide effective dysphagia management for residents at risk of swallowing problems, a multidisciplinary team approach is required, including input from a speech pathologist.	III & IV	180	5.8
33. The aged care team should ensure that the texture, consistency and type of food and fluid are as prescribed.	III & IV	180	5.8
34. The aged care team should ensure that feeding techniques are undertaken in accordance with the specific methods recommended by the speech pathologist or physician, and they should also be aware of the safe feeding techniques generally recommended for individuals with neurogenic dysphagia.	III & IV	180	5.8

GUIDELINES		LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
Mouth care				
35.	Oral complications can be reduced by good hygiene, regular assessment, cleansing of dentures and use of oral fluids.	QE	186	5.9
36.	Asking an older person "How would you describe the health of your teeth and gums? Would you say it is excellent, very good, good, fair or poor?" is an accurate way to identify individuals with any denture-related needs, as well as those who do not need dental care. It is recommended that this question be included in oral health assessments as a reliable basis for determining when to refer for further evaluation and dental treatment.	III-3	187	5.9
37.	The most effective oral cleansing routine is rinsing with water and cleansing with a soft toothbrush and toothpaste. Dentures require regular soaking in a weak non-toxic solution.	II	191	5.9
38.	A multidisciplinary approach to oral health is preferable, with collaboration between the aged care team, dental services, occupational therapists and dieticians to ensure that members of the aged care team are supported in their practice of oral care for residents.	QE	182	5.9
Skin integrity				
39.	The use of air-fluidised and low-air-loss mattresses is effective in the reduction of ulcers.	I	193	5.10
Bowel care				
40.	A daily assessment of bowel function is required. Management decisions may take account of the resident's preferences for treatment and their history of bowel habits.	III-3	197	5.11
41.	A discussion between the doctor and nursing staff to decide on the most appropriate laxative for use with a resident should be encouraged.	II	198	5.11
42.	The combined use of bulk laxatives and suppositories is associated with the lowest rates of faecal incontinence. The use of the suppository *after* bowel clearing prevents recurrent constipation.	II	198	5.11
43.	If a laxative is used, compensatory measures for dehydration and electrolyte depletion are recommended.	II	198	5.11

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
Dyspnoea			
44. A complete history and physical examination will generally provide enough information to determine a diagnosis of dyspnoea. The history should cover factors that are likely to have influenced the severity of the symptom, including pre-existing illnesses (such as chronic obstructive pulmonary disease), exacerbating factors (such as anaemia or profound anxiety) and additional factors (such as pulmonary embolism, infection or left ventricular failure).	II	201	5.12
45. Non-pharmacological interventions based on psychosocial support, controlled breathing and learned coping strategies can help people cope with dyspnoea, which will further reduce physical and emotional distress.	II II	201 206	5.12
46. People with dyspnoea can benefit from the use of a sustained-release low-dose oral morphine administered orally or parenterally.	I II	204 200	5.12
47. A comprehensive plan of care, including ready access to appropriate medication treatment along with non-pharmacological interventions to reduce psychological distress, may prevent residents with gradually increasing dyspnoea being transferred to hospital unnecessarily.	IV	202	5.12
Complementary and alternative therapies			
48. In general, complementary and alternative therapies for symptom management in palliative care are beneficial for those who refuse or cannot tolerate pain medications in enhancing their sense of control and cultural sensitivity.	II	208	5.13
49. The combination of traditional analgesic treatments with acupuncture, TENS, relaxation and imagery, and hypnosis are helpful in symptom management.	II	208	5.13
50. To treat the underlying causes of dyspnoea (for people with moderate to severe breathing difficulties) and to improve functional capabilities (e.g. walking), the use of acupuncture, acupressure, muscle relaxation with rebreathing training, and rebreathing training combined with coping strategies are considered to have a beneficial effect.	II	208	5.13
51. An aromatherapy intervention to treat agitation and neuropsychiatric symptoms in people with dementia can have positive effects.	II	209	5.13
52. A massage with essential oils is beneficial for reducing anxiety and improving quality of life when used with people receiving a palliative approach.	III-1	210	5.13
53. The use of ginkgo for older persons with mild to moderate dementia is not recommended as it was found to be an ineffective treatment.	II	214	5.13

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
PSYCHOLOGICAL SUPPORT			
Depression			
54. Using a Geriatric Depression Scale (GDS) to screen for depression can increase the frequency of treatment or referral of residents in RACFs by their doctors.	II	228	6
55. Although suicide attempts or requests may seem understandable, they are often an indication of clinical depression and require an active response.	IV	52	6
Anxiety			
56. Gentle massage can reduce anxiety levels or agitated behaviours for residents with chronic pain and/or dementia.	III-2	242	6
Delirium			
57. Using the standardised confusion assessment tool is recommended for residents with delirium as it enables non-psychiatric clinicians to quickly detect delirium in older persons.	III-2	245	6
Dementia			
58. Many residents can answer questions on their quality of life even when significant symptoms of dementia are present. Therefore a resident's preferences for quality of life concerns should still be sought and incorporated into decision-making.	IV	247	6
Psychological distress			
59. Incorporating the use of a specialised palliative team who have some expertise in assessment and care of those with depression, agitation, loss and/or anxiety is considered beneficial.	QE QE	221 249	6
FAMILY SUPPORT			
60. The family may play a particularly important role in assisting with managing symptom distress, communicating with the resident, and assisting with their physical care needs.	III-2	253	7
61. Deteriorating health and the death of the resident may impact on the physical and emotional health of family members. Therefore the family members' stress requires monitoring by the aged care team.	III-2 III-2	253 257	7
62. Families appreciate good communication with the aged care team, affirmation from the team that the family's input is valued, and permission to withdraw at times from the caregiving situation.	QE QE	254 255	7
63. Families benefit from emotional support and an opportunity to discuss their concerns about the resident's illness or ageing process. This support can be provided during a family conference.	III-2 QE QE QE	257 258 261 267	7

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
SOCIAL SUPPORT, INTIMACY AND SEXUALITY			
Social support			
64. A lack of social support may lead to deteriorating psychological wellbeing, depression and diminished functional health. Therefore, a thorough assessment of the resident's social network is required, including the resident's perceptions, appraisal and interpretation of what contact is most important to them.	III-2 IV	278 279	8
Intimacy			
65. The use of comfort touch (e.g. massage, hand holding) by a member of the aged care team can enhance the resident's sense of wellbeing and self-regard.	III-2	284	8.1
Sexuality			
66. Rather than denying the existence of residents' intimacy and sexuality needs, the aged care team needs to acknowledge the importance of this area of resident care.	QE	283	8.2
ABORIGINAL AND TORRES STRAIT ISLANDER ISSUES			
67. Respectful attention to the individual needs of Indigenous residents, taking into account beliefs regarding illness, healing, comfort, care practices, location of care, and death and dying is needed in a palliative approach to residential aged care.	QE	118	9
68. Aboriginal health workers, liaison officers, other Indigenous Australian health care practitioners and community organisations have important knowledge about local cultural values and individual situations. When developing protocols and when working with individual Indigenous Australian residents it is beneficial to involve them.	QE	118	9
69. Communication with Indigenous Australian residents in their own language enhances understanding and attention to their needs. Regular reviews of these residents' needs are required, as their needs may change.	QE	118	9
CULTURAL ISSUES			
70. Understanding care preferences of cultural groups is important in a palliative approach, and efforts to accommodate these promote individualised care for the resident.	QE QE	299 294	10
71. Where possible, information about a palliative approach should be provided to the resident in their own language as this enhances cultural sensitivity for culturally and linguistically diverse residents and their families.	II III-2	297 295	10

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
SPIRITUAL SUPPORT			
72. A palliative approach supports residents and families to express their unique spirituality. Respecting their privacy and providing an opportunity for them to continue their spiritual practices enhances a resident's spiritual care and quality of life, as does spiritual counselling.	QE QE QE QE	303 304 307 308	11
73. Understanding the resident's current or desired practices, attitudes, experiences and beliefs by obtaining a comprehensive history helps meet the spiritual needs of the resident, as does a regular review.	III-2 QE QE	257 303 307	11
74. The aged care team is encouraged to respond in an open, non-judgemental manner to residents' questions relating to spiritual matters. Involving a chaplain or pastoral care worker with experience and knowledge about these issues is considered best practice.	QE	303	11
VOLUNTEER SUPPORT			
75. Trained volunteers can be integrated into multidisciplinary teams to help provide a palliative approach for residents.	QE QE	310 311	12
76. Volunteers who are part of a multidisciplinary team providing a palliative approach require ongoing support and education from a trained coordinator of volunteers.	QE	311	12
77. Suitably screened and matched volunteers may act as a companion and confidant to the resident and their family. All those involved consider that this support is valuable.	QE QE	310 314	12
END-OF-LIFE (TERMINAL) CARE			
78. Family caregivers need to be advised that the changes their family member may experience in the end-of-life phase (e.g. noisy breathing) are a normal part of the dying process. Families should be reassured that their relative is not necessarily distressed by these changes.	II	201	13
79. Well-planned family conferences, conducted in private and attended by the GP and other members of the aged care team, provide an opportunity for building trust and discussing end-of-life issues of concern.	III-2	257	13

GUIDELINES	LEVEL OF EVIDENCE	REFERENCE	CHAPTER/ SECTION
BEREAVEMENT SUPPORT			
80. Members of the aged care team can experience loss following the death of residents with whom they have established meaningful relationships. Therefore the team should be provided with opportunities to formally acknowledge the loss, and have access to adequate bereavement support. Even members who have experienced many deaths might still require access to these support services.	QE IV	345 346	14
81. A memorial service is a valuable resource which facilitates the grieving process for residents, family members, the aged care team and volunteers.	QE	340	14
82. The more social support a family has access to, the better their ability to cope with the bereavement of their family member will be. However, it is the quality of the support rather than the quantity that enhances this resilience.	III-3 QE	342 343	14
MANAGEMENT'S ROLE IN IMPLEMENTING A PALLIATIVE APPROACH			
83. Formal management systems will support the introduction and maintenance of a palliative approach through the allocation of appropriate resources.	QE QE QE	6 351 354	15

CHAPTER 1

A palliative approach

A society's philosophical beliefs and attitudes about death and dying, and a palliative approach, will affect the provision of guidelines for this type of care. This chapter examines some of the key beliefs and attitudes that may influence a palliative approach.

In most western societies, any discussion of death and dying creates discomfort.[10] 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. These barriers may make it more difficult for members of the aged care team to provide care for residents who are dying. Therefore, RACFs who try to adopt a palliative approach to care for residents may feel challenged to overcome some of the 'death-denying' attitudes pervasive in the wider culture.

At the same time, people entering RACFs are increasingly frail. Authors of a recent Australian study projected a 70% increase over the next 30 years in the number of older persons with profound disabilities, particularly for those aged 65 years or older[5] (Level QE). The main conditions for older persons with profound disability are neurological, musculoskeletal, circulatory and respiratory conditions. Stroke also severely debilitates. Mild to moderate disabilities are associated with poor vision and hearing, psychiatric disorders and cancer. Residents are likely to have more than one of these disabilities and their management is therefore likely to be complex. These disabilities significantly restrict daily activities such as self-care, mobility and communication. A major increase in the number of people aged 75 to 94 with a profound restriction is also projected to occur from 2011 to 2021. This increase is expected to have major implications for care delivery.

1.1 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.

(i) A palliative approach

When the resident's condition is not amenable to cure and the symptoms of the disease require effective symptom management, a *palliative approach* is appropriate. Providing active treatment for the resident's disease may also still be important and may be provided concurrently with a palliative approach. However, the primary goal of a palliative approach is to improve the resident's level of comfort and function, and to address their psychological, spiritual and social needs.

(ii) Specialised palliative service provision

This form of palliative care involves referral to a specialised palliative team or health care practitioner. However, this does not replace a palliative approach but rather augments it with focused, intermittent, specific input as required. The goals are:

- assessing and treating complex symptoms experienced by the resident; and
- providing information and advice on complex issues (e.g. ethical dilemmas, family issues, or psychological or existential distress) to the aged care team.

(iii) End-of-life (terminal) care

This form of palliative care is appropriate when the resident is in the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on the resident's physical, emotional and spiritual comfort, and support for the family.

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 1.2.1, '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[11] (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[12] (Level QE).

McGrath 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[11] (Level QE). 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[13] (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.

1.2 WHEN SHOULD A PALLIATIVE APPROACH BE IMPLEMENTED?

Unlike people who are dying of cancer, residents in RACFs generally have a gradual decline in functional ability, so[15] there is usually no sharp delineation between curative care and the acceptance that the goal of care is palliation. 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.[14] However, 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.[16]

The aged care team needs to understand that the transition from curative care to a palliative approach is important for residents. More attention should be paid to these transitions and the decisions that residents, their families and care teams are called upon to make.[17] Such timely recognition provides an opportunity for tailored support for residents and their families.[18] Some residents (and/or family) may accept a palliative approach much earlier in a disease trajectory or the ageing process. Alternatively, a resident may not be able or willing to decide upon one course of action over another and this could hinder a decision about which is the most appropriate. A discussion with the resident's family would be beneficial in such situations.

Although the discussion of a palliative approach may be difficult or unfamiliar to some members of the aged care team, it is important that the decision to consider a palliative approach should be made in collaboration with the resident, the family and the team. 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.[19] (The process of discussing care plans is elaborated upon in Chapter 3, 'Advance care planning'.)

Families are frequently concerned about pain control.[20] As well, families need information about the prognosis, trajectory of the condition and care decisions that need to be made[20] (Level QE). Families and residents should be left in no doubt that symptoms such as pain and

nausea can usually be controlled, provided there is continuous access to care. A combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach is considered best practice[21] (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[21] and facilitate continuity of care.

In one of its publications, Palliative Care Australia recommends four straightforward steps to providing continuity of care.[22] The following recommendations have been adapted from this document:

1. Should referral to a specialist palliative service be appropriate, then this should be timely and preferably not in response to a crisis.
2. Should acute care be appropriate, then the resident's admission to acute care should be quick and straightforward.
3. The resident and families should have access to the same aged care team, wherever possible, to promote continuity of care and coordinated care delivery.
4. The resident's team leader or suitable delegate should centrally coordinate care provided by external services to the RACF.

1.2.1 Prognostication

Prognosis and survival time are profoundly linked, yet the methods used to identify survival time have limitations in accuracy and precision[23] (Level I). These methods are, therefore, not recommended.

An alternative method involves using a set of 'trip wire' questions that can help determine when to introduce a palliative approach with residents of RACFs. This could be in the form of an ongoing review or dialogue among the aged care team, family members and the resident.

The questions might include:

1. Does the resident and/or the family choose treatment goals directed towards the relief of symptoms, rather than curing the underlying disease?
2. Has there been a new diagnosis? Significant diagnoses might include cancer, dementia, multiple sclerosis, motor neurone disease, stroke or heart failure.
3. Has the resident had a recent decline in functional status (e.g. bathing, dressing, mobility, verbal communication, energy level, and mood)?

At some point the severity and number of symptoms may increase, with the resident's condition rapidly deteriorating. These situations may not allow for slower-paced discussions with the resident and their family. Nevertheless, the principles of symptom management should be followed to ensure that the resident is able to receive optimum comfort and relief of symptom distress (see Chapter 5, 'Physical symptom assessment and management'). Regular communication with the resident's other care providers becomes particularly important, and documentation of who is involved in providing care needs to be current.

Members of the aged care team also need sound interpersonal skills and good listening abilities to help the resident talk through issues such as their wishes and hopes for the future in the context of their advancing illness. The transition through the decision-making process may also be stressful and the resident and family should ideally be involved in this process. Conflict between the resident and family members may surface or may even be exacerbated during these times. 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[24] (Level QE). However, the views of the family are also relevant and need to be understood[25] (Level EO).

Guideline: When should a palliative approach be implemented?

		Level of evidence	Reference
1.	Methods used to identify survival time have limitations in accuracy and precision, and are therefore not recommended. Rather, a combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach is considered best practice.	I IV	23 21

1.3 WHERE CAN A PALLIATIVE APPROACH BE PROVIDED?

A palliative approach can be used in any setting,[26] and should ideally be provided wherever people who require this approach reside. Therefore, RACFs may be an appropriate care setting because residents in RACFs face many of the same issues as others with a life-limiting condition[27] (Level QE).

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[27] (Level QE);[28] (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 they had provided and/or were providing a palliative approach to approximately 10% of their residents[29] (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.

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 of a South Australian study as the probable reason for the finding that rural terminally ill cancer patients were less likely to receive a palliative approach (59% compared to 71%) [30] (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.

The type of RACF, and especially the range of medications that can be provided, tempers the capacity for assessment and the provision of a palliative approach. If the RACF is a low-care facility then the aged care team (including GPs) needs to be aware of the restrictions that occur when providing S8 medications to control symptoms. (These vary to some degree throughout Australia and therefore no generic statement can be made regarding this point.)

1.3.1 Transfers/discharges of residents requiring a palliative approach

Without the support of appropriate protocols and procedures, especially at night, the aged care team is likely to choose referral to acute settings rather than attempting a palliative approach in an RACF[28] (Level QE). A study of the provision of a palliative approach in RACFs found that a third had transferred or discharged a resident requiring a palliative approach to another facility or the community (76% to an acute hospital, 14% to a hospice, and 8% home, to their homeland or to a different city)[6] (Level QE).

The main reason for these transfers or discharges was that the resident needed expert or acute care or extra resources (57%). The lack of resources was attributed to such factors as a lack of time, low staff-resident ratios, insufficient nursing and personal care hours, and a lack of education and training for all the aged care team (including GPs and volunteers). However, where adequate skilled care is available in the resident's familiar surroundings, the aged care team and GPs need not transfer or discharge residents to other settings[31] (Level III-2). Therefore, adequate support and education for the aged care team is considered essential to reducing the inappropriate transfer or discharge of residents requiring a palliative approach in the RACF.[6, 14, 28]

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[33] (Level IV). The NHMRC recommends that people should be encouraged to make their own decisions concerning medical interventions or approaches to care.[9] This recommendation should also apply to residents in RACFs. To facilitate participation in decision-making, the resident (and/or their family) should be given adequate information in a way that promotes understanding. Family members report greater satisfaction with the care their relative receives if they perceive that either they or their relative had control of care decisions[32] (Level QE).

Giving information about a palliative approach may also help residents and their families to consider a palliative approach as active care rather than the withdrawal of treatment[34] (Level QE). However, the reverse is also true when residents are transferred from acute care settings to an RACF. 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[35] (Level QE). Before such a transfer, it will usually be necessary to explain to the family that good care with a palliative approach is available in RACFs.

A palliative approach in RACFs provides opportunities for intervention, especially improved control of pain symptoms and terminal care of residents with greater functional disability, in a setting that is familiar to them and their family[36] (Level QE). Anecdotal evidence also suggests that many directors of nursing actively encourage residents requiring a palliative approach to remain in the RACF rather than transferring them to an acute setting.[6, 26] These decisions are usually based on the resident's familiarity with the aged care team and the facility, adequate care already being provided in the RACF, a request from the resident, their family or the GP, or a lack of hospice beds.[6, 28]

A palliative approach can usually be provided in an RACF.[6] This offers benefits to the resident and family through consistency and continuity of care. In some instances there may be a need for intermittent specialised palliative support when residents have complex symptoms or the aged care team requires additional support. However, this consultation can often occur while the resident remains in the RACF.

Guidelines: Where can a palliative approach be implemented?

		Level of evidence	Reference
2.	Implementing a palliative approach in RACFs can reduce the potential distress to residents and their families caused by a transfer to an acute care setting.	QE	34
3.	A palliative approach can be provided in the resident's familiar surroundings if adequately skilled care is available.	III-2	31
4.	Providing information about a palliative approach may help residents and their families to consider a palliative approach as active care rather than withdrawal of treatment.	QE	34

1.4 WHO CAN PROVIDE A PALLIATIVE APPROACH?

A palliative approach requires a multidisciplinary team, which is consistent with current aged care practices in RACFs. A team approach to care planning facilitates the aged care team in providing an appropriate palliative approach for residents and allows for discussion of treatment plans, including the potential benefits and disadvantages of treatment decisions[37] (Level QS).

1.4.1 What is a 'multidisciplinary team'?

A multidisciplinary team is a group consisting of three or more people from different disciplines who collaborate in making decisions about all aspects of diagnosis, treatment and care of residents and their families. Multidisciplinary teams can provide support and symptom control to improve the quality of both living and dying for residents and their families through a palliative approach. This multidisciplinary approach is critical to the success of a palliative approach because the wide variety of forms of distress experienced by residents and their families requires a broad range of skills.[37]

The multidisciplinary team focuses its efforts on addressing the problems that are of most concern to the resident. Barriers to appropriate treatment, such as confusion over pain medications, whether a facility has access to requisite medications, and uncertainty about the benefits of treatment, can also be addressed.

1.4.2 Who are potential members of a multidisciplinary team?

Potential members of a multidisciplinary palliative team[38] (Level QE) might include, but are not limited to:

- Care assistants;
- General practitioners (GPs);
- Generalist nurses (i.e. Registered Nurses (RN), Enrolled Nurses (EN));
- Specialist nurses (e.g. continence, wound care, palliative care, nurse practitioners);
- Aboriginal health workers;
- Volunteers and coordinators of volunteers;
- Pharmacists;
- Chaplains/pastoral care workers;
- Recreational activities officers (these aged care team members are commonly used in RACFs and have considerable direct contact with residents);
- Pain specialists;
- Allied health practitioners (e.g. occupational therapists, physiotherapists, speech pathologists, social workers, diversional therapists, dieticians, music therapists and podiatrists);
- Specialist physicians (e.g. surgeons, neurologists, geriatricians, oncologists, wound care specialists and radiotherapists);
- Community palliative services; and
- Psychologists/psychiatrists.

The resident and their family, as well as being recipients of care, if willing, are also essential members of the palliative team.

1.4.3 How should a multidisciplinary team function?

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)[39] (Level QE). Depending on their roles, different members of the team have varying perceptions of a palliative approach, necessitating cooperation and good communication among members[40] (Level IV). Effective communication and teamwork are considered by nurses and GPs working in RACFs to be essential aspects of a palliative approach[20] (Level QS).

Effective multidisciplinary teams are able to articulate common goals and work in a collaborative, non-hierarchical environment. [41] They meet regularly to assess and discuss progress and are able to devise protocols for providing a palliative approach.[37, 42]

1.4.4 Staffing skill mix

There is no sound evidence on the minimum number of representatives from each discipline (nursing, social work, pastoral care, etc) needed to develop a palliative approach. RACF managers should determine the skill mix and allocated hours of the aged care team, taking into consideration the level of dependency of residents, the complexity of needs, and the availability of external palliative care services. Given that a palliative approach, rather than specialised palliative care teams is more appropriate for RACFs, alternate models and approaches about how to create a palliative approach or access palliative care expertise for different RACFs is likely to be the best approach.

One approach is the creation of a palliative nurse practitioner role in RACFs[43] (Level QE). A palliative nurse practitioner is a suitably qualified RN experienced at an advanced level who provides a leadership role and coordinates clinical consultation and care to residents of RACFs, their families and members of the palliative team.[43] In one study, a 'link nurse' was also established to facilitate continuity of care in the RACF. A link nurse was defined as a nurse who is interested in, has received training in, and pursues continuous education in a palliative approach.[43] This nurse is not expected to be an expert in a palliative approach, but understands the philosophies and practices of palliative care, and will promote and facilitate the care of residents in the RACF to ensure an appropriate palliative approach is provided. In the study referred to, an evaluation of the service at six months indicated that 17 residents that previously would have been transferred to an acute care facility were able to die at the RACF.[43]

Despite variations in RACFs, Maddocks and colleagues [43] recommend that, at the minimum, one member of the aged care team (preferably an RN) should have some formal qualification in a palliative approach. This level of training and expertise would also assist the aged care team ensure staff receive adequate direction and supervision and that accurate symptom assessment, using validated assessment tools, occurs (see also Section 5.1, 'Symptom assessment'). Ideally, all aged care teams in RACFs should have sufficient training to apply the sensitive interpersonal communication required for a palliative approach that improves the level of satisfaction of residents and their families[31] (Level III-2).

Guideline: Who can provide a palliative approach?

		Level	Reference
5.	A multidisciplinary team that promotes goal setting in collaboration with the family is critical to the success of a palliative approach. This approach decreases discomfort for residents, saves valuable resources and improves satisfaction levels for the family when they recall the care provided.	III-2 QE QS	45 43 37

CHAPTER 2

Dignity and quality of life

Promoting a person's sense of dignity is central to a palliative approach,[44] and dignity and quality of life are inextricably linked in this approach. Several researchers have explored what people's views on quality of life mean to them as their death approaches. 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[45] (Level QE).

2.1 DIGNITY

Researchers also highlight the difficulty in describing and evaluating the concept of 'dying with dignity'. In one study, the authors note three important factors of dignity: the capacity to communicate, the ability to recognise friends and family members, and being continent[46] (Level IV).

People may hold different views about what dignity means, and in the face of a progressive illness or the ageing process the meaning of dignity may change over time. It is also important to note that the aged care team's perception of dignity may differ from the resident's view. The best way to understand what dignity means for an individual resident is to ask each resident and their family what are the most important factors for him or her in regard to dying with dignity. The aged care team members who endeavour to respect the dignity of residents need to acknowledge the things that are considered important to the individual in enhancing and maintaining their dignity.

Chochinov and colleagues[47] (Level III-3) have undertaken the most thorough empirical work in relation to understanding the concept of dignity in the context of a palliative approach. This research team identified a Dignity-Conserving Care Model for a palliative approach that is aimed at helping the individual to feel valued. The framework can be used to discuss end-of-life care when residents are able to make informed decisions and develop a sense of closure. Chochinov[48] (Level EO) argues that the notion of dignity may be influenced by the nature of the illness, as well as by culture and ethnicity. The framework his team has described is sufficiently broad to encompass these issues. Chochinov and colleagues[47] (Level III-3) also argue that the resident, family members and the aged care team may define dignity differently; they advise the aged care team to be alert to whose perspective of dignity is being considered.

A 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[47] (Level III-3). Illness/ageing related concerns are those things that directly result from the illness or ageing progression (see Table 1). Dignity-conserving strategies are those influences related to the

resident's psychological and spiritual resources (see Table 2). Finally, the social dignity inventory includes those environmental influences that can affect dignity, such as privacy boundaries, social support, and concerns of being a burden (see Table 3)[47] (Level III-3). The following tables indicate the factors that contribute to undermining a resident's dignity. Included are questions that can be asked to determine the resident's concerns as well as therapeutic interventions to help promote their dignity.

Table 1: A practical model of dignity-maintaining interventions regarding illness and ageing considerations

Illness/ageing-related factors	Dignity-related questions	Therapeutic interventions
Symptom of distress:		
• Physical distress	• Is there anything we can do to make you more comfortable?	• Vigilance to symptom management • Frequent assessment • Application of comfort care
• Psychological distress	• How are you coping with what is happening to you?	• Be supportive • Empathic listening • Referral to counselling • Volunteer support
• Medical uncertainty	• Is there anything more you would like to know about your illness/ageing?	• Upon request, provide accurate, understandable information
• Death anxiety	• Are there things about the later stages of your illness/ageing that you would like to discuss?	
Level of independence:		
• Independence	• Has your illness/ageing made you more dependent on others?	• Involve residents in decision-making regarding both medical and personal issues.
• Cognitive acuity	• Are you having any difficulty with your thinking?	• Treat delirium • When possible, avoid sedating medication(s)
• Functional capacity	• How much are you able to do for yourself?	• Use orthotics, physiotherapy and occupational therapy

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Table 2: A practical model of dignity-conserving interventions regarding psychological and spiritual considerations

Illness/ageing-related factors	Dignity-related questions	Therapeutic interventions
Perspectives:		
• Continuity of self	• Are there things about you that you consider are not affected by your physical deterioration or limitations?	• Acknowledge and take interest in those aspects of the resident's life that they value most • See the resident as worthy of honour, respect and esteem
• Role preservation	• What things did you do before that are important to you?	
• Maintenance of pride	• What aspects about yourself or your life are you most proud of?	
• Hopefulness	• What things can you still do?	• Encourage and enable the resident to participate in meaningful or purposeful activities
• Autonomy/control	• How in control do you feel?	• Involve the resident and/or their family in treatment and care decisions
• Generativity/legacy	• How do you want to be remembered?	• Making a life album i.e. audiovisual or photographic journal
• Acceptance	• How at peace are you with what is happening now?	• Support the resident in their outlook • Encourage them to do things that enhance a sense of wellbeing, e.g. music, prayer, meditation, light exercise
• Resilience/fighting spirit	• What part of you is strongest right now?	
Practices:		
• Living in the moment	• Are there things that take your mind away from your physical concerns/ limitations, and offer you comfort?	• Allow the resident to participate in normal routines or take comfort in momentary distractions, e.g. massage, meditation, patting animals
• Finding spiritual comfort	• Is there a religious or spiritual community that you are, or would like to be, connected with?	• Make referrals to a chaplain or pastoral care worker (see Glossary for explanation) • Enable the resident to participate in particular spiritual and/or culturally based practices

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Table 3: A practical model of dignity-conserving interventions regarding social considerations

Illness/ageing-related factors	Dignity-related questions	Therapeutic interventions
• Privacy boundaries	• What is it about your privacy or your body that is important to you?	• Ask permission to examine the resident • Proper draping to safeguard and respect privacy
• Social support	• Who are the people that are most important to you?	• Liberal policies about visitation, rooming in • Enlist the involvement of a wide support network
• Care tenor	• Is there anything in the way you are treated that is undermining your sense of dignity (or that makes you feel 'bad' or 'dirty')?	• Treat the resident as worthy of honour, esteem and respect; adopt a manner of conveying this
• Burden to others	• Do you worry about being a burden to others? If so, to whom and in what ways?	• With the resident and/or their family, encourage explicit discussion about these concerns with those they fear they are burdening
• Aftermath concerns	• What are your biggest concerns for the people you will leave behind?	• With the resident and/or their family, encourage the settling of affairs, preparation of an advanced care plan, making a will, and funeral planning

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2.2 QUALITY OF LIFE

Quality of life is similar to the notion of dignity, in that it defies clear definition and yet is frequently described as an essential aim of a palliative approach. An appropriate definition for quality of life pertaining to older persons requiring a palliative approach is the one devised by the WHO Quality of Life Group:[49, p.153]

> *"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."*

Quality of life measures usually include questions regarding the physical, social, psychological and spiritual domains. Other issues, such as sexual function, body image and financial concerns, may be incorporated as well.[50]

The following story indicates the need to always seek the resident's views on their care decisions and how they perceive their current quality of life. Although family views should also be considered, the most important person in a palliative approach is the resident.

James

James, an 89-year-old war veteran, came into the high-care facility with one leg having been amputated several years before. Now ischaemic heart disease and other medical complications indicated his life expectancy was short. When the telltale signs of poor circulation appeared in his other leg, a family meeting was called. "He couldn't take another operation", was the opinion of one son. "Can't you just keep him comfortable?"

It was very difficult to keep James comfortable, because the pain was severe. No one at that stage had thought to ask James, who appeared to be increasingly miserable, refusing to get out of bed. The family and the aged care team agreed that he had "no quality of life". As the pain increased the doctor presented James with the options: "We could operate but it would mean another amputation." James said, "Well, I'd rather have that than the pain. The pain is killing me!" James's post-operative recovery was uneventful, he ventured into using his self-propelling wheelchair again, his sense of humour returned, and he lived for several more months.

If a resident makes a statement that reflects a desire for hastened death, then it is essential that this remark is comprehensively explored by a suitably qualified member of the aged care team, as illustrated by the stories of both James and Robert (below).

2.3 'DESIRE TO DIE' 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 team may find themselves grappling to determine if the resident is depressed, suicidal or seeking help to hasten death; or they may believe the expressed wish is an understandable response to the resident's circumstances.[51] Occasional thoughts of suicide are not uncommon in palliative settings[52] (Level IV). However, sustained suicidal ideation is less common and all statements of this nature warrant care and attention[53] (Level QE).

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

- feelings of hopelessness, depression, guilt, unrelieved suffering and a wish for self-punishment[54] (Level EO);
- a perception of being a burden to others, anxiety, existential distress and family issues[55] (Level EO);
- a sense of loss of dignity and a perceived lack of control[56] (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 bring about a more hopeful outlook for the resident, even at the end of their life[52] (Level IV).

Robert

Robert continually stated he wanted to die, refusing to eat and being reluctant to cooperate with any care offered. Eventually he was transferred to hospital for full investigation and advice regarding his ongoing care. No physical cause could be found for his wish to hasten death, although it was clear his weight loss and reluctance to accept care would lead to life-threatening complications. He was returned to the facility 'for a palliative approach'. A sensitive and discerning RN invited Robert to the care planning meeting she'd arranged with Robert's doctor and his family. On careful questioning it became clear that Robert was grieving for his wife, who had recently died. He was also angry that he had not been permitted to attend his wife's funeral, family and staff having decided he was too ill. When asked what his wishes were for the remainder of his life, he was quite clear. He wished to visit his wife's grave, he wanted the "damn catheter out" and did not want to be forced to eat. When these wishes were met, together with appropriate pain relief for symptoms recently developed, Robert stopped his saying "I want to die" and became less distressed.

2.4 PRIVACY AND CONFIDENTIALITY

It is important to ensure that the aged care team maintains the privacy and confidentiality of the resident as much as possible. This can be difficult when family members demand to know private information pertaining to the resident. Therefore, the aged care team need to have an understanding of the relevant State and Commonwealth legislation, regulations and instruments concerning privacy so they can be informed as to their legal responsibility to ensure that the resident's information remains private and confidential. Examples of legislation, regulations and instruments include the Privacy Amendment Act (Private Sector) (2000), the Freedom of Information Act (1986), professional codes of conduct and Registration Acts.

In Australia no medical services can be provided without the consent of the person concerned. This consent is considered informed consent when the person assents 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 (see Appendix F).

Although residents with the capacity for informed decision-making must have the right to privacy and confidentiality regarding their health care information and the right to exclude their family members, it is rarely appropriate to exclude appropriate members of the family from acting as the commonsense advocate for vulnerable older persons. *The Guidelines on Privacy in the Private Health Sector* (available at www.privacy.gov.au/publications) allow disclosure of health information to a 'responsible person' (e.g. family member) when this is necessary for care and treatment or on compassionate grounds. The aged care team can use professional judgement when defining the responsible person to ensure that anxiety about privacy laws are not used as a means of excluding caregiving family and friends from appropriate health information.

Care should be taken to ensure that all the steps are documented regarding a resident's treatment decisions. These decisions need to be regularly assessed to ensure that they are current for the resident. It is also important that the aged care team be guided by legislation and other relevant documents and standards regarding what should be recorded on the resident's file, who should have access to these records, and how these documents are to be stored.

Guidelines: Dignity and quality of life

		Level	Reference
6.	Care that enhances the dignity of the resident is part of a palliative approach and is a general therapeutic goal for all people who are dying. Factors that contribute to retaining dignity are: having adequate pain and symptom management, appropriate incontinence management, relieving burdens, achieving a sense of control, strengthening relationships with loved ones, having the capacity to communicate, being able to recognise friends and family members, and avoiding inappropriate prolongation of dying.	III-3 IV QE	47 45 46
7.	Appropriate care that maintains a resident's dignity may lead to a more hopeful outlook for the resident at the end of their life, which reduces the desire for a hastened death.	IV QE	52 53

CHAPTER 3

Advance care planning

Care of any type involves decisions about how to actively pursue treatments, which treatments to accept, and which treatments to refuse. These decisions take on greater complexity in RACFs, where some residents may feel uncertain about discussing treatment options. An advance care plan is an interactive process of communication between a competent resident and the aged care team. 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[58] (Level II). Advance care planning does not have to be a legalised formal process. It should revolve around ongoing communication with the resident and/or family, as communication is the fundamental principle of advance care planning.

The *Code of Ethics and Guide to Ethical Conduct for Residential Aged Care* [57] states that providers should "... act in the best interests of residents in determining, particularly before admission, whether or not the organization has the capability of providing them with care appropriate to their needs" (p.9). The Code also emphasises the right of residents to make choices about their care, including the right to refuse or agree to treatments offered. This code is beneficial in providing the aged care team with direction regarding how to care for residents, their families and carers. Another beneficial guide has been developed by the New South Wales Department of Health, which is entitled *Guidelines for Decision Making at the End of Life.* (Please note; these two documents are not research-based but reflect expert opinion).

3.1 IMPLEMENTING ADVANCE CARE PLANNING

Advance care planning empowers the individual to state their wishes in writing, in accordance with how they define quality of life[45] (Level QE). By doing so, the burden of responsibility is removed from the surrogate and control is maintained by the resident. When residents are unable to express their own views regarding treatment, it is important for families to be involved in all decisions about ongoing care, including the acceptance or refusal of certain treatments. If these discussions do not occur, treatment decisions may be made by 'default', resulting in unnecessary transfers to acute care settings or other interventions that may not be in accordance with the goals of the aged care team and/or the family.

As with preparation of a will, these discussions can never occur too early, and having a discussion about advance care planning before admission to an RACF is an excellent first step. If this preliminary discussion has not occurred, a discussion will need to be initiated at the time of admission. At this time, there may be special considerations if the resident is no longer able to make their wishes known (see Chapter 4, 'Advanced dementia'). Ongoing discussion and updating of perceptions and wishes relating to advance care planning are also essential, as they help ensure that communication on these matters remains current.

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[59] (Level QE). Advance care planning documents vary considerably[59] (Level QE). 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.[60] (For examples of some advance directives see Appendix E.)

The following story illustrates how knowledge of a resident's preferences for treatment options can facilitate care plans.

Mrs Adams

Mrs Adams had lived alone, suffering from a chronic, degenerative condition and requiring frequent hospitalisation over many years. When she could no longer care for herself at home she made her wishes quite clear after admission to the high-care facility. "If I'm ever in the position where I can't answer for myself please take me to my hospital. They have a huge file on me there. They know me well. They'll say 'Here comes Lily again' as I come through the door and I know they'll try their hardest. Then, if they can't do anything for me, they can send me back here to my second home."

Two weeks later Mrs Adams suffered a brain stem stroke. She was immediately transferred to 'her' hospital for diagnosis, with comprehensive documentation outlining her wishes and advance care planning. It was anticipated Mrs Adams would not regain consciousness. Through consultation with the hospital it was agreed that Mrs Adams should return to the facility for a palliative approach, where she died 48 hours later surrounded by her family. Her wishes had been respected and the changed goals for care were achieved.

Before a resident is transferred to another facility, it is beneficial for them and/or their family to have the reasons for the transfer explained. These discussions can provide an opportunity for the resident and/or the family to talk about the future, their fears or uncertainties, and some of the treatment options that might arise. Such discussions can also empower the aged care team by providing an opportunity to raise such issues with the resident and/or family.

Ideally, an advance care plan will involve a discussion with the resident, the family and the health care team[61] (Level QE). A facilitated discussion about advance care planning between residents and the aged care team helps define and document the resident's wishes[62] (Level II). When a plan is systematically implemented in RACFs, residents and families report satisfaction with their involvement with end-of-life decisions[58] (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[63] 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 advance care plans may also include treatment decisions for acute episodes such as hip fracture or pneumonia. A transition period to facilitate the resident's 'settling into' the RACF should be provided for the new resident and family members before discussing the advance care plan in detail. These discussions require clear communication and assessment strategies regarding the goals and expectations of treatment.[64] These discussions should involve family members and carers, and their involvement in planning the management of critical changes in the resident's condition should be actively promoted within the RACF. However, family members should not be compelled to participate in such discussions. Instead, it is suggested that family members be consulted about their capacity or willingness to be involved in a palliative approach to the resident's care, particularly when it involves providing direct assistance.

3.2 ADVANCE CARE PLANNING FOR RESIDENTS WITH ADVANCED DEMENTIA

Discussions about advance care planning should ideally involve the resident, but when they are suffering from dementia the situation becomes more complicated. According to Rempusheski and Hurley[63] (Level EO), these discussions should occur around the time of diagnosis because a resident's cognitive ability may decline with time. This may mean the resident can be involved to a degree, but often the role of making such decisions will soon fall to family members instead.

The evidence suggests that family members of people with dementia may have unresolved emotional needs stemming from the illness itself, and from their relative's admission into an RACF, that find them unprepared for involvement in end-of-life treatment decisions[65] (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[66] (Level QE).

To assist them in these decision-making efforts family members need information about the expected trajectory of the resident's disease and factors that might impede a natural death[65] (Level QE). They may also need emotional support and information about what is meant by a palliative approach, so that they can process difficult and painful emotions.[65] Access to well-timed support and sensitive information may help families cope more effectively and allow them to contribute to end-of-life care decisions with more comfort.

3.3 LEGAL CONSIDERATIONS AND DOCUMENTATION

An initial assessment of the resident's wishes alone is inadequate, because it does not ensure that the resident's current requirements are documented. 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[58] (Level II). Therefore it is advisable to commence discussions before or at the time of admission and to review the advance care plan document several times to ensure that it is comprehensive. Although it is preferable that such discussions take place with the resident's GP before admission, this can still be done as soon as practical after admission.

If the resident cannot manage a great deal of decision-making in one sitting, it is still possible to determine their basic values and wishes immediately. For example, it may be possible to determine whether the resident wants life-sustaining treatment and under what conditions, and whether they want to be transferred to hospital or remain in the RACF if they become acutely ill. Additional wishes can be recorded over time. When adequate time has been taken to discuss relevant issues related to advance care plans, the aged care team is better able to respond to questions as they arise and as circumstances change. This may involve arranging for a legal representative to visit the resident, ensuring appropriate privacy and providing assistance when needed.

3.3.1 Legal requirements

If the resident has lost their cognitive abilities, their appointed representative should be asked to make such basic decisions at the time of, or soon after, admission.

In some jurisdictions, the appointment of an 'enduring health advocate' has been given legal recognition by special legislation. This legislation allows a person to appoint someone to make decisions about medical treatment on their behalf if they become incapable of making such decisions for themselves. Such an appointment is made under an 'enduring power of attorney (medical treatment)', sometimes referred to colloquially as a 'living will'. Some forms of artificial nutrition are regarded as medical treatment rather than palliative care (see Gardner; re BWV [2003] VSC 173 [29 May 2003]). Therefore, a simple enduring power of attorney that covers financial and lifestyle decisions, but not medical treatment, might not be sufficient to ensure that a resident's preferences regarding artificial nutrition can be acted upon.

A person who is required to make a decision on behalf of another person under an enduring power of attorney (medical treatment) must take into account:

- what would be in that person's best interests; and
- how that person would have acted if they were not incapacitated.

If a resident has already lost the capacity to make reasonable judgements, it is not possible for them to appoint someone to make decisions for them under an enduring power of attorney (medical treatment). If a decision needs to be made about continuing or ceasing artificial nutrition for a resident in this situation, it might be necessary for a guardian to be appointed to make the decision.

3.3.2 Documenting the plan

The best way to document advance care plans is in the resident's case notes, or to note recommendations for revisions to such plans when the resident's circumstances change, as directed by legislation in the particular State or Territory. Additionally, the following triggers may help determine the need to reassess a resident's advance care plan:

- A change in their health status;
- A change in personal/carer situations (e.g. if a spouse or other person who is the appointed decision-maker dies or loses capacity);
- Transfer (either into or from the facility) (McGough and Ladd[67] (Level EO) recommend that a plan of care be transferred with the resident, as with other medical documentation; and
- Routine requirement, such as a review period scheduled for every three months[68] (Level QE).

Studies have shown that education about advance care planning for the aged care team, residents and their families increases the likelihood of these plans being completed and implemented in RACFs[58] (Level II). A corresponding increase in satisfaction for the family about the resident's end-of-life care also occurs when the family has been educated about advance care planning[58] (Level II).

The following story illustrates the benefits of including the family in advance care planning to ensure the aged care team is aware of the resident's preferences.

Mr Jones

Mr Jones suffered from chronic obstructive pulmonary disease, epilepsy and dementia. As he was unable to articulate his own concerns, his family clearly stated their preference should his symptoms warrant urgent attention: "He's absolutely terrified of hospital. We'd hate him to be sent off alone by ambulance in the middle of the night." A family conference was arranged in consultation with the local medical officer and advice was received from the regional palliative consultant, who had particular expertise in managing respiratory crises. A step-by-step plan was formulated and shown to the family. The plan proved effective on several occasions when Mr Jones suffered distressing symptoms of dyspnoea. An appropriate plan was also developed for his epilepsy. When he suffered a major seizure, the crisis was managed in the aged care facility. Both the family and the aged care team expressed satisfaction that his symptom control could be managed well by the nurses, that he had a well-formulated care plan, and that he was spared a distressing and disorienting hospitalisation.

3.4 THE RIGHT TO REFUSE FOOD

Consenting to food or refusing food is an expression of the resident's autonomy.[69] One of the most difficult ethical issues that families and aged care teams confront is uncertainty about how to manage residents who refuse food or can no longer eat.

Use of advance care plans is one way for the aged care team to discuss the resident's and family's views and preferences regarding feeding and artificial nutrition. These discussions also offer an opportunity for the aged care team to give information to the resident and family about appropriate options. Families who do not have access to sound information may make decisions on behalf of the resident that are difficult to reverse and that they may later regret.

In some instances there may have been no discussion regarding the resident's preferences regarding feeding or artificial nutrition. As well, there are times when residents refuse to eat and the aged care team and family may feel uncertain about how to respond. 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:[69]

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 amounts of food and fluids, even if the person is dying—but do not use undue force and always defer to the resident's cues.

Additionally it is stressed that, even when a resident is no longer taking food or fluids, exemplary mouth care must be maintained (see Section 5.9, 'Mouth care', for more details).

Gillick[70] (Level EO) recommends that, due to the evidence regarding the questionable benefits of tube feeding, artificial nutrition should not be initiated as a general rule (see Section 5.4, 'Nutrition and hydration').

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 their families on the issues around end-of-life care, a palliative approach, and advance care planning. This will help residents communicate their wishes and will 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[58] (Level II); [62] (Level II). Whether or not there is access to an advance care plan for each resident, it is important for the RACF to provide opportunities for end-of-life matters to be discussed with the multidisciplinary team whenever required.

Guidelines: Advance care planning

		Level	Reference
8.	Advance care planning that is systematically implemented in an RACF and involves communication between the resident, family, and doctor increases the satisfaction of the resident and their family with end-of-life care. Advance care planning helps define the resident's wishes, which can then be clearly documented.	II II	58 62
9.	Regular education programs for the aged care team, residents and their families on issues about end-of-life care and the completion of advance care plans increases the frequency of these plans being completed and implemented in RACFs, and increases satisfaction with end-of-life care.	II	58
10.	Ongoing assessment is required to develop a comprehensive advance care plan that addresses all relevant issues as a resident's state of health changes over time.	II	58

CHAPTER 4

Advanced dementia

Advanced dementia, also known as 'late stage' or 'severe' dementia, is a neurological disease characterised by severe cognitive decline of an irreversible nature. It 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[71] (Level II). The progression from diagnosis of advanced dementia to death is usually three years[72] (Level III-2), and poorer prognosis is likely if the resident develops an acute illness such as pneumonia[73] (Level III-2) or an infectious disease [72] (Level III-2). Thus, advanced dementia is a progressive degenerative disease that is life-limiting, and a palliative approach to care should be offered[31] (Level III-2).

The fundamental principle in caring for residents with advanced dementia is to understand that their dementia will not necessarily follow a predictable course. Consequently, prognostication is unlikely to be beneficial for determining survival rates for these residents. However, the aged care team should have an understanding that advanced dementia is a life-limiting progressive disease. The resident's family should also be helped to understand this information and be given the opportunity to discuss how a palliative approach can be of assistance.

4.1 HOW PREVALENT IS DEMENTIA?

According to a recent report, more than 162,000 Australians had dementia in 2002,[5] and it is anticipated that 500,000 people will have dementia by the year 2040.[5] 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[5] (Level QE).

Approximately half of the people diagnosed with dementia live in an RACF.[74] Overall, 30% of residents in low-care facilities and approximately 60% of those in high-care facilities have dementia. Only 10% of high-care residents have no cognitive impairment.[74] However, this data is based upon a documented diagnosis, suggesting these figures probably underestimate the prevalence of the condition.

4.2 ADVANCED DEMENTIA AND THE PALLIATIVE APPROACH

There is evidence to suggest that a palliative approach benefits not only the person with the disease but also their family[75] (Level IV). 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[75] (Level IV). 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.

4.3 ASSESSMENT

A study of 42 RACFs in the United Kingdom 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%)[76, 77] (Level QE). Symptoms of people with dementia were compared to the symptoms of people with cancer and it was found that people dying from dementia have symptoms and health care needs comparable to those dying from cancer.

In any assessment of a resident with advanced dementia, their current health status and past medical history should be considered. This approach rules out other symptoms or concerns that may be prompting a resident to have increased agitation or aggressive behaviours (for example, history of breast cancer and subsequent bone metastases must be considered).

4.3.1 Pain assessment

One of the most difficult aspects for the aged care team who is caring for the resident with advanced dementia is assessing whether they are experiencing pain. One study conducted in the United States compared the rating by cognitively intact residents of their pain intensity to the rating given by their nursing staff[76] (Level QE). The study reported disagreement between residents' and nurses' perceptions of pain-related behaviours, raising concerns about the abilities of nurses to correctly assess the pain of residents who are unable to communicate.[76] However, it should be noted that members of the aged care team who have cared for a resident for some time may be the first to detect any changes in their condition.

A further study found that 86% of people with a Mini-Mental State Examination (MMSE) score of <15 could locate pain on themselves.[78] Therefore, it appears that even for a resident with advanced dementia the most reliable way to locate pain is to ask the resident. However, assessing the intensity of pain is more problematic. Studies confirm that people with advanced dementia give confounding reports when asked to give a comparison of pain over the previous two weeks.[79] Some suggestions to overcome this are for members of the aged care team to ask the resident about pain when moving or palpating of the area thought to be painful. At rest, the resident might not remember the pain, but during movement they are more likely to verbalise an indication of pain.[80]

When residents with advanced dementia cannot voluntarily control their expressions or vocalisations, members of the aged care team need to assess the resident's pain by observing their behaviour and facial expressions as indicators of internal states. Therefore, the concept of a pain assessment tool for advanced dementia is that discomfort is observed but the patient cannot verbally express it.

Several tools have been developed to assist the aged care team to assess pain in residents with dementia. However, many of these tools are complex and are not often used well in clinical settings. Validated pain scales are considered more accurate for determining pain intensity than other methods. However, studies indicate that there are poor completion rates for older persons with advanced dementia using a variety of pain scales. One study assessed the ability of residents to complete five frequently used scales (average age was 85 with a mean MMSE score of 12).[81] 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.[81]

The draft *Residential Aged Care Pain Management Guidelines*[82] recommend that the Pain Assessment in Advanced Dementia Scale (PAINAD) 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. The PAINAD scale is a five-item observational tool based on behavioural observations, with a scale of 0–2 for each item, as follows:[83]

- Breathing (independent of vocalisations)—normal (0) vs laboured (1) vs noisy laboured, or long periods of Cheyne-Stokes respirations (2);
- Negative vocalisation—none (0) vs occasional moans or muttering (1) vs repeated troubled calling out or loud moaning or crying (2);
- Facial expression—smiling or inexpressive (0) vs sad, frown (1) vs facial grimacing (2);
- Body language—relaxed (0) vs tense and pacing (1) vs rigid with fists clenched, or striking out (2); and
- Consolability—no need to console (0) vs distracted or reassured (1) vs unable to distract or console (2).

Unfortunately, there is little research regarding the PAINAD Scale, and further validation is required before its use can be supported.

Recently a new tool has been specifically developed for people with advanced dementia: the Abbey Pain Scale.[84] This scale has been trialled in RACFs in various states of Australia and reasonable validity levels have been reported[84] (Level QE). The scale is based on the assumption that a perception of pain severity by nurses is the best indicator in these circumstances for determining a resident's pain intensity. Although further substantiation of this scale is required, given its brevity and reasonable preliminary validity estimates the tool has merit and may be helpful for use in RACFs.

Some additional tips for improved assessment of pain in patients with dementia include:

- Ask 'yes/no' questions;
- Palpate areas while asking questions;
- Ask 'yes/no' questions;
- Use simple descriptor (aching, hurting);
- Assess pain associated with movement;
- Don't dismiss pain behaviours as 'just part of dementia';
- Also consider UTI, constipation, urinary retention, compression fractures;
- Ask family about previous pain complaints; and
- Assess pain in any patient with poor sleep, appetite, change in function or agitated behaviour.

Systematic evaluation of end-of-life care for people with advanced dementia has been hampered by a lack of appropriate evaluation tools[85] (Level QE). Consequently, several scales and assessment tools have been developed as outcome measures to assess the effectiveness of treatment in end-of-life care:

- the Assessment of Discomfort in Dementia (ADD) protocol [86] (Level QE); and
- the Discomfort Scales for Dementia of the Alzheimer Type (DS-DAT) [87] (Level III-3).

These tools were developed to improve the recognition and treatment of physical pain and affective discomfort in people with advanced dementia who can no longer articulate their care needs. The ADD was shown to prompt action to effectively decrease symptoms in 83.5% of a sample of people for whom it was trialled; this supports the notion that people with severe dementia can be assessed and treated for pain and discomfort[88] (Level IV). However, both scales are considered very difficult and time-consuming to use and thus, are not recommended for use in daily assessment of pain, but rather for assessing end-of-life care.

In using these tools, it is important to listen to the care assistants and nurses involved in the direct care of the resident because they have often learned the resident's cues and may be able to interpret the resident's needs. It is also important to include a reassessment of the resident's medications to determine if any changes are required.

4.3.2 Acute illness

One study found that individuals with advanced dementia who are admitted to hospital with acute illness after having been under the care of a palliative team may have their preferences for a palliative approach abandoned by the hospital staff, resulting in more aggressive treatments[71] (Level II). The limitations of the study included a small sample size and the possibility that the research team intervened in treatment plans by their mere presence. However, the study highlights the need to prioritise goals of treatment before a person is sent to hospital. Another study documented the extent of disruption to the resident when inappropriate hospitalisation occurs, and recommended a shift from cure-oriented interventions to comfort care[72] (Level III-2).

4.4 MANAGEMENT

Aggressive medical treatment of infections is not effective in preventing the progression of severity in dementia of the Alzheimer type[31] (Level III-2). However, despite a lack of sound research upon which to base use of systemic antibiotic therapy for people with a poor prognosis of severe end-stage dementia in the last six months of life, there is evidence that this practice is prevalent[89] (Level III-3). People with severe dementia receive similar treatment to those with mild or no dementia. Shuster argues that antipyretic measures (medicines that lower the body's temperature to prevent or alleviate fever) for symptom relief may be appropriate in this population.[90] However, the evidence suggests that the cost of hospital care for fever management of people with advanced dementia is financially and emotionally too high[72] (Level III-2). Instead, it is recommended that a palliative approach be used for the comfort of the resident, though this may include short-term antibiotic therapy with the intention of easing symptoms and improving quality of life[72] (Level III-2).

End-of-life treatment decisions need to take into account any significant co-morbidities of the resident, to ensure that treatment or refusal of treatment is appropriate. For example, one study found that people with advanced dementia and hip fracture or pneumonia had a 53% and 55% mortality rate at six months respectively, compared with 13% and 12% for people who were cognitively intact[91] (Level QE). The mortality rate of those who subsequently acquire pneumonia is dependent on the severity of the dementia, in conjunction with other intermediary factors that actually cause mortality[92] (Level III-2). Residents with moderate dementia who had lost a significant amount of weight and had aspirated, had an increased risk of mortality within three months of pneumonia. From these studies it would appear that advanced dementia is a significant co-morbidity.

The palliative approach for residents with dementia is focused entirely on the resident's preferences and is aimed at enhancing their quality of life. Decisions should ideally involve the resident's family or other suitable persons to act as the resident's proxy in providing information to the multidisciplinary team on the resident's preferences, personal values and history. The aged care team may be able to contribute observations to the discussions, particularly observations during any moments of lucidity when the resident may say something about their desires for specific treatments. The aged care team also needs to develop an understanding of the resident's unspoken communication, such as facial movements, to indicate levels of pain and/or distress.

A systematic review of current best practice on physical restraint in acute care settings and RACFs recommended that restraint-free care be provided through the Restraint Minimisation Program[93] (Level II). The program has two components: 1) education to change the culture of the organisation and to provide strategies to remove restraints; and 2) restraint alternatives. The specifics of the restraint alternatives should be used with caution, as little evaluation has been completed[93, 94] (Level II).

4.5 FAMILY SUPPORT

Family members of residents with dementia may have unresolved emotional needs, stemming from the illness itself and RACF placement, that may make it difficult to be involved in end-of-life treatment decisions[65] (Level QE). It is the responsibility of the aged care team to encourage and facilitate family involvement. However, the team must avoid making negative judgements about family members whose involvement appears (to team members) to be inadequate or if family members choose to withdraw.

Care planning meetings need to be held to protect the vulnerability of residents with advanced dementia and to ensure that, where appropriate, families are involved in decision-making[95] (Level QE). The aged care team also needs to be aware that families and carers of a resident with dementia are at great risk of psychological problems, due to the prolonged dying trajectory of the resident[95] (Level QE). The following story illustrates the need for the aged care team to be flexible in their involvement with the family, to ensure they are able to cope and participate in the demands of decision-making.

Anna

Anna was an 82-year-old lady originally from Germany. She was admitted to the dementia unit shortly after the death of her husband. Anna had one adult child, Helen, who found it extremely difficult to accept her father's death and her mother's declining mental capacity. Helen held legal power of attorney and was the immediate next of kin for her mother. However, Helen evaded attempts by staff to involve her in planning for her mother's care.

Over a short period of time Anna's physical health began to deteriorate significantly. She began to suffer more frequent angina attacks and became wheelchair-bound as a result of a fall, which had fractured her right hip. Anna's condition deteriorated when her oxygen levels fell severely and she experienced extreme tiredness and shortness of breath.

Attempts to engage the daughter, Helen, in care planning meetings were unsuccessful. Eventually contact was made with Anna's adult grandson, David, who at this critical time assisted staff to make pertinent decisions about Anna's health needs. Despite Anna's mental confusion and her ill health she recognised David and responded well to his suggestions about her health needs and care options. With Anna and Helen's agreement staff were able to liaise directly with David about the level and type of care provided to Anna in the final stages of her life. Through David the aged care team was also able to explain the physical and psychological processes Anna was going through, enabling him to more fully support his grandmother and to keep other family members advised of her situation.

Guidelines: Advanced dementia

		Level	Reference
11.	A palliative approach benefits the family as well as the resident, particularly when it incorporates continual follow-up evaluation, attention to distressing symptoms and avoidance of hospitalisation, and emphasises and promotes the resident's quality of life and dignity.	IV	75
12.	Remaining in familiar surroundings is beneficial for residents with advanced dementia as this helps maintain their palliative care plans and promotes feelings of orientation and security.	III-2	71
13.	Residents with advanced dementia can be assessed and treated for pain and discomfort with the use of dementia-specific assessment tools.	III-3	81
14.	The use of aggressive medical treatment of infections is not recommended for residents with advanced dementia. Instead, a palliative approach is recommended for the resident's comfort, which might include short-term antibiotic therapy to ease symptoms and improve quality of life.	III-2 III-2	72 31
15.	A policy of restraint-free care using a restraint minimisation program is considered best practice. Through education designed to change a facility's culture, such a program minimises the use of restraints and provides strategies for the removal of restraints.	II II	93 94

CHAPTER 5

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[96] (Level III-2). For this reason, those working in the aged care sector have identified the management of symptoms as a priority area.

This chapter provides guidelines for the assessment and management of physical symptoms frequently experienced in the final phase of illness and/or the ageing process, with a focus on symptoms relevant to RACF residents. Where there is limited research in the specific area of aged care and a palliative approach, research from pain studies has been reviewed for its appropriateness to the aged care setting. Recommendations and examples are provided, as well as a review of the barriers to achieving symptom control in this resident group.

Note that there are existing guidelines—*Australian Therapeutic Guidelines: Palliative Care*[97]—which outline the clinical assessment and therapeutic management of symptoms frequently experienced by people receiving a palliative approach. Issues covered include pain, symptom control and fatigue. It is recommended that facilities refer to these Guidelines for specific assistance with care management.

5.1 SYMPTOM ASSESSMENT

Residents living in RACFs who require a palliative approach can experience a range of physical symptoms that require prompt attention, such as fatigue, pain, dyspnoea, constipation and anorexia[96] (Level III-2), and most residents also have dementia. Therefore, holistic care that focuses on regular, detailed assessment and review, establishing as far as possible the resident's priorities and goals for treatment, is central to a palliative approach in RACFs. Studies of peoples' (including families') perceptions of the things that are important to them in end-of-life care found that adequate pain relief and symptom management were crucial[98] (Level QE).

Symptom assessment needs to be carried out on a regular basis to respond to changes in the resident's physical health as well as potential changes in their goals for care. Care based on the use of reliable and validated assessment tools has been shown to decrease the distress occurring due to a range of symptoms, including, pain, decubitus ulcers, mucositis and bowel problems (see [19] in Reference List for example). Assessment of common problematic symptoms in this group of residents assists in the provision of adequate and timely care. The common areas of symptom distress include nutritional problems, bowel problems, dyspnoea, fatigue, insomnia, pain, nausea and dysphagia[96] (Level III-2).

A detailed assessment is the cornerstone of all symptom management, and includes a review of possible causes, the history of the symptom and the impact of the symptom on all aspects of the resident's daily function. The quality of the assessment depends upon the communication skills of the aged care team in ensuring that the experiences and distress of the resident are understood and accurately interpreted. A comprehensive assessment of the resident's concerns, including early identification of their main symptoms, leads to appropriate treatment plans[99] (Level QE). Central principles to assessment include:

- ongoing assessment, not a single event;
- self-reporting (for the cognitively intact, this is the most accurate source of information);
- identification of the best proxy (for residents unable to communicate) to ensure the resident's wishes are considered;
- discussion of the efficacy of any interventions tried or being considered (assessment should not be limited to an exploration of symptoms);
- clear documentation of all assessments;
- all relevant members of the aged care team providing input;
- a focus on psychological, social and spiritual domains;
- agreement, whenever possible, on the goals of care by the resident and/or family/proxy; and
- consideration of the disease trajectory/ageing process for each resident, as this may have implications for management.

RACFs already use a variety of tools to assess residents' symptoms. Various tools that have been validated will be highlighted throughout these Guidelines. It is anticipated that RACFs can adopt these tools for use; however, there is no one tool that is recommended.

The use of symptomatic assessment can result in a quicker response to symptom control. If a systematic assessment of symptom distress is not undertaken, then this increases the likelihood these symptoms will be under-treated. Overall, assessment tools have demonstrated an improvement in the management of symptoms when used in conjunction with a detailed clinical interview.

There are tools for assessing specific conditions such as pain, shortness of breath and depression (See Sections 5.2, 'Pain management', 5.9, 'Dyspnoea', and Chapter 6, 'Psychological support', for further information on specific assessment tools). As the distress of symptoms is a subjective matter, the 'gold standard' is the resident's own assessment[100] (Level III-3). Unfortunately, few tools are validated in RACFs; therefore, those from palliative settings may be the best currently available.

Three symptom screening tools used in a palliative approach that have been successfully used with older persons are listed below.

The *Edmonton Symptom Assessment Scale* (ESAS)[100] (Level III-3) was derived from the measurement of different symptoms using 0- to 10-cm visual analogue scales. The ESAS has been validated in the cognitively intact terminally ill population and is frequently used in clinical studies as an assessment tool. Individual symptoms evaluated in the ESAS include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, sensation of wellbeing, and shortness of breath. For all items, 0 is absence of the symptom or best possible status, and a score of 10 indicates the worst possible status. An overall distress score is calculated by averaging the individual symptom scores.

The *Symptom Assessment Scale* (SAS)[101] (Level III-3) 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 *Abbey Pain Scale*[84] (Level QE) is a new Australian tool, specifically developed for people with advanced dementia. The scale is based on the assumption that nursing staff's perception of pain severity is the gold standard for determining a resident's pain intensity. Although further substantiation of this scale is required, given its brevity and validity it may be a worthwhile addition to pain assessment.

Guidelines: Symptom assessment

		Level	Reference
16.	Residents and their families perceive good care with a palliative approach to include adequate relief of pain and effective symptom management.	QE	98
17.	Appropriate treatment plans are developed from a comprehensive assessment of the resident's needs, including early identification of their main symptoms.	QE	99
18.	The resident's own determination of the intensity of pain is considered to be the best assessment.	III-3	100

5.2 PAIN MANAGEMENT

Pain is under-treated in many clinical settings.[102] Pain management requires a systemic and holistic approach to treatment that is tailored to the individual's physical, psychological and spiritual needs.[103] As Dickinson states, "Pain is a subjective sensation and therefore pain is what the individual says it is and not what others think it should be".[104, p.78]

Dame Cicely Saunders first described the concept of 'total pain', articulating the view that pain is not limited to physical distress but also includes psychological, social and spiritual elements.[105] Recognition of an emotional and psychological component to pain points to the need for a multidimensional assessment for effective pain management.[106]

Although the notion of total pain is accepted when using a palliative approach, this section of the Guidelines will focus on physical pain only. However, it is important to recognise that pain in any of the domains (spiritual, social, etc) will impact on the other domains of pain. Attention to these dimensions will be discussed further in the relevant sections of the Guidelines (see Chapters 6, 'Psychological support', 8, 'Social support, intimacy and sexuality' and 10, 'Cultural issues').

5.2.1 Incidence of pain in residents of RACFs

Studies have found that older persons may experience more pain than younger persons, yet are less likely to complain[107] (Level III-1). 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)[108] (Level III-2). A further study found that residents over 85 years of age were more likely to receive no analgesia than younger residents[107] (Level III-1). 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[109] (Level QE).

One reason for this inattention to pain may be inadequate assessment tools, especially for those with advanced dementia who cannot articulate their care needs[110] (Level QE). Poor care practices and difficulties with prescribing adequate and appropriate medication, especially in some rural and remote regions, have also been cited as possible reasons for under-treatment of pain. However, there is evidence indicating that residents enrolled with a specialised palliative team have better analgesic management of daily pain than residents who are not[111] (Level III-3).

The following story illustrates the benefits of a palliative approach to pain for a resident.

Mr Johnson

A month before his 100th birthday, Mr Johnson had fallen and fractured his hip. He underwent surgery but became virtually chair-bound. Mr Johnson developed a pressure area on his leg that quickly deteriorated, leading to a necrotic and heavily infected foot which was extremely painful. He was well aware of his circumstances and, after being advised of the treatment options available, decided that rather than amputation he would prefer a palliative approach. This required a specific dressing management routine that addressed the pain and the smell, together with a regulated pain management regimen to give him comfort without sedation. Mr Johnson was able to participate in and enjoy his centennial birthday celebrations.

5.2.2 Barriers to effective pain management

The evidence suggests that lack of knowledge of pain assessment among some nurses[112] (Level QE) and doctors[113] (Level II) is contributing to poor pain management of residents. An additional concern is the low level of knowledge of pain management of some doctors, as they have had little formal education in this area.[114] The literature citing these deficiencies calls for a collaborative approach between doctors and nurses to manage pain consistently and well in the aged care setting[115] (Level QE). It also cites the need for educational programs that give definitive and objective information on drugs[113] (Level II); [114] (Level EO). Some practices have begun to change. These changes have included improved education of doctors and nurses about pain assessment and prescribing, development of more responsive assessment tools, improved treatment strategies, and better practices for monitoring of residents' pain levels.[116] However, other barriers to effective pain management still need to be addressed.

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[76] (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[117] (Level III-3).

Effective pain management may also be difficult for some residents due to their cultural beliefs. For example, a recent study found that in some Indigenous Australian communities there was considerable fear regarding morphine being given at the end of life[118] (Level QE). The common belief was that morphine was the drug that was given to "get rid of me [them]".[118, p. 146] This study also noted that many Indigenous Australians had a fear of needles and did not understand about drugs and palliative care. This study highlights the need to identify cultural issues for each resident in all aspects of care delivery. (See also Chapters 9, 'Aboriginal and Torres Strait Islander Issues' and 10, 'Cultural issues'.)

There is a large body of research demonstrating that some aged care team members may have misconceptions or myths about pain management[113] (Level II). These misconceptions can present major barriers to effective pain management. The following table provides an overview of some of these myths, and the facts in each case.

Table 4: Common myths about pain management

Myth	Fact
1. The best judge of whether a resident has pain is the doctor or nurse caring for the resident.	The resident is the authority on their pain. Their self- is the most reliable indicator of the existence and report intensity of pain.
2. Residents should not receive analgesics *until* the cause of pain is diagnosed.	Symptomatic relief of pain should be provided while the investigation proceeds. Unrelieved pain is unacceptable and if ignored it can make it more difficult for adequate pain control to be achieved. It is also important to remember that the clinician's primary diagnostic tool is not pain.
3. People with advanced dementia are unable to use pain rating scales.	When an appropriate pain rating scale (e.g. 0–10) is used and the person is given sufficient time to process and respond, many cognitively impaired residents can use a pain rating scale.
4. There is no reason for a resident to hurt when no physical cause for pain can be determined.	As the study of pain is a new science, not all aspects are understood. Therefore it is better to accept that a resident is in pain, given their authority on the matter.
5. To determine the resident's true pain status, clinicians should rely on their own personal opinions and beliefs as to whether the resident is truthful.	Personal beliefs are neither consistent nor adequate to determine pain management. It is essential to establish the resident's self-report of pain as the standard.
6. Pain never killed anyone.	Chronic pain has many serious adverse effects, such as suppressing the immune system, which can lead to further deterioration for the resident and may indeed hasten their death.
7. Pain relief should only be given for pain that is currently present.	It is better to give analgesics in anticipation of movement, as this gives the resident control over the resulting pain.

(Adapted from McCaffery & Pasero)[119]

5.2.3 Types of pain

It is not always easy to distinguish between various types of pain; this difficulty tends to result in omissions or overlaps in providing adequate pain relief. The literature related to pain frequently refers to three types: acute pain (relatively brief that subsides as healing occurs), cancer pain, and chronic non-malignant pain.[120] However, this typology has limited value in helping direct the aged care team in assessing and managing pain. Instead, the method adopted by the *Therapeutic Guidelines: Palliative Care*,[97] based on the inferred pathophysiology of the pain and classified into two broad groups, has been found to be most helpful and will be used. (However, because much of the literature specifically refers to chronic pain, this term will also be used in this section). The two broad groups are:

- nociceptive pain (stimuli from somatic and visceral pain); and
- neuropathic pain (results from an injury to the nervous system).

The following table provides examples of nociceptive and neuropathic pain types and recommendations for referral.

Table 5: Pathophysiological classifications of pain, classification characteristics, and examples and recommendations for referral

	Nociceptive —superficial somatic	Nociceptive —deep somatic	Nociceptive —visceral	Neuropathic
Origin of stimulus	• Skin, subcutaneous tissue • Mucosa of mouth, nose, sinuses, urethra, anus	• Bone, joints, muscles, tendons, ligaments • Superficial lymph nodes • Organs capsules and mesothelial membranes (pleura and peritoneum)	• Solid or hollow organs • Deep tumour masses • Deep lymph nodes	Damage to nociceptive pathways
Examples	• Pressure ulcers • Stomatitis	Arthritis, liver capsule distension or inflammation	• Deep abdominal or chest masses • Intestinal, biliary, ureteric colic	• Tumour-related: brachial, lumbosacral plexus or chest wall invasion, spinal cord compression • Non-tumour-related: post-herpetic neuralgia, post-thoracotomy syndrome, phantom pain
Description	• Hot • Burning • Stinging	• Dull • Aching	• Dull • Deep	• Dysesthesia, e.g. pins and needles, tingling, burning, lancinating/ shooting • Allodynia • Phantom pain • Pain in numb area
Localisation (to site of stimulus)	• Very well defined	• Well defined	• Poorly defined	• Nerve or dermatome distribution
Movement	• No effect	• Worsening pain (resident prefers to be still)	• May improve pain	• Nerve traction provokes pain, e.g. sciatic stretch test
Referral	• No	• Yes	• Yes	• Yes
Local tenderness	• Yes	• Yes	• Maybe	• No
Autonomic effects	• No	• No	• Nausea, vomiting, sweating, blood pressure and heart rate changes	• Autonomic instability: warmth, sweating, pallor, cold, cyanosis (localised to nerve pathway)

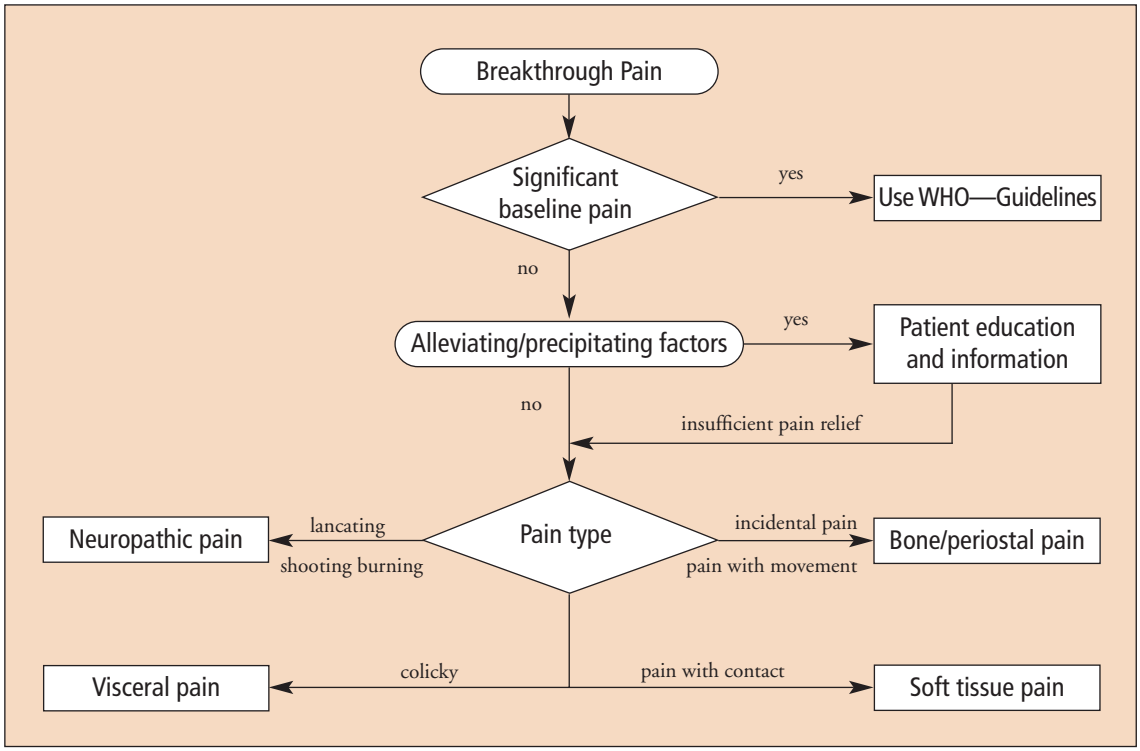
This table is reproduced with permission from the *Therapeutic Guidelines: Palliative Care*[97]

5.2.4 Breakthrough pain

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.[121] 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.[121] 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 (see Figure 1 for an example). The algorithm includes identification of the following characteristics:[119]

- duration;
- intensity;
- quality, characteristics (e.g. aching, shooting);
- precipitating factors (if any), such as bowel movement, change in the weather;
- factors that relieve the pain;
- sudden or slow onset;
- occurrence in relation to time of analgesic doses; and
- frequency (numbers of occurrences in 24 hours).

Figure 1: Algorithm for treatment of breakthrough (episodic) pain[121]



5.2.5 Pain assessment tools

Pain assessment should include a history of the resident, including pain location, type, frequency and severity as well as the impact on the resident's daily life activities. One study compared the simple question "Do you have pain?" with three assessment tools (VAS, BS, PDS) and found that the assessment tools were more accurate than simply asking the question about pain[122] (Level III-3). A range of pain assessment tools can be used, such as:

The *Functional Pain Scale* (FPS). The FPS is considered a reliable, valid, responsive and acceptable tool for use with older persons[123] (Level III-2).

The *Numerical Rating Scales* (NRS). The 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[124] (Level IV). The disadvantage of this tool is that it is not recommended for use with people with advanced dementia because some studies found that 30–50 % of residents in RACFs could not complete this scale.

The *McGill Pain Questionnaire* (MPQ). The MPQ is a multidimensional questionnaire that assesses the individual's site of pain, sensory, affective and quality, changes over time, and intensity[124] (Level IV). The criticisms of the questionnaire centre on the complexity and length of the questionnaire.[124]

The *Brief Pain Inventory* (BPI). The 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[125] (Level III-2). It takes about 15 minutes to complete and has been translated into Vietnamese, Chinese, Filipino and French.[119]

Pain can lead to behavioural changes in residents. One study assessed residents with chronic pain in RACFs to ascertain how easy it was for the aged care team to recognise the presence of pain. There was disagreement between residents and their family members reporting on the types of behaviours that indicated pain. Pain-related behaviours of residents with advanced dementia were more difficult to assess than those of residents without advanced dementia[76] (Level QE) (see also Chapter 4, 'Advanced dementia'). The pain assessment scales for residents with cognitive impairment or English-language or speech difficulties include:

Visual Analogue Scales (VAS). This is a horizontal 10cm line with word anchors at the extremes, such as 'no pain' on one end and 'pain as bad as it could be' on the other. The resident is asked to mark on the line, the point that best represents their level of pain. The VAS can be relatively easy to administer; however, scoring is time-consuming because the number indicated must be measured in millimetres up to the point the resident indicated. Many older persons with advanced dementia have difficulty completing this scale, so its use with this group is not recommended.

The FACES Scale. 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.[126] 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.[119] 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). 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 patients who lack abstraction skills to translate reliably a crying face to severe pain instead of to a depressed or sad face.

Pain Descriptive Scales. This scale consists of a list of adjectives describing different levels of pain intensity, such as no pain, mild, moderate and severe pain. A score of 0 to 3 is assigned to these words, thus the scale is easy to understand and score.

Abbey Pain Scale. This scale is a new Australian tool, specifically developed for people with advanced dementia, as described earlier in this chapter[84] (Level QE).

Pain Assessment in Advanced Dementia (PAINAD) Scale. The PAINAD scale was developed in response to the need for an easy-to-use, valid and reliable pain assessment tool in advanced dementia. The PAINAD scale was based on the earlier DS-DAT protocol but was simplified, with a score of 0–10 for severity of pain making it more easily comparable to other pain scales used in clinical practice.[83]

5.2.6 Incident pain

Incident pain results from a specific event for an individual, such as being moved or wound care. Therefore, incident pain is different to other types of pain and this difference needs to be identified to ensure appropriate management of the resident's pain. Appropriate management is for analgesics to be given in anticipation of a resident's movement to reduce the prevalence of this type of pain occurring. For instance, when it is known that a resident is to be turned or to have wound care, analgesics should be given prior to the event with sufficient time allowed to ensure the analgesic has taken effect.

5.2.7 Management

Principles of pain management

Individualisation of the dose is the key principle of pain management[120] (Level EO). Some members of the aged care team may be reluctant to increase doses in older persons[76] (Level QE); however, dose increases can be undertaken safely when they are based on the resident's response in terms of their comfort and side effects rather than a preconceived idea of the amount of medication the resident might require[76] (Level QE).

Research has shown that many older persons have become resigned to their pain, are reluctant to complain, and are ambivalent about the benefit of any intervention to control it[76] (Level QE). As older persons are often reluctant to ask for pain medication, and if opioids are prescribed, they should be administered around the clock if pain is present most of the day. Continuous administration also avoids the toxicity associated with the high peak effect (toxicity) typical of PRN (as needed) doses.[120] Dosing PRN is only appropriate when pain is intermittent. In such cases, pain requires regular assessment and offering of analgesics. [127]

A further principle of pain management is the need to fully assess the probable cause of pain, because many people have more than one pain and different types of pain have different causes. The evidence suggests that comprehensive assessment of pain and evidenced-based analgesic decision-making processes enhance pain management[128] (Level II), as illustrated in the following story.

Mrs Harris

Mrs Harris is an 82-year-old who has been an RACF resident for the past eight months. A review of her medical history indicated she had rheumatoid arthritis, which left her with significant hand and wrist deformities and considerable pain associated with movement during the day. She also suffered considerably from the pain associated with morning stiffness. Additionally, her medical history indicated that she had osteoporosis, particularly in her spine.

Mrs Harris's health was otherwise remarkably good, except for a progressive short-term memory loss, which meant that she could no longer live at home. She woke one morning with severe pain that rendered her bed-bound. She needed assistance with all activities of daily living. An x-ray of her spine showed that she had suffered from further spinal damage. The neurological examination did not reveal any new weakness or sensory change. She was already on regular paracetamol and a low dose of regular indocid. Her GP chose to commence her on 10mg of sustained-release morphine morning and evening to try and improve her analgesia, and at the same time introduced coloxyl with senna regularly. After three days Mrs Harris was more comfortable but still not totally pain free. Her evening dose of sustained-release morphine was increased to 20mg and within another 48 hours she was comfortable and back to her previous level of function. She was not drowsy and showed no other symptoms as a result of the careful introduction of opioids.

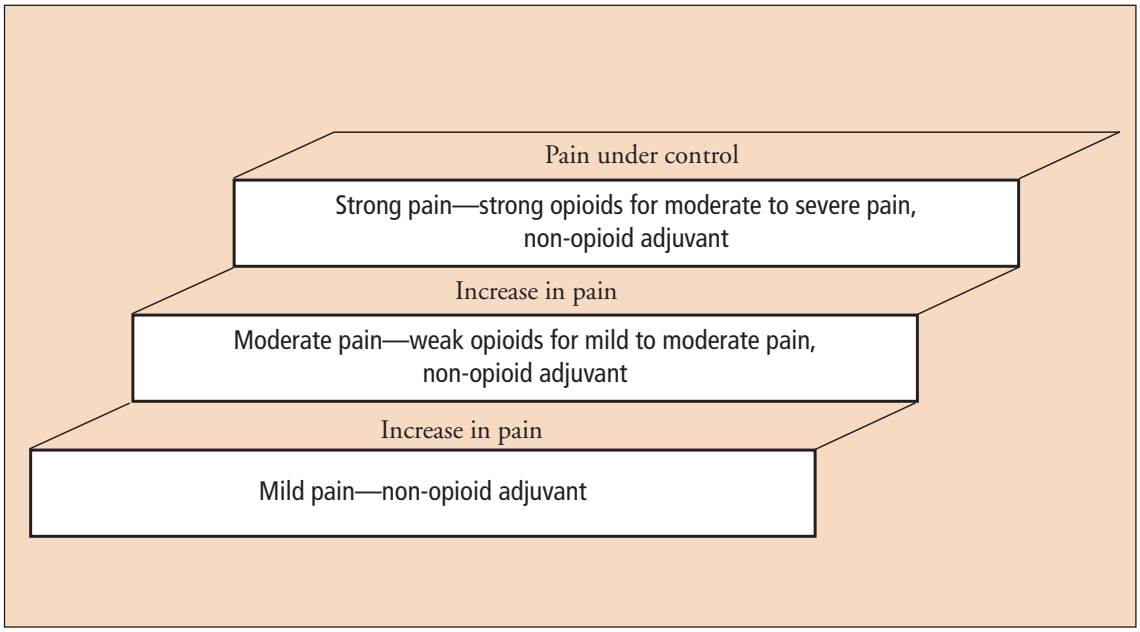
Within two months Mrs Harris was moving comfortably and her GP decreased her opioids by 10mg every three days until they were no longer required.

Pharmacological management

The *Australian Medicines Handbook*[129] outlines information on analgesics for pain management of chronic and acute pain, with drug information on opioid, non-opioid and compound analgesics and other drugs used for pain management. An electronic version of this resource is available on the Internet for medical practitioners at www.amh.hcn.net.au.

Consistent throughout the pain literature is the recommendation that the choice of medication needs to be based on the severity of the pain and not the stage of disease. The WHO analgesic ladder[130] recommends a three-step approach for pharmaceutical treatment of mild, moderate and severe pain, as shown in Figure 2.

Figure 2: The WHO analgesic ladder for pharmaceutical treatment of pain [130]



It is recommended that drugs be administered in standard dose at regular intervals in a stepwise fashion. If a non-opioid or a weak non-opioid is insufficient, a strong opioid should be used. Either a strong or weak opioid should be used, but not both. Adjuvants may be added at any stage, as their primary indication will be for other painful conditions (e.g. corticosteroids, non-steroidal anti-inflammatory drugs, tricyclic antidepressants, anticonvulsants and antiarrhythmic drugs). 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[131] (Level II).

Misconceptions regarding opioid use

Pargeon and Hailey outline the many misconceptions regarding the use of opioids in the minds of doctors, nurses, family members and others.[132] According to the WHO guidelines on pain management, opioids are the medications of choice for the management of moderate to severe pain.[130] This group of medications is effective and easily titrated, and has risks that are easily managed. For most people receiving a palliative approach, morphine is the opioid analgesic of choice.[133] However, a number of myths abound regarding use of opioids, particularly their use with older persons. This results in limits to effective pain management. Examples of some of these myths and their counter evidence are provided in the following table.

Table 6: Common myths regarding the use of opioids

Myth	Fact
Opioids create addiction	Physical dependence and tolerance may occur, but addiction (psychological dependence) is rare and almost never occurs in a person without a history of drug use prior to their illness.[134]
Opioids cause respiratory depression	If respiratory depression occurs, it is usually in opioid-naive individuals following acute administration of an opioid and is associated with other signs of central nervous system depression (e.g. sedation). Reduction in dose or temporary withdrawal of the opioid is usually all that is required.[135]
	Clinically important respiratory depression is a very rare effect in the person whose opioid dose has been titrated against pain.[135] A study demonstrated that, in a population of terminally ill cancer people with respiratory failure and dyspnoea, administration of subcutaneous morphine actually improved dyspnoea without causing a significant deterioration in respiratory function [136] (Level II).
Opioids must not be used too early in an illness to avoid hitting a 'ceiling dose'	There is no ceiling to the analgesic effects of full agonist opioids.[137] As the dose is raised, analgesic effects increase as a log linear function. In practice, the appearance of adverse effects imposes limits on the useful dose of an opioid agonist.
Opioids hasten death and should not be used with older persons	Doses must be titrated carefully. The older person is more at risk than younger people due to greater sensitivity to doses of opioids, but this does not mean that they should not receive opioids.[137]

As with any medication, opioids have side effects that with careful planning can be prevented or relieved. Side effects related to use of opioids include:[137]

- constipation (most common);
- nausea and vomiting (occurs initially and is usually easily controlled);
- daytime drowsiness and mental cloudiness (usually resolves within days);
- dry mouth;
- urinary retention (more common in older people);
- multifocal myoclonus (can be dose related, can be treated or an alternate opioid used);
- dizziness (usually resolves within days);
- dysphoria;
- confusion and hallucinations (rare but may occur in older persons); and
- sleep disturbances.

Organisational issues regarding pain management

The policies and procedures of each RACF regarding administration and use of opioids need to be readily accessible. The policies should specify who can administer opioids, where opioids are located, and how they are to be stored. High-care facilities are legislated with regard to their provision and storage of drugs, whereas low-care facilities are internally controlled. Despite different State and Territory legislation on the prescribing and administering of medication, adequate pain management should not be affected. It is important not to leave any resident in pain, and appropriate analgesics should be available in a timely fashion. For further guidance refer to the legislation in each State or Territory.

GPs and nurses working in RACFs need to understand the principles of titrating doses, conversions, and differences in dosages—when the route of administration is changed from oral to subcutaneous, for example. For further information and greater detail the *Therapeutic Guidelines: Palliative Care*[97] is recommended.

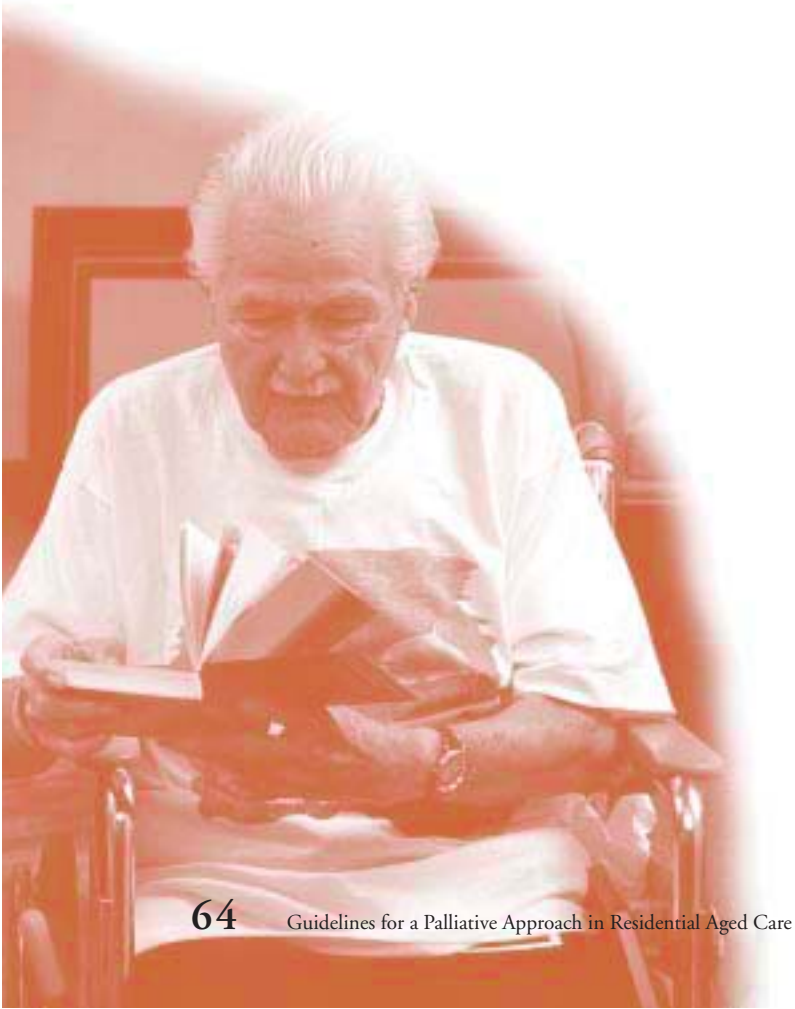
Non-pharmacological pain management

A systematic review of the literature on pain found that the identification of non-opioid pain receptors and the development of products to target them are just two of the changes that have altered the way clinicians think about treating pain[123] (Level II). A simple technique, such as the use of temperature (cold and warm), is an effective alternative therapy that is often overlooked. For example, cold can be used to suppress the release of products from tissue damage and warmth can stimulate production of endogenous opioids. Another 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[138] (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.

A systematic study examined whether progressive resistance strength training for physical disability in older persons was beneficial[139] (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.

Guidelines: Pain management

		Level	Reference
19.	Pain management is enhanced by a comprehensive assessment of the resident's pain and evidence-based analgesic decision-making.	II	128
20.	The use of assessment tools for pain is more accurate than just asking the resident "Do you have pain?" For the resident who is unable to verbalise their pain, accurate reporting based on good observation skills using behavioural cues, by a skilled person, is particularly important for determining pain.	III-3	122



5.3 MANAGEMENT OF 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.[140] Fatigue is recognised as a multi-factorial symptom, with complex pathology, that may occur alone or in combination with other symptom complexes.[141] Fatigue is the most frequently cited physical concern reported by individuals approaching death[141] (Level QE). 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.[142] There is some evidence to indicate that although many residents may experience fatigue the symptoms may be poorly recognised and consequently under-treated[140] (Level QE).

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.[140] However, while no clear leading cause is evident, fatigue has consistently been associated with depression and anxiety[143, 144] (Level IV). Fatigue may also be associated with pain, a reduction in intermediate activities of daily living, number of medications, and physical function[140] (Level QE).

5.3.1 Assessment

The assessment of fatigue is usually based on the resident's report of the symptom. Some residents may voluntarily report fatigue, but often it remains unrecognised unless the aged care team specifically asks the resident or observes changes in them. Under-reporting of fatigue is presumed to occur because residents may be reluctant to mention fatigue, believing that it is to be expected at their age. They may also feel that their complaint of fatigue is not important enough to report. However, fatigue may interfere with a resident's ability to make end-of-life plans and decisions, and affect their quality of life. Therefore, fatigue needs to be assessed and addressed by the multidisciplinary team. A number of tools to assess fatigue have been developed, though few have been tested for use with older persons. One exception is the Piper Fatigue Scale, which was developed for patients with cancer and, as part of a study, was adapted for use with older persons living in an RACF[140] (Level QE); this study reported acceptable validity and reliability estimates when tested with older persons.

5.3.2 Management

To enable realistic goals for the management of fatigue to be achieved, in accordance with the wishes of the resident and their family, the aged care team should initiate a discussion with those concerned. The first step is to assess the resident and identify any other symptoms, diseases or circumstances that may contribute to fatigue. For example, depression and anxiety, insomnia, anorexia, pain, dehydration, and anaemia may respond to treatment, which can improve the level of energy available.

Pharmacological management

No RCTs have been conducted to date that specifically address pharmacological interventions for fatigue.[141]

Non-pharmacological management

Suggested non-pharmacological methods for relieving fatigue, such as exercise programs and energy conservation, may be effective for people receiving a palliative approach[143] (Level IV). Winningham and colleagues[144] (Level IV) 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[145] (Level EO) 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[146] (Level I), bright light therapy[147] (Level I) and cognitive behavioural interventions[148] (Level I) for sleep disturbances in adults aged over 60 years. The reviewers concluded that, while some trials of physical exercise had promising results, there was little evidence to support the effectiveness of exercise for sleep efficiency. No trials on the use of bright light therapy were found. Cognitive behavioural therapy was found to have a mild effect on sleep disturbances in older persons. However, concern was expressed regarding this therapy's reduced value for the older aged group (i.e. over-80 years age group). 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.

Guidelines: Fatigue

		Level	Reference
21.	Fatigue is the most frequently cited physical concern reported by people approaching death, and warrants attentive assessment.	QE	141
22.	Potential factors associated with fatigue include depression, anxiety, pain, a reduction in intermediate activities of daily living, number of medications, and physical function. These factors, therefore, need to be carefully assessed.	QE	140
23.	Suggested non-pharmacological methods for relieving fatigue, such as exercise programs and energy conservation, may be effective for people receiving a palliative approach.	IV	144

5.4 NUTRITION AND HYDRATION

Nutritional and hydration issues for residents receiving a palliative approach are complex and raise ethical questions for the aged care team, residents and family members (see Chapter 3, 'Advance care planning'). A palliative approach endeavours to address these issues in the light of the best available evidence.

Nutrition and hydration are associated with more than physiological need. There are many psychological and social factors, especially pertaining to expressions of love, care, safety, security, etc, that influence decision-making in this aspect of care. The sharing of meals is usually associated with social gathering and communication among the resident and family members. If residents are unable to eat or share a meal with others the experience of meal times can be extremely unpleasant. Adequate discussion with the resident and their family regarding nutritional and hydration needs may help to alleviate the psychological and social distress often experienced.

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. Family members may request that everything possible be done for their relative, including treatments that are considered by the aged care team as invasive or potentially burdensome, contributing to increased suffering and discomfort for the resident. 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[149] (Level IV). 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.

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. Indeed, eating and drinking may no longer be relevant to the resident who has already withdrawn and whose attention is now more inward.[150] Nonetheless, many people who are dying often receive intravenous fluids when they are no longer able to maintain a normal fluid balance.[151] The main reason for this appears to be a belief that dehydration in a person close to death is distressing. However, professionals providing a palliative approach generally consider that hydration may be detrimental.

5.4.1 Nutrition

There is no universally recognised definition for malnutrition or under-nutrition (either term can be used)[152] (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".[153, p.590] Malnutrition is a medical condition determined by chemical tests and is usually treated by medical intervention. Thus, it should not be confused with hunger, which is not considered a medical condition. The most common nutritional problems for residents in RACFs are weight loss and associated protein energy malnutrition[154] (Level III-2).

The reasons for malnutrition are diverse and include physiological, psychological and social changes associated with the process of ageing, which affects food intake and body weight and can be intensified by illness or disease[152] (Level I). Depression and adverse drug effects are the most common causes of weight loss for residents. Finally, food intake itself can cause postprandial hypotension (which in turn may precipitate falls), produce electrolyte shifts, and result in aspiration pneumonia.

Careful attention to the nutritional intake of residents in RACFs is both a clinical issue and a quality-of-life issue.

Assessment

There are many causes for weight loss in RACF residents; therefore, an assessment of potential causes should be made with a view to identifying malnutrition and reversing the causes[154] (Level III-2). Reversible causes of malnutrition include adverse drug effects and depression[154] (Level III-2). Other likely causes include anorexia (see Section 5.6, 'Cachexia'), late-life paranoia (where the resident believes they are being poisoned and refuses to eat), swallowing disorders, oral health factors, advanced dementia, and the use of therapeutic diets (e.g. low salt, low-cholesterol diets; see Glossary for definition).[155] Recognising the varied risk factors for poor nutritional status in RACF residents is the key to successful assessment and management strategies[154] (Level III-2). The most frequently used measures of nutritional status are the Body Mass Index (weight in kg/[height in m]^2), triceps skin fold thickness and arm muscle circumference (measures of anthropometry), and history of recent weight loss[152] (Level I). Additionally, serum albumin has been used, as malnutrition causes a decrease in the rate of synthesis of albumin. However, fluid balance changes and illness itself affect this measure.

Management

Pharmacological management

Oral nutrition via a diligent hand-feeding program, rather than nasogastric enteral feeds, is best practice management for older persons[152] (Level I) and for those receiving a palliative approach.[156] The preferences of the resident should guide the dietary selection and the amount of nourishment[157] (Level II). A multidisciplinary team is helpful in encouraging oral nutrition. For example, the aged care team and family members can provide information on the resident's likes and dislikes, lifelong food habits, and identification of swallowing problems[154] (Level III-2). A dietician, in collaboration with other relevant members of the aged care team, can then plan meals in accordance with the resident's cultural diversity, preferences and swallowing ability.

Evidence supporting the effectiveness of nutritional supplementation exists for oral protein and energy feeds, but the reviewers considered that the strength of this evidence was weak[158] (Level I). However, not all residents are willing or able to consume oral nutrition or nutritional supplements. Therefore, efforts to encourage residents to eat for comfort and enjoyment and to provide assistance with feeding, if required, is considered best practice[156] (Level EO).

Enteral feeding to prevent the development of severe protein energy malnutrition is advocated providing it is used early in the management of a resident's nutrition[154] (Level III-2). A recent systemic review examined the evidence from 31 RCT and quasi-RCT studies for improvement in the nutritional status and clinical outcomes when protein and energy food were used (generally in the form of commercial 'sip-feeds')[152] (Level I). The reviewers concluded that supplementation appeared to produce a small but consistent gain and that there was a significant effect on mortality. However, the reviewers tempered their conclusion by cautioning that the time scales of most studies were too short to realistically detect differences in morbidity, functional status and quality of life. They also stated that the challenges faced by medical practitioners to fulfil individual needs and preferences, both organisational and practical, were not considered by any of the studies. Therefore, the gathering of additional data was recommended based upon large-scale multi-centre trials to clarify any perceived benefits from protein and energy supplements on mortality rates.

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[159] (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.

Individuals with advanced dementia who have difficulty eating or swallowing are often given enteral feeding to prevent aspiration pneumonia, ulcers or malnutrition. However, there is no evidence that tube feeding makes a resident with advanced dementia more comfortable, provides any benefit (including longer survival), or prevents aspiration pneumonia[157] (Level II).

Several studies have found that tube feeding is a risk factor for pneumonia and morbidity[157] (Level II). Concern exists that enteral and parenteral nutrition therapies are too aggressive and therefore do not fit within the philosophy of a palliative approach[160] (Level EO).

Continuing percutaneous endoscopic gastrostomy (PEG) feeding when death is imminent may actually cause discomfort due to the body's limited capacity to tolerate such intake at this time.[161, 162] If the resident has been receiving sustenance via a PEG tube then reviewing the benefits of this treatment should be discussed with the resident's doctor.

In making the decision about tube feeding, the resident's best interest and preferences are the cornerstone. When residents cannot speak for themselves, it is best to gather as much information as possible from those who have known them best. This process does not ensure that the interests of the vulnerable resident are guaranteed, but it does reduce the likelihood that the values of one individual will dominate. To assist in such a discussion, a decision aid has been devised (see table below) which can be used for the cognitively intact and the cognitively impaired alike[163] (Level 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[163] (Level IV).

Table 7: Tube feeding decision aid

Information to be provided to the resident and family should include:	Steps to decision-making should include:
• common causes of eating and swallowing problems in older persons; • technical considerations regarding the placement and use of PEG tubes; • principles of substitute decision-making (if not already discussed); • the risks and benefits of tube feeding; • the option of supportive care (e.g. hand feeding); and • some considerations regarding future discontinuation of PEG tube. [163] (Level IV)	• guiding the resident and their family through what they have learned about PEG tubes; • applying this knowledge to the resident's preferences, personal values and clinical situation; • the resident's situation; • what the resident would want; • how the decision is affecting the family; • what questions need answering before the resident or their family can decide; • who should decide about PEG placement; • when the PEG feeds should be disbanded; and • what the resident or their family's overall thoughts about the decision are. [163] (Level IV)

Finally, the decision-making process should be recorded. This decision can help to determine the right course of action for residents and/or their families to facilitate informed decision-making about tube feeding based on the resident's preferences. Often the dilemma that families face concerns when to discontinue PEG feeds once they have begun. This decision aid helps to pre-empt this by recording what interventions the resident would prefer. Everyone involved in the decision-making process needs to be aware that withholding or withdrawing treatments is legally and ethically sound if the decision is based on fully informed consent.[164]

The diets of residents should also be considered as potential causes for nutritional problems. Studies have shown that weight loss, low albumin levels and postural changes (orthostatism) are associated with therapeutic diets[154] (Level III-2) and therefore these diets should be avoided whenever possible for RACF residents. Low blood levels for a variety of vitamins have been found in many residents in RACFs[154] (Level III-2). Low levels of Vitamins B1, B2 and C have been associated with cognitive dysfunction. Supplementation of thiamine has improved cognitive function for older persons in RACFs with vitamin deficiencies[154] (Level III-2). Assessment of blood levels for these vitamins in residents is warranted because the treatment of these deficiencies is not aggressive and the potential benefits, such as increased cognitive function, are worthwhile.

Non-pharmacological management

Physical activity programs are an important component of care in RACFs and may have an effect on nutritional status. Simple, cost-effective programs may be as beneficial as high-technology programs. Physical activity can encompass 'exercise', 'play', 'movement' or 'sport' for groups, teams or individuals.[165] Physical activity implies motor activity that is pleasurable, exceeds the level used for daily activities, and is appropriate for older persons of varying levels of physical ability. The benefit of such an activity is the potential to enhance the quality of life for older persons[165] (Level EO). One study found that physical activity for the older person has also been suggested to have benefits for nutrition-related concerns, such as enhanced appetite, enhanced protein intake, improved bowel function (decreased constipation) and decreased likelihood of glucose intolerance[166] (Level QE). Whether these benefits are applicable and appropriate for residents receiving a palliative approach or who have co-morbidities such as dementia requires further research.

5.4.2 Hydration

Dehydration is the loss of normal body water. It is a medical condition determined by chemical tests and is usually treated by medical procedures. Dehydration should not be confused with thirst. Thirst can be treated without medical intervention and generally does not respond to medical treatments. Instead, thirst is best treated by small amounts of fluid or ice chips (finely crushed) and careful attention to keeping the resident's mouth and lips moist (See Section 5.9, 'Mouth care'). One study found no significant relationship between the level of hydration of an individual and symptoms such as feeling thirsty and having a dry mouth[167] (Level QE).

Assessment

Dehydration has a variety of clinical signs, including dry skin and mucous membranes, thickened secretions, decreased urine output, postural hypotension, headaches, cramps, irritability, drowsiness, constipation, weight loss, disorientation and orthostatic hypotension (changes in blood pressure due to postural change). Many of these clinical signs occur for other reasons, such as medication side effects, prolonged bed rest, mouth breathing and the use of oral supplements[168] (Level QE). However, if several of these signs appear together or are different from the resident's usual presentation, dehydration may be the cause. Additionally, when assessing the resident, the aged care team should be aware that clinical signs might not appear until dehydration is far advanced. Therefore, early assessment of signs of dehydration may be important to consider (e.g. high sodium, high blood–urea–nitrogen, and creatinine).

A systematic review was conducted that examined the existing clinical evidence regarding the effects of fluid status and fluid therapy on the dying[169] (Level I). Given the limitations in the studies reviewed, it was considered impossible to draw firm conclusions regarding clinical care. The only suggestion regarding management was to assess each person's individual circumstances, including the person's and their family's wishes, in order to formulate recommendations regarding fluid therapy for that person[169] (Level I).

Although there is low-level evidence that dehydration can increase the risk of ulcers and constipation there is no evidence to date that rehydration makes people more comfortable[149] (Level IV). Rehydration may also have a negative effect on cognition. According to some research, improved cognition has been reported after withdrawal of the hydrating process[170] (Level QE).

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.[151]

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.[151] Thus, artificial hydration alone is unlikely to resolve the symptom of dry mouth in most people[171] (Level QE). A study of 32 competent people with a terminal illness who chose not to receive artificial hydration and nutrition found that 20 of the people did not report sensations of hunger or thirst[172] (Level IV). In addition, all individuals' symptoms of hunger, thirst and dry mouth were alleviated with small portions of food, sips of liquid and adequate mouth care. They reported that 1 to 2 millilitres of water delivered by pipette or syringe into the dependent side of the mouth every 30 to 60 minutes was effective in alleviating sensations of thirst. Finely crushed ice chips have also been found to be comforting[173] (Level QE).

Management

The decision regarding rehydration should focus on the resident's individual circumstances, including the wishes of the resident and their family[169] (Level I). The comfort of the resident is the primary goal, rather than providing optimal nutrition and hydration[170] (Level QE). For each resident, the solutions and decisions are unique; however, some key principles are listed in the following table that can guide the resident, the family and aged care team in making decisions in this clinical situation.

Table 8: Principles to guide discussions and decisions regarding hydration[170]

In planning for care, and introducing a palliative approach, explore with the resident and their family their wishes in the event that the resident is not being able to maintain hydration. These wishes should be clearly documented and regularly reviewed over time with the resident and their family.

- Identify cause(s) for inability to maintain hydration.
- Where possible, and if the resident wishes, treat reversible causes.
- Review the resident's prognosis and the goals of treatment.
- Assess whether the decrease in intake is having a negative impact on quality of life.
- Consider simple non-invasive interventions first.
- If a more invasive intervention is considered necessary, establish review time lines and indications for withdrawal before commencing therapy.
- Regardless of the interventions instigated, oral discomfort can be treated with good oral care.

Guidelines: Nutrition and hydration

		Level	Reference
Nutrition			
24.	As there are many causes for weight loss in residents, an assessment of the cause is required with a view to identifying inadequate nutrition and reversing the causes.	III-2	154
25.	It is considered best practice for residents requiring a palliative approach to receive oral foods and fluids, even in minimal amounts, rather than enteral (nasogastric or PEG) feeding.	I	152
26.	Weight loss, low albumin levels and postural changes (orthostatism) are associated with therapeutic diets, so these diets should be avoided whenever possible for RACF residents.	III-2	154
Hydration			
27.	In order to formulate recommendations regarding fluid therapy, each resident's circumstances, including the wishes of the resident and their family, require assessment.	I	169
28.	Frequent small sips of fluids can reduce the sensation of thirst and oral discomfort associated with dehydration.	IV	172

5.5 ANOREXIA

Anorexia, or a reduced desire to eat,[174] may occur for some residents. Anorexia can be intermittent and associated with other medical problems, such as infection, constipation or depression[175] (Level IV);[154] (Level III-2). This condition can also be chronic, leading to problems with nutritional state, weakness and increasing debility. In severe cases anorexia can be associated with cachexia, a complex syndrome associated with muscle wasting and weight loss (see Section 5.6, 'Cachexia').

The prevalence of anorexia in RACFs is not known in Australia. However, North American studies indicated that 30–50% of high-care residents had substandard body weight and mid-arm circumference, and low serum albumin levels[175] (Level IV);[176] (Level II). While these findings are not necessarily applicable to Australian RACFs, they do provide an indication of the prevalence of potential nutritional problems.

As with any symptom, the decision about how and if to treat entails balancing the potential benefits against adverse effects while recognising the resident's wishes for treatment and exploration of simple measures.

5.6 CACHEXIA

Cachexia has been defined as a complex syndrome that combines weight loss, lipolysis, loss of muscle and visceral protein, anorexia, chronic nausea and weakness.[156] The prevalence of cachexia in the general population of older persons is not known. However, studies indicate that cachexia is likely to be predictive of morbidity[176] (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[176] (Level II). The cachexia syndrome is a source of psychological distress for individuals and family members, and prompts attempts to supplement the nutritional status of the resident. Most people see weight loss as a sign of decline and may begin more aggressive questioning about their relative's prognosis. Family members may experience more anxiety at this time and may require some education regarding the nutritional needs of the resident. The family can also be helped to understand the importance of not force-feeding their family member, in order to avoid the resulting nausea and psychological distress for the resident. (See Section 5.4, 'Nutrition and hydration', for further discussion of enteral and parental nutrition).

5.6.1 Assessment

A diagnosis is required to determine the cause for the resident's loss of appetite and weight. It is important to differentiate between simply reversible causes for anorexia and weight loss (e.g. depression, infection, thyroid problems, mouth problems, poor caloric intake) and the anorexia/cachexia associated with illnesses such as cancer, heart failure and dementia, which is not simply reversible. 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.[176] A nutritionist can help assess the resident's nutritional status and advise regarding dietary options to maximise nutritional intake[176] (Level II).

5.6.2 Management

The management of anorexia and cachexia should be multidisciplinary and individualised[154] (Level III-2). 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[154] (Level III-2), if this is in accordance with the resident's preferences. Management is also aimed at providing psychological support and improving quality of life[160] (Level EO).

5.6.3 Corticosteroids

No evidence to date has shown a significant effect between treatment groups for the use of corticosteroids. Some uncontrolled studies have suggested that corticosteroids (e.g. dexamethasone) may stimulate appetite, but these effects are only temporary and are not associated with a gain in weight. Prolonged corticosteroid treatment has been associated with significant side effects, including hyperglycemias, weakness, delirium, osteoporosis and immunosuppression[160] (Level EO). The use of corticosteroids is therefore not recommended based on the lack of benefits when compared with the potential side effects.

Guidelines: Cachexia

		Level	Reference
29.	A diagnosis of cachexia can be made from the resident's clinical history, presence of substantial weight loss, laboratory tests and physical examination.	II	176
30.	Residents should be encouraged to have as many calories orally as possible. For the frail resident, a trial of single nutrients or liquid meal replacements is warranted before more invasive techniques are used.	III-2	154

5.7 NAUSEA AND VOMITING

Nausea is the unpleasant feeling of the need to vomit. Vomiting is the forceful expulsion of gastric contents from the mouth.[177] Nausea can occur without vomiting (the reverse is also true). For example, if a resident says they feel sick but they have not vomited, then the resident has only nausea. This distinction facilitates accurate assessment and management, because there are differential diagnoses for nausea and vomiting.

Although nausea and vomiting are common among individuals with advanced cancer, little is known about the prevalence of these symptoms in RACF residents. Residents often experience a range of co-morbidities that can cause nausea and vomiting, including renal failure and cardiac failure.[178] The causes of nausea and vomiting may be related to the slowing of gastrointestinal motility due to colonic (large bowel) slowing or gastroparesis (slowing of the upper gastrointestinal tract) from medications or poor neuromuscular coordination. This is particularly the case for residents with diabetes, residents who have had a stroke and have nerve damage around the pharynx and epiglottis or positional changes due to weight loss in the neck that affects the upper pharynx.

Nausea may also occur as a side effect of a number of medications commonly used in RACFs. Consequently, the potential causes of nausea are usually numerous and a full history and clinical examination are necessary. 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[178] (Level EO).

5.7.1 Assessment

The resident needs to be properly assessed to determine the cause of nausea and/or vomiting. This should involve the family, where possible, to gain a history of the resident's eating habits and previous nutritional difficulties, if any. During this assessment the family can also be educated about the causes of nausea and/or vomiting and what treatment, if any, the resident desires.

Before the prescription of antiemetic drugs, the resident's environment should be assessed to reduce the stimulus to nausea.[178] Such stimuli could include cooking smells and unpleasant odours. Mannix[178] 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.

5.7.2 Management

Pharmacological management

It is often not possible to identify or correct the underlying cause of nausea and/or vomiting when a person is in the end stages of life. However, when causes are known, the potential benefit of any intervention should not outweigh the burden. If the cause is gastrointestinal, such as poor gastric emptying, then a prokinetic agent (e.g. metoclopramide, cisapride or domperidone) should be used. Should constipation be the cause, then promethazine should be effective. Hyperacidity can produce considerable nausea, heartburn, acidity or a bitter taste and has been associated with vomiting. Treatment of hyperacidity can be accomplished by unabsorbable antacids (magnesium plus aluminium hydroxide preparations), antacid plus alginate preparations, histamine H2-receptor antagonist (e.g. ranitidine) or a proton pump inhibitor (e.g. omeprazole). The *Therapeutic Guidelines: Palliative Care*[97] 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.[179] For the gerontological literature the same finding would also apply. Consequently, the management of nausea and vomiting will continue to be based on expert opinion until such studies are conducted.

5.8 DYSPHAGIA

Dysphagia, or difficulty in swallowing, can lead to significant weight loss for residents in RACFs. 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[180] (Level III & Level IV). 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[180] (Level IV).

The signs of dysphagia may include:[181]

- difficulty swallowing;
- facial droop;
- choking when eating or drinking;
- coughing before, during or after swallowing food or liquids;
- refusal to open the mouth and/or accept a large bite of food; and
- retention of food in the mouth or pharynx.

5.8.1 Assessment

A resident at risk of swallowing problems requires early assessment and referral to a speech pathologist or GP[180] (Level III & IV). In rural and remote areas where access to speech pathologists may not be readily available, qualified nurses can be educated to perform screening assessments of the resident's ability to swallow in order to identify early signs of dysphagia[180] (Level III & IV). Assessment should involve asking the resident, and/or their family, if there is any difficulty swallowing food or liquids. Questions that could be used during this assessment might include:

- Do you choke when eating or drinking?
- Do you experience coughing associated with eating or drinking?
- Does food ever stick in your throat?
- Do you have any problem controlling your saliva?
- Does food ever escape from your mouth?

It is also important for the aged care team to be aware that residents who aspirate do not always present clinical symptoms of dysphagia.[180]

The following recommendations regarding assessment are suggested[180] (Level IV):

- knowledge of risk factors and signs and symptoms is essential for early detection and management; and
- once an individual has been identified as having, or being at risk of having, dysphagia, they must be referred for further assessment to a medical practitioner or speech pathologist.

5.8.2 Management

Dysphagia should be managed in accordance with the agreed goals of care as determined in collaboration with the resident, their family and carers. In addition, the aged care team will require education on how to feed residents with swallowing disorders. Inadequate staffing can lead to an overburdened aged care team having insufficient time to assist residents who do not eat quickly, and can lead to labelling such residents as 'uncooperative', 'lazy' or 'combative'.[181] The following suggestions for management of dysphagia may be beneficial[180] (Level III & IV):

- A formalised multidisciplinary management program should be used to help in promoting early recognition, appropriate management and prevention of complications;
- Early and prompt referral should be made to a speech pathologist for assessment and guidance on management strategies;
- The aged care team should ensure that the texture, consistency and type of food and fluid are as prescribed; and
- The aged care team should ensure that feeding techniques are undertaken in accordance with the specific methods recommended by the speech pathologist or physician, and they should also be aware of the safe feeding techniques generally recommended for individuals with neurogenic dysphagia.

Dysphagia can be managed through various interventions which can reduce the risk of aspiration. During meal times, residents need to be physically well supported in an upright position. 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.[181] After the meal, residents should have their mouths inspected to ensure that food that could be aspirated does not remain in their cheeks. Education on how to perform emergency measures is important for the aged care team because residents with swallowing disorders may aspirate. A suction machine and oxygen should also be readily available.

Guidelines: Dysphagia

		Level	Reference
31.	A formal multidisciplinary assessment program may be beneficial in promoting early recognition, appropriate management and prevention of complications associated with dysphagia.	III & IV	180
32.	To provide effective dysphagia management for residents at risk of swallowing problems, a multidisciplinary team approach is required, including input from a speech pathologist.	III & IV	180
33.	The aged care team should ensure that the texture, consistency and type of food and fluid are as prescribed.	III & IV	180
34.	The aged care team should ensure that feeding techniques are undertaken in accordance with the specific methods recommended by the speech pathologist or physician, and they should also be aware of the safe feeding techniques generally recommended for individuals with neurogenic dysphagia.	III& IV	180

5.9 MOUTH CARE

Studies have revealed a high incidence of poor oral health in residents of RACFs[182] (Level QE);[183] (Level QE). There are many explanations as to why residents are likely to have poor oral health. Ageing itself can contribute to oral complications due to changes in the mouth (such as in tooth structure), wear and tear causing chewing surfaces to become smooth and enamel to be lost, and decreased or increased levels of salivation. Gum recession also creates 'pockets' where food debris and micro-organisms can collect, causing periodontal disease[184] (Level QE). Increased oral problems may occur due to medications (including oxygen therapy), mouth breathing, particular medical conditions and poorly fitting dentures. In one RCT, oral side effects were noted in persons receiving treatment for cancer[185] (Level I), and other RCTs have been conducted for people with cancer regarding best practice interventions for the prevention of mouth ulcers (oral mucositis). However, it is not known whether these interventions are transferable to older persons who do not have cancer as their major illness.

Poor oral health for residents in RACFs is considered to contribute to problems with eating and the low nutrient and vitamin C levels found[183] (Level QE). 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[182] (Level QE). Plaque retention, sore or fissured tongues, and oral ulceration were considered the main problems for residents regarding oral health[183] (Level QE). Poor oral health was also attributed to:[182, 183]

- RACFs not implementing a systematic approach to dental care;
- Not implementing an evidence-based approach to dental care; and
- Reluctance to provide mouth care to residents.

The aged care team needs to understand the components of a healthy mouth in order to promote good oral care practices[184] (Level EO). A resident with a 'healthy mouth' is able to chew food adequately, has an absence of plaque and debris, has adequate levels of salivation, and regularly cleanses by mechanical means (assistance may be required).

5.9.1 Assessment

A thorough oral assessment is required to provide the basis for sound management of oral care and to facilitate prevention or minimisation of oral complications[186] (Level QE). Although a number of assessment tools have been devised, there are concerns that many of these lack reliability and validity, limiting their clinical utility[186] (Level QE). However, the D-E-N-T-A-L screening tool was found to have reasonable validity and reliability for assessing severe periodontal and denture needs, though it was not sensitive to identifying persons with severe need for denture-related care[187] (Level III-3).

The D-E-N-T-A-L is a self-report questionnaire that looks at the older person's perception of dental treatment needs.[188] It is not an assessment tool; rather it helps to determine the individual's need for referral for further evaluation. The older person completes the assessment by responding 'yes' or 'no' to the following areas of concern:

	Point value
Dry mouth	2
Eating difficulty	1
No recent dental care (within 2 years)	1
Tooth or mouth pain	2
Alternation or change in food selection	1
Lesions, sores or lumps in the mouth	2
Score	

For each 'yes' the point value is given ('no' = 0). Positive items are then calculated, which provides a score. A score greater than 2 points indicates that a dental problem exists that might affect the resident's wellbeing.[188] The D-E-N-T-A-L is appropriate for use with older persons with no cognitive impairment; however, further research is required before the tool can be used for people with advanced dementia. Similarly, further testing is required to determine the validity and reliability if the tool is completed by anyone other than the older person.

One further tool that studies found had reasonable reliability and validity was the single-item self-report Geriatric Oral Health Assessment Index to dental care (GOHAI)[189] (Level IV);[187] (Level III-3). The GOHAI uses a single question: "How would you describe the health of your teeth and gums? Would you say it is excellent, very good, good, fair or poor?" [190] The responses are then scored from 1 to 5, 1 for 'excellent' through to 5 for 'poor'. This single question was found to be better than the D-E-N-T-A-L at identifying people with a severe need for denture-related care, severe dental need or severe periodontal need[187] (Level III-3). Scores of 4 or 5 were found to be the most accurate for identifying dental care needs and a suitable cut-off point for ensuring that referrals for dental evaluation and treatment were made[187] (Level III-3).

The GOHAI could be an appropriate screening tool to include in a resident's assessment, given its brevity. However, as with the D-E-N-T-A-L, the GOHAI's appropriateness for older persons with advanced dementia has not been determined and further research is required. The most appropriate screening tool for use with residents is the GOHAI, as the tool is very accurate at identifying older persons who do not require care, which was something the D-E-N-T-A-L was unable to do[187] (Level III-3).

Irrespective of what tool is considered to be the most appropriate, clear standards are required regarding routine mouth care. These standards need to 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[182] (Level QE). Assessment should include the fit of dentures, moistness of the oral cavity, presence of gum inflammation, infections such as candida, and presence of mucosal lesions or ulcers. Those most at risk of poor oral care are residents who are reluctant to eat and drink, who have lost their thirst reflex and are dehydrated, or are receiving medications (e.g. antidepressants, antihypertensives, antipsychotics, diuretics, narcotic analgesics) that exacerbate oral problems, i.e. xerostomia (dry mouth; see Glossary).

The fundamental principles for oral care are that it must be individualised and that the frequency of care is more important than the use of specialised agents. 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[182] (Level QE).

5.9.2 Management

No single intervention is appropriate for oral care of residents receiving a palliative approach. Instead, a range of simple measures is the most effective in managing and improving oral care. These measures, when instigated early, can prevent and reduce oral complications. Regular oral hygiene, including cleansing with water, is essential for the resident's comfort. 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[191] (Level II).

A multidisciplinary approach is preferable, with collaboration between the aged care team, dental services, occupational therapists and dieticians to ensure that the aged care team are supported in their practice of oral care for residents[182] (Level QE). Improved referral and feedback procedures are also required to ensure that all the aged care team are aware of these protocols. A continuing education program for the aged care team (of all levels) is also recommended to promote good oral care practices[182] (Level QE).

Guidelines: Mouth care

		Level	Reference
35.	Oral complications can be reduced by good hygiene, regular assessment, cleansing of dentures and use of oral fluids.	QE	186
36.	Asking an older person "How would you describe the health of your teeth and gums? Would you say it is excellent, very good, good, fair or poor?" is an accurate way to identify individuals with any denture-related needs, as well as those who do not need dental care. It is recommended that this question be included in oral health assessments as a reliable basis for determining when to refer for further evaluation and dental treatment.	III-3	187
37.	The most effective oral cleansing routine is rinsing with water and cleansing with a soft toothbrush and toothpaste. Dentures require regular soaking in a weak non-toxic solution.	II	191
38.	A multidisciplinary approach to oral health is preferable, with collaboration between the aged care team, dental services, occupational therapists and dieticians to ensure that members of the aged care team are supported in their practice of oral care for residents.	QE	182

5.10 SKIN INTEGRITY

The major skin problems associated with ageing include oedema of limbs, wounds and ulcers. Normally the goal of wound management is to promote healing; however, in a palliative approach this may not be possible, particularly in terminal care (See Chapter 13, 'End-of-life (terminal) care').

It is anticipated that most care assistants and nurses in RACFs will have considerable experience in providing adequate skin care, so these procedures will not be repeated here. Suffice to say that skin integrity is important for residents receiving a palliative approach. The complexity of maintaining skin integrity with a palliative approach requires a multidisciplinary team intervention that involves family members and carers. Any provision of information for the family and carers must be approached in a sensitive and realistic manner. With this in mind, the treatment for skin integrity should be realistic and agreed to by all concerned.

Although it has been common practice to turn the resident every two hours to prevent ulcers, a more suitable approach is one based on the individual resident's assessed need. To determine the appropriateness of such practices the following questions have been proposed[192] (Level EO):

- Is it essential to alter the position of the resident?
- Will the intervention cause more discomfort than is necessary?
- Can we use other alternatives? (For example, there is good evidence for the effectiveness of air-fluidised and low air loss mattresses[193] (Level I), though there is no conclusive evidence to determine the most effective surface for either prevention or treatment of ulcers[193] (Level I). See Chapter 13, 'End-of-life (terminal) care', for further discussion of comfort associated with frequent position changes).

5.10.1 Oedema of the limbs

Assessment

The limbs should be examined for any signs of swelling. Residents and their families can also indicate if they perceive that any limbs seem more swollen than normal. Assessment should include investigations to determine low albumin levels, which are associated with loss of protein.

Management

Oedema of the limbs can cause the resident, family members and carers concern, but there is sometimes little that can be done to resolve the swelling. Support for the family might include providing them with information on the causes of the oedema, as well as involving the family in using techniques that may yield some relief. Some of the suggested options could include[192] (Level EO):

- elevation of the swollen limbs;
- daily or more frequent washing (only if necessary);
- minimal handling;
- a bed cradle;
- pain relief;
- leaving limbs uncovered on water-resistant non-stick disposable sheets to protect bed linen (from weeping that may occur from the tissues in extreme cases);
- massage (if the oedema is not extreme), as this might provide some relief for the resident—this can be provided by the family or a massage therapist; and
- dietary interventions—depending on albumin levels, stage of the resident's illness and/or ageing, and their preferences.

5.10.2 Wound care

Assessment

Careful assessment when dressings are changed is essential to identifying infection early. Other areas of assessment relevant to wound care should also be considered, such as pain. (See also Section 5.2, 'Pain management', for a brief discussion of incident pain and recommended use of analgesia for wound care.)

Management

Wound care specialists fulfil an important role as part of a multidisciplinary team as part of a palliative approach in RACFs. They can be consulted for their expertise; however, their services are generally limited to the more populated or metropolitan areas and hence they may be unavailable in rural and remote facilities.

Wounds can occur in residents for a variety of reasons, such as immobility, inadequate skin integrity, trauma and malnutrition. The same principles for wound management in general health care are usually applicable to a palliative approach (see the *Australian Standards for Wound Management*[194]). However, a central focus when devising a treatment plan for wound care is the preference of the resident and/or their family. Residents in the terminal phase of ageing or illness may be unlikely to have wounds that will heal before they die, but care should remain attentive and be focused on ensuring their comfort.

5.10.3 Ulcers

As it is anticipated that the aged care team will have a sound understanding of the assessment and management of ulcers, this will not be covered in this section. Should further direction be required, contact the Australian Wound Management Association (see Appendix F for details). However, as non-pharmacological interventions are frequently used in the treatment or prevention of ulcers, the literature for this area has been reviewed and is provided below.

Non-pharmacological management

Systematic reviews of randomised clinical trials to assess the effectiveness of the use of therapeutic ultrasound[195] (Level I) and electromagnetic therapy[196] (Level I) in the treatment of ulcers found no evidence of these therapies being beneficial. One study of trace mineral deficiencies (e.g. zinc deficiency) in older persons found that these deficiencies can negatively affect the immune system and slow wound healing[154] (Level III-2). However, in the terminal stage of progressive illness or ageing the use of minerals is unlikely to be warranted.

Guideline: Skin integrity

		Level	Reference
39.	The use of air-fluidised and low air loss mattresses is effective in the reduction of ulcers.	I	193

5.11 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[197] (Level III-3). 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[198] (Level II). 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.

5.11.1 Assessment

Bowel assessment is an ongoing component of care in all RACFs. Because medications frequently used in a palliative approach can increase the risk of bowel symptoms, including constipation, increased vigilance by the aged care team is required. A daily assessment of bowel function is required and should include the resident's preferences for treatment, history of bowel habits, and management[197] (Level III-3). Assessment could include consideration of issues such as whether the resident expresses a desire to defecate, whether they are showing signs of discomfort, whether they are eating and drinking, whether the rectum is full, and whether there are skin problems caused by bowel leakage due to overflow from constipation.

Any symptoms of constipation should be considered, as the cause dictates the treatment. Symptoms may include:[199]

- nausea or vomiting;
- straining during defecation;
- infrequent bowel movements;
- feelings of incomplete emptying after bowel movements;
- frequent small amounts of diarrhoea;
- rectal pain on defecation;
- stomach pain, distension or discomfort (stimulant laxatives, i.e. lactulose, can cause these problems, so it is important to assess if the laxative itself is causing the symptom);
- hard stools; and
- faecal incontinence.

5.11.2 Management

Pharmacological management

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[199] (Level QE). The most significant factor for residents receiving a palliative approach is opioid-induced constipation[198] (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[198] (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[198] (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[198] (Level II).

If a laxative must be prescribed for a resident, then a discussion between the doctor and RACF nursing staff to decide on the most appropriate laxative is encouraged[198] (Level II). Brocklehurst and colleagues[198] (Level II) 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[198] (Level II).

Non-pharmacological management

Interventions to prevent constipation may be of assistance. These may include dietary advice, gentle exercise, establishing effective bowel habits, and ensuring there are appropriate toileting facilities[199] (Level QE).

Guidelines: Bowel care

		Level	Reference
40.	A daily assessment of bowel function is required. Management decisions may take account of the resident's preferences for treatment and their history of bowel habits.	III-3	197
41.	A discussion between the doctor and nursing staff to decide on the most appropriate laxative for use with a resident should be encouraged.	II	198
42.	The combined use of bulk laxatives and suppositories is associated with the lowest rates of faecal incontinence. The use of the suppository *after* bowel clearing prevents recurrent constipation.	II	198
43.	If a laxative is used, compensatory measures for dehydration and electrolyte depletion are recommended.	II	198

5.12 DYSPNOEA

Dyspnoea is defined as an awareness of uncomfortable breathing that can seriously affect quality of life and is frequently associated with the end stage of various diseases, such as cancer, cardiac failure, obstructive airway disease, and neurodegenerative disorders[200] (Level II). The experience of dyspnoea comes from multiple physiological, psychological, social and environmental factors that can result in secondary physiological and behavioural responses[201] (Level II). The experience of dyspnoea (i.e. breathlessness) may not be directly attributed to the disease, because other factors such as anxiety exacerbate the symptoms[202] (Level IV). 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[201] (Level II). It can also be a sign of a deteriorating condition in residents receiving a palliative approach.

Dyspnoea triggers panic, and panic exacerbates dyspnoea, so the pattern becomes cyclical. The evidence suggests that 70% of people receiving a palliative approach experience dyspnoea in the last six weeks of life[203] (Level QE). In the terminal phase of ageing and/or illness, fear of suffocation may be the most troubling symptom. This may significantly affect the ultimate place of death[202] (Level IV).

Dyspnoea may also be a distressing and frightening symptom for the family. Advice and support regarding the management of dyspnoea [201] (Level II) from the aged care team, as well as reassurance and a calm presence, can help lessen the anxiety experienced by the resident and their family. It is important to note that even after a resident's dyspnoea has been relieved family members might require more attention from the aged care team[203] (Level QE). Family members' perceptions of a resident's suffering can influence how the family makes meaning of, and come to terms with, the dying experience of the resident.

5.12.1 Assessment

A complete history and physical examination will illicit enough information to determine a diagnosis of dyspnoea in most people. The history should cover factors that are likely to have influenced the severity of the symptom[201] (Level II), including pre-existing illnesses (such as chronic obstructive pulmonary disease), exacerbating factors (such as anaemia or profound anxiety) and additional factors (such as pulmonary embolism, infection or left ventricular failure).

The resident's perception of dyspnoea can also be measured using a visual analogue scale, with 0 being no shortness of breath and 10 being the worst shortness of breath. This measure provides the aged care team with some understanding of how distressing dyspnoea is for the resident.

5.12.2 Management

The aim of managing dyspnoea for a resident receiving a palliative approach is to minimise suffering and not to prolong life[203] (Level QE). If there are specific causes of dyspnoea these should be treated in accordance with the resident's preferences. These causes may include cardiac failure, pulmonary embolus, infection, anaemia, arrhythmia, pleural effusion, bronchospasm or pneumothorax. Managing the symptoms of dyspnoea should include supportive care for the resident, family members and their carers, and the use of medications, which may include opioids. A comprehensive plan of care, including ready access to appropriate medication treatment along with non-pharmacological interventions to reduce psychological distress, may prevent unnecessary transfers to acute care settings of residents with gradually increasing dyspnoea[202] (Level IV).

Pharmacological management

Pharmacological intervention depends on the early recognition of the symptoms of dyspnoea[201] (Level II). Pharmacological treatments that have been considered for use with dyspnoea include use of oxygen, sedatives and opioids.

Opioids

A systematic review of studies was conducted to examine the effectiveness of opioid drugs given by any route to relieve the symptoms of dyspnoea in people receiving a palliative approach[204] (Level I). The reviewers concluded that there was a beneficial effect on the symptom of breathlessness for opioid drugs administered orally or parenterally. However, no effect was found to support the use of nebulised opioids for dyspnoea, and the reviewers concluded that it was hard to justify the continued use of this treatment[204] (Level I).

A further study found that people with dyspnoea benefited from sustained-release low-dose oral morphine[200] (Level II). Opioids decrease the perception of dyspnoea and decrease oxygen consumption. Therefore opioid therapy is the main intervention recommended in managing dyspnoea.

Oxygen

Initiating a dose (or a change of dose) of oxygen may be contra-indicated (particularly for residents with chronic respiratory condition), and the commencement of oxygen should only be undertaken under the direction of a medical practitioner. Oxygen is often considered to be a non-specific treatment for dyspnoea; however, individuals can become highly dependent on oxygen supplementation to the extent that some people consider it to be their 'lifeline'[205] (Level EO).

Not all residents with dyspnoea will benefit from oxygen and extreme caution is warranted regarding the use of oxygen supplementation due to its contraindications and risk of dependency for some residents. However, if the use of supplemental oxygen were indicated, then a nasal cannula is recommended, because masks make some residents feel isolated and frightened. An initial 24-hour trial of continuous or intermittent oxygen supplementation is recommended, followed by some form of subjective assessment by the resident to determine the therapy's benefit[205] (Level EO). However, it should be explained to residents and their families that only a small number of residents benefit from oxygen and that other alternatives might be more beneficial (these are discussed below).

Non-pharmacological management

Two studies have been conducted regarding a therapeutic intervention that combined breathing retraining, psychosocial support and development of adaptive strategies for the management of dyspnoea[201] (Level II);[206] (Level II). Both studies found that interventions using psychosocial support, breathing control and learned coping strategies helped individuals to cope with dyspnoea and reduced their physical and emotional distress. Both studies also involved the individual's family members.

Other non-pharmacological interventions that are considered beneficial for reducing the distress of dyspnoea, include[205] (Level EO):

- reducing the resident's need for exertion;
- propping the resident up;
- having a cool fan blow on the resident's face; and
- physiotherapy.

Guidelines: Dyspnoea

		Level	Reference
44.	A complete history and physical examination will generally provide enough information to determine a diagnosis of dyspnoea. The history should cover factors that are likely to have influenced the severity of the symptom, including pre-existing illnesses (such as chronic obstructive pulmonary disease), exacerbating factors (such as anaemia or profound anxiety) and additional factors (such as pulmonary embolism, infection or left ventricular failure).	II	201
45.	Non-pharmacological interventions based on psychosocial support, controlled breathing and learned coping strategies can help people cope with dyspnoea, which will further reduce physical and emotional distress.	II II	201 206
46.	People with dyspnoea can benefit from the use of a sustained-release low-dose oral morphine administered orally or parenterally.	I II	204 200
47.	A comprehensive plan of care, including ready access to appropriate medication treatment along with non-pharmacological interventions to reduce psychological distress, may prevent residents with gradually increasing dyspnoea being transferred to hospital unnecessarily.	IV	202

5.13 COMPLEMENTARY AND ALTERNATIVE THERAPIES

The National Center for Complementary and Alternative Medicine (NCCAM) in North 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.[207] The Center also distinguishes between 'complementary' and 'alternative' medicines, with complementary medicines being used *together with* conventional medicine and alternative medicines being used *in place of* conventional medicine.

A systematic review of therapies involving complementary and alternative medicines (CAM) for symptom management near the end of life found that, despite a dearth of evidence, there is adequate data to support the use of some CAM therapies.[208] The authors' conclusions were that for people who were dying or who had cancer:

- CAM therapies were beneficial for those who could not tolerate or did not want to take pain medications;
- CAM therapies were helpful adjuvants to analgesic therapies;
- CAM therapies may be culturally sensitive for many people, and were beneficial in enhancing a person's sense of control;
- For pain management, in addition to using traditional analgesics (including opioids), it may be useful to combine such treatments with acupuncture, TENS, relaxation and imagery, and hypnosis; and
- To treat the underlying causes of dyspnoea (for people with moderate to severe breathing difficulties) and to improve functional capabilities (e.g. walking) it is valuable to use acupuncture, acupressure, muscle relaxation with rebreathing training, and rebreathing training combined with coping strategies[208] (Level II).

Aromatherapy has been the subject of some research and investigation. A systematic review found an aromatherapy intervention had positive outcomes for measures of agitation and neuropsychiatric symptoms in people with dementia.[209](Level I) There is some evidence that using essential oils with massage reduced anxiety and improved quality of life scores in hospice patients[210] (Level III-1).

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, Phillips, Hamel and Eisenberg found that 30% of North Americans aged 65 years and over reported using alternative medicines and 19% had visited an alternative medicine provider.[211] Chiropractic and herbal use were the most common treatments[211] (Level QE).

Spoelhof and Foerst have commented on issues and concerns in managing CAM therapies in RACFs.[212] 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 reviewed the data on published adverse effects of botanical preparations,[213] and concluded that, given the extent of use, there is an urgent need for serious research into the risks of phytomedicines (Level QE). 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[214] (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'). The process involved the use of a reality orientation board which 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 has drafted guidelines relating to pain management.[82] These guidelines advocate principles regarding the use of CAM therapies. These principles are reproduced here, with some adaptations, due to their clarity:[82]

- 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.

CAM therapies may be beneficial for some residents, depending on their symptoms, culture, and beliefs about the use of such therapies. There is some evidence to support the use of a limited number of CAM therapies for pain management, symptom alleviation and improvement in quality of life. However further studies, particularly focusing on palliative care and RACFs, are still required.

Guidelines: Complementary and alternative therapies

		Level	Reference
48.	In general, complementary and alternative therapies for symptom management in palliative care are beneficial for those who refuse or cannot tolerate pain medications in enhancing their sense of control and cultural sensitivity.	II	208
49.	The combination of traditional analgesic treatments with acupuncture, TENS, relaxation and imagery, and hypnosis are helpful in symptom management.	II	208
50.	To treat the underlying causes of dyspnoea (for people with moderate to severe breathing difficulties) and to improve functional capabilities (e.g. walking), the use of acupuncture, acupressure, muscle relaxation with rebreathing training, and rebreathing training combined with coping strategies are considered to have a beneficial effect.	II	208
51.	An aromatherapy intervention to treat agitation and neuropsychiatric symptoms in people with dementia can have positive effects.	II	209
52.	A massage with essential oils is beneficial for reducing anxiety and improving quality of life when used with people receiving a palliative approach.	III-1	210
53.	The use of ginkgo for older persons with mild to moderate dementia is not recommended as it was found to be an ineffective treatment.	II	214

CHAPTER 6

Psychological support

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[215] (Level EO). Similarly, a palliative approach focuses not only on physical symptoms but on psychological care. Psychological care is concerned with the psychological and emotional wellbeing of the resident and their family, including issues such as self-esteem and adapting to ageing, illness and the RACF environment. The fundamental principle for psychological support is an accurate diagnosis of the factors contributing to psychological distress.

Psychological distress is the term applied predominantly to anxiety, phobic and depressive symptoms.[216] 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[216] (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[217] (Level QE). Therefore, the interactive effects of psychological and physical wellbeing need to be carefully considered.

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[218] (Level IV). Both somatic and psychological symptoms of depression and anxiety can make a diagnosis more difficult[219] (Level EO). For example, anxiety might appear as nausea or dyspnoea, and depression may manifest as intractable pain.[219] These symptoms may respond poorly to medical interventions and not appear to be based on medical pathology.

The following story illustrates the need for family involvement in the assessment of a resident's psychological distress.

Mr Poulton

It was time for the regular review of Mr Poulton's care, his two sons being invited to attend. They were also anxious to discuss with the doctor what they perceived as signs of their father's depression. Mr Poulton, aged 89, suffered the debilitating effects of Parkinson's disease, as well as cardiac problems and signs of dementia. Given the choice, he wanted to come to the meeting "to speak for myself". The process of asking him about his response to life in the RACF was painfully slow, because his replies were given in halting, hesitant speech. "What do you miss most?" he was asked. "The loss of speech", he replied, with some emotion. His older son explained that until he was 85 Mr Poulton had been a regular participant in an elite play-reading group, having significant skills in performing Shakespeare's characters. Through the ensuing discussion it became evident that more understanding was needed on the part of the aged care team when communicating with Mr Poulton. It was also agreed that medication might help to lift his mood. His care plan was adjusted to highlight his preference for more time to be spent on verbal communication than trying to improve his mobility: "I don't mind if I can't walk, but I do mind if I can't have a chat." Some of the aged care team and family members had perceived his low mood as indicating a wish for death. Although severely disabled and increasingly dependent, he said with animation, "I hope I can look forward to a few more years yet".

6.1 DEPRESSION

Depression is one of the most common psychiatric disorders in older persons. A recent Australian survey suggested that 40% of residents in RACFs were mildly depressed, with higher rates of depression evident in residents in high-care facilities compared to low-care facilities[220] (Level QE). However, there is evidence that there is significant under-treatment of late-life depression.[216]

Prevalence rates of depression range from between 25% and 45% among people receiving palliation[218] (Level IV), yet the percentage of those receiving treatment for depression is significantly lower. Findings suggest that potentially large numbers of psychologically distressed residents are not receiving appropriate psychological care[216] (Level IV).

Psychological symptoms differ in severity, persistence and quality from 'normal' distress. Residents with depression may be unhappy about their current situation and speak of little else than their wish to be 'done with it'. This expression may be a manifestation of the burden they feel they are to others, a pervasive loss of interest and pleasure, and/or an overall feeling of apathy. Depression is frequently associated with suicidal thinking[221] (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[222] (Level QE). Although suicide attempts or requests may seem understandable, they are often an indication of clinical depression, and referral for psychological assessment should be made[52] (Level QE).

6.1.1 Death statements and depression

A comprehensive assessment and appropriate response to a resident's expression of a desire for death is vitally important[52] (Level QE). Depression is frequently undiagnosed and should therefore be considered as a potential reason for 'desire to die' statements[52] (Level QE). Diagnosing depression in people with a terminal illness or in the end stage of the ageing process can be complicated (see Table 9 for symptoms of depression). An alternative to the *Diagnostic Statiticians Manual* (4th ed) (DSM-IV)[223] criteria for depression is available (see table 10) and may be a useful guide for members of the aged care team who are suitably trained[224] (Level IV).

Physical manifestations of depression may also be useful in screening for depression in RACF residents. A number of symptoms have been described that may be indicators of depression (see Table 9). If several of these symptoms are apparent to the aged care team, the resident should be referred to an appropriate professional (e.g. geriatrician or psychologist).

Table 9: Symptoms of depression (Adapted from DSM-IV)[223]

- Loss of interest or pleasure
- Depressed mood
- Sleep disturbance
- Poor pain and symptom control
- Suicidal thoughts
- Inability to think or concentrate
- Feelings of worthlessness, hopelessness or helplessness, inappropriate guilt, and/or persistent negativism
- Agitation or retardation
- Fatigue
- Altered appetite
- Flattened mood (lack of expression in situations that previously had been pleasurable)
- Frequently expressed death desire
- Recurring thoughts of suicide or death
- Social withdrawal (attempts to remain away from people when previously would engage, no connection with care givers)

6.1.2 Assessment

It is important to note that no tool currently exists that can assist in distinguishing between delirium, depression and dementia; therefore, different screening tools are required for each. Depression can be screened by the use of very brief scales, suitable for use with residents. 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[224] (Level IV). The tool found to be most effective was the Mental Health Inventory (1-Item Version; MHI-1),[225] which asks: "How much of the time over the past month have you felt downhearted and sad?"[224] (Level IV). Possible responses range from 1 to 6, as shown below, with a score of 3 or higher indicating potential depression. The aged care team could incorporate this question into their plan of care as a simple way of screening residents for depression.

Table 10: Mental Health Inventory (1-item version)[225]

Question: How much of the time over the past month have you felt downhearted and sad?

Response choices:

All of the time	6	Some of the time	3
Most of the time	5	A little of the time	2
A good bit of the time	4	None of the time	1

It should be noted that the MHI-1 is only recommended for identifying those who require further assessment for depression; it should not be used in the place of a formal assessment for depression, such as the Geriatric Depression Scale or the Cornell Scale.

The Geriatric Depression Scale (GDS) is available in two formats: a 30-item scale (GDS-30)[226] and a 15-item scale (GDS-15).[227] The GDS is an assessment tool to assist in determining depression for older persons, including those in long-term care. A study of the GDS found the use of this scale for screening for depression could increase the frequency of treatment or referral of people in long-term care by primary care physicians[228] (Level II). A recent study of the GDS-15 found that the tool was suitable for diagnosing depression in the over 85-year-old population[229] (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[229] (Level QE).

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).[230] 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:[230]

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.[231] Additionally, CSDD scores have demonstrated moderate to high correlations with clinical diagnoses of major depression for older persons with or without dementia.[231] However, further rigorous analysis of the CSDD found evidence of four factors rather than the five proposed by the authors of the CSDD.[232] These results indicate that the CSDD sub-scales should be interpreted with some caution until further studies determine the factor structure of the CSDD. In the interim, this scale appears preferable to the GDS, given the CSDD's reliability for assessing depression in older persons with dementia.

The CSDD and GDS are available as part of a kit called Challenge Depression, which aims to reduce the level of depression in Australian RACFs. Visit www.dementia.com.au/depression.htm for further information regarding this kit.

6.1.3 Management

Pharmacological management

The first factor that is generally considered when choosing pharmacological interventions is the resident's life expectancy[233] (Level EO). According to Martin and Jackson[233] (Level EO), residents who are expected to live for more than two months may have time to respond to antidepressants, such as SSRIs (selective serotonin re-uptake inhibitors). These medications have fewer side effects than other antidepressants and are less sedating.

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[233] (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[234] (Level EO). Methylphenidate is considered the most appropriate of these for use in a palliative approach[235] (Level QE).

Irrespective of which intervention is preferred, psychological changes in residents should never be dismissed as untreatable or inevitable. Improvements in the resident's psychological state can be achieved in spite of deteriorating physical functioning. Failing to investigate the resident's psychological state would deny them appropriate treatment, thus projecting a sense of hopelessness.

Non-pharmacological management

Counselling and psychiatric interventions can improve the psychological wellbeing of residents in the palliative phase of their ageing or illness. Residents may need an opportunity to verbalise their feelings, beliefs and regrets about death and dying. Emotional and social supports are important characteristics of intervention techniques. Simply providing a listening ear can be therapeutic. These types of interventions, combined with assessment and treatment of depression, confusion and anxiety, are essential components of a palliative approach[53] (Level QE).

Residents and their families should be given an explanation of how the ageing or illness process is progressing. They may also need to express their feelings without fear of censure or abandonment. However, a recent study found that the aged care team may have difficulty determining symptoms of depression, because residents may be reluctant to disclose their feelings for fear of being labelled a 'bad' or 'weak' person[218] (Level IV). An open, supportive environment can promote trust, which could help to overcome this barrier and help the resident's adjustment process, thus enabling them to move towards accepting their situation.

Education and training in communication skills for the aged care team could also help to remedy this barrier to open communication. Knowing the resident's previous personality and psychological state is helpful in identifying high-risk individuals or those with developing symptoms. The family's observations of any recent changes in the resident's mental state should also be noted.

6.2 ANXIETY

Anxiety is an arousal state. People experience anxiety in different ways, but the following three elements are considered to be common symptoms[236] (Level III-3):

1. A conscious feeling of fear and danger without the ability to identify immediate objective threats that could account for these feelings;
2. 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
3. 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[236] (Level III-3). Hence, a resident's psychological history should be documented to determine any previous episodes of anxiety. A study by Keogh and Birkby[237] (Level QE) found that the more pain a person suffered, the greater their level of anxiety. A further study found that anger intensity was significantly related to pain intensity, pain behaviours and the level of interference with daily functioning[238] (Level QE).

6.2.1 Assessment

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[239] (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[240] (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[241] (Level III-2).

6.2.2 Management

Non-pharmacological management

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)[242] (Level III-3). 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.

6.3 CONFUSION

Residents experiencing confusion may appear forgetful, and disoriented to time and place, and exhibit changes in mood or behaviour[219] (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[243] (Level QE). 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:[243]

- 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.[243] 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.

6.4 DELIRIUM

Delirium refers to a clouding of consciousness. The severity of the delirium fluctuates and can worsen after dark. Most prevalence studies of delirium have been conducted in hospitals with medically ill people, in whom the prevalence rate was about 25%[244] (Level EO). Delirium may involve paranoid ideas, which may manifest as an idea that the food has been poisoned, for example. Residents with delirium may be noisy, demanding or aggressive, which may upset or harm others. Family members or others may report a rapid and drastic decline in the resident's functioning, which is useful in distinguishing delirium from dementia.

6.4.1 Assessment

A standardised confusion assessment method is available which enables non-psychiatric clinicians to detect delirium quickly in high-risk settings in older persons[245] (Level III-2). The confusion assessment instrument consists of nine operationalised criteria from the DSM-III-R. The diagnoses made by the confusion assessment method were validated against the diagnoses made by psychiatrists. It was concluded that the confusion assessment method is sensitive, specific, reliable and easy to use for identifying delirium and could be appropriate for suitably qualified members of the aged care team to use.

6.4.2 Management

Prescribed drugs and acute infections are perhaps the most common cause of delirium, particularly in older persons[244] (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)[244] (Level EO). Good management of delirium requires[244] (Level EO):

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

Table 11: Distinguishing delirium from dementia

Indicators	Delirium	Dementia
Onset		Acute or subacute Insidious
Course	Fluctuating, usually resolves over days to weeks	Progressive
Conscious level	Often impaired, can fluctuate rapidly	Clear until later stages
Cognitive defects	Poor short-term memory, poor attention span	Poor short-term memory, attention less affected until severe
Hallucinations	Common, especially visual	Often absent
Delusions	Fleeting, non-systematised	Often absent
Psychomotor activity	Increased, reduced or unpredictable	Can be normal

British Medical Journal, 2002, 325 (7365), 644–647, with permission from the BMJ Publishing Group[244]

6.5 DEMENTIA (PSYCHOLOGICAL ASPECTS)

Dementia is a syndrome of progressively deteriorating cognitive function associated with an underlying disease process such as Alzheimer's disease. A resident who exhibits a diminished ability to communicate and comprehend needs specialised psychological care and support (see Chapter 4, 'Advanced dementia', for more information). This should include the family as appropriate, and should be instituted as a part of a palliative approach. For the resident with dementia, psychological support will include alternative communication strategies. For the family, psychological support will address issues such as an ongoing sense of loss and difficulty in finding a caring role (see Chapters 7, 'Family support', and 8, 'Social support, intimacy and sexuality').

6.5.1 Assessment

There are various assessment tools available for determining a resident's level of cognitive impairment. One that is frequently recommended is the MMSE.[246] Nurses generally undertake the routine administration of the MMSE in palliative settings and it is frequently used in aged care.

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?"[247] (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. This finding requires further research, but it does bear important consideration when working with residents with dementia, particularly the need to still communicate with them regarding their preferences.

Behavioural disturbances

There is a wide variation in rates of behavioural and psychological symptoms of dementia reported in RACFs[248] (Level QE). One study found that over 90% of residents exhibited at least one behavioural disturbance. Specifically, there was evidence of psychosis in 60%, depressed mood in 42% and activity disturbance or aggression in 82% of residents[248] (Level QE). More functionally impaired residents with a diagnosis of psychosis had higher behavioural and psychological symptom rates. The researchers concluded that behavioural disturbances are frequently associated with psychosis and/or depression. Unfortunately, there is little evidence regarding behavioural disturbances in RACFs to provide direction regarding assessment and management. It is suggested that the need for psychogeriatric services for RACFs is essential in aiding the aged care team in dealing with such residents.

6.5.2 Management

Psychological/psychiatric intervention is recommended when the resident presents with various psychological symptoms which have lasted longer than a few weeks[219] (Level EO). However, it is recognised that in many rural and remote areas it would be difficult to access a psychiatrist or psychologist on a regular basis to complete assessments of residents. In such situations the use of Telehealth or other forms of electronic communication could overcome such a barrier, as could the involvement of a GP to complete the assessment.

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[221] (Level QE);[249] (Level QE);[250] (Level EO).

Guidelines: Psychological support

		Level	Reference
Depression			
54.	Using a Geriatric Depression Scale (GDS) to screen for depression can increase the frequency of treatment or referral of residents in RACFs by their doctors.	II	228
55.	Although suicide attempts or requests may seem understandable, they are often an indication of clinical depression and require an active response.	IV	52
Anxiety			
56.	Gentle massage can reduce anxiety levels or agitated behaviours for residents with chronic pain and/or dementia.	III-2	242
Delirium			
57.	Using the standardised confusion assessment tool is recommended for residents with delirium as it enables non-psychiatric clinicians to quickly detect delirium in older persons.	III-2	245
Dementia			
58.	Many residents can answer questions on their quality of life even when significant symptoms of dementia are present. Therefore a resident's preferences for quality of life concerns should still be sought and incorporated into decision-making.	IV	247
Psychological Support			
59.	Incorporating the use of a specialised palliative team who have some expertise in assessment and care of those with depression, agitation, loss and/or anxiety is considered beneficial.	QE QE	221 249

CHAPTER 7

Family support

The palliative approach generally refers to the family as the 'unit of care'. However, such a view is often tied to the more traditional western society view of the family as a nuclear entity based on biological or marital ties. Modern society does not always reflect this traditional view of the family and therefore the aged care team's notions of 'family' must be much broader and more inclusive.

7.1 WHAT IS A FAMILY?

A family member can be considered as any person who is part of the central core in the support network of an individual, including non-family carers. Palliative Care Australia[251] uses the Canadian Palliative Care Association[252] definition of family:

> *"... those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (not related biologically, by marriage/contract" (p.10)*

Based on this definition, family could include carers, friends, neighbours or the aged care team; this description extends the boundaries beyond biological and legal relationships. Both definitions highlight that a person considered as family by a resident might not be a relation by birth or marriage.

7.2 FAMILIES AND A PALLIATIVE APPROACH

For some family members this may be their first experience of a palliative approach or their first experience of impending death. They need an opportunity to have privacy to attend to such matters as:

- treatment decisions;
- family members' history; and
- tensions that may surface at this time (e.g. relationships, financial concerns).

The family will also require education on how a palliative approach works, and an explanation of the signs of impending death, to reduce the family's fears.

Research undertaken to evaluate the effectiveness of a palliative approach has suggested that a palliative approach may be at least of equal value and may often be of more value to the family than to the resident[253] (Level III-2). The evidence suggests that families value not only technically competent physical care, but also regard emotionally sensitive care as especially important[254]

(Level QE). Families appreciate good communication with the aged care team, affirmation from the team that their input is valued, and permission to withdraw at times from the care-giving situation[255] (Level QE). Families describe the importance of time with the aged care team, being kept informed about the resident's condition, and being treated as if they have an active and equal role in the care planning process[66] (Level QE).

Specific palliative approach interventions found to be helpful to families include:

- Access to 24-hour medical and nursing advice (in rural and remote areas a 24-hour service is not always possible to maintain, and that support may be available through metropolitan-based services after hours)[254] (Level QE);
- Use of family conferences to obtain and share information[256] (Level III-2);[257] (Level QE);
- Attention by the aged care team to the resident as a 'whole person'[258] (Level QE); and
- Competent pain management and comfort measures[256] (Level III-2).

The family's trust in the aged care team is essential, helping them build a satisfactory partnership with the team[259] (Level QE). By entering into a care-giving partnership with the aged care team, some family members are able to express their love for the resident through contributing to their care[260] (Level QE);[261] (Level QE). Therefore, if a resident is admitted towards the end of their illness trajectory or ageing process, the aged care team needs to help the family build a satisfactory partnership as members of the team[35] (Level QE). To build this trust and fulfil families' needs, extra time and good communication skills are required from all the aged care team, including medical practitioners[257] (Level QE). The direct involvement of families at all stages of the resident's care is preferable, including prior to admission.

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[262] (Level QE);[259] (Level QE);[35](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[35] (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[35] (Level QE).

Depression was also found to occur for wives following the placement of their husbands in an RACF[263] (Level QE);[264] (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) [264] (Level QE) for residents, family and carers. However, if residents and their family were involved in decision-making, and were supported pre- and post-transfer, they reported higher levels of satisfaction[262] (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[254] (Level QE). Similarly, giving the family the option of having an ongoing caregiving role can also help them cope with any separation anxiety they might feel. 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[254] (Level QE).

7.3 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[258] (Level QE). This can be aided by such tools as a genogram (see Appendix G) or an ecomap (see Appendix H), which help visually document the resident's significant relationships. 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.[265] The ecomap extends beyond the genogram to include formal and informal social supports. It can therefore help in assisting the aged care team to understand the broader experience of loss and grief for those whose friend or relative is admitted to residential care.

An ecomap or genogram can also include information such as the type of participation individual family members wish to have in the care of the resident. Family members can raise at this time their need for training so they can be involved in daily activities such as feeding, particularly if the resident has swallowing difficulties. It is important to remember, however, that not all families wish to be involved in the ongoing care of the resident and this should be accepted and respected by the aged care team in a non-judgmental manner, as is illustrated in the following story.

Joan

Joan always appeared aloof and distant on the infrequent visits to her husband. Now that Joan's husband Tom was dying, the aged care team wanted to involve Joan by encouraging her to visit more often and to assist with his care. Joan felt there was an expectation placed upon her, until she explained the situation to a nurse she trusted: "I know I may seem uncaring but I'm exhausted from looking after him 24 hours a day at home. I just can't do any more. We haven't been a close couple for many years and I find it such a relief to have some life of my own at last." When this explanation was conveyed to other members of the care team, it reinforced the concept of individualised care, grounded in a comprehensive assessment of family processes, expectations and goals.

7.4 FAMILY INVOLVEMENT

The role of family in decision-making centres on the need for individualised care and providing a link to the community. The family's role is also important in providing relevant personal history and information about the resident's preferences[66] (Level QE). The role of family members as advocates for high-care residents may be limited by the weak position they may have in the organisation and by the complexity of their relationships with the aged care team. It might be beneficial for members of the team to encourage families to voice any concerns they may have and to encourage their participation in the resident's care, if this does not already occur. The following story illustrates how the aged care team can initiate family member involvement in their relative's care.

Doreen

Doreen faithfully visited her sister, Vera, for several hours each day. She was usually asked to leave the bedside when the aged care team were in attendance, until a particularly intuitive nurse asked, "Doreen, would you like to assist in Vera's care? Is there anything particular you would like to do for her?" "Yes", came the immediate response. "I would like to help make her comfortable. I could even wash her ... You see ... when I was about eight years old and Vera would have been about fifteen, I was very ill with a high fever. I remember Vera sponging me and it seemed at the time she helped save my life. I can't do much for Vera now that she's dying but I would like to repay her in some small way."

Doreen was pleased to be included in the care team, massaging Vera's limbs with fragrant oil and assisting the nursing staff with other care when appropriate. When Vera died the following entry was noted in the record of care: "Vera's sister wanted to assist by washing Vera's body and dressing her in a favourite nightgown." Doreen expressed her appreciation for this involvement, stating it had assisted her in closing the final chapter in the relationship with her sister, to whom she owed so much.

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[266] (Level III-2). Families benefit from emotional support and an opportunity to discuss their concerns about the resident's illness or ageing process[267] (Level QE). Holding a family conference can facilitate this support and information exchange[256] (Level III-2);[267] (Level QE);[257] (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[261] (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[268] (Level QE).

Health deterioration and death of the resident may also impact upon the physical and emotional health of family members[253] (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[269] (Level QE). The caregiver burden has been found to be heaviest on spouses, followed by daughters, other relatives and then sons[270] (Level QE). Some spouses, especially those of residents with advanced dementia, report feeling like a 'married widow'[263] (Level QE) and the term 'quasi-widowhood' is used in the gerontology literature[264] (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[271] (Level QE);[272] (Level QE). Management of agitated delirium is a frequent source of conflict between families and nurses[273](Level QE). Family members of confused or unconscious people may have higher expectations of nurses than family members of people who are lucid[274] (Level III-2). The higher the variance between expectations and perceptions, the poorer the family functioning in the bereavement period will be[274] (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[275] (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[276] (Level QE). 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[263] (Level QE);[268] (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[277] (Level QE).

Guidelines: Family support

		Level	Reference
60.	The family may play a particularly important role in assisting with managing symptom distress, communicating with the resident, and assisting with their physical care needs.	III-2	253
61.	Deteriorating health and the death of the resident may impact on the physical and emotional health of family members. Therefore the family members' stress requires monitoring by the aged care team.	III-2 III-2	253 257
62.	Families appreciate good communication with the aged care team, affirmation from the team that the family's input is valued, and permission to withdraw at times from the caregiving situation.	QE QE	254 255
63.	Families benefit from emotional support and an opportunity to discuss their concerns about the resident's illness or ageing process. This support can be provided during a family conference.	III-2 QE QE QE	257 258 261 267

CHAPTER 8

Social support, intimacy and sexuality

A palliative approach takes into account the social needs of the resident, such as the need for social support, and also considers issues of intimacy and sexuality.

8.1 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[278] (Level IV). Social isolation in older persons has been found to lead to poorer psychological wellbeing, such as depression, and diminished functional health[278] (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[279] (Level III-2).

More recently, Fratiglioni and colleagues[279] (Level III-2) 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%. Fratliogini and colleagues surmised that extensive social networks might delay the onset of dementia by providing emotional and intellectual stimulation and practical support[279] (Level III-2). 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.

8.1.1 Assessment

To help maintain the resident's links with their social network, it may be beneficial to assess their level of social support[278] (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[280] (see Section 7.3, 'Documenting family relationships', and Appendix G). Mapping a network of support via the genogram can vary in the time it takes, depending on factors such as individual differences and cultural diversity. An ongoing commitment to updating the genogram ensures that it remains current.

8.1.2 Management

The aged care team needs to provide opportunities for residents to maintain and begin new social relationships. Determining pre-existing social supports and promoting social integration of residents can reduce social isolation. It is recognised however that the aged care team may not have the time to assess a resident's social supports. A referral to a social worker or pastoral care worker may help to ensure the resident's needs are addressed. Volunteers can also play a role in helping to provide social support for residents receiving a palliative approach.

It is important to remember that not all residents perceive that they are lacking in social support and as a consequence may not wish to participate in social activities. Their wishes should be respected first and foremost. It is also important to acknowledge that some residents may consider the aged care team as family (and vice versa), especially those with whom they have established meaningful relationships. Research supports the occurrence of surrogate family bonds by staff members in RACFs, particularly for those facilities in rural locations[281] (Level III-2).

8.2 INTIMACY AND SEXUALITY

The following WHO definition of sexuality provides a basis for understanding the importance of sexuality for the resident:[282]

> *"Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships ... Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled."*

Intimacy and sexuality are basic human needs that are often neglected in discussions about the wellbeing of people receiving a palliative approach, particularly those in RACFs. However, sexuality does not disappear as a person ages. A person's ability to express their sexuality and have this need recognised with understanding and care may be an important factor in enhancing a person's wellbeing. It is easy to assume that residents requiring palliation would have other more important things than sexuality with which to be concerned, but this is not always the case. An individual's needs in this area require the aged care team to be non-judgmental and comfortable in acknowledging and discussing issues of sexuality.

8.2.1 Assessment

Few studies of sexuality in long-term care residents have been conducted. However, residents living in the same care facility are essentially compelled to live together until their death. Therefore, it should not be surprising to find that intimate relationships are sometimes formed. Residents who form relationships may be content to simply enjoy talking and participating in activities together. Companionship may be all that is sought and needed. However, there may also be a desire to express mutual affection in physical ways. Therefore, the aged care team needs to be aware of residents' requirements regarding intimacy and sexuality. For instance, 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[283] (Level QE).

Acknowledging the importance of touch is also important for both the aged care team and residents[284] (Level III-2). If residents experience touch primarily through routine handling procedures they may perceive touch in a negative way (even though it is not the intention of the aged care team to cause pain or discomfort); they may, therefore, miss opportunities to experience touch in a positive way. Access to massage therapists could help to meet a resident's need for caring and gentle touch. However, family might also be able to fulfil this role.

In a study of institutionalised older persons and gerontology nurses covering numerous topics, including female sexuality, Nay found that older women longed for closeness, touch and intimacy but were often afraid to reach out to other women in this way[283] (Level QE). Due to a loss of control over much of their lives, the only pleasure available to them was self-pleasuring and fantasy, but guilt, lack of privacy, and fear of being 'caught' negated these options. Nay also found that gerontology nurses who held ageist views of older women's sexuality were not providing holistic care. Until such ageist views are changed, the author considered that it was not possible to provide care aimed at maximising potential, independence and control.[283]

In another study of older female residents, Butts[284] (Level III-2) found that comfort touch (i.e. back rub, massage, hand holding, a friendly hug) improved residents' perceptions of themselves. These perceptions included self-esteem, wellbeing and social processes, health status, life satisfaction, self-actualisation, faith and belief. Butts concluded that nurses in RACFs could enhance residents' sense of wellbeing and self-regard through comfort touch.

8.2.2 Management

Imaginative programming and provision of leisure pursuits in RACFs leads to many and various opportunities for social contact between the aged care team, residents and families, as illustrated by the following story.

The masquerade ball

It was the evening of the masquerade ball. The facility's lounge was a blaze of colour, the musicians were playing and the wheelchair dancing commenced. Ethel and Doris were sitting together, their respective husbands too ill and frail to join the festivities. Ethel and Doris, each in her early eighties, visited their husbands daily, returning to their empty homes, experiencing the emotional and physical impact of 'pre-widowhood'. "Would you like to dance?" one of the aged care team asked Ethel. "Who, me?" Ethel replied, overcome by surprise. Linking arms, staff member and relative danced to the old tunes, Ethel flushed with excitement and stimulated by her memories. "Do you know, Fred and I used to go dancing every Saturday night. Since his stroke we've never even been able to embrace. I think that's the first time anyone has put their arms around me for months. Thanks so much." Doris plucked up courage to join hands with a male resident in a wheelchair. Joe, usually passive and uncommunicative, tapped his feet as Doris twirled him around, daring to give him a hug at the end. "Thanks for the dance", she said. Joe seemed to grow taller and straighter in his chair, beaming a rare smile.

Although there needs to be a positive acceptance of residents' need for intimacy and sexuality, it should also be acknowledged that any coercive or unsafe behaviours are unacceptable. Measures need to be taken to ensure the protection of any resident who is deemed vulnerable on this basis. Similarly, cases of hyper-sexuality should also be addressed immediately for the sake of all concerned. For example, public masturbation is unacceptable because it can affront other residents' sense of dignity; therefore, any resident wishing to engage in this activity should be directed to their own room (if private) or to a room designated for private purposes. The aged care team needs to acknowledge that even behaviour that is unacceptable is driven by some unmet need. The challenge is to seek to understand the message in order to help the resident to fulfil this need in acceptable ways.

Although companionship and intimacy between two residents may appear benign at first glance, these relationships may be objectionable to their spouses or adult children, as found by a recent survey[285] (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. Privacy was the primary determinant of appropriateness for behaviours for all groups. Staff and spouses were more likely than residents to endorse counselling for behaviours perceived as inappropriate.

It would appear that any form of intimacy between residents may be problematic. A simple problem-solving framework offers some direction for addressing these types of concerns:

- Describe and document the behaviour in objective terms. Then ask "Is this really a problem and, if so, for whom?" If it is a problem that exists for a resident, the aged care team, family member or the facility then further assessment is required to identify the triggers of the problem; and
- Develop a plan of care to be implemented and evaluate it to determine its effectiveness.

Advocacy for residents should be foremost during this process. Therefore, a great deal of education and counselling of the aged care team, families and other residents may be required to aid them in accepting the need for residents to express intimacy and sexuality. Members of 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. The complex issues of intimacy and sexuality should be included in staff orientation programs as well as in ongoing education and training programs for the aged care team. Members of the aged care team may also need to air their concerns about close relationships among residents, and a process to facilitate this discussion should be available as required. Residents and families are generally left out of training programs; families who have concerns about these issues deserve an opportunity to discuss their feelings.

8.2.3 Confidentiality

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. 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. Two key questions to ask before sharing such confidences are:

1) Do I need to document this?

2) Do I need to tell my colleagues this information?

This process should prevent any unnecessary disclosures, thereby maintaining the resident's dignity.

Consideration of residents' sexuality should be a routine component of care; however, in practice it is often neglected. There may be an assumption that as the resident is receiving a palliative approach their sexuality needs are not important. Although this may be the case, the aged care team needs to be aware of any cues regarding needs for intimacy or sexuality from residents and to facilitate support for these needs as appropriate.

Guidelines: Social support, intimacy and sexuality

		Level	Reference
Social support			
64.	A lack of social support may lead to deteriorating psychological wellbeing, depression and diminished functional health. Therefore, a thorough assessment of the resident's social network is required, including the resident's perceptions, appraisal and interpretation of what contact is most important to them.	III-2 IV	278 279
Intimacy			
65.	The use of comfort touch (e.g. massage, hand holding) by a member of the aged care team can enhance the resident's sense of wellbeing and self-regard.	III-2	284
Sexuality			
66.	Rather than denying the existence of residents' intimacy and sexuality needs, the aged care team needs to acknowledge the importance of this area of resident care.	QE	283

CHAPTER 9

Aboriginal and Torres Strait Islander issues

The values underpinning both a palliative approach and aged care in Australia are strongly grounded in the non-Indigenous culture that dominates health and social services. 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[286] (Level EO);[287] (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[288] (Level QE)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[288] (Level QE). Willis discusses Indigenous Australians' strong preference for care to be provided by particular relatives and the importance of traditional healers[287] (Level EO). Complex family relations may mean that the appropriate decision-makers are not the immediate caregivers.

From the perspective of a member of the aged care team adopting a palliative approach, the decisions of Indigenous Australian residents and their family and significant community members may not be consistent with the views of some team members. However, consistent with a palliative approach, the role of the aged care team is to work with the resident, family, community members and relevant services to find ways to enable the resident's goals to be achieved. 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[118] (Level QE).

9.1 BACKGROUND

In addition to their distinct culture, other aspects of Indigenous Australians' experience have led to a large burden of unresolved grief and loss that is inherent in Indigenous Australian communities as a result of premature death, family separation and community breakdown. This can have far-reaching effects and impact significantly on the dying and bereavement experience of Indigenous Australians and their family members. It also affects the ability of Indigenous Australian health workers to provide ongoing care. 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.[118] A consequence is that Indigenous Australian residents requiring a palliative approach are likely to be relatively young compared with non-Indigenous Australian residents.

The delivery of a palliative approach among Indigenous Australians is a largely underdeveloped area of health care. Indigenous Australians tend to access both mainstream palliative services and RACFs infrequently. Factors associated with this infrequent use of palliative services include lack of information about these services, culturally inappropriate care provided, and the lack of availability of the services in rural and remote areas where Indigenous Australians are more likely to live than non-Indigenous Australians.

Indigenous Australians' access to primary health care has gradually improved through the establishment of Indigenous Australian community-controlled health organisations that are able to offer culturally appropriate and accessible care. However, across Australia few services are funded specifically to provide a palliative approach to Aboriginal or Torres Strait Islander peoples[118] (Level QE). Nevertheless, there are Indigenous Australian residents and staff in many RACFs.

9.2 PROVIDING APPROPRIATE SUPPORT

Members of the aged care team need to be proactive in their efforts to provide appropriate support for Indigenous Australian residents and family members.

First, this requires being aware of the resident's cultural identity, that is, whether the resident and the resident's family identify themselves as Aboriginal or Torres Strait Islanders. Importantly, Indigenous Australian residents may have non-Indigenous Australian family members. Additionally, family members of non-Indigenous Australian residents may be Indigenous Australians.

Second, the use of Indigenous Australian aged care team members, Indigenous Australian health workers and liaison officers are an important though often under-used resource for consulting with the individual resident, their family and other significant cultural or community members [118] (Level QE). Sullivan recommends initiating protocols to involve an appropriate cultural broker (such as an Indigenous Australian health worker) in the care team, with the resident's and family members' consent [118] (Level QE).

Third, RACFs will be better placed to meet the needs of Indigenous Australian residents and family members if they establish dialogue and relationships with the local Indigenous Australian community and particularly the relevant Aboriginal Community Controlled Health Organisation. These groups can provide valuable referral services and advice about local cultural issues regarding dying to ensure that Indigenous Australian residents' and families' total needs are met.

Finally, Eckerman and colleagues[289](Level EO) warn about transporting simplistic views of traditional values into rural and urban settings. Traditional Indigenous Australian culture is far from simple. Adopting a standard view of Indigenous Australian culture and expecting it to 'fit' every Indigenous Australian does not do justice to a complex culture. Indigenous Australian populations are not, of course, homogenous. Indigenous Australians live in a wide spectrum of ecological zones, speak several hundred languages and have varying religious and healing practices, diets, family traditions, political structures and economic strategies. Eckerman and colleagues take this even further with an exhortation "to be aware ... of differences within cultural groups [and] see Aboriginal people as individuals".[289, p.4] All members of the aged care team should receive locally delivered cultural awareness training.

In March 2002 the Australian Government Department of Health and Ageing commissioned a study, led by Dr Kate Sullivan, into the palliative care needs of Indigenous Australians across Australia. This study has identified significant issues in the delivery of a palliative approach to Aboriginal and Torres Strait Islander people and will make recommendations about how these gaps in service might be addressed[118] (Level QE). The following guidelines have been extrapolated from this study's findings.

Guidelines: Aboriginal and Torres Strait Islander issues

		Level	Reference
67.	Respectful attention to the individual needs of Indigenous residents, taking into account beliefs regarding illness, healing, comfort, care practices, location of care, and death and dying is needed in a palliative approach to residential aged care.	QE	118
68.	Aboriginal health workers, liaison officers, other Indigenous Australian health care practitioners and community organisations have important knowledge about local cultural values and individual situations. When developing protocols and when working with individual Indigenous Australian residents it is beneficial to involve them.	QE	118
69.	Communication with Indigenous Australian residents in their own language enhances understanding and attention to their needs. Regular reviews of these residents' needs are required, as their needs may change.	QE	118

CHAPTER 10

Cultural issues

Australia has a rich multicultural population. According to the 2001 census, 22% of Australia's population was born overseas, representing over 200 different ancestries.[290] 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[291] (Level QE). As migration to Australia is as old as European settlement itself, many other residents would have had parents or grandparents born in these other regions, although a statistical enumeration is not available. Residents and family members from culturally and linguistically diverse populations may have particular needs that members of the aged care team should address in order to provide compassionate and effective palliative approach to care.

Definitions of culture refer to a set of beliefs, values, norms and practices that are learned, shared, and dynamic and which influence individuals' thoughts, expression and actions in a patterned way. Culture is not static; it changes over time and place and between and within persons. No individual can be reduced either to a simplistic set of cultural norms or to a set of exotic or quaint rules.

Multiculturalism is now a defining characteristic of contemporary Australian life. Not only are there many cultural groups but, importantly, many relationships exist between groups. Within nations, societies and communities there are dominant and marginalised cultures. The dominant culture of an RACF may favour certain styles of behaviour and ways of talking and interacting, and privilege certain residents over others.

Conflicting points of view often centre on what the notions of equality and equity involve. Some argue that it means treating everyone in the same way. Others argue that it means acknowledging difference, especially when that difference is associated with disadvantage. However, one of the issues that is clear in Australia is that power is not distributed evenly within or between cultures. The dynamics of power relationships and the way they affect individuals and groups must be an integral part of our understanding of cultures. Such an understanding is essential for the creation of RACF environments and guidelines that will value diversity, and thus promote the emotional and physical health of all members of that community.

All residents require careful assessment to ensure that assumptions are not made for cultural needs based on a resident's language abilities alone. The need for the aged care team to understand the health and caring perspectives of different cultural groups is especially important in the context of a palliative approach. It is often at this stage that residents and families turn to more culturally familiar and comforting beliefs and practices. 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[292] (Level QE). When the aged care team responds sensitively to the cultural beliefs and practices of residents and families, their satisfaction with care is increased[293] (Level EO).

Unfortunately, evidence suggests that members of the aged care team frequently experience communication difficulties with those they care for if they are from different cultural and linguistic backgrounds. These team members can experience stress and frustration caring for ethnic minority patients[294] (Level EO). Communication difficulties are reported to compromise the provision of holistic care, including psychosocial support. Furthermore, physical care may be sub-optimal as well[295] (Level III-2). 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[286] (Level EO).

Cultural understandings

An older woman from Pakistan was admitted to a hospital with malignant bowel obstruction. The family, who had limited English, had indicated they did not want more cancer treatment and surgery was not an option. While her symptoms were well controlled she was deteriorating and it was likely that she was going to die in a few days; this was explained to the family. Some members of the aged care team became upset when they saw a family member trying to force-feed a mixture of rice and broth to their mother. An explanation of why their mother could not be given food was given and the family was shown how to give good mouth care. The family yet again was seen force-feeding their unresponsive mother. This time when staff talked to the family they asked them why they were continuing to feed their mother. They explained that they were disturbed by the cold water and ice chips being given and were afraid that they were weakening her further. To counteract the cold fluids they wanted to give her something warm. Together, staff and family agreed that the mother would be given warm water for mouth care, supplemented by occasional use of the clear broth. All parties were satisfied and there were no more conflicts between the family and aged care team.

(Hall and colleagues)[296]

10.1 TRANSCULTURAL COMMUNICATION

Whenever possible information about a palliative approach should be provided to culturally and linguistically diverse residents and their families in their own language[297] (Level II). To adequately respond to the needs and concerns of residents and families of other cultural backgrounds, explicit efforts must be made to identify a shared understanding and negotiate a solution. Sensitive communication of this kind can diffuse conflict about care by pointing to alternative strategies which are culturally acceptable to the resident, their family and the aged care team[296] (Level QE).

It is important to recognise that consent to medical treatment cannot be given unless the resident (or their proxy) demonstrates that they have a clear understanding of what the treatment involves. One-way conversations consisting of 'explaining' procedures are not evidence that communication or understanding has taken place. Within this context the importance of using interpreter services cannot be over-emphasised.

10.2 INTERPRETER SERVICES

When involving an independent interpreter, the aged care team should explain the interpreter's role and the issues of confidentiality to the resident and/or their family. The resident's consent for the interpreter to be involved during decision-making processes must be obtained before commencing. In rural and remote areas using telephone interpreter services is recommended. The National Accreditation Authority for Translators and Interpreters (NAATI) is recommended, depending on availability, particularly for rural and remote areas.

Generally, the involvement of family members, friends or other unqualified people to assist with interpreting is not considered prudent practice because family members and/or friends may inadvertently or deliberately censor or alter information. Additionally, as with unqualified people, their language skills may be inappropriate to enable them to work effectively under such circumstances. The issue of the interpreter's gender also needs to be considered, because for many cultures it is inappropriate to speak with the opposite gender about health care issues.

10.2.1 Assessment

The best approach to identifying the resident's cultural needs is to assess their individual practices and beliefs. This could be done at the same time as the spiritual assessment, depending on the resident's ability to do so, because cultural and spiritual beliefs can overlap. Whenever possible, involvement of the resident's family should be sought, to assist the team's understanding of the resident's cultural beliefs. For some cultures it is the family, rather than the resident, who make decisions and this needs to be clearly determined[298] (Level EO). Any assessment needs to be mindful of the comfort level for the resident regarding their ability to talk about death or dying[298] (Level EO).

10.2.2 Management

Cultural sensitivity requires that the aged care team be aware of how culture forms residents' values, beliefs and basic assumptions; the team must also acknowledge that difference exists and have respect for these differences[299] (Level QE). 'Cultural competence' refers to the aged care team's knowledge and skills rather than their attitudes[299] (Level QE). 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[299] (Level QE).

An alternative term to cultural sensitivity and competence is 'cultural brokerage'[296] (Level QE). The principles are the same as for cultural competence, but some steps have been articulated which may be beneficial for RACFs to consider when developing appropriate cultural support. These steps are:

- having an awareness of one's own framework of attitudes, values and beliefs, and of its potential impact on the care provided to residents receiving a palliative approach;
- establishing open, non-threatening relationships;
- using effective communication skills to elicit important aspects of other people's framework of attitudes, values and beliefs;
- using effective communication skills to share important aspects of one's own framework; and
- Negotiating common ground.

(Adapted from Hall and colleagues)[296] (Level QE)

To help the aged care team in becoming cultural brokers, education on cultural diversity is recommended[299] (Level QE);[294] (Level QE).

Privacy issues are also relevant and have different levels of importance for varying cultural groups. For example, some Chinese residents receiving a palliative approach may experience a cultural conflict with the aged care team[300] (Level QE). '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[301] (Level III-2). 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[302] (Level III-2). This behaviour is sometimes referred to as 'a conspiracy of silence' and may lead to frustration for the aged care team and family members[300] (Level QE). 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[300] (Level QE). Other cultures may have some beliefs and practices that will direct how privacy is to be handled. Most importantly, individuals within a cultural group may not share these beliefs, highlighting the importance of an individualised assessment of the resident's and their family's culture.

Guidelines: Cultural issues

		Level	Reference
70.	Understanding care preferences of cultural groups is important in a palliative approach, and efforts to accommodate these promote individualised care for the resident.	QE QE	299 294
71.	Where possible, information about a palliative approach should be provided to the resident in their own language as this enhances cultural sensitivity for culturally and linguistically diverse residents and their families.	II III-2	297 295

CHAPTER 11

Spiritual support

Spirituality was found to be an important predictor of the quality of life of individuals receiving a palliative approach[303] (Level QE);[304] (Level QE). Indeed, impending death is considered a powerful stimulus for reflection on the significance of life and destiny for residents in RACFs[305] (Level IV). Providing spiritual support is a responsibility of the aged care team that must be fulfilled to enhance a resident's quality of life[303] (Level QE). Early assessment of the spiritual needs of residents is important and should not be relegated to a later stage of the illness.

11.1 ASSESSMENT OF SPIRITUAL NEEDS

Spiritual assessment is an ongoing process. Understanding the resident's current or desired practices, attitudes, experiences and beliefs assists in meeting their spiritual needs[303] (Level QE). The aged care team needs to determine whether a resident embraces some form of spirituality and the ways in which they practise this belief. Simply asking a resident which religion they belong to is not an adequate means of determining spiritual needs. Some suggestions about how the aged care team might begin discussions of spiritual needs are given in Table 12.

Table 12: How to assess spiritual needs

Possible questions:

- How are you in yourself?
- What is your source of hope and strength?
- What are your spiritual needs?
- Are there ways we might help with your spiritual needs or concerns?

Things to look for:

- Social isolation;
- Depression;
- Resident questioning the meaning of their existence;
- Resident seeking spiritual assistance;
- Resident attending spiritual services; and
- Religious items.

Similarly, obtaining a comprehensive social/family history that includes these issues from the resident or family at time of admission may help identify the resident's own past and present resources for their spiritual care[303] (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[303] (Level QE).

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[303] (Level QE);[307] (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[308] (Level QE). Social isolation, questions on the meaning of life, depression or a search for spiritual assistance may indicate that a resident requires spiritual attention.

A regular review of spiritual needs will guide practice, ensuring that spiritual care is flexible and adaptable, meeting the needs of the resident and family, particularly when needs change (e.g. when death is imminent)[256] (Level IV). The following story illustrates the importance of a regular review.

Jack

Jack was quick to respond to the question on admission regarding religion. "Just put down nil", he said. "I've never been interested and it's too late now." Over the next few months, Jack became more and more acquainted with the new chaplain, who would always acknowledge him on her visits to his roommate. When his roommate died, Jack went to the funeral in the chapel and was very comforted by the way the chaplain acknowledged his roommate's life and his place in the facility. She acknowledged the grief of other residents, stopping to speak to each one present at the funeral. A few days later Jack asked the nurse, "Do you think I could have that chaplain visit me when my time comes? She does a good funeral and I'd like her to do mine!" And so, a relationship of trust was established between Jack and the chaplain. She listened to Jack and took careful note of his requests, so that when the time came for Jack's funeral there was a distinctively personal element.

11.2 MANAGEMENT OF SPIRITUAL SUPPORT

Spiritual care involves assisting residents to articulate those things that are important to them personally. 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[309] (Level EO). This care includes an awareness of the feelings of isolation the resident may experience at the end-of-life[24] (Level QE). Table 13 provides an overview of spiritual interventions for the aged care team.

Table 13: Spiritual interventions to support residents

1. Allow the resident to guide all interventions.

2. Silent support:

- Be with the resident;
- Provide a supportive presence;
- Avoid judgment.

3. Liaison:

- Coordinate services and people (e.g. chaplains/pastoral care workers, family, friends) as requested by the resident;
- Ensure access to spiritual activities (e.g. Bible study, worship ceremonies);
- Obtain requested spiritually related items (e.g. books, rosaries, statues, videos, music);
- Avoid interrupting the resident during spiritual activities.

4. Active listening:

- Engage in conversation with the resident;
- Be alert to the resident's comfort level—watch for eye contact, bodily movement (turning away, restlessness) and disengagement from conversation;
- Repeat themes of the conversation to ensure accurate interpretation.

11.3 CHAPLAINS AND PASTORAL CARE WORKERS

Chaplains and pastoral care workers can provide spiritual care to people in a variety of settings. Chaplains usually have been ordained into their religion, though this may not always be the case. The inclusion of either a chaplain or pastoral care worker in an aged care team creates a palliative approach that considers each resident's spiritual care needs.

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[308] (Level QE). Fourteen percent had called in support from other faiths, such as Judaism, Baha'ism and Humanism. This external help was requested because 67% of the RACF managers felt that it would benefit the resident. 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.[308] These findings point to the relevance of access to chaplains and pastoral care workers for residents requiring a palliative approach. However, unless the resident wants spiritual support, a visit from a chaplain or pastoral care worker can be considered as an intrusion, as illustrated in the following story.

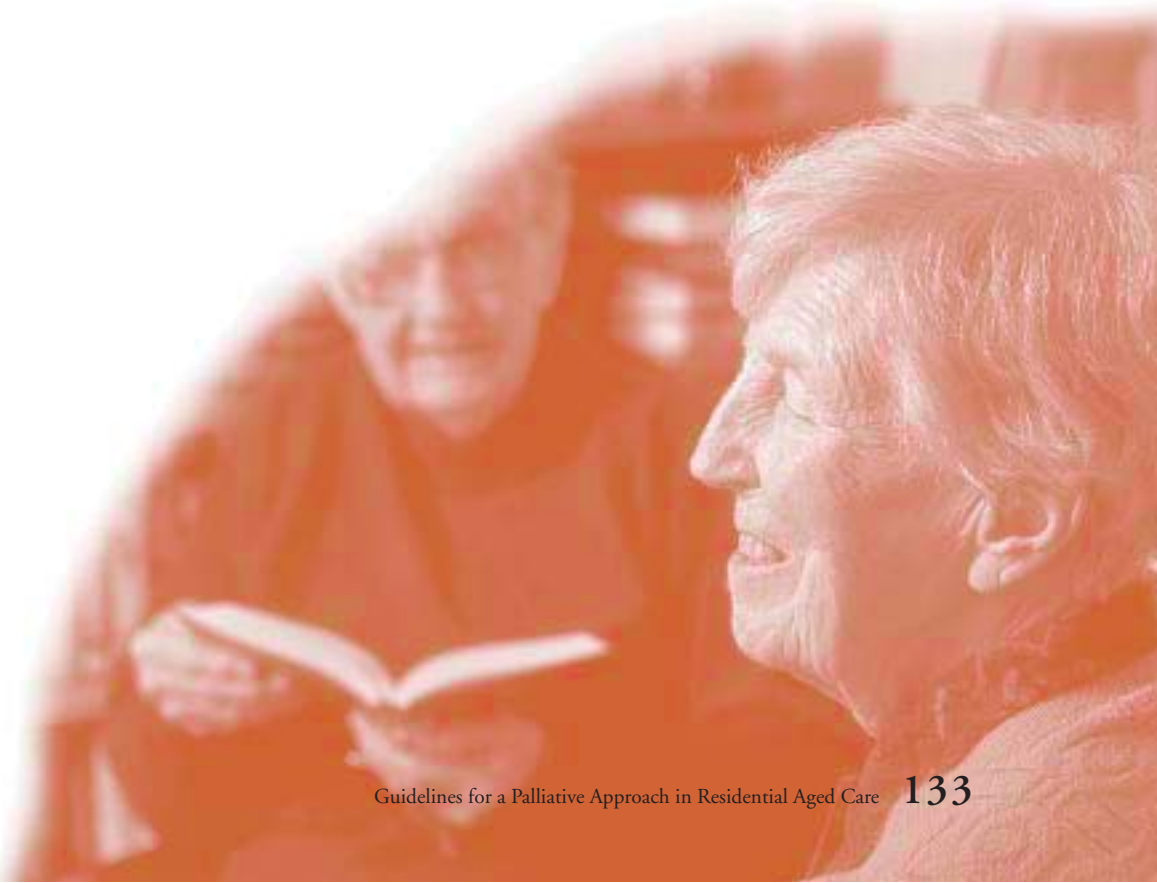
Alison

Alison had never learned to read or write, having been considered too 'slow' for normal schooling. After entering the RACF aged 89, her life flourished. She made friends with another resident, entered into all the social events and attended the weekly chapel service. The pastor would visit twice a week and read Bible stories to Alison. Although she would remain politely attentive, the aged care team who knew her well perceived that she was not interested despite the pastor's best efforts to engage her. The aged care team was unsure whether to act on Alison's behalf, as they were reluctant to intrude into 'religious' territory. However, one time Alison was also able to speak on her own behalf when the pastor asked if she would like to have further visits from him. "No thank you" was her response to the query and the pastor respected her preference.

To be effective in providing spiritual support, the chaplain or pastoral care worker should have experience and knowledge about spiritual issues and should be an integral part of a multidisciplinary team[303] (Level QE). However, other members of the aged care team are often asked questions relating to spiritual matters by residents and these are best addressed at the time by the aged care team in an open, non-judgemental manner[303] (Level QE).

Guidelines: Spiritual support

		Level	Reference
72.	A palliative approach supports residents and families to express their unique spirituality. Respecting their privacy and providing an opportunity for them to continue their spiritual practices enhances a resident's spiritual care and quality of life, as does spiritual counselling.	QE QE QE QE	303 304 307 308
73.	Understanding the resident's current or desired practices, attitudes, experiences and beliefs by obtaining a comprehensive history helps meet the spiritual needs of the resident, as does a regular review.	III-2 QE QE	257 303 307
74.	The aged care team is encouraged to respond in an open, non-judgemental manner to residents' questions relating to spiritual matters. Involving a chaplain or pastoral care worker with experience and knowledge about these issues is considered best practice.	QE	303



CHAPTER 12

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[310] (Level QE);[311] (Level QE). Volunteers have been found to be helpful in providing personal support, and to possess adequate interpersonal skills,[310, 311] as is illustrated in the following story.

Joyce and Miss Walker

"She just crept into my heart." This comment was made by Joyce, a volunteer, who spontaneously offered to give a eulogy at Miss Walker's funeral. Joyce had been assigned to assist Miss Walker with her meals whenever she could spare the time. Now bed-bound with little independent movement, experiencing the inexorable decline of Alzheimer's disease, Miss Walker seemed to recognise Joyce at each visit. "I think it's the perfume. I always wear the same perfume and talk to Miss Walker about it. I just chatter on when I'm feeding her. She probably doesn't understand a word I say, but I carry on anyway. I also think she likes my singing! Although she never says a word I'm sure she knows me." At the funeral, the priest referred to Miss Walker as "a person we know little about". Joyce, one of the four people present, disagreed: "I know a lot about her. May I say a few words please?" Unknown to the aged care team, Joyce had pieced together some of Miss Walker's past, so that she could talk to her about her early life as a dancer and a dressmaker. Joyce's contribution transformed an impersonal, perfunctory funeral into a lively celebration of Miss Walker's life.

RACFs' access to volunteers varies widely, as does the role volunteers play within a facility. However, as volunteers are an integral part of palliative teams, it is suggested that residents in RACFs would benefit from the support and assistance offered by appropriately trained volunteers[312] (Level EO).

Coordination of volunteers

Effective inclusion of volunteers requires appropriate support and supervision. To facilitate the inclusion of volunteers into the facility, the aged care team may require education in managing volunteers in an RACF setting, or preferably a coordinator of volunteers position could be introduced.

A coordinator who has the requisite experience and/or training in volunteer support[311] (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[311] (Level QE). For success in this role, it is important for the coordinator to have autonomy and authority, and for the position to be salaried[311] (Level QE).

Coordinators of volunteer services have reported that a wider range of volunteers is entering the unpaid palliative workforce[311] (Level QE). The potential contributions of this varied group of volunteers are valued. However, there is a notable gap in the literature related to how to screen, train, monitor and evaluate volunteer services. Given the magnitude of the volunteer work performed, the vulnerability of residents receiving volunteer services, and the relatively unsupervised support provided by volunteers, greater attention to personal issues, standards of volunteer care, and related management issues for this unpaid workforce is needed. Policies and procedures relating to volunteer recruitment, selection, orientation and training can inform volunteer involvement and ensure that volunteer roles are clearly defined. It is suggested that RACFs contact organisations such as Volunteering Australia to review their standards on these matters (see Appendix F).

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[313] (Level QE). Following a suitable recruitment, orientation and matching process, volunteers may act as a companion and confidant to the resident and their family[310] (Level QE). Volunteers may also provide bereavement care if they have been trained in this area, and receive ongoing support and supervision[314] (Level QE).

Frank and Andrew

Frank had been admitted to an RACF on discharge from hospital. His condition deteriorated rapidly and the staff contacted the local palliative service for support. As Frank had limited family support, Frank agreed that he would like Andrew, a volunteer from the palliative service, to sit with him. On his last visit, Andrew found that Frank was no longer responsive, but appeared agitated and restless. Andrew sat with Frank for several hours, playing his guitar. "I don't know if it was any help but he seemed calmer while I was there," said Andrew. The staff reported that Frank did in fact settle while Andrew was with him. Frank died peacefully several hours later.

Guidelines: Volunteer support

		Level	Reference
75.	Trained volunteers can be integrated into multidisciplinary teams to help provide a palliative approach for residents.	QE QE	310 311
76.	Volunteers who are part of a multidisciplinary team providing a palliative approach require ongoing support and education from a trained coordinator of volunteers.	QE	311
77.	Suitably screened and matched volunteers may act as a companion and confidant to the resident and their family. All those involved consider that this support is valuable.	QE QE	310 314

CHAPTER 13

End-of-life (terminal) care

How people die remains in the memories of those who live on.[315]

This chapter focuses on care of the residents and their families when death appears imminent. The key points are discussed, but other publications—such as the *Oxford Textbook of Palliative Medicine,*[134] *Therapeutic Guidelines: Palliative Care*[97] and *Care of the Dying Patient: A Pathway to Excellence*[316]—should also be consulted to complement the information given here. Many of the symptoms discussed should also be considered alongside other references to symptom management in this document.

13.1 WHAT IS OPTIMAL END-OF-LIFE 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. Despite these obstacles various theories abound as to what are the common factors that exist when optimal end-of life care is achieved. The following list should help aged care team members raise their awareness about some of these common factors for optimal end-of-life care. Residents who are dying may need to:

- know when death is coming, and to understand what can be expected;
- be able to maintain a sense of control and have their wishes given preference;
- be afforded dignity and privacy;
- have control over pain relief and other symptom control;
- have choice over where their death occurs (RACF, home or elsewhere);
- have access to information and excellent care;
- have access to spiritual and emotional support as required;
- have access to a palliative approach;
- have control over who is present and who shares the final moments;
- be able to issue advance care plans, which ensures that their wishes are respected;
- have time to say goodbye; and
- not have life inappropriately prolonged.

(Adapted from the Centre for Policy on Ageing)[317] (Level QE)

This list may serve as a reminder for the aged care team to assess these issues each time they are aware of a resident's imminent death, so they can take comprehensive steps towards optimal end-of-life care. The list may also act as an agenda for a family conference, prompting the resident and their family to express their ideas of what optimal end-of-life care means to them.

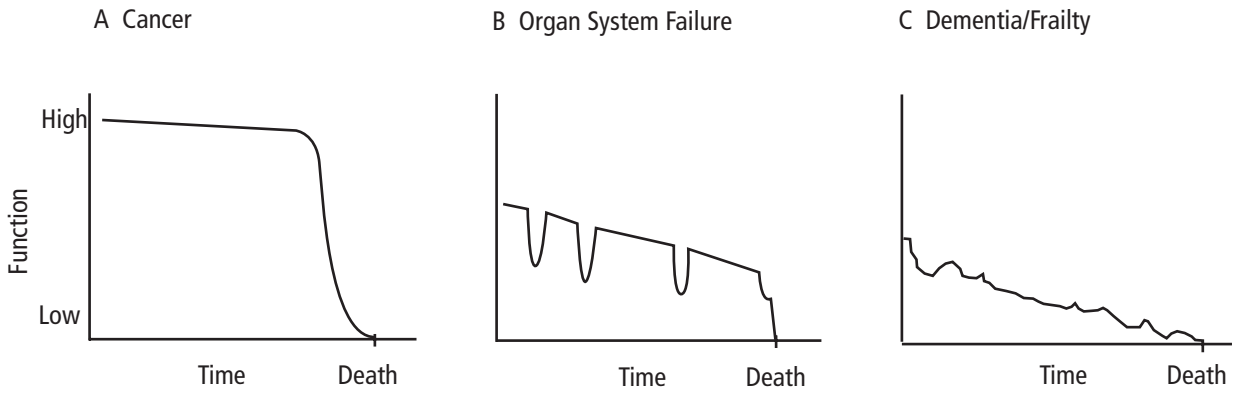
It is also important at this time to determine the appropriateness of unwanted or unhelpful interventions (also known as 'clinical futility') for residents who are dying. Determining clinical futility is a step towards providing a successful palliative and end-of-life approach[17] (Level QE). For residents without an established advance care plan (see Chapter 3, 'Advance care planning'), 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[34] (Level QE).

13.2 RECOGNISING WHEN A RESIDENT IS DYING

End-of-life care refers to the phase where death may be expected within a period of hours to several days. Determining when the terminal phase has commenced may be difficult. Most residents have multiple clinical diagnoses involving multi-system pathology, and the diagnosis of dying is often made only by exclusion.[318] There are different illness trajectories for people with cancer, organ system failure and dementia (as shown in Figure 3):

- *Cancer.* Residents diagnosed with cancer have a more predictable course and can usually perform activities of daily living until quite late in their disease process (see Section 1.2.1, 'Prognostication', for further details).
- *Organ system failure.* Residents dying of chronic organ system failure tend to follow a second trajectory. With conditions such as heart failure, obstructive lung disease and cirrhosis, those affected may be ill for many months or even years, with occasional exacerbations. Each exacerbation may trigger fears of death, with uncertainty regarding the resident's ability to recover from the most recent episodes.
- *Dementia/frailty.* A large and increasing number of people with progressive disabilities such as strokes, dementia and frailty due to old age may experience a third trajectory and need long-term help with activities of daily living; they will generally experience a more gradual decline in health.[319] 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%)[77] (Level QE). Symptoms commonly experienced during the last 48 hours of a resident's life include pain, dyspnoea, respiratory congestion, delirium, dysphagia, fever and muscle twitching (myoclonus)[320] (Level IV).

Figure 3:General trajectories of function and wellbeing over time in eventually fatal chronic illnesses



Permission to reproduce this figure received from Author[319, p.930]

Recognising when the death of a resident without cancer is imminent is more difficult to determine due to co-morbidities[23] (Level I). The aged care team and families need to be made aware that for some residents death may occur more quickly than expected, while for others the dying process may be longer than expected. However, immediately before death (within hours to days) several of the following symptoms and signs may be present:

- peripheral shutdown and cyanosis;
- changes in respiratory patterns (e.g. 'Cheyne Stokes' breathing);
- drowsiness or reduced cognition (e.g. Not responding to verbal and/or physical stimuli);
- uncharacteristic or recent restlessness and agitation;
- retained upper airway secretions; and
- cardiac—hypotension, tachycardia.

If a resident's death appears to be imminent, the resident's doctor should be informed immediately and an assessment conducted to determine if there are any reversible causes. When a decline is unexpected, assessment should be aimed at identifying causal factors, which could include assessment of temperature, heart rate, bowels, urination, respirations, blood pressure, urinalysis, hydration status and level of response.

Where death is imminent and reversible causes have been excluded, all interventions should be reconsidered in terms of benefit versus harm, and the resident's comfort should remain the ultimate goal. Consideration should be given to ceasing interventions such as oxygen, parenteral therapy, blood glucose monitoring, PEG/nasogastric feeding, and unnecessary medications.

There is no single description of an individual's last hours of life, and the aged care team needs to be alert to individual differences and the resident's reactions to their impending death. The family may also require more support at this time and the aged care team needs to be able to provide this. 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[307] (Level QE). This support may need to be practical as well as emotional[321] (Level QE). (See Chapters 7, 'Family support', and 14, 'Bereavement support', for further information).

The following story highlights some of the responses residents and their families may have when facing imminent death.

Ann and Mr Andrew

Ann, the nurse in charge, was aware that Mr Andrew's death was imminent and she phoned the family accordingly. Knowing the family, through her many discussions with them over the previous year, she was aware of the difference of opinion between some family members regarding the palliative approach to care and she knew that one daughter was concerned about the recent introduction of opioids. Ann's colleague thought it was "too late" to call a family meeting: "Anyway, it's not our business to get involved in their family dispute!" Ann knew otherwise and gave the family this option: "You realise your father's condition is deteriorating, and as I've explained before, we can never predict precisely when death will occur. I'm aware some of you are uncomfortable with the morphine infusion, so I wonder if you'd like to meet with the doctor and myself about 2.30p.m. It's important that the whole team, which includes the family, agrees with the plan of care. It's also important, particularly at this stage, to ask ourselves again, what is in your father's best interests? This meeting will give you the opportunity to openly discuss any questions and concerns."

13.3 MEDICATION ISSUES

Practical comfort measures are very important in managing end-of-life symptoms, and are often more effective than other interventions. Medical intervention is, however, frequently required for specific symptoms. Several medications are recommended in the next section, but for specific information such as dose levels relevant resources such as the *Therapeutic Guidelines: Palliative Care*[97] or the *Australian Medicine Handbook Drug Companion Aged Care* (www.amh.net.au) should be consulted.[129]

RACFs, in consultation with GPs and local pharmacies, should develop strategies to ensure that residents who are approaching death have ready access to common terminal phase medications. It is best to have the relevant medication orders and prescriptions ready for possible symptoms in the end-of-life phase. For example, restlessness, delirium and excessive respiratory secretions are common symptoms that can develop quickly, so relevant medications should be readily available, with sufficient ranges of dose to deal with a worsening of symptoms; these should be ordered by the GP.

When the resident is approaching death, the use of oral medications should be reviewed. Some medications, such as hypoglycaemics, anticoagulants and antihypertensives, may no longer be relevant,[97] and may even worsen symptoms if continued. However, such decisions should be made through negotiations between the resident and/or the family and the doctor. The guidelines for medication management in residential aged care facilities[322] should be consulted when making any decisions about medication management; those guidelines are not specific to palliative care but they provide support for medication management generally in RACFs.

Oral administration of medications is not feasible if there are swallowing difficulties, nausea, intestinal obstruction and decreased level of consciousness. Some medications may be administered in transdermal, sublingual or rectal routes; however, in most circumstances subcutaneous administration will be required for effective symptom management. The subcutaneous route is preferred to other parenteral routes (intramuscular, intravenous and epidural) because it is less invasive and has fewer risks of infection.

Syringe drivers (e.g. the Graseby Pump) are commonly used for a palliative approach in the home-care setting to administer subcutaneous medications when death is imminent and other routes of administration (e.g. oral) are not appropriate. However, the routine use of syringe drivers should be avoided in RACFs and their use should be governed by the need for 24-hour administration of a medication and/or staff resource considerations. Common issues regarding the use of syringe drivers, including practical advice and drug compatibilities, are discussed in the *Therapeutic Guidelines: Palliative Care*.[97] RACFs need to develop strategies to facilitate ready access to a syringe driver (should one be required) and information on relevant medications. If more than one syringe driver is being used in a facility, they should be of the same make and model to reduce the risk of error.

Where appropriate, members of the aged care team (including GPs) should be selected for training in the setting up and maintenance of syringe drivers. Local community palliative services and the syringe driver manufacturers should also be contacted where necessary to assist in developing syringe driver strategies and protocols.

13.4 MANAGEMENT OF END-OF-LIFE CARE

Although most end-of-life care can be provided in the RACF, if a resident's symptoms remain uncontrolled the aged care team should consult the nearest community palliative service. It is also important to clarify the wishes of the resident and their family concerning hospitalisation. Ideally residents should remain in their familiar environment (i.e. the RACF), provided the aged care team has access to the necessary resources for optimal symptom management. (See Section 1.3, 'Where can a palliative approach be provided?', for further information on the suitability of RACFs to provide a palliative approach).

13.4.1 Pain and discomfort

When death is imminent, the resident's comfort is paramount. However, it is a myth that uncontrollable pain frequently develops in the last hours of life when it has previously not been a problem[323] (Level EO). (Information on the pharmacological and non-pharmacological management of pain has already been provided (see Section 5.2, 'Pain management') and is not restated here.) All residents who are dying are at risk of rapid skin breakdown, and the associated discomfort should be avoided by proactive management. 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[324] (Level EO). (See also Section 5.10, 'Skin integrity', for further discussion of skin care and the use of special mattresses). However, it is also important to consider the close tactile comfort of gentle repositioning. For a very small number of residents with advanced cancer there is a risk of catastrophic terminal haemorrhage (e.g. erosion of a large artery). Planning for this event is important so that if haemorrhage occurs then medications to lessen pain and agitation are readily available. An opioid such as morphine and/or a benzodiazepine such as midazolam are recommended.[97]

13.4.2 Delirium, restlessness and sedation

Delirium is commonly associated with agitation or restlessness. However, there are difficulties with defining restlessness and delirium[325] (Level III-3). (See Chapters 4, 'Advanced dementia' and 6, 'Psychological support' for further discussion of issues relevant to cognitive impairment). 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[323] (Level EO).

Common signs of delirium and restlessness include:

- pulling at bed clothes;
- frequent changes of position (being unable to relax physically);
- myoclonus;
- moaning; and
- calling out (often incoherently).

Management of delirium involves addressing reversible causes (such as urinary retention and constipation) and medication side effects. The common pharmacological intervention for delirium is haloperidol and the benzodiazepine drug, clonazepam.[97] Clonazepam is a long-acting agent and can assist in easing restlessness. It can be administered in droplet format sublingually or subcutaneously. Sedation in end-of-life care is warranted when symptoms are unrelieved (including existential or psychological distress). There are, however, various levels of sedation, and medications should be titrated according to effect[326] (Level EO). For recommended doses of sedating medications see the *Therapeutic Guidelines: Palliative Care*.[97]

13.4.3 Respiratory secretions

Respiratory congestion—the 'death rattle'—is usually evident when residents approaching death cannot clear upper respiratory tract infections. This occurs in approximately 92% of people that are dying[316] (Level EO). Although most residents who experience respiratory congestion are likely to be unconscious, it has been suggested that uncontrolled respiratory congestion may contribute to dyspnoea and restlessness. Furthermore, uncontrolled and exacerbating respiratory congestion can cause distress to families.

Treatment involves changes in positioning and use of medications[23] (Level EO). Although suctioning may be appropriate where there are copious thick secretions in the upper airways, routine suctioning is not recommended. Medications such as hyoscine hydrobromide or atropine sulphate may be helpful.[97] If respiratory congestion is present in a resident who does not appear to be imminently dying, then a diagnosis of cardiac failure needs to be considered.

13.4.4 Dyspnoea and changes in breathing patterns

As the resident's death approaches, breathing patterns may alter significantly, ranging from slow to irregular to rapid. Cheyne-Stokes breathing is usually associated with apnoea, followed by a period of rapid breathing. 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[201] (Level II). A small proportion of residents may benefit from oxygen therapy; however, the need for this should be comprehensively assessed before commencement and its effectiveness closely monitored. The decision to administer oxygen should be made by the GP, who should also prescribe the appropriate rate. Recommendations on the use of oxygen therapy for end-of-life care are given in the *Therapeutic Guidelines: Palliative Care*.[97] (See Section 5.12, 'Dyspnoea', for further discussion of oxygen therapy).

13.4.5 Elimination issues

Urinary output decreases as death approaches. Urinary retention should be considered if the resident is restless. If catheterisation is required to relieve retention it does not necessarily follow that the catheter should remain in situ. Routine catheterisation for residents who are dying should be avoided as it may cause unnecessary discomfort. Incontinence can usually be managed with absorbent pads[324] (Level EO).

The other important consideration is the resident's dignity. For example, what does 'dying with dignity' mean to this particular resident and their family? Wherever possible, even when death is imminent, the aged care team should arrange a family conference to explore the resident's and/or family's wishes, fears and anxieties. Cultural and spiritual needs should also be formally evaluated, particularly if a frank discussion of death is culturally inappropriate.

13.4.6 Family conference

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[256] (Level III-2). Such a conference needs to take place in privacy and in an appropriate setting for discussion to occur. During the conference the resident and family need to understand that the emphasis at this stage of life is on ensuring comfort and that the palliative approach does not mean withdrawing care. The conference also permits a reciprocal exchange of information and can help educate family members on what to expect. Typical questions that families may have include:

- What are the signs that death may be imminent?
- What are the usual changes to the body when dying?

It would be appropriate to initiate a discussion of the common changes that occur when death is imminent, if the family have not already raised these questions.

Other important issues to raise include the following signs that may be observed in the person who is dying:

- a decrease in consciousness;
- an inability to swallow;
- changes in breathing patterns;
- peripheral shutdown; and
- incontinence.

Assurance should be given that the resident's comfort will be the primary goal of care. Some questions the family may ask at this point include:

- Can we talk to them? (It should be presumed that the resident can still hear them even when death is imminent.)[327]
- Can we hug them (or hold hands, touch, play music, bring the grandchildren, etc)?
- What will happen to their body after they've died? (Assurance needs to be given that the body will be cared for in a dignified and culturally appropriate manner.)

13.4.7 Site of care

When the resident is in a shared room, the aged care team need to ensure that the choices of the resident and their family, and of other residents and their families, are respected wherever possible. Often the resident and family members may prefer to maintain the company and comfort of others in the same room. A resident who is dying should not be moved without prior consent of the resident and/or the family, except in an emergency.

Other options may include transfer to:

- an inpatient hospice if appropriate care is not available in the RACF;
- a single room in the RACF (depending on resident's or family's choice and availability of room);
- a more private space for selected periods of the day or night (depending on resident's or family's choice and availability of space); and
- their home for the final days (as long as there is adequate community support services, e.g. palliative care, and making sure to keep the RACF bed open, within the requirements of the legislation, in case re-admission is needed. Home care may be an important option to explore for some residents and families, empowering them in their decision-making role. For others, of course, it may be inappropriate to discuss the option of home care.)

13.5 PREPARING FOR IMMINENT DEATH—PRACTICAL CONSIDERATIONS

Formalised plans aid the provision of optimal end-of-life care. To this end, the following list contains various tasks or concerns that may require attention from the aged care team. The list is only a suggested guide and provides a starting point for RACFs needing to develop policies and practices on preparing for a resident's death:

1. Check for documentation of advance care plans, particularly regarding preferences for site of care and resuscitation orders.
2. Check availability of the GP, including after hours. If pertinent ask that the GP visit to confirm the likelihood of imminent death.
3. Determine if the local community palliative service has the capacity to provide a consultancy service if required.
4. Check that all equipment, drugs, etc, are readily available and accessible, especially after hours.
5. Consider dignity issues (e.g. What is the most appropriate clothing for the resident—day clothes or bed attire—and would they prefer to remain in their bed or be transferred to a chair?).
6. Consider the physical comforts and needs of family members and other visitors. This might include information and assurance regarding 24-hour visiting.
7. Confirm the proposed funeral plans with key family members.
8. Confirm contact details and the family's preferences for visiting (particularly at the time of death and/or immediately after death).

13.6 SIGNS OF DEATH

The following list provides a guide to the common signs of death. These may be particularly beneficial for family members or carers who ask for an explanation of the signs of death. Not all the signs should be discussed, only those that seem appropriate to the particular circumstances. Near the time of death:

- there is an absence of pulse;
- breathing ceases;
- the pupils are fixed and dilated;
- the body becomes pale;
- body temperature decreases;
- muscles and sphincters relax;
- urine and faeces may be released;
- eyes may remain open;
- the jaw may fall open; and
- trickling of fluids internally can be heard from the resident's body.

(Adapted from Ferris, von Gunten & Emmanuel)[323] (Level EO)

13.7 CARE AFTER THE RESIDENT HAS DIED

The aged care team needs to be familiar with the details of relevant legal requirements, which vary among the States and Territories. *The Therapeutic Guidelines: Palliative Care*[97, p.106] indicate that when a death has occurred:

- a determination must be made that life is extinct. This may be performed by a GP or an RN in some states, or only by a GP in other states;
- a Certification of Death must be completed. This does not have to be done by the GP who pronounced life extinct, but the treating medical practitioner is usually the one to complete this document; and
- if there is uncertainty about the cause of death (e.g. if there has been a fall that may have contributed to the resident's death), then the coroner may need to be informed.

However, as the legal requirements do vary throughout Australia, each RACF should formulate their own policies and procedures, depending on legal requirements and their local circumstances. These should be developed with a view to being sufficiently flexible to incorporate diverse cultural and spiritual issues. Policies and procedures may include:

- determining that death has occurred;
- notification of death (dependent on State or Territory legislation, cultural issues, and RACF policy). This may also vary according to the RACF's proximity to an acute hospital and/or other services. The procedure would include the order in which people should be notified (e.g. GP, family, funeral director, senior management);

- notifying other residents, family members and the aged care team about the resident's death;
- the role of the GP (e.g. in relation to signing the death certificate);
- care of the resident's clothing and belongings;
- giving the resident's family and the aged care team the chance to say their farewells before the resident's body is removed (cultural practices and personal wishes should also be given preference). The need to provide formal debriefing for the aged care team should also be included when drafting policies and procedures;
- how to care for the resident's body after death, including acknowledging cultural sensitivities and family wishes, removing equipment from the body, and removing the body from the RACF (having first determined that the coroner does not need to be involved);
- funeral preparations; and
- evaluating outcomes of care delivery.

13.8 SUMMARY

There is no one approach to caring for someone whose death is imminent. Although various strategies and interventions have been suggested, the circumstances will always vary. However, with comprehensive assessment and a multidisciplinary team approach, residents dying in RACFs can receive the best of care. This does not occur without advance planning and appropriate education of the aged care team and families, supported by clear policies and procedures. These elements contribute to family members' increased confidence that the aged care team will meet the needs of residents who are dying by respecting their choices wherever possible.

In order to respect the resident's and family's end-of-life choices, it is important to reassess the situation when death seems imminent. With careful planning, a conference can be arranged with the aged care team, the GP and the family to make sure the goals of care are agreed on, and to check that the resident's preferences are respected. The time spent ensuring there is a reciprocal exchange of information will contribute greatly to satisfaction with the outcome for both the aged care team and the family, leaving positive memories for those who remain.

Guidelines: End-of-life (terminal) care

		Level	Reference
78.	Family caregivers need to be advised that the changes their family member may experience in the end-of-life phase (e.g. noisy breathing) are a normal part of the dying process. Families should be reassured that their relative is not necessarily distressed by these changes.	II	201
79.	Well-planned family conferences, conducted in private and attended by the GP and other members of the aged care team, provide an opportunity for building trust and discussing end-of-life issues of concern.	III-2	257

CHAPTER 14

Bereavement support

When a resident dies, loss and grief may be experienced by the aged care team, the family, and other residents. To assist in understanding bereavement, the following definition of terms is provided:

- *Loss* is the severing or breaking of an attachment to someone or something, resulting in a changed relationship.
- *Grief* is the normal response to loss. It includes a range of responses: physical, mental, emotional and spiritual. These are usually associated with unhappiness, anger, guilt, pain and longing for the lost person or thing.
- *Bereavement* is the total reaction to a loss and includes the process of healing or 'recovery' from the loss. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and recover in their own way.

14.1 CHARACTERISTICS OF GRIEF, LOSS AND BEREAVEMENT

The models that are frequently used for grief assume that it is an illness; hence, grief reactions become outcome focused (e.g. 'the person will recover'). Such assumptions focus interventions on an individual's 'deficits', suggesting there is something 'wrong' with the person who is grieving. However, grief can be unresolved, complicated or delayed and should not be regarded as something to get over or recover from. The aim of grief counselling is not to prevent stress or to try to get the person to 'let go' or 'leave the past behind'. Rather it aims to promote competence; grief should be considered as a process that occurs during a person's life cycle, so it is assumed that people already have skills and abilities they can use to help them through the process.

Grief is a beneficial process as it can provide continuing bonds with the person who has died, and these bonds are dynamic and changing. These bonds can provide continuity, comfort and solace.

It is impossible to predict how an individual will respond to the death of someone they cared about. The following table provides some guidance as to how people make meaning of their grief, loss and bereavement.

Table 14: Grief, loss and bereavement indicators

Grief is felt according to the individual's:	Loss varies for each person, but may include feelings of loss of:	Bereavement is not a simple reaction to a single event; it is:
• Culture • Family • Personality • Developmental stage (development never stops—it is where one understands oneself in relation to others)	• A life • A relationship • The role (their concept of 'self') they had in a relationship • A way of life	• Emotional • Social • Economic • Spiritual

The following table shows psychological characteristics of grief, though not all these will be experienced by those who mourn.[328]

Table 15: Psychological characteristics in grief

Characteristic:	How it may be expressed:
Numbness or denial	"This hasn't really happened."
Guilt	"If only I had ..." "I should have ..."
Anger	"Why did she do this to me?"
Sadness (Under denial, guilt, and anger is often a pervasive sadness.)	"I am alone, and life will never be okay now."
Ambivalence	Fluctuating between love and anger
Anxiety	Feeling of loss of control Tears flow with little or no provocation A nervousness or sensitivity to what others say, do, or do not do.
Unfairness	"It's not fair!"
Intense yearning	"I wish, I wish—Oh how I wish!"

The following table outlines other common reactions to grief.

Table 16: Common grief reactions

Mental:	Emotional:	Physical:	Behavioural:	Spiritual:
• Disbelief/ confusion • Preoccupation • Sense of the dead person's presence • Hallucinations	• Anxiety • Fear • Sadness • Anger • Guilt • Inadequacy • Hurt • Relief • Loneliness	• Hollowness in the stomach • Tightness in the chest (chest pain) • Tightness in the throat • Digestive and related problems • Over-sensitivity • A sense of de-personalisation • Breathlessness • Muscle weakness • Lack of energy (or a deep and total fatigue) • Dry mouth • Insomnia • Loss of appetite	• Crying • Sleep disturbance (either a lack or an increased need for sleep) • Sighing • Restlessness and over-activity • Appetite disturbances • Absent mindedness • Social withdrawal • Dreams of the deceased • Avoiding reminders of the deceased • Searching and calling out for the deceased • Visiting places and carrying reminders of the deceased, or treasured objects which belonged to them	• Feelings of anger • Feelings of alienation from God • Feeling that hope appears lost • Feeling that life has lost its meaning

(See Chapter 11, 'Spiritual support', for further information on spiritual matters)

14.2 EXTREME GRIEF

People naturally experience grief after a death, but for some the reaction is so strong that it moves beyond 'normal' grief to what is known as pathological or 'complicated' grief. In recent years the criteria for complicated grief have been redefined.[329] Horowitz and colleagues[329] argue that some prolonged and turbulent grief reactions include symptoms that differ from the DSM-IV[223] criteria for major depressive disorders. The authors have 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 complicated grief disorder:[329]

- 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 complicated grief and the distinction between complicated (or pathological) grief and normal grief is not straightforward and that there is a critical lack of evaluation.[330] Given this lack of agreement of definitions, rather than determining the individual's 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.

Assessing those who might need more support is a 'balancing act', based on observations, with clinical judgment and input from the aged care team, other residents, family, etc. The aged care team may feel that a person needs further support if:

- the death was traumatic;
- the death is less 'real' for them for some reason (e.g. unable to attend funeral, the death occurred overseas or interstate);
- they believe the death was preventable;
- they are ambivalent towards the person who died;
- there is decreased role diversity;
- they have decreased social support;
- there are pre-existing factors (e.g. psychiatric disorder);
- they are facing other crises at the same time; and
- it was an overly prolonged death.

14.3 MANAGEMENT OF BEREAVEMENT SUPPORT

Focused management of bereavement support reduces risk and improves bereavement outcomes, whereas untargeted support may not have such an overall beneficial effect[331] (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[332] (Level QE). Cultural differences may also affect the ways in which people respond to death (see Chapter 10, 'Cultural issues', for further information).

14.3.1 Public acknowledgment of death

Death is the ultimate rite of passage and needs to be marked in a public way[333] (Level EO), such as a memorial service[334] (Level EO);[335] (Level EO). There is considerable anecdotal evidence that suggests that a chance for family members to say 'goodbye' is crucial, especially if they were not present at the death[331] (Level EO). This is also true for friends of the person who has died, other residents of the RACF, and the aged care team[336] (Level EO);[337] (Level QE). Cultural differences may also affect the ways in which individuals respond to death (see Chapter 10, 'Cultural issues').

A WorkCover NSW report[338] (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[339] (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[340] (Level QE). The following story provides some examples of written reflections:

Reflections

When provided with a small reflections booklet after each resident's death, staff welcomed the opportunity to make a personal comment. Examples included, "Anna was a kind and affectionate soul who despite her pain was grateful for the comfort we could provide."

"I remember Anthony was a trial at times, though I understood his frustration. I enjoyed him very much on his good days and I'll miss him and Leila."

"I will always remember Noel for his huge smile and his beautiful, kind manner."

However, formalised grief and bereavement services in RACFs are limited. One study found that 55% of RACFs sent sympathy cards and 64% attended the funeral if the resident died while in the facility[341] (Level III-2). Most RACFs surveyed did not offer any follow-up bereavement support, either in the form of information, referrals or phone calls. However, 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.

Davidson[277] (Level QE) has 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[342] (Level III-3). 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[342] (Level III-3).

Often, listening to and understanding the multiple losses that a family member may have experienced acknowledges their loss and validates their feelings. Providing families with the option to stay with the resident during the night can help reduce the 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 and they may have been able to contribute to the care. 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.

Mollie

Mollie had cared for her husband at home for eight years until his dementia made him increasingly dependent and debilitated. She felt nothing but guilt and remorse because of the decision to have him admitted to residential care. Spending many hours of every day assisting with her husband's care, Mollie also made herself available to assist other residents, particularly with leisure activities. When her husband died, the aged care team wondered how Mollie would cope, as she had no close family. Her husband, and now the RACF, had become her whole life. "I used to feel guilty that I'd put him in here", she said. "Now I feel guilty that I didn't take the step much earlier. He's received such wonderful care, much better than I could have done at home." "This is my second home." When she was asked, Mollie indicated that she had no need for formal bereavement counselling. "No, I don't want to talk to anyone, particularly a stranger. Everyone here understands me." Mollie continued to come to the RACF each day for several months, until she felt ready to reshape her life in another context.

14.3.2 Bereavement support for other residents

The evidence suggests that the support needs of residents is often centred on practical and emotional support[343] (Level QE). It is interesting to note that, in addition to the expected negative consequences, there can be benefits for other individuals who witness a death. For example, hospice patients who witnessed a fellow patient's death found this awareness of dying to be both comforting and distressing[344] (Level III-3). The authors found that those that had witnessed a death were significantly less depressed than those patients who had not had this experience. This finding is relevant for RACFs where concern has been expressed regarding the impact of a resident's death on those sharing the same room.

14.3.3 Bereavement support for the aged care team

The aged care team will experience loss following the death of residents with whom they have established meaningful relationships. Therefore the team should be provided with opportunities to formally acknowledge the loss, and have access to adequate bereavement support[345] (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[346] (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[346] (Level IV).

Emotional support for the aged care team could include bereavement support services, stress management training, and debriefing sessions. Volicer[347] (Level EO) argues for the inclusion of bereavement support in the aged care setting, as is the practice in many palliative services (e.g. use of sympathy cards, memorial services, debriefing meetings for the aged care team, follow-up visits to bereaved family members). For example, a simple ceremony, held annually in the RACF chapel (or lounge) can provide an opportunity for family members of residents who died during the previous year to return and to acknowledge (e.g. by lighting a candle) the life and death of these residents. This represents a public acknowledgment that each resident's life and death have not passed unnoticed, but remain recorded in the RACF's history.

These types of bereavement support could take into consideration all personnel that work at the facility, as well as other residents and families. However, not everyone will feel the need to participate and this should also be respected. Access to a confidant has also been found to be one of the best indicators as to whether a person will require bereavement support[348] (Level QE). If a person has at least one friend in whom they can confide this enhances their resilience in successfully adjusting to bereavement.

14.3.4 Bereavement support for residents with advanced dementia

The mourning process is not exclusive to those who are cognitively able to manage the grieving process. Residents with advanced dementia are also affected by grief and loss, but may not have the cognitive skills to resolve or make sense of their grief. A resident's fluctuating lucidity may make it difficult for the aged care team and family to determine what the resident knows, understands or comprehends regarding the death of another resident. Benbow and Quinn[349] (Level EO) recommended that the aged care team be honest and consistent with residents, allowing them time to grieve even if they forget the details. Protecting residents from the truth can create greater confusion, because the story will not match the reality. Residents with advanced dementia may need bereavement support for an extended length of time before they can accept the reality of the loss.

14.3.5 Bereavement support for family members

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[95] (Level QE).

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[350] (Level III). 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.

Guidelines: Bereavement support

		Level	Reference
80.	Members of the aged care team can experience loss following the death of residents with whom they have established meaningful relationships. Therefore the team should be provided with opportunities to formally acknowledge the loss, and have access to adequate bereavement support. Even members who have experienced many deaths might still require access to these support services.	QE IV	345 346
81.	A memorial service is a valuable resource which facilitates the grieving process for residents, family members, the aged care team and volunteers.	QE	340
82.	The more social support a family has access to, the better their ability to cope with the bereavement of their family member will be. However, it is the quality of the support rather than the quantity that enhances this resilience.	III-3 QE	342 343

CHAPTER 15

Management's role in implementing a palliative approach

Managing an RACF requires a significant set of business and organisational skills. Regulatory requirements have led to many facilities using management and business frameworks that enable the processes of control, feedback and development to be handled systematically. Frameworks such as business cycle planning and quality management systems enable organisations to focus on their responsibilities and can lead to improved performance in the facility[351] (Level QE).

Quality management systems aim to assure customers a consistent and improving level of service, while business planning ensures that operationally the organisation formally assesses needs, revenues and resources. Integral to both processes is the role of communication with customers and with the aged care team.

Introducing a palliative approach is a strategic decision for an RACF in providing continuing care for their residents through to the end-of-life. This will require the organisation to include a palliative approach in their formal planning and monitoring cycles, and to commit the appropriate resources to its implementation. Among the resources required are aged care team members, management time, training and education costs, appropriate facilities, reporting requirements and access to external supports.

Although education and training are essential elements of successful implementation of a palliative approach they may not, by themselves, bring about the desired change[352] (Level QE);[353] (Level EO). Other factors have been identified as influencing the success of changing practices. For example, a commitment of adequate resources is fundamental to implementing changes in practices[6] (Level QE); [354] (Level QE). The organisational culture and leadership in the operational area can also be important in introducing and sustaining change[355] (Level EO);[356] (Level EO);[357] (Level EO). Therefore, boards of management should be included when training in a palliative approach is undertaken by RACFs, to ensure that the entire organisation understands the philosophy of providing a palliative approach.

The context for the change and the process of facilitation can also affect the change environment[307] (Level EO); [358] (Level EO). Time restrictions and a lack of appropriate members for an aged care team have also been identified as impediments to change. Implementing a palliative approach in an RACF requires attention to these potential barriers, as well as focused problem-solving.

Management structures and processes

There are many RACFs whose management has embraced a palliative approach to care. Some examples of these include:

- having a section about a palliative approach in the RACF's public relations material (e.g. brochures);
- advising all residents upon admission about the policies and procedures for implementing a palliative approach;
- setting up relevant systems to enable referral to specialised palliative teams when required; and
- developing formal mechanisms for involving all visiting GPs in formulating and implementing palliative approach policies.

Guideline: Management's role in implementing a palliative approach

		Level	Reference
83.	Formal management systems will support the introduction and maintenance of a palliative approach through the allocation of appropriate resources.	QE QE QE	6 351 354

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Glossary

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 their 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 up to date.

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.[71] 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 their 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.

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.[360]

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 slow onset and a long, drawn-out duration.

cognitive behavioural intervention/therapy

Cognitive behavioural intervention is a psychological therapy focused on changing particular thoughts or behaviour patterns, or acquiring specific coping strategies. Included in this category are 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 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'.)

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 applied to the supportive care delivered by all health care practitioners. 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.

disease-related symptoms

Disease-related symptoms arise because of the illness itself rather than the treatment.

dysfunctional attitude

A dysfunctional attitude is when an individual maintains a belief or thought based on an irrational premise, which can lead to an unnecessary increase in distress for that person.

emotional adjustment

Emotional adjustment is the extent that a resident and/or their 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 adjustment. This adjustment includes the resident's and/or 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 the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on the resident's physical, emotional and spiritual comfort needs, and support for the 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 closest to the patient in knowledge care and affection". This includes the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (not related biologically, 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 who their more distant supports are. A genogram helps the aged care team to determine a resident's prior social history, which can be helpful in understanding their 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. Geriatricians would be the best people to deal with residents who are delirious, as well as the myriad medical problems experienced by the resident.

geropsychologist

A geropsychologist is a specialist doctor who deals mainly with the psychological aspects of a resident's condition.

Graseby pump

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

informed consent

Informed consent is a crucial competent prior to any intervention involving a resident. Informed consent is voluntary, and is required before the commencement of a medical procedure, test or medication. Managers of RACFs are directed to seek independent legal advice regarding informed consent, particularly for residents with advanced dementia.

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) is a network of people who provide 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 palliative care for residents in RACFs. To participate in the NCISN, individuals completed an online registration at 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 EN (Enrolled Nurse—trained through the vocational education and training sector) and the RN (Registered Nurse—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 some States and Territories. When the term 'nurse' is used in these guidelines 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 semisynthetic) 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 and their families, by reducing their suffering through early identification, assessment and treatment of pain and physical, psychological, social and spiritual problems. A palliative approach is not delayed until the end stages of an illness. Instead it provides a focus on active comfort care and a positive approach to reducing an person'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

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

pharmacological interventions

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

problem-solving technique

Problem-solving technique is a strategy which 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 psychological and behavioural aspects of a resident's condition. This would include depression and the management of disruptive behaviour secondary to dementia.

psychosocial interventions

Psychosocial interventions are treatments that address psychological, social and some spiritual needs. The term 'community psychological interventions' is also used, which incorporates a focus on these elements plus cultural diversity, empowerment, social justice, and recognition that all people exist and function within systems that influence behaviour.

psychosocial support

Psychosocial support is 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 their position in life in the context of the culture and value systems in which they live, and in relation to their 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 use random assignment to compare the effect of an intervention between otherwise equivalent groups (for example, comparing a randomly assigned group aged care team members who took part in a palliative approach training program with those who did not).

quasi-experimental design

Quasi-experimental methods make comparisons between groups that are not equal (e.g. program participants vs those on a waiting list) or use of comparisons within a group over time, such as in an interrupted time series in which the intervention may be introduced sequentially across different individuals, groups or contexts.

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.

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-esteem is how people perceive themself. This self-evaluation is generally thought to influence their feelings and behaviours.

social functioning

Social functioning is a resident's ability to function within their current social environment.

specialised palliative team

A specialised palliative team is a team that 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 workers 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 the resident considers provides for their emotional, psychological and practical care needs. A support network usually includes family members and carers. (See also 'family' and 'carers'.)

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.[361]

treatment-related symptoms

Treatment-related symptoms are symptoms which arise as a consequence of a particular treatment (such as a side effect of a medication), rather than from the disease itself.

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.

APPENDIX A:

Working Party of the Australian Palliative Residential Aged Care Project

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APPENDIX B:

The Australian Government Project Reference Group— Terms of Reference and Membership

TERMS OF REFERENCE

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.

MEMBERSHIP

Dr Joanne Ramadge (Chair)	Advisor, Ageing and Aged Care Division Australian Government Department of Health and Ageing
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APPENDIX C:

Methodology for the literature review

This appendix outlines the methodology for the systematic literature review that formed the basis for the development of the guidelines in this document.

1 PURPOSE OF THE LITERATURE REVIEW

The purpose of this systematic literature review was to identify the evidence supporting best practice in a palliative approach that might be applied to residential aged care (for residents aged 65 years and older). A secondary aim of the review was to identify any gaps in the evidence, with a view to suggesting future research directions.

2 REVIEW METHODOLOGY

Evidence-based guideline development traditionally involves searching 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, and research in these fields crosses many disciplines and draws on a multitude of study designs and approaches. It was therefore not possible to define a specific clinical question.

Without a clinical question to guide the search strategies, the project team 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.[45, 91] Domains represented an area for guideline development or an acknowledged area of research. The domain structure is outlined in Table 17.

Table 17: Domains for the literature review

Domain	Examples of content covered
Palliative Care Model	Holistic care; World Health Organization (WHO) definition; volunteers; ancillary workers; staff; interdisciplinary teams; bereavement support; communication; education; training; staff development
Assessment Tools	Quality of life; pain; dignity, activities of daily living (ADL); confusion
Care Practices	Decision-making; end-of-life decision-making; advanced directives; legislation; living wills, ethics, surrogacy; power of attorney; guardianship
Co-morbidities	Cancer; age-related; chronic obstructive pulmonary disease (COPD); diagnosis; heart failure; Parkinson's disease; haematological malignancies
Physical Care	Pain; symptom control; anorexia and cachexia; hydration; thirst; respiratory; cancer pain; dyspnoea; nausea; pressure ulcers; dysphagia
Psychological Support Social Support	Depression; grief; anxiety; sexuality and intimacy; social work; psychosocial factors; environment
Spiritual Support	Spirituality; religious beliefs; pastoral care; human development; crisis intervention; emotional responses; sociocultural factors; attitudes to death and dying; coping behaviours; grief
Family/Carer Support	Family; extended family; family relations; genogram; caregivers; bereavement; after-death care
Indigenous Issues	Indigenous needs; traditional beliefs; Aboriginal and Torres Strait Islanders; cultural safety
Rural and Remote Issues	Rural; country; isolated and remote sites
Cultural Issues	Cultural; multicultural; English as a second language (ESL); cultural and linguistic diversity (CALD); ethnicity; beliefs, practices and language
Cognitive Impairment	Dementia; dementia care, Alzheimer's; confusion; behavioural and psychological symptoms

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

Preliminary work in searching showed that two search strategies would be necessary to capture all the relevant literature for the development of evidence-based practice guidelines. The first sweep of the literature aimed to acquire relevant studies (both quantitative and qualitative) using the domain structure outlined above. This top-down approach elicited articles covering a broad range of issues. The second strategy used specific terms that emerged from articles found during the first search strategy phase.

Inclusion and exclusion criteria were established for initial decision-making on articles and abstracts.

Inclusion criteria:

- Evidence based
- Published in a peer-reviewed journal, book chapters, government and non-government reports, therapeutic guidelines, standards of care and other guidelines
- Published between January 1990 and September 2003
- Published in an English language
- Originating in a country with a health system comparable to that in Australia
- Originating in a country with social or cultural similarities to Australia
- Originating in a country where residential aged care facilities are similar to those in Australia.

Exclusion criteria:

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

3 SEARCH STRATEGIES

The contextual framework for search strategies was provided by a hand search of books and publications at Flinders University libraries (Sturt, Medical and Central) and Repatriation General Hospital libraries (Daw House and Medical) between July and September 2002. These publications were not required as part of the literature for evaluation as evidence and were not included in the literature review. 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 and September 2002.

The literature was searched electronically for English-language articles published in peer-reviewed 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 2 November 2002. Both search strategies were conducted on databases MEDLINE, CINAHL, Embase, Cochrane Library and current contents, APAIS, DRUG, PsychINFO and Dissertations Abstracts International. Relevant secondary references were included in this review.

The search terms used are outlined in Table 18.

Table 18: Search terms for the literature review

Aboriginal terms	Aboriginal; Indigenous; koori
Advanced directives terms	Advanced directives; decision making; end-of-life care; legislation
Aged care terms	Aged Care Facility; Gerontological Care; Group Homes; Homes for the Aged; Residential Facilities; Residential Care; Halfway Houses; Health Services for the Aged; High Level Care; Long Term Care; Nursing Homes
Australia terms	Exp Australia/; South Australia; Royal College of Nursing, Australia
Bereavement terms	Exp bereavement/; exp grief/; death and dying; hospice; death rites; occupational stress; hospital programs; memorial service; life experiences; rite (nonreligious); symbolism; ritual referral; unresolved grief; at risk population; treatment; psychopathology; pathological grief; coping behaviour
Breast Cancer	
Cancer terms	Neoplasms; cancer; malignancy
Care givers	Family
Cardiac care	
Clinical terms	Evidence; Random Controlled Trials; Guidelines
Complementary therapy	Complementary therapy; alternative therapy
Cultural	
Dementia terms	Dementia care; cognitive impairment
Depression	
Education terms	Training; education; skills; staff development; inservice training
Hospital terms	Hospitals—special; Hospitals—teaching; Hospitals—urban; Acute care setting
Non-clinical staff terms	Maintenance staff; non-clinical staff
Non-professional staff terms	Domestic; non-professionals; ancillary; uneducated; volunteers; nurses' aides
Neurologica	
New Zealand	
Nursing terms	Exp Nursing role/; exp terminal care/; end-of-life care; exp quality of nursing care/; exp registered nurses/; exp. Registration/
Occupational therapy	
Pain terms	Exp Pain/
Palliative care terms	Exp Hospice Care/; exp palliative care/; End of Life; Dying; Death; Terminal care
Pastoral	Spiritual
Prognosis terms	Prognosis; treatment
Psychological terms	Psychosocial; Quality of Life; psychological
Quality terms	Quality improvement; quality systems
Renal	
Respiratory	
Rural terms	Rural; Remote
Social Work terms	Social work; Counsellor
Therapeutic environment terms	Person Environment Fit; Home Environment; Environment
Volunteer terms	Volunteer; non-clinical staff

Following a preliminary analysis of the evidence that was retrieved subsequent to the search, additional specific searches on identified gaps were conducted between July 2003 and September 2003. These searches involved specific word searches on the major electronic databases outlined above, 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.

4 REVIEWING THE EVIDENCE

All the retrieved evidence from the literature review was reviewed, graded and summarised.

One of the significant challenges of the evidence review was locating and valuing research from the non-medical fields. The project team responsible for reviewing the literature developed evaluation tools built around the National Health and Medical Research Council (NHMRC) criteria and drawing upon work done by the Cochrane and Campbell Collaborations in evaluating quantitative and qualitative studies (see Appendix D for an example of these tools). The tools also reflected issues being discussed in the literature relating to the inclusion of research outside the biomedical model.

Evaluation strategies

The evidence was rated according to the NHMRC (1999) criteria.

Level of evidence

This rating system refers to the design of reviewed studies.

Level I	A systematic review of all relevant randomised controlled trials (RCT).
Level II	At least one properly designed RCT.
Level III-1	Well-designed pseudo-RCTs.
Level III-2	Comparative studies with concurrent controls and allocation not randomised, case-control studies or interrupted time series with a control group.
Level III-3	Comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group.
Level IV	Case series, either post-test or pre-test and post-test.
Quality of evidence	This rating refers to the quality of the methods used in a study to minimise bias.
Strength of evidence	This classification refers mainly to the magnitude of the intervention effect.
Relevance of evidence	The relevance of outcome measures and the applicability of the study results to the clinical question are considered by this criterion.

Two evaluation tools were developed, one for use with intervention studies and one for use with research studies using a quasi-experimental or empirical design. The tool for use with intervention studies used the level of evidence categories outlined by the NHMRC directly.

A separate criterion for the quality of evidence was included. For the quasi-experimental or qualitative studies, the level of evidence and the quality of evidence were combined to create a single category that dealt with the intent of the study and the methodological appropriateness of the study. The strength of evidence and relevance of evidence criteria were the same for both tools.

5 PROCESS OF EVALUATION

There were several informal processes of selection of relevant articles to be included in the review: first the title of the article was sighted, second the abstract, and third the full text. Full text articles deemed appropriate by the inclusion criteria were obtained and evaluated.

The SA investigators and Project Officer, using the developed tools, systematically evaluated the studies identified by the searches. A single evaluation was undertaken, except where the evaluator reported uncertainty. A second evaluation was then undertaken.

6 LIMITATIONS TO THE STUDY

There are several limitations to the literature review, which are inherent in the method of using electronic databases. The searches were limited to articles published in English and much research in palliative care and aged care has occurred in European countries and is published in other languages, particularly German, Dutch and Swedish. 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 a recent study were presented at the Australian and New Zealand Society of Palliative Medicine Meeting, Townsville, Australia, in September 2002 reported that approximately 30% of the palliative care literature was missed on the electronic databases (Abernethy, Currow & Butler 2002). 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 team. 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. The number of articles requiring evaluation meant that it was impractical to have duplicate evaluations for internal consistency. For most 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 project team's preliminary review of the found 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.

7 RESULTS

More than 12,000 references were sighted and assessed for their potential for inclusion in the evidence evaluation phase. In total, 939 articles were formally evaluated.

From the initial searches, 446 articles were identified as having possible relevance to project needs and were evaluated. Of this set, 206 were found to meet the evidence criteria.

From the subsequent searches, a further 483 relevant articles were found. Of these, 87 met the evidence standard, creating a total evidence set of 293 articles and studies.

APPENDIX D:

An evaluation tool appropriate for both qualitative and 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 applicable
3	applicable
2	somewhat applicable
1	not applicable

Relevance to APRAC project: _____

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

Evaluator/s:

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 2003
- 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—it will be given a score out of 8.

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

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

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.

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 applicable
3 applicable
2 somewhat applicable
1 not applicable

Relevance to APRAC project: _____

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

Evaluator/s:

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 2003
- 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 and strength of the evidence as it relates to the particular study cited—it will be given a score out of 12.

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

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

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.

APPENDIX E:

Examples of advance directive documents currently used in various States

NOTE: These are examples only —please refer to your own State or Territory legislation.

The 'Good Palliative Care Order Form'[359]

Include the names of family members and staff members who have been involved in discussions regarding the patient's condition and future care plan.

Under the Guardianship and Administration Act 1993 family members are able to make medical decisions should there not be a guardian or medical agent. A family member includes spouse, official de facto, parent, child over eighteen and sibling over eighteen.

Describe the patient's condition and likely prognosis.

Identify if the patient is competent, that is, able to make decisions regarding their medical care.

Under the Consent to Medical Treatment and Palliative Care Act, patients can also write down their wishes regarding their future medical care which come into effect only if they are not able to make decisions regarding that care. Once sighted, these documents, called anticipatory directions or advance directives, must be followed.

Select the option which best conforms to the patient's, or delegate's, desire for future medical treatment. Should none of the three written options be appropriate, provision is made for specific instruction under point four.

Identify how long you wish this document to be in force for and when you believe that it should be reviewed.

Date the document, sign it and clearly print your name. This document should be signed by a medical practitioner. It is expected that the care team will be consulted as part of its completion.

If using the accompanying sticker to indicate the existence of the Order in the notes, affix it to the front of the case notes and note the date the Order is completed.

Good Palliative Care Order Form

Anticipatory Direction

_____

_____

_____

_____

I have discussed with patient

_____

or with their medical agent

_____

(Please ensure the medical power of attorney, authorising agent, is sighted.)

and/or family members or attending persons

_____

_____

_____

_____

_____

and with staff members

_____

_____

_____

_____

the patient's current condition, which can be described as

_____

_____

_____

_____

The patient is competent ☐

Incompetent ☐

Circle one of the options:

We have agreed that in the event of further deterioration in the patient's condition:

1 Full cardiopulmonory resuscitation with total body support as required will be undertaken

2 Intensive medical support will be undertaken, but cardiopulmonory resuscitation will not be initiated, and no long-term support measures, including ventilation or dialysis, will be undertaken

3 The emphasis of management will be on Good Palliative Care, highlighting the relief of symptoms and discomforts. No artificial measures designed to supplant or support bodily function will be undertaken

4 Other. Please specify:

_____

_____

_____

_____

This form will be in force for:

1 week ☐

1 month ☐

3 months ☐

12 months ☐

indefinitely ☐

or until revoked by the patient ☐

Date: _____

Signed:_____

Print name of legally qualified medical practitioner

_____

Schedule 1

MEDICAL POWER OF ATTORNEY

CONSENT TO MEDICAL TREATMENT AND PALLIATIVE CARE ACT 1995

1. I, _____

_____

_____

(insert name, address and occupation)

appoint the following person(s) to be my medical agent(s):

. 1 _____

_____

_____

2 _____

_____

_____

3 _____

_____

_____

(Set out name, address and occupation of the agent. If 2 or more agents are appointed, the order of appointment must be indicated by placing the numbers 1,2,3 ... beside each name. This indicates that, if the first is not available the second is to be consulted, if the first and second are not available, the third is to be consulted and so on. It should be noted that a medical power of attorney cannot provide for the joint exercise of power. ***(See Section 8 (6) of the Consent to Medical Treatment and Palliative Care Act 1995)***

2. I authorise my medical agent to make decisions about my medical treatment if I should be unable to do so myself.

3. I require my agent to observe the following conditions and directions in exercising, or in relation to the exercise of, the powers conferred by this power of attorney:

_____

_____

_____

_____

_____

_____

_____

(here set out any conditions to which the power is subject and any directions to the agent)

4. This is an enduring power of attorney made under the:

Consent to Medical Treatment and Palliative Care Act 1995

_____

(Signature of the person appointing the agent)

DATED the _____day of _____19 _____

Acceptance of Power of Attorney

1. I, _____

_____

_____

2. I, _____

_____

_____

3. I, _____

_____

_____

(here set out name(s), address(es) and occupation(s) of medical agents(s))

accept appointment as a medical agent under this medical power of attorney and undertake to exercise the powers conferred honestly, in accordance with the conditions and directions set out above, and, subject to that, in what I genuinely believe to be my principal's best interests.

_____

_____

_____

(Signature(s) of the medical agent(s))

Witness's certificate

I, _____

(here set out name and address of the witness and the qualifications of authorised witness)

certify:

(a) that the grantor and grantee of the power of attorney signed it freely and voluntarily in my presence; and

(b) both appeared to understand the effect of the power

_____

(Signature of JP, solicitor, member of clergy, pharmacist; or proclaimed bank manager, postal manager or police officer;)

DATED the _____day of _____19 _____

APPENDIX F:

Resource list

PALLIATIVE CARE SERVICES

National Office of Palliative Care Australia
Suite 2, 37 Geils Court
DEAKIN ACT 2600
(02) 6232 4433
pcainc@pallcare.org.au
www.pallcare.org.au

AGED CARE SERVICES

Aged and Community Services Australia
Level One, 36 Albert Road
South Melbourne VIC 3205
(03) 9686 3460
info@agedcare.org.au

Australian Nursing Homes and Extended Care Association (ANHECA) Limited
Level 1, 25 Napier Close
Deakin ACT 2600
(02) 6285 2615
office@anheca.com.au
www.anheca.com.au

PUBLICATIONS

Palliative Care

National Palliative Care Strategy: A national framework for palliative care service development (2000), October.

O'Connor, M. & Aranda, S. (2003) *Palliative care nursing: A guide to practice* (2nd ed) Melbourne, VIC: Ausmed Publications, www.ausmed.com.au.

Palliative Care Australia (2004) *Palliative care national directory 2004: palliative care services and hospices in Australia,* www.pallcare.org.au.

Bereavement risk

Centre for Palliative Care (2000) *Guidelines for the assessment of bereavement risk in family members of people receiving palliative care.*

Multicultural

Die-Trill, M. & Holland, J.C. (1993) Cross-cultural differences in the care of patients with cancer: a review. *General Hospital Psychiatry*, 15(1), 21–30.

Hall, P., Stone, G. & Fiset, V.J. (1998) Palliative care: How can we meet the needs of our multicultural communities? *Journal of Palliative Care*, 14(2), 46–49.

McNamara, B., Martin, K., Waddell, C. & Yuen, K. (1997) Palliative care in a multicultural society: perceptions of health care professionals. *Palliative Medicine*, 11(5), 359–67.

Spiritual

Hermann, C.P. (2001) Spiritual needs of dying patients: a qualitative study. *Oncology Nursing Forum*, 28(1), 67–72.

Hume, S. K. (1991). Support in a time of need. The team approach at Mercy Medical Hospice addresses medical, emotional, and spiritual needs. *Health Progress*, 72(7), 40–5, 54.

Thomson, J.E. (2000) The place of spiritual wellbeing in hospice patient's overall quality of life. *Hospice Journal*, 15(2), 13–27.

Resources for both palliative care and aged care facilities

Hockley, J. & Clark, D. (eds) (2002) *Palliative care for older people in care homes*. Buckingham, UK: Open University Press (enquiries@openup.co.uk, www.openup.co.uk).

Consider the options: End stage clinical care for chronic degenerative disorders. Resthaven Incorporated (PO Box 327, Unley SA 5061, (08) 8373 0211)

Indigenous

Sullivan, K., Johnston, L., Colyer, C., Beale, J., Willis, J., Harrison, J. & Welsh, K. (2002). *Indigenous palliative care needs study—final report.* Canberra, ACT: Commonwealth of Australia.

Willis, J. (1999) Dying in country: implications of culture in the delivery of palliative care in Indigenous Australian communities. *Anthropology & Medicine*, 6(3), 423–35.

Multicultural

Palliative Care Australia (1999) *Multicultural palliative care guidelines*. (Suite 2, 37 Geils Court, Deakin ACT 2600, (02) 6232 4433, www.pallcare.org.au)

Crawley, L.M., Marshall, P.A., Lo, B. & Koenig, B.A. (2002) Strategies for culturally effective end-of-life care. *Annals of Internal Medicine*, 136, 673–79.

Jewish customs and practices, contact Mrs Vera Link, Vera_link@hotmail.com.

Volunteering

National standards for involving volunteers in not for profit organisations. Volunteering Australia (Suite 2, Level 3, 11 Queens Road, Melbourne VIC 3004, (03) 9820 4100, www.volunteeringaustralia.org, volaus@volunteeringaustralia.org)

Resources specific to aged care facilities

Outside looking in: A resource kit for aged care facilities. Carers Victoria (Level 5, 130 Little Collins Street, Melbourne VIC 3000, (03) 9650 9966)

Ethics

Code of ethical standards for Catholic health and aged care services in Australia. Catholic Health Australia (PO Box 330, Deakin West ACT 2600).

Department of Health and Ageing (2001) *Code of ethics and guide to ethical conduct for residential aged care*. CommonwealthAvailable from www.health.gov.au.

Fleming, J.I., Tonti-Filippini, N. & Pike, G.K. (2001) *An ethics handbook for aged care facilities*. Adelaide, SA: South Australia Network for Research on Ageing.

Nutrition

Best practice food and nutrition manual for aged care facilities. Nutrition Department, Central Coast Health (PO Box 361, Gosford NSW 2250, (02) 4320 3691).

Pain management

Australian Pain Society (2004) *APS Residential aged care pain management guidelines*. Crows Nest, New South Wales: Australian Pain Society.

Psychological

Challenge Depression—resource kit for meeting the challenge of depression in residential aged care. Hammond Care Group (Sydney NSW, (02) 9825 5081).

NSW Health (2000) *Best practice model for the use of psychotropic medication in residential aged care facilities and guidelines on the management of challenging behaviour in residential aged care facilities in New South Wales*. Available from www.health.nsw.gov.au.

Spiritual

Ronaldson, S. (ed) (1997) *Spirituality: The heart of nursing. Ausmed Publications* ((03) 9375 7311, ausmed@ausmed.com.au).

Hicks, T.J.J. (1999) Spirituality and the elderly: Nursing implications with nursing home residents. *Geriatric Nursing*, 20(3), 144–146.

MacKinlay, E. (2001) Health, healing and wholeness in frail elderly people. *Journal of Religious Gerontology*, 13(2), 25–34.

Orchard, H. & Clark, D. (2001) Tending the soul as well as the body: spiritual care in nursing and residential homes. *International Journal of Palliative Nursing*, 7(11), 541–546.

Wound care

Guidelines for Wound Care. Australian Wound Management Association ((08) 9431 2605, www.awma.com.au, prentice@cyllene.uwa.edu.au).

PUBLISHERS

A series of books covering various topics on palliative care

Oxford University Press
GPO Box 2784Y
Melbourne VIC 3001
1300 605 616
www.oup.com.au

Source National Breast Cancer Centre
PO Box 572
Kings Cross NSW 1340
Fax: (02) 9326 9329
www.health.gov.au/pq/cancer/nbcc.htm

Palliative Supportive Care
Cambridge University Press
Print ISSN: 1478-9515
Electronic ISSN: 1478-9523
www.cambridge.org

Insite: The Aged Care Industry Newspaper
DPS Publishing
433 Goodwood Road
Westbourne Park SA 5041
(08) 8272 5554

St Luke's Innovative Resources
137 McCrae Street
Bendigo VIC 3550
www.stlukes.org.au

ENDURING POWER OF ATTORNEY AND GUARDIANSHIP

AUSTRALIAN CAPITAL TERRITORY

Office of the Community Advocate
PO Box 1001, Civic Square
Canberra ACT 2608
(02) 6207 0707
oca@act.gov.au
www.oca.act.gov.au/

NEW SOUTH WALES

Office of the Public Guardian
Level 15, Piccadilly Tower
133 Castlereagh St
Sydney NSW 2000
(02) 9265 3184
www.lawlink.nsw.gov.au
informationsupport@opg.nsw.gov.au

QUEENSLAND

Department of Justice and Attorney General
(07) 3239 3520
mailbox@justice.qld.gov.au.
www.justice.qld.gov.au/guardian/

TASMANIA

Tasmania Department of Justice
The Guardianship and Administration Board is located at
99 Bathurst St
Hobart TAS 7000
(03) 6233 3085
guardianship@justice.tas.gov.au
www.justice.tas.gov.au

VICTORIA

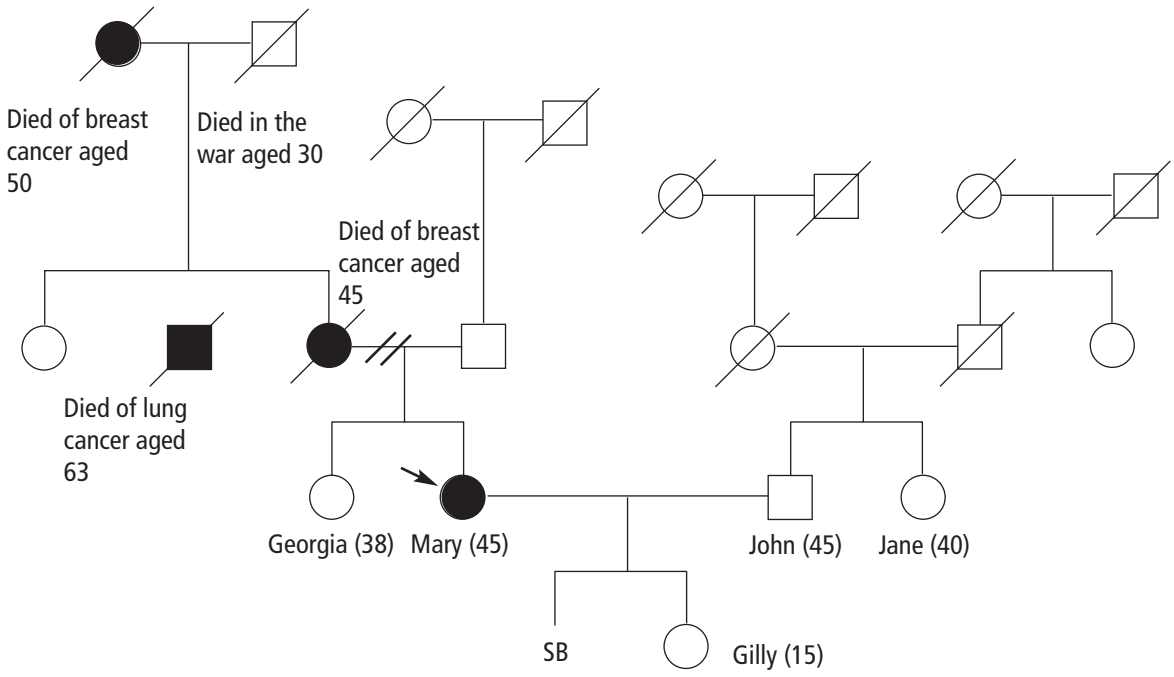
Office of the Public Advocate
5th Floor , 436 Lonsdale Street
Melbourne VIC 3000
(03) 9603 9500

WESTERN AUSTRALIA

Department of Justice
Office of the Public Advocate
1st floor, 30 Terrace Road
East Perth WA 6004
(08) 9278 7300 or 1800 807 437
www.justice.wa.gov.aux

APPENDIX G:

An example of a Genogram



Key to symbols

- Affected male
- Unaffected male
- Affected female
- Unaffected female
- One person, sex unknown
- Dead
- Identical twins
- Nonidentical twins
- Minimally or unaffected carrier or proven transmitter
- No offspring, sterility, sterilization or reproductive period ended

SB Stillborn

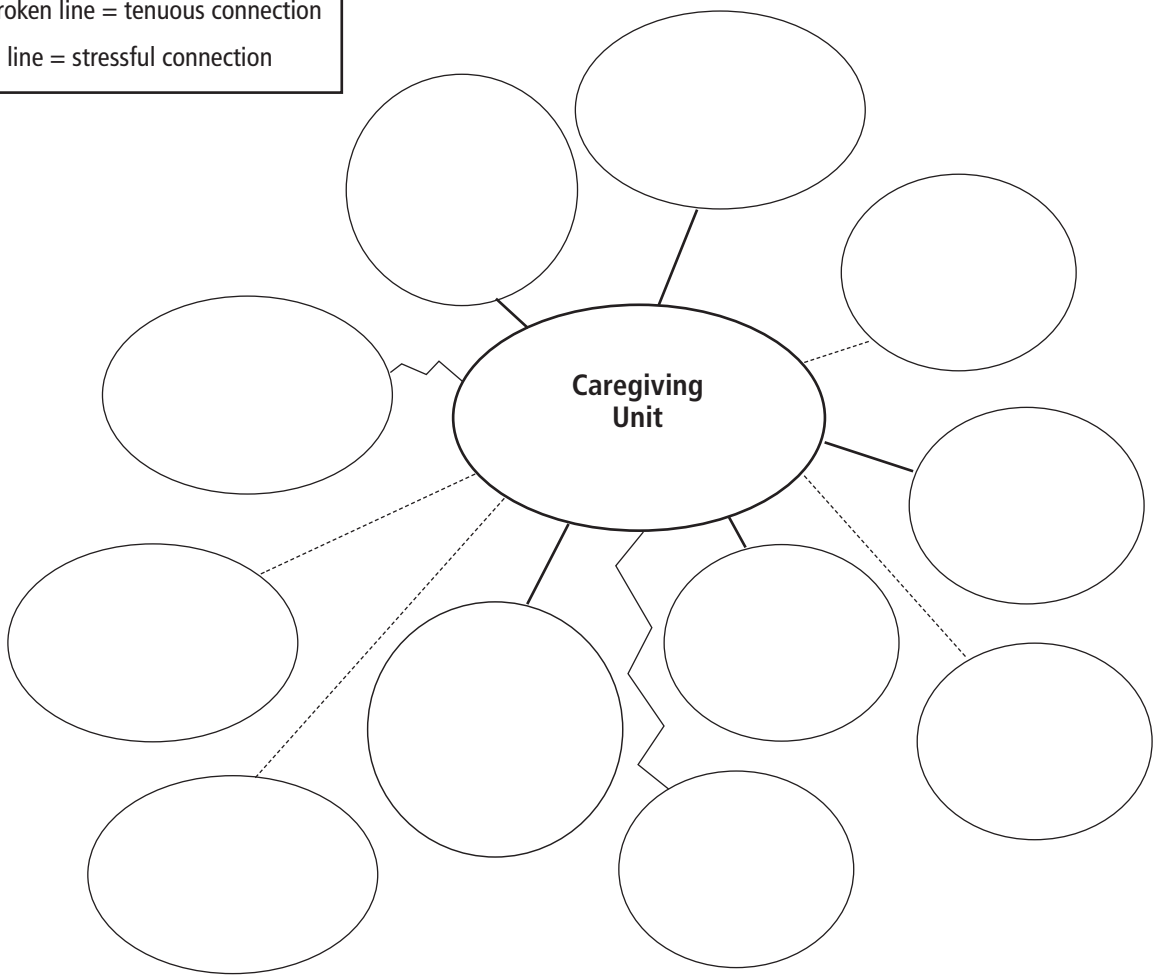
ID Infant death

APPENDIX H:

An example of an Ecomap

KEY:

- thick line = strong connection
- thin, broken line = tenuous connection
- jagged line = stressful connection



Considerations:

- who is in the network?
- proximity
- what the do/could do
- frequency of contact
- quality of relationship
- satisfaction with help
- changes in network

Family supports

- immediate family—spouse, parents, children
- extended family—siblings, cousins, nephews/nieces, in-laws, former partners, grandchildren, etc

Non-family informal supports

- friends, neighbours
- work colleagues
- community groups

Formal supports

For example community, medical, private, volunteer, residential.

Index

Guidelines for a Palliative Approach in Residential Aged Care

Feedback sheet

Please complete the following information and detach the sheet, fold as indicated and mail to the address which is at the back of this form.

Name (optional)

Organisation title

Contact details (optional):

Address

Phone Fax

Email

Type of organisation (tick box):

Residential Aged Care Facility ☐

Educational Facility ☐

General health service provider/organisation ☐

Other (please specify) ☐

How do you plan to use/have you used the Guidelines for a Palliative Approach? (tick box):

Personal use ☐

Training ☐

Other (please specify) ☐

Research/study ☐

Policy development ☐

How can the Guidelines for a Palliative Approach by improved for future editions (consider layout, structure, content etc)?

If you are aware of research that needs to be included in the next edition please provide details below:

Author

Year Title

Publication Details

Thank you

Affix Stamp Here

Palliative Care Australia
PO Box 24
DEAKIN WEST ACT 2600